

More participation, choice making and meaningful activities in everyday life for people with intellectual disabilities?

EVALUATION OF ACTIVE SUPPORT AND FRONTLINE PRACTICE LEADERSHIP IN GROUP HOMES IN SWEDEN



Jenny Aspling



More participation, choice making and meaningful activities in everyday life for people with intellectual disabilities?

Evaluation of Active Support and Frontline Practice Leadership in group homes in Sweden

Jenny Aspling

Marie Cederschiöld University

© Jenny Aspling, 2025

ISSN: 2003-3699

ISBN: 978-91-985807-1-6

Thesis series within the field The Individual in the Welfare Society

Published by:

Marie Cederschiöld University

www.mchs.se

Cover photo/illustration: Elín S. M. Ólafsdóttir, Inuti Collection

Printed by Eprint AB 2019

Institutionen för Socialt arbete

More participation, choice making and meaningful activities in everyday life for people with intellectual disabilities?

Evaluation of Active Support and Frontline Practice
Leadership in group homes in Sweden

Jenny Aspling

Akademisk avhandling
som för avläggande av filosofie doktorexamen vid
Marie Cederschiöld högskola offentligen försvaras

fredag den 23 maj 2025, kl 09.00
Plats Aulan, Campus Ersta, Marie Cederschiöld högskola



Handledare:

Magnus Tideman, professor, Marie
Cederschiöld högskola

Veronica Svärd, docent, Södertörns
högskola

Opponent:

Thomas Strandberg, professor,
Örebro universitet

Abstract

More participation, choice making and meaningful activities in everyday life for people with intellectual disabilities? Evaluation of Active Support and Frontline Practice Leadership in group homes in Sweden

Jenny Asplång

Active Support is an internationally well-researched staff practice to improve quality of life for people with intellectual disabilities living in group homes. However, research findings from Sweden are lacking about Active Support. The aim of this doctoral thesis was to investigate the two-year effect of Active Support, including Frontline Practice Leadership, in Swedish group homes for people with intellectual disabilities.

Four group homes participated in this intervention project. A mixed methods approach was used, combining interviews with managers and service users, observations of leadership and staff-service users' interactions and staff questionnaires. Data was collected on repeated occasions, both before and after the training, to evaluate the longitudinal effects of Active Support training.

Results showed that better support was given in all four group homes after Active Support training. Services users said that their influence, choices and emotional support had improved. Observations over two years confirmed that staff-service users' interactions had improved with more activity and choices. Practice leadership, a part of Active Support, was important for working with Active Support and feedback sessions were particularly important to continuously develop staff support.

This intervention project shows that Active Support is a promising staff practice that develops staff's support skills in group homes in Sweden. These findings also show the importance that people with intellectual disabilities are heard when evaluating new staff practices.

Keywords: Intellectual disability, Active Support, staff practice, Frontline Practice Leadership, interviews, staff development, group homes

*To all people with disabilities,
their family members,
and their support workers
that I have had the privilege to meet*

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I. Aspling, J., Svärd, V., Humphreys, L., Bigby, C., & Tideman, M. (2024). A Scoping Review of Outcomes Measured and Involvement of People With Intellectual Disabilities in Active Support Research. *Journal of Applied Research in Intellectual Disabilities*, 37(6), e13309.
<https://doi.org/10.1111/jar.13309>
- II. Aspling, J., Svärd, V., & Tideman, M. (2024). Active support as good support in group homes? A longitudinal interview study with service users. *Journal of Intellectual & Developmental Disability*, 50(1), 33-44.
<https://doi.org/10.3109/13668250.2024.2400097>
- III. Aspling, J. The effect of Frontline Practice Leadership in Swedish Group Homes – Observations of Frontline Managers and their Experiences. (submitted)
- IV. Aspling, J., Svärd, V., Humphreys, L., Bigby, C., & Tideman, M. Implementation and Evaluation of Active Support in Swedish group homes. (manuscript)

Reprints were made with permission from the respective publishers.

Content

List of Papers	7
Abbreviations	13
Lättläst sammanfattning	15
1. Introduction	19
1.1. A good life for people with intellectual disabilities	19
1.2. The living conditions for people with intellectual disabilities	22
1.3. Improving the quality of life for people with intellectual disabilities	24
2. Rationale	25
3. Aim and Research Questions	26
4. Background	27
4.1. People with intellectual disabilities	27
4.2. What is disability? Different models of disability	29
4.3. Social work with people with intellectual disabilities – a historical perspective	31
4.4. From institutions to group homes	36
4.5. The Social Services Act and the Act concerning Support and Service for Persons with Certain Functional Impairments	37
4.6. The group homes today	39
4.7. Staff qualifications and training	40
5. Previous research	42
5.1. Previous Swedish research about group homes	42
5.2. Staff practices in group homes	45
5.3. Can Active Support add new knowledge? A comparison with other staff practices	47
6. Active Support	48
6.1. Active Support – a staff practice to increase engagement	48
6.2. Training in Active Support	51
6.3. The online training resource of Active Support	52

6.4. The Frontline Practice Leadership training	54
6.5. Research about Active Support and Practice Leadership	55
7. Theoretical frameworks	57
7.1. Quality of Life – different definitions	57
7.2. The Quality of Life framework	58
7.3. An Ethics of Care perspective	62
8. Method	66
8.1. Study design and context	66
8.2. Data collection process	68
8.3. Implementation strategies	70
8.4. The implementation process	74
8.5. Study population	76
8.6. Methods and measures used for data collection	77
8.7. Adaptations and modifications	80
8.8. Methods of analysis	82
8.9. Trustworthiness and generalisation	83
8.10. Ethical considerations	85
8.11. My own previous experience	87
9. Summary of articles	90
9.1. Article I	92
9.2. Article II	94
9.3. Article III	96
9.4. Article IV	98
10. Overall analysis and discussion	100
10.1. Active Support in a Swedish context	100
10.2. The findings of the project	103
10.3. The voices of people with intellectual disabilities in research about interventions	104
10.4. The importance of continuous training for staff	106
10.5. Active Support for people with a variety of support needs	109
10.6. Active Support and the Quality of Life framework	110
10.7. Methodological considerations	116
10.8. Strengths and weaknesses	119

10.9. Practical implications	120
11. Conclusions	122
12. Future research	124
Sammanfattning	127
Acknowledgements	136
References	139
Appendices	163
Papers	181
Thesis from Marie Cederschiöld University	182

Abbreviations

Abbreviation Term

ABA	Applied Behavior Analysis
ASM	Active Support Measure
CRPD	Convention on the Rights of Persons with Disabilities
EMAC-R	Engagement in Meaningful Activity and Relationships
FPL	Frontline Practice Leadership
FRAME	Framework for Reporting Adaptations and Modifications-Enhanced
FUB	The Swedish National Association for People with Intellectual Disability
ICF	The International Classification of Functioning, Disability and Health
LSS	Lag [1993:387] om stöd och service till vissa funktionshindrade [English: the Act concerning Support and Service for Persons with Certain Functional Impairments]
SABS	The short form of the Adaptive Behaviour Scale
QoL	Quality of Life
UK	United Kingdom
USA	United States of America

Lättläst sammanfattning

Det här är en bok om hur personal i gruppboendestäder kan bli bättre på att ge stöd till personer med intellektuell funktionsnedsättning.

Det är inte alltid att personal vet hur man ska göra så att det blir bra stöd.

Flera rapporter visar att personalen behöver mer kunskap.

Därför har Jenny forskat om hur stödet kan bli bättre och skrivit den här boken.

Den här boken handlar om ett arbetssätt som heter Aktivt Stöd.

Aktivt stöd används i gruppboendestäder i Australien och England.

Jennys forskning har undersökt om Aktivt stöd kan användas i gruppboendestäder i Sverige.

Gör Aktivt stöd så att de boende kan bestämma mer själva och bli mer delaktiga?

Fyra svenska gruppboendestäder har varit med i forskningen.

Personalen i gruppboendena fick träning i Aktivt Stöd

och sedan undersökte Jenny om stödet blev bättre.

Jenny frågade de som bor på gruppboendena vad de tyckte om Aktivt stöd.

De har intervjuats två gånger.

Intervjuerna visade att de tyckte att personalen gav bättre stöd efter att de fått träning i Aktivt Stöd.

De boende sa att de fått fler aktiviteter.

De boende tyckte att de fick välja och bestämma mer själva.

De sa också att personalen gav bättre stöd så att det blev lättare att få kontakt med grannar och vänner.

Personalen blev också bättre på att ge stöd när man var ledsen.

Men det finns också saker som boende tycker kan bli ännu bättre.

De vill ha fler aktiviteter utomhus.

Personalen måste också lära sig att ge stöd till träning och sport.

Personalen måste också bli bättre på att komma i tid så de boende inte behöver vänta så mycket.

Aktivt Stöd tränar också chefer att

hjälpa personalen göra ett bra jobb.

Jenny har intervjuat cheferna på boendena och tittat på hur cheferna jobbar på dagarna.

Hon ville se om cheferna kan hjälpa personalen mer så de kan göra ett bättre jobb.

Det visade sig att cheferna var mer på plats i gruppboendena efter att man börjat jobba med Aktivt Stöd.

Men det visade sig också att cheferna tyckte att de hade mycket annat att göra så det var svårt att hinna med att handleda personalen.

Därför tränades några av personalen, stödpedagoger, i att vara de som ska visa personalen när cheferna inte kan göra det.

Den sista delen av den här boken handlar om det är så att personalen blev bättre på att ge stöd.

Jenny har många gånger tittat hur personalen jobbar.

Personalen har också fyllt i enkäter

om vilket stöd som de tycker behövs.

Resultatet av forskningen visar att Aktivt Stöd gör att personalen ger bättre stöd till de som bor i gruppbestäderna.

Det betyder att Aktivt stöd kan användas på andra gruppbestäder.

Den här boken visar att det är viktigt att

personer som bor i gruppbestäder får vara med

och säga vad de tycker

när personalen lär sig arbeta på ett nytt sätt.

Men för att veta helt säkert att det blir bra med Aktivt stöd för alla behövs mer forskning.

1. Introduction

Society is responsible for safeguarding and accommodating the needs of equality, participation and influence for people with disabilities (Tideman, 2000). Being able to live in your own home, being included in the community and having access to support for ensuring this, are fundamental human rights (United Nations, 2006). People with intellectual disabilities are often dependent on services provided by society and support from support workers in daily activities to be able to live a life with participation and active choices. The training and competence of support staff working with people with intellectual disabilities is therefore important to guarantee human rights as well as a good quality of life (QoL). This is particularly important for adults with intellectual disabilities living in group homes, which in Sweden is a common form of accommodation, provided for those in need of support 24/7.

1.1. A good life for people with intellectual disabilities

Adults with intellectual disabilities who live in group homes should have the same rights as everybody else to exercise choice and decision making (United Nations, 2006). The support provided by staff in group homes, usually support workers and first-line managers, is essential to fulfil this ambition. It is necessary for service users' participation in activities and for their relationships with others (Mansell & Beadle-Brown, 2012). The support should enable them to be active members of society, increasing their engagement and self-determination. However, national reports show that support workers often need greater competence to be able to fully provide skilled support, to adapt their behaviour to meet the needs of people with intellectual disabilities, to be able to communicate with augmentative and alternative communication and to strengthen the voices of people with intellectual disabilities (Health and Social Care Inspectorate, 2015; National Board of Health and Welfare, 2021).

I have more than 15 years' experience of working in the disability field, for more than ten years as a manager of services such as group homes, short term stays and day activity centres. I often met dedicated staff who wished for more training to improve their support. I also met people with intellectual disabilities who wanted

better support from staff. I was therefore delighted when the Active Support project began at Marie Cederschiöld University in 2020 and I was given the opportunity to examine how this staff practice could improve the QoL for people with intellectual disabilities. In this research project, we have implemented the internationally well-known and evidence-based Active Support practice, including Frontline Practice Leadership, in four group homes and evaluated its effect on the support and everyday life for people with intellectual disabilities.

1.1.1. Rights and Participation for Persons with Disabilities

People with intellectual disabilities have a long history of vulnerability and marginalization. The last decades have seen several important developments, both political and social, to improve living conditions for people with intellectual disabilities. One significant milestone is the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). By March 2025, a total of 192 countries had ratified the CRPD and declared that they would follow the principles of the CRPD (United Nations, n.d.). Sweden ratified the CRPD in 2008 (United Nations, n.d.).

The CRPD is an instrument for human rights and social development for all people with long-term physical, mental, intellectual, or sensory impairments that interact with multiple barriers, which hinder their extensive participation in society in an equal way to others without disability (United Nations, 2006). The CRPD declares that it should “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and [to] promote respect for their inherent dignity” (United Nations, 2006, p.5).

The CRPD views people with disabilities as subjects who can claim their own rights and should be treated and respected as members of society (United Nations, 2006). The CRPD affirms in Article 19 “The equal right of all persons with disabilities to live in community, with choices equal to others” and further urges all member states to take “effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community” (CRPD, 2006, p.12). The CRPD further incorporates good living conditions and the equal right of people with disabilities to make choices regarding their accommodation. Several articles of the

Declaration concern housing, living conditions and the home environment of people with disabilities. For example, the CRPD states that people with disabilities should be able to choose their residence (Article 19), have access to a variety of in-home support services (Article 19) and have an adequate standard of living with social protection (Article 28) (United Nations, 2006).

Sweden's national policy and policy guidelines also declare the importance of equality for people with intellectual disabilities. The foundation for the national disability policy goals is a national action plan: "From patient to citizen – a national strategy for disability politics" (prop. 1999/2000:79). This was a significant contribution at the time, focusing on creating an inclusive society through societal efforts and responsibility. It takes the view that it is best for all citizens to live in a society that includes everyone and that societal barriers to participation should be eliminated. The goals were "a community based on diversity; a society designed so that people with disabilities of all ages can fully participate in social life; equality in living conditions for girls and boys, women and men with disabilities" (prop.1999/2000:79, p.23). It further declared that the policy should be focused on "identifying and removing barriers to full participation in society for people with disabilities; preventing and combating discrimination against people with disabilities; and providing children, young people and adults with disabilities with the conditions for independence and self-determination" (prop.1999/2000:79, p.23).

Since the national action plan in 2000, Sweden has ratified the CRPD in 2008 and, in 2016, the Swedish government recommended that national goals should be directly related to human rights. A new objective has consequently come into force which is based on the CRPD (prop. 2016/17:188). It declares: "The national goal for disability policy is, with the UN Convention on the Rights of Persons with Disabilities as a starting point, achieving equality in living conditions and full participation in society for people with disabilities. The goal is to contribute to increased gender equality and the children's rights perspective being taken into consideration"(prop. 2016/17:188, p.22). It further declared that the political work should focus on four areas: "the principle of universal design; existing accessibility gaps; individual support and solutions for the individual's independence and preventing and counteracting discrimination" (prop. 2016/17:188, p. 26). The aim is to ensure good living conditions for people with

disabilities and to enable them to live a life like everybody else. This is also the declared aim of the Act concerning Support and Service for Persons with Certain Functional Impairments [in Swedish: Lag om stöd och service till vissa funktionshindrade] (SFS 1993:387) (from now on abbreviated as LSS. Further described in chapter 4.5). However, despite the ambitions presented above, people with disabilities continue to encounter adverse life outcomes and inequalities in living conditions prevail (see for example Cooper et al., 2015; Emerson et al., 2012; Umb Carlsson & Adolfsson, 2023).

1.2. The living conditions for people with intellectual disabilities

People with intellectual disabilities are disadvantaged in several ways. These include for instance a higher mortality rate than the rest of the population (Heslop & Glover, 2015; Hirvikoski et al., 2021), fewer opportunities for good physical health (Gulati et al., 2020; Lante et al., 2010; Perera et al., 2020; Umb Carlsson, 2021), smaller social networks than others (Gilmore & Cuskelly, 2014) and societal barriers and obstacles to community inclusion (Hall, 2017). Loneliness is common. When asked about which activities they most wished to be involved in, adolescents and young adults with intellectual disabilities mentioned community and relationship building activities (Hankle et al., 2021). Other aspects of life are also affected. These include continuing financial challenges, such as difficulty in paying for activities or going on holiday (Conder & Mirfin-Veitch, 2020). People with intellectual disabilities experience difficulties in finding work and their employment status is lower than the rest of the population (Arvidsson et al., 2016; Taubner et al., 2023). They are twice as likely than others to have one, two, three or more mental health conditions (Cooper et al., 2015). There is also a growing body of evidence showing that people with intellectual disabilities are at risk of verbal, physical and psychological assaults, as well as neglect (see for example Hewitt, 2014). They are more likely than people with no intellectual disabilities to have experienced sexual assaults and violence (Christoffersen, 2020; The Swedish Agency for Participation, 2017; 2025). These findings call for action to reduce and eliminate the inequalities between people with and without intellectual disabilities.

Even though CRPD and rights-based policy documents have paved the way for social justice for people with intellectual disabilities, a recent report shows that

many people with disabilities are afraid that their human rights might be questioned or changed (Human Rights Institute, 2024). Furthermore, people with intellectual disabilities may not know when these rights are being violated or how to complain. In their report, the Human Rights Institute (2024) showed that only 35% of 1833 participating people with disabilities were aware of the CRPD and their rights. If they do not know their rights, it is quite likely that they will not know what they should expect from support services.

Rights can be threatened in small, everyday situations that at first glance may not be seen as violations. This can be exemplified by the restrictions concerning control over one's environment in everyday life. The Swedish Health and Social Care Inspectorate (2023) identified shortcomings in the support provided for people with intellectual disabilities in 80 of the 90 group homes which they inspected. For example, staff in 64% of the group homes used unauthorised restrictions that limited the everyday life of the service users (Health and Social Care Inspectorate, 2023). Restraints can give rise to harmful emotions such as physical exhaustion, anxiety and insecurity in both the person with intellectual disabilities and the person who uses the restraint (Nijs et al., 2019). Research about Swedish group homes has found the use of coercive methods to be common. In Björne et al.'s (2022) study, in a total of 250 responses, a third of staff reported that they used restricted measures daily or weekly. Research from Australia and United Kingdom (UK) also shows that people with intellectual disabilities are at risk of living everyday life in passivity unless staff provide active support (Mansell & Beadle-Brown, 2012). Some research shows that people with intellectual disabilities in group homes only spend 50% of their everyday lives in activity, which is much lower than for the general population (Mansell & Beadle-Brown, 2012). The activity level is even lower if the person has a severe intellectual disability (Mansell & Beadle-Brown, 2012). This leads to the need for development and improvement of staff working practices.

1.3. Improving the quality of life for people with intellectual disabilities

One essential way to improve living conditions for people with intellectual disabilities is good staff support which empowers people with intellectual disabilities to be engaged, in control and make active choices about their lives. With regard to stopping abuse and neglect, Robinson and Chenoweth (2011) found that control and choice cannot be stressed enough for people with intellectual disabilities. Many people with intellectual disabilities who live in group homes move in as young adults and stay in the same group home for many years. The environment in the group home most likely plays a fundamental role for each person, which makes the value of training staff to provide skilled support even more important. Several reports show the need for evidence-based methods in this field (Health and Social Care Inspectorate, 2021; National Board of Health and Welfare, 2021). The National Board of Health and Welfare (2021) describes the need among staff for skilled training in augmentative and alternative communication, pedagogic methods and regulations, and general knowledge about LSS. Only 64 % of the staff in group homes for adults had a basic qualification in health and social care or equivalent (National Board of Health and Welfare, 2021), which suggests that improved competence, by means of in training programmes like Active Support, would be of great value.

2. Rationale

The rationale behind this doctoral thesis is the limited previous research about staff interventions in group homes in Sweden. There is a risk that people with intellectual disabilities will lead passive and isolated lives if they do not receive support that is person-centred, individualised and of good quality. Evidence and value-based staff training is thus important for the quality of support and for it to be aligned with LSS (SFS 1993:387) and other legislations. The Active Support staff practice has the potential to fill this knowledge gap and to suggest how increased participation and influence for people with intellectual disabilities can be put into practice. Even though Active Support has been shown positive effects on service user' outcomes in international research (see for example Flynn et al., 2018; van Herwaarden et al., 2025), Active Support has not yet been implemented in Sweden, so this thesis presents the country's first systematic use of Active Support. Based on a large intervention project, this doctoral thesis anticipates accruing new knowledge about how Active Support can affect the daily lives of people with intellectual disabilities and how it challenges views about what constitutes good staff support, and how this support can be managed in daily practice in group homes in Sweden. To achieve this, it is important to include the different perspectives of people with intellectual disabilities and of managers as well as to observe the interactions between staff and service users taking place in group homes.

3. Aim and Research Questions

The overall aim of this doctoral thesis is to investigate the effects of Active Support over two years in four Swedish group homes for people with intellectual disabilities. The following research questions were asked:

- In what way does Active Support in group homes influence the daily lives of people with intellectual disabilities, for example in participation, choice making and engagement in meaningful activity?
- In what way does training in Active Support improve the staff's competence to provide high-quality support to service users, and what role does strengthened leadership play in practice to make this possible in group homes?
- What are the service users' perceptions of good support from staff, and do they feel that the support changed after the implementation of Active Support?
- How can people with intellectual disabilities be involved in evaluating effects of Active Support practice?

This doctoral thesis is structured in chapters. Chapter 4 includes a presentation of intellectual disability, different models of disability, the historical context, Sweden's laws and regulations, and chapter 5 is about previous research about group homes and staff training programs. Chapter 6 is about Active Support. It includes a description of the training in Active Support, essential aspects of Active Support, previous research about Active Support, and the development of Active Support. Chapter 7-8 contain the actual implementation of Active Support, its theoretical frameworks and methodology. It is followed by chapter 9 that presents the main findings of the Active Support intervention through a summary of the four articles of the thesis. Chapter 10 comprises a discussion about results and practical implications and chapter 11 an overall conclusion. Chapter 12 includes suggestions for future research.

4. Background

For contextual reasons, it is valuable to understand the setting and the society where the intervention is taken place. The following chapter describes an introduction of definitions of intellectual disabilities, the differing perspectives on intellectual disability, and the historical context of living with an intellectual disability.

4.1. People with intellectual disabilities

People with disabilities have always existed in all societies, but the perceptions of who has a disability have varied over time and contexts. Today, estimations and surveys suggest that between 10-30% of the population have at least one form of disability in Sweden (National Board of Health and Welfare, 2022). However, such estimations vary depending on the inclusion criteria.

Many people with disabilities do not need special support and services from the state or the municipality or have chosen to not apply for support (National Board of Health and Welfare, 2022). However, good support in everyday life is imperative for most people with intellectual disabilities. International research shows that around 1% of a population has an intellectual disability which is long-lasting and usually requires support services throughout life (Maulik & Harbour, 2010; Maulik et al., 2011). A recent Swedish study investigating the prevalence of intellectual disability among 10-year-olds in Sweden between 2011 and 2021, showed an increase from 0.64% (2011) to 1% (2021) (Morinaga et al., 2024). The main increase was in mild, moderate and unspecified intellectual disability and the authors suggested that this could be due to changes in diagnostic practices over time in Sweden (Morinaga et al., 2024).

The diagnosis of intellectual disability is usually reached by means of a medical and/or psychological assessment. Most obtain such a diagnosis before or during their school years (Region Stockholm, 2025). Although the medical perspective is not in focus in this thesis, I will describe the diagnostic criteria of intellectual disability, since this determines who, according to LSS, is entitled to municipal support services, for example, a flat in a group home.

The dominating diagnostic system used for intellectual disability is the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), published by the American Psychiatric Association (American Psychiatric Association, 2013). DSM-5 is mainly used in Sweden for clinical assessments in psychiatry, while another classification system, the International Statistical Classification of Diseases and Related Health Problems (ICD-10) is used in the registration of health problems, illnesses and other causes of people's contact with healthcare services (National Board of Health and Welfare, 2024).

According to the DSM-5 criteria, an intellectual disability should have its onset during the developmental period (i.e. childhood/adolescence) and include deficits in intellectual functioning like reasoning, abstract thinking, problem solving, the ability to learn from experience, and deficits in adaptive functioning compared to peers (American Psychiatric Association, 2013). The fifth edition estimates the severity of intellectual disability according to the level of support required in daily life, as well as clinical assessments and standardised testing. Intellectual disability is usually categorised on a spectrum and can be mild, moderate, severe or profound (American Psychiatric Association, 2013). Estimations of level of severity of intellectual disability are usually based on cognitive, social and practical ability. A diagnosis of intellectual disability can be made if a person scores approximately two standard deviations below the normal range ($IQ < 70$) on a standardized test, however if the adaptive level meets the criteria for intellectual disability, then a diagnosis can be made on $IQ < 75$ (Region Stockholm, 2025).

The majority of people with intellectual disabilities are diagnosed with a mild intellectual disability (Region Stockholm, 2025). Nevertheless, individual differences are significant, and the above categories are simply categories and broad definitions. One should always look at the person behind the disability and their uniqueness, potential and abilities. The criteria should therefore be regarded as the criteria for a diagnosis of intellectual disability. Having such a diagnosis is essential for being granted specific support services by the municipality. The diagnosis of intellectual disability is most often made in health care or school settings but is also used as a criterion for eligibility for special support (see also section 4.5).

4.2. What is disability? Different models of disability

Several models and perspectives have been developed to understand what disability means (Stiker, 1997). The models play an important role in how society perceives disability and this understanding impact on what kinds of support the society offer and the lives of people with disabilities (Lewitt, 2017). The models can therefore also be seen as mental maps (Zaks, 2023). There are different views of which the main models are, and I choose to describe three main models of disability: the medical model, the social model, and relational model. The main perspective in this thesis, which also will be described here, is the relational model/perspective (Söder, 1982).

The medical model was long the dominant perspective on disability and is still prevalent in western countries (Zaks, 2023). It is based on a medical perspective which focuses on the individual aspects of disability, and perceives disability as abnormality, trying to make disabled people conform to the idea of a normal person (Zaks, 2023). This model's focus is on treating or curing a person with a disability, and it sees barriers as coming mainly from the individual and the diagnosis. From this perspective, disability exists as a problem in a person's body and requires medical attention (Goering, 2015). However, many people with disabilities describe the problems they encounter in society as stemming from the view represented by this traditional medical model of disability (Goering, 2015), which leads us to the next model.

The social model emerged as a reaction against the medical model and started to spread during the 1960s and 1970s through the civil rights movement (Goering, 2015). The social model perceives disability as a constructed concept and the problems experienced by a person with disabilities are caused by societal hindrances (Lewitt, 2017). For example, a person who arrives at a university in a wheelchair may not experience any problems because of the disability if there are appropriate arrangements for wheelchair users at the university entrance. However, if the only way to enter the university is by a staircase, the hindrance is constituted by the environment that causes the disability. According to this point of view, there are structures in society that degrade and exclude certain groups of people, and these barriers can be overcome with appropriate societal changes and

arrangements. The social model makes a clear distinction between impairment and disability (Goering, 2015; Oliver, 1990). Impairment is a state of the body that is nonstandard and can be evaluated by its possessor as either negative, positive or neutral (Silvers, 2003). Disability is, rather, the disadvantage caused by social organisations that give little or no consideration to the disadvantaged and exclude their participation in activities because of institutional norms and social arrangements that could be changed (Goering, 2015; Oliver, 1996). The disability movement has been a series of activities based on the social model (Oliver, 2004). The social model has also been criticised for not fully acknowledging the disability experience (Shakespeare, 2006).

A third perspective, which also takes social as well as individual factors into consideration, is the relational model of disability. It was defined in a disability policy report in 1976 and has been established in Swedish disability policy since then: “Disability is influenced by the individual's living conditions and the structure of society. A certain injury may constitute a disability in some situations but need not do so in others. Disability is therefore a relative concept” (Prop. 1976/77:87, p.7). This perspective is valuable since it acknowledges both the individual and the environmental aspects of disability. Similarly to the social model, the relational perspective perceives environmental factors as crucial for creating barriers for people with intellectual disabilities. This thesis therefore draws on Söder's (1982) relational definition of disability, which recognises that both individual and environmental characteristics impact people's living conditions. This perspective emphasises the interaction/relationship between the individual and the environment in a broad sense, which means that not only individual abilities but also the quality and quantity of support received affect the prevalence of disability.

There are also other perspectives and models in the field of disability, one of which is the biopsychosocial model, which was launched in 1977 by a psychiatrist named George Engel (1977). It looks at the psychological, social and biological aspects of health and disease (Engel, 1977). The International Classification of Functioning, Disability and Health (known as ICF) takes its structure from the biopsychosocial framework (Leonardi et al., 2022). The ICF is the World Health Organization framework and the international standard for measuring and describing health and disability (World Health Organization, 2024). Bolton (2023)

describes how the main additional value of the biopsychosocial model is that it brings personal, interpersonal, and institutional factors in clinical care together. However, it has also been criticised for being too theoretically underdeveloped (Bolton, 2023).

4.3. Social work with people with intellectual disabilities – a historical perspective

This doctoral thesis is written within the discipline of social work and focuses on people with intellectual disabilities. Social work aims to support many groups of people at different stages in life. However, people with disabilities are a particularly important group because they often have a lifelong need of support. This chapter will begin with an overview of the historical context for people with intellectual disabilities, followed by a description of the organisation of support services today (in particular accommodation services).

Professional care and education for people with intellectual disabilities in Sweden began with the philanthropic work of the 19th century. Before the middle of the 19th century, the primary caretaker for people with intellectual disabilities was the family (Jormfeldt, 2016). From the mid-1850s, institutions were built to provide care for people with intellectual disabilities (Jormfeldt, 2016). A number of women, mainly from wealthy backgrounds, dedicated their lives to improving society and working with the social problems of poverty and the poor circumstances of vulnerable social groups (such as people with intellectual disabilities) (Grunewald, 2009). Emanuella Carlbeck (1829-1901) was a pioneer who dedicated her life to working with children with intellectual disabilities (Røren, 2007). In 1866, Carlbeck started the first schooling and care for children with intellectual disabilities (Røren, 2007). She worked according to the principles of social justice and social change, which makes her a pioneer in the field of social work.

From the 1850s, educational and medical ideas dominated social work. The aim was to educate people with disabilities so they could participate and be more involved in society as citizens (Stenström-Jönsson, 1995). For example, Carlbeck aimed to improve the skills of the children with intellectual disabilities that she educated and believed that they could improve with the right education (Røren, 2007). The late 19th century was filled with positive ideas about including people with disabilities in society (Stenström-Jönsson, 1995). The view was that they could become full citizens in society with the right education (Stenström-Jönsson, 1995). The role of pioneers and the establishment of disability organisations were important steps towards the more inclusive treatment of people with disabilities (Røren, 2007). However, times were changing at the beginning of the 1900s. In the first half of the 20th century, until the mid-1950s, these previous ideas were superseded by a belief in eugenics, perceptions of heritage, and a mainly medical outlook on disability (Stenström-Jönsson, 1995; Wolff, 2025). This was a dark period in institutional care in Sweden. The dominating belief was that the care of people with intellectual disabilities should take place away from society, thereby protecting society from people with intellectual disabilities (Grunewald, 2009).

Sweden, like other Nordic countries, saw an expanding system of institutions for people with intellectual disabilities during the first 70 years of the 20th century (Tøssebro et al., 2012). Although large institutions were common, they varied in size. Some large ones housed 500 or more, whereas some “only” accommodated 20-30 people. The mixed size was mainly for practical purposes (Tøssebro et al., 2012). In the 1950s, large institutions were the preferred first choice in the Nordic countries (Tøssebro et al., 2012).

People with intellectual disabilities were at that time on the periphery of society (prop. 1999/2000:79). There were few opportunities for finding work, joining activity groups or having social encounters in society. This period was characterised by negative assumptions and attitudes about people with intellectual disabilities and they were considered a burden to society (Grunewald, 2009). Barron (2004) describes how diligence in people with intellectual disabilities was considered important. Work and sexuality were the dominant areas of life where diligence was emphasised. Sexuality was restricted and controlled, based on the belief that the lack of morals of women with intellectual disabilities could otherwise impact society negatively. There was also a perception that women with

intellectual disabilities were vulnerable to being sexually assaulted and therefore needed to be protected from society. In 1934, Sweden's first law regarding sterilisation came into force. It targeted women with intellectual disabilities, mental health problems and other kinds of "disturbances of their soul" (Barron, 2004, p. 72) and was not abandoned until 1975. Between 1934 and 1975 an estimated 63,000 people (mainly women) were sterilised, many against their will or without their consent (SOU2000:20). The law from 1935 was updated in 1941. The new law stated that sterilisation needed consent and was based on voluntarism, but in reality, many sterilisations took place by coercion (SOU2000:20). Many of the people, both women and men, who lived in institutions had limited contact with family members and were isolated from society, which made them susceptible to abuse of power. Barron (2004) exemplifies this by looking at one institution, Västra Mark, which was a hospital for women who were considered antisocial and had an intellectual disability. Women were considered sexually unreliable, and their days were filled with work and discipline to control them. In Västra Mark, 90% of the patients worked unpaid (Barron, 2004). Many tasks, like cleaning, sewing, washing clothes and other domestic tasks, occupied the patients' everyday lives. This was in line with the common belief at that time that such activities would keep them occupied and away from other thoughts and destructive activities. This common belief also considered people with intellectual disabilities as a specific group that needed to be taken care of.

A new era began after World War II, and the negative view of people with intellectual disabilities would gradually change over the following decades. However, these steps came slowly, and the initial postwar years focused on the general population rather than people with intellectual disabilities. The new view was that welfare should cover the general population and be universal (Tideman, 2000). The welfare state should meet and accommodate a variety of needs such as financial security, housing, education, healthcare, social care and help in situations of crisis (Tideman, 2000). Furthermore, on 1 December 1948, the United Nations General Assembly adopted the Universal Declaration of Human Rights, which stated in Article 5 that "No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment" (United Nations, 2024). Fundamental human rights were for the first time protected universally and a

substantial majority of countries, including Sweden, voted for the declaration to be adopted (United Nations, 2024). The new era forced people who had previously been treated inhumanly to be recognised. Secondly, the old views about people who were not part of the employed work force, such as those with mild intellectual disabilities, changed due to a shortage of labour during the war and the years afterwards (Mallander, 1999). Many of those who were employed during the war had previously not had access to the job market. This resulted in a positive change, with marginalised groups remaining in employment after the war had ended. One investigation found that by 1962, almost half of all former students in special schools during the years 1935-39 had been employed on the open job market (Gustin & Wessman, 1964). Labour shortages had paved the way for people with mild intellectual disabilities to be part of the workforce to a greater extent than previously (Mallander, 1999). Thirdly, the beliefs about eugenics that had affected people with intellectual disabilities before and during World War II, were largely, if not completely, abandoned in the postwar years. In the 1950s, several scandals in the institutions were highlighted in Swedish newspapers and people started to reflect on the poor circumstances in institutions for people with intellectual disabilities. Mallander (1999) describes how the public was initially upset by the fact that some people ended up in institutions because of misdiagnosis. Later, public attention shifted and started to question the institutional treatment of people with disabilities. During the same decade, perceptions about children with intellectual disabilities started to change and some important policy improvements were introduced. One of them was the recognition that children with a disability should be entitled to education. From 1954, the Swedish education law included more children with disabilities, and by 1968 all children were obliged to go to school through compulsory school attendance (Mallander, 1999). In 1952, the Swedish “Organisation for mentally disabled children” (shortened FUB) was started in Stockholm, becoming a national organisation in 1956 (FUB, 2024). In the 1960s, ideologies and ideas in society started to change still further, and there was more criticism of state institutions and the living conditions of people with intellectual disabilities (Ehliasson et al., 2016; Tøssebro et al., 2012). In the growing welfare state, ideas about what constituted good living conditions were at odds with the poor conditions in the institutions (Ehliasson et al., 2016; Tøssebro et al., 2012).

Furthermore, institutional segregation was far from being in line with the idea of full citizenship (Tøssebro et al., 2012).

However, new ideas and values that would soon be adopted in society would make a profound difference for the situation of people with intellectual disabilities. The new era included ideas about integration and normalisation, both of which became central concepts in the forthcoming changes (Ehliasson et al., 2016; Tideman, 2000). Integration meant that people with intellectual disabilities should be part of society just like anyone else (Stenström-Jönsson, 1995) and no longer be separated from the rest of society. The integration concept is closely linked to the normalisation principle and can be seen as an aim as well as a means to achieve the normalisation principle (Tideman, 2000). The greatest influence from the Nordic countries on the development of international policies and legislation for services for people with intellectual disabilities was the vision of normalisation (Tøssebro et al., 2012), a principle first described systematically and published by Bengt Nirje in 1969 (Nirje, 1969). According to the Nordic view of normalisation as defined by Nirje (1970, p.47-51), people with intellectual disabilities were entitled to:

1. A normal circadian rhythm
2. A normal weekly pattern
3. A normal development of the life cycle
4. That choices, desires and needs are respected
5. To live in a two-sex world
6. Normal economic conditions
7. Normal standard of physical facilities (for example the home environment)

The normalisation principle emerged first as criticism towards living conditions in institutions, that they wished to reform (Tideman, 2000). It was argued that if nr 1-7 above would be fulfilled, the situation in institutions would substantially improve. However, it proved to be difficult to fulfil the normalisation principle at institutions, and this would eventually lead to the decommissioning of the institutions (Tideman, 2000). Therefore, normalisation embarked a new period

towards improved inclusion for people with intellectual disabilities (Culham & Nind, 2003; Wolfenberger, 1983).

The definition of normalisation differed between how it was defined in the Nordic countries and how it was defined primarily by Wolfenberger in the United States of America (USA) (see for example Wolfenberger, 1983). In the Nordic countries, normalisation was associated with having the same life patterns and rhythms as everyone else in society, whereas the American concept emphasised that people with disabilities should be more accepted by society, either by means of cultural adjustments or by changing society's perception of people with disabilities (Stenström-Jönsson, 1995). Normalisation from the American perspective mainly focused on improving the low status of people with disabilities (Tideman, 2000). The dominant view of normalisation in Sweden, shared with the other Nordic countries, concentrated on the right of people with disabilities to live their lives in similar circumstances to everybody else.

4.4. From institutions to group homes

The normalisation movement had an extensive influence on deinstitutionalisation (Tideman, 2000). Nevertheless, institutions were still the first option in Sweden in the 1970s and 1980s, and group homes were rare during that time (Mallander, 1999). It was not until the 1980s that group homes were given official recognition and became standardised (Mallander, 1999). In 1986, a new law for the care of people with intellectual disabilities came into force (SFS 1985:568). It clearly stated for the first time that large institutions should gradually be replaced by group homes. This development was also found in other Western countries: larger institutions were replaced by smaller group homes and access to ordinary education, health and leisure activities were prioritised (Culham & Nind, 2003). The institutions were also expensive, and the smaller living arrangements were considered better financially for society (Tideman, 2000).

Deinstitutionalisation in Sweden occurred in the same time frame as many other Western countries, such as the UK and the USA. As a result, the improvements achieved by closing institutions and building group homes and community living arrangements have been researched extensively internationally. Community living has been repeatedly shown to be better than the old institutions (Mansell &

Beadle-Brown, 2012; Mansell et al., 2010). In an international systematic review from 1996, Emerson & Hatton examined 71 articles published between 1980 and 1994 and concluded that community-based residential services were associated with many positive outcomes. These include increased engagement in activities, increased contact with staff, increased use of community facilities, increased adaptive behaviours and reduced challenging behaviours, increased choice making; increased contact with family and social network; a better material standard of living; and increased community acceptance (Emerson & Hatton, 1996). Similarly, in a study of the municipalisation of care services in Sweden, 88% believed that group homes were better than living in institutions (Tideman, 2000). In 2003, all former institutions were closed in Sweden.

4.5. The Social Services Act and the Act concerning Support and Service for Persons with Certain Functional Impairments

Normalisation and integration paved the way for today's laws regulating services for people with intellectual disabilities. In Sweden, two laws ensure that people with intellectual disabilities receive adequate municipal support: the Social Services Act (SFS 2001:453) and the Act concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993:387, the Swedish abbreviation LSS will be used in the following). The Social Services Act applies to everyone, whereas LSS is a specific law for people with considerable support needs. The Social Services Act, Chapter 4, §7, declares that the municipality is responsible for guaranteeing that people with disabilities in need of accommodation with special services are provided with such accommodation (SFS 2001:453). This is also regulated in LSS. According to §7 LSS, people with disabilities are eligible for support from society to guarantee good living conditions (Ehliasson & Markström, 2020). The overall objective of LSS is to ensure that persons with a disability are "able to live like others" (SFS 1993:387, §5). It focuses on the unique needs of the individual with regard to autonomy, choice, empowerment and integrity (Ehliasson et al., 2016).

There is a distinct difference between LSS and the Social Services Act. Where LSS declares that the law should ensure good living conditions, the Social Services Act

only provides for reasonable living conditions. However, to be eligible for one or more of the 10 LSS rights (see below), a person should have considerable support needs, which are durable and lasting and cannot be ensured by any other laws or types of support. They should also belong to one of the three following categories: 1) People with intellectual disabilities and/or autism spectrum, 2) People with significant and permanent intellectual disabilities following brain injury in adulthood caused by external violence or bodily illness, or 3) People with other long-term physical or mental disabilities which are manifestly not due to normal ageing. These disabilities should be considerable, cause significant difficulties in daily life and thus give rise to a significant need for support or services (SFS 1993:387, §1).

According to LSS §9, the ten rights for special support and services are:

1. Counselling and other personal support that requires special knowledge of the problems and living conditions of people with severe and permanent disabilities
2. Assistance of a personal assistant or financial support for reasonable costs for such assistance, to the extent that the need for support is not covered by the assistance hours granted pursuant to Chapter 51, Social Insurance Code
3. Assistance with companion services
4. Assistance of a contact person
5. Replacement support in the home
6. Short-term stay outside the own home
7. Short-term supervision for schoolchildren over the age of 12 outside their own home in connection with the school day and during holidays
8. Living in a family home or housing with special services for children or young people who need to live outside the parental home
9. Housing with special services for adults or other specially adapted housing for adults
10. Daily activities for people of working age who are not in gainful employment and not in education (SFS2010:480).

No 9 of the above gives the right to supported accommodation for adults (SFS 1993:387).

4.6. The group homes today

In Sweden at the moment, 30 389 adults with disabilities live in supported accommodation in accordance with LSS 9, §9 (National Board of Health and Welfare, 2025). The LSS provides for three main kinds of accommodation (National Board of Health and Welfare, 2018):

- Group homes
- Service homes
- Other specially adapted housing

Group homes are for persons with higher support needs, service homes are for those with fewer support needs. However, most people with intellectual disabilities or autism who need support 24/7 and are entitled to the rights of LSS, live in group homes. Since LSS came into force three decades ago, smaller group homes have been the most common form of supported living. A group home should have a limited number of residents and there is a guiding principle that only 3-5 people with disabilities should live in each group home (see National Board of Health and Welfare, 2018). However, there is an acceptance of a maximum of six flats in each group home, and this has become the gold standard. Group homes consist of a flat for each person, each fully furnished with a kitchen and a bathroom. Flats are usually fairly small, comprising one or two rooms. In addition to individual flats, there are also shared areas in group homes for social activities with support workers and other residents. There is usually a shared living room and kitchen which is included in the rent. There is also often a laundry (even though in newly built group homes many have their own washing machines). Finally, there is usually an office for staff and a room for staff to stay overnight, since group homes are staffed with 24-hour supervision and care. Group homes can be found both in residential areas and in the countryside. However, according to the government bill prop.1992/93:159, group homes should be integrated into society, so that residents are able to participate in activities in the community. The number of staff working per shift depends on the support needs of each resident.

The usual number of staff for each group home is 2 to 3 support workers per shift, supporting approximately six service users.

4.7. Staff qualifications and training

Paragraph 6 in LSS states: “For activities under this Act, there must be enough staff for the service to provide good service and support” (SFS 1993:387). National guidelines and regulations were published by the National Board of Health and Welfare in 2014. They recommended that staff should have a formal upper secondary school qualification in one of the following programmes: health and social care, children and leisure programme, or equivalent (SOSFS 2014:2). Further requirements included good knowledge of LSS, CRPD, as well as communication skills and knowledge about different forms of disability and support needs associated with the disability (SOSFS 2014:2). The requirements did not clearly state how these skills would be obtained.

The new role of senior support worker (in Swedish: stödpedagoger) has been implemented recently in group homes and day activity centres. The senior support worker must have a specialist training of 200 credits, gained from Higher Vocational Education, which is a post-secondary form of education (National Board of Health and Welfare, 2021). The senior support worker is trained to specialise in supporting and supervising other staff, especially other support workers, in special educational methods, documentation, and augmentative and alternative communication (National Board of Health and Welfare, 2021). However, not all Swedish municipalities have employed staff in this new role. Some group homes have a senior support worker while others do not. Furthermore, lack of formal training and high staff turnover can be considerable in some group homes, and it may be difficult to fill these positions.

The training and formal qualifications of staff vary, not just among senior support workers, but among all staff in group homes. In a national survey in 2021, 53% of managers reported that they had difficulties hiring people with the right competence for available positions in group homes (National Board of Health and Welfare, 2021). As a consequence, the quality of support services varies (National Board of Health and Welfare, 2021). Some group homes have a good

standard and can ensure good living conditions, while others lack adequate quality of support. The lack of general, evidence-based staff practices means that staff are often left to make their own judgements.

5. Previous research

This chapter presents an overview of research on people with intellectual disabilities regarding group homes, staff training programmes, staff practices in group homes and a comparison between Active Support and other staff practices.

5.1. Previous Swedish research about group homes

Disability studies has been a growing research field in Sweden over the last 20 years. In the 1980s and 1990s, research reflected the closure of institutions or exploration of public attitudes towards people with disability. Following the closure of institutional care, both Stenström-Jönsson (1995) and Mallander (1999) examined the culture in group homes and institutions. Stenström-Jönsson (1995) found that service users' lives were better after relocation to group homes, in terms of improved living conditions and social improvements. These results are supported by Tideman (2000), who found that service users enjoyed better living conditions in the years after moving from institutions into group homes. Only three out of 242 persons reported that living in an institution was better than living in a small-scale group home (Tideman, 2000).

However, control and integrity are key aspects when studying group homes (Stenström-Jönsson, 1995). For example, a clear association was found between institutional behaviour, disrespect of service users or overprotection of service users and negative outcomes such as lack of development in service users (Stenström-Jönsson, 1995). These findings highlighted the necessity to discuss the professional role of staff and focus on staff's behaviour towards each person living in the group home.

Previous research has also looked at routines and control as well as participation and self-determination. Mallander (1999) found an extensive impact of routines in daily life at the residential services and a negative impact of staff on the service users' social life. Similarly, Ringsby Jansson (2002) studied three group homes and the living conditions and social life of people with intellectual disabilities living there. She observed three types of social style among the service users: the informally oriented contact seeker, the club oriented and the staff and relative

oriented (Ringsby Jansson, 2002). The arenas of social life differed with the three styles, with the first and second having more social networks and the third having more limited social networks (Ringsby Jansson, 2002). This shows how the lives of people with intellectual disabilities differed between different group homes depending on their relationships with staff and neighbours. The existence of rules, routines and regulations was in line with the findings in both Kåhlin (2015), Mallander (1999), Ringsby Jansson (2002) and Widerlund (2007). Kåhlin (2015) argued that routines about mealtimes and coffee breaks determined how and when other activities were initiated. Lövgren (2013) found that service users adjust their living according to the support workers' schedules.

In line with these results, Olin's (2003) analysis showed how young adults with intellectual disabilities demonstrated an ability and interest in their growing independence, but that some regulations found in the group homes were specific for that type of accommodation. Group homes were found to have strict rules about keeping the place tidy, regulations about food intake or visits from friends (Olin, 2003). These rules contradicted the intention (stated in LSS SFS1993:387 §5) to be able to live "like others", because a comparable situation was not found among young adults without disability. Deficient working methods have been identified and described as an obstacle to promoting participation (Berlin Hallrup, 2019), while many routines found in daily practice obstructed greater participation.

Widerlund (2007) also found that staff in group homes can be very ambiguous about the concepts of self-determination and participation. This accounts for multiple levels. Thus, on the one hand they emphasised the importance of service users exercising participation and self-determination, but on the other hand they were the ones making most decisions. Paradoxically, staff were anxious that the service users would start to have too much control, while at the same time believing that service users' lack of self-confidence was the reason for them not exercising more participation and self-determination. It was difficult to change routines because they provided security (Widerlund, 2007). Also, if staff improve their communication skills, this could increase the service users' opportunities for exercising autonomy (Jormfeldt, 2016).

Participation in everyday life can be particularly conditional for people with profound intellectual disabilities when living in group homes (Talman, 2018). For adults with profound intellectual disabilities, participation was found to be restricted and rarely covered decision-making processes, social contacts or leisure activities. The attitudes of staff created a barrier to participation for people with profound intellectual disabilities living in group homes (Talman, 2018).

Larsson (2021) reviewed what conditions for self-determination persons with moderate to severe intellectual disabilities were given within the context of the support services provided for by LSS (SFS 1993:387). She found that self-determination is limited in the everyday lives of people with moderate to severe intellectual disabilities living in group homes. The study concluded that new working methods and better staff practices could increase self-determination for such people.

Gäddman Johansson (2021) analysed how vulnerability is expressed and managed in social interactions between service users and support workers in sheltered accommodation (i.e. group homes) as an aspect of everyday support. Gäddman Johansson (2021) aimed to develop an understanding of the vulnerability of people with intellectual and developmental disabilities. The author outlined two overarching forms: 1) vulnerability associated with situational uncertainty seen as a risk individuals' health and safety, and 2) vulnerability related to ritual automatization seen as a threat to each person's individual freedom and well-being (Gäddman Johansson, 2021). This novel method described how vulnerability is rarely thought about but needs to be analysed to gain a better understanding of interactions in everyday living in group homes.

In conclusion, much attention in previous research has concerned limited participation. There is a need for more research into how progress can be accomplished. Research about intervention strategies to increase self-determination, participation and autonomy could further facilitate and explore how increased participation could be put into practice. One such way is to examine interventions such as Active Support.

5.2. Staff practices in group homes

In the next section, I will go through the main staff practices used in group homes in Sweden. Training is usually only operationalised on a local level. Hence, whether or not support workers receive training depends on the municipality or the private organisation in charge of the support. Several limitations have been identified in evidence-based practice in disability organisations and services (Eriksson & Karlsson, 2016). Many training programmes are launched but they lack a clear grounding in research and systematic follow-ups (Eriksson & Karlsson, 2016). Several initiatives to develop support have been made in recent years. These include Pict-O-Stat and the Participation Model, with the latter gaining most recognition (Eriksson & Karlsson, 2016). Pict -O-Stat is a web-based material which uses symbols and photographs to facilitate communication. The Participation Model uses a structured form for communication to enhance influence in daily activities for people with intellectual disabilities (the Participation Model, 2020). Despite the fact that the Participation Model has been assessed as improving service users' influence, the authors conclude that it cannot be regarded as evidence-based (Eriksson & Karlsson, 2016).

Staff in group homes often say that they use specific working practices, but to varying extents. Over the last few decades, a number of psychosocial and educational interventions have been developed internationally (Virues-Ortega et al., 2013). Two of these training programmes are TEEACH and the Low-Arousal approach (Mesibov et al., 2005; Hejlskov Elvén & Hansén, 2023; Hejlskov Elvén & Sjölund, 2018). TEEACH was started as a programme in 1972 in USA by Eric Shopler, and is now both a clinical service and also a training programme based at the University of North Carolina (Mesibov & Shea, 2010). In TEEACH, standardised tests are used to examine a person's abilities, after which the specialist tailors structured learning procedures that meet that the person's unique needs (Virues-Ortega et al., 2013). TEEACH emphasises a close partnership between practitioners and the parents of children with autism (Van Bourgondien & Schopler, 1996). It makes use of each person's ability for visual processing and uses visual structures for organising activities (Virues-Ortega et al., 2013). In a meta-analysis of 13 studies of TEEACH, Virues-Ortega et al. (2013) found conclusive evidence of its positive impact on social behaviour and a reduction in maladaptive behaviour. Structured teaching is based on methods from the

TEEACH-model (Mesibov & Shea, 2010). In Sweden, Structured teaching has been increasingly known in services like group homes and daily activity centres, and not just practiced for supporting autistic people but people with intellectual disabilities as well.

Another staff practice that has gained attention in Sweden in educational and care settings and prisons, is the Low Arousal Approach. This aims to de-escalate situations of concern and is attuned to the needs of people with disabilities (McDonnell & Deveau, 2018). Staff who are positive about low arousal approaches have been found to make less use of negative restrictive interventions (McDonnell & Deveau, 2018). The Low Arousal Approach has been described as a crisis management strategy that demonstrates that stress as well as physiological arousal can be conveyed through behaviours of concern (McDonnell et al., 2024). The Low Arousal Approach has been developed to meet the needs of people in vulnerable situations who have behaviours of concern, when “common sense” is not enough to meet the needs professionally (Hejlskov Elvén & Hansén, 2023). Furthermore, Hejlskov Elvén and Hansén (2023) stress that Low Arousal Approach is only one of several approaches and that it is important to continue evaluating the work practices we use in social work.

In the USA, the Positive Behaviour Approach (PBS) has been implemented in services for people with intellectual and developmental disabilities and is especially taught to staff to use with people who need support and show behaviours of concern/challenging behaviour (Carr et al., 2002; Mahon et al., 2021; Strydom et al., 2020). When implemented successfully, PBS has been proven to reduce behaviours of concern and increase skills (Dewey et al., 2023). However, a systematic review showed that it is important how staff are trained, and simply describing the method was not effective (Mahon et al., 2021). The review found that effectiveness increased by adding components, such as modelling, role play and feedback. Both the Low Arousal Approach and PBS share similarities in that they focus on behaviours of concern.

Despite the existence of the practices and methods described above, Jones (2013) concluded that systematic staff practices are generally seldom implemented. It is also common for staff themselves to develop practices to be able to meet individual support needs in the services (National Board of Health and Welfare,

2012). Nevertheless, skills and in-depth knowledge that are tailored to individual needs are of great importance. While training programmes and staff practices focusing on QoL have been successfully implemented in group homes in many Western countries (Bigby et al., 2017; Bigby et al., 2020a), this has not been the case on a large-scale in Sweden so far.

5.3. Can Active Support add new knowledge? A comparison with other staff practices

As showed above, Active Support is not the only staff practice to be found in the disability field. It is important to acknowledge that the practices mentioned above are valued by staff in social care settings and there is a growing body of findings showing that these practices are valuable in increasing skills or reducing behaviours of concern (see for example Virues-Ortega et al., 2013; McDonnell & Deveau, 2018). It is therefore important to address differences and similarities between Active Support and these other practices. All staff practices (Structured teaching/TEEACH, Low Arousal Approach, PBS and Active Support) are person-centred and address the importance of providing support that suits each person's individual needs. However, there is one major difference between Active Support and the other practices or interventions. These practices focus on, for example, improved behaviour or are specifically developed for people with autism. Active Support focuses on how staff can provide active support for people's involvement in meaningful activities and relationships and provides a framework for how to do this. In Active Support, the aim is to engage people with intellectual disabilities to reduce passivity and isolation. It is a practice based on decades of research and has been specifically developed for people with intellectual disabilities living in group homes (Mansell & Beadle-Brown, 2012). Other staff practices have been developed either for people with autism or for those with behaviours of concern and they do not share Active Support's long history of research about group homes (see for example Mansell & Beadle-Brown, 2012). This is therefore a real opportunity to examine whether Active Support can fill the training shortcomings that exist among staff in group homes. In the next chapter, I will provide a more in-depth description of the staff practice which is the focus for this thesis, namely Active Support.

6. Active Support

The following chapter introduces Active Support, the main features of Active Support training, a summary of Practice Leadership training, and previous research into Active Support and Practice Leadership.

6.1. Active Support – a staff practice to increase engagement

The Active Support practice was developed in the UK during the transition from institutions to community living in the 1980s and 1990s (Mansell et al., 2010). The core components of Active Support were conceived and developed between 1981 and 1986 in the first community accommodation for people with intellectual disabilities in the UK (Totsika et al., 2008). Three researchers should be acknowledged for their early contributions to the development of Active Support: Jim Mansell, David Felce, and Judith Jenkins (Totsika et al., 2008). They promoted the concept of engagement, a key aspect of Active Support, and highlighted the importance of engagement for having a good QoL. Active Support has its philosophical roots in normalisation, Applied Behavior Analysis (ABA) and an ordinary lifestyle (Totsika et al., 2008). The concept of an ordinary lifestyle comes from the policy document *An Ordinary Life* (Kings Fund Centre, 1980) which declared that people with intellectual disabilities should have the same value as anyone else and should be included in the community like everyone else. The *Ordinary Life* concept emerged at the same time as the normalisation movement (Totsika et al., 2008). The organisational technology of Active Support comes from ABA, to which Active Support is related. Totsika et al. (2008, p. 219) have described the following components of ABA related to Active Support and used the definition of ABA by Baer et al (1968):

“Applied – The way behaviour must be socially important as well as important to the person or others

Behaviour – Behaviour must be precisely measured and demonstrate whose behaviour changed

Analysis – The procedures used must demonstrate functional relations to the best degree possible, given the nature of behaviour and context within which the procedures are being used”

Research into and implementation of Active Support has progressed in recent decades and has particularly been led by disability researchers such as Professor Julie Beadle-Brown and Professor Christine Bigby. Active Support is a staff practice with the overall objective to increase engagement in meaningful activities, daily lives and interpersonal relationships in order to improve living conditions for people with intellectual disabilities (Mansell & Beadle-Brown, 2012). Active Support is, further, a person-centred practice, which means that it is tailored to each person’s unique support needs. Active Support aims to train staff and first line managers to provide better support for people with intellectual disabilities. It encompasses two elements; a) planning and examining the activity of each individual throughout the day, b) training support workers to help each person with intellectual disabilities to be involved in activities they would not be able to do by themselves (Smith et al., 2002). All parts of Active Support aim at involving people with intellectual disabilities in their day-to-day activities. Without support, or quality support that reflects people’s own preferences, the consequences would eventually be a life with greater isolation and of lower quality (Mansell et al., 2002).

Fundamental aspects of Active Support involve *meaningful activities*, *engagement*, *enabling* and *empowering* (Mansell & Beadle-Brown, 2012). *Meaningful activities* implies that the activity should be of value for the individual, purposeful and real (Mansell & Beadle-Brown, 2012). *Engagement* means that staff should support the person to actively participate and be involved in an activity, based on preferences, choices and possibilities. Engagement implies that the support worker is doing with, rather than doing for. Several factors determine whether staff will adopt Active Support principles. Active Support emphasises an *enabling* relationship. Previous research suggests that support workers can adopt various approaches in their work with people with intellectual disabilities, such as the Enabling approach, the Task-oriented approach and the Friendly approach (Mansell & Beadle-Brown, 2012).

The enabling relationship is defined by respect for the person with intellectual disabilities and an understanding that life could be better. It involves a critical

approach towards how work is being done, and which improvements could be formalised. This highlights the fact that staff's ability to begin working with Active Support reflects not only their qualifications, but also their values and attitudes. Staff's general perception of people with intellectual disabilities will reflect how much they will try to adjust and work according to Active Support. Furthermore, a good rapport is necessary to build a professional relationship between staff and people with intellectual disabilities (Mansell & Beadle-Brown, 2012). According to Carr (1994), a good rapport is defined as a warm, empathetic relationship between staff and service users which involves sharing, cooperation and trust. A poor rapport with staff results in service users not cooperating or engaging in self-stimulatory behaviour (Guthrie & Beadle-Brown, 2006; Mansell & Beadle-Brown, 2012). Poor rapport can also be characterised by support workers having a child-parent attitude towards the person they are supposed to support, with communication characterised by negative forms of body language and paternalistic behaviour (Mansell & Beadle-Brown, 2012).

Active Support is also a practice that emphasises *empowerment* (Mansell & Beadle-Brown, 2012). Empowerment can be defined as “the capacity of individuals, groups, and/or communities to take control of their circumstances, exercise power and achieve their goals, and the process by which, individually and collectively, they are able to help themselves to maximise the quality of their lives” (Adams, 2017, xvi). Adams (2017) describes that empowerment in practice is an ongoing interaction between critical reflection and a practice that is empowering.

In Active Support, *empowerment* can be seen through the many opportunities to be involved in activities that are meaningful for each person, as well as the emphasis on each person being in control of their own life. This means that staff should adapt their behaviour to the needs and preferences of each person. Staff must also recognise that individual needs and preferences can change from day to day. It is therefore necessary to combine the continuity in routines that individuals might need with a readiness to change these routines if so requested. Active Support therefore acknowledges that both routines and spontaneity are needed. It should be adapted and tailored to the unique needs of each individual.

6.2. Training in Active Support

Active Support training was originally developed in the UK and has been updated in Australia (see Bigby & Humphreys, 2023; Mansell & Beadle-Brown, 2012). The Australian version was used in this intervention project. The interactive staff training in Active Support consists of eight learning modules, videos with group exercises, and individual assignments, developed by La Trobe University, Australia (Bigby & Humphreys, 2023). The overall purpose is to provide support workers with the skills to adapt their own behaviour and support engagement. After two days of training with video modules, a hands-on training with structured observations is provided with detailed individual feedback sessions. The training focuses on four essentials, which will help staff remember the training and how support work should be carried out (see Figure 1).

The four essentials are, according to Bigby and Humphreys (2023) and Mansell and Beadle-Brown (2012):

‘Every moment has potential’ – All daily activities and social interactions hold moments for the service user to be involved in all tasks, and this potential needs to be grasped by the support workers.

‘Graded assistance to ensure success’ – Graded assistance is a combination of providing support at the right level and with the right type of communication aids and providing step-by-step instructions. This means improving communication techniques such as using sign language, verbal instructions more clearly, symbols, prompts, visual aids and pictures in everyday activities. Graded assistance also suggests that all individuals, no matter how disabled they are, can participate in everyday activities, with careful person-centred planning by the support workers.

‘Maximising choice and control’ – to feel competent and increase the opportunity of exercising control in your own life, it is imperative for support workers to provide opportunities for choice making. Making choices and exercising autonomy depends on the support people receive. However, to be able to choose, one must have some sort of knowledge or experience of the alternatives. Developing and experiencing new activities and situations, guided by the individual preferences and interests, is part of the training programme and monitored through observations and feedback sessions.

‘Little and often’ – providing support is often emphasised in Active Support. Little and often means all support should be designed on an individual basis to fit the needs of the individual and to avoid a passive life. The higher the support needs, the more Active Support is needed. Active Support focuses on providing support little and often.

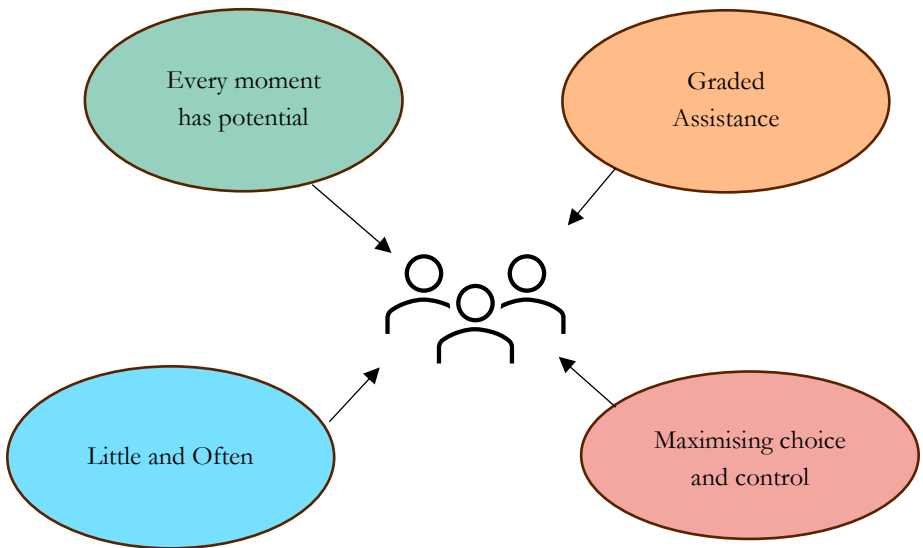


Figure 1. The four essentials in Active Support training.

6.3. The online training resource of Active Support

Active Support training begins with working with eight modules on the “Skills for Active Support” online website (see Bigby & Humphreys, 2023). The website has been updated with new videos since the training began in 2021, but the main concepts remain the same. The updated version of the modules is presented below. Each module contains videos and questions with exercises.

Module 1: ‘Active Support and engagement’ consists of information about Active Support and signs of engagement, why engagement is important and signs of

disengagement. It has been updated with a comparison between Active Support and “the hotel model”, where the latter represents an outdated form of service support which perceives people with intellectual disabilities as passive service receivers.

Module 2: ‘Every moment has potential’ starts with an overview of the four essentials. The module then moves on to the first essential: Every moment has potential, consisting of videos about how to involve people with intellectual disabilities in everyday activities, such as cleaning, cooking etc.

Module 3: ‘Graded assistance to ensure success’ focuses on how support workers can adapt the amount and type of support they give to individual needs and preferences.

Module 4: ‘Maximising choice and control’ is about how support workers can maximise the number of choices in everyday life for each person they are supporting. Every opportunity to make an active and responsive choice gives the person control over their own life.

Module 5: ‘Little and often’ demonstrates how support workers should help people with intellectual disabilities to be able to participate in activities according to their own preferences and support needs. It also shows that it is important to be able to dip into and dip out of activities.

Module 6: ‘Supporting relationships and interactions’ does not look at a specific essential but rather demonstrates the importance of creating a warm atmosphere and having an enabling support worker role. This module is about how always to be respectful, how to treat people with intellectual disabilities in an empathetic way when giving support, and how to increase opportunities for social interactions.

Module 7: ‘Supporting more than one person’, does as the title suggests: it recognises that it may be difficult for support workers to support several people at once, and suggests ways to do so.

Module 8: ‘Person centred practices and continuous improvement’ is an updated module looking at other person-centred practices, such as PBS. It also addresses how to improve support over time and encourages support workers to reflect on

their own performance by asking themselves a number of questions about their support, how it feels, and what could be improved.

In conclusion, the training consists of a two-day workshop with 8 video modules and then followed by observations with regular feedback sessions (in this project once a month, with me and then practice leaders), an updated training course after approximately one year, and also followed by implementation of practice leadership (see below).

An additional link to resources is provided at the end of the online training, with downloads, further reading and more. For more information, please visit the website at <https://www.everymomenthaspotential.com.au/>.

6.4. The Frontline Practice Leadership training

One of the main principles of Active Support is to introduce a Frontline Practice Leader role (Bigby & Humphreys, 2023; Bigby & Humphreys, 2024a). A one-day workshop training in Frontline Practice Leadership (FPL) was carried out specifically for the practice leaders, in addition to the Active Support training. All first-line managers received a one-day training in FPL to become practice leaders. The practice leader has five main tasks: 1) Facilitate team meetings 2) Allocate and organise staff support 3) Observe, give feedback, and coach staff 4) Focus staff's attention on various QoL aspects, and 5) Supervise support workers (Bigby & Humphreys, 2023). The practice leader is not a managerial but rather a group leader role. The FPL training consists of six video modules and practical assignments, developed by La Trobe University (Bigby & Humphreys, 2024a).

The first module explains the core components of FPL which are the five main tasks: 1) Facilitating teamwork and team meetings, 2) Allocating and Organising support 3) Observing / giving feedback 4) Focusing staff attention of QoL 5) Supervising practice of each staff member. For each task there is a module with videos and exercises.

The practice leaders also received feedback sessions together with me, to practice the new role and how to conduct feedback sessions. This training was given on a couple of occasions after the workshop training. FPL suggest that

practice leaders should observe, give feedback and coach staff on a regular basis. In this project, we interpreted it to be planned at least once a month.

The practice leaders participated in FPL online training which can be found on the following website: <https://www.practiceleadershipresource.com.au/>.

6.5. Research about Active Support and Practice Leadership

Active Support has been implemented and researched in group homes for several decades in England and Australia (Bigby et al., 2020b). Studying the possible increased engagement in meaningful activities has been the primary aim of Active Support research. Two literature reviews have shown that if Active Support is successfully implemented, it increases the engagement in meaningful activity of people with intellectual disabilities living in group homes (Stancliffe et al., 2008; Flynn et al., 2018). There are also several studies which show an association between Active Support and decreased levels of depression (Beadle-Brown et al., 2012; Stancliffe et al., 2010), improved adaptive behaviour (Stancliffe et al., 2010), improved opportunities for choice (Beadle-Brown et al., 2012; Graham et al., 2013) and improved quality of support (Baker et al., 2017; Riches et al., 2011).

A number of studies have examined the relationship between staff and people with intellectual disabilities after the Active Support intervention. For example, Baker et al. (2017) found that the relationships between people with intellectual disabilities and support workers improved. Furthermore, Qian et al. (2017) found that support workers focused on the positive aspects of supporting service users post-training and had an overall change in mindset. For example, they saw themselves as “helpers” rather than caretakers, after Active Support training (Qian et al., 2017, p. 335).

Other studies demonstrate more mixed findings. Some results show that Active Support trains staff to shift their attention from people with lower support needs to those with higher support needs (Jones et al., 1999), but that staff's support for people with higher needs did not improve post-training (Bradshaw et al., 2004). While some studies demonstrate a clear positive association between Active

Support and a decreased level of challenging behaviour (Beadle-Brown et al., 2012; Qian et al., 2017), others did not find a significant reduction (see for example Riches et al., 2011).

There is limited research about the potential benefits for staff (such as turn-over, job satisfaction, etc) after an Active Support intervention. However, one study found that staff experienced increased job satisfaction (Rhodes & Toogood, 2016).

Although a considerable body of research shows the benefits of Active Support training, it also identifies some challenges to implementation (Mansell et al., 2013). Several contextual factors contribute to whether Active Support is successfully implemented (Bigby et al., 2020b); these include commitment and focus from senior management, strong practice leadership organisation and adherence to Active Support. In another study, Qian et al. (2017) identified factors contributing to less successful implementation. These include lack of support from managers and lack of policies supporting Active Support. In a large-scale longitudinal study covering six of the leading organisations with services such as group homes in Victoria, Australia, only one organisation provided good Active Support over time (Bigby et al., 2017). Data were collected for four years (2009–2012) for three organisations, three years (2009, 2010, 2012) for one organisation, and two years (2011–2012) for two organisations (Bigby et al., 2017). Support improved for the most able service users, but not for those with higher support needs (Bigby et al., 2017). They concluded that providing skilled hand over hand assistance to those with the higher support needs seemed most difficult for staff.

Over the last decade, there has been more research examining FPL and its important role for successful implementation of Active Support (Beadle-Brown et al., 2015; Beadle-Brown et al., 2014; Bigby et al., 2020b; Bigby & Humphreys, 2024b; Bould et al., 2016b; Deveau & McGill, 2014). The implementation of practice leadership has been found to be an important component of Active Support implementation (Beadle-Brown et al., 2014). Furthermore, studies show that the presence of practice leadership improved quality of support and reduced stress among staff (Deveau & McGill, 2014; Deveau & McGill, 2016).

7. Theoretical frameworks

In this chapter, I will describe the theoretical framework of Active Support, namely the Quality of Life (QoL) framework (Schalock et al., 2002), after which I will compare it with one additional theoretical perspective of this thesis: An Ethic of Care (Tronto, 1993). While the QoL perspective is highly valuable in Active Support as a foundation and a perspective for staff on skilled support and QoL, an Ethic of Care provides new perspectives. The two perspectives together provide a more complete picture of support, and I will therefore explore them.

7.1. Quality of Life – different definitions

A goal for both individuals and society is for citizens to have a good life and experience QoL. What QoL is and how it can be measured has been and is the subject of much research. QoL frameworks are widely used in many contexts. Not least as a complement to other ways of measuring wealth, there is a need for measuring values other than economic. Previously, there has been a Nordic tradition of trying to measure objective indicators of conditions rather than subjective experiences of well-being (Rapley, 2003). However, this has shifted and researchers stress that the focus of QoL is on people's subjective experience of their well-being and person-referenced outcomes (Schalock, 2000; Schalock et al., 2002). Schalock et al. (2002) describes that the QoL includes two components: “quality” points out that it is related to superior human values, such as happiness, success, wealth, health, and satisfaction, while “of life” suggests that it relates to the very core or essential features of human existence.

There is no uniform definition of QoL and there are many different frameworks focusing on different meanings (such as perceived happiness, meaningfulness, good health, social inclusion but also material conditions). There are also many different instruments for measuring QoL with different descriptions of what is included in the concept. The conceptual understandings vary across different academic disciplines. In the field of health care, specific QoL assessments have been developed and used for evaluation of outcomes in a particular disease (cancer, asthma, liver disease etc) (see for example Casanovas et al., 2010; Daly et al., 2020). Spanning over the past decades of research and practice, the concept of QoL has been used in the field of disability as a sensitizing

notion and an essential principle for service delivery (Schalock, 2000). By sensitizing notion, it means that it guides us from the individual's point of view and focuses on the individual and the surrounding environment (Schalock et al., 2002). QoL is a widely adopted concept for monitoring and evaluation of service delivery, quality improvement, challenging theory as well as developing policies, for research and so on (see for example Schalock, 2000; Schalock et al., 2018).

There has been a change from the view that scientific, medical, and technological developments lonely would result in a better life and towards a recognition that personal, family, community, and society well-being develop from multifaceted combinations (Brown et al., 2009). The QoL concept in the disability field is seen as a logical enhancement from the 1960's normalisation movement that emphasized integrated community-based services (Brown et al., 2009). QoL is also related to a human rights perspective and the CRPD has the same core values as the QoL concept, for example participation in society (Brown et al., 2009; Buntinx & Schalock, 2010). By promoting participation and support based on improving an individual's QoL, is therefore grounded in a values system on a macrolevel (Buntinx & Schalock, 2010). Active support is (see chapter 6) based on the ambition to contribute to an everyday life with a good QoL for people with intellectual disabilities. Therefore, QoL is relevant as a theoretical perspective in this thesis.

7.2. The Quality of Life framework

The theoretical framework of Active Support is QoL (Schalock, 2000; Schalock et al., 2002) (see Table 1). The primary aim of using the QoL framework is to enhance wellbeing.

The QoL framework is based on core life concepts and is centred around positive aspects of living. The core ideas in QoL are also reflected in Active Support practice and training. These core ideas are *well-being, inter- and intrapersonal variability, the personal context, a life-span perspective, holism, values, choices and personal control, perception, self-image, and empowerment* (Schalock et al., 2002).

The domains of the core idea *well-being* in QoL are universal, but the framework recognises that there is variability in what is essential, both between persons as well as across the lifespan (Schalock, 2000). Eight domains of well-being

(sometimes called dimensions) have been recognised in the literature as the desired conditions of emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights (Schalock et al., 2002). Active Support aims to improve all domains of QoL. For each domain, there are indicators of how it can be interpreted and operationalised (see Table 1).

Table 1. The concept of QoL (Schalock et al., 2002)

Quality of Life		
(Schalock et al., 2002; indicators updated in Mansell & Beadle-Brown, 2012)		
Domains	Example of Indicators	
Emotional wellbeing	Safety	Freedom from stress
	Spirituality	Self-concept
	Happiness	Contentment
Interpersonal relations	Intimacy	Friendship
	Compassion	Social support
	Family	Interactions
Material well-being	Ownership	Employment
	Financial	Possessions
	Security	Socioeconomic status
	Food	Shelter
Personal development	Education	Personal competence
	Skills	Meaningful activity
	Fulfilment	Advancement
Physical well-being	Health	Health care
	Nutrition	Health insurance
	Mobility	Leisure activities of daily living
Self-determination	Autonomy	Personal control
	Choices	Self-directions
	Decisions	Personal goals/values
Social inclusion	Acceptance	Community activities
	Status	Roles
	Supports	Volunteer activities
	Work environment	Residential environment
Rights	Privacy	Due process
	Voting	Ownership
	Access	Civic responsibilities

One core idea, *inter- and intrapersonal variability*, reflects the fact that the above-mentioned domains may be experienced differently depending on individual and cultural differences (Schalock et al., 2002). A person's life is complex and long, and preferences, needs and choices may change because of environmental factors as well as personal development, health and family factors. Therefore, a person is best understood in *the personal context* (i.e. the family, culture, home setting – where they live and work). According to Schalock et al. (2002), the environmental context should be considered changeable and people as well as places have the ability to boost a person's life. This is also consistent with Söder's (1982) definition of disability, showing how the environment can influence and impact how the disability is manifested. The *lifespan* perspective also means that factors in childhood may have an impact later in life. For example, the education a child with a disability receives will likely impact the occupation they will be able to have as an adult (Schalock et al., 2002). The QoL model is based on a *holistic* perspective that acknowledges that some aspects or domains may, from time to time, dramatically influence other aspects and domains. It is therefore imperative to employ activity, participation and motivation in one domain to enhance development in other domains. The core ideas of *values, choices and personal control* reflect the fact that QoL is emancipatory because it recognises a variety of value systems (Schalock et al., 2002). Choices made by a person are associated with different QoL and whenever it is feasible, personal control over preferences regarding activities etcetera is needed (Schalock et al., 2002). The core idea of *perception* suggests that the maximum change in perception can occur in effective interventions. Further, perception may best be understood from a multidimensional perspective, since the perception of family members, stakeholders and the organisation that provides support can differ (Schalock et al., 2002). The perception of the individual receiving support can also differ from one person to another. I therefore conclude that there are several central perceptions involved in understanding a person's QoL. It may often be necessary to identify individual choices using a person's nonverbal responses if they do not communicate verbally. The authors describe the core idea of *Self-image*, that relates to the fact that the purpose of any intervention and practice should be to enhance a person's self-image. Lastly, *empowerment* should be emphasised as essential to the above-mentioned core ideas, since personal empowerment in life is needed to

have a sense of control over one's activities, interventions and surroundings (Schalock et al., 2002).

A fundamental belief is that an enhanced QoL is achievable for all people, with or without intellectual disabilities (Schalock, 2004). According to Schalock et al. (2002, p. 461), "when assessing the QoL of people with disabilities, we adopt the value that all people, with and without disabilities, share the human experience together and that every human being is entitled to live a good life within his or her environment".

Schalock et al. (2018) suggest that, as the field evolves with new ways to assess for example QoL scores, QoL strategies at individual level might be used to determine QoL-associated individual goals, examine support needs across QoL domains, and assess QoL outcomes. In this sense, the QoL lens has the potential to explore the overall well-being of each person in a group home, by examining the indicators for each domain and looking at the opportunities and support the service delivers to achieve this aspect of QoL. In Active Support, the QoL framework can be used as a ground for conceptualising outcomes (Mansell & Beadle-Brown, 2012). The overall aim in Active Support - to engage in meaningful activities and relationships- has also been found to be especially important as a way to realise the domains in quality of life (Beadle-Brown et al., 2021).

7.3. An Ethics of Care perspective

For people with intellectual disabilities, QoL is largely dependent on the support and help of others, not only periodically but often throughout life. Following the development of a support paradigm, support systems have been defined as a combination of resources and approaches to promote an individual's progress, education and interests, as well as to increase human functioning and personal well-being (Schalock et al., 2010; Schalock et al., 2021). However, support work can also be related to care, which makes care a central element. The feminist perspective of 'ethics of care', developed over recent decades by proponents such as Carol Gilligan, is a potentially radical standpoint because it is closely related to value. It challenges what matters in life in terms of social connection and focuses on what is central to humankind (Beasley & Papadelos, 2024). Care ethics is therefore rooted in moral philosophy, yet it challenges traditional moral

philosophy in suggesting that autonomy and independence should be prioritised. It provides a justification for moral virtues that acknowledge the essential interconnection between people (Beasley & Papadelos, 2024). From this point of view, care is fundamental to every society (for example care of children, the elderly or, as in this thesis, of people with intellectual disabilities). The care ethics perspective makes care as labour visible and constitutes a compelling antidote to other perspectives that disregard caring for, about and with others (Beasley & Papadelos, 2024). If care is essential to humankind and care work, often traditionally performed by women, is necessary for survival, the ethics of care perspective provides a potential shift in thought about how support work is valued in society. I have chosen a feminist perspective of ‘ethics of care’ as a response to and stand against the fact that care is often relegated to a peripheral location in society (see for example Tronto, 1993). As Tronto (1993) suggests, if care were at the centre of our attention, our society would look very different.

Fisher and Tronto (1990) have, accordingly, defined care broadly as follow: “we suggest caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web” (Tronto, 1993, p. 103).

By this definition, caring can also include objects and is not limited to human interaction with others. Furthermore, care can be either a single activity or an ongoing process. According to Tronto (1993), the process of care is usually culturally defined and can therefore vary between different cultures.

Fisher and Tronto (1990) have divided the phases of care into the following categories:

‘Caring about’: The first phase of care involves caring about something or someone. This phase is about the recognition of someone’s need, is contextual and influenced by social and cultural factors. Caring about can, according to Tronto (1993), also be described on a political level as involving society’s approach to people. In this thesis, caring about can be the way society (macro-level) and support workers (micro-level) care about people with intellectual disabilities.

‘Taking Care of’: Taking care of is the second phase of care. It involves responsibility and taking care of someone or something. It concerns action and might include organising the tasks which are carried out to meet needs. In this context, it can be managing a group home, hiring staff and creating staffing schedules to provide care for the service users living in a group home.

‘Caregiving’: This phase involves the actual caregiving or the actual action of care, recognising the need for care but also carrying out the physical work itself. Whereas caring about, and particularly, taking care of, involve the most powerful in society, caregiving and care-receiving involve the least powerful in society. In line with Tronto (1993), most caregivers/support workers in group homes were women.

‘Care-receiving’: The last phase of care involves recognising the person receiving care, who will respond in some way. Tronto (1993) sees it as a priority to include care-receiving in the process of care, because it is the only way to be able to examine whether needs have been met. Within this context, care-receiving would include service users’ responses to Active Support and whether their care needs have been met.

Caring is intertwined with most aspects of human life (Tronto, 1993). Yet, care is degraded in our society and most care work can be viewed through a lens of intersectionality. Gender, class, and ethnicity contribute to who provides most care work in society. ‘Taking care of’ is associated with masculinity, and broader and political issues, whereas women traditionally have been related to care about private and local concerns. Care work, the actual ‘caregiving’, is also closely linked to opposites of autonomy and rationality. Tronto (1993, p. 117) describes it this way: “care is also devalued conceptually through a connection with privacy, with emotion, and with the needy”. However, care has got a central value in society and using an ethic of care perspective in the analytical phase in Article II is a way to emphasise the two latter phases of care (the importance of caregiving and care-receiving). The phases of care can also be explored in research about Active Support to discover central aspects of support work, how care in Active Support is perceived in relation to support, and the balance between the different phases. How much attention is given to phases such as care-receiving, in contrast to the phase of taking care of? Also, when examining what good care consist of, the

phases worked as perspectives to explore features of care such as how it is organised and how it is perceived from different perspectives, but in particular from the point of view of the service users.

8. Method

This chapter is about the methodologies used in this intervention project. It begins with a presentation of the study design, the context, the data collection process, the strategies to implement the intervention, and the implementation process itself. It is followed by a summary of the study population, measures and methods used for data collection, the translation process, adaptations and modifications, methods of analysis, trustworthiness and generalisation. It ends with ethical considerations about conducting research like this and my own previous experience.

8.1. Study design and context

This project involved a staff training intervention to support workers and first-line managers working in group homes. Four group homes were selected through purposeful sampling and the organisations all expressed an interest in being part of the study. They were organised according to 9§9 LSS (SFS1993:387) and staffed 24 hours a day. Two to three support workers worked each shift, except at night, when only one was on duty. All four services had opened recently (<2 years), had a similar size of six flats and all were situated in residential areas accessed by public transport. A few flats in one group home were not rented out at the beginning of the intervention because the home was recently built.

The intervention was a combination of Active Support training (for staff and first-line managers) and FPL training (for first-line managers), which were delivered in the classroom. The Active Support training was followed by feedback sessions in everyday support situations in the group homes once a month. The plan was to systematically evaluate the effects of the intervention, both short-term and long-term. The group homes were therefore followed for two years after the workshop training to examine long-term effects, and the effects were studied with multiple methods (mixed methods) and with different data sources (both quantitatively and qualitatively).

A stepped wedge design was chosen to implement and examine the effects of the intervention. This is a form of quasi-experimental design (Barker et al., 2016; Hemming & Taljaard, 2020; Spiegelman, 2016). A quasi-experimental design means that a non-randomised design is used to evaluate an intervention such as a

training program (Miller et al., 2020). In a stepped wedge design, all groups receive the intervention, but at different time points, in a staggered fashion (Miller et al., 2020). A benefit of this design is the possibility to examine each group home pre- and post-intervention. A stepped wedge design was considered less disturbing for the participants (staff and service users) in the group home environment. It also allowed us to take contextual factors into consideration that might impact the intervention effects, such as the Covid-19 pandemic that occurred at the beginning of the intervention. Since Active Support intervention has not been associated with any negative effects in previous studies, it was deemed feasible for everyone to receive the intervention and to use a stepped wedge design. Unlike an experimental design/randomised control trial (RCT), a stepped wedge design usually takes place in a natural setting and without a control group. While an experimental design/RCT is considered the gold standard in some research (Miller et al., 2020), it was not feasible in this study because of difficulties in comparing the group homes with each other. For example, service users' characteristics, their disabilities and support needs, the location of the group home and the organisation of staff and managers differed greatly. It was therefore better to examine before and after results for each group home. See Figure 2 for the start and end dates for the four group homes in this project.

Group homes A-D:

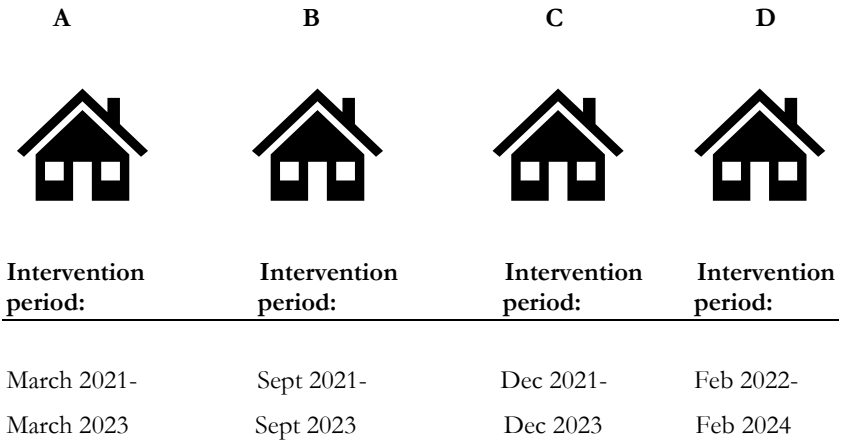


Figure 2. The start and end dates for the intervention time for each group home, according to the stepped wedge design.

The intervention time involves the time for the training and study period afterwards, which lasted for two years at each group home. All four group homes were also examined pre-test at baseline, for approximately three months before the intervention began, with the purpose of examining baseline with the possible long-term effects.

8.2. Data collection process

This project included several types of data collection. One was a systematic literature search in international research databases (Article I), and the others consisted of empirical data collection at four group homes (Articles II, III and IV). To be able to contribute new knowledge about Active Support of value in both a Swedish and an international context, I began this research project by examining the previous research into Active Support, looking at which research methods have been used previously and how people with intellectual disabilities have been included in the evaluation of Active Support interventions. The first article in this doctoral thesis was therefore a scoping review of previous methods and outcomes in Active Support research, as well as an investigation of how

people with intellectual disabilities have been included in evaluating the intervention. The scoping review was felt to be suitable because it could identify possible knowledge gaps (Tricco et al., 2018).

To examine the effects of the intervention, several data sources over time were used (such as observations, interviews and questionnaires). For an overview of the training and empirical data collection see Figure 3. The empirical sampling process started at baseline, before the Active Support training was carried out. This consisted of interviews with service users as well as three observations for each group home - a total of 12 observations (1440 minutes). Questionnaires about service users' adaptive behaviour were also collected at baseline.

After the Active Support training, the observations were repeated over a total period of two years. The observations were divided into three years: 12 baseline observations before Active Support training; 23 observations 1 year after staff had received training; and 18 observations year 2 after staff training. One more observation in year 2 was excluded since only newly employed temporary staff were working. At follow-up 1, both service users and first-line managers were interviewed to get their opinions after the Active Support training and implementation. At follow-up 1, practice leadership implementation was examined by means of a two-hour long observation. At follow-up 2, two years after training, all staff answered questionnaires about their support skills, the adaptive behaviour of service users and their levels of disability. Repeated observations were also conducted. Practice leadership was examined three times in total, with the last occasion in year 2.

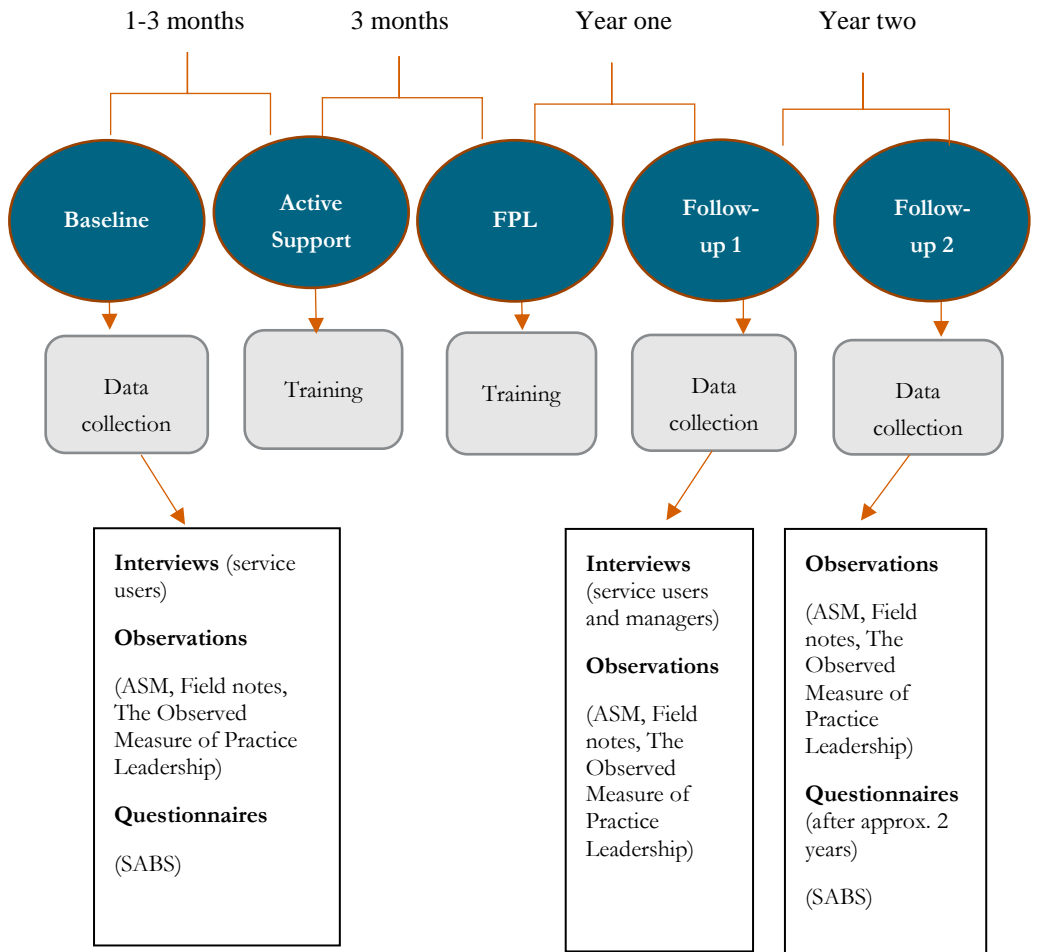


Figure 3. An overview of the training and data collection in the Active Support project.

8.3. Implementation strategies

The Active Support and FPL intervention in this project made use of several implementation strategies. These can be defined as strategies or methods to enhance the adoption and maintenance of an intervention or practice (Curran et

al., 2012; Proctor et al., 2013). The goal of implementing Active Support in group homes is to change staff behaviour towards service users, to increase participation and engagement in meaningful activities, and to improve QoL for service users. It aims for behaviour change in staff and to teach staff new methods to generate person-centred support and create daily opportunities for participation. A number of implementation strategies can enhance the integration of a new practice in services. Powell et al. (2012) identify 68 discrete implementation strategies which they group into six main implementation processes: planning, educating, financing, restructuring, managing quality, and attend to the policy context strategies. They define a discrete strategy as a process or action, such as educational meetings, reminders etc (Powell et al., 2012). In this intervention, several discrete strategies were used and are summarised here and grouped into the six main implementation processes.

Plan strategies: Powell et al. (2012) identify a number of strategies during the planning process. These include gathering information (for example assessing for readiness, local needs, etc), selecting strategies (for example shaping strategies to overcome barriers), building buy-in (for example involving consumers and family members and performing consensus discussions), initiating leadership (for example recruiting/training for leadership and mandate change), and developing relationships (for example building a coalition).

This Active Support implementation project began with meetings with the organisations that were responsible for the group homes. Careful planning was carried out with the responsible managers to assess readiness. Since all the group homes were newly built, the project began when permanent support workers had been employed and were working shifts. Staff in every group home wished to be trained together as a team. This preference was respected and training sessions (i.e. workshops) were scheduled for each group home. Prior to the training, meetings were arranged with people with intellectual disabilities as well as their family members to involve them in the planning process and inform them about the intervention. It was also important during this stage that both support workers and service users became familiar with me before the intervention began. The managers had overall responsibility for the services and were responsible for mandating change, scheduling training sessions, and leading the staff's day-to-day

work. It was therefore important to develop a collaboration with the first-line managers.

Educating strategies: Powell et al. (2012) describe several educating strategies. These include developing material (for example, effective training materials), educating (distributing material and conducting educational meetings), educating through peers (for example, creating a learning partnership), informing and influencing stakeholders (for example, preparing them to be active participants).

The training was conducted in a similar way to previous projects in Australia and therefore uses a classroom training strategy (two-day workshop). The online training consists of training videos in English. These were used similarly in this project, but all the online written information was translated into Swedish (i.e. the exercises) and handed out as a pamphlet during the workshop. The workshop training was conducted for support workers and first-line managers from each group home. Initially, the managers and organisations had no contact with each other, but the senior management from each organisation contacted each other to collaborate during the project (to create a learning partnership). During the second year of the project, practice leaders created a network and planned meetings to learn from each other's experiences of Active Support and to continue the practice. Support workers were encouraged to reflect on the training and contact me with questions at any time. A folder was created to remind staff about Active Support, and information about the four essentials was put up on a wall so everyone could see it (in the office and staff rooms). This is in line with the recommendation to create easy-to-use sheets (Powell et al., 2012).

Individual feedback sessions were conducted for each support worker to train them in real-life situations, first by me and then by a trained practice leader for each group home. This was in line with the staff practice (see for example Mansell & Beadle-Brown, 2012) and also in case classroom training alone is not enough to fully implement a new staff practice.

Finance strategies: Powell et al. (2012) have two main financial strategies listed in their compilation: modifying incentives (for example altering incentives) and facilitating financial support (for example, funding and contracting for clinical innovation).

The funding was carefully organised, and the intervention was already planned before the project began. Managers organised the daily shifts in such a way as to make it possible for staff to work, be observed and be given feedback sessions afterwards. For maintenance over time, resources for training new staff may be planned in the future.

Restructure strategies: Powell et al. (2012) found several restructure strategies (for example, revising professional roles). Leadership and tasks that involve practice leaders were discussed with managers in an interview after the first year. Managers often reflected on their own work role, as well as support worker role, during this project. Discussing and reflecting on the skills needed to provide good support appeared to be a natural response to the intervention. The skills that a practice leader should have to facilitate a learning and educating environment were also brought up during interviews with managers and feedback sessions. An adaptation was initiated and the role of managers as well as senior support workers was revised, so that Active Support could be even better integrated into the group homes. This involved two senior support workers beginning to do feedback sessions with staff, and one manager dividing their time between being a manager and working as a practice leader.

Quality management strategies: Powell et al. (2012) found many quality management strategies (n=17). This includes, for example, developing tools for quality monitoring, reminders, using advisory boards and workgroups, obtaining and using feedback, and intervening with consumers to enhance uptake.

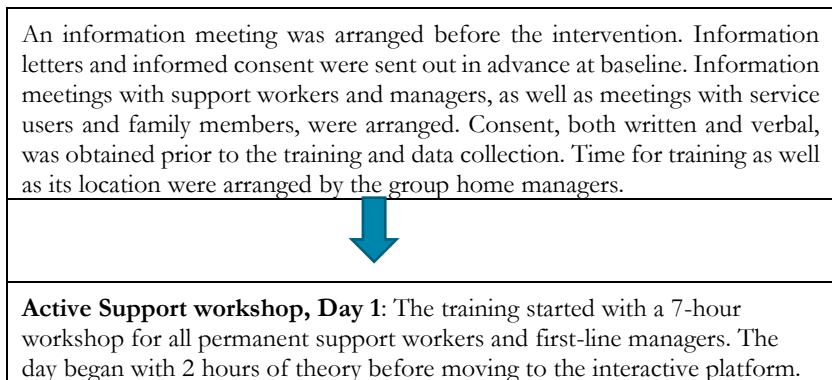
During the two-year follow-up period, many strategies that involved quality management were used. The staff created several tools (for example measures of QoL domains to be used when updating individual plans) to improve uptake. In some group homes, they used the four essentials to analyse different support situations and created written plans based on this (for example in specific domestic activities like supporting a person to prepare a meal). All group homes were encouraged to discuss and reflect on Active Support during staff meetings by having it on the agenda (as a reminder). The managers were encouraged to bring Active Support up during team meetings. The regular visits I made to the services may also have served as a reminder of the intervention and are likely to have contributed to adherence.

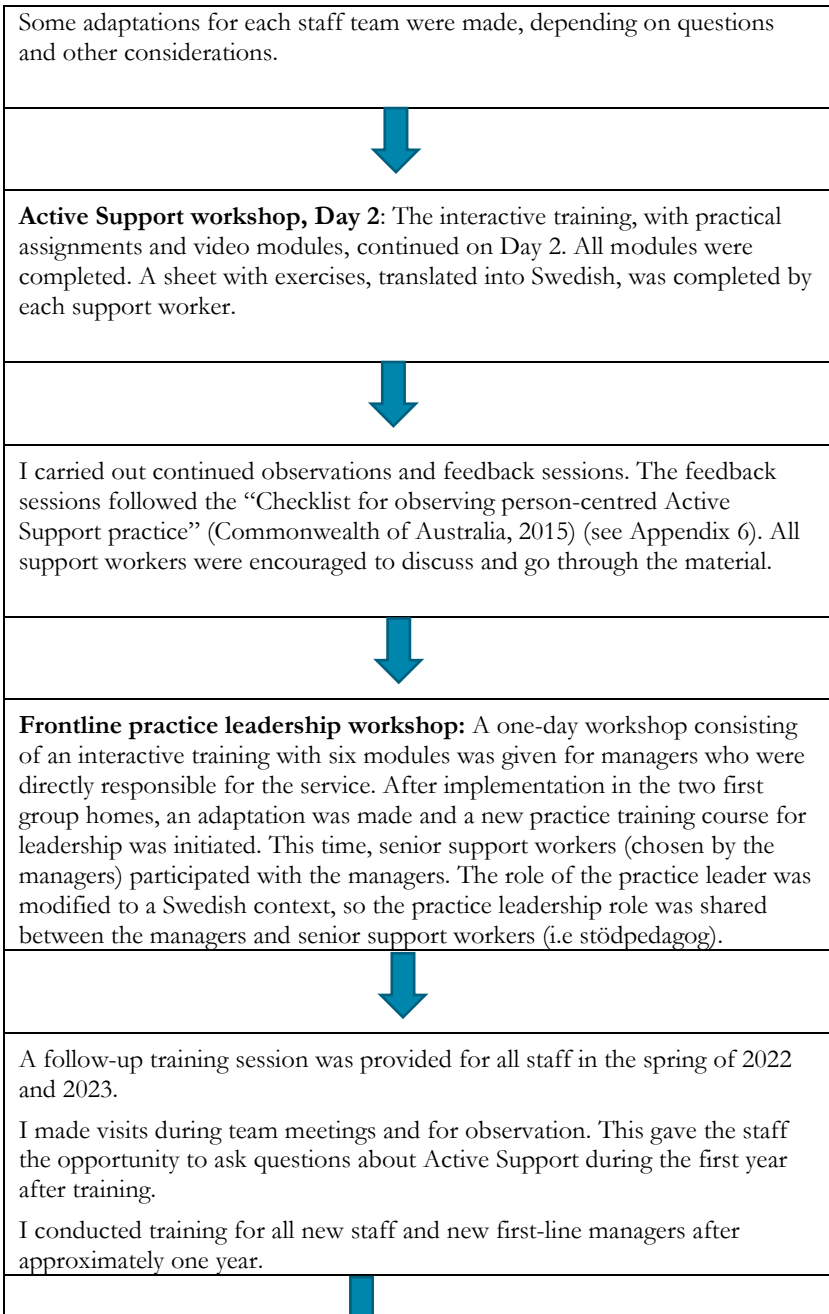
This research project had an advisory board of two researchers from La Trobe University. They followed the project and have extensive knowledge about Active Support and how to train and enhance uptake. They gave me advice along the way. This project was also followed by two reference groups as well as my supervisors, who gave me feedback, suggestions and comments during the whole process. I also had contact with and was given feedback by service users' family members/stakeholders who were interested in the project. This was done in an informal way but benefitted the intervention by providing me with valuable insights and views about support regarding daily activities. I also attended staff meetings to talk about Active Support so that videos could be seen as well as create discussions about Active Support. I intervened with both staff and managers as reminders of the project. These were all strategies to enable staff to continue working with Active Support and to fully integrate Active Support into their daily support.

Attend to policy context strategies: The last group of strategies from Powell et al.'s (2012) compilation, involves a number of policy context strategies (for example, changing accreditation or membership requirements). These are not relevant here since this is a research project. Staff, however, liked the idea of, for example, certificates for Active Support training (even if this was not done here).

8.4. The implementation process

The following schedule shows the overall information and training provided to the four group homes:





<p>Practice leaders continued working with Active Support within the project. Depending on the contextual circumstances, a manager or a senior support worker made observations and carried out feedback sessions. Each group home was encouraged to continue watching video modules and discuss Active Support at team meetings. Practice leaders were encouraged to teach part-time staff the basic principles of Active Support and to show video clips. I made regular observations to collect data.</p>
--

8.5. Study population

The present research project was conducted in four group homes.

A total of 20 people with intellectual disabilities were included in the project (23 service users were invited at baseline, but two relocated and one declined to be part of the study). Two service users moved in at the end of follow-up and were not included in the study. All the service users in the project were adults between 22-60 years old. Most had mild to medium intellectual disabilities as well as other disabilities, such as physical (n=4), visual (n=7), hearing (n=3), speech (n=6) and autism (n=8). The majority were women (75%).

A total of 28 support workers agreed to participate in the project, no one declined to participate. Inclusion criteria were employment for longer than three months with a permanent position or a long-term temporary position. Most staff in this study were women (60%), had an upper-secondary school qualification in social care, and were on average middle-aged. Three were employed as senior support workers (i.e. stödpedagoger). A few had a bachelor's degree in social work or education (n=3). Some also had experience of previous training in short courses, mostly in the Low Arousal Approach and augmentative and alternative communication. Four support workers had no prior training. A total of five support workers left their employment during follow-up and were replaced by six support workers (who received Active Support training when they started). Five managers were trained in FPL and Active Support. Of these, two managers found new jobs during the follow-up and two started at the end of the follow-up period. Consequently, the number of participating managers varies between Article III (n=3) and the managers that received training (n=5).

Other temporary staff were informed of the training and study and a specific folder about Active Support for temporary staff was designed in the group homes.

8.6. Methods and measures used for data collection

8.6.1 Interviews with service users

Interviews with service users were conducted at two time-points: at baseline before Active Support implementation and at follow-up after one year. An interview guide (see Appendix 1) was developed to explore the perceptions of Active Support among service users. The interview guide for service users was developed with the main supervisor. A reference group consisting of people with intellectual disabilities from the self-advocacy group Inre Ringen discussed the questions and gave advice for easy-to-read versions and how to rephrase sentences. The interview questions concerned activities, the daily schedule and the possibilities to change plans and make flexible arrangements. Other questions concerned opportunities for choice making, exercising self-control, and graded assistance from staff. This included questions about the quality of staff support, self-determination and plans, and whether there was any support the person would like but did not receive. Prior to the follow-up interviews, some questions about what had changed since the previous interview were added to the interview guide (what had changed during the last year in terms of support, decision-making and restrictions).

Symbol-based communication aids were used in two interviews to make it easier to understand the interview questions and answer them non-verbally. Where so requested by the service user, the interviews were conducted in the presence of a stakeholder (for example a family member), who knew the service user well and could adjust the questions if this was needed to enable comprehension. A stakeholder was present in interviews with two service users.

The interviews lasted between 16-55 minutes (on average 30 minutes/per interview), and, with the permission of the service users, the interviews were recorded, and a verbatim transcript of the interviews was written.

8.6.2 Observations of interactions between staff and service users

One observational measure was used in this project to examine staff-resident interactions and quality of support: Active Support Measure (ASM) (Mansell & Elliott, 1996; revised by Mansell et al., 2005). The revised version was used in this project. The observations were ongoing during the two years. I used and answered the ASM in the repeated observations of the group homes, as well as additional field notes.

The observations took two hours (between 4-6 pm), and the ASM was used in the two-hour sessions to examine the overall quality of support provided. ASM further assessed the interaction between staff and service users by 15 questions on topics such as interpersonal warmth, “real” activities, choice, staff noticing and responding to client behaviour, and demands presented carefully. Two items regarding challenging behaviour and differential reinforcement of other behaviour were excluded, as there was no challenging behaviour observed in the group homes. After ASM had been documented, field notes were written to examine subjective opinions about the overall session. Before any observations were carried out, I had five training sessions with a researcher from La Trobe University who went through how to conduct the observations.

8.6.3 Questionnaire about service users’ adaptive behaviour

One questionnaire was answered by staff to document and examine service users’ adaptive behaviour and disabilities, both at baseline and after approximately 1-2 years. This questionnaire included the Short form of the Adaptive Behaviour Scale (SABS) (Hatton et al., 2001), consisting of 24 items covering three subscales: personal self-sufficiency, community self-sufficiency, and personal-social responsibility. A higher total score on SABS is consistent with a higher level of adaptive behaviour. SABS has good reliability and validity in previous research, and Cronbach’s $\alpha = 0.96-0.97$ (Hatton et al. 2001).

8.6.4 Interviews with managers

Interviews with three managers were performed one year after the implementation. The interview questions were developed previously as part of the Observed Measure of Practice Leadership (see Beadle-Brown et al., 2015). The questions were translated to Swedish from English (see appendices). The interview guide asked questions about practice leadership, the managers' work role, and their view of group homes and the quality of work in the group home. It also included the managers' views on success and challenges. The interviews lasted for approximately 45 minutes, were recorded and transcribed verbatim.

8.6.5 Observations of Practice Leadership

Practice leadership was examined three times (at baseline, after one year and after two years) in every group home. The Observed Measure of Practice Leadership was used (Beadle-Brown et al., 2015). This includes an assessment of practice leadership rated after a visit in the group home by the researcher and some short questions to staff concerning allocation of staff and priorities in supporting service users. The researcher also reviews the written material, such as support plans during the visit. Ideally, this assessment should also include interviews with managers, however, in this project the interviews with managers were held separately (see 8.6.4). After the observation and short questions to staff, the researcher makes an assessment of practice leadership according to a rating of five aspects of Frontline Practice Leadership: 1) Allocating and organising staff to support service users in a way that fulfils the needs of the service users, 2) Coaching staff to provide improved support by observing their interactions, 3) Improving the quality of support provided by each support worker through one-to-one supervision, 4) Reviewing and constantly considering how to improve support to enable people to engage in meaningful activity and relationships, 5) The manager/house supervisor focuses on QoL and how staff support focuses on QoL for service users (see Beadle-Brown et al., 2015). The authors of the Observed Measure of Practice Leadership have shown that the measure has good reliability in all domains, although with some variability across domains. The average Kappa value across the five domains was 0.63 and the internal consistency was high (Cronbach's alpha 0.925) (Beadle-Brown et al., 2015).

8.7. Adaptations and modifications

This project followed the Framework for Reporting Adaptations and Modifications-Enhanced (FRAME) (Wiltsey Stirman et al., 2019) to carefully document any changes made for contextual purposes (language, culture, etc) as well as content (any part of the training added, emphasised more, or removed). FRAME consists of careful considerations of the modification process, such as 1) When did the modification occur? 2) Were adaptations planned? 3) Who participated in the decision to modify? 4) What is modified? 5) How was it modified? 6) What is the nature of the content modification? 6) Reasons for modification (sociopolitical, organisation/setting, provider and recipient)? (for a comprehensive view of the FRAME framework, see Wiltsey Stirman et al., 2019). Another key concept in implementation science is fidelity. Fidelity is defined as the degree to which an intervention is implemented as was intended in the original version or by the programme developer (Damschroder et al., 2022). Active Support is a staff practice with a flexible approach that can be tailored to each person receiving support, rather than a manual-based method that should be strictly followed. Wiltsey Stirman et al. (2019) define two kinds of fidelity modifications: fidelity-consistent modifications that preserve core elements of a treatment that are needed for effective intervention, and fidelity-inconsistent modifications that are changes that do not keep core elements of the intervention. An important aspect of modifications in this project is cultural adaptations such as language, etcetera. According to Bernal et al. (1995), cultural adaptation can be characterised as the systematic modification of an intervention to take into consideration languages, culture and the surrounding environment, in line with the client's cultural patterns, meanings, and values. The longitudinal design, together with two reference groups following the project as an advisory board, allows for such issues to be taken into consideration during the project. Analysing adaptations in implementation projects is now considered crucial and encompasses any changes made to the intervention (Wiltsey Stirman et al., 2019). Adaptation can be defined as the process of reflective and intentional alteration to the intervention design or implementation to enhance the outcome or effectiveness of the intervention in a specific context (Wiltsey Stirman et al., 2017).

In this project, three major adaptations can be analysed by using the FRAME framework. One initial fundamental adaptation was the translation of all research material from English into Swedish. Specific steps were taken to adapt the material to a Swedish context. Material provided by researchers from Australia, both observational tools, questionnaires and interview guide (with managers), were translated to Swedish from English. The questions and other text were translated in three steps: 1) initial translation by me, and 2) the responsible project leader checked the questions and made changes to facilitate comprehension. Finally, 3) an assistant checked the translation using the back-translation method (for questionnaires) (Brislin, 1970). When the research material and instruments had been translated back to the original language, the two versions were compared and analysed for possible differences. Apart from a few specific sections that needed to be adjusted because of contextual factors in Sweden, no major changes were needed.

Regarding the online training, the questions and exercises were also translated into Swedish. Although the training videos remained in English, Swedish subtitles were added to ensure that all participants were able to follow the training programme.

Two adaptations were made for cultural reasons. These included changing alternatives in the questionnaires regarding what languages the person spoke, because the original alternatives were languages seldom spoken in Sweden. These modifications were small and did not impact the overall analysis of the material. The second major adaptation of the training programme was that not only first-line managers but also senior support workers were practice leaders after year one (see 9.3). An adaptation of the FPL was made after one year, when one manager and two senior support workers were trained to give feedback and act as practice leaders in the project. Equally, the results of observations and interviews suggested that this outcome would be better for the project for adherence and to improve uptake of the programme.

The decision to make the practice leader a senior support worker (i.e. stödpedagog) was suggested by the managers and supported by the reference groups. The findings from the data collected in year 2 demonstrated afterwards

that the modification was efficient in creating better opportunities for the durability of the programme.

A third important adaptation was that a training session was repeated after one year (usually during a staff meeting). The purpose was to remind staff to continue working with Active Support and strengthen its effect by ensuring that new staff also received training. Staff would also continue to reflect on the support they were giving and watch videos again from the online resource site. This session usually included discussing how they were implementing the staff practice in their everyday work.

8.8. Methods of analysis

The following analyses were conducted:

Interviews with service users were analysed by thematic analysis (Braun & Clarke, 2006). The transcriptions were first read and re-read on several occasions, so I became familiar with each interview. Then all interviews were coded by hand. After the codes had been created, I began to create themes and sub-themes and analysed all interviews to grasp the latent meaning. (see Article II)

Observations of staff and service users were analysed by calculating descriptive statistics such as means and percentages of the observational tool ASM (Mansell et al., 2005). Each item of the ASM is scored on a scale from 0 to 3. Descriptions of how to calculate the instruments were provided by researchers at La Trobe University. Crosstabulation and means were calculated with Excel. (see Article IV)

Field notes from observations were examined qualitatively with inductive content analysis (Graneheim et al., 2017) by writing notes and categorising the different codes and themes. The field notes were also assessed quantitatively by calculating the frequency of occurrence, for example how many times a leader was on site during the observations. (see Article III)

Interviews with managers were analysed by inductive content analysis (Graneheim et al., 2017). The transcriptions were first read and then all interviews were coded by hand. The themes were created after the codes had been created and categorised. (see Article III)

The Observed Measure of Practice Leadership was analysed similarly to previous papers about practice leadership (Beadle-Brown et al., 2015). The observational tool has a questionnaire with a couple of questions that are answered by the researcher after the observation and short talk with staff. It can have a total score of between 5 (minimum) and 25 (maximum). The total score was calculated for each group home and was analysed by hand-calculated descriptive statistics, i.e. means. The means for each year (examined three times; baseline, year 1 and year 2) were calculated and compared. (see Article III)

Short form of the adaptive behaviour scale (SABS) (Hatton et al., 2001) was analysed, and a total score of SABS was calculated for each person with intellectual disability. SABS was reported by staff twice for each person with intellectual disability, at baseline and after approximately 1-2 years. Cronbach alpha was calculated. IBM SPSS version 28 was used as software for statistical calculations. (see Article IV).

8.9. Trustworthiness and generalisation

Qualitative research methods involve the systematic collection, organisation, and interpretation of textual data coming from talk or observation (Malterud, 2001). This project relies on qualitative methods such as interviews and field notes from observations. Interviews and observations provide detailed data that can explore the research questions in depth. It can also explore research questions from different angles and examine the subjective opinions and thoughts of the study's participants. However, a number of methodological issues must be taken into consideration regarding the qualitative aspects of this project. Ensuring trustworthiness is important for determining the credibility and reliability of qualitative findings (Ahmed, 2024). To ensure trustworthiness, it is important to establish whose voice is heard through the project, that of the participants or that of the researchers (Graneheim et al., 2017). For this reason, the text was written throughout in such a way that it is clear to the reader whose opinion or view is being explored. To achieve credibility, it is important to include participants with experience of the explored phenomenon (Graneheim et al., 2017). This research project included first-person accounts from managers and also included the

voices of people with intellectual disabilities. Trustworthiness is an umbrella term and also refers to concepts such as ‘dependability’, ‘confirmability’, ‘transferability’, and ‘authenticity’ (Graneheim et al., 2017). Dependability can be achieved through detailed documentation, while confirmability refers to peer debriefing, the degree to which the findings can be confirmed by other researchers, and reflexivity (Ahmed, 2024; Korstjens & Moser, 2017). For example, the themes of Article II were discussed both with supervisors and with a reference group of people with intellectual disabilities. The research findings were described and discussed with the service users in a meeting after the intervention ended. The participants responded that they recognised the results from the interviews.

To achieve transferability in qualitative research, one needs to include enough interviews to cover important variations in the findings (Graneheim et al., 2017). It is not possible to determine the specific number of interviews needed, but the data must provide rich material to explore (Sandelowski, 1995). In this study, there were a limited number of participants for interviews with managers (Article III), but more for interviews with service users (Article II). The interviews thus provided material of differing richness, and while some were wordy and involved detailed descriptions, others were more concise. To increase the richness of the material, some of the interviews with service users were combined with symbol-based communication aids, so as not to rely only on verbal communication.

Providing examples of the abstraction and interpretation processes (e.g., using quotations) is a way to enable the reader to assess the authenticity of the results (Graneheim et al., 2017). Therefore, the data collected in articles II and III include quotes from this project to increase authenticity. The Consolidated Criteria for Reporting Qualitative Research: 32-item checklist (Tong et al., 2007) was used in this project for examining and writing articles based on qualitative methods.

This project also uses quantitative methods, such as statistical analysis based on questionnaires. The generalisation of this material is limited because of the small number of participants. This causes a low statistical power, and it may be difficult to reach statistical significance. Two categories of error may be introduced in quantitative scientific studies: random error and systematic error (Tripepi et al., 2010). Random errors reflect the problem of a study’s precision and are due to

chance, whereas systematic error reflects the problem of validity in the study (Tripepi et al., 2010). Validity can, on the other hand, be described both in terms of internal as well as external validity. External validity pertains to the extent to which the study can be scientifically and statistically generalised (Rothman, 2002). For example, external validity tells us how well the results of a study can be representative of a population. The group homes in this research project shared similarities with other group homes in society (such as size, location, characteristics of the service users, number of staff, staff education, etc). However, due to the limited number of group homes in this project, the generalisation of the findings is limited. On the other hand, internal validity mirrors systematic or random errors and is mostly negatively affected by selection bias, information bias or confounding (Tripepi et al., 2010). The organisations running the group homes chose to be part of this project, and the staff expressed an interest in being part of the study, which could have impacted the results. Possible biases encountered in this project are further discussed in the discussion section.

8.10. Ethical considerations

Conducting research about people with intellectual disabilities involves ethical considerations. Research projects about vulnerable populations require attentiveness and sensitivity to ensure that the research benefits the population of people with intellectual disability. The research must also be alert to the potential risks of conducting research about specific groups of people, so that it does not introduce biases or feed stereotypical images of an already vulnerable group. In the present project we tried to prevent this by involving people with intellectual disabilities in the project. This was deemed crucial to reduce the risk of reproducing stereotypes. For ethical reasons, the involvement of the service users, i.e. people with disabilities, should be central when evaluating interventions like Active Support – because they are the most affected by the intervention. This central principle is important for promoting social justice for people with intellectual disabilities.

This form of research necessitates careful considerations prior to and during all parts of the process to avoid causing any inconvenience to the involved participants. Participants (both service users, support workers and managers) were asked for informed consent for the observations, questionnaires and interviews when they were recruited. All study participants were informed that they could withdraw consent at any time up until the data had been finally analysed and published. Informed consent (both written and verbal) (see Appendix 4) was obtained from all service users in the group homes except for one, who declined to participate. Information for service users was adjusted in several steps in the process in order to include everyone in the process (see Appendix 3). For example, written information was adjusted with easy-to-read versions and with symbol-based communication aids. Written information was also given to service users' family members or formal legal guardians. An optional information meeting with family members and formal legal guardians was held before the study started. Family members were encouraged to contact me at any time if they had any concerns regarding the project. Verbal consent was also obtained from service users for each interview and observation at the group homes, and they were informed that they could choose not to be observed at any time. I followed the observational guidance by Mansell & Beadle-Brown (2005) in their "Handbook for observers" to ensure that the service users were always at the centre. If any service users indicated that they did not wish to participate or if they closed their doors, no observations were conducted for that session, without any further questions being asked. Observations of interactions between staff and service users were only carried out in communal areas or when a flat's door was open. This was to avoid causing unnecessary interruptions to the service users' everyday lives. Most observations were carried out in the common area and living room, or in the service user's private kitchen or living room.

Most of the service users were further interviewed, and the interview guide was tested before the interviews were conducted on a reference group of people with intellectual disabilities. Family members/formal legal guardians were asked for permission and were, when suitable, encouraged to be part of the interview, to ensure that the service user had someone with them who knew them well. This allowed the service users to express themselves verbally as well as non-verbally with someone who could support them with the conversation.

The whole research process was carefully monitored and assessed by two reference panels twice a year, to provide an insider perspective and to safeguard the perspective of people with intellectual disabilities in all steps of the research. One of the reference panels included people with intellectual disabilities, some of whom were recruited from the disability organisation Inre Ringen. The other reference panel consisted of members of organisations such as the National Board of Health and Welfare, the Health and Social Care Inspectorate, the Swedish National Association for People with Intellectual Disability (FUB), the Swedish Agency for Participation, Ersta diakoni and the Union for Professionals (SSR). They were invited because of their expertise and extensive knowledge of people with intellectual disabilities, to safeguard that perspective. At the meetings, all members of the reference panels gave valuable advice from ethical viewpoints during the study. Ethical permission was approved by the Swedish Ethics Review Authority (dnr 2020-03155).

There are also several ethical considerations regarding the support workers and managers who participated in the project. An information meeting with staff and managers was held prior to the intervention, at which they received both written and verbal information about the project. They also gave written and verbal consent before the project began (see information letter and consent form in Appendix 5). Support workers were informed that they could cancel their participation after receiving the training if they wished to do so, and it would not affect their employment. They were also encouraged to talk to me if they had any questions about Active Support during the project and were reassured that it would not be shared with the manager or other senior staff members in the organisation.

8.11. My own previous experience

I have previously worked with people with intellectual disabilities in social work and for many years before that in special education. My previous work experience of meeting adults with intellectual disabilities and/or autism has been a great strength in this project, both when conducting observations and interviewing people with intellectual disabilities, as well as when training staff in Active

Support. I was familiar with the setting, routines, culture and context. I have also previously been taught a variety of communication aids, and I adopted positive strategies such as how to communicate with pictures and symbols when it was needed. However, it was important that I should reflect on my preconceived ideas and knowledge gained from previous experience in the new research role – and take precautions to minimise the risk of my past experience interfering with my assessments and interpretations. During the observations, for example, inter-rater agreement was examined by means of parallel observations. In addition, transcribed interview data was read by and discussed with supervisors to ensure accurate analysis and interpretations. Not jumping to conclusions – or not simply confirming previous opinions or thoughts – was a challenge. It was therefore important to keep the aim of the study in mind and to keep reflecting on my research role. I was simultaneously navigating the roles of researcher, trainer and observer and I tried always to keep reflecting on my own communication with staff, managers and service users, and the effect that what I say might have on the project. I encouraged support workers to convey their thoughts about the project but always made it clear that they would be treated confidentially and that I would not relay them to others (such as colleagues or managers). I kept notes during the project in order to remain focused and analytical on the project's overall aim. I discussed the project on a regular basis with supervisors, at seminars with colleagues, and with the project's reference groups. I also gained new insights during the process, which sometimes gave rise to new perspectives. For example, drawing on theories about intersectionality and how disability and gender can interact has made me more aware of the struggles many women with disability face in society today. The observations of and interviews with women with disability have made me realise that it is not only disability that can contribute to difficulties in day-to-day life but also gender, social class, age, religion and much more. The project also confirmed, or even strengthened, some of my previous ideas, for example the important role played by key persons (for example managers or senior support workers) in continuing to improve the support in practice.

My previous work experience was also important when training and implementing Active Support in the group homes. Without previous experience and knowledge, it would have been more difficult to address and suggest improvements in support

to staff. Their knowledge that I know what it is like to be a support worker helped to build trust between myself and them. It is therefore important to recognise that future trainers in Active Support need to have a good understanding of disability and practical experience of working with people with intellectual disabilities and autism.

9. Summary of articles

The findings of this doctoral thesis are presented in four articles about the Active Support staff practice including FPL. The overall aim of this thesis was to investigate the two-year effect of Active Support in four Swedish group homes for people with intellectual disabilities. One main focus was to examine whether it leads to people with intellectual disabilities having more influence, meaningful activity in everyday life, and being able to make more choices. In this chapter, I will describe the main findings of the four papers. A summary of the specific research designs, methods and materials included for each article is given in Table 2.

Table 2. Summary of the four articles included in this thesis.

	Article I	Article II	Article III	Article IV
Aim/ research questions	1) Identify the outcomes of staff using Active Support and how these are measured 2) Identify how the views of people with intellectual disabilities have been included in Active Support research	1) How do service users reflect on good support in everyday living in group homes? (2) How do service users report on their support before and after an Active Support intervention?	To examine the two-year effect of Frontline Practice Leadership in four Swedish group homes	1) How did Active Support training affect the quality of staff support in four Swedish group homes? 2) Did Active Support benefit service users with different levels of adaptive behaviour, and did the adaptive behaviour change after staff began working according to Active Support?
Research design	Scoping review	Longitudinal Interviews	Longitudinal Mixed methods	Longitudinal Stepped wedge design

Participants	-	People with intellectual disabilities	Staff and Managers from four group homes	People with intellectual disabilities and staff
Number of participants	16 articles	9 people with intellectual disabilities	28 staff and three managers	28 staff, 20 people with intellectual disabilities
Time period	2009-2023	2021-2022	2021-2024	2021-2024
Methods	Database searches	Semi-structured interviews in a pre- and post-design	Observations and Interviews with managers	Observations Questionnaire
Material	Articles from four databases were included: Cinahl, Pubmed, Web of Science and PsycInfo.	An interview guide was created and used at baseline and at follow-up.	The Observed Measure of Practice Leadership, observational field notes and interviews with managers	<i>ASM</i> <i>SABS</i>
Main results	Observations were the most used data collection method ASM and EMAC-R were mostly used as instruments Most common outcome were quality in staff support and engagement	Service users were more satisfied with support a year after staff received Active Support training, in particular in choice making, control in everyday life, relationships, and emotional support.	FPL was successfully implemented in all four group homes Practice leaders were more present in everyday support Managers experienced difficulties to conduct observations and feedback sessions Practice leaders can be both	Quality in support improved in all four group homes. Active Support benefitted service users with a variety of support needs No significant change in service users' adaptive behaviour was found at follow-up.

	<p>in meaningful activities</p> <p>Only two papers included people with intellectual disabilities in the evaluation</p>		<p>managers as well as senior support workers (i.e. stödpedagoger)</p>	
--	---	--	--	--

Abbreviations: ASM=Active Support Measure; SABS=Short form of the Adaptive Behaviour Scale, FPL= Frontline Practice Leadership

9.1. Article I

Article I was a scoping review which had the following aims: 1) identify the outcomes of staff using Active Support and how these are measured, and 2) identify how the views of people with intellectual disabilities have been included in Active Support research.

The review examined scientific articles from four databases (PsycInfo, Cinahl, Pubmed and Web of Science) between 2009-2023. Sixteen peer-reviewed scientific articles were included. The review generated some important findings. Firstly, observations were the most frequently used data collection method, followed by staff surveys and interviews with staff. Eleven studies used non-participant observations for data collection. Many studies used several data collection methods, most commonly combining non-participant observations (examining engagement or quality of staff support) with surveys answered by staff (for example examining staff perceptions of service users' adaptive behaviour or choice making).

Secondly, the article demonstrated the consistency of measures used in Active Support research over time. The most frequently used measures were the observational measurements ASM (Mansell et al., 2005) and Engagement in Meaningful Activity and Relationships (EMAC-R) (Mansell & Beadle-Brown, 2005). The ASM was often used in combination with EMAC-R. The ASM measures the quality of staff support and EMAC-R measures the type and

frequency of engagement of people with intellectual disabilities in various activities. EMAC-R also measures the type and frequency of support each person receives from staff: assistance or contact. The repeated use of these measures allows for comparisons between studies and between different contexts, different study populations and different cultures and countries. This can be considered an asset in Active Support research and increases the validity of the research.

Thirdly, this review examined which outcomes for people with intellectual disabilities that have been researched in the sixteen articles. Most frequent was consistent outcome evaluation of service users' engagement and social interactions between staff and people with intellectual disabilities, chiefly using the ASM and EMAC-R observational instruments. Other examined outcomes are challenging behaviour (mainly with EMAC-R), choices (through surveys and interviews), and quality of staff support (through ASM). This article identifies the different instruments and scales used in Active Support research and which of these have been used to examine specific outcomes. Adaptive behaviour has been examined broadly, most commonly by using SABS (Hatton et al., 2001; Nihira et al., 1993), which was used in five studies, or the Inventory for Client and Agency Planning (ICAP) (Bruininks et al., 1986), which was used in another five studies.

Fourthly, this scoping review identified a considerable knowledge gap about the first-person accounts of Active Support evaluation from the perspectives of service users. This review only found two peer-reviewed articles about Active Support evaluation with first-person accounts of people with disabilities (Graham et al., 2013; Stewart et al., 2018). Graham et al. (2013) examined four residents' views in a care facility two years after Active Support had been implemented. However, their study included only one person with intellectual disability, while the other three participants had global cognitive impairment. Further, the study examined the residents' views two years after the intervention and there was no assessment of how well staff were working according to Active Support practice. In Stewart et al. (2018), eight people with intellectual disabilities were interviewed about their support according to Active Support. However, they all lived in individual homes with supported living, rather than in group homes. In total, between 2009-2023, only nine people with intellectual disabilities have been involved in evaluating Active Support.

This article highlighted the need for more research including people with intellectual disabilities in the outcome evaluation. Also, the recommended modifications to the ASM that is discussed in the article, i.e. related to Humphreys et al.'s (2024) finding that the ASM measures two aspects of support: (a) technical dimensions of supporting an individual's engagement in activities and (b) interpersonal dimensions of support, could also contribute with potential extra insights about dimensions of support obtained from the views of people with intellectual disabilities.

9.2. Article II

Article II was an interview study to examine what people with intellectual disabilities think is good support in group homes and to examine whether Active Support improved support. This study sought to answer the following research questions: 1) How do service users reflect on good support in everyday living in group homes? 2) How do service users report on their support before and after an Active Support intervention?

Interviews with nine people with intellectual disabilities living in group homes were conducted twice: at baseline (before staff received training), and at follow-up (approximately one year after staff received training in Active Support). The interviews were analysed with thematic analysis. This article used two theories, an Ethic of Care perspective (Tronto, 1993) and the Competence Framework by Illeris (2012), both of which reflect the overall aim of Active Support to improve staff behaviour in a care setting. The Ethic of Care theory has been recommended previously for examining staff support in group home settings (Bigby et al., 2015).

Three main themes were created: 1) *Home is more than just a place, it is a feeling*, 2) *Good care is caring with accessible communication*, and 3) *Time is precious*. They all demonstrate what is important in support from staff from the perspective of the service users. The interviews showed that a combination of knowledge-based competence together with interpersonal skills, was important in providing qualified support.

The themes had several sub-themes. *Home is more than just a place, it is a feeling* had the following sub-themes: *choice, feeling safe, support with relationships and emotions*, and *staff being kind-natured, having a sense of humour and being attentive*. From *Good care is*

caring with accessible communication, the following sub-themes were created: *clarity in communication*, *use of augmentative and alternative communication*, and *competence in staff*. The third theme, *Time is precious*, had the following sub-themes: *trust*, *sufficient staff-to-service user ratio*, *support with weekly schedule and day activity centre*, and *planning and support with activities*.

The findings showed positive results, demonstrating that the support workers were providing more choices and had increased the interviewees' influence on everyday life situations. This was primarily in daily activities and in domestic tasks such as cooking and cleaning. The interviews also demonstrated that staff were giving service users more support with interpersonal relationships and emotional support at follow-up. However, the Active Support training seemed to have less influence on outdoor activities, physical activity and punctuality. At follow-up, these still needed to be improved. Lack of punctuality, i.e. staff being late for meetings or support time, was closely related to whether the people with intellectual disabilities could trust the staff and whether staff were found to be reliable. Punctuality was therefore seen as a key to providing good support from the perspective of people with intellectual disabilities.

An important new finding of this interview-based research was that emotional support had improved at follow-up. The service users reported that they could rely more on staff to comfort them in troublesome situations, and that staff were there if they needed them. They also felt they were able to demonstrate different emotions, such as anger, without being targeted as aggressive.

The findings indicate that the different phases of an Ethic of Care perspective were noticeable in the interviews. Tronto (1993) describes how the phases of care develop from four ethical elements of care: attentiveness, responsibility, competence, and responsiveness. All these features came up in the interviews and were discussed in relation either to the lack of them (poor care) or gratitude at having them (good care).

This theory is helpful to examine whether needs are being met and the responses from the service users provided a first-person perspective. The interviewees reflected on the different phases of care (Fisher & Tronto, 1990), such as what it means to care for someone (phase one), how to organise care so that a sufficient number of staff can support each person (phase two), and which characteristics

are important for the caregiver role (phase three). To be able to give feedback on the support, was also lifted (phase four). The fourth phase of care-receiving is helpful in Active Support research to improve the support worker role. This is also in line with the core principle of Active Support to train support workers to be more attentive which resembles with the opinions and feedback of care receivers.

This article showed that valuable new perspectives can be obtained by examining the effects of Active Support through the voices of people with intellectual disabilities.

9.3. Article III

The aim of Article III was to examine the longitudinal two-year effect of FPL training in four Swedish group homes. This study included three managers and 28 support workers. It made use of three data collection methods. During observations, data was collected by field notes on 49 occasions, and by filling in the Observed Measure of Practice Leadership on three occasions (Beadle-Brown et al., 2015). See Figure 3 in Chapter 8.2 for data collection timelines.

The role of managers was further examined through structured interviews with managers one year after Active Support implementation.

The Observed Measure of Practice Leadership was analysed by means of descriptive statistics (calculating mean) and the field notes were analysed qualitatively (with themes and categorisations) as well as quantitatively (counted the presence of a practice leader). The interviews and field notes were analysed by inductive content analysis (see Graneheim et al., 2017).

The findings from field notes and the measures showed that FPL training had a positive effect in all four group homes. The five main dimensions of FPL were found in all four services after the training. The scores improved substantially from baseline to year 1 in three group homes but then levelled off or even declined slightly in year 2. Three group homes (group homes A, B, and D) had a low initial score at baseline. For one group home (group home C), no data was collected at baseline because of the Covid-19 pandemic, visiting restrictions, and

because this group home had just opened. However, altogether, three group homes demonstrated a similar pattern of improvement from baseline to year 1 and small changes from year 1 to year 2 based on the Observed Measure of Practice Leadership (Beadle-Brown et al., 2015). For example, group home A had a total score of 12 points before training, which improved to 19 points in year 1, but remained the same in year 2. Group home B had the lowest score at baseline (8 points) but improved to 12 points in year 1 and further to 13 points in year 2.

Several post-training improvements were found when the data collected from interviews with managers, observational data and the Observed Measure of Practice Leadership were combined. These improvements were: visual signs of practice leadership in the planning of support, increased presence of a practice leader in everyday support, feedback sessions with staff, and regular team meetings at which Active Support was discussed. For example, at baseline, a leader was present in everyday support in an average of 17% of the observations. This improved to 33% (year 1) and 69% (year 2).

The findings also demonstrated the importance of conducting regular feedback sessions and observations. In addition to discussing Active Support at team meetings, the regular feedback sessions allowed staff to critically reflect on their own individual performance as well as the group's overall team performance.

However, the interviews also revealed how managers struggled to conduct feedback sessions on a regular basis. The lack of time for feedback sessions was seen as a problem for managers, whose time was often fully booked, and who sometimes worked in several group homes in different parts of the city. The interviews with managers showed they thought others could become practice leaders, or that observations with feedback sessions could be divided between other staff, such as senior support workers or group leaders. For this reason, two senior support workers received the FPL training during this intervention project. A conclusion drawn from this study is therefore that, in the Swedish context at least, it can be beneficial to train other staff than managers to become practice leaders who can carry out observations in group homes.

9.4. Article IV

Paper IV examined the two-year long-term effect of Active Support training on the quality of staff support and changes in service users' adaptive behaviour before and after the Active Support intervention in four Swedish group homes. Two research questions guided the study: 1) How did Active Support training affect the quality of staff support in four Swedish group homes? 2) Did Active Support benefit service users with different levels of adaptive behaviour, and did the adaptive behaviour change after staff began working according to Active Support?

The group homes were followed for two years after the Active Support training. This study included a total of 28 support workers and 20 people with intellectual disabilities.

Two data collection methods were used. The range of adaptive behaviour in service users was examined through SABS (see Hatton et al., 2001) which was filled in by staff twice: firstly, before staff received Active Support training and secondly a year after staff received training. I also conducted 53 observations in the four group homes. These were divided into three periods; at baseline, before Active Support training, one year after staff received training, and two years after staff received training. During the observations, data were collected by filling in the ASM instrument (Mansell et al., 2005), which examines the quality of support for people with intellectual disabilities (Mansell et al., 2013). See Figure 3 in Chapter 8.2 for data collection timelines. ASM data were analysed and examined by means of descriptive statistics, such as percentages calculated before and after Active Support intervention. For SABS, the percentages and scores were calculated, and a chi-square test was conducted.

The ASM results showed a positive effect of improved quality of support in all four group homes. According to ASM, all results above 66.66% are clear indicators of qualified Active Support in the group homes (Mansell et al., 2013). The pre-training observations gave ASM results of between 56%-65%, which can be seen as indicating that the group homes were underperforming. However, a year after the intervention, the average results of the ASM score improved substantially and ranged between 74%-83%. After two years, there was a further, but smaller, improvement, with the ASM scores ranging between 80-86%. Scores

for some of the items increased more than others, such as tasks appropriately analysed, graded assistance to ensure client success, sufficient staff contact and improved choice of activities. These findings suggest that the quality of staff support improved, particularly in these aspects of support.

The results showed that the service users had a range of different levels of adaptive behaviour. The findings also demonstrate that a majority (n=14) service users had a better SABS score at follow-up than at baseline, but the results were statistically non-significant ($p=.282$). This may be because of the small sample size, or because changes in adaptive behaviour may take time and that one year is not enough to measure follow-up and potential changes. Also, many participants had disabilities other than intellectual disabilities. It might also mirror the fact that Active Support focuses on engagement and staff providing active support and is not necessarily an educational programme for teaching service users skills.

Despite this, longitudinal observations were a valuable method to examine staff-service users' interactions in group homes, and the results found that these interactions and the quality of staff support improved at follow-up, both for year 1 and year 2. These novel findings, that the effects persist over time, are promising for further implementation of Active Support in new contexts.

10. Overall analysis and discussion

This doctoral thesis studied the adoption and implementation in Sweden of a staff practice that has been developed abroad including evaluation of the effects of the staff practice over time. The well-researched Active Support approach was introduced in four group homes for people with intellectual disabilities and the implementation was followed for two years. This concluding chapter contains answers to the research questions of this thesis and discuss the most important results. Initially, a brief description is given of the context of Active Support in Sweden. This is followed by summary of the answers to the research questions and a discussion of the results of the thesis. After, a discussion follows of the methodology and review of strengths and weaknesses, practical implications, and lastly, conclusions as well as suggestions for future research.

10.1. Active Support in a Swedish context

This doctoral thesis shows that the evidence and value-based staff training Active Support improves staff support given to people with intellectual disabilities living in group homes. Despite decades of discussions on the need for evidence-based practice in social work, there is still a lack of implementation (Liedgren & Kullberg, 2021). One reason for this is because the evidence-based movement can be criticised for not having a holistic perspective, which is a foundation in social work. This is also the case in the disability field. This holistic perspective is one of the key strengths of Active Support, which has the ambition to view all aspects in life in empowering and enhancing the living conditions for each person.

For social work aiming to tailor society's support services to the needs of people with intellectual disabilities, Active Support provides a promising introductory training for disability services which can have an important impact on the support provided. Active Support can be a way to concretise ideology, norms and values that are envisioned in rights-based policies such as CRPD (United Nations, 2006), LSS (SFS 1993:387), and national guidelines, national action plans and objectives (see prop. 2016/17:188). For example, according to LSS, each person should be given the greatest possible influence and control over the support that is provided. Active Support trains staff to actively listen and pay attention to the voices of people with intellectual disabilities, and to involve people with intellectual

disabilities in everyday life situations that they see as meaningful for themselves. This is stated in the Active Support essentials 'Every moment has potential', which stresses that every task or activity can actively involve each person, and 'Maximising choice and control', which trains staff to offer choices to increase a person's control over their life. Active Support derives from a humanistic, holistic and person-centred viewpoint and can be a staff practice to visualise and operationalise the national guidelines on good living conditions and dignified treatment that encourages confidence in one's own abilities and is adapted to each person's circumstances (National Board of Health and Welfare, 2018). To adapt support and social care to individual circumstances, the Active Support essential 'Little and often' reminds staff of the various ways a person can participate in activities and that staff should adjust the support to enable the person to participate on their own terms (for example allowing a person to dip in and dip out of activities) (Bigby & Humphreys, 2023). It stresses that support should be provided often and actively, instead of focusing on a specific weekly activity. Active Support emphasises that staff should provide opportunities for engagement in everyday activities, and it is the support worker's role to identify these opportunities. It can facilitate participation, which may be a route to the service user gaining improved confidence in their own abilities. The essential 'Graded Assistance' prompts staff to ensure successful engagement in an activity for a person, by providing just the right amount and type of support to enable them to participate. This will undoubtedly influence the likelihood that a person will engage in a similar activity in the future. By trying to ensure success, this may create a virtuous cycle, that positively reinforces a better QoL outcome over time.

The National Board of Health and Welfare (2018) declares that it is crucial to good support that interventions are based on each individual's needs and wishes. Active Support encourages staff to adopt an enabling support worker role and to become aware of all the activities and social interactions that are meaningful for each person to be engaged in (Mansell & Beadle-Brown, 2012). However, to ensure this, it is important that staff have an in-depth knowledge of each person, something which is emphasised in Active Support and by the National Board of Health and Welfare (2018).

By emphasising choice, control and influence in everyday life for each person, Active Support takes a stand against previous care ideologies and power disparity

between support workers and people with intellectual disabilities. This staff practice counteracts ideas that the support worker knows best and instead stresses the importance of staff listening actively and continuously developing their support to increase empowerment for each person with intellectual disability. The support worker role should entail critical self-reflection on one's own performance and continuous work to improve skills to meet the needs and preferences of each person with a disability (Mansell & Beadle-Brown, 2012). In this way, Active Support represents a power shift, giving people with intellectual disabilities more autonomy over their daily lives and opportunities for development. By also emphasising person-centred practice, Active Support moves away from a paternalistic care ideology that perceives support through a collective lens and instead highlights support based on individualised considerations.

The overall aim of this intervention project was to investigate the two-year effect of Active Support in four Swedish group homes for people with intellectual disabilities. The following four research questions were asked:

- In what way does Active Support in group homes influence the daily lives of people with intellectual disabilities, for example in participation, choice making and engagement in meaningful activity?
- In what way does training in Active Support improve the staff's competence to provide high-quality support to service users, and what role does strengthened leadership play in practice to make this possible in group homes?
- What are the service users' perceptions of good support from staff, and do they perceive that the support changed after the implementation of Active Support?
- How can people with intellectual disabilities be involved in evaluating the effects of Active Support practice?

In the following, I will elaborate on how the thesis answers these questions and discuss the findings.

10.2. The findings of the project

This project builds on the bulk of research from the UK and Australia about the improved quality of support achieved through Active Support training (Beadle-Brown et al., 2012; Bradshaw et al., 2004; Chou, 2011; Flynn et al., 2018; Hamelin & Sturme, 2011; Jones et al., 2001; Mansell et al., 2002; Stancliffe et al., 2008; Stancliffe et al., 2010; Totsika et al., 2008). Beadle-Brown et al. (2021, p. 43) state that: “Over many years, research has shown that one of the key determinants of QoL, and in particular whether people spend their time meaningfully engaged (apart from severity of disability), is whether the support they receive is enabling and empowering—helping people to do as much as possible themselves and then, when support is needed, doing with people rather than doing for or to people/.../ this approach is usually referred to as Active Support”. Continued practice of Active Support is the most well-studied predictor of quality in group homes for people with intellectual disabilities (Bigby & Beadle-Brown, 2018). Through the social interactions between staff and service users, staff shape and boost either engagement in meaningful activity or passivity and inactivity (Beadle-Brown et al., 2016). I will therefore elaborate on some key aspects of the findings regarding Active Support outcomes: staff-service user interactions, the service users’ participation and engagement in activities, and improved opportunities for more choice in everyday life.

The first research question asked in what way Active Support influences the daily lives of people with intellectual disabilities, for example in participation, choice making and engagement. The main results showed that people with intellectual disabilities (Article II) and managers (Article III) emphasised that the quality of support, participation and opportunities for choice improved after the Active Support training. The results demonstrated that both subjective experiences (Article II) and objective observations (Article IV) were similar in perceiving positive outcomes from Active Support. Training in Active Support improved the staff’s competence to provide skilled support, in line with research question two. The findings to research question two, regarding what role strengthened leadership play in practice to make this improvement possible, shows that practice leadership is important to improve support and embed Active Support in service (Article III). Article III also confirmed the importance of practice leader training to be able to maintain Active Support over time. This supports previous research

on the importance of practice leadership (Beadle-Brown et al., 2014; Beadle-Brown et al., 2015; Bigby et al., 2020a; Bigby & Humphreys, 2024b; Bould et al., 2016a, 2016b; Deveau & McGill, 2016). The practice leaders enabled Active Support to be discussed at team meetings and practised both individually and with feedback sessions (Article III). Results from studies III and IV suggest substantial improvements after training compared with pre-test results and further slight improvements in year 2 (Article IV). This shows that Active Support and FPL training benefited the support work, and that this effect was sustained over the two years. However, there were also indications that the effect levelled off, and this doctoral thesis cannot answer whether the effect can be sustained for longer than the two years of follow-up. Drawing conclusions about the longer-term effects (>2 years) requires caution and further research.

In this research project, I have tried to adopt several perspectives and methods. My research focused on examining how support for the relational aspects of everyday encounters between service users and support workers can be improved, and how this corresponds to what people with intellectual disabilities want to be supported with. This corresponds well to Hastings' (2010) suggestions for future research. Hastings (2010) identified three main areas of research in disability services: 1) developing systems for measuring components of the relationships between support staff and people with intellectual disabilities, 2) the need to research service user–support staff relationships from both perspectives, and 3) the need to examine the qualities and dimensions of these relationships with regard to outcomes for both support workers and people with intellectual disabilities. In the literature about group homes, staff-reported assessments are common. This project, therefore, examined the relationships between support staff and people with intellectual disabilities from the standpoint of the latter.

10.3. The voices of people with intellectual disabilities in research about interventions

It is important to include people with intellectual disabilities in research for ethical reasons, for the soundness of the research, and for the overall benefits for society. The voices and perspectives of people with intellectual disabilities should be included in all evaluations which involve them, in line with the CRPD-associated motto “Nothing about us, without us” (United Nations, 2018).

There are two important reasons for including people with intellectual disabilities in the evaluation of Active Support. Firstly, despite the long history of practising Active Support, little previous research has included an intervention evaluation from their perspective (Article I). In research question three, I asked what the perceptions of good support from the perspective of service users were and whether the support changed after implementation of Active Support? Notably, Article II is the first research to my knowledge that has examined the views of people with intellectual disabilities by means of interviews conducted both before and after Active Support training. The results reveal new aspects of what constitutes good support, such as emotional support, supporting relationships and interpersonal skills. Some interviewees reflected on their trust in staff a year after the staff training. Emotional support and trust are not aspects that are discussed much in Active Support training but could be given more focus, given the views of those living in the group homes. However, some aspects, such as physical activity and punctuality, did not seem to have improved post-intervention, suggesting that this is something staff need to pay more attention to. Similarly, the Active Support intervention did not particularly improve outdoor activities. This is interesting, since a previous study by Beadle-Brown et al. (2016) showed that people with intellectual disabilities who received better active support had higher levels of engagement in the community (staff rated). However, outdoor activities are just one form of activity in the community, and this finding needs to be explored further. Another important consideration is that the Covid-19 pandemic took place at baseline and during the first year of the intervention, which may have impacted opportunities to participate in activities in the community.

A reason to include people with intellectual disabilities in the evaluation of Active Support has to do with social justice. A paradigm shift is needed away from the long history of exclusion of people with intellectual disabilities from many aspects of society, as well as the perception that they are too disabled to participate in evaluating interventions that affect their daily lives. The answer to research question four, how people with intellectual disabilities can be involved, showed that interviews with accessible language, pictures and the presence of a stakeholder can enable people with intellectual disabilities to participate in outcome evaluation. Similarly, Stewart et al. (2018) showed that Talking Mats

could be used to explore the service users' views and experiences of Active Support. Interviews may not be possible for people with profound intellectual disability. Here, ethnographic research can be a valuable tool to explore the lived experiences of these people (Clement & Bigby, 2010). Interviewing family members or close allies is a further step that can be taken, which was not done in this project. Their perspective is also missing from group home research (Bigby et al., 2023).

10.4. The importance of continuous training for staff

Evidence-based staff practices are increasingly recognised as needed in social work as well as in the disability field to improve everyday life for people with intellectual disabilities (see for example Courtade et al., 2014; Hastings, 2010). The need for good practice aligned with the rights of people with disabilities is further recognised in CRPD, Article 4, which urges states: "To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights" (United Nations, 2006, p.5). This project shows that it is possible to change and improve staff support by training with relatively small funds, but with a systematic method. It also indicates that staff continued their work to improve support over two years (Article IV). However, all of this requires a committed trainer, a practice-oriented leader, and regular supervision and feedback.

Social work in the field of disability should not change people or teach them to adapt to circumstances and be content with what is offered. The support worker role involves promoting, assisting and strengthening individuals, encouraging them and identifying opportunities for change. They should work for equality and justice and to realise the goal that people with disabilities should live a life like others, among others. Maximising choices, participation, influence and meaningfulness in life, as highlighted by Active Support, is central to this work.

Social work has a strong commitment to social change and needs evidence-based methods in line with this. Social work needs to be able to take advantage of all opportunities for social change and new developments for marginalised groups.

Active Support is one such instrument, but social work must always have a critical and questioning eye in order to promote development. As this doctoral thesis shows, Active Support is effective with many positive consequences for both staff and people with intellectual disabilities, but it is not perfect, but it also has shortcomings in some respects. One of the observations in this thesis is that communication is an area where progress is needed. It is fundamental for people to be able to communicate their needs and wishes and their visions for their lives. More work is needed here to increase the communication skills of staff. Communication is the basis for the design and content of support for people with intellectual disabilities. Active Support could be further developed to be combined with methods that specialise in communication, such as AKKtiv ComBo. AKKtiv ComBo (Thunberg, 2024) is a staff-oriented programme, based on research, to support communication support strategies. A cornerstone of Active Support is influence for the individual, but social work also needs to pay attention to collective influence. A group, for example all service users in a group home, also needs to be given the opportunity to express common wishes and views and have a collective influence. Here, a model such as BIKVA (Hultman & Tideman, 2024) may be used as a tool to supplement Active Support and to examine group experiences.

New methods are needed to improve skills in augmentative and alternative communication, in how to respond to challenging situations, and in how to improve QoL and prevent malpractice (Health and Social Care Inspectorate, 2021; 2023). In addition, the need for support may not always be linked to disability, but rather to demands and situations that most adults face during the life course, such as grief, loss, unemployment and accidents (Bigby & Frawley, 2010). However, disability adds another layer to this, and the combined effect of the impairment and unresponsive systems makes these situations even more difficult (Bigby & Frawley, 2010). For example, a person with intellectual disability may find it difficult to express the need to share an emotionally upsetting life situation due to speech impairment. Without skilled support which recognises how the person communicates, these needs might go unmet. An attentive support worker, however, with the skills to respond to each person's unique communication style, can respond and support the person through difficult situations. No matter whether one has a disability or not, close and caring

relationships are indisputably associated with well-being throughout the life course, and relational support can have long-term effects on thriving (Feeney & Collins, 2015). An important finding of this project, related to the importance of social support in tackling difficult life situations, is therefore that interpersonal relationships and emotional support improved after Active Support training (Article II).

Overall, this intervention project demonstrated that it is possible to improve staff skills to provide better support for people with intellectual disabilities. With training and continued reflections about their own performance, this project showed the value of offering staff evidence-based training. Senior support workers (i.e. stödpedagoger) undertake a two-year, part-time post-secondary programme (Higher Vocational Education), providing them with a range of specialised skills and competences, such as knowledge of LSS (SFS 1993:387) and an understanding of different disabilities and support methods, communication aids etc (see National Board of Health and Welfare, 2021). Their role includes supervising support workers in their everyday work (National Board of Health and Welfare, 2021). The last ten years' establishment of the role as senior support workers (i.e. stödpedagoger) is an improvement, and it is likely to be an important step towards more specialist competence in services. However, most group homes only have one senior support worker, which makes the services vulnerable to changes in quality if the senior support worker should leave.

It is therefore important to provide basic training for all staff, not just senior support workers. This project demonstrates that Active Support, in the form of a short 2-day training with video modules and feedback sessions, might be a relatively simple and cost-effective way to do so. One observation in year 2 revealed a considerable gap in skilled support between trained support staff and newly employed temporary staff without Active Support training. When only untrained temporary support workers were on duty, the ASM was 48% rather than above 80%. This observation was excluded from the analysis since this research only examined those staff who had received training. However, this incidental finding supports the idea that all staff (both permanent and temporary staff) should receive Active Support training.

I also believe, in line with Hastings (2010), that there is much to gain from examining why support workers continue working in this field and the value that they place on positive contributions. This reflects positive aspects of providing support such as the intrinsic value of continuing to develop skills in supporting people with a range of support needs. These are important insights not only for Active Support, but also for interventions in group homes in general. This suggests that it is not only support workers' attitudes or opinions that influence the everyday support they give, but that actual skills and methods are needed to improve competence. These issues are important for progressing the status and professionalisation of the support worker role. According to an Ethic of Care perspective (Tronto, 1993), care is central in all societies and for everyone at some point in life, but particularly for children, the elderly and people with intellectual disabilities. Valuing the work of those who give support more highly and continuing to improve the competence and status in this field, will likely affect how society views care and support in general.

10.5. Active Support for people with a variety of support needs

People with intellectual disabilities share certain characteristics but are also individuals with many differences. They are not a homogeneous group and their abilities vary greatly. These individual differences must be taken into consideration in the design and content of support services. This is where Active Support is perhaps most valuable; in that it seeks to increase staff's competence in adapting support to each individual and each different situation. Each individual's support needs are unique, and each individual has their own personality, social circumstances, and disability. Active Support can be said to have some similarities with another type of LSS support provided for some people with lifelong support needs due to disability, namely the personal assistance for people living in their own homes. The starting point in both Active Support in group homes and personal assistance is precisely the unique person's living conditions, needs and wishes. The present project mainly includes people with mild to moderate intellectual disabilities. This adds new knowledge to research into Active Support because it demonstrates that Active Support benefited people

with different levels of support needs, not only people with moderate to severe intellectual disability which previous studies often have focused on (Beadle-Brown et al., 2016; Mansell & Beadle-Brown, 2012; Smith et al., 2002). The finding that people with mild intellectual disabilities benefitted from better support after staff had been trained in Active Support is in line with a recent RCT which demonstrated Active Support's effectiveness in improving support, well-being and QoL for people with mild to moderate intellectual disabilities (van Herwaarden et al., 2025). The benefits of Active Support for people with mild intellectual disabilities are especially important because this is the largest group of people with intellectual disabilities (Region Stockholm, 2025). In the study by van Herwaarden et al. (2025), assessments were conducted three times: at the start of the trial, after six months and after nine months. In this project, I studied the changes over an even longer period of two years.

10.6. Active Support and the Quality of Life framework

In this section, I will discuss some of the findings in light of the QoL framework. QoL is an essential aspect of supporting people with intellectual disabilities according to Active Support, and Schalock et al. (2002) provide a theoretical framework for it. The purpose of applying the QoL framework is to understand and measure increases in an individual's well-being. Schalock et al. (2002) list eight domains in QoL for people with intellectual disabilities: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights.

Further analysis is needed to assess which key determinants of QoL are affected by Active Support, and how. Although I did not use any instrument which specifically assessed QoL, the empirical results of this project can be found in QoL, particularly in the domains of emotional well-being, interpersonal relations, physical well-being, personal development, social inclusion, and self-determination. I will therefore discuss the results through a QoL lens.

Schalock et al. (2002) list 'emotional well-being' as the first domain and describe it as safety, stable and predictable environments, and positive feedback. The interviews in Article II identified the importance of emotional well-being for

people with intellectual disabilities, who said that emotional support had improved at follow-up after the intervention. This article describes how the value of being able to express emotions and receive emotional support was emphasised by people with intellectual disabilities themselves. They described the significance of feeling safe and of staff being kind-natured, attentive and having a sense of humour (Article II). A sufficient staff-to-service user ratio was also described as essential, which is in line with Schalock et al.'s description of a stable environment (2002).

Schalock et al. (2002) call the second domain 'interpersonal relations' and exemplify it as affiliations, affection, intimacy, friendships and interactions. In Article II, interviewees said that staff support with relationships was important, and most of the participants said that their relationships had improved at follow-up. Similarly, observations in Article IV showed a small increase in interpersonal warmth at follow-up, which can also be seen as indicating improved interactions with staff.

Schalock et al. (2002) exemplify the domain 'physical well-being' as health care, mobility, wellness and nutrition. Few examples from this domain can be found in the empirical material. Nutrition was discussed in Article II, in terms of more choice in what to eat, but was more related to self-determination. Health care was not discussed in Article II, nor in Articles III and IV. The only clear finding related to this domain is that physical activity still needed to improve after the intervention (Article II), hence the intervention did not impact this dimension of life.

'Self-determination' is another core domain in QoL, and Schalock et al. (2002) exemplify it as choices, personal control, decisions and personal goals. All three empirical articles (II, III and IV) in this project coherently show that choice making improved after the intervention. Interviews with service users (Article II) and managers (Article III) as well as the observational study in Article IV, all showed an increase in choice making. The ASM item, "Choice of Activities", improved from 1.4 to 2.38 on average in year 2 in the four group homes (Article IV).

The domain 'personal development' is related to education and habilitation, purposeful activities and assistive technology (Schalock et al., 2002). Being

supported with changing day activity centres and experiencing new activities is related to personal development and was stressed as important by several participants in Article II. Almost half of them had changed day activity centres at follow-up and said that they had been helped with that.

‘Social inclusion’ can be understood as integrated environments, and participation in terms of community involvement (Schalock et al., 2002; Mansell & Beadle-Brown, 2012). No improvements in this domain were found at follow-up in Article II concerning outdoor activities, and this was not examined in the other two articles (Article III and IV). For the remaining domains of ‘material well-being’ and ‘rights’ no empirical results were found, which indicates that further research is needed.

Nevertheless, findings of this project suggest that several indicators in QoL domains had improved at follow-up. There has hitherto been limited research into Active Support implementation and its association with QoL domains. However, two recent articles by van Herwaarden et al. (2025) and Beadle-Brown et al. (2021) examined this association. Van Herwaarden et al. (2025) measured QoL with the Dutch version of the Personal Outcomes Scale (see van Loon et al., 2008), which assesses QoL in people with intellectual disabilities according to the eight domains established by Schalock et al. (2002). They found a positive association between Active Support implementation and improved QoL in emotional, physical, and material well-being, as well as improved independence. However, similarly to this project, they failed to find an association between community involvement and Active Support. This suggests that this domain may need to be given more emphasis in Active Support training, for example in terms of staff supporting more opportunities for social encounters and involvement in the community.

The results from articles II and IV can also be compared with Beadle-Brown et al. (2021). Their study showed that the better active support a group experienced, the better the outcomes were in terms of emotional well-being, personal development, interpersonal relationships, social inclusion, and self-determination.

Many QoL frameworks, such as that of Schalock et al. (2002), have the advantage of being written in a way that makes them easy to apply in both practice and research. More recent approaches and perspectives in the QoL literature add valuable views to the discussion about QoL for people with disabilities,

particularly in terms of seeing them as capable. This supports the important Active Support principle of doing with, rather than doing for (Mansell & Beadle-Brown, 2012), which has also been seen as an essential dimension of higher performing group homes (Bigby et al., 2012). A new theoretical approach has the potential to broaden how we view opportunities in life for people with intellectual disabilities. Viewing Active Support through the lens of Nussbaum's (2006; 2013) Capabilities Approach makes it possible to emphasise core aspects of psychological well-being on a profound level. There have traditionally been two main views of well-being, namely the hedonistic and eudaimonic (Deci & Ryan, 2008). While the hedonistic tradition relates to joy and happiness through positive effects and the lack of negative effects, the eudaimonic tradition looks at how to live life in a profoundly satisfying manner (Deci & Ryan, 2008). Eudaimonic well-being relates to an individual's self-actualisation, purpose in life and the fulfilment of virtuous potential (Deci & Ryan, 2008). This is related to Nussbaum's (2013) capabilities, since capabilities mean opportunities for choice making and to be able to select. Nussbaum (2013) explains that it draws down to one key question about how society provides opportunities for each person to fulfil his or her purpose and meaning in life – “what is each person able to do and to be?” (Nussbaum, 2013, p. 20). This approach is therefore linked to freedom in life, opportunities for living the kind of life one most deeply wants to live, and the support provided by a society to do so. The Capabilities Approach can be a new way to conceptualise outcomes from Active Support research, as well as to explore living conditions for people with intellectual disabilities. Similarly, Nussbaum's Capabilities Approach has previously been used to analyse QoL and life chances for autistic people (Pellicano et al., 2022). The review by Pellicano et al. (2022) examined each of the capabilities in the available autism research to explore life chances by means of the list of ten capabilities. It revealed societal disadvantage with regard to several capabilities (in particular in Life, Bodily Health and Integrity) which prevent autistic people from living the life they should be able to live and have the right to live (Pellicano et al., 2022).

By adopting Martha Nussbaum's (2013) Capabilities Approach, which can be used to assess comparative QoL and fundamental social justice in society, important insights can be gained into disadvantages experienced by people with intellectual disabilities, because her approach looks at resources and opportunities

in society. This is in line with a relational perspective on disability (Söder, 1982). From a relational point of view, disability is always dependent on the interaction between the individual and environmental factors. Active Support can be seen as an example of how disability can be reduced through changes in the environment, in this case, the competence development of staff. By developing how the staff give support work aiming to engage people in activities and by becoming simultaneously systematic and individual, obstacles in the environment are reduced while the individual's abilities are strengthened. Furthermore, Nussbaum (2006) perceives care as a fundamental social entitlement, which is related to Tronto's (1993) perspective of putting care at the centre of society. However, while care is important in support services, the Capabilities Approach views each person as an end, or as a subject (Nussbaum, 2013). Therefore, capabilities should not be considered a way for some to achieve their capabilities (for example staff) by reducing the ability for others to achieve theirs (for example service users). Care is an essential aspect of support work in the disability field, but with Active Support the practice focus moves away from a care tradition that sees service users as passive recipients of care and support (what might be referred to as the Hotel model in Active Support) (see Bigby & Humphreys, 2023). Care has a tradition of paternalism, with clear superiors and subordinates in the shape of care deliver and care recipient. Active Support, instead, focuses on empowerment and challenges the power imbalance that can exist in the relationship between the service user and the support worker. By training staff to actively listen to the needs and wishes of each person with intellectual disability, and to reflect on their own approaches and actions, Active Support has the potential to reduce inequality. There is an inevitable power aspect in Active Support as well, but it is a way (with Active Support essentials such as 'Maximising choice and control' and 'Graded assistance to ensure success') of trying to balance power more equally. In addition, it can be assumed to be easier to receive care and support, if it is clearly based on the individual's wishes and needs.

Most of Nussbaum's capabilities are found in Schalock et al.'s (2002) framework, but Nussbaum also elaborates on the relationship to 'other species' in terms of a capability: "To be able to live with and for concern of others like animals, plants and so on" (Nussbaum, 2013, p.33). This capability explores and shows how interpersonal relationships are a wide and complex phenomenon, showing that

we as humans also connect emotionally with other species, nature, etcetera. An incidental finding from the interviews with people with intellectual disabilities (not included in the analysis for Article II), was that some stressed the importance of having a pet and sharing life with an animal and some wished to be able to have a pet in the future. Although there was no sign of there being rules about not having a pet in the four group homes, this is likely a reflection of a common disadvantage in society experienced by people with intellectual disabilities. There is no legislation against having a pet when living in a group home, although one report shows that many municipalities and organisations have rules that reduce the opportunity to live with pets in group homes (FUB, 2015). Furthermore, a recent article by Holmes & Mortenson (2024) that explored 18 people with intellectual disabilities' view of what facilitated or hindered their quality of life, found that many participants described that having a pet made their life better.

The Capabilities Approach adds a new layer on how to view emotions in the capability of 'emotions', by recognising the central value for a person to express a variety of emotions. It is defined as to "Be able to form relationships, and to have attachments to people and things outside ourselves, to be able to love and to grieve, to be able to experience longing and gratitude, and also express justified anger. Not having one's emotional development destroyed by anxiety and fear" (Nussbaum, 2013, p.33). Being able to show anger without the fear of being seen as aggressive was an important finding in Article II. While anger is often seen as a prime negative emotion (Tiedens, 2001), it can have the positive effect of bringing about prosocial actions as a response to social injustice and of mobilising people to act for equity and social change (Lindebaum & Geddes, 2016; White et al., 2023). In order for people with intellectual disabilities to be involved in shaping good and equal living conditions, it is important that staff are able to receive and deal with emotional responses as a way for service users to express their concerns about life. Anger can be seen as a sign of what matters in life, and a desire to change life to each person's eudaimonic well-being.

These are examples of the added value achieved by seeing lives through the lens of Nussbaum's Capabilities Approach (2013). The QoL framework (Schalock et al., 2002) is a useful and central base of Active Support, which most likely contributes to Active Support be seen as meaningful and value-based for both service users and staff, but for a more profound approach to QoL, Nussbaums'

Capabilities Approach can contribute in-depth nuances that may tend to be overlooked otherwise. It reflects aspects of life that deserve more attention when recognising the rights of people with intellectual disabilities to live a life like others. The ten capabilities also strongly emphasise the view of people with disabilities as individuals who should be entitled to all the capabilities, just like everybody else. This perception particularly challenges all obstacles encountered by service users in group homes to their freedoms and choices or any restrictions imposed on them in daily life. When implementing a new staff practice, the four ethical elements of care; attentiveness, responsibility, competence, and responsiveness, can also be used to analyse care (see Tronto, 1993). These elements were all lifted in the interviews with service users as important aspects of care and support (Article II). Furthermore, the four phases of care; *caring about*, *taking care of*, *caregiving* and *care-receiving* (Tronto & Fisher, 1990) can be adopted to examine dimensions of care as well as the balance between different phases of care, for example how caring about (relational aspects of care), taking care of (such as organising support), care-giving (how a support worker should be) can be realised from the perspectives of care-receivers (i.e. service users).

10.7. Methodological considerations

There are several methodological strengths in this research project. The stepped wedge design is a valuable design for assessing each of the four group homes, since it enabled comparisons before and after intervention, with a pre- and post-training design. The real-life setting provides insights on multiple levels into interventions in social work, particularly in group homes, instead of merely looking at questionnaires answered by staff once after a short training. Equally, the mixed methods design using several different data collection methods, allowed me to compare the results from different kinds of data and from the participants' different perspectives.

A number of biases also need to be taken into consideration in this thesis. In this section, I will discuss the possible biases that might have affected the results of this research project and could have affected the internal as well as the external validity of the study. Firstly, it is possible that other circumstances influenced the positive results of this project. For instance, Covid-19 disruptions at the beginning of the project could have affected opportunities for service users to engage in

activities at baseline. This could have contributed to fewer outdoor activities during the first year, which in turn could have impacted the results.

The four group homes were chosen for a number of reasons. They were newly built and had been open for no more than two years. They reflected ordinary group homes in resident size, location and population. They also showed an interest in participating. The interest of staff and managers in participating could have impacted the results of this intervention study favourably. However, the longitudinal study design meant that any possible initial interest was likely to wear off in the long-term effects. Another way to reduce impact due to selection bias was to choose methods that did not directly involve the staff's opinions about Active Support.

Another consideration that might threaten the validity of the study is whether the participants, especially staff, were representative of staff in group homes generally. One way to examine this is to look at their educational background, age and gender. Most staff in this study were women, had an upper-secondary education qualification in social care, and were middle-aged. This is likely to reflect the general population of support workers in group homes. Recent statistics show that there are 59 200 people employed as support workers or senior support workers in the municipalities, of whom approximately 75% are women (Swedish Association of Local Authorities and Regions, 2024). One group home was an exception. Here, some support workers had a university degree in education or social work, and the majority were men. The pattern of improved activity levels after training was consistent across the four group homes, regardless of gender, age and previous educational background.

Having the same person train staff, conduct the observations and interview the participants with intellectual disabilities (myself) had both advantages and disadvantages. The Hawthorne effect is a possible participation effect when people change their behaviour because they are aware that they are being observed (McCambridge et al., 2014). The belief in researcher expectations, conformity and social desirability bias may lead to changes in behaviour (McCambridge et al., 2014). To prevent this from happening, and to make people feel as comfortable as possible even if they are being observed, Paradis and Sutkin (2017) suggested that the researchers invest in interpersonal relationships. Unease was prevented

when the participants became familiar with me over a period of two years. This familiarity with the researcher further minimised the potential biases that could have occurred at the beginning of the research, such as the Hawthorne effect. However, being part of a research project, and having me regularly visiting the group homes during the intervention period to collect data, may have motivated staff to continue working with Active Support. The results might have been different if the follow-up had ended earlier.

Having the same researcher training staff in Active Support, conducting the observations and collecting data is likely to introduce bias. This kind of bias was unavoidable, but one way to minimise it was to reduce confirmation bias, which can be defined as the tendency for people to favour information that confirms their pre-existing beliefs, expectations and hypotheses while ignoring disconfirming information (Nickerson, 1998). To reduce confirmation bias, observational data collected in the project were analysed after the follow-up period ended. I only became aware of the results afterwards to not impact the behaviour of participants nor alter my own behaviour towards more favourable outcomes. Biases were further discussed with the two reference groups along the way, to critically reflect on the methodology.

The possible different assessments of different observers were acknowledged as a possible bias. Interobserver reliability was therefore examined through simultaneous observations with one student and another researcher on two occasions. The results demonstrated some disagreement in the results of ASM but shared the same positive indications.

Today there is a considerable body of evidence that demonstrates how memory can be affected by recall bias. Psychological research shows that recall bias often occurs in affective past events (Colombo et al., 2020; Skowronski, 2010). Colombo et al. (2020) distinguish between two aspects of recall bias. Positive affective recall bias is the tendency to retrospectively over- or underestimate positive affective events, while negative affective recall bias is the tendency to retrospectively overestimate or underestimate negative affective events. It was likely that recall bias could impact the results of the interview studies, both with managers and service users. Several steps were accordingly taken to avoid this. For example, the interview questions in Articles II and III were formulated to

address current life events instead of asking the participants to recall earlier events. In Article II the same questions were asked twice, except for some minor differences, namely before training and a year after training. This also avoided socially desirable answers about whether the situation was better or worse, which might have skewed the answers in a more positive direction. The findings, and in particular the differences in answers, were then compared before and after to examine the possible changes in answers after Active Support was implemented in the group homes. Furthermore, individual differences in disability may also have created difficulties in memorising past experiences. When participants recalled previous experiences, they were acknowledged but not focused on, because the two interview sessions addressed current life situations. However, it is important to acknowledge that several participants were able to recall many previous experiences from group homes in the past.

10.8. Strengths and weaknesses

There are several strengths and limitations to acknowledge in this project. One considerable strength is the systematic and longitudinal study design, which is rare in research about staff practices in group homes in Sweden. Another strength is that the same training material and process with classroom training and in-situ situations were used as in Australia (see for example Bigby & Humphreys, 2023). Previous research suggests that one important predictor of good Active Support is staff trained in both classroom training and in-situ methods (Bigby et al., 2020a; Flynn et al., 2018). An experienced advisory board of researchers with experience of Active Support followed the project. In addition, the data collection methods used in this project have been used very widely previously in Active Support research (see Article I). Observations, especially systematic and structurally conducted with well-implemented instruments like ASM, have many benefits as a data collection method. The strength of observations in group homes has been acknowledged previously as a reliable and valuable method, especially when participants may not be able to express themselves verbally (Bigby & Beadle-Brown, 2018; Mansell et al., 2013). Nevertheless, a number of important issues must be addressed. Observations were carried out over a lengthy period, which required the observer to be responsive and caring in all situations in the group home environment. Any ethical concern was discussed with stakeholders and meant that observations could be cancelled if anyone felt uncomfortable with the

situation. This happened on two occasions when staff had forgotten that observations were planned and had arranged activities outside the group home. Further, the number of participants varied in the observations, either because they were not at home at the time of the observation or because they declined to be observed.

Additionally, the lack of statistical power means that there are limitations in generalisability and the results must be viewed as initial, exploratory findings in a new context. Furthermore, only one trainer (i.e. me) trained all support workers in the four group homes. The results might have been different if other trainers with different past work experience and training had been involved.

10.9. Practical implications

The Active Support training was easy to comprehend and adapt to Swedish conditions, and the two-day workshop was both time- and cost efficient. How to support people with intellectual disabilities with Active Support was perceived positively by staff. They expressed that the practice was a natural and humanistic way to approach and support people. With consistent feedback sessions, the staff practice was sustained for two years and showed positive results in improved quality of staff support. To fully implement Active Support in services it is important to include the observations and team meetings as well as the FPL training in the training package. This project shows that it is possible to transfer an internationally well-known and evidence-based staff practice to Swedish group homes. On the basis of the results of this project, it is now possible to implement Active Support in more group homes in Sweden. However, the Active Support trainer needs to have a good knowledge of working with people with intellectual disabilities as well as practical work experience in group homes. The managers found it difficult to make time for the feedback sessions, so an adapted version with two senior support workers trained to become practice leaders was put into practice (Article III).

To improve the training further, video films in Swedish are recommended in the future. Active Support training can be given to both permanent and temporary staff. This means, for example, that Active Support training could be used as a work introduction for temporary staff during the summer holiday season.

It is furthermore important to acknowledge that Active Support is one of several staff practices. Active Support would benefit from being combined with other practices such as the Low-Arousal approach (see McDonnell & Deveau, 2018). Although few other staff practices provide the same overall framework in group homes as Active Support, a combination of staff practices is needed to provide the skilled support that all practices aim for. Active Support would be suitable to be combined with the Low-Arousal Approach or Positive Behaviour Support (for PBS, see Mahon et al., 2021). There are some gaps in Active Support that other methods emphasise better, such as the close working relationship between families and practitioners in TEEACH (see for example Virues-Ortega et al., 2013) and the pedagogical augmentative and alternative communication strategies in Structured teaching.

In another study at Marie Cederschiöld University (Ingemarson et al., 2025), the implementation process of this project has been followed and analysed in a new report. This found that the Active Support training was appreciated by both managers and support workers (Ingemarson et al., 2025). More information about implementation considerations and strategies can be found in this report, as well as an analysis of the material that could be further applied to Swedish conditions. Active Support worked; however, some adaptations are needed, and the staff practice can now be used in more services. Solid international research findings internationally support the benefits and now also in Sweden.

11. Conclusions

This is the first systematic longitudinal research project into Active Support, along with FPL, conducted in Sweden. The findings showed that the quality of support improved considerably in the four group homes for people with intellectual disabilities after Active Support implementation (Articles II, III and IV). The positive results are based on observations of staff support as well as interviews with people with intellectual disabilities and frontline managers. The influence, opportunities for making choices and staff's competence to meet the needs of people with intellectual disabilities were enhanced at follow-up. In particular, these improvements led to heightened competence in interacting and paying attention to the service users' needs (Article II). The results suggest that Active Support can be an effective staff practice in group home settings, to facilitate a shared understanding among the staff of how support work should be carried out. However, to embed Active Support in services and to encourage staff to continue working according to Active Support practice over two years, strengthened leadership is important (Article III). In this context strengthened leadership among both managers and senior support workers (i.e. stödpedagoger) was in forms of training and implementation of FPL.

It is essential that both staff and managers work actively with Active Support. This is particularly crucial after the intervention ends or when new staff are being recruited. It is important that staff continue to be observed, are given feedback, and discuss Active Support at team meetings, especially during the first couple of months after training. The managers, as well as practice leaders, play an important role in encouraging support workers to continue working with Active Support and facilitating time for reflection and listen to their observations.

An important finding was that the interviews with people with intellectual disabilities gave rise to new perspectives that can further develop staff practices generally and Active Support in particular (Article II). The interviews showed how support with relationships and emotional support were important in everyday life when living in group homes and had improved at follow-up. Accordingly, it is important to evaluate Active Support from the perspectives of service users, which have been lacking in previous Active Support research (Article I).

To further develop staff support, it is important to ensure flexible and comprehensive work across multiple QoL domains. “To be able to live like others”, the overall objective in LSS (SFS 1993:387, §5), means that the support provided should be focused on participation in activities and relationships that are meaningful for each person. Furthermore, to acknowledge the CRPD fully, researchers need to ensure that the full and effective participation of people with intellectual disabilities in all aspects of society can be realised (see United Nations, 2006). The perspectives of people with intellectual disabilities can be examined by means of interviews, observations, and ethnographic studies to further develop the Active Support staff practice. They are, after all, the ones who are directly affected by staff practices and new interventions in group homes. Ultimately, Active Support can be one piece of the puzzle to create good everyday living, drawing on Nirje’s normalisation principle (1969) of equal living conditions for people with or without intellectual disabilities and the goal of living an ordinary life with normal conditions. It does not solve all problems, such as employment or financial difficulties, but it does help to create an as ordinary everyday life as possible in the group home. The Active Support approach provides a way forward on our path to achieving more inclusive society with greater equality in everyday circumstances as well as respect for rights and human dignity.

12. Future research

On the basis of the last couple of years of research about Active Support, I have a number of main suggestions for future studies. Most research about Active Support comes from Australia and the UK (see for example Flynn et al., 2018; Mansell & Beadle-Brown, 2012). Australia and the UK are western, liberal countries with a similar history of deinstitutionalising care and hospitals for people with intellectual disabilities. The dominance of English-language research into Active Support makes findings from other countries hard to find. There is a knowledge gap about the effects of Active Support in other settings with different welfare systems and languages, for example in the Nordic countries. I therefore recommend that implementation research about Active Support, as well as other evidence-based practices, should be conducted in group homes in Nordic countries to examine similarities and differences in the implementation process and specific adaptations. Furthermore, this is the first systematic research project about Active Support in a Swedish context. The results are promising but need to be replicated for validity. A strength of this doctoral thesis is that the longitudinal design made it possible to examine the effects of Active Support after two years. The data collected over two years is more reliable than quick follow-ups directly after training. However, both Active Support and FPL can be difficult to maintain for a longer period (Bigby et al., 2019; Bigby et al., 2020a). The findings of the present study support previous research (Bigby et al., 2019) in suggesting that even longer follow-ups (of five or ten years) are important to examine the extent to which Active Support and FPL can be sustained in practice in Swedish group homes.

Future studies of Active Support could benefit from using a participatory approach to include the perspectives of people with intellectual disabilities. A future study could involve watching and analysing the training material together with people with intellectual disabilities and conducting group interviews to ask them their opinions about the films. The active participation of people with intellectual disabilities in research is further acknowledged and reflected in the “Inclusive research” carried out over the last two decades (Nind & Vinha, 2014; Walmsley & Johnson, 2003; Walmsley et al., 2017). Inclusive research makes people with intellectual disabilities co-researchers (Walmsley et al., 2017). When they are co-researchers, they offer different perspectives, help to make sure that

the research is relevant for them, capture outcomes that are important to them and is empowering (Grant & Ramcharan, 2007). However, involving people with intellectual disabilities also comes from value-based strategies such as emancipatory research which aims “to create a different world, one where power is shared, where people with intellectual disabilities have respect and valued roles” (Walmsley et al., 2017, p. 753). Another perspective that has been largely missing is that of family members and stakeholders about Active Support evaluation and implementation. This perspective has also been largely missing from research into the implementation of staff practices (Tournier et al., 2021). During the implementation of Active Support in this study, family members and stakeholders suggested that future studies should involve them. A few family members also advocated for the importance of including family members in the training so they would be part of the strategies to support their family members in a similar way to the support workers.

The scoping review (Article I) outlined several knowledge gaps and aspects that could be investigated in future studies. Most articles found that Active Support were about group homes for people with intellectual disabilities. One, however, looked at Active Support in day activity centres (Lin et al., 2020) and found positive effects in increased engagement. Future research could investigate Active Support in day activity centres or short-term stays for people with intellectual disabilities.

The findings of Article III also generated new directions for future studies. This was the first Swedish study of the systematic implementation of FPL. I suggested the possibility of having senior support workers (i.e. stödpedagoger) as practice leaders. However, the study only included interviews with three managers. To be able to examine the adaptation of the practice leadership role, further research needs to be undertaken. New research could either refute or validate these first new findings from the Swedish context examined in Article III. There is a need for more Swedish studies to make use of the staff practices that have been developed internationally. Sweden has lost its former leading position in the field of disability and can learn a lot from others. By introducing and carefully studying work approaches and methods, important steps can be taken both in practice and research. Much remains to be done in order for us to get closer to the goal of

equal living conditions, self-determination and participation for people with intellectual disabilities.

Sammanfattning

Det finns idag 30 389 vuxna personer i Sverige som bor i bostad med stöd och service enligt LSS, där en majoritet bor i gruppboende (National Board of Health and Welfare, 2025). Flera rapporter visar dock på ett stort behov av kompetensutveckling bland personal som arbetar i gruppboende (se bland annat Health and Social Care Inspectorate, 2023; National Board of Health and Welfare, 2021). Utan evidensbaserade arbetsmetoder, så finns det risk för att personer som bor i gruppboendena får ett isolerat och passivt liv. För att minska användningen av otillåtna tvångs- och begränsningsåtgärder, öka kunskapen om alternativ och kompletterande kommunikation och möjliggöra en ökad delaktighet för personer med intellektuell funktionsnedsättning, behöver personal och chefer få verktyg hur de ska stödja stödandarna på ett långsiktigt sätt. Ett internationellt väletablerat arbetssätt är Active Support, som har implementerats i gruppboende i främst England och Australien under flera decennier (Mansell & Beadle-Brown, 2012). Active Support, vilket kan översättas till Aktivt stöd på svenska, är en grundläggande basutbildning i hur man som personal aktivt kan påverka delaktighet och inflytande för stödandarna och skapa en ökad delaktighet i meningsfulla aktiviteter och relationer. Om arbetssättet utbildas till personal i gruppboende på ett systematiskt sätt, så visar upprepade studier på goda resultat i form av ökad delaktighet i meningsfulla aktiviteter, mer inflytande och fler valmöjligheter för personer som bor i gruppboendena (Beadle-Brown et al, 2012; Flynn et al., 2018; Stancliffe et al., 2008). Det finns dock mycket liten kunskap om hur Aktivt stöd skulle kunna tillämpas och implementeras i en svensk kontext och vilken effekt arbetssättet har i svenska gruppboende. Denna avhandling avsåg därför att fylla denna kunskapslucka och undersöka om Aktivt stöd kan utveckla kvaliteten på stödinsatser till personer med intellektuell funktionsnedsättning som bor i gruppboende i Sverige. Avhandlingen är en interventionsstudie med syftet att utbilda personal och chefer i Aktivt stöd och undersöka den två år longitudinella effekten av införandet av Aktivt stöd i fyra svenska gruppboende.

Fyra forskningsfrågor undersöktes i denna avhandling:

- På vilket sätt påverkar Aktivt stöd vardagen för personer med intellektuella funktionsnedsättningar som bor i gruppboenden i form av till exempel delaktighet, val och engagemang i meningsfulla aktiviteter?
- På vilket sätt förbättrar utbildning i Aktivt Stöd personalens kompetens att ge högkvalitativt stöd till stöd användare och vilken roll spelar ett starkt ledarskap i praktiken för att möjliggöra detta i gruppboenden?
- Vad är stöd användarnas uppfattning om bra stöd från personalen och upplever de att stödet förändrats efter implementeringen av Aktivt stöd?
- Hur kan personer med intellektuella funktionsnedsättningar involveras i utvärderingen av effekterna av Aktivt stöd?

Interventionen genomfördes på fyra nystartade gruppboenden. Sammanlagt 20 personer med intellektuell funktionsnedsättning, 28 medarbetare och fem chefer deltog i detta projekt (antalet stöd användare/chefer som medverkar i respektive delstudie varierar dock utifrån eventuell inflytt/utflytt från gruppboendet under studieperioden, om stöd användarna ville delta eller inte i specifika delstudier, och om chefer avslutade sin anställning under uppföljningsperioden).

Denna interventionsstudie använder en s.k. stepped-wedge design, vilket är en form av kvasiexperimentell design där samtliga verksamheter får interventionen (dvs utbildning i Aktivt stöd) men i olika tidsintervaller (se tex Spiegelman, 2016). Utbildningen i Aktivt stöd genomfördes i två delar; en initial tvådagarsworkshop med samtlig personal och chefer och därefter kontinuerlig handledning i stödinsatser på gruppboendet ca 1g/mån. Grundutbildningen bestod av en teoretisk del om Aktivt stöd och därefter genomfördes den interaktiva australiensiska webb utbildningen med åtta moduler och träningsfilmer (se Bigby & Humphreys, 2023). Chefer och särskilda nyckelpersoner såsom stödpedagoger fick också en endags utbildning i praktisk ledarskap (FPL), som är en viktig komponent av Aktivt stöd. Även den genomfördes med en australiensisk webbaserad utbildning med moduler (se Bigby & Humphreys, 2024a).

Gruppboendena följdes under två år för att undersöka både kortsiktiga och långsiktiga effekter av Aktivt stöd. Mixade metoder användes där både kvalitativa

och kvantitativa data samlades in genom observationer, intervjuer och enkäter. Initialt genomfördes en första datainsamling innan medarbetare och chefer utbildades i Aktivt stöd, för att kunna undersöka både före och efter resultat. Därefter genomfördes upprepade observationer under två års tid, där både samspelet mellan personal och personer med intellektuell funktionsnedsättning undersöktes, aktivitetsnivå och kvaliteten på stödet mättes. Dessutom undersöktes hur väl praktisknära ledarskap implementerades i gruppbestäderna. Individuella intervjuer genomfördes med stöd användare och chefer.

Avhandlingen består av fyra vetenskapliga artiklar; en scoping review (artikel I) som undersökte eventuella kunskapsluckor i tidigare forskning om Aktivt stöd, en kvalitativ intervjustudie med personer med intellektuell funktionsnedsättning (artikel II) och två empiriska effektstudier som använder mixade metoder (artikel III och IV).

Scoping reviewen (artikel I) undersökte vetenskapliga artiklar om Aktivt stöd publicerade mellan 2009-2023 i fyra vetenskapliga databaser; PsycInfo, Cinahl, Pubmed och Web of Science. Artikeln hade två syften, nämligen att; 1) identifiera vilka utfallsmått som har använts i Aktivt stöd och hur har de mätts, samt 2) identifiera hur personer med intellektuell funktionsnedsättning har inkluderats i forskning om Aktivt stöd. Sammanlagt 16 vetenskapliga artiklar om Aktivt stöd inkluderades. Resultatet visade att observationer var den mest frekventa metoden i Aktivt stöd forskningen, följt av enkäter och därefter intervjuer. En styrka i forskningen om Aktivt stöd är att flertalet artiklar använt en kombination av flera metoder, i en så kallad triangulering. Två validerade mätinstrument har återkommande använts i strukturerade observationer, Active Support Measure (ASM) och Engagement in Meaningful Activity and Relationships (EMAC-R) (se Mansell et al., 2005; Mansell & Beadle-Brown, 2005). Genom att ASM och EMAC-R använts i flertalet observationsstudier i olika kontexter, möjliggör det för jämförelser mellan studier, vilket kan ses som en styrka för forskningen. De vanligaste utfallen av Aktivt stöd som undersökts är stöd användares delaktighet i meningsfulla aktiviteter och relationer, samt kvalitet i stödsatser. Översikten undersökte även hur personer med intellektuell funktionsnedsättning varit aktiva deltagare i utvärderingar av Aktivt stöd. Mellan 2009–2023 var det enbart 9 personer med intellektuell funktionsnedsättning som aktivt deltagit genom att bli intervjuade om Aktivt stöd, baserat på två vetenskapliga artiklar (Graham et al.,

2013; Stewart et al., 2018). Det finns därför ett stort behov av att inkludera fler personer med intellektuell funktionsnedsättning i utvärderingen av Aktivt stöd.

Artikel II är en intervjustudie med nio personer med intellektuell funktionsnedsättning och/eller autism från de fyra gruppboheter där Aktivt stöd implementerades. Åldern varierade mellan 22–60 år och majoriteten var kvinnor. Syftet med studien var dels att undersöka vad bra stöd innebär för personer med intellektuell funktionsnedsättning och huruvida stödinsatserna förbättrades efter att personalen och chefen fått utbildning i Aktivt stöd. Intervjuerna genomfördes vid två tillfällen; före utbildningen i Aktivt stöd och i uppföljande intervjuer ett år efter utbildningen. Längden på intervjuerna varierade mellan 16–55 min. I några fall användes bildstöd som kommunikationsstöd och det förekom även att en stödperson närvarade vid intervjutillfället som stöd för den enskilde. Intervjuerna analyserades med hjälp av tematisk innehållsanalys (se Braun & Clarke, 2006). Artikeln baserades på två teoretiska ansatser, genom ramverket Ethic of care (Tronto, 1993) och ett kompetensramverk av Illeris (2012). De fyra faserna caring about, taking care of, caregiving och care-receiving i Ethic of care (Fisher & Tronto, 1990) användes i dataanalysen när koder genererades och teman skapades.

Analysen genererade tre övergripande teman om vad som definieras som gott stöd av personer med intellektuell funktionsnedsättning; 1) Hem är mer än bara en plats, det är en känsla 2) God omsorg är omsorg med tillgänglig kommunikation 3) Tid är dyrbart. De tre övergripande temana belyste vad som är viktigt för personer med intellektuell funktionsnedsättning för att uppleva ett gott stöd av personal i gruppboheter. De uppföljande intervjuerna jämfördes därefter med resultatet från intervjuerna vid baslinjeintervjuerna. Detta visade att stödinsatserna upplevdes förbättrade efter att personal gått utbildning i Aktivt stöd. De personer med intellektuell funktionsnedsättning som intervjuades upplevde fler valmöjligheter i vardagslivet och fick ett förbättrat inflytande i vardagliga situationer. Dessutom upplevde de ett förbättrat emotionellt stöd och att deras relationer hade förbättrats. Men det fanns också vissa aspekter som personalen behövde fortsätta utveckla, däribland var det förbättrad punktlighet och stöd med fler utomhusaktiviteter och fysisk träning. Sammantaget visade uppföljningsintervjuerna att deltagarna hade fått ett bättre stöd och ökad livskvalitet efter att personal och chef fått utbildning i Aktivt stöd. Det finns dock

en möjlighet att även andra faktorer, exempelvis att covid-19-pandemin pågick vid basmätningen, kan ha influerat resultatet.

En viktig komponent av Aktivt stöd är att införa så kallade praktiktäna ledare i verksamheterna. Den praktiktäna ledaren har fem huvudsakliga arbetsuppgifter i Aktivt stöd: 1) möjliggöra verksamhetsmöten, 2) tilldela och organisera personalstöd, 3) observera, ge feedback och instruera personal, 4) betona personalens uppmärksamhet på olika livskvalitetsaspekter, och 5) att stödjande och handleda stödassistenterna (se Bigby & Humphreys, 2023). Den tredje artikeln undersökte därför den två år longitudinella effekten av att införa praktiktäna ledarskap i verksamheterna. Flera datainsamlingsmetoder användes och triangulerades för att undersöka resultatet av praktiktäna ledarskap, bland annat intervjuer med cheferna ett år efter utbildningen i praktiktäna ledarskap, kontinuerliga observationer (n=49) under två års tid med fältanteckningar och även tre tillfällen då instrumentet The Observed Measure of Practice Leadership (Beadle-Brown et al., 2015) fylldes i (vid baslinjemätning, samt efter 1 respektive 2 år efter utbildningen i Aktivt stöd). Intervjuerna och fältanteckningarna analyserades genom att skapa koder och kategoriseringar kvalitativt och med hjälp av induktiv innehållsanalys (Graneheim et al., 2017). Närvarande ledarskap beräknades genom att undersöka procentuella skillnader före och efter utbildningen i Aktivt stöd. The Observed Measure of Practice Leadership beräknades genom att summera poängen på fem olika delskalor, vilket kunde variera mellan 5–25 i totalpoäng, där 25 motsvarar bästa möjliga resultat. Resultatet från de tre mättillfällena jämfördes för respektive gruppbestad, likväl som för samtliga gruppbestäder.

Resultatet av studien visade att praktiktäna ledarskap hade implementerats framgångsrikt efter utbildningen, med mer närvarande ledarskap, stödjande observationer och handledning av stödassistenterna. Samtliga data uppvisade förbättringar utifrån de fem aspekterna av praktiktäna ledarskap. Intervjuerna med cheferna visade dock på svårigheter att aktivt vara närvarande som praktiktäna ledare i vardagliga moment, då de upplevde att andra arbetsuppgifter fick större utrymme (tex budgetarbete, administrativa sysslor mm). Ett alternativ som föreslogs var därför att en stödpedagog övertar delar av arbetsuppgifterna som praktiktäna ledare såsom att ge feedback, handleda och genomföra observationer. Detta förslag innebar också att två stödpedagoger också

genomgick utbildningen i praktiktära ledarskap och övertog föreslagna arbetsuppgifter vid två gruppboenden.

Artikel IV var en observationsstudie som undersökte den longitudinella effekten av Aktivt stöd i samtliga fyra gruppboendestäder. En kombination av observationer tillsammans med enkäter användes för att undersöka om Aktivt stöd utvecklade stödinsatserna, vilken nivå på adaptiv förmåga stöd användarna hade och huruvida det förändrades efter personalen erhöll utbildning och började arbeta enligt Aktivt stöd. Sammanlagt 53 observationer genomfördes (varav 12 var initiala observationer vid basmätning) och det validerade instrumentet Active Support Measure (ASM) användes för att undersöka samspelet mellan personal och stöd användare och om kvaliteten på stödinsatser förändrades efter utbildning i Aktivt stöd. Resultatet mättes utifrån procentuell summering av ASM-poäng och alla poäng över 66,66% räknas som ett kvalitativt, bra stöd (se Mansell et al., 2013). Dessutom undersöktes stöd användarnas adaptiva förmåga och huruvida den hade förändrats efter att personalen arbetade med Aktivt stöd. Detta gjordes genom att medarbetarna fyllde i enkätformuläret SABS vid två tillfällen för varje stöd användare (före och ett år efter Aktivt stöd utbildningen). SABS mäter adaptiv förmåga och har befunnits ha en god validitet och reliabilitet i tidigare studier (se Hatton et al., 2001).

Resultatet visade på en väsentlig förbättring av ASM-poäng efter Aktivt stöd hade implementerats. Samtliga gruppboendestäder ökade i poäng både år 1 och år 2, i jämförelse med resultatet vid basmätningen. Gruppboendestäderna hade en baslinjemätning på intervallet 56–65% innan utbildningen. Vid år 1 hade detta intervall ökat till 74–83%. Resultatet för andra uppföljningen (2 år efter utbildningen) visade snarlika resultat som år 1, med ASM i intervallet 80–86%. Sammantaget visade resultatet att stödinsatserna hade förbättrats vid uppföljningsmätningarna. Detta resultat varade under hela den två år långa uppföljningsperioden. Framtida studier skulle dock med fördel ha ännu längre uppföljningsperioder, på ca 5–10 år, för att undersöka huruvida resultatet fortgår under en längre period.

Resultatet visade också att stöd användarnas adaptiva förmåga varierade. Detta resultat är intressant då det visar att Aktivt stöd kan användas för personer med olika stödbehov. Dessutom undersöktes eventuella förändringar i adaptiv

förmåga. Det visade att 14 av sammanlagt 20 personer hade förbättrat sin adaptiva förmåga, men dessa resultat av SABS visade inte på statistisk signifikans. Detta resultat kan bero på att stödbehov är långvariga och att en uppföljningsperiod på ett år inte är tillräcklig för att mäta eventuella förändringar i adaptiv förmåga. Dessutom hade flera av deltagarna i studien också andra funktionsnedsättningar, vilket kan ha påverkat resultatet. En annan förklaring kan vara att Aktivt stöd syftar till att utveckla involvering i meningsfulla aktiviteter och inte specifikt är ett pedagogiskt program för att förbättra den adaptiva förmågan.

Avhandlingen uppvisar flera styrkor, likväl som svagheter. En styrka är att effekten av Aktivt stöd mättes longitudinellt med en två år lång uppföljningsperiod. Detta möjliggör att mer långsiktiga resultat uppvisas och att inte enbart kortare förbättring mättes som sedan kan ha ebbat ut. Dessutom var en fördel att studien använde observationer som mätmetod, vilket i tidigare studier har ansetts som pålitliga och möjliggör internationella jämförelser (se Mansell et al., 2013). Dock finns även potentiella svagheter. Det är möjligt att det positiva resultatet kan ha orsakats av andra omständigheter än Aktivt stöd. Till exempel så medförde Covid-19-pandemin begränsningar i början av interventionen, vilket kan ha inneburit att färre aktiviteter erbjöds under den perioden. Observationerna genomfördes av samma person som också utbildade personal, vilket kan ha medfört en risk för partiskhet. Det finns därför en risk att personalen förändrade sitt beteende när observationerna genomfördes, en s.k. Hawthorne effekt (McCambridge et al., 2014). För att skapa en vänlig atmosfär, genomfördes därför flera möten initialt så att anställda, chefer och stöd användare lärde känna mig innan observationerna påbörjades. En annan risk är att jag kan ha påverkat resultatet. En åtgärd för att minska risken för detta är att inga resultat från observationer, intervjuer med chefer eller enkäter till personal analyserades innan uppföljningsperiodens slut, för att minska risken för att dra för snabba slutsatser av tidiga preliminära resultat och därför eventuellt påverka hur jag bemötte personal vid besök i gruppbestäderna. Dessutom undersöktes diskrepansen mellan två observatörers bedömningar av ASM, genom att observationer genomfördes tillsammans med annan observatör, för att undersöka huruvida resultat skiljde sig åt, s.k. interrater reliabilitet. Resultatet visade på skillnader, 79% och 66%, men var ändå förbättrade resultat vid båda mätningarna.

Sammantaget så visar avhandlingen på lovande positiva effekter av Aktivt stöd som arbetssätt i gruppbestäder för personer med intellektuell funktionsnedsättning. Både stöd användarna själva, likväl som observationer av personal och chef visade på förbättrat stöd, fler valmöjligheter och inflytande efter att personal och chefer utbildades i Aktivt stöd. Några viktiga slutsatser kan dras; dels att det på relativt kort tid går att märkbart förbättra stödinsatser genom utbildning och kontinuerlig handledning av personal som arbetar i gruppbestäder, dels att det evidensbaserade och internationellt väl använda arbetssättet Aktivt stöd tycks fungera väl att införa på gruppbestäder i Sverige. Eftersom Aktivt stöd är en grundläggande basutbildning har den förutsättning att både kunna användas för att skapa ett gemensamt ramverk för personal och chefer i gruppbestäder, och även fungera som introduktion för nyanställda och för vikarier. Aktivt stöd ersätter inte andra arbetssätt, utan kan med fördel användas i kombination med andra arbetsmetoder inom fältet, tex lågaffektivt bemötande (se Hejlskov Elvén & Sjölund, 2018). Det är dock viktigt att både den webbaserade utbildningen med träningsfilmer och praktiska övningar (den s.k. två dagar långa workshopen) genomförs tillsammans med kontinuerlig handledning och observationer, för att utveckla stödinsatserna i praktiken. Dessutom är det av vikt att det praktiska ledarskapet också implementeras i verksamheten, för att möjliggöra att nyckelpersoner i verksamheterna aktivt leder arbetet med Aktivt stöd. Annars finns det risk för att arbetssättet prioriteras ned eller glöms bort och inte fullt ut implementeras och upprätthålls i verksamheterna (se bl a Ingemarson et al., 2025).

Även om avhandlingen uppvisar goda resultat ska man ta hänsyn till att enbart fyra gruppbestäder deltog i denna interventionsstudie och att fler studier behövs för att undersöka om resultatet kan replikeras. Dessutom vore det av intresse att undersöka huruvida resultatet består även med längre uppföljningsperioder, såsom efter 5–10 år. Dessutom vore det att föredra att vid framtida studier även inkludera familjemedlemmar mer i utbildningen, då det fanns en önskan om att få vara mer delaktig som anhörig och deras röster skulle kunna tillföra viktiga perspektiv.

Sist men inte minst visar resultatet av denna avhandling på vikten av att stöd användare själva är delaktiga i att utvärdera Aktivt stöd, då deras perspektiv och slutsatser var av stor betydelse för att utvärdera arbetssättet. Intervjustudien (artikel II) med personer med intellektuell funktionsnedsättning är den första i sitt

slag, där intervjuer genomfördes både före och efter Aktivt stöd implementerades. Reflektioner i intervjustudien skapade en ökad förståelse för vad ett bra stöd innebär i praktiken och vad som är av särskild vikt vid utformning av stödinsatser. Stöd användarna beskrev vikten av att personalen har formell kunskap såväl som lämpliga personliga egenskaper, dvs en kombination av interrelationella egenskaper såväl som mer formell kompetens kring exempelvis bildstöd och alternativ och kompletterande kommunikation. Deras perspektiv gav också nya insikter om att personalen var bättre på att ge ett emotionellt stöd efter utbildningen i Aktivt stöd, vilket bidrar till nya kunskaper i den internationella forskningen om Aktivt stöd. Ur ett socialt rättviseperspektiv är det förstås också centralt att den grupp som ska leva med en intervention också är med och utvärderar denna.

Acknowledgements

I owe my deepest gratitude to the people with intellectual disabilities who participated in this study. Without them and their engagement, as well as their generosity to share their own personal experiences with me, this doctoral thesis would not have been the same. Thank you for sharing your life experience with me. Thank you for also sharing laughter and joy and having fika breaks together! It has been a privilege to get to know you. I would also like to thank your family members for believing in this project and for having contact with me along the way with important reflections. I am very grateful for all staff and managers in the group homes for putting in the effort and valuable time to participate in this study. I am exceptionally grateful for your curiosity and reflections about Active Support, as well as your interest in the research project and for answering the questionnaires!

My warmest thanks go to my main supervisor Professor Magnus Tideman and my co-supervisor Associate Professor Veronica Svård for all your support throughout this project. Your extensive knowledge and acting as role models have been incredibly valuable for me. Over the years we have had many thoughtful discussions, and you always have supported me throughout the work with caring and constructive comments. I am grateful for Magnus in believing in me and for getting me onboard on the Active Support project. Veronica, thank you for being so dedicated to this research project, for all your thorough and wise comments – as well as for being my friend!

I would also like to thank Professor Christine Bigby and research fellow Lincoln Humphreys at Living with Disability Research Centre at La Trobe University in Melbourne, Australia for my training in Active support, critical reflections and constructive advice along the process. Your comprehensive knowledge about Active Support has been indispensable, as well as your expertise about living conditions and everyday support for people with intellectual disabilities. The material used in this research project was generously provided for the purpose of this project and distributed by Christine and Lincoln.

A big thank you to Petra Björne for her wise reflections about Active Support, as well as living conditions for people with intellectual disabilities in Sweden. I am happy to have had your important suggestions on the development of study design and for helping us to improve the project by introducing the stepped wedge design. I am very thankful for our philosophical discussions throughout the project.

Many thanks go to representatives from disability organisations, national authorities and a union in Sweden for giving advice on the project. I am particularly grateful for the important suggestions made by the self-advocacy group Inre Ringen, and by persons with intellectual disability for contributing as a reference group! The regular meetings with the two reference groups over four years have been so valuable in providing me a space and time to discuss, reflect on and adapt the process accordingly with their ideas and great knowledge. Thank you Helena Taubner and Linn Börjeson for conducting observations with me!

The unique opportunity as a doctoral student to implement and follow the effects of Active Support was made possible by financial support from Ersta Diakoni and Marie Cederschiöld University. For this invaluable support, I am very grateful.

A particular thank you to Professor Karina Huus, Professor Malin Lövgren and Professor Ulla-Karin Schön for your time and important feedback as opponents at my manuscript seminars.

Thank you, Anna Whitaker who followed the project, both as a supervisor in the beginning and a lovely colleague. A big thank you to all my colleagues, teachers, fellow PhD students and researchers at Marie Cederschiöld University. A special thank you to Caroline, Ellen, Hélène, Karin, Maria, Martin, Magnus J, Mia and Veronica! The interesting research seminars at the department as well as fika breaks with my colleagues have contributed with new perspectives and insights into research. My PhD friends, Anna, Lena, Liv, Louise, Peter, Sara and Åsa, thank you for our regular meetings to discuss research and sharing this experience with me. I would like to thank my inspiring friend in research, Chantelle, for advice and for her suggestions on final edits! Thanks to my past colleagues at Karolinska Institute for great collaboration and sharing your passion for research.

I would also like to thank Katarina for being my mentor in research as well as for our regular walks and interesting discussions.

I am so thankful for my fantastic relatives, friends and previous coworkers for always believing in me and for all your support. Thanks to my Dad for our shared times in the countryside and allowing me to write extensively in his holiday house without disturbances except for making me fika and lovely dinners!

A special thank you that goes beyond all words that can be expressed - goes to my lovely and wonderful family - Tyra, Ella and Johan.

Jenny

April 2025

References

- Adams, R. (2017). *Empowerment, Participation and Social Work*. (4th ed.). Bloomsbury Publishing.
- Ahmed, S. K. (2024). The Pillars of Trustworthiness in Qualitative Research. *Journal of Medicine, Surgery, and Public Health*, 2(100051).
<https://doi.org/10.1016/j.glmedi.2024.100051>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.).
- Arvidsson, J., Widén, S., Staland-Nyman, C., & Tideman, M. (2016). Post-School Destination-A Study of Women and Men With Intellectual Disability and the Gender-Segregated Swedish Labor Market. *Journal of Policy and Practice in Intellectual Disabilities*, 13(3), 217-226.
<https://doi.org/10.1111/jppi.12157>
- Baer, D.M., Wolf, M.M., & Risley, T.R. (1968). Some current dimensions of Applied Behavior Analysis. *Journal of Applied Behavior Analysis*, 1, 91-97.
- Baker, P., Appleton, P., & Williams, R. (2017). An examination of the addition of video informed reflective practice to the active support toolkit. *British Journal of Learning Disabilities*, 45, 180-189.
<https://doi.org/10.1111/bld.12193>
- Barker, D., McElduff, P., D'Este, C., & Campbell, M. J. (2016). Stepped wedge cluster randomised trials: a review of the statistical methodology used and available. *BMC Med Res Methodol*, 16, 69.
<https://doi.org/10.1186/s12874-016-0176-5>
- Barron, K. (2004). *Genus och funktionsbinder*. Studentlitteratur
- Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2012). Person-Centred Active Support – Increasing Choice, Promoting Independence and Reducing Challenging Behaviour. *Journal of Applied Research in Intellectual Disabilities*, 25, 291-307. <https://doi.org/10.1111/j.1468-3148.2011.00666.x>
- Beadle-Brown, J., Mansell, J., Ashman, B., Ockenden, J., Iles, R., & Whelton, B. (2014). Practice leadership and active support in residential services for people with intellectual disabilities: an exploratory study. *J Intellect Disabil Res*, 58(9), 838-850. <https://doi.org/10.1111/jir.12099>

- Beadle-Brown, J., Bigby, C., & Bould, E. (2015). Observing practice leadership in intellectual and developmental disability services. *J Intellect Disabil Res*, 59(12), 1081-1093. <https://doi.org/10.1111/jir.12208>
- Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T., & Bradshaw, J. (2016). Quality of Life and Quality of Support for People with Severe Intellectual Disability and Complex Needs. *Journal of applied research in intellectual disabilities: JARID*, 29(5), 409–421. <https://doi.org/10.1111/jar.12200>
- Beadle-Brown, J., Beecham, J., Leigh, J., Whelton, R., & Richardson, L. (2021). Outcomes and Costs of Skilled Support for People With Severe or Profound Intellectual Disability and Complex Needs. *Journal of Applied Research in Intellectual Disabilities*, 34 (1), 42–54. <https://doi.org/10.1111/jar.12782>
- Beasley, C., & Papadelos, P. (2024). What's care go to do with it? Feminism and the uncertain radical potential of care. *Thesis Eleven*, 183(1), 12-32. <https://doi.org/10.1177/07255136241287238>
- Berlin Hallrup, L. (2019). *Experiences of everyday life and participation for people with intellectual disabilities* [Doctoral dissertation, Malmö University]. DiVA. <https://mau.diva-portal.org/smash/record.jsf?pid=diva2%3A1404246&cdswid=-4939>
- Bernal, G., Bonilla, J., & Bellido, C. (1995). Ecological validity and cultural sensitivity for outcome research: issues for the cultural adaptation and development of psychosocial treatments with Hispanics. *Journal of abnormal child psychology*, 23(1), 67–82. <https://doi.org/10.1007/BF01447045>
- Bigby, C., & Frawley, P. (2010). *Social Work Practice and Intellectual Disability*. Palgrave Macmillan.
- Bigby, C., Knox, M., Beadle-Brown, J., Clement, T., & Mansell, J. (2012). Uncovering dimensions of informal culture in underperforming group homes for people with severe intellectual disabilities. *Intellectual and Developmental Disabilities*, 50, 452–467. <https://doi.org/10.1352/1934-9556-50.06.452>
- Bigby, C., Knox, M., Beadle-Brown, J., & Clement, T. (2015). 'We Just Call Them People': Positive Regard as a Dimension of Culture in Group Homes for People with Severe Intellectual Disability. *Journal of applied research in intellectual disabilities : JARID*, 28(4), 283–295. <https://doi.org/10.1111/jar.12128>

- Bigby, C., Bould, E., & Beadle-Brown, J. (2017). Implementation of active support over time in Australia. *Journal of Intellectual & Developmental Disability*, 44(2), 161-173. <https://doi.org/10.3109/13668250.2017.1353681>
- Bigby, C., & Beadle-Brown, J. (2018). Improving Quality of Life Outcomes in Supported Accommodation for People with Intellectual Disability: What Makes a Difference? *Journal of Applied Research in Intellectual Disabilities*, 31, 182-200. <https://doi.org/10.1111/jar.12291>
- Bigby, C., Bould, E., Iacono, T., Kavanagh, S., & Beadle-Brown, J. (2019). Factors that predict good Active Support in services for people with intellectual disabilities: A multilevel model. *Journal of Applied Research in Intellectual Disabilities*. <https://doi.org/10.1111/jar.12675>
- Bigby, C., Bould, E., Iacono, T., & Beadle-Brown, J. (2020a). Predicting good Active Support for people with intellectual disabilities in supported accommodation services: Key messages for providers, consumers and regulators. *Journal of Intellectual & Developmental Disability*. , 45(3), 279-289. <https://doi.org/10.3109/13668250.2019.1685479>
- Bigby, C., Bould, E., Iacono, T., & Beadle-Brown, J. (2020b). Quality of practice in supported accommodation services for people with intellectual disabilities: What matters at the organisational level. *Journal of Intellectual & Developmental Disability*., 45(3), 290-302. <https://doi.org/10.3109/13668250.2019.1671965>
- Bigby, C., Carney, T., Then, S.-N., Wiesel, I., Sinclair, C., Douglas, J., Duffy, J. (2023). Diversity, Dignity, Equity and Best Practice: A Framework for Supported Decision-Making. *La Trobe Report*. <https://doi.org/10.26181/21965183.v2>
- Bigby, C., & Humphreys, L. (2023). *Skills for Active Support*. <https://www.everymomenthaspotential.com.au/>
- Bigby, C., & Humphreys, L. (2024a). *Frontline Practice Leadership*. <https://www.practiceleadershipresource.com.au/>
- Bigby, C., & Humphreys, L. (2024b). The strength of Frontline Practice Leadership in Australian supported accommodation services: Challenges confronting service providers. *Journal of Applied Research in Intellectual Disabilities*, 37(3). <https://doi.org/10.1111/jar.13227>
- Björne, P., Deveau, R., McGill, P., & Nylander, L. (2022). The Use of Restrictive Measures in Community Services for People With Intellectual Disabilities in Sweden. *Journal of Policy and Practice in*

- Intellectual Disabilities*, 19(2), 193–201.
<https://doi.org/10.1111/jppi.12399>
- Bolton, D. (2023). A revitalized biopsychosocial model: core theory, research paradigms, and clinical implications. *Psychological medicine*, 53(16), 7504–7511. <https://doi.org/10.1017/S0033291723002660>
- Bould, E., Beadle-Brown, J., Bigby, C., & Iacono, T. (2016a). Measuring practice leadership in supported accommodation services for people with intellectual disability: Comparing staff-rated and observational measures. *Journal of Intellectual & Developmental Disability*, 43(2), 174-182. <https://doi.org/10.3109/13668250.2016.1259466>
- Bould, E., Beadle-Brown, J., Bigby, C., & Iacono, T. (2016b). The role of practice leadership in active support: impact of practice leaders' presence in supported accommodation services. *Int J Dev Disabil*, 64(2), 75-80. <https://doi.org/10.1080/20473869.2016.1229524>
- Buntinx, W. H. E., & Schalock, R. L. (2010). Models of Disability, Quality of Life, and Individualized Supports: Implications for Professional Practice in Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7(4), 283–294. <https://doi.org/10.1111/j.1741-1130.2010.00278.x>
- Bradshaw, J., McGill, P., Stretton, R., Kelly-Pike, A., Moore, J., Macdonald, S., Eastop, Z., & Marks, B. (2004). Implementation and Evaluation of Active Support. *Journal of Applied Research in Intellectual Disabilities*, 17(3), 139-148. <https://doi.org/10.1111/j.1468-3148.2004.00190.x>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706QP063OA>
- Brislin, R. W. (1970). Back-Translation for Cross-Cultural Research. *Journal of Cross-Cultural Psychology*, 1, 185-216. <https://doi.org/10.1177/135910457000100301>
- Brown, R. I., Schalock, R. L., & Brown, I. (2009). Quality of Life: Its Application to Persons With Intellectual Disabilities and Their Families—Introduction and Overview. *Journal of Policy and Practice in Intellectual Disabilities*, 6(1), 2–6. <https://doi.org/10.1111/j.1741-1130.2008.00202.x>
- Bruininks, R. H., Hill, B.K., Weatherman, R.F., & Woodcock, R.W. (1986). Inventory for Client and Agency Planning (ICAP). Riverside.
- Carr, E.G. (1994). *Communication-based Intervention for Problem Behaviour: A User's Guide for Producing Positive Change*. Paul H. Brookes.

- Carr, E. G., Dunlap, G., Horner, R. H., Koegel, R. L., Turnbull, A. P., Sailor, W., Anderson, J. L., Albin, R. W., Koegel, L. K., & Fox, L. (2002). Positive Behavior Support: Evolution of an Applied Science. *Journal of Positive Behavior Interventions*, 4(1), 4-16.
<https://doi.org/10.1177/109830070200400102> (Original work published 2002)
- Casanovas, T., Jané, L., Herdman, M., Casado, A., Garcia, B., Prat, B., & Fabregat, J. (2010). Assessing Outcomes in Liver Disease Patients: Reliability and Validity of the Spanish Version of the Liver Disease Quality of Life Questionnaire (LDQOL 1.0). *Value in Health*, 13(4), 455–462. <https://doi.org/10.1111/j.1524-4733.2009.00688.x>
- Chou, Y.-C., Harman, A.D., Lin, C.-J., Lee, W.-P., Chang, S.-C., Lin, M.L. (2011). Outcome Evaluation of Active Support Training in Taiwan. *Research in Developmental Disabilities*, 32(3), 1130-1136.
<https://doi.org/10.1016/j.ridd.2011.01.011>
- Christoffersen, M. N. (2020). Sexual Crime Against Schoolchildren With Disabilities: A Nationwide Prospective Birth Cohort Study. *Journal of Interpersonal Violence*, 37(3-4), NP2177-NP2205.
<https://doi.org/10.1177/0886260520934442> (Original work published 2022)
- Clement, T., & Bigby, C. (2010). *Group Homes for People With Intellectual Disabilities: Encouraging Inclusion and Participation*. Jessica Kingsley.
- Colombo, D., Suso-Ribera, C., Fernández-Álvarez, J., Cipresso, P., Garcia-Palacios, A., Riva, G., & Botella, C. (2020). Affect Recall Bias: Being Resilient by Distorting Reality. *Cognitive Therapy and Research*, 44(5), 906–918. <https://doi.org/10.1007/s10608-020-10122-3>
- Conder, J. A., & Mirfin-Veitch, B. F. (2020). “Getting by”: People with learning disability and the financial responsibility of independent living. *British Journal of Learning Disabilities*, 48(3), 251–257.
<https://doi.org/10.1111/bld.12329>
- Cooper, S. A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F., & Morrison, J. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC family practice*, 16, 110.
<https://doi.org/10.1186/s12875-015-0329-3>
- Courtade, G. R., Test, D. W., & Cook, B. G. (2014). Evidence-Based Practices for Learners with Severe Intellectual Disability. *Research and Practice for*

- Persons with Severe Disabilities*, 39(4), 305–318.
<https://doi.org/10.1177/15407969145667>
- Culham, A., & Nind, M. (2003). Deconstructing normalisation: clearing the way for inclusion. *Journal of Intellectual & Developmental Disability*, 28(1), 65–78. <https://doi.org/10.1080/1366825031000086902>
- Curran, GM., Bauer, M., Mittman, B., Pyne, J.M., Stetler, C. (2012). Effectiveness-implementation hybrid designs: combining elements of clinical effectiveness and implementation research to enhance public health impact. *Med Care*, 50 (3), 217-226.
<https://doi.org/10.1097/MLR.0b013e3182408812>
- Daly, L. E., Dolan, R. D., Power, D. G., Ní Bhuachalla, E., Sim, W., Cushen, S. J., Fallon, M., Simmons, C., McMillan, D. C., Laird, B. J., & Ryan, A. M. (2020). Determinants of quality of life in patients with incurable cancer. *Cancer*, 126(12), 2872–2882.
<https://doi.org/10.1002/cncr.32824>
- Damschroder, L. J., Reardon, C. M., Opra Widerquist, M. A., & Lowery, J. . (2022). Conceptualizing outcomes for use with the Consolidated Framework for Implementation Research (CFIR): the CFIR Outcomes Addendum. *Implementation science*, 17(7).
<https://doi.org/10.1186/s13012-021-01181-5>
- Deci, E. L., & Ryan, R. M. (2008). Hedonia, eudaimonia, and well-being: An introduction. *Journal of Happiness Studies: An Interdisciplinary Forum on Subjective Well-Being*, 9(1), 1–11. <https://doi.org/10.1007/s10902-006-9018-1>
- Deveau, R., & McGill, P. (2014). Leadership at the front line: Impact of practice leadership management style on staff experience in services for people with intellectual disability and challenging behaviour. *Journal of Intellectual & Developmental Disability*, 39(1), 65-72.
<https://doi.org/10.3109/13668250.2013.865718>
- Deveau, R., & McGill, P. (2016). Practice Leadership at the Front Line in Supporting People with Intellectual Disabilities and Challenging Behaviour: A Qualitative Study of Registered Managers of Community-based, Staffed Group homes. *Journal of Applied Research in Intellectual Disabilities*, 29, 266-277. <https://doi.org/10.1111/jar.12178>
- Dewey, K., Evans, S., Horsley, S., & Baker, E. (2023). The effectiveness of positive behaviour support in reducing challenging behaviour and increasing quality of life for individuals with intellectual

- disability. *Advances in Mental Health and Intellectual Disabilities*, 17(4), 245-252. <https://doi.org/10.1108/AMHID-03-2023-0007>
- Ehliasson, K., Ericsson, U., & Bengtsson-Tops, A. (2016). Support to individuals with comprehensive disabilities: Ideas in the Swedish Disability Act. *Scandinavian Journal of Disability Research*, 18(3), 234-244. <http://doi.org/10.1080/15017419.2015.1064024>
- Ehliasson, K., & Markström, U. (2020). Revealing the Ideas in the Swedish Social Services Act Regarding Support to Individuals with Disabilities. *Scandinavian Journal of Disability Research*, 22(1), 393-402. <https://doi.org/10.16993/sjdr.720>
- Emerson, E., & Hatton, C. (1996). DEINSTITUTIONALIZATION IN THE UK AND IRELAND: OUTCOMES FOR SERVICE USERS. *Journal of Intellectual & Developmental Disability*, 21(1), 17-37.
- Emerson, E., Llewellyn, G., Honey, A., & Kariuki, M. (2012). Lower well-being of young Australian adults with self-reported disability reflects their poorer living conditions rather than health issues. *Australian and New Zealand journal of public health*, 36(2), 176–182. <https://doi.org/10.1111/j.1753-6405.2011.00810.x>
- Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science (New York, N.Y.)*, 196(4286), 129–136. <https://doi.org/10.1126/science.847460>
- Eriksson, B., & Karlsson, P.-Å. (2016). *Utvärdering av nationell satsning på utveckling av EBP*. Verksamhetsområde funktionshinder. SKR. https://www.hb.se/globalassets/global/hb---extern/fous/aktuellt-inom-valfardsomradet/utvardering-nationell-satsning-utveckling-ebp_pak-o-bengt-eriksson_161014.pdf
- Feeney, B. C., & Collins, N. L. (2015). A new look at social support: a theoretical perspective on thriving through relationships. *Personality and Social Psychology Review : An Official Journal of the Society for Personality and Social Psychology, Inc*, 19(2), 113–147. <https://doi.org/10.1177/1088868314544222>
- Fisher, B., & Tronto, J. C. (1990). Toward a feminist theory of caring. In E. Abel, & M. Nelson (Eds.), *Circles of care: Work and identity in women's lives* (pp. 36–54). SUNY Press.
- Flynn, S., Totsika, V., Hastings, R. P., Hood, K., Toogood, S., & Felce, D. (2018). Effectiveness of Active Support for adults with intellectual disability in residential settings: Systematic review and meta-analysis. *J*

- Appl Res Intellect Disabil*, 31(6), 983-998.
<https://doi.org/10.1111/jar.12491>
- FUB. (2015). *Ett gott liv - Om bostad och stöd i bostaden, nu och i framtiden, för personer med utvecklingsstörning*. <https://www.fub.se/nyheter/ett-gott-liv-rapport-om-bostad-och-stod-i-bostaden-2/>
- FUB. (2024). *Historik*. <https://www.fub.se/om-fub/historik/>
- Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: An explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192–199. <https://doi.org/10.1111/jppi.12089>
- Goering, S. (2015). Rethinking disability: the social model of disability and chronic disease. *Current reviews in musculoskeletal medicine* 8(2), 134–138. <https://doi.org/10.1007/s12178-015-9273-z>
- Graham, F., Sinnott, K. A., Snell, D. L., Martin, R., & Freeman, C. (2013). A more "normal" life: residents', family, staff, and managers' experience of active support at a residential facility for people with physical and intellectual impairments. *J Intellect Dev Disabil*, 38(3), 256-264. <https://doi.org/10.3109/13668250.2013.805738>
- Graneheim, U. H., Lindgren, B.-M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today*, 56, 29-34. <https://doi.org/10.1016/j.nedt.2017.06.002>
- Grant, G., & Ramcharan, P. (2007). *Valuing people and research: The learning disability research initiative: Overview report*. London: The Stationery Office
- Grunewald, K. (2009). *Från Idiot till Medborgare. De utvecklingsstördas historia*. 1st ed. Gothia Förlag AB.
- Gulati, G., Fistein, E., Dunne, C. P., Kelly, B. D., & Murphy, V. E. (2020). People with intellectual disabilities and the COVID-19 pandemic. *Ir J Psychol Med*, 1-2. <https://doi.org/10.1017/ipm.2020.66>
- Gustin, T., & Wessman, L. (1964). *Efterundersökning av särskoleelever födda 1935-1939: elevernas anpassning till arbetsliv och samhälle*. Kungliga Skolöverstyrelsen.
- Guthrie, K., & Beadle-Brown, J. (2006). Defining and Measuring Rapport: Implications for Supporting People with Complex Needs. *Tizard Learning Disability Review*, 11(3), 21-30. <https://doi.org/10.1108/13595474200600024>
- Gäddman Johansson, R. (2021). *Managing Vulnerability: Everyday Interaction in Sheltered Accommodations*. [Doctoral dissertation, Uppsala

University].DiVA. <https://uu.diva-portal.org/smash/record.jsfpid=diva2%3A1526176&dswid=-4074>

Hall, S. A. (2017). Community Involvement of Young Adults with Intellectual Disabilities: Their Experiences and Perspectives on Inclusion. *Journal of applied research in intellectual disabilities : JARID*, 30(5), 859–871. <https://doi.org/10.1111/jar.12276>

Hamelin, J. P., & Sturmey, P. (2011). Active support: a systematic review and evidence-based practice evaluation. *Intellect Dev Disabil*, 49(3), 166–171. <https://doi.org/10.1352/1934-9556-49.3.166>

Hankle, Z. J., Bluestone, D. C., Kramer, J. K., Bassi, P., & Goreczny, A. J. (2021). What activities individuals with intellectual disabilities do for fun: exploration into self-care. *International journal of developmental disabilities*, 68(5), 712–722. <https://doi.org/10.1080/20473869.2021.1884788>

Hastings, R. P. (2010). Support staff working in intellectual disability services: the importance of relationships and positive experiences. *Journal of intellectual & developmental disability*, 35(3), 207–210. <https://doi.org/10.3109/13668250.2010.492710>

Hatton, C., Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., Perry, J., ... Linehan, C. (2001). The adaptive behavior scale-residential and community (part I): Towards the development of a short form. *Research in Developmental Disabilities*, 22(4), 273–288. [https://doi.org/10.1016/S0891-4222\(01\)00072-5](https://doi.org/10.1016/S0891-4222(01)00072-5)

Health and Social Care Inspectorate. (2015, Feb). *Kan jag leva som andra? Insatser i bostad med särskild service för vuxna med funktionsnedsättning*. IVO-2015-58. <https://www.ivo.se/aktuellt/publikationer/rapporter/kan-jag-leva-som-andra/>

Health and Social Care Inspectorate. (2021, Dec 15). *Uppföljning av LSS-boenden Slutredovisning av regeringsuppdrag*. <https://www.ivo.se/globalassets/dokument/publikationer/rapporter/rapporter-2021/slutredovisning-regeringsuppdrag-s2020-09593-uppfoljning-lss-boenden.pdf>

Health and Social Care Inspectorate. (2023, Sep). *Att inte få rätten att leva som andra*. IVO 2023-14 <https://www.ivo.se/globalassets/dokument/publikationer/rapporter/rapporter-2023/ivo-att-inte-fa-ratten-att-leva-som-andra.pdf>

- Hejlskov Elvén, B., & Sjölund, A. (2018). *Hantera, utvärdera, förändra : med lågaffektivt bemötande och tydliggörande pedagogik*. Natur & Kultur.
- Hejlskov Elvén, B., & Hansén, P. (2023). *Beteendeproblem i socialt arbete bland utsatta - Lågaffektivt bemötande och konflikthantering*. Natur & Kultur.
- Hemming, K., & Taljaard, M. (2020). Reflection on modern methods: when is a stepped-wedge cluster randomized trial a good study design choice? *Int J Epidemiol*, 49(3), 1043-1052. <https://doi.org/10.1093/ije/dyaa077>
- Heslop, P., & Glover, G. (2015). Mortality of People with Intellectual Disabilities in England: A Comparison of Data from Existing Sources. *Journal of Applied Research in Intellectual Disabilities*, 28, 414-422. <https://doi.org/10.1111/jar.12192>
- Hewitt, O. (2014). A survey of experiences of abuse. *Tizard Learning Disability Review*, 19(3), 122–129. <https://doi.org/10.1108/TLDR-06-2013-0031>
- Hirvikoski, T., Boman, M., Tideman, M., Lichtenstein, P., & Butwicka, A. (2021). Association of Intellectual Disability With All-Cause and Cause-Specific Mortality in Sweden. *JAMA network open*, 4(6), e2113014. <https://doi.org/10.1001/jamanetworkopen.2021.13014>
- Holmes, H. M., & Mortenson, W. B. (2024). What makes life better or worse: Quality of life according to people with intellectual disabilities. *Journal of applied research in intellectual disabilities : JARID*, 37(5), e13280. <https://doi.org/10.1111/jar.13280>
- Hultman, L. & Tideman, M. (2024). *Brukarinflytande i daglig verksamhet och gruppboende: Ett pilotprojekt om BIKVA och Qualid i LSS-verksamheter*. Stockholm: Marie Cederschiöld högskola.
- Human Rights Institute. (2024). *Allt ifrågasätts. Kunskap om och upplevelser av mänskliga rättigheter hos personer med funktionsnedsättning i Sverige 2023*. [https://mrinstitutet.se/wp-content/uploads/2022/01/Rapport-Allt ifragasatts_2024.pdf](https://mrinstitutet.se/wp-content/uploads/2022/01/Rapport-Allt-ifragasatts-2024.pdf)
- Humphreys, L., Bigby, C., Araten-Bergman, T., & Iacono, T. (2024). Active Support Measure: A Multilevel Exploratory Factor Analysis. *Journal of Intellectual Disability Research*, 68 (6), 564–572. <https://doi.org/10.1111/jir.13126>
- Illeris, K. (2012). *Kompetens- vad, varför och hur*. Studentlitteratur.
- Ingemarsson, M., Oom, N., Aspling, J., & Tideman, M. (2025). *Implementering av arbetssättet Active support i Sverige. Erfarenheter från fyra gruppboendestäder för personer med intellektuell funktionsnedsättning*. Marie Cederschiöld högskola: 124

- Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., Allen, D., & Pagler, J. (1999). Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: the impact of training staff in active support. *Journal of Intellectual Disability Research*, 43, 164-178.
- Jones, E., Felce, D., Lowe, K., Bowley, C., Pagler, J., Strong, G., Gallagher, B., Roper, A., & Kurowska, K. (2001). Evaluation of the Dissemination of Active Support Training and Training Trainers. *Journal of Applied Research in Intellectual Disabilities*, 14(2), 79-99.
<https://doi.org/10.1046/j.1468-3148.2001.00064.x>
- Jones, E. (2013). Back to the future: developing competent residential services for people with intellectual disabilities and challenging behaviour. *Advances in Mental Health and Intellectual Disabilities*, 7(1), 5-17.
<https://doi.org/10.1108/20441281311294657>
- Jormfeldt, M. (2016). *Tid, rum och självbestämmande: Möjligheter och hinder i vardagen för äldre personer med intellektuell funktionsnedsättning på gruppboende* [Doctoral dissertation, Jönköping University]. DiVA. <https://hj.diva-portal.org/smash/get/diva2:1045873/FULLTEXT01.pdf>
- Kings Fund Centre. (1980). *An ordinary life: Comprehensive locally-based residential services for mentally handicapped people*.
- Korstjens, I., & Moser, A. (2017). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and Publishing. *European Journal of General Practice*, 24, 120-124.
<https://doi.org/10.1080/13814788.2017.1375092>
- Kåhlin, I. (2015). *Delaktig (även) på äldre dar Äldrande och delaktighet bland personer med intellektuell funktionsnedsättning som bor i gruppboende* [Doctoral dissertation, Linköping University] DiVA. <https://liu.diva-portal.org/smash/get/diva2:781377/FULLTEXT01.pdf>
- Lante, K., Reece, J., & Walkley, J. (2010). Energy expended by adults with and without intellectual disabilities during activities of daily living. *Research in Developmental Disabilities*, 31(6), 1380-1389.
<https://doi.org/10.1016/j.ridd.2010.06.022>
- Larsson, S. (2021). *Självbestämmande i LSS: En villkorad rättighet för personer med intellektuell funktionsnedsättning* [Doctoral dissertation, Ersta Sköndal Bräcke Högskola]. <https://esh.diva-portal.org/smash/record.jsfp?pid=diva2%3A1543060&dswid=-51>
- Leonardi, M., Lee, H., Kostanjsek, N., Fornari, A., Raggi, A., Martinuzzi, A., Yáñez, M., Alborg, A. H., Fresk, M., Besstrashnova, Y., Shoshmin,

- A., Castro, S. S., Cordeiro, E. S., Cuenot, M., Haas, C., Maart, S., Maribo, T., Miller, J., Mukaino, M., Snyman, S., ... Kraus de Camargo, O. (2022). 20 Years of ICF-International Classification of Functioning, Disability and Health: Uses and Applications around the World. *International journal of environmental research and public health*, 19(18), 11321. <https://doi.org/10.3390/ijerph191811321>
- Levitt, J. M. (2017). Exploring how the social model of disability can be re-invigorated: in response to Mike Oliver. *Disability & Society*, 32(4), 589–594. <https://doi.org/10.1080/09687599.2017.1300390>
- Liedgren, P., & Kullberg, C. (2021). ‘Easy ride or born to be wild’? The travelling of evidence-based social work to Sweden. *European Journal of Social Work*, 25(2), 224–237. <https://doi.org/10.1080/13691457.2021.1918064>
- Lin, J., Manokara, V., Ng, J. S., & Penchaliah, S. (2020). Implementing Active Support in disability day services: A 6-month prospective study on engagement and behaviours of concern among adults with intellectual disability. *J Appl Res Intellect Disabil*, 33(6), 1307-1317. <https://doi.org/10.1111/jar.12750>
- Lindebaum, D., & Geddes, D. (2016). The place and role of (moral) anger in organizational behavior studies. *Journal of organizational behavior*, 37(5), 738–757. <https://doi.org/10.1002/job.2065>
- Lövgren, V. (2013). Villkorat vuxenskap: levd erfarenhet av intellektuell funktionshinder, kön och ålder [Doctoral dissertation, Umeå university]. <https://www.diva-portal.org/smash/record.jsfpid=diva2%3A619615&dswid=367>
- Mahon, D., Walsh, E., Holloway, J., & Lydon, H. (2021). A systematic review of training methods to increase staff's knowledge and implementation of positive behaviour support in residential and day settings for individuals with intellectual and developmental disabilities. *J Intellect Disabil*, 17446295211022124. <https://doi.org/10.1177/17446295211022124>
- Mallander, O. (1999). *De hjälper oss till rätta: normaliseringsarbete, självbestämmande och människor med psykisk utvecklingsstörning*. [Doctoral dissertation, Lund University].
- Malterud, S. (2001). Qualitative research: standards, challenges, and guidelines. *The Lancet*, 358, 483-488. [https://doi.org/10.1016/S0140-6736\(01\)05627-6](https://doi.org/10.1016/S0140-6736(01)05627-6)

- Mansell, J., & Elliott T. E. (1996). *Active Support Measure*. Tizard Centre, Canterbury.
- Mansell, J., Elliott, T., Beadle-Brown, J., Ashman, B., & Macdonald, S. (2002). Engagement in meaningful activity and "active support" of people with intellectual disabilities in residential care. *Res Dev Disabil*, 23(5), 342-352. [https://doi.org/10.1016/s0891-4222\(02\)00135-x](https://doi.org/10.1016/s0891-4222(02)00135-x)
- Mansell, J., & Beadle-Brown, J. (2005). *Engagement in meaningful activity and relationships (EMACR): Handbook for observers*. In (1st ed.): Tizard Centre.
- Mansell, J., Elliott, T., & Beadle-Brown, J. (2005). *Active Support Measure (ASM): Handbook for Observers*. Tizard Centre.
- Mansell, J., Beadle-Brown, J., & Special Interest Research Group. (2010). Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. *J Intellect Disabil Res*, 54(2), 104-112. <https://doi.org/10.1111/j.1365-2788.2009.01239.x>
- Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. Jessica Kingsley.
- Mansell, J., Beadle-Brown, J., & Bigby, C. (2013). Implementation of active support in Victoria, Australia: an exploratory study. *J Intellect Dev Disabil*, 38(1), 48-58. <https://doi.org/10.3109/13668250.2012.753996>
- Maulik, P., & Harbour, C. (2010). Epidemiology of intellectual disability. In J. H. Stone & B. Blouin (Eds.), *International Encyclopedia of Rehabilitation*. University at Buffalo, State University of New York.
- Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: a meta-analysis of population-based studies. *Research in developmental disabilities*, 32(2), 419–436. <https://doi.org/10.1016/j.ridd.2010.12.018>
- McCambridge, J., Witton, J., & Elbourne, D. R. (2014). Systematic review of the Hawthorne effect: New concepts are needed to study research participation effects. *Journal of Clinical Epidemiology*, 67(3), 267-277. <https://doi.org/10.1016/j.jclinepi.2013.08.015>
- McDonnell, A., & Deveau, R. (2018). Low arousal approaches to manage behaviours of concern. *Learning Disability Practice*. <https://doi.org/10.7748/ldp.2018.e1882>
- McDonnell, A. A., Page, A., Bews-Pugh, S., Morgalla, K. A., Kaur-Johal, T., & Maher, M. (2024). Families' experiences of the Low Arousal Approach:

- a qualitative study. *Frontiers in psychology*, 15, 1328825.
<https://doi.org/10.3389/fpsyg.2024.1328825>
- Mesibov, G., Shea, V., & Schopler, E. (2005). *The TEACCH approach to autism spectrum disorders*. New York: Plenum.
- Mesibov, G. B., & Shea, V. (2010). The TEACCH program in the era of evidence-based practice. *Journal of autism and developmental disorders*, 40(5), 570–579. <https://doi.org/10.1007/s10803-009-0901-6>
- Miller, C. J., Smith, S. N., & Pugatch, M. (2020). Experimental and quasi-experimental designs in implementation research. *Psychiatry research*, 283(112452). <https://doi.org/10.1016/j.psychres.2019.06.027>
- Morinaga, M., Ahlqvist, V. H., Lundberg, M., Hollander, A. C., Rai, D., & Magnusson, C. (2024). Changes in the prevalence of intellectual disability among 10-year-old children in Sweden during 2011 through 2021: a total population study. *Journal of neurodevelopmental disorders*, 16(1), 58. <https://doi.org/10.1186/s11689-024-09576-3>
- National Board of Health and Welfare. (2012). *Rätt kompetens hos personal i verksamheter för personer med funktionsnedsättning*.
<https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/vagledning/2012-2-17.pdf>
- National Board of Health and Welfare. (2014). *SOSFS 2014:2 Socialstyrelsens allmänna råd om kunskaper hos personal som ger stöd, service eller omsorg enligt SoL och LSS till personer med funktionsnedsättning*.
<https://www.socialstyrelsen.se/kunskapsstod-och-regler/omraden/funktionshinder/regelverk/>
- National Board of Health and Welfare. (2018). *Bostad med särskild service för vuxna enligt LSS*. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2018-6-12.pdf>
- National Board of Health and Welfare. (2021). *Kompetens i LSS-boenden*.
<https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7312.pdf>
- National Board of Health and Welfare. (2022). *Insatser och stöd till personer med funktionsnedsättning Lägesrapport 2022*.
<https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2022-3-7815.pdf>
- National Board of Health and Welfare. (2024). *Klassifikationen av ICD-10*.
<https://www.socialstyrelsen.se/statistik-och-data/klassifikationer-och-koder/icd-10/>

- National Board of Health and Welfare. (2025). *Statistik om stöd och service till personer med funktionsnedsättning*. <https://www.socialstyrelsen.se/statistik-och-data/statistik/alla-statistikamnen/personer-med-funktionsnedsattning/>
- Nickerson, R. S. (1998). Confirmation Bias: A Ubiquitous Phenomenon in Many Guises. *Review of General Psychology*, 2(2), 175-220. <https://doi.org/10.1037/1089-2680.2.2.175>
- Nihira, K., Leland, H., & Lambert, N. (1993). *AAMR Adaptive Behavior Scale—Residential and Community*. 2nd ed. Austin, TX: Pro-ED.
- Nijs, S., Taminiau, E. F., Frielink, N., & Embregts, P. J. C. M. (2019). Stakeholders' perspectives on how to improve the support for persons with an intellectual disability and challenging behaviors: a concept mapping study. *International journal of developmental disabilities*, 68(1), 25–34. <https://doi.org/10.1080/20473869.2019.1690859>
- Nind, M., & Vinha, H. (2014). Doing research inclusively: bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*, 42(2), 102-109. <https://doi.org/10.1111/bld.12013>
- Nirje, B. (1969). The normalization principle and its human management implications. In R. Kugel & W. Wolfensberger (Ed.), *Changing patterns in residential service for the mentally retarded*. (pp. 179–195). President's Committee on Mental Retardation.
- Nirje, B. (1970). The normalisation principle—implications and comments. *Journal of Mental Subnormality*, 16, 62–70.
- Nussbaum, C. M. (2006). *Frontiers of Justice: Disability, Nationality, Species Membership*. The Belknap Press of Harvard University Press.
- Nussbaum, C. M. (2013). *Creating Capabilities The Human Development Approach*. The Belknap Press of the Harvard University Press.
- Olin. (2003). *Uppbrott och förändring – När ungdomar med utvecklingsstörning flyttar hemifrån*. [Doctoral dissertation, Göteborgs university].
- Oliver, M. (1990). *The politics of disablement*. Macmillan.
- Oliver, M. (1996). *Understanding disability: from theory to practice*. St. Martin's Press.
- Oliver, M. (2004). The Social Model in Action: If I Had a Hammer. In C. Barnes and G. Mercer, *Implementing the Social Model of Disability: Theory and Research*, 18–31. The Disability Press.
- Paradis, E., & Sutkin, G. (2017). Beyond a good story: from Hawthorne Effect to reactivity in health professions education research. *Medical education*, 51(1), 31–39. <https://doi.org/10.1111/medu.13122>

- Participation model. (2020). *Delaktighetsmodellen*.
<https://delaktighetsmodellen.se/>
- Pellicano, E., Fatima, U., Hall, G., Heyworth, M., Lawson, W., Lilley, R., Mahony, J., & Stears, M. (2022). A capabilities approach to understanding and supporting autistic adulthood. *Nature reviews psychology*, 1(11), 624–639. <https://doi.org/10.1038/s44159-022-00099-z>
- Perera, B., Laugharne, R., Henley, W., Zabel, A., Lamb, K., Branford, D., Courtanay, K., Alexander, R., Purandare, K., Wijeratne, A., Radhakrishnan, V., McNamara, E., Daureeawoo, Y., Sawhney, I., Scheepers, M., Taylor, G., & Shankar, R. (2020). COVID-19 deaths in people with intellectual disability in the UK and Ireland: descriptive study. *BJPsych Open*, 6(6), e123. <https://doi.org/10.1192/bjo.2020.102>
- Powell, B. J., McMillen, J. C., Proctor, E. K., Carpenter, C. R., Griffey, R. T., Bunker, A. C., Glass, J. E., & York, J. L. (2012). A Compilation of Strategies for Implementing Clinical Innovations in Health and Mental Health. *Medical Care Research and Review*, 69(2), 123–157.
<https://doi.org/10.1177/1077558711430690>
- Proctor, E.K., Powell, B.J., & McMillen, J.C. (2013). Implementation strategies: recommendations for specifying and reporting. *Implementation Sci*, 8, 139. <https://doi.org/10.1186/1748-5908-8-139>
- Prop. 1976/77:87. Om insatser för handikappades kulturella verksamhet.
https://www.riksdagen.se/sv/dokument-och-lagar/dokument/proposition/om-insatser-for-handikappades-kulturella_g00387/
- Prop. 1992/93:159. About support and service for certain disabled persons.
https://www.riksdagen.se/sv/dokument-och-lagar/dokument/proposition/om-stod-och-service-till-vissa-funktionshindrade_gg03159/
- Prop. 1999/2000:79. Från patient till medborgare - en nationell handlingsplan för handikappolitiken. <https://www.regeringen.se/rattsliga-dokument/proposition/2000/03/prop.-1999200079/>
- Prop. 2016/17:188. Nationellt mål och inriktning för funktionshinderspolitiken.
<https://www.regeringen.se/rattsliga-dokument/proposition/2017/05/prop.-201617188/>
- Qian, X., Tichá, R., & Stancliffe, R. (2017). Contextual Factors Associated with Implementing Active Support in Community Group Homes in the United States: A Qualitative Investigation. *Journal of Policy and Practice in*

- Intellectual Disabilities*, 14(4), 332-340.
<https://doi.org/10.1111/jppi.12204>
- Rapley, M. (2003). *Quality of Life Research - A Critical Introduction*. Sage Ltd.
- Region Stockholm. (2025). Lindrig intellektuell funktionsnedsättning hos vuxna.
<https://kunskapsstodforvardgivare.se/omraden/psykisk-halsa/regionala-varldprogram/lindrig-intellektuell-funktionsnedsattning-hos-vuxna>
- Rhodes, J. A., & Toogood, S. (2016). Can active support improve job satisfaction? *Tizard Learning Disability Review*, 21(2), 54-60.
<https://doi.org/10.1108/tldr-07-2015-0028>
- Riches, V. C., Harman, A. D., Keen, D., Pennell, D., Harley, J. H., & Walker, M. (2011). Transforming staff practice through active support. *J Intellect Dev Disabil*, 36(3), 156-166.
<https://doi.org/10.3109/13668250.2011.598499>
- Ringsby Jansson, B. (2002). *Vardagslivets arenor : om människor med utvecklingsstörning, deras vardag och sociala liv* [Doctoral dissertation, Göteborg University].
- Robinson, S., & Chenoweth, L. (2011). Preventing abuse in accommodation services: from procedural response to protective cultures. *Journal of intellectual disabilities: JOID*, 15(1), 63-74.
<https://doi.org/10.1177/1744629511403649>
- Røren, O. (2007). *Idioternas tid. Tankestilar inom den tidiga idiotskolan 1840-1872*. [Doctoral dissertation, Stockholm University].
- Rothman, K. (2002). *Epidemiology. An Introduction*. Oxford University Press.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing and Health*, 18(2), 179-183.
- Schalock, R. (2000). Three decades of quality of life. *Focus on autism and other developmental disabilities*, 15(2), 116-127.
<https://doi.org/10.1177/108835760001500207>
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D., & Parmenter, T. (2002). Conceptualization, Measurement, and Application of Quality of Life for Persons With Intellectual Disabilities: Report of an International Panel of Experts. *Mental Retardation*, 40(6), 457-470. [https://doi.org/10.1352/0047-6765\(2002\)040<0457:CMAAOQ>2.0.CO;2](https://doi.org/10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2)
- Schalock, R. L. (2004). The Concept of Quality of Life: What We Know and Do Not Know. *Journal of Intellectual Disability Research*, 48(3), 203-216.

<https://doi.org/10.1111/j.1365-2788.2003.00558.x>

- Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., et al. (2010). Intellectual disability: Definition, classification, and systems of supports. *American Association on Intellectual and Developmental Disabilities*
- Schalock, R. L., Baker, A., Claes, C., Gonzalez, J., Malatest, R., van Loon, J., Verdugo, M. A., & Wesley, G. (2018). The Use of Quality of Life Scores for Monitoring and Reporting, Quality Improvement, and Research. *Journal of Policy and Practice in Intellectual Disabilities*, 15(3), 176–182. <https://doi.org/10.1111/jppi.12250>
- Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). An Overview of Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports (12th ed.). *American journal on intellectual and developmental disabilities*, 126(6), 439–442. <https://doi.org/10.1352/1944-7558-126.6.439>
- SFS 1985:568. Lag om särskilda omsorger om psykiskt utvecklingsstörda m. fl.
- SFS 1993:387. Lag om stöd och service för vissa funktionshindrade.
- SFS 2001:453. Socialtjänstlagen
- Shakespeare, T. (2006). *Disability rights and wrongs*. Routledge.
- Silvers, A. (2003). On the possibility and desirability of constructing a neutral conception of disability. *Theor Med*, 24, 471-487. <https://doi.org/10.1023/B:META.0000006924.82156.5b>
- Skowronski, J. J. (2011). The positivity bias and the fading affect bias in autobiographical memory: A self-motives perspective. In M. D. Alicke & C. Sedikides (Eds.), *Handbook of self-enhancement and self-protection* (pp. 211–231). The Guilford Press.
- Smith, C., Felce, D., Jones, E., & Lowe, K. (2002). Responsiveness to staff support: evaluating the impact of individual characteristics on the effectiveness of active support training using a conditional probability approach. *Journal of Intellectual Disability Research*, 46(8), 594-604. <https://doi.org/10.1046/j.1365-2788.2002.00433.x>
- SOU 2000:20. (2000). Steriliseringsfrågan i Sverige 1935-1975. <https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2000/03/sou-200020/>
- Spiegelman, D. (2016). Evaluating Public Health Interventions: 2. Stepping Up to Routine Public Health Evaluation With the Stepped Wedge Design.

- Am J Public Health*, 106(3), 453-457.
<https://doi.org/10.2105/AJPH.2016.303068>
- Stancilffe, R. J., Jones, E., Mansell, J., & Lowe, K. (2008). Active support: a critical review and commentary. *J Intellect Dev Disabil*, 33(3), 196-214.
<https://doi.org/10.1080/13668250802315397>
- Stancilffe, R., McVilly, K. R., Radler, G., Mountford, L., & Tomaszewski, P. (2010). Active Support, Participation and Depression. *Journal of Applied Research in Intellectual Disabilities*, 23, 312-332.
<https://doi.org/10.1111/j.1468-3148.2009.00535.x>
- Stenström-Jönsson, U.-B. (1995). *Mot självständigare liv? Om nedläggningen av Furubagens vårdhem för utvecklingsstörda*. [Doctoral dissertation, Stockholm University].
- Stewart, K., Bradshaw, J., & Beadle-Brown, J. (2018). Evaluating Service users' Experiences Using Talking Mats®. *Tizard Learning Disability Review*, 23 (2), 78–86. <https://doi.org/10.1108/TLDR-05-2017-0023>
- Stiker, H.-J. (1997). *A History of Disability*. University of Michigan Press.
- Strydom, A., Bosco, A., Vickerstaff, V., Hunter, R., group, P. B. S. s., & Hassiotis, A. (2020). Clinical and cost effectiveness of staff training in the delivery of Positive Behaviour Support (PBS) for adults with intellectual disabilities, autism spectrum disorder and challenging behaviour - randomised trial. *BMC Psychiatry*, 20(1), 161.
<https://doi.org/10.1186/s12888-020-02577-1>
- Swedish Agency for Participation. (2017). *Mäns våld mot kvinnor med funktionsnedsättning*. 2017:29.
<https://www.mfd.se/material/publikationer/rapport/mans-vald-mot-kvinnor-med-funktionsnedsattning/>
- Swedish Agency for Participation. (2025, 7 Feb). *Motverka våld bland barn och unga med funktionsnedsättning*. <https://www.mfd.se/samhallsomraden/brott-och-utsatthet/valdsutsatthet/#:~:text=I,%C3%A4r%20dig%20om%20hur%20du%20och%20din%20myndighet,funktionsneds%20och%20agera%20n%20det%20redan%20har%20intr%20ffat.>
- Swedish Association of Local Authorities and Regions. (2024). *Personalen i välfärden- Personalstatistik för kommuner och regioner*.
<https://skr.se/download/18.3529ff5c18e517e099c7125c/1714741578688/Personalen%20i%20v%C3%A4lf%C3%A4rden%202023.pdf>

- Söder, M. (1982). *Handikappbegreppet : en analys utifrån WHO:s terminologi och svensk debatt*. Beredningsgruppen för internationella handikappåret 1981.
- Talman, L. (2018). *Participation in everyday life for adults with profound (and multiple) disabilities*. [Doctoral dissertation, Mälardalens university].
<https://www.diva-portal.org/smash/get/diva2:1230447/FULLTEXT02.pdf>
- Taubner, H., Tideman, M., & Staland-Nyman, C. (2023). People with intellectual disability and employment sustainability: A qualitative interview study. *Journal of Applied Research in Intellectual Disabilities : JARID*, 36(1), 78–86. <https://doi.org/10.1111/jar.13036>
- Thunberg, G. (2024, Oct 29). ComBo-training staff of adults in need of AAC-views of participants, managers, and users. ISAAC Virtual Event, AAC Awareness Month
- Tideman, M. (2000). *Normalization and categorization. Disability ideology and welfare politics in theory and practice for people with intellectual disability*. Studentlitteratur.
- Tiedens, L. Z. (2001). Anger and advancement versus sadness and subjugation: The effect of negative emotion expressions on social status conferral. *Journal of Personality and Social Psychology*, 80(1), 86–94. <https://doi.org/10.1037/0022-3514.80.1.86>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349 – 357. <https://doi.org/10.1093/intqhc/mzm042>
- Totsika, V., Toogood, S., & Hastings, R. P. (2008). Active Support: Development, Evidence Base, and Future Directions. *International Review of Research in Mental Retardation*, 35, 205-249.
[https://doi.org/10.1016/S0074-7750\(07\)35006-4](https://doi.org/10.1016/S0074-7750(07)35006-4)
- Tournier, T., Wolkorte, R., Hendriks, A., Jahoda, A., & Embregts, P., J,C, M. . (2021). Family Involvement in Person-Centered Approaches for People with Intellectual Disabilities and Challenging Behaviors: A Scoping Review. *Journal of Mental Health Research in Intellectual Disabilities*, 14(4), 349-374. <https://doi.org/10.1080/19315864.2021.1959689>
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garrity, C., Lewin, S., ... Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and

- Explanation. *Annals of internal medicine*, 169(7), 467–473.
<https://doi.org/10.7326/M18-0850>
- Tripepi, G., Jager, K. J., Dekker, F. W., & Zoccali, C. (2010). Selection Bias and Information Bias in Clinical Research. *Nephron Clinical Practice*, 115, c94–c99. <https://doi.org/10.1159/000312871>
- Tronto, J. (1993). *Moral Boundaries - A political argument for an Ethic of Care*. Routledge.
- Tøssebro, J., Bonfils, I., Teittinen, A., Tideman, M., Traustadóttir, R., & Vesala, H. (2012). Normalization Fifty Years Beyond—Current Trends in the Nordic Countries. *Journal of Policy and Practice in Intellectual Disabilities*, 9(2). <https://doi.org/10.1111/j.1741-1130.2012.00340.x>
- Umb Carlsson, Ö. (2021). Health-promotion intervention in a group home: Perspectives of residents, staff and rehabilitation professionals. *Journal of intellectual disabilities : JOID*, 25(2), 210–229.
<https://doi.org/10.1177/1744629519874970>
- Umb Carlsson, Ö., & Adolfsson, P. (2023). No ordinary adult life: Living conditions from the perspective of adults with intellectual disabilities. *Journal of intellectual disabilities : JOID*, 27(4), 944–963.
<https://doi.org/10.1177/17446295221107284>
- United Nations (n.d). *UN treaty body database*. Retrieved 2025-03-21
https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?Treaty=CRPD
- United Nations (n.d.). *Convention on the Rights of Persons with Disabilities*. Department of Economic and Social Affairs- Social inclusion. Retrieved 2025-03-21.
<https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd>
- United Nations. (2006, Dec 6). *Convention on the Rights of Persons with Disabilities*. https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf
- United Nations. (2018, Nov 9). General comment No.7 on Article 4.3 and 33.3 - the participation of persons with disabilities in the implementation and monitoring of the Convention.
<https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no7-article-43-and-333-participation>

- United Nations. (2024, Nov 8). *Universal Declaration of Human Rights (1948): 30 Articles - 30 Documents: Exhibit for the 75th Anniversary*.
<https://research.un.org/en/udhr75#s-lg-page-section-5992686>
- Van Bourgondien, M. E., & Schopler, E. (1996). Interventions for adults with autism. *Journal of Rehabilitation*, 62, 65-71.
- Van Herwaarden, A., Peters-Scheffer, N. C., Mulders, M., Totsika, V., & Didden, R. (2025). Effectiveness of Active Support on the quality of life and well-being of people with moderate to mild intellectual disabilities. *Research in developmental disabilities*, 157, 104925.
<https://doi.org/10.1016/j.ridd.2025.104925>
- Van Loon, J., Van Hove, G., Schalock, R. L., & Claes, C. (2008). Personal outcomes scale. *Middleburg, Holland: Arduin Steiblich*.
- Virues-Ortega, J., Julio, F. M., & Pastor-Barrusio, R. (2013). The TEACCH program for children and adults with autism: a meta-analysis of intervention studies. *Clin Psychol Rev*, 33(8), 940-953.
<https://doi.org/10.1016/j.cpr.2013.07.005>
- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: past, present and futures*. Jessica Kingsley Publishers.
- Walmsley, J., Strnadová, I., & Johnson, K. (2017). The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 31, 751-759.
<https://doi.org/10.1111/jar.12431>
- White, T. L., Gonsalves, M. A., Zimmerman, C., Joyce, H., Cohen, R. A., Clark, U. S., Sweet, L. H., Lejuez, C. W., & Nitenson, A. Z. (2023). Anger, agency, risk and action: a neurobehavioral model with proof-of-concept in healthy young adults. *Frontiers in psychology*, 14, 1060877.
<https://doi.org/10.3389/fpsyg.2023.1060877>
- Widerlund, J. (2007). *Nya perspektiv men inarbetad praxis. En studie av utvecklingsstördas självbestämmande och inflytande*. [Licentiate thesis, Luleå University of Technology]. DiVA. <https://www.diva-portal.org/smash/get/diva2:989891/FULLTEXT01.pdf>
- Wiltsey Stirman, S., Gamarra, J., Bartlett, B., Calloway, A., & Gutner, C. (2017). Empirical Examinations of Modifications and Adaptations to Evidence-Based Psychotherapies: Methodologies, Impact, and Future Directions. *Clinical psychology : a publication of the Division of Clinical Psychology of the American Psychological Association*, 24(4), 396-420.
<https://doi.org/10.1111/cpsp.12218>

- Wiltsey Stirman, S., Baumann, A. A., & Miller, C. J. (2019). The FRAME: an expanded framework for reporting adaptations and modifications to evidence-based interventions. *Implementation science*, *14*(1), 58.
<https://doi.org/10.1186/s13012-019-0898-y>
- Wolfenberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation*, *21*(6), 234-239.
- Wolff, E. (2025). A Legacy of Revision: Maintaining Professional Expertise Over the Changing Diagnosis and Classification of Intellectual Disability in the United States. *The Sociological Quarterly*, *66*(1), 191–214.
<https://doi.org/10.1080/00380253.2024.2378968>
- World Health Organization. (2025). International Classification of Functioning, Disability and Health (ICF).
<https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>
- Zaks, Z. (2023). Changing the medical model of disability to the normalization model of disability: clarifying the past to create a new future direction. *Disability & Society*, *39*(12), 3233–3260.
<https://doi.org/10.1080/09687599.2023.2255926>

Appendices

Appendix 1. Interview guide for interviews with people with intellectual disability (for Article II).

Intervjuguide

Inledning:

Information om studien, bekräftelse av samtycke. Anonymitet.

Kort om vilka ämnen jag tänker ta upp idag

Frågor om intervjun/studien?

Jag är intresserad av din berättelse eftersom du bor på en gruppbostad, jag är inte här för att bedöma dig

Alla svar är bra, finns inga rätt eller fel

Jag kommer ställa följdfrågor så att vi är överens om vad du menar

Säg till när du vill ta en rast

Jag kommer spela in intervjun och sedan skriva ner vad du har sagt

Vi träffas nu, och kanske träffas vi en gång till om det behövs

Uppmuntra att ge exempel

Pictogrambilder eller andra former av AKK (Alternativ och kompletterande kommunikation) kan komma att användas i samband med intervju om det underlättar kommunikationen med intervjupersonen.

Bakgrundsfrågor

- Hur gammal är du?
- Hur länge har du bott här?
- Var bodde du innan du flyttade hit?
- Vem bestämde att du skulle flytta hit?
- Berätta om din lägenhet.
- Hur var det att flytta hit till gruppboenden?

Tema 1: En vanlig dag

- Hur ser en vanlig dag ut i ditt liv?
- Vad gör du en vanlig dag?
- Hur nöjd är du med det som du gör under en vanlig dag?

- Finns det saker du vill göra under din dag men som du inte gör? Kan du ge exempel?
- Vad brukar du göra på helgerna?

Tema 2: Om att bestämma själv

- Vad bestämmer du om? Varför är det så?
- Vad bestämmer personalen om?
- Hur är det att bo med dina grannar? Kommer du överens med dem?
- Vad är viktigt för dig i ditt liv att kunna göra och bestämma över?
- Hur vill du ha stöd från personalen att göra det som är viktigt?
- När brukar personalen ge dig stöd?
- Vilken sorts stöd, kan du ge exempel?
- Hur bestäms vilka aktiviteter du gör på helgerna?
- Kan du, om du vill, gå ut på kvällar med (eller utan) personalen? Måste du bestämma i förväg?
- Kan du ha någon som sover över hemma hos dig?
- Har det hänt att det har varit förbjudet för dig att ta emot besök av vänner eller familj? När i så fall?

Är det något som du vill göra mer? Tex när det gäller att:

- Få vänner
- Träffa familj
- Få en pojkvän/flickvän
- Göra fritidsaktiviteter
- Hålla rent i min lägenhet
- Få ett jobb
- Vara mer ute på stan eller i samhället
- Byta till annan daglig verksamhet
- Annat?

Är det något du skulle vilja ha mer stöd av personal för att kunna göra? Om ja, i vilka situationer?

- Få nya vänner
- Träffa familj

- Få en pojkvän/flickvän
- Göra fritidsaktiviteter
- Hålla rent i min lägenhet
- Få ett jobb
- Vara mer ute i samhället
- Byta daglig verksamhet
- Annat?
-
- Skulle du vilja att personalen ger stöd på något annat sätt än de gör idag?

Avslutning

- Vad är det bästa med gruppboenden?
- Är det något som du saknar på gruppboendet?
- Vad skulle du vilja ändra på på gruppboendet?
- Hur skulle du vilja bo om några år?
- Är det något mer du skulle vilja berätta för mig?

Tack för att du ville ta dig tid och svara på mina frågor.

Om vi ska träffas igen för att fullfölja intervjun, bestäm dag/tid. Alternativt att vi håller det öppet om det skulle behövas. Inspelningen avslutas.

Appendix 2. Interview guide for interviews with managers (for article III).

Praktiknära ledarskap – Intervjufrågor

1. Berätta om **din arbetsroll** och ditt ansvar.
 - a. Vilka är dina huvudsakliga arbetsuppgifter?
 - b. Vad spenderar du mest tid på att göra?
 - c. Vilka utmaningar och belöningar finns i din arbetsroll?
2. Vilket är målsättningen med gruppbestaden – vad finns det för förutsättningar för att nå det målet?
3. Vad tycker du är viktigast i rollen som stödassistent? Vad lägger stödassistenter mest tid på? Vad skulle du vilja att de prioriterade?
4. På vilket sätt vet du om stödassistenten gör ett bra jobb?
5. Beskriv hur du berättar för personalen om de gjort ett bra eller dåligt jobb?
6. På vilka sätt hjälper du dem att förbättra sig i det direkta arbetet med brukarna?
7. Hur ger du personalen feedback på deras arbete?
8. Hur vet personalen vad som är viktigt att prioritera? Kan du ge några exempel på vad du har observerat när det gäller prioritering av arbetsuppgifter och på vilket sätt du gav feedback på det?
9. Håller du formell handledning med personalen?
 - a. Om ja, hur ofta?
 - b. Vad är i fokus på handledningen? Vad brukar ni diskutera? Grupp/enskild handledning? Kan du ge exempel på något du diskuterat med personal under ett handledningstillfälle?
 - c. Skriver ni anteckningar från handledningstillfället, kan jag få se något exempel i så fall?
 - d. Om inte, på vilket sätt ger du feedback?

10. Arbetar du själv i verksamheten med direkt stöd till brukarna?
11. Arbetar du tillsammans med medarbetare på schema? Hur ofta?
12. Ger du direkt handledning till personalen när ni arbetar sida vid sida, tex instruerar och vägleder?
13. Tycker du att du kan vara en förebild som stödassistent?
14. Hur delar du/ni upp vem som ger stöd till vem? Har du ett schema som jag kan titta på?
15. Finns det bestämda fritidsaktiviteter som boende kan göra en speciell dag i veckan tex bowling eller vardagsaktiviteter som tvätt?
 - a. Om ja, hur planeras personalen in till de olika aktiviteterna?
 - b. Hur väl kan man ändra på tiden på schemat utifrån vad och när boende behöver och vill ha aktiviteten? Vilken flexibilitet finns? Hur långt i förväg behöver personalen få veta eventuella förändringar/önskemål från brukaren?
 - c. Behövs det göras några förändringar på schemat för att förbättra personalstödet?
 - d. Finns det tillräckligt med personal för att bedriva en kvalitativt god verksamhet?
16. Hur vet personalen vad som ska göras under ett arbetspass? Finns det en skriftlig planering? På vilket sätt vet personalen hur de ska stödja brukarna, deras gillande/ogillande?
17. Hur introduceras ny personal? Finns det rutiner/schemaplanerare som jag kan titta på? Finns det aktivitetstavla/pictogramtavlor/loggböcker?
18. Finns det flexibilitet i schemat? Om en boende skulle vilja gå på oplanerad aktivitet en kväll tex gå på bio en vardagskväll, besöka en vän eller anhörig med personalstöd- finns den möjligheten? Hur ska personalen göra i en sån situation om brukaren vill göra nåt sånt? Skulle te x en medarbetare behöva stanna på gruppboenden ensam med några av brukarna?

19. Har du regelbundna teammöten? Är de separerade från APT?
- Vad diskuteras?
 - Vad prioriteras?
 - Har du några minnesanteckningar som jag kan titta på?
 - Diskuteras Active support? Diskuteras ni möjligheter för brukarna att delta mer i samhällslivet? Hur man kan utveckla medverkan i aktiviteter i samhället? Och utveckla nya relationer?

Praktiskt ledarskap handlar om: Bestämma prioriteringar för personalen att arbeta efter, fördela personal på olika arbetsuppgifter, coacha personal och ge handledning/feedback. Strukturera lärande utifrån erfarenhet (observationer, tillsyn, handledning, gå bredvid, teammöten). Praktiskt ledarskap definieras som utveckling av och upprätthållande av bra stöd till personer som bor på gruppboenden. Detta sker genom ledarskapet: genom att spendera tid med att observera personal jobba, ge feedback och agera förebild genom gott stöd själv, erbjuda personal 1-1 handledning och organisera teammöten genom att utveckla brukarens engagemang.

Svensk översättning från Beadle-Brown et al. (2015)

Appendix 3. Easy to read written information letter about the Active Support project.

Hej!

Vill du vara med i min forskning?

Jag heter Jenny Aspling och jag är doktorand på Ersta Sköndal Bräcke Högskola i Stockholm. Det betyder att jag går i forskarskola och lär mig att forska.

Min forskning handlar om hur personal kan ge bra stöd till de som bor på gruppboende. Ett bra stöd är bland annat att de som bor på gruppboenden kan bestämma mycket själva. Det är Ersta Sköndal Bräcke högskola som ansvarig för att forskningen sker på ett bra och riktigt sätt. Det är Ersta Diakoni som betalar för min forskning.

Du får det här brevet för att du bor på en gruppboende som jag vill besöka. Nu undrar jag om du vill vara med i min forskning? Om du vill vara med så kommer jag att komma till din gruppboende flera gånger och titta på när

personalen och chefen jobbar. Personalen kommer att lära sig ge stöd som heter Active Support. Du kommer få veta i förväg när jag besöker gruppboenden och mellan vilka tider. Jag kommer att vara i gemensamma utrymmen. Jag kommer också att ställa frågor till chefen på boendet och personalen hur de jobbar på boendet. Och om du vill så vill jag gärna prata med dig också och ställa frågor om vad du tycker om din gruppboende.

Det är frivilligt att vara med. Du bestämmer själv om du vill vara med. Om du säger ja först så kan du ångra dig sen. Du behöver inte förklara varför, utan du säger bara att du inte vill vara med. Du kan ångra dig fram tills att jag har skrivit klart en bok om forskningen. När jag skriver eller berättar om den här forskningen kommer du att vara anonym. Det betyder att vad du heter och annan information om vem du är inte kommer med.

Har du några frågor? Kontakta mig!

Jag har telefonnummer XXXX. Du kan ringa eller skicka sms.

Du kan också mejla mig på xxxx

Du kan även ringa eller skicka mail till den som är ansvarig för forskningen. Han heter Magnus Tideman och arbetar på högskolan. Magnus har telefonnummer XXX och mail xxx

Hälsningar Jenny

Appendix 4. Consent form for service users

Jag heter..... och har fått information om forskningsstudien ”Active Support – ett arbetssätt för inflytande och ökad delaktighet för personer med intellektuell funktionsnedsättning på gruppbostäder?”.

Jag har fått information från Jenny Aspling. Jag har fått information om varför den här forskningen görs och hur resultaten ska användas både berättat för mig och på papper. Jag har fått svar på de frågor jag haft.

- Jag vet att det är frivilligt att vara med.
- Jag vet att jag kan avbryta när jag inte vill vara med längre.
- Om jag vill avbryta behöver jag inte förklara varför. Jag kan avbryta för en paus eller för att sluta vara med i studien.
- Jag vet att jag kommer att vara anonym när resultaten presenteras.

Jag samtycker till att vara med i studien.

Jag förstår att Jenny Aspling kommer att observera hur personalen arbetar på gruppboenden. Jag har fått information när det kommer att ske.

Jag samtycker till att bli intervjuad i studien. Jag har sett frågorna innan och vet vad Jenny kommer att fråga om.

Jag förstår att personalen kommer att bli intervjuad. Jag godkänner att de får besvara frågor som gäller stöd till mig.

Den här blanketten finns i två exemplar. Jag har det ena och Jenny Aspling har den andra.

Ort och datum:

Deltagare skriver under här: Jenny Aspling skriver under här:

.....

.....

Appendix 5. Information letter and written consent form for staff

Information om forskningsprojekt till dig som är personal eller chef om "Active Support – ett arbetssätt för inflytande och ökad delaktighet för personer med intellektuell funktionsnedsättning på gruppboende"

Du arbetar på ett gruppboende som ingår i forsknings- och utvecklingsprojektet "Active Support - ett arbetssätt för inflytande och ökad delaktighet för personer med intellektuell funktionsnedsättning på gruppboende". Projektet syftar till att införa Active Support på boendet och undersöka hur metoden används, vilka effekter den får och vad de boende, personalen och chefer tycker om arbetsmetoden. Ersta Sköndal Bräcke högskola är forskningshuvudman och ansvarig för projektet.

Vi frågar dig nu om du kan tänka dig att delta i studien av Active Support? Projektet bygger på att det är viktigt att undersöka om detta är en metod som leder till att personer med funktionsnedsättning som bor på gruppboende får ökat självbestämmande, blir mer aktiva och får större delaktighet i vardagslivet.

Enligt Förenta nationernas konvention om rättigheter för personer med funktionsnedsättning och svensk funktionshinderpolitik är självbestämmande, aktivitet och delaktighet grundläggande rättigheter och personer med funktionsnedsättning har rätt till att vara involverade och delaktiga i alla situationer och processer som berör dem. Därför tycker vi att det är viktigt att utvärdera om Active Support är ett bra sätt att arbeta på för att nå dessa mål och att både boende, personal och chefer själva får vara med i studien och berätta om sina upplevelser.

Om du samtycker till att delta innebär att du i samband med att Active Support införs på gruppboendet deltar i utbildning och handledning i metoden och får möjlighet att svara på frågor om din arbetssituation och erfarenheter av Active Support. Det innebär dels att du under en 3-årsperiod deltar i genomförandet av Active Support, dels besvarar enkäter och blir intervjuad vid några tillfällen samt att forskare kommer att närvara i

gruppbestanden vid ett antal tillfällen och observera verksamheten. Intervjuerna vill vi gärna spela in och därför vill vi också fråga dig om du samtycker till att det samtalet spelas in.

Vad innebär det att delta?

Intervjun är ett samtal där inga svar är rätt eller fel, utan där det är din åsikt och upplevelse som är det viktiga. Intervjun tar som mest en timme. Inspelning av intervjun på digital inspelningsutrustning är helt frivillig: du kan välja att inte spela in samtalet eller att radera inspelningen efter samtalet. Om du vill kan du ta del av utskriften, rätta det som blivit fel eller lägga till något som inte kom med.

Deltagande är frivilligt

Deltagande i studien är helt frivilligt. Genom att delta i forskningsprojektet är du inte skyldig att svara på alla frågor som ställs. Du kan välja att låta bli att svara på frågor utan att Du behöver tala om varför. Du kan också när som helst säga till forskarna (telefonnummer och mailadress nedan) att du inte vill delta i studien längre. Det kan du göra före, under eller efter intervjuerna eller andra aktiviteter som enkätbesvarande eller observationer

Om du har synpunkter på deltagandet

Om du har frågor eller vill klaga på antingen hur studien går till, eller hur du bemötts när det gäller studien, kan du kontakta antingen forskningsansvarig Magnus Tideman eller doktorand Jenny Aspling (se kontaktuppgifter nedan).

Hantering av data och sekretess

Dina svar på intervjuer och andra data kommer att behandlas så att inte obehöriga kan ta del av dem. Den information du lämnar lagras med en särskild kod (i stället för namn och personnummer används ett nummer som bara forskarna har tillgång till) i ett särskilt utrymme för forskningsmaterial på högskolan. Kodnyckeln som talar om vilken person som har fått vilket nummer förvaras på ett annat ställe, så att det inte ska vara möjligt för obehöriga att koppla ihop uppgifterna barnet lämnar med barnet. De inspelade intervjuerna skrivs ut och då tar vi bort alla uppgifter som kan identifiera intervjupersonen. Ljudinspelningen förvaras inlåst i ett säkerhetsskåp på högskolan. Materialet förvaras i 10 år och förstörs sedan. Om du själv vill ha ut kopia på uppgifterna som du har lämnat går det självklart bra – se nedan hur ni går tillväga

Ersta Sköndal Bräcke högskola är forskningshuvudman och ansvarig för dina personuppgifter är Institutionen för socialvetenskap, Ersta Sköndal Bräcke

högskola. Enligt EU:s dataskyddsförordning artikel 6 har den som deltar i forskning, det vill säga du, rätt att kostnadsfritt få ta del av de uppgifter om dig som hanteras i studien, och vid behov få eventuella fel rättade. Du kan också begära att uppgifter om dig raderas samt att behandlingen av personuppgifterna begränsas. Radering och ändring av uppgifter är möjlig så länge data är obearbetade, dvs innan analyser av data har gjorts.

Om du vill ta del av uppgifterna ska du kontakta professor Magnus Tideman vid Institutionen för socialvetenskap, Ersta Sköndal Bräcke högskola, e-mail: , telefon: . Dataskyddsombud på Ersta Sköndal Bräcke högskola är Klas Eriksson, e-mail: , telefon: . Om du är missnöjd med hur dina personuppgifter behandlas har du rätt att ge in klagomål till Datainspektionen, som är tillsynsmyndighet.

Resultatet av forskningen publiceras på svenska och engelska i olika tidskrifter och rapporter. Vi skriver inte om enskilda personer utan resultaten presenteras så att enskilda deltagare inte går att identifiera. Man kommer alltså inte att kunna se vad just du har berättat eller tyckt.

Om du vill fråga om något kan du kontakta någon av oss (se nedan)

Med Vänliga Hälsningar

Jenny Aspling
Doktorand
Telefon:XXXX
E-post:

Magnus Tideman
Professor
Telefon: XXX
E-post:

SAMTYCKE TILL DELTAGANDE I STUDIEN:

”Active Support ett arbetssätt för inflytande och ökad delaktighet för personer med intellektuell funktionsnedsättning på gruppbostäder”

Jag har fått information om ovan nämnda studie muntligt och skriftligt av en forskare från Ersta Sköndal Bräcke högskola. Jag har fått tillfälle att ställa frågor om studien och fått dessa besvarade.

Jag samtycker till att delta i studien.

Datum

Underskrift:

Namnförtydligande

.....

**Jag samtycker även till att intervjuer med mig spelas in
Jag har förklarat studiens uppläggning och syfte samt besvarat frågor.**

Datum

Forskarens underskrift

.....

Namnförtydligande

.....

Personen har fått Kodnummer:

Appendix 6. Checklist for providing feedback to staff after observations (translated to Swedish)

Checklista för att observera personcentrerat stöd

Kommunikation	Individuellt anpassat stöd	Anpassade stödassistenten sin kommunikation till hyresgästen? Förstod hyresgästen vad hen blev inbjuden att göra? Förstod hyresgästen vad som förväntades av henne/honom?
	Ledtrådar snarare än ord	Använde stödassistenten visuella ledtrådar som föremål eller bilder för att hjälpa personen att förstå? Använde stödassistenten tecken eller gester för att visa personen vad som förväntades?
	Uppmärksamhet	Uppmärksammade stödassistenten vad hyresgästen kommunicerade? Noterade hyresgästen kroppsspråk eller gester?
	Positivt språk	Undvek stödassistenten att säga nej? Försökte stödassistenten formulera svar så positivt som möjligt?
	Reducera distraktioner	Pratade stödassistenten för mycket under aktiviteten och distraherade hyresgästen och hindrade hans koncentration?
Omgivningsmiljö	Möjliggörande	Var miljön rätt för hyresgästen och aktiviteten? Var det för bullrigt? Var det för krävande (fysiskt eller socialt) För många stimuli?
	Anpassad miljö för personen	Passade miljön aktiviteten efter personens behov? Kan hyresgästen lätt nå föremål, material etc. som ska användas? Fanns det anpassningsbara hjälpmedel som kunde ha använts?

Förberedelse och preparation	”Setting the scene”	Tog stödassistenten tid att presentera allt material och aktiviteten noggrant? Var det tydligt vad aktiviteten skulle innebära? Visade stödassistenten steg för steg vad som skulle hända?
	Meningsfull och verklig	Var denna en verklig aktivitet som behöver göras eller som är meningsfull för hyresgästen? Speglade aktiviteten personens intressen och var meningsfull för hen?
	Organiserad	Hade stödassistenten förberett sig för aktiviteten? Fick hyresgästen alla nödvändiga föremål, material etc. som hen skulle behöva? Förberedde stödassistenten utrymmet så det var klart vad aktiviteten skulle vara?
	Respektfull	Var stödassistenten respektfull i allt samspel? Var stödassistenten för krävande eller tjtade hen på hyresgästen för mycket?
Små steg	Tillräckligt med stöd	Gav stödassistenten tillräckligt med rätt typ av stöd? Bröt stödassistenten upp uppgiften i tillräckligt små steg? Förväntades hyresgästen att göra för mycket av en uppgift på en gång?
	Säkerställer framgång	Gav stödassistenten personen tillräckligt med tid för att svara på förfrågningar eller inbjudningar? Gör stödassistenten det möjligt att ta en paus och fundera över alternativen? Var stödassistenten för angelägen om att slutföra uppgiften?
	Ge kontroll och självbestämmande	Lät stödassistenten hyresgästen ha kontroll över aktiviteten? Tog stödassistenten hänsyn till hyresgästens preferenser?

Stödassistent som observerades:

Observatör:

Gruppbestad:

Plats och aktivitet:

	Vad fungerade väl	Tankar att ta med sig till nästa gång
Kommunikation <ul style="list-style-type: none">• Anpassad till personen• Ledtrådar snarare än ord• Uppmärksamhet• Positivt språk• Minska distraktioner <i>Alternativa kommunikationsstrategier</i>		
Miljö <ul style="list-style-type: none">• Anpassad till personen• Möjliggörande		
Förberedelse och presentation <ul style="list-style-type: none">• Förbereda aktiviteten steg för steg• Meningsfull och verklig• Organiserad• Respektfull		
Små steg <ul style="list-style-type: none">• Bara tillräckligt med stöd (inte för mycket assistans)• Säkerställer framgång• Ge kontroll och verkliga val		

Svensk översättning från Every Moment Has Potential Person Centred Active Support Online Learning Resource © Commonwealth of Australia 2015

Papers

Thesis from Marie Cederschiöld University

Nr 1. Anna Holmqvist (2019). Integritet på undantag? En studie av barns röst i patientlagen och patientorganisationer.

Nr 2. Megan Weber Falk (2020). Development and Evaluation of the Grief and Communication Family support Intervention for Parentally Bereaved Families in Sweden.

Nr 3. Lilian Pohlkamp (2020). Bereaved mothers and fathers. Grief and psychological health 1 to 5 years after losing a child to cancer.

Nr 4. Bodil Holmberg (2020). Assisterad kroppslig omvårdnad i livets slut på vård och omsorgsboende. När kroppen inte räcker till.

Nr 5. Rakel Eklund (2020). Barns erfarenheter av ”The Family Talk Intervention”. Att leva med en svårt sjuk förälder som vårdas inom specialiserad palliativ hemsjukvård.

Nr 6. Filip Wollter (2020). The reasoning behind social work intervention design.

Nr 7. Elin Hjort (2020). Experiences of care and everyday life in a time of change for families in which a child has spinal muscular atrophy.

Nr 8. Hannes Rolf (2020). En fackförening för hemmen. Kollektiv mobilisering, organisering och maktkamp på hyresmarknaden i Stockholm och Göteborg 1875-1942.

Nr 9. Karin Robertsson (2021). Mellan civilsamhälle och folkrörelse. Ett aktörsperspektiv på rekrytering och organisering av medborgerligt engagemang.

Nr 10. Susanne Larsson (2021). Självbestämmande i LSS – en villkorad rättighet för personer med intellektuell funktionsnedsättning.

- Nr 11. Anna O'Sullivan (2021). Bereaved family members' VOICES of support and care during the last three months of life for people with advanced illness.
- Nr 12. Linnea Lundgren (2021). A Risk or a Resource? A Study of the Swedish State's Shifting Perception and Handling of Minority Religious Communities between 1952-2019.
- Nr 13. Anna Mankell (2021). Collective Patient Participation. Patient Voice and Civil Society Organization in Healthcare.
- Nr 14. Victoria Wallin (2022). Mealtimes in palliative care contexts. Perspectives of patients, partners and registered nurses.
- Nr 15. Therese Ydremark (2022). Efter flykten. En studie av civilsamhällets betydelser för deltagande och tillhörighet efter påtvingad migration.
- Nr 16. Rebecka Andersen (2022). I kvinnornas värld. Omsorg och tvång på uppfostringsanstalten Viebäckhemmen 1905–1947.
- Nr 17. Maria Norinder (2023). A person-centred approach to support family caregivers in specialised home care. The Carer Support Needs Assessment Tool Intervention.
- Nr 18. Sissela Odhnoff (2023). Mellan det förflutna och framtiden. En studie av Hyresgästföreningen på 2000-talet.
- Nr. 19. Ebba Henrekson (2023). Exceptions in the Swedish School System: Exploring the conditions facing secular and confessional nonprofit schools.
- Nr. 20. Liv Widing (2025). Mellan häst och behandlare. En kritisk granskning av hästunderstödd terapi vid ett HVB för sexuellt utsatta flickor.
- Nr. 21. Ingrid Thermaenius (2025). Implementering av familjeinterventionen The Family Talk Intervention när ett barn eller en förälder har en svår sjukdom. Hälso- och sjukvårdskuratorers perspektiv.

Active Support is an internationally well-known and researched staff practice in group homes for people with intellectual disabilities. However, the effects of Active Support have not yet been investigated in Sweden. Accordingly, in this interventional project, four group homes for people with intellectual disabilities in Sweden were followed longitudinally with a mixed-methods approach after implementing Active Support alongside Frontline Practice Leadership. The aim of this doctoral thesis was to investigate the effects of Active Support over two years in the group homes, in terms of quality of support, choice making, participation, and meaningful activities. The perspectives of service users, i.e. people living in the group homes, observations of interactions between staff and service users as well as interviews with managers were explored. The findings demonstrate that service users believed that their influence, emotional support, and choice making increased after staff received training in Active Support. The observations demonstrated a considerable improvement in quality of support in all four group homes, and the positive effects of Active Support were maintained for two years. However, it was important that Active Support was implemented alongside Frontline Practice Leadership and that practice leaders continued working with Active Support in regular feedback sessions as well as team meetings.

Jenny Aspling has extensive experience working with people with intellectual disabilities and autism, including ten years as a manager in group homes, day activity centres and centres for short term stays. Jenny holds a Bachelor of Social Science with a Major in Psychology and a Master of Public Health Epidemiology. She has been employed at Marie Cederschiöld University since 2020, where she has combined her PhD project with research in the disability field as well as teaching courses in Psychology and Disability Studies for students in social work. Marie Cederschiöld University offers a PhD programme within the field "The Individual in the Welfare Society". The area frames a field of knowledge in which both the individual in care and welfare, as well as societal interests and conditions, are accommodated. This is a doctoral thesis in Social Work.



ISSN 2003-3699

ISBN 978-91-985807-1-6

THESIS SERIES WITHIN THE FIELD
THE INDIVIDUAL IN THE WELFARE SOCIETY