

Learning from Persons with Profound Intellectual and Multiple Disabilities:

An Ethnographic Study Exploring Self-Determination
and Ethics of Professional Relations

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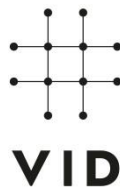
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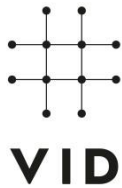
Synne Nese Skarsaune

Dissertation Submitted
in Partial Fulfilment of the Requirements
for the Degree of Philosophiae Doctor (Ph.D)

VID Specialized University

2023





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ISBN: 978-82-8456-043-4 e-version

ISSN: 2535-3071

Dissertation Series for the Degree of Philosophiae Doctor (Ph.D.) at VID Specialized University No. 52

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Cover: Dinamo

Printed in Norway: Totaltrykk, Oslo, 2023.

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To Julie and Johanne

Whose lives touched and affected those of us fortunate to know them.

Acknowledgements

I want to express my deepest gratitude to the people featured in this thesis: Vera, Karen, Erik, their families, and the professionals who allowed me into their lives. Learning about dependency and embodied being will forever influence my understanding of humans and relationships.

My excellent supervisors, Anita Gjermestad and Halvor Hanisch, have guided me with great care and knowledge. Anita's ability to facilitate others' growth and support my premature thoughts in modest and wise way, combined with Halvor's analytical gaze and high ambitions, always intending to stretch the project a little further — you make the best supervisor team. I have learned so much from you: how to navigate in theories, methods, ethical processes, writing, and how to cope when I get tired, to mention just a few—thank you so much. You have contributed highly to making the process positive, rewarding, and at times even filled with great humor, and always with lots of care.

The project has received valuable feedback and guidance from several others, and I am very grateful for the input at the midterm from Inga Bostad and Magdalene Thommasen, and Kristin Vindhol Evensen at the final seminar. The project is also very much indebted to my prior work experiences as a psychological-pedagogical consultant. The people I met and, not least, the collaboration with the gifted social educator Signy Refsnes, have been invaluable for the project.

The Centre of Diaconia and Professional Practice deserves my thanks for the scholarship and the way they have supported me during these years: Tormod Kleiven, Annett Leis-Peters, and James McGuirk for their good leadership, and Erlend Hovdkinn From for practical assistance. The fellowship with other scholars at the SDP program, and the opportunity to get to know some of you on a personal level and many on an academic level, have been inspiring. I want to thank my SDP colleagues at VID Stavanger: Kjersti Velde Helgøy, Marianne Sund and Kristina Høydal, for their support and care through the entire journey, and especially Anne Linn Midttun and Anna Chalachanovà for both collegial support and friendship. The excellent, funny, and hard-working colleagues who I share office space with: Kristin Husby Dyrstad, Karin Hakalax, Randi Skumsnes, Mari Refve Furuhaug, Medhat Youssef, Joanna Bauer, Hans Eskil Vigdel, and Bjarte Hatlebakk—the companionship with you have been much appreciated, especially when writing was tough.

Thanks to my colleagues at the University of Stavanger, Department of Early Childhood Education, for facilitating the combination of my teaching with writing this thesis.

My mother and father deserve thanks for always being interested and supportive. Thank you for being good role models of learning and academic curiosity.

My husband Erlend has contributed in so many ways. I want to thank you for being so engaged, reading drafts, and being an excellent and skilful discussion partner for my many unfinished philosophical thoughts. You have really contributed to pushing the project forward. Thanks for sharing, celebrating, and comforting me during the ups and downs of the project.

Finally, my children Sjur, Eirik, and Ragna—living life with all its great trivialities together with you have been the best source to keep this project on track, ensuring balance in life. I love you to the moon and back.

Synne Nese Skarsaune

Stavanger, 30.05.23

Abstract

Persons with profound intellectual and multiple disabilities (PIMD) are often excluded both from research and several areas of society. These people depend on others in all matters, relying on care that often involves professional services. There are challenges embedded in providing services for persons with PIMD, connected to embodied and dependent ways of being. For instance, abuse of power and ignorance can occur due to dependence on one from the other in the relationship, and also practices not ensuring the person's value as a human being. One basic demonstration of humanity is the entitlement to human rights. This thesis puts a lens on the human right to experience self-determination, recognizing that this right is often violated in the case of persons with PIMD. An exploration of self-determination is seen as an adequate entrance to broader questions regarding professional practices and how they should be conducted in the context of persons with PIMD. To explore such issues, the person with PIMD should be included, with knowledge grounded in their perspectives. This thesis seeks to shed light on the overall question: *What can we learn from persons with PIMD about self-determination and ethics in professional relations?*

An ethnography was chosen as method, involving observations of three persons with PIMD interacting with their care professionals, and focusing on the professional relationship. The data material consists of close observations, with the use of filming in some delimited situations, and interviews with the professionals and family. This study method is informed by phenomenological intents to stay close to the first-person perspective, engaging with embodied communication; elements from sensory ethnography and infant observation have thus been useful. The theoretical framework applied when engaging with the data consists of three philosophers: Kittay, Lindemann, and Stein.

The thesis' three articles explore the case of self-determination from three angles: the theoretical, practical, and methodological. Starting out with a psychological understanding of self-determination as the congruence between behaviour and one's preferences and values, the thesis suggests a theoretical rethinking of the concept, moving beyond the traditional understanding to involve independent choice-making. The ethnography suggests that self-determination unfolds within partnerships with the professional, engaging with self-determination as an ongoing process of being understood through one's embodied communication. Building upon this understanding, the thesis further explores how self-determination can be ensured and practiced within professional relations. It is suggested that, to facilitate another's self-determination, one must be able to hold that person in identity; this

involves professionals being capable of holding the other. To hold another is suggested possible through professionals being enabled to grasp the person's identity through embodied empathy and through involvement with the person. The thesis further explores how knowledge can be built in ways that value persons with PIMD as subjects of knowledge, exploring the possibilities in empathy. This is relevant both in the concrete case of ensuring self-determination but also, on a more general level, on how to include the perspective of persons with PIMD. It is argued that persons with PIMD hold competencies regarding embodied being and affective language, as well as ambiguous communication and dependency relations—all of which motivate the empathic process.

The thesis argues that self-determination must be understood as a profound and multiple phenomena, involving a broadening in understanding both on how meaning is communicated and understood and how the phenomenon is experienced. Self-determination can be communicated and understood through verbal and rational insights as well as through the embodied and non-rational, and can involve both independent choice-making and being understood within dependency relations. Such broadenings come with the implication that self-determination is made relevant for more people, including those dependent and portraying embodied ways of being. Further, it involves a messier concept, putting high demands on the professional, leading to a discussion on what can be learned from persons with PIMD about the ethics of professional relations. Departing from the ethnography, and moving into a dialogue with the theoretical framework, it is argued that ethics should be based on the particular and complex, rather than on the universal, and on notions of dependence and otherness, rather than independence, and the embodied and ambiguous rather than relying solely on the rational. As a contribution from this thesis, an ethics of holding is suggested as a way of meeting the comprehensive and demanding ethical task involved in caring for persons with PIMD—arguing for emotional holding, embodied holding, and holding-together. The thesis contributes with methodological attempts to move closer to the perspective of the person in question, applying methods sensitive to the epistemic resource of feelings when understanding the other. The study combines an optimistic understanding on the possibilities of relying on the immediate understanding of another's embodied communication, with sceptical notions of what is not understood. Suggestions through empathic understanding should not be taken for representing the 'truth', but hopefully it might motivate others to engage directly and learn from persons with PIMD. Such encounters can provide us with essentials relevant for understanding humanity.

Sammendrag

Personer med alvorlig grad av psykisk utviklingshemming blir ofte ekskludert fra forskning og mange områder i samfunnet. Dette er personer som er avhengig av andres omsorg og omfattende profesjonelle tjenester. Det er flere utfordringer med å skulle gi tjenester til personer med alvorlig grad av psykisk utviklingshemming, blant annet knyttet til kroppslig kommunikasjon og en dyp avhengighet av andre. Asymmetrien i relasjonen kan medføre utfordringer knyttet til maktmisbruk og uvitenhet. I ytterste konsekvens kan dette føre til krenkelser av menneskeverdet, eksempelvis knyttet til menneskerettigheter. Denne avhandlingen utforsker retten til å erfare selvbestemmelse, en rettighet som har vist seg utfordrende å realisere for personer med alvorlig grad av psykisk utviklingshemming. Å undersøke fenomenet selvbestemmelse er en relevant inngang til flere temaer knyttet til profesjonelle praksiser. Her bør personene det angår inkluderes – kunnskapen bør bli fundert på deres perspektiv. Denne avhandlingen tar utgangspunkt i det overordnede spørsmålet: *Hva kan vi lære av personer med alvorlig grad av psykisk utviklingshemming når det gjelder selvbestemmelse og etikk innenfor konteksten av profesjonelle relasjoner?*

Som forskningsmetode ble etnografi valgt, og bestod av observasjoner av tre personer med alvorlig grad av psykisk utviklingshemming i interaksjon med profesjonelle omsorgsgivere. Datamaterialet består av observasjoner, hvor utvalgte situasjoner også ble filmet, samt intervju med profesjonelle og familie. Studien informeres av fenomenologiske ambisjoner om å være tett på førstepersonsperspektiv, gjennom kroppslig kommunikasjon. Element fra metoden «Sensory ethnography» og «Infant observation» ble vurdert som nyttig. Det teoretiske rammeverket som er brukt i møte med data består av tre filosofer; Kittay, Lindemann, og Stein.

Avhandlingens tre artikler utforsker selvbestemmelse fra tre perspektiv; teoretisk, praktisk og metodisk. Det teoretiske aspektet tar utgangspunkt i en psykologisk forståelse av selvbestemmelse som å erfare kongruens mellom egen atferd og preferanser. Avhandlingen foreslår en nytenkning av konseptet, hvor en beveger seg videre fra en tradisjonell forståelse hvor selvbestemmelse forstås som å gjøre uavhengige valg. Det foreslås at selvbestemmelse utfoldes innenfor et partnerskap med den profesjonelle, gjennom pågående prosesser av å bli forstått med kroppslige kommunikasjon. Med utgangspunkt i en slik innsikt utforskes det videre hvordan selvbestemmelse kan bli lagt til rette for og praktisert innenfor profesjonelle relasjoner. Det blir foreslått at en må være i stand til å «holde den andres identitet». Dette innebærer profesjonelle som er i stand til å holde tak i den andre gjennom kroppslig empati

og involvering. Avhandlingen utforsker videre hvordan kunnskap kan skapes gjennom å anerkjenne personene som kunnskapssubjekt, ved hjelp av empati. Dette er relevant når det gjelder å sikre selvbestemmelse, men også mer generelt når det gjelder å inkludere perspektivet til personer med alvorlig grad av utviklingshemming. Det blir argumentert at personer med alvorlig utviklingshemming har kompetanser knyttet til kroppslig væremåte og affektivt språk, i tillegg til karakteristikk av tvetydig kommunikasjon og avhengighetsrelasjoner. Dette motiverer empatiske prosesser.

Avhandlingen argumenterer for at selvbestemmelse må bli forstått som både et dypt og mangfoldig fenomen. Dette innebærer en utvidelse av forståelse både når det gjelder hvordan mening blir kommunisert og forstått, og hvordan fenomenet blir erfart utfoldet. Selvbestemmelse kan kommuniseres og forstås både gjennom verbale og rasjonelle måter, men også gjennom kroppslige, ikke-rasjonelle tilnærminger. Dermed kan selvbestemmelse innebære både å gjøre uavhengige valg, men også å bli forstått innenfor relasjoner med avhengighet. En slik innsikt innebærer at selvbestemmelse blir relevant for flere, også personer som er avhengige av andre og som kommuniserer kroppslig. Videre innebærer en slik forståelse et mer uryddig konsept, med høye krav til profesjonelle som skal bidra til å fasilitere for selvbestemmelse. Dette bringer diskusjonen videre til hva en kan lære fra personer med alvorlig grad av utviklingshemming når det gjelder profesjonell etikk. Med utgangspunkt i etnografien, og i dialog med det teoretiske rammeverk, blir det argumentert for at etikk bør baseres på det partikulære og komplekse, heller enn det universelle, på antagelser om avhengighet og annenhet, heller enn på uavhengighet, og det kroppslige og tvetydige, heller enn å utelukkende stole på det rasjonelle. Som et bidrag fra denne avhandlingen blir en «ethics on holding» foreslått, som en måte å møte den omfattende omsorgsoppgaven og de etiske krav som følger fra møter med personer med alvorlig grad av utviklingshemming. Tilnærmingen foreslår tre måter viktige å «holde» den andre på: «emotional holding», «embodied holding» og «holding-together». Avhandlingen bidrar metodisk ved å utforske muligheter for å komme nærmere personene det gjelder, ved en sensitiv forståelse av erkjennelse fra følelser når en skal forstå den andre. Avhandlingen balanserer en optimistisk tiltro til forståelse av en annens kroppslige kommunikasjon, med mer skeptiske antagelser knyttet til det som en ikke kan forstå. Empatiske forståelser skal ikke bli forstått som å representere «sannheten», men kan forhåpentlig bidra til å motivere til å forholde seg direkte til personer med alvorlig utviklingshemming, og lære fra deres liv. I slike møter kan viktige elementer for å forstå det å være menneske finnes.

List of articles

Article 1: Published

Skarsaune, S.N, Hanisch, H.M & Gjermestad, A. (2021). Self-Determination: What can we Learn from Persons with Profound Intellectual and Multiple Disabilities? *Scandinavian Journal of Disability Research*, 23(1), 317-32. <https://doi.org/0.16993/sjdr.830>

Article 2: Published

Skarsaune, S.N. & Hanisch, H.M (2023). Holding and Professional Care – On Self-Determination for Persons with Profound Intellectual and Multiple Disabilities. *Research and Practice for Persons with Severe Disabilities*, 48 (1), 25-40. <https://doi.org/10.1177/1540796923115357>

Article 3: In review

Skarsaune, S. N. (2023b) Persons with Profound Intellectual and Multiple Disabilities as Subjects of Knowledge – Exploring the Possibilities of Empathy (Manuscript submitted for publication).

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CHAPTER 1: Introduction

'That which we believed we valued, what we – I – thought was at the center of humanity, the capacity for thought, for reason, was not it, not it at all'.

(Kittay, 1999/2020, p. 160)

The quotation from the American philosopher Eva Feder Kittay reveals her rising awareness upon humanity; the qualities that makes us human, after becoming mother to Sesha, a girl with significant cognitive and physical disabilities. Persons with profound intellectual and multiple disabilities, PIMD, depict lives that challenge ethical understanding, due to hallmarks of limited rational capacity, non-verbal ways of communicating, and a profound dependency— notions that might reduce a person's value as human. These are persons that risks exclusion both in research and on many arenas of society (Nind & Strnadova, 2020b). Professional care practices providing services to persons with PIMD might suffer shortcomings on how to ethically ensure humanity, e.g., through the realisation of the human right to experience self-determination (Vehmas & Mietola, 2021).

Kittay (1999/2020) indicates that humanity and moral value must be based on matters other than rationality. Although representing lives considered unlike most, persons with PIMD might be found to shed light on essentials of being human (Vorhaus, 2018), challenging philosophical presumptions of rationality and independence as what should constitute moral grounding for all (Carlson & Kittay, 2010). This thesis aims to explore what we can learn from persons with PIMD, starting with a practical ambition related to the question on how to understand and ensure the human right and need for self-determination for persons with PIMD within professional caring relations, moving onto philosophically-informed reflections on ethics and humanity.

Persons with PIMD are seldom included in knowledge production (de Haas et al., 2022; Gjermestad et al., 2023; Mietola et al., 2017), leading to the loss of knowledge that could be attained from their involvement (Skarsaune, 2023a). Several methodological challenges connected with inclusion have affected progress in the field (Maes et al., 2021), amongst others associated with issues of informed consent and validity. Therefore, the use of methods that are primarily based on significant others' views have dominated (Nind & Strnadova, 2020b), such as, e.g., the work of Talman et al. (2019), Axelsson et al. (2014b), or Voss et al. (2021). Such studies clearly contribute with important knowledge, letting family and/or staff close to the person with PIMD portray essentials, as they experience it. But there

is still a cavity in the field that lacks the perspectives of the person in regard. There are exceptions though, and this study leans on research that has aimed to ground knowledge more explicitly on the perspective of the persons with PIMD's lived life experiences through close observations, like Simmons and Watson (2015), Mietola et al. (2017), Stefánsdóttir et al. (2018), Haines (2017), and Evensen & Standal (2017). Embedded in such attempts, are also a reliance on supplements to the observations, e.g., interviews with significant others guiding interpretations to suggest what bodies are communicating. As such, 'perspective' is understood as somewhat mediated (Cluley, 2017), involving elements of interpretations and inferences (Ware, 2004). Although this is an understanding also informing this study, attempts are made to explore the possibilities of getting a more direct grasp on the other, reducing the element of interpretation and inferences, acknowledging persons with PIMD as individuals that can inform on matters regarding their lives. The concept, 'nothing about us, without us', has been important within the field of disability, and Oliver (2019) argues the significance of placing the experiences of disabled people at the centre of knowledge production. Can we stretch this aim to include even those with profound need for support who communicate in non-formal, non-verbal ways? Agreeing with Mercieca (2013) that it is through the lives of the persons with PIMD themselves that we can rethink and understand in new ways, this thesis attempts to ground knowledge on the perspective of persons with PIMD, recognising them as subjects of knowledge.

The initial outset of the study was the exploration of the phenomenon of *self-determination*, an entrance suitable to aid the exploration of persons with PIMD as the subject, due to the focus on grasping the person's perspective. Self-determination is argued for, both from a psychological outlook reasoning that all humans have a basic need to experience self-determination, and also through a human rights perspective. The Universal Declaration of Human Rights, article 1, declares that 'all humans are born free and equal in dignity and rights' (UN, 1948, p. 2). This involves the right to experience self-determination, a principle guiding the Convention on the Rights of Persons with Disabilities (UN, 2006) CRPD. Article 3 states 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of person' (p. 5). This right is fundamental because of its importance for well-being and quality of life. Not being met on this need might lead to 'lowered vitality, loss of volition, greater fragmentation, and diminished well-being', according to Ryan and Deci (2017, p. 86). Self-determination is thus a human right and an important need vital for quality of life and should apply to all humans. Practice, however, demonstrates that persons with disabilities are endangered of not having

this right realised (Skarstad, 2018). This endangerment is even more outspoken for persons with the most profound need for support (Kuld et al., 2023) and persons with PIMD have been devalued and assumed not able to experience or exercise self-determination (Voss et al., 2021; Watson, 2012).

In effect, there is this human right and need of self-determination, which is important to facilitate for. The question is: how can we go about securing it within the context of caring relations in ways that are proper for persons with profound needs for support? The professional caring relation is a highly ethical undertaking, and the thesis aims to contribute with knowledge relevant for practitioners, enhancing both understanding and practice when it comes to fostering possibilities for persons with PIMD to experience self-determination. Even with this practical outset, the questions at stake and the aim to include persons with PIMD as subjects of knowledge touches upon philosophical reflections regarding ethics and what should count as knowledge. The thesis is therefore indebted to thinkers raising such philosophical issues in connection to the context of persons with PIMD like Vorhaus (2014) and Kittay (2019), informing the attempt to combine practical ambitions with philosophy. The title of this thesis is a homage to Kittay's book 'Learning from my daughter' (2019).

1.1 Core elements of the study

Before concretising further research questions and design, a short introduction and clarification will be given regarding the three core elements of this study: namely persons with PIMD, self-determination, and professional care relations and ethics.

1.1.1 Persons with Profound Intellectual and Multiple Disabilities

To secure clarity of whom we are speaking of, a proper introduction is called for, starting with the characteristics of profound intellectual and multiple disabilities, PIMD. This labelling involves describing needs and impairments—a task not particularly comfortable, as Nind and Strnadova (2020b) also posit. Categories can be abused as stigmatic ways of defining persons. But at the same time, the field of knowledge is using descriptions in inconsequential ways, making it difficult to find the relevant knowledge. As this study aims to put the lens on a specific group of persons, and to prevent misunderstandings, it is thus important to state clearly who this study is about and for.

The terminology chosen is PIMD. This is preferred as it might be considered the terminology that travels best internationally. Persons with PIMD comprise a heterogenous

group, but they share the trait of having a profound intellectual disability in combination with other disabilities. The World Health Organisation classifies disorders of intellectual development in the International Classification of Diseases for Mortality and Morbidity Statistics, ICD – 11 (WHO, 2018). Under the category 6A00.2 Profound Disorder of Intellectual Development, it is described as intellectual functioning and adaptive behaviour approximately 4 or more standard deviations below the mean. It is further described that limited communication abilities and capacity for acquisition of academic skills is restricted to basic concrete skills. Co-occurring motor and sensory impairments are common, leading to the requirement of daily support. According to Nakken and Vlaskamp (2007) this understanding is often embedded in what is described as having profound intellectual and multiple disabilities, but often lacking clarity in the description of the variations and types of PIMD. They (Nakken & Vlaskamp, 2007) suggest a taxonomy that comprise the two key defining characteristics of limited intellect and physical functions, and in addition a multi-axial, model-based taxonomy that distinguishes visual and/or auditory impairments, other physical impairments, and mental health problems.

A similar term, persons with profound and multiple learning difficulties, PMLD, is much used in the UK (Nind & Strnadova, 2020b), and has several overlaps with the PIMD definition. PMLD underscores traits of extremely delayed intellectual and social functioning, limited ability to engage verbally, often requiring others to interpret communication intent, and frequently has an associated medical condition (Bellamy et al., 2010). There are also several other terminologies in use, involving different combinations of profound or severe disabilities, disabilities involving intellect, learning, senses or motor skills/functioning and complex needs (for an overview, see Nakken & Vlaskamp, 2007).

In addition to such understanding, this thesis also leans on writers recognising the many potentials, competencies, and capabilities that persons with PIMD possess (Brigg et al., 2016; Kittay, 2019; Vorhaus, 2021) as entrances of describing essentials. A person's competencies will thus be used as indications of their hallmarks, rather than merely deficits. This way of understanding disability coheres with the Nordic tradition of the social-relational model, where disability is understood as a mismatch between the individual's conditions and the environment, thus being sensitive of the capabilities of a person. Reindal (2008) describes the social-relational model as to recognise that disability is a contingent phenomenon imposed on the individual by social hindrances and restrictions on top of the social effects impairments may bring to the individual. The degree of disability might be reduced by facilitating and supporting the individual. The person-environment fit might also be framed within the social-

ecological model. This model acknowledges that each person has a unique profile of capabilities and limitations, and disability occurs at the interaction between the person and the environment. Of importance is thus to determine the support needed to enable the person to be successful in the environment (Shogren et al., 2018).

1.1.2 Self-determination

Self-determination for persons who are dependent might seem contradictory. Some initial reflections upon the concept of dependency are called for to position this thesis. Self-determination has traditionally been equated with self-endorsement, self-sufficiency, and independent choice-making (Kittay, 2019; Young, 2002). This has also been a focus when dealing with the concept within the field of disability, struggling to enhance independence and being allowed to be agents in one's own lives. Emerging in the 1960s the disability movement arose because of visible flaws in the post-war welfare states (Shakespeare, 2018), and calls for independence were crucial in counteracting paternalistic services. Movements like the Union of the Physically Impaired Against Segregation (UPIAS) and the Independent Living Movement Activists, and prominent activist like the disabled sociologist Michael Oliver lay out the social model of disability. This model argued that it is society that disables physically impaired people (Oliver, 1996). This stands in contrast to the medical model, arguing that disability is caused by biological deficits (Shakespeare, 2013). Several issues were at the agenda of the movement, and of utmost importance were equal opportunities and self-determination, e.g., through receiving services that one had control over. The principle of independent living argued that disabled people had the same needs as everyone else, but these were not met due to social barriers (Shakespeare, 2018). Embedded in the battles were a view that people with impairments were made dependent, in the same manners as they were made disabled (Kittay, 2019). By removing barriers, the goal of independence could be reached.

But some voices questioned this goal of independence, reflecting upon whether it was a sound one, or even possible. Some disability scholars have insisted that rather than battle independence, one should acknowledge the importance of human dependency. In this lies a critique of the social model, and its neglect of individual experiences (Shakespeare, 2013). As Kittay (2019) underscores, even when barriers are removed, some persons will still experience impairments and dependency. And of central relevance in Kittay's writing is the belief that dependency is not just merely to be seen as a burden or a problem, but rather as a positive human attribute facilitating for interaction and closeness (Kittay, 2019). Further, she argues that this dependency is not something relevant only for persons with profound need for

support, but also comes to show in different identifiable periods in life where our dependency is unavoidable and profound, as in the case of infancy, illness, disability, and dementia. As such, dependency should not be viewed as an exceptional circumstance, but rather as what constitutes our entire lives, through our interconnectedness. From this one might further argue that dependency must even be embedded in the concept of self-determination.

Such views can be found in relational approaches to the concept, e.g., as suggested by Mackenzie and Stoljar (2000), and even implemented in research regarding persons with PIMD (Stefánsdóttir et al., 2018). These approaches will be more thoroughly addressed in Chapter 3, addressing the theoretical framework. The concept of relational autonomy opposes fundamentally individualistic views, arguing that persons are socially embedded and that identities are formed within the context of social relationships. Such a view also informs the definition on self-determination that this thesis is grounded on, namely from Ryan and Deci (2017, p. 10) stating that the hallmark of the concept is that ‘behaviors are self-endorsed, or *congruent* with one’s authentic interests and values’.

1.1.3 Professional care relations and ethics

The context of the study is the relation between persons with PIMD and professional caregivers. Persons with PIMD live lives characterised by the ongoing need for support. Most often they receive services from a range of institutions and professionals; from school, daycentre, housing facilities, and healthcare to name a few. The services are further hallmarked by being intimate, as these are persons that needs support in everyday caring. The relations are characterised by asymmetry, i.e., the dependent depends on the carer and the carer does not reciprocate the dependency (Kittay, 2019). This does not mean that there are no dependencies on behalf of the carer, as the thesis will demonstrate, but rather that in the matter of surviving—the person with PIMD depends on the carer in ways not equal. The person dependent is only secure if the other chooses to provide for that person (Kittay, 2019). This thus serves to demonstrate the potential challenges embedded in caring relations, due to the aspect of power that exist in asymmetrical relations. Kittay (2019) argues that such asymmetry is part of the human condition, as we are not always equally situated and equally empowered. For persons with PIMD this condition is fortified, present throughout life, and where characteristics of having a profound intellectual disability might enhance potential vulnerability towards unjust and power abuse.

Professionals standing in such asymmetrical relations are involved in practices that engage with ethics, involving questions on how to act and how to manage the asymmetry and

power it comes with. Ethics is the scholarly study of morality (Lindemann, 2019), engaging with questions like ‘what is good?’ and ‘how should one act toward others?’ The landscape of ethics and moral philosophy is comprehensive and deals amongst others with normative aspects of what the structuring principles of an ethical system should be (Stout, 2008). Within caring professions, ethics are central, as the care provider represents work that is very important but also risky—the professional being able to influence the quality of life of the individual receiving services (Hugman, 2005). What norms and standards should be used to guide actions are questions that normative ethics undertake (Lindemann, 2019), questions also central in this thesis. The case of self-determination is viewed as an informative case, functioning as a litmus test regarding professional practices, highlighting essentials in the professional relationship, and perhaps being able to inform on ethics.

The empirical base for this project did not pre-define a specific professional context, but rather set out with a thought that relations might be experienced with the same characteristics of dependency cross contexts—the importance being the uniqueness of the relationship, rather than the specifics of a given professional context. The ethnography thus resulted in professionals from four different arenas: housing facility, school, daycentre, and leisure activities, all being caring professions. The aim of the thesis is to contribute with knowledge relevant for professionals engaged in relations with persons with PIMD, regardless of the professional context or educational background of the professional.

1.2 Aim, research question, and design

With this backdrop and the belief that persons with PIMD should be included in knowledge production, the aim of the thesis is to explore the following: *What can we learn from persons with PIMD on self-determination and ethics on professional relations?*

This overall aim has been guided by four research questions, addressing both the case of how to ensure the human right and need to experience self-determination and how this might further inform philosophical questions regarding ethics on professional relations. Regarding the case on self-determination: An exploration from three different angles were found necessary; including both how to understand the concept on a theoretical level (article 1), how to practically go about it within professional practices (article 2), and how to build knowledge on the topic (article 3).

Research questions:

- 1: How can the concept of self-determination for persons with PIMD be *understood* within the context of professional relations?
- 2: How can self-determination for persons with PIMD be *practiced* within professional relations?
- 3: How can *knowledge be built* on the topic in ways valuing persons with PIMD as subjects of knowledge?
- 4: How can the case of self-determination in the context of PIMD inform *ethics* on professional relations?

The articles comprising this thesis explicitly address the three first questions. Although the three entrances are at stake in all the articles, each of the articles nevertheless has a specific focus upon one of these questions, as indicated above. Research question 4 is more implicitly addressed in the articles and will be thoroughly undertaken in this extended introduction. Together, the four research questions all inform the thesis' main intent, contributing on both a practical and philosophical level—learning from the person in regard.

The research design developed to approach these different areas of inquiry is based on the intent to include the perspective of the persons in regard, namely the persons with PIMD. Ethnography is suggested as a fruitful way of including persons not able to contribute in formal, verbal ways (de Haas et al., 2022; Gjermestad et al., 2023). Through detailed, thick descriptions (Fetterman, 2020), it is argued that essentials of the persons in focus might come to show. In this thesis the attempt has been informed by phenomenology and its focus on the first-person perspective, and addressing the essentials of a phenomenon (Zahavi, 2019b).

1.3 Practical and philosophical implications for value-based professional practice

The study is a result of a call from the Centre of Diaconia and Professional Practice on the topic of professional practice and challenging professional relations. The professional relations under the lens in the current study comes with possibilities of power and violations due to the asymmetry, and the proposal is thus aiming to contribute with knowledge on relational competencies within the context of professional practice. Following the encouragement from the program, the questions at stake have been explored in close cooperation with professionals and citizens (Centre of Diaconia and Professional Practice, 2018).

As already touched upon, persons with PIMD are profoundly dependent upon the other in all aspects of life, thus putting a great responsibility on the professional, inflicting challenges of the relations. Furthermore, the non-verbal way of existing and communicating that hallmarks the lives of persons with PIMD further contributes to the experience of this being a challenging relation. The study is situated within practices that highlight issues regarding ethics and the human worth of persons that can be viewed in vulnerable situations, and as such relevant for the PhD Programme Diaconia, Values and Professional Practice.

The project started out in a practical landscape based on a view that persons with PIMD are potentially not treated as citizens with opportunities to be self-determined (Skarstad, 2018). The study has an integrated transformative worldview (Creswell & Creswell, 2018), due to its aim to enhance abilities for self-determination in everyday life. It further entails an ontological belief that researchers ought to uncover different versions of reality, and determine which version is most in accord with furthering human rights (Mertens et al., 2011). The study aims to contribute with knowledge that can inform an understanding of the phenomenon of self-determination capable of including persons with PIMD, which further might inform practices regarding how to facilitate self-determination. Such knowledge can be relevant for enhancing quality of life through suggesting ways to manage relations that are embedded with power, avoidance, and other implications that might come from the asymmetrical condition, thus underpinning the ethical dimensions of professional relations. The study has an outlook to suggest concrete ways of securing human rights regarding self-determination, and to unfold ethical guidance on the professional relations.

Further, the study aims to extend knowledge with novel ways of including persons with PIMD, both in research and in society. It is one of rather few studies that intend to present perspectives of the person and as such contribute with methodological innovations. Through the ethnographic material, suggestions on issues related to involvement of persons with PIMD in research, and furthermore, pointing to both methodological and epistemological implications of such efforts are attempted. The study thus touches upon philosophical questions like moral worth, humanity, and what meanings should be added weight when producing knowledge.

Even more, this is a case that represents an extreme, and as such, it might contribute to philosophy and ethics in general. The lives of persons with PIMD might be helpful in endeavours of challenging our 'commonsensical naivete' (Gallagher & Zahavi, 2021, p. 24). As Kittay (2019, p. 17) states, these are persons representing hard cases, and 'hard cases challenge philosophical dogmas'. It can be argued that if our moral reasoning does not meet

the claims coming from persons with PIMD, then it is not a complete moral theory. Vorhaus (2018) argue that the illumination on issues like humanity, dignity, dependency, citizenship—all relevant for the phenomenon of self-determination—from the perspective of persons with PIMD, can shed light on how we understand and value humans in general. Therefore, this study aims to contribute with a broadened scope on the phenomenon of self-determination and the valuing of positioning all persons as subjects. Embedded in the intent is the aim to explore what is of importance and centrality when dealing with questions of humanity, as Kittay (1999/2020) spurred us toward, at the start of this thesis.

1.4 My entrance into the field

Recognising that the ‘reality’ this thesis can contribute with is highly influenced by me as a researcher (Alvesson & Sköldberg, 2018) some brief reflections upon my own pre-conceptions and where I depart from are relevant, to be transparent on values guiding my perspective. My entrance into the field of disability and more specifically persons with PIMD was through working as a pedagogical-psychological counsellor in a community, providing services to persons with special needs within institutions of upbringing. In this work I collaborated with young persons with different learning needs, their staff in school or kindergarten, and their parents. The encounters with persons with the most profound needs for support were highly educational for me, both testing and enhancing my understandings of the possibilities for these persons to experience good lives. When I started as a teacher at the Bachelor’s programme for Social Educators at VID Specialized University, this understanding was further broadened, being exposed to research and welfare structures of health institutions providing services for persons with PIMD. Even though professional practices in Norway are guided by regulations stating the importance of including the perspective of the care-receiver in performing services, practice provided several demonstrations of challenges in the realisation of self-determination. Several dilemmas came to the fore when teaching students the importance of self-determination, both from theoretical entrances but even more so when discussing real-life experiences of students when having an internship period, often with experiences connected to difficulties in securing this right. Encounters with persons with PIMD made me aware of the important role of the professionals and the support needed to entitle these persons their citizenship (Vorhaus, 2018). Questions regarding moral worth were thus actualised in a profound sense. Being aware of attitudes in society arguing that these are persons not entitled of moral value, such actualizations were concretized in several of the experiences I had when visiting daycentres and housing facilities, experiencing that persons

with the most profound intellectual disabilities often were not included in efforts towards self-determination.

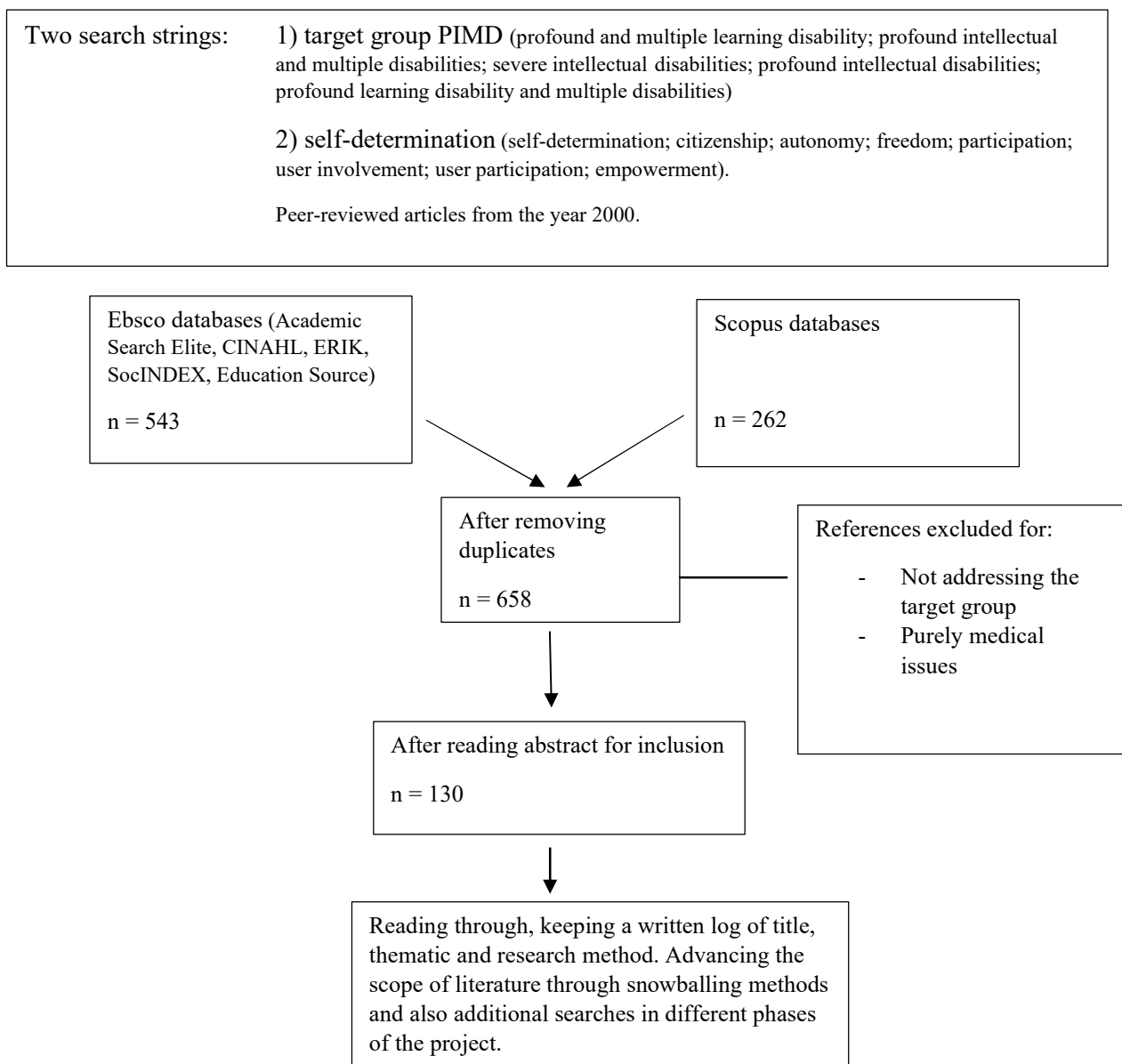
1.5 Overview of the thesis

In this introductory chapter, the rationale and purpose of the study has been outlined. In the following chapters I will go more in depth on the field of the study: self-determination for persons with PIMD within professional relations. In Chapter 2, the scene will be set regarding what this study is about. It starts with an outline of current research in the field, defining what we know and what is perhaps missing, and positioning the project. Chapter 3 introduces the main theoretical contributions, focusing on the theories of Kittay, Lindemann, and Stein. Their approaches will be briefly outlined and positioned. In Chapter 4, Methods, the different choices, and issues related to the ethnography and further analysis will be outlined. Findings are then presented in Chapter 5, consisting of a description of the main contributions from each of the three articles. Finally, in Chapter 6, the main findings are discussed and reflected upon regarding how they contribute to the main question at stake, the thesis as a whole, and relating to existing literature and research, stating what this thesis adds and its implications.

CHAPTER 2: Research informing the thesis

Before entering the theories and material that comprise this study, a contextualization regarding the scope of the study will be undertaken. This starts out in an outline of the current research within the field, contributing both with awareness on relevant research informing the study and identifying gaps that this thesis aims to contribute filling. An initial search was conducted at the start of the project (October 2019) aiming to get an overview of the topic on self-determination and persons with PIMD. Searches were conducted under guidance from the library service of VID.

Figure 1: Flow chart of the initial literature selection process



Additional searches were completed at several points during the project, including more sophisticated explorations, e.g., attempts to scope a broad picture of research on/with persons with PIMD and more specific topics like ethics and professional practice. The presentation that follows are based on the totality of searches, also including books, reports, and other grey literature found useful during the project.

Four main questions have been of guidance when reviewing the literature. The two first questions address an intention of getting an overview of the field of research regarding persons with PIMD, thus not solely excluded to self-determination, asking what the main research topics are, and how persons with PIMD have been included, or not included, in such research. The two last questions were directed more specifically to the topic of the thesis, asking how self-determination has been approached and understood in the context of PIMD, and what factors have been indicated as relevant for the facilitation of self-determination. Research touching upon ethical issues have been in focus throughout, primarily regarding two issues: ethics connected to inclusion of persons with PIMD in research, and ethical reflections regarding professional practices.

2.1 Main research topics regarding persons with PIMD

Persons with PIMD have traditionally been absent in disability research and are virtually missing from key theoretical and methodological discussions, as well as from empirical studies in the field (Vehmas & Mietola, 2021). Nind and Strnadova (2020b) describe how if they have been researched, there has been a tendency to focus on deficits and on the possibilities of fixing them. This traditional reporting can be argued to reflect a medicalised and objectified understanding of individuals with PIMD (Simmons & Watson, 2014). Knowledge though is expanding, representing more nuances, which will be indicated in the future sections.

A broad search on research regarding persons with PIMD, including both social science and medical databases from the last 10 years, generated a list of nearly 4,000 articles. Due to the amount, it was hard to read through each abstract, but rather the list of references was imported to EndNote and further searched. The following synthesised topics emerged as dominating the field: health, communication, family, activities, education and professional practices. The table underneath presents the topics with examples of a few of the most recent studies.

Table 1: Main research topics and example of studies

Research topic	Examples of studies	Focus
Health, physical	Zhao et al. (2022) Nishizawa et al. (2022)	Clinical and genetic features Syndromes
Health, mental	Vascelli et al. (2022) Damiani et al. (2020)	Reducing unwanted behaviour Mental diagnosis, e.g., autism
Communication	Rensfeldt Flink et al. (2022) Martin et al. (2022)	Communication strategies and effects
Family	Van Keer et al. (2022) Kruithof et al. (2021)	The need for support for families How family views the future care for their family member with PIMD
Activities	Kruse Gyldhof et al. (2022) Grace (2020) Wilson & MacDonald (2019) Van Delden et al. (2020)	How to engage in family activities The use of multisensory rooms Musical engagement Alertness; precondition for activity
Education	Peltomäki et al. (2021) Walker et al. (2022)	How to set individual goals Staff competencies
Professional Practices	Matérne & Holmefur (2022)	The important role of staff

Two comments to this table: Firstly, persons with PIMD have ‘complex’ healthcare needs (Simmons & Watson, 2014, p. 4), which contributes to the substantive focus upon such issues in research. A vast amount of the studies, nearly half of the results from this search, was generated from MEDLINE, involving studies addressing issues regarding physical and mental health. Secondly, there are overlaps in topics in several of the studies, e.g., studies on communication also informing on the topic of professional practices.

The topics generated might be argued to reflect dominant discourses on the lives of persons with PIMD. Even though this review does not represent a full overview, there are indications that there are rather few studies that take the person’s resources or potential as a point of departure, partly due to the vast number of health-based studies. There is thus a gap in the field researching capabilities, expanding the important work of, e.g., Brigg et al. (2016) exploring laughter and capabilities in children with PIMD or Vorhaus’ (2016; 2018; 2015) extensive writings on capabilities and dignity. Likewise, Nind and Strnadova (2020a) present

several pieces that push inclusion further, arguing for the place of persons with PIMD in education, research, and society, and thus constituting an important contribution on writings that emphasise potential rather than deficits.

2.2 Moving towards more inclusive attempts?

Nind and Strnadova (2020b) demonstrate that persons with PIMD have traditionally been researched via proxies. This is also the case for the majority of studies so far presented, relying on proxies, e.g., family or professionals reporting through interviews, surveys, or observations of a person with PIMD's behaviour to measure or validate effects of, e.g., training programmes. To build arguments on the perspective of persons with PIMD is challenging due to questions regarding research ethics and informed consent (Maes et al., 2020). Issues on consent are debated in several articles, and ways to include persons who are not able to give an informed consent are attempted. McClimens and Allmark (2011) argue the importance of detaching the notion of consent from ideas about autonomy and think instead of it to avoid wronging others. There are also others making strong cases for the importance of including this group, suggesting ways to do this in ethical manners (Boxall & Ralph, 2011; Cluley, 2017; Haines, 2017; Mietola et al., 2017).

Another objection regarding inclusion includes questions on validity: if we find ways to involve persons with PIMD, how can we argue that it is the person with PIMD's view that is portrayed if they communicate in embodied manners? It can be argued that embodied communication will always involve interpretations (Maes et al., 2021). Underlining the challenges of including persons with PIMD, Nind and Strnadova (2020b, p. 10) argue that, 'including people with profound intellectual disabilities in research is more likely to be research *on* rather than *by them*, but it can be *for them* and in some ways *with* them'. Several researchers now advocate the importance of including persons with PIMD in ways that make them more than objects (de Haas et al., 2022), arguing for research methodologies moving beyond individualistic approaches toward views stating that knowledge is co-created and situated (Simmons & Watson, 2015).

de Haas et al. (2022) reflect upon attempts to include persons with PIMD in research. They point to the use of ethnography as one key advance, where the use of non-verbal, non-symbolic language is recognized and accepted. Ethnography is also pointed to as fruitful by reviews on the topic pointing to possible knowledge contribution otherwise left unknown (Gjermestad et al., 2023; Skarsaune, 2023a). Research involving ethnographic or

observational data (Boahen, 2015; Evensen, 2018; Haines, 2017; Mercieca, 2013; Mietola et al., 2017; Stefánsdóttir et al., 2018; Watson et al., 2017) contributes with arguments that are built on the lived experiences of the persons in regard, thus pushing research toward a more inclusive approach.

There have also been other, important attempts to include the perspective of the person with PIMD, using creative methods like photo voice and video (Boxall & Ralph, 2011; Cluley, 2017; Warwick, 2020). These are approaches aiming to display lived life through the visual mode of photo/video, e.g., portraying pictures taken from the vantage point of the person with PIMD. In such attempts of ‘shifting the gaze’ the focus is upon participant control and making visible the experiences of people with PIMD, as the doctoral study of Warwick (2020) suggests.

All the mentioned studies supplemented data with the voice of significant others and proxies, underlining the importance of building knowledge upon several points of view. Cluley (2017, p. 41) describes it as ‘mediated approach’, involving that persons with PIMD need the support from others to survive, thus living mediated lives. What is important in several of the studies though, is that the significant other’s voices were not taken as an absolute representation of the views of PIMD, but rather an addition, offering further details. This is argued for, e.g., in the study of Watson (2020), stating that the interviews are not to be viewed as proxy interviews but rather providing confirmation on what was observed. Still, the research is demonstrating a reluctance, perhaps necessary, to rely solely on the attempts to grasp the person with PIMD directly.

2.3. Approaches to self-determination in the context of PIMD

Even though the knowledgebase on self-determination and disability in general has expanded in line with historical changes, emphasising the right to self-determination for persons with disability (Stancliffe et al., 2020) the focus has, for the most part, not been on persons with PIMD but rather including persons with disability that can communicate verbally. There are exceptions though, and this section will synthesise relevant literature, displaying different understandings and approaches on the phenomenon in the context of PIMD, and providing examples of studies.

Table 2: Different takes on self-determination and examples of studies

Self-determination explored as:	Example of studies:	Description:
Independence and choice-making	Cannella-Malone & Sabielny (2020) Lancioni et al. (2018) Ivy et al. (2018) Benford (2017)	Supporting choice-making Microswitch technology in choice-making Enhance independence through graduated guidance Enhancing independence through mobility
An element of quality of life, QOL	Niewenhuijse et al. (2022)	The capability to influence environment
Participation	Talman (2018) Axelsson et al. (2014a) Hanzen et al. (2017)	Suggesting strategies for participation, involving choice-making Underlining autonomy in participation
Supported decision making	Arnstein-Kerslake et al. (2017) Watson (2012, 2016)	Broadening the scope beyond individual choice-making, including support systems
Relational autonomy	Stefánsdóttir et al. (2018)	The relational aspect in choice-making (building on the conceptualization of Mackenzie and Stoljar, 2000)

As indicated in Table 2 there is great focus on independence and choice-making. This is also confirmed through recent reviews regarding self-determination: Alsaeed et al. (2023) demonstrates how self-determination is connected with choice-making, decision-making, goal-setting and self-monitoring, when exploring interventions to promote self-determination for students with extensive support needs, while the systematic review conducted by Kuld et al. (2023) concludes that most studies on self-determination focused on choice making and independence, disregarding the influence that relationships between significant others and people with severe or profound intellectual disability have on self-determination. Such an

understanding of the concept underlines that the act of making a choice is further connected to having control. However, Wehmeyer (2005), who wrote on the topic regarding persons with severe disabilities, argues that control, understood as having absolute control in our lives, does not capture the intention of self-determination and that a rethinking of the concept is necessary.

Hence, there is a move in understanding, arguing that this should not involve merely independent choice-making, but also embed relational understanding, e.g., through supported decision-making. This is an approach evolving from the demands of Article 12 (Equal Recognition before the Law) in the CRPD, where the core is that people with cognitive disability have access to assistance for decision-making in a legal manner. The approach has generated systematic attempts to replace a substitute model of decision-making, amongst others implemented in Canada, the United Kingdom, Sweden, and Australia (Watson, 2016). In Norway there is yet to be a system implemented for this, but it is explored by the Independent Living Movement, Uloba (n.d.). Within this conceptualisation is embedded a view that decisions are made within relations.

Leaning on the understanding that self-determination involves the experience of congruence in life (Ryan & Deci, 2017), a further rethinking of the phenomenon of self-determination, perhaps moving beyond independence and choice-making is possible. Such explorations might be fuelled by writers extending the understanding of persons with PIMD, like that of Simmons and Watson (2015). They do not engage directly with self-determination, but still provide valuable insights on the related concept of *agency*. Like the relational concepts on autonomy, Simmons and Watson (2015) argue that to understand agency, and in particular voice, we must move beyond individualistic approaches and rather understand it as something that comes into being through relationships. Another related concept is that of *citizenship*, which is a concept Vorhaus (2016) engages with. He describes the need to move beyond understandings connected to political decision-making, and rather to be understood by who you are and hence your communication. He leans amongst others on the writings of Kittay (2019), who theorises *personhood*. Determining who is entitled to personhood has implications for whom we give the moral value to be citizens, and hence who is treated as subjects entitled to the fulfilment of human rights, e.g., the right to be self-determined. Kittay (2019) demonstrates how it is our relational co-existence that grounds our moral worth. These writers all share that they approach the matter from the field of philosophy, focusing upon ethical ways to understand persons with PIMD.

2.4 Relational factors relevant for self-determination

In this thesis, the context of inquiry is set to the relationship between professionals and the person with PIMD and essentials of this relationship that might be found to foster self-determination. The importance of close relationships for persons with high support needs are well-documented (Hostyn & Maes, 2009; Mansell, 2010), and in this section examples of studies exploring relational factors connected to attitudes and competencies relevant for self-determination will be presented. This is not to an exhaustive list but serves to demonstrate a scope of relational factors.

Table 3: Examples of studies exploring relational factors

Studies	Relational factors
Hanzen et al. (2021)	Professional attitude regarding participation
Bigby et al. (2009)	Professional attitude affecting opportunities of self-determination
Voss et al. (2021)	Negative perceptions leading to limited opportunities for decision-making
Hostyn & Maes (2013)	Relational skills in interaction, the value of video analysis for practitioners
Forster & Iacono (2014)	Relational skill regarding affect attunement
Watson et al. (2017)	Communicative skills; responsiveness
Greathhead et al. (2016)	Communicative skills: recognizing communication bids
Kantor (2020)	Relational/communicative skills: through music
Embregts et al. (2020)	Relational skills: using technology to enhance alertness
Nagra et al. (2017)	Relational/communication skills: through the method of Intensive Interaction
Koski et al. (2010)	Communicative skills: through the method of OIVA; Communication training
Beadle-Brown et al. (2012)	Relational skills: through the method of Active Support

The attitude and skills connected to strategies on relations and communication as suggested above, are all relevant informing professional ethics, and some studies explore this field more explicitly. The ethical dimension of the relationship is highlighted, and ethics of

care has been argued as an entrance to, e.g., secure transitions (Jacobs et al., 2021). In a similar vein, Wilson et al. (2008) suggest that professionals should lean on an ethical framework accommodating the relational aspect of practice. Ethics within professional care is also touched upon in a study from Nieuwenhuijse et al. (2022) regarding professionals' perspectives regarding good or poor quality of life, QOL. One area of specific ethical concern is end of life decisions for persons profoundly disabled. Zaal-Schuller et al. (2018) studied nurses' experiences of being included in such decisions, demonstrating moral distress if not. Voss et al. (2021) explored practitioners' perspectives and practices and found that more training is needed, particularly in involving the persons with PIMD in the decisions.

There is thus a body of literature highlighting the importance of staff's attitudes and competencies, and some of them also touch upon what this ought to be, e.g., the importance of positive expectations, responsiveness, and sensitive communication skills. Still, research indicates a scarcity of knowledge on how to practically go about ensuring the proper support to enable self-determination (Nicholson et al., 2021; Vehmas & Mietola, 2021). Even more so, much of the reported studies focus on the perspectives of the professionals, demonstrating a void in how to understand the delicate and intimate relations from the perspectives of the person with PIMD.

2.5 Positioning the project

The review indicates that the topic on self-determination for persons with PIMD is rather unexplored, at least beyond the scope of independence and choice making (Kuld et al., 2023). Several of the included articles in this review are approaches that indirectly touch upon the phenomenon through related concepts of independence, participation, and quality of life. Research further indicates that both professionals' attitudes and competencies influence the possibilities of self-determination for persons with PIMD, and that there is a need to further explore specifics on how professionals might support the person in this regard. So far, the professional relations have mainly been explored through the perspectives of the professionals, indicating a lack in knowledge on details in the relationships departing from the person with PIMD. Leaning on promising attempts of including these suggest the importance of bringing the field forward by exploring ways of including persons with PIMD in research and not rely solely on proxies.

Implicit in the research questions guiding the current study is an expectation that the phenomenon of self-determination might be explored in an extensive way, if we allow the lived experiences of the persons with PIMD in relation with professionals informing our

understanding. With this also comes the ethical dimension exigent to explore, regarding humanity and what we put at the centre for moral worth, through the case of persons with PIMD.

CHAPTER 3: Theoretical framework

The thesis leans on a theoretical framework, and a description on how the theoretical field was approached in the initial phase and how theories emerged during the project will now be undertaken. A clarification of the choices I made will be given, starting with a brief description of main concepts and themes found essential in an exploration of self-determination within the context of professional relations. A brief situating of the theoretical lenses applied to illuminate the themes will be provided, along with how the theories might overlap and diverge from each other, and how this project can be placed within these.

3.1 Preconceptions and theories guiding in the initial phase

In the initial phase of the project, I was informed by preconceptions that can be linked to certain perspectives, namely that persons with PIMD have moral worth and should be valued as subjects, and that self-determination is possible for persons also profoundly dependent. These assumptions are guided by theoretical lenses that will be shortly addressed, namely from philosophers arguing the moral worth of persons with PIMD, like Kittay (2019), Curtis and Vehmas (2021), and Vorhaus (2018), and that self-determination can be understood within a relational perspective, an argument departing from Ryan and Deci (2017).

3.1.1 On moral worth

Explicit in this project is the view that persons with PIMD have moral worth and that human rights regarding, e.g., self-determination also concern people experiencing profound dependency due to intellectual disabilities. This is a view that moral individualist will oppose, e.g., illustrated by the writings of McMahan (2010). He argues that to have moral worth necessitates a threshold of cognitive capacities, which he finds lacking in persons with PIMD. McMahan (2010) compares persons with profound intellectual disabilities with animals and argues that they hold no higher value than pigs. This thesis starts out in notions opposing such views, being guided by a thought that persons with PIMD are owed the same moral value as all humans.

Such view can be argued through different philosophical positions. Kittay (2005) is one proponent arguing that psychological capacities as rationality and autonomy are not to be deemed as requisites for the moral consideration of personhood. What is determining a person's moral value is rather connected to our relational essentials. She applies the rhetorics

of ‘being some mother’s child’ (Kittay, 2020, p. 30), a trait that includes all humans, as what should count as determining a personhood. Another line of argument is suggested by Curtis and Vehmas (2021). They initially started out within a relational argumentation (Vehmas & Curtis, 2017), inspired by Kittay, but have come to find that this is not sufficient to explain personhood (Curtis & Vehmas, 2021). Their argument builds on the following: if an individual’s moral status is entirely constituted by the holding of certain relations, then if those relations were to fail, that individual would not have a moral status and thus it does not provide a solid argument for moral worth (Curtis & Vehmas, 2021). Likewise, they argue, moral individualism fails to identify an intrinsic property possessed by humans with PIMD that explains why they have a moral status equal to non-disabled humans. They suggest combining the two approaches, searching for an intrinsic property possessed by all humans that has a relational significance. This would lean on the argument that being a person is an intrinsic property that all humans have and also implies a relational moral significance that should appeal to us to care. Those persons experiencing some existential loss should be treated with utmost respect, and as having a moral status equal to all humans (Curtis & Vehmas, 2021). Also, Vorhaus (2018) writes extensively on the moral value of persons with profound intellectual disabilities, departing from a position underlining relationship, as Kittay also argues, although not in the exact same way. He applies an argument based on the co-membership of the human species and a sense of fellow creatureliness as providing grounds for why human beings might be especially concerned with other human beings, not excluding the most profoundly impaired human beings. He argues that any account of why profoundly disabled people are owed respect will have to supplement discussions of their particular capacities with a normative account of their humanity (Vorhaus, 2021).

In this thesis, I lean on such sensitive attempts to move beyond moral individualism and the belief that humanity is not to be understood or constituted through rationality. Whether the philosophical argument is based upon relational aspects, some intrinsic capacities, or normative assumptions on humanity, this thesis departs in a view that these are persons who should be treated as moral subjects, aiming to explore how this might unfold within professional caring relations.

3.1.2 On self-determination

A dictionary definition on self-determination (‘self-determination’, n.d.) points to the power and capacity to act independently, and synonyms might include herein autonomy, self-reliance, or self-sufficiency. Autonomy is equated with liberty, freedom of will, individuality

and independence, and Agich (2003) points to how this traditionally has involved independence of action, speech, and thought. Mackenzie (2019) describes how a libertarian autonomy concept underlines maximal choice and non-interference. As described in the former, such understandings, highlighting the individual choice-making, has informed much research on the topic and embossed understanding in both philosophy and politics. As already demonstrated, the CRPD (UN, 2006) uses phrases like ‘individual autonomy’, ‘freedom to make choices’, and ‘independence’, thus contributing to the rationale that all humans strive toward independence. Self-determination is also linked to decision-making, and in political documents is equalised with the right to choose, e.g., where to live, and how to receive help, which are matters that might be described as important, big life-choices. For persons with PIMD, such decisions are hard to make, as they lack the ability to vocalise their view. As such, much of the written policies and strivings for persons with intellectual disabilities comes forward as of little relevance to persons with PIMD, thus excluding them from the debate (Dowling et al., 2019).

This thesis starts out in a belief that persons with PIMD can be self-determined, but perhaps in ways challenging the dominant view on self-determination. I base this assumption on psychological theorisations upon self-determination, rather than political documents, and primarily on the psychological theory of Ryan and Deci (2017) arguing that to be self-determined is to experience congruence, that life is in harmony with one’s own preferences and values. This psychological viewpoint allows for a broadened and nuanced view on the matter. Ryan and Deci (2017) also lean on other theories, such as those from Stoljar and Mackenzie (2000) and their view on relational autonomy to propose a view on self-determination as something that unfolds within relations. Ryan and Deci (2017, p. 57) state that the idea of the fully ‘independent person’ is largely mythical, and that the social context is of utmost importance.

Although the thesis leans on understandings from psychology, I am also informed by research located within the field of supported decision making (Watson, 2012) or the more overall discourse on citizenship (Vorhaus, 2018), providing important notions on respectively legal and philosophical matters regarding self-determination. The reason, though, for choosing to situate the project within the psychological terminology of self-determination is that it is found to move beyond political rights and focusing on the human need to be self-determined. This is experienced to enhance the possibility to get close to the life of persons with PIMD, as the right-based language is not fully appropriate to scope the nature of being that persons with PIMD represents. With the starting point in Ryan and Deci (2017) comes an

attempt to open understandings beyond a legal engagement, and the concept of experiencing congruence in life is the understanding of self-determination that I brought into fieldwork, influencing my gaze.

3.2. Approaching the theoretical field abductively

Within the philosophy of science there exists different ways of explaining and understanding a phenomenon, where the tradition of induction and deduction is a common division, with the former departing from empirical data and the latter in theory. This project is found to fit better within an abductive approach, defined as starting from an empirical basis, but still not rejecting theoretical conceptions (Alvesson & Sköldbberg, 2018).

How this abductive approach has been applied on the ethnography and its aim to get close to the subjective, first-person perspective, will be more thoroughly argued for in chapter 4 on Methods, through a phenomenological view on the philosophy of science. In this chapter, though, there is a need to briefly clarify the project's application of phenomenology and more specifically the understanding on the epoche, as it influences the view upon theories. Husserl (1950/1970b) introduced the concept of epoche, i.e., the bracketing or suspension of the natural attitude to avoid naivety. In the epoche lies an understanding that one can neutralize all dogmatic attitude held through theories (Gallagher & Zahavi, 2021). So how should we understand the epoche? I have already demonstrated the theories that guided this project in the initial phase, does this make the project non-phenomenological? There are different understandings on the matter, and this thesis depends on the argument of Zahavi (2021) stating that while Husserl (1950/1970b) was dealing with philosophical endeavors, those who seek to use phenomenological ideas in a non-philosophical context, do not have to employ the epoche to qualify their work as phenomenological. Zahavi argues that it will be counterproductive if researchers are to be prohibited from employing important notions from their field of study (Zahavi, 2021). Following the abductive intent of letting the ethnography steer exploration, the abductive approach was thus applied, one that resembles Finlay's exploration of the nature of 'the phenomenological attitude' (Finlay, 2008, p. 2), described as sliding between bracketing pre-understandings and exploiting them as source of insights.

After engaging with fieldwork, inspired by phenomenological approaches highlighting the possibilities in building research on the phenomenological conceptual framework (Fernandez, 2020), leaning on essential phenomenological features of the lifeworld (Finlay, 1999), the exploration of self-determination was found to involve reflection upon three

essentials: Notions on *self*, *being in the world*, and *being in relation to others*. A brief introduction of these will be given, leading up to what ended up as the thesis' main theoretical framework by the philosophers Eva Feder Kittay (2019), Hilde Lindemann (2016), and Edith Stein (1989).

3.2.1 Self

The aim of detecting what someone intends or wants through the concept of self-determination must reflect some thoughts on the concept of self. Identity is a concept that is intertwined with self, and I found identity relevant to explore after participating in the field, where the professionals and family led the focus to questions evolving around 'who is this person'. Agich (2003) argues that self-determination is primarily about being understood on one's identity. To experience a life in harmony with one's own preferences involves being understood on one's identity.

There are different views upon 'self' and 'identity', and the position one take might have implications on how to understand and meet another person regarding self-determination. Gallagher and Zahavi (2021) present three different notions: self as a pure identity pole; as a narrative construction; and as an experiential dimension. The first, self as a pure identity pole, is described as experiencing different experiences, like tasting a drink, or admiring a painting. These are different experiences, but they all have the same subject, and they are all lived through the same self, me. We can infer that it exists, but it is not itself something experiential (Gallagher & Zahavi, 2021). Self as a narrative construction, in contrast to the former, views self as constructed in and through self-interpretations. This account is one that also stresses the social dimension of selfhood, whereby who we are depends upon the story we and others state about ourselves (Gallagher & Zahavi, 2021). Some advocate the importance of understanding self as comprehended through relation to others; close relationships thus being central to the sense of self (Markus & Kitayama, 1991). The experiential dimension is one that classical phenomenologists defend, arguing that there must be some experience-based notions on selfhood linked to self-consciousness. The self is an intrinsic aspect of an embodied agent engaged in the world (Gallagher & Zahavi, 2021). Zahavi is one that argues that even though selfhood is partly socially constructed, a more multifaceted view is called for, pointing to the need to embed the experiential element (Zahavi, 2016).

Moving from the philosophical take on the self towards a more psychological

understanding, Ryan and Deci (2017) argue that self and identities represent the concepts that people hold about themselves. Further, they state that identity is something that needs support from others, e.g. from parents in the formative years, thus highlighting the relational aspect (Ryan & Deci, 2017). Within the many different psychological positions on self, Ryan and Deci (2017) are positioned within the view of self-as-process, i.e., that self is phenomenally experienced as both a centre of experience and as the initiator and regulator of volitional behaviour (Ryan & Deci, 2017). This is a view highly influenced by phenomenology, arguing that self is not an object to be perceived, but rather an ‘active and agentic being-in-the-world’ (Ryan & Deci, 2017, p. 53).

Without getting lost in philosophical and psychological theories on the concept of self, the ethnography indicates a multifaceted view. Persons with PIMD exist and develop in close cooperation and relationship with others, thus advocating views upon self that incorporates a phenomenological understanding underlining the experiential self but also the relational aspects, demonstrating an unfolding within caring relations with others. In this lies a reliance on both self as linked to the basic structures of experience and self as linked to sociality (Gallagher & Zahavi, 2021). As will be demonstrated, the theoretical framework of this thesis is based on relational understandings of humans, rather than individualistic, and this also goes for the concept of self.

3.2.2 Being in this world

Persons with PIMD represent a heterogenous group, but one of the specifics shared is the trait that they communicate and exist in ways where formal, symbolic language is not in use, but rather their bodies are. This representing a way of being that might challenge the environment on how to understand intentions. The embodied being and efforts to understand is one that is predominant in the ethnographic material, and I found it fruitful to apply theoretical lenses, which contribute with resources regarding how this might be grasped and accounted for.

As a backdrop, a brief outline of the mind and body debate within philosophy, which refers to how to understand a subject, is thus called for. Are we primarily a reflective, subjective mind within an objective body, or are the two intertwined? Traditionally, there has been a view that mind and body are fundamentally different substances. This is proposed within a Cartesian dualistic tradition, reasoning that the nature of mind and body are completely different from one another and could each exist by itself (Skirry, 2005). In this lies

a reliance on the mind, underlining the rational aspect of human beings. Knowledge of reality is hence derived from ideas of the intellect, not the external senses. Through phenomenology, an alternative approach was suggested, clearly stated by Merleau-Ponty and the phenomenology of the body. He argues that our knowledge of the world is corporeal, rather than intellectual. We know the world bodily and through our embodied actions (Merleau-Ponty, 1962/1998).

Phenomenology has provided us with some essentials regarding how to understand this embodied being, amongst others through the distinction between ‘Leib’ and ‘Körper’, translated to the lived and corporeal body. In short, the lived body is connected to the experiences from the first-person and might be associated with subjectivity, whilst the corporeal body is associated with objectivity, and the body as experienced through a third-person perspective (Fernandez, 2020). Zahavi (2020) argues that the phenomenological theoretical framework, including core concepts of, e.g., embodiment, can enhance researchers and professional practices by being concerned with the life situation of the concrete person, attending to their lived and corporeal body.

Despite suggestions of phenomenology, there is still a strong reliance on the rational, favouring the verbal, thus making the embodied ways of being less relevant in debates—or at least more challenging to approach. I thus found it fruitful to lean on theoreticians who might substantiate and argue embodied ways of being to make that knowledge count. The aim would be that the theoretical framework, which dialogues with the ethnographic material, might feed the phenomenological theoretical framework with demonstrations from lived experiences.

3.2.3 Being in relations with others

Husserl (1970a, p. 108) gave us the concept of intersubjectivity, and he argues that each ‘I-the-man and all of us together, belong to the world as living with one another in the world; and the world is our world, valid for our consciousness as existing precisely through this living together’. We are beings in relations with others.

But despite this, to be independent is a virtue we grow up to value, at least within many Western societies. Mackenzie and Stoljar (2000) describe how the focus upon individual autonomy has come to occupy a central, if contested, place in both moral and political philosophy, as also demonstrated in the Introductory chapter.

Such thoughts, although important in counteracting imposed dependencies (Shakespeare, 2018), still do not seem relevant in regard to persons with PIMD. The

ethnographic testimonies from the study described existence as unfolded through interconnections with others, whereby striving towards independence seemed futile. The persons with PIMD exist in close interaction with other, e.g., their professional caretakers. Reindal (1999) proposes that we, rather than using the independence-dependence dichotomy, instead should understand the human condition as interdependencies, and that independence is not a matter for individualization but partnership. From a feminist tradition, I find the concept of relational autonomy (MacKenzie & Stoljar, 2000) relevant, involving a view that persons are socially embedded, meaning that identities are formed within the context of social relationships. We are formed and exist together (Mackenzie, 2019).

In the case of persons with PIMD, dependency will prevail no matter what modifications of the social and physical environments are done; hence, theories that can incorporate this view on humans as utterly dependent are thus called for. Further, inherent in such views are the embedded sociality of all humans. Within phenomenology, this is suggested through the concept of intersubjectivity, and where Husserl advocates that the personal 'I' has its origin in social life (Zahavi, 2016). Within the thematic of being in relations with others, the ethnography suggests the need for theories exploring how one might intersubjectively grasp the other.

3.3 Philosophical guidance

Staying close to the ethnographic data, although being aware of preconceptions and underlying theoretical assumptions, the suggested essentials called for a theoretical framework able to enlighten regarding matters of a self that entails notions on relations, that being in the world is embodied and that we exist in intersubjective relations with others, it shapes our identity. These are aspects that I argue can be found in the contributing theories of Kittay (2019), Lindemann (2014), and Stein (1989), although from different points of view. A positioning of the three philosophers and some highlights from the theories guiding this thesis will be given.

3.3.1 Eva Feder Kittay on dependency

Kittay is an American professor in philosophy. Born in 1946 in the shadow of the Holocaust, she describes how she first desired to approach the philosophical domain because she wanted to know if one could be a good person in an evil world, thus motivated by an ethical impulse (Kittay, 2019). She did not pursue this question at once, but rather entered the

discipline of philosophy of language (see, e.g., Kittay, 1987). Before starting her philosophical education, she gave birth to Sessa, a girl diagnosed as severely intellectually disabled. Kittay describes how, after several years of denial and suppressing the growing understanding of all that her daughter's life could not become, she became determined to explore philosophy from the point of departure of her daughter, the most recent result being the book *'Learning from My Daughter'* (Kittay, 2019).

Her earlier book *'Love's Labor'* (Kittay, 1999, republished in a second edition 2020) received international attention, and from that point onward her writing was situated within disability, focusing upon issues like moral worth, within the framework of an ethics of care. Ethics of care is a feminist approach to ethics, and Kittay's writing is positioned within such traditions, inspired by thinkers like Gilligan (1982) and Noddings (2013). Moral reasoning had long been based on a rational-cognitive approach (Noddings, 2013) and Gilligan (1982) demonstrated how this, e.g., was the approach that informed Kohlberg's theory on moral development. Gilligan argued against this, stating that it was lacking a different perspective, a different voice, one arguing that relations are what steer our moral judgment (Gilligan 1982). Moral decisions require strategies that aim to maintain relational ties where possible, rather than a deductive employment of general principles (Meyers & Kittay, 1987). Kittay describes how care as a moral value is not new, but the argument that care requires articulation as an ethical perspective is (Kittay, 2019).

One of Kittay's important contributions, highly relevant for this thesis, is her explication of dependency, unfolded as a human condition. Instead of trying to avoid dependency, one should rather recognize it, manage it, and value it as something that can nurture strong relationships (Kittay, 2019). In a complex society, we all depend on others in some way or another, for instance for getting food or mobility, or as demonstrated through pandemics or a war in Europe—all showing how interconnected we are. There are periods in life that bring about more intimate aspects of dependency, e.g., in infancy or if becoming a frail elderly person, when needing care in more profound ways—perhaps as demonstrated the greatest by the lives of persons with PIMD—underlining the phenomenon of interdependency (Kittay, 1999/2020). And this human condition of dependency is what constitutes a ground of our moral world (Kittay, 2019).

The ethics of care proposed by Kittay (2019) is derived from the best practices of the care of vulnerable dependent persons, and where the management of dependency is of importance. Kittay's argument is that instead of 'joining the 'abled' on a quixotic quest for a nonexistent independence, I suggest that we aim for a relative independence through the

appropriate management of dependency' (Kittay, 2019, p. 162). Kittay (2019) describes how this ethical approach deals with responsibilities in relationships of asymmetry, and the importance of being attentive to and responsive of the genuine needs of the other. Kittay describe how most ethical theories begins with an understanding of the self often described in terms of autonomous individual agents. An ethics of care, though, begins with embodied selves who are regarded as inextricably connected to other embodied selves (Kittay, 2019).

3.3.2 Hilde Lindemann on identity

Similarly to Kittay, Hilde Lindemann, born in 1947, is also an American professor in philosophy. Her main contribution is within the field of moral philosophy. She is situated within narrative approaches of bioethics, feminist ethics, and the ethics of families. She has described the relationship between narratives and ethics, and the use of storytelling within bioethics (see e.g. Lindemann, 1997). Lindemann (2019) presents her take on feministic ethics as being about power and a way of thinking that informs our ethical practices. Within feminist-based ethics comes a view on persons as situated within a web of relationships and where the person's need is in focus. This goes for both feminist bioethics, or ethics of care, or a feminist ethics of responsibility.

One of her main contributions, and the one contributing to this thesis is her understanding of personal identities, and her concept of *holding*, thoroughly described in '*Holding and letting go. The social practice of personal identities*' (Lindemann, 2014). This is a concept arguing that personhood evolves within relations with others, and through Lindemann's understanding, this is a narrative endeavour: We tell stories on ourselves and others, contributing to identity formation. In ordinary identity-work, one typically presents first-person narratives of who one wants to be understood as, but also it consists of others telling stories of us. Persons will in some situations need help in sustaining their identity, as is the case for children who are unable to verbalise their own narratives. But the need for support can also be triggered due to limited crises, e.g., experiencing traumas that make one endangered of losing oneself or more persistent challenges like dementia (Lindemann, 2010). In such cases, when not able to inform with first-person stories in a direct manner, Lindemann applied the concept of *holding another in identity*.

To hold someone in identity involves the active support provided in situations where it is challenging to hold on to identity. Lindemann (2014, p. iiiii) describes how personhood constitutes of four elements: 1) a human being has sufficient mental activity to constitute a personality; 2) aspects of this personality are expressed bodily; 3) other persons recognize it

as an expression of a personality; and 4) they respond to what they see. Ultimately, when you engage in holding another in identity through recognition and response, you understand who someone is and treat them accordingly.

This holding process thus underlines the relational aspect of being human, where identities are formed in the support of the family (Lindemann, 2010). Furthermore, it is a view upon the self as embodied, and the personality is expressed bodily. As Lindemann states, ‘it is people’s bodies that express whether they are excited, puzzled, or interested; whether they are amused, fearful, or determined’ (Lindemann, 2014, p. 14). We must thus pay close attention to the body’s communication when trying to hold someone in identity.

Where Kittay (2019) can be argued to use an autobiographical approach, demonstrating her philosophical project through her own experiences as being the mother of Sessa, Lindemann also substantiates her theorization through storytelling. She uses different stories and displays different lives, both in persons from her own family, like her demented grandmother (Lindemann, 2010) and her baby-sister Carla who suffered from hydrocephaly (Lindemann, 2014), in addition to, e.g., a person depicting a pregnant woman and the fetus in her womb or the son that is upset with his dad; these are all stories that contribute to explaining Lindemann’s writing on social identities.

3.3.3 Edith Stein on understanding others

Edith Stein, a German Jewish philosopher that later converted to Catholicism, was killed in 1942 in an Auschwitz concentration camp, at the age of 50. She was beatified as a martyr in 1987 and declared a saint 11 years later (Andrews, 2022b).

She studied under Husserl, and she was convinced that phenomenology was the most appropriate approach to the investigation of the human person (Stein, 1989). Her writings have been characterized as contributing within three categories: studies in general philosophy and the philosophy of religion; studies in pedagogy; and studies in hagiography (Stein, 1987). She was the assistant of Husserl for 18 months (Parsons, 2005), assisting him on varying philosophical manuscripts, like ‘Ideen’, and she granted him much inspiration on own work (Stein, 1989, p. 2). Her admiration of his work is displayed through her personal letters to other phenomenologists, like Ingarden, saying that, ‘I consider the publication of his work more important than any possible product I might eventually present to the world’ (Stein, 1993, p. 16).

Stein demonstrates a strong feminist perspective, and she was a supporter of women entering into professional life and gaining greater freedoms (Stein, 1987). Her approach on

feminism is one occupied with underscoring and highlighting understanding of women's nature: 'Seeking to embrace that which is living, personal, and whole' (Stein, 1987, p. 45). The emotional connectedness that characterizes the soul of women make them particularly capable of human relations, she argues, 'the strength of woman lies in the emotional life' (Stein, 1987, p. 65).

In this thesis it is her contribution regarding philosophy, aiming to understand human nature that is of importance, and in particular her undertaking of empathy and her understanding of the emotional aspect in this process. These thoughts are mainly to be found in the book: '*On the problem of empathy*' (Stein, 1989), based on her doctoral thesis. Her master, Husserl, also engaged in the understanding of other, and according to Zahavi there are several overlaps in understanding between Husserl and Stein, but Husserl does not treat it in the same succinct way as Stein, but rather touched upon it in several manuscripts (Zahavi, 2016). Her writing departs from the tradition of '*Einfühlung*', a concept that was later translated to empathy (Zahavi, 2016). '*Einfühlung*' is a concept that is based on the understanding that one can access the mind of the other through 'feeling into the other'. Stein describes empathy as a kind of act of perceiving sui generis, as an act that is primordial as present experience though non-primordial in content (Stein, 1989). Through empathy I can experience the other's pain, but this does not involve me perceiving the pain through outer perception as primordial. She posits clearly that empathy does not have the characteristics of oneness, whereby one can fuse their own horizon with the person they empathize with, but rather one can feel into the other—still holding on to the understanding that the other is different—as there are two subjects in the empathic act (Stein, 1989). Furthermore, through empathy, one can 'not only know what is expressed in facial expressions and gestures, but also what is hidden behind them' (Stein, 1989, p. 5). Although Stein is clearly describing empathy as an act of perception, it is not reduced to merely the visuals of perceiving. Through empathy, it is possible to grasp even what is not to be seen, but rather what is felt or sensed. Understanding the other involves engaging with the other's living body and the different sensations it projects. It is through the medium of corporeality that we obtain information on the other (Stein, 1989). Embedded in her theorization is a view of persons as interconnected and highly relational, and where empathy contributes both in grasping the other, but also to confirm oneself (Stein, 1989).

Contrary to the writing of Kittay and Lindemann, Stein does not explicate ethics, but her writing is still valued as highly ethical (Andrews, 2022b; Haney, 1994; Parsons, 2005; Urban, 2022); she puts the lens up to the importance of addressing the other through

particularities, and also emphasizing relationships as essential (Parsons, 2005).

3.3.4 Overlaps, differences, critics, and positioning the project

Kittay (2019) and Lindemann (2019) can be placed within a feminist tradition of philosophy, both writing on the ethics of care, although Lindemann is grounded in a wider feminist ethics, underlining the responsibilities of all types of relations—stated in an ethics of responsibility (Lindemann, 2019). Kittay takes disability as her main entrance to philosophical issues and is explicitly addressing professional relations, while Lindemann is primarily writing from the field of dementia within family relations. They are contemporaries and have contributed to the same publication (Kittay & Carlson, 2010), thus being acquainted with each other's writings. I have not been able to find that Kittay or Lindemann apply thoughts from Stein in their writing.

Kittay, Lindemann, and Stein all depart from philosophy, although emerge from different strands: Kittay starts within the philosophy of language and moves into moral philosophy; Lindemann emerges from bioethics and moves into the social construction of persons; and Stein is the only one situated in phenomenology. Despite their different philosophical departing, it can be argued that both care ethics and phenomenology elucidate the normative significance of human experience, emotion, and embodiment (Vosman & Nortvedt, 2020).

The feminist strand informing Kittay and Lindemann is connected to the eclectic body of theories that entered colleges and universities in the early 1970s (Lindemann, 2019). Both Kittay and Lindemann are linked to the idea that feminist ethics should inform on how one should act towards another. Kittay argues that her outline of an ethics of care has emerged from both feminist philosophy and from her own personal experiences with her daughter (Kittay, 2019), and where her distinct contribution is related to her aim to make the embedded power in the asymmetrical relationship enriching for both the cared for and the carer alike. Urban (2022) describes the remarkable feminist element present in Stein's thought, linked to her fight for women's rights, engaging in vocational counselling for female students. Urban puts forward that Stein's ethical thought makes her a forerunner of the ethics of care. This builds on Stein's feminist personalism and her deeply-rooted relational perspective on humans (Urban, 2022). Urban (2022) further points to her view of humans to be marked by interdependence as an overlap with the ethics of care and her emphasis on the concrete and practical, rather than abstract moral reasoning.

As indicated, although there are overlaps in understanding between the philosophers,

they depart from different times in history, from different philosophical traditions, and place the lens on somewhat different areas of being human. One difference that Urban (2022) points to, regarding Stein and care ethics, is how they approach values. He argues that Stein represents emotional value realism, i.e., the absolute value of human persons, while most care ethics will emphasise the context-related and situating of all moral knowledge.

The feminist ethics, and particularly ethics of care and the view that relations should steer judgments, also come with critics: amongst them pointing to the possible indifference of others outside of the relationship and the possibility of losing sight of the separateness between the two parties of the relations (Kittay, 2019). The first criticism relates to the debate on impartiality in justice. Ethics of care can be found to struggle when it comes to manage structural issues, e.g., when conflicting moral claims, e.g., between care for a particular person and impartial justice (Nordhaug & Nortvedt, 2011). The other criticism regarding the ‘collapse of relationality’ (Kittay, 2019. p. 181) puts the lens on the potential challenges of the intermingling of desires and interests within relationships. Likewise, the phenomenological approach on empathy suggested by Stein (1989) might be criticized for relying on emotional resources; it could be argued that knowledge risks not being objective or reliable (Bloom, 2016). Criticism on an ethics of care will be dealt with further in chapter 6, Discussion, and where it will be suggested that notions from phenomenology might add valuable reflections perhaps counteracting the criticism. The critique on relying on emotional knowledge, as the theorisations of Stein suggest, will also be touched upon in the Methodological Reflections in the Discussion.

As already indicated in the former, the theoretical framework of this thesis is built upon notions on self that underlines relations, that being in the world is embodied and that we exist in intersubjective relations with other, perspectives found in all three philosophical contributions. The thesis is further very much grounded in feminist ethics, and in particular an ethics of care as proposed by Kittay, a perspective applied in all the thesis’s articles. Her account, explicitly grounded on the inclusion of persons with profound intellectual disability, making her especially relevant. Her writings have been of importance throughout the project and explicitly informing on how to manage dependency. Vehmas & Mietola (2021) argue that Kittay writes in a personal style, using her experience as the mother to a child with severe intellectual disabilities, but that she otherwise engages little with empirical research literature on persons with PIMD. As they further point to, this might be due to the lack of research. This thesis aims to contribute by lifting up Kittay’s theoretical framework using empirical material. Lindemann has contributed, together with Kittay, in the article exploring how to practice self-

determination (article 2), and where her notions on identity as a social construct has been of upmost importance. Furthermore, a phenomenological view upon knowledge has informed the scientific approach and thus been relevant throughout fieldwork. The article exploring the question regarding how knowledge production might include the persons in regard (article 3) is based on Stein's view of humans and how to understand another through empathy. An attempt to merge these theoretical frameworks will be attempted in chapter 6, Discussion, building on the similarities, and highlighting the differences.

CHAPTER 4: Methodology

This thesis has an outspoken aim of including persons with PIMD and building an argument on their perspective, and the chosen method for this is the ethnography. Although recognising the potential challenges and pitfalls regarding the inclusion and issues regarding representing the ‘voice’ of persons with PIMD (Maes et al., 2021), the project aims to contribute with methodological attempts of the kind. Whether the pursuit can contribute to push inclusion further will be more thoroughly discussed in chapter 6, while the intent of this chapter is to describe the methodological choices I made.

The foundation for the study’s rationale and argumentation is to be found in ethnography and phenomenology. An explication of the application of these will be given, before design, recruitment, and data collection are described. The chapter ends with a description of how analyses has been undertaken along with ethical considerations.

4.1 Positioning the project

Ontological, epistemological, and methodological questions are intertwined, and it is found useful to present the two main foundations of this study, namely the phenomenological view on science representing a certain ontological and epistemological view and the method of ethnography, in the same section. Central to the project is a focus on exploring phenomenon through actual lived experience, getting hold of the person’s perspectives and thus a section reflecting upon possibilities of such is included, before the actual ethnography has been conducted.

4.1.1 Phenomenology

Phenomenology is the study of essences (Merleau-Ponty, 1962/1998), and in this study it is the phenomenon of self-determination and the essentials in the professional relations that is under exploration. The founding father of phenomenology, Husserl, propagated a return in philosophy to the things themselves, i.e., considerations should be based on the way things are experienced (Gallagher & Zahavi, 2021). Although this thesis is based on notions from Husserl, it is applied in a non-philosophical manner, moving away from Husserl’s more transcendental arguments. Leaning on Zahavi’s (2021) suggestions on why it is safe to ignore the epoche (as also described in Chapter 3), this thesis aims to use phenomenology in ways that give meaning in the qualitative, empirical landscape.

A positioning within the vast area of phenomenology is thus called for, as

phenomenology is not just one thing. Numerous distinct methodologies and strands have evolved: interpretative phenomenological analysis (IPA); hermeneutic phenomenology; and descriptive phenomenology to mention a few (Finlay, 2013). One of the conflicts contributing to the different strands are connected to the question regarding how deeply rooted one must be in phenomenological philosophy when applying it in empirical research. Different acclaimed phenomenologists accuse each other of not doing it properly, e.g., Van Manen (2017) disagreeing with Smith's IPA, or Zahavi (2019a) disagreeing with both Van Manen and Smith (see Køster & Fernandez, 2021 for more details). Without going too deep into these conflicts, this thesis is based on a position that a study can be termed phenomenological without aiming to 'hyper-philosophize' (Zahavi & Martiny, 2019, p. 161). The current study is in line with Zahavi's (2021) suggestions that elements from Husserl's transcendental philosophy, like the epoche and reduction, are safe to ignore in non-philosophical application of phenomenology and that there are other features of philosophical phenomenology that are far more relevant to the qualitative researcher. Zahavi and Martiny (2019) argue, e.g., the importance of phenomenology's careful analysis of human existence, where the subject is understood as an embodied, socially, and culturally embedded being in the world. Such notions and whether its application allow for new insights into a practical field and to the scientific community is more important than a methodologically strict use of Husserl's instructions. The aim is to strike the right balance between a too superficial and an overly orthodox engagement with the philosophical ideas (Gallagher & Zahavi, 2021).

Phenomenology has influenced the project regarding how to grasp the meaning of a phenomenon. Finlay (2013) describes phenomenology as a way of seeing how things appear to us through experience, examining taken-for-granted human situations as they are experienced in everyday life, but which typically go unquestioned. It is that which appears by the phenomena that is important, but it makes no sense to talk about things that are 'simply there' (Husserl, 1950/1970b, p. 9). Things come to be constituted by mental processes, by consciousness. Consciousness has a directness to it, namely intentionality, and this intentionality involves the perceiver to take a perspective in the perception.

Phenomenologists are typically concerned with understanding a phenomenon in terms of the meaning it has for the subject, and thus is said to take a first-person approach. This is in opposition to a third-person perspective where a scientist typically functions as an external observer (Gallagher & Zahavi, 2021). In this thesis, the aim is to explore self-determination as unfolded in the relation between a person with PIMD and the professional. As such, both of these perspectives are of interest. The professionals can display their first-person perspective

verbally through interviews. Persons with PIMD though are unable to vocalise verbally and thus necessitate other means of portraying lived experiences. In this study close observational descriptions were determined, and here lies this project's potential methodological innovation—aiming to include the perspective of the persons with PIMD through observation.

Although interviews are a predominant in phenomenological research (Klinke & Fernandez, 2022), observations are also argued for as evidence. Klinke and Fernandez (2022) demonstrate this through the writings of Merleau-Ponty (1964b, p. 65) stating that 'nothing prevents me from explaining the meaning of the lived experience of another person, as so far as I have access to it, by perception'. The behavioural evidence can further be understood through Merleau-Ponty's notion on intercorporeality, a way of describing the intersubjectivity that occurs through bodies (Moran, 2017). The phenomenological tradition contains rich accounts on intersubjectivity (Gallagher & Zahavi, 2021), starting with Husserl (1970a, p. 231) who states that, 'the experience of others is given only through the mediated type of experience called empathy'. And in such perceptions of bodies are vital, as the concept of intercorporeality suggests. Merleau-Ponty describes how we can grasp another through the body and that 'it is through his body that the other person's soul is soul in my eyes' (Merleau-Ponty, 1964a, p. 172). Such understandings were during the project further completed through the theorisations of Stein (1989), providing sensitive descriptions on the essentials of human nature. Phenomenology has also informed the analytical process, as will be described later in this chapter.

4.1.2 Ethnography

Ethnography comes with an ethical commitment to see the lives of persons with PIMD as valuable and worthy of being understood (Vehmas & Mietola, 2021). The method can imply a range of approaches and its label is not used in a standard fashion. Hammersley and Atkinson (2019) state that ethnographic work involves doing study in the everyday context, gathering data from a range of services often in a relatively unstructured manner, where the focus usually is on a few cases, and where analysis involves interpretation of the meanings, functions, and consequences of actions.

Services for persons with PIMD are often characterised by several professionals and high staff turn-over (Murray et al., 2022). This was also the case for the persons recruited in the current study, interacting with various professionals during a week. It was decided to design the study as a 'best-practice study' (Benner, 1984), involving the recruitment of rather a few professionals who knew the person with PIMD relatively well. The alternative, to

observe the totality of services and the manifold relations that a person might experience could have provided valuable insights on the many shifts and breaks in interactions a person with high support needs might experience. But, as the project intended to explore the specifics in relations and possibilities within these, it was deemed that the inclusion of professionals knowing the person well would be more relevant than to observe professionals with little knowledge of the person. The findings will thus not represent all possible encounters, but rather pertain to so-called ‘success stories’ that can aid and indicate possibilities for improved practice (Benner, 1984). Implications of this choice will be further addressed in methodological reflections in the chapter 6 on Discussion.

The ethnography aims to get as close as possible to non-verbal ways of being, trying to get hold of these persons’ perspectives. I was inspired by the sensory ethnography in the preparation of doing fieldwork. According to this method’s main proponent, Pink (2015), the sensory ethnography aims to re-think ethnography through the senses. Researchers must attend to the everyday life that is not always verbalised (Pink, 2012). There is a clear connection between an embodied phenomenological approach and the use of a sensory approach in the ethnographic activities. Pink states that, ‘Merleau-Ponty’s ideas are relevant to the formulation of sensory ethnography because he placed sensation at the centre of human perception’ (Pink, 2015, p. 29). The approach’s focus upon the experiencing, knowing, and enlivened body has been relevant when preparing for and observing in the context of persons with PIMD.

Although sensory ethnography is a helpful guide in holding on to the senses of the body, like what can I see, smell, taste, touch, I still experienced that the method came short regarding more emotional experiences from fieldwork. My experiences while observing were not just of a sensual character, they were embedded with feelings. Therefore, inspiration was sought from the method of Infant observation (Bick 1946/2002) due to its focus on how emotions might inform understanding. This is a method that aims to understand and gain awareness of the complexities in non-verbal interactions, intending to make sense of the feelings and thoughts of others (Music, 2012). The method recognises the subjectivity of the researcher (Hollway 2016), arguing that over time and with repeated reflection, researchers can gain valuable information from intuitive, emotional experiences—guiding the understanding of others. The methodology has evolved beyond the context of infant studies, and has been used in many different forms of research, both in new contexts and alongside other methods, e.g., that of Datler et al. (2012) observing in residential homes for elderly or Shuttleworth’s (2012) work on observing in a mosque. These are examples demonstrating that

infant observation is being extended beyond those of infants and their families. I thus found it relevant to apply elements of the method to the current study, where non-verbal relations were under scrutiny. The method demonstrates overlapping thoughts with phenomenology regarding a view that one can perceive and understand another through bodily expressions (Merleau-Ponty, 1964a), and where feelings serve as entrances to understand another's mind (Stein, 1989).

4.1.3 The projects methodological attempt—getting hold of the person's perspective

In this thesis it is deemed an ethical responsibility to include the persons with PIMD, arguing that exclusion will lead to further marginalization (Nind & Strnadová, 2020b). Still, such efforts come with great responsibility, treating the person unable to formalize a verbal or written consent to participate, with outmost respect, a matter that I will address more thoroughly in the section on ethics. How can such inclusion be done and understood when the person with PIMD communicates in embodied manners? Three lines of argument will be pursued connected to somewhat different approaches: mediation, co-construction, and a direct understanding through empathy.

Cluley (2017) uses the concept of *mediation* in her research involving persons with PIMD, underlining the fact that these are persons that rely on mediation, or support, throughout life; it is a pre-condition for a person with PIMD's very being. They live their lives in this way: when being fed, nurtured, transported, participating, and in situations of self-determination, through the support of another. This sort of mediation can be understood through the theorizations of Vygotsky (1978), involving the tools that support action, thus connecting the mind with the world. Tools might be both physical, linguistic, or understood as persons providing support—the latter being in focus in this study. In Cluley's (2017) understanding, this demonstrates the necessary inferences that the supporting person must make on behalf of the person with PIMD, thus being realistic on what we can understand.

Somewhat similarly, but perhaps adding to the understanding, is the concept of *co-construction*. Teachman et al. (2018) describe how the dominant assumption—that voice is a personal attribute or property that can be possessed—reproduces conventional positivistic notions of autonomous speakers whose voice and views are faithfully 'captured' through the research process. Leaning on the writings of Bakhtin (1981) and the view that all communication is relational and situated, Teachman et al. (2018) argue that voice should be understood as multivoiced, i.e., that an utterance is inextricably connected to what was said

before, and anticipates what will be said next. Embedded in this is an understanding that voice is not something that researchers can retrieve from an individual and possess, e.g., through interviews, but rather it is co-constructed. This is also in line with de Haas et al. (2022) and their claim that getting direct access of anyone is a myth, and that all communication is co-constructed. Inference is an ordinary part of all communication, including verbal, symbolic language. In the current study, both mediation and the view that voice is always co-created is informing, a line of thinking that involves understanding of reality as co-constructed and subjectively based (Denzin & Lincoln, 2018). This understanding has informed when designing the study, including several voices, both family members and staff, when approaching the perspective of the person with PIMD.

Additionally, this thesis also aims to explore a third line of understanding, namely the possibility to get hold of the first-person perspective of the person with PIMD more directly. This should not be understood as an attempt to eliminate mediation or co-construction, but rather to explore efforts of adding to the element of inference, exploring possibilities of recognising persons with PIMD as subjects of knowledge. The background and motivation for this attempt is to counteract views that persons with PIMD can not be included due to challenges of grasping their intention. As demonstrated, most research involving persons with PIMD, rely on the view of significant others, and as such, this exploration might provide insights on ways to include the persons in regard in more direct manners. This is approached through phenomenological takes on possibilities of grasping another through intersubjective understanding, through empathy. The context of persons with PIMD is a context where empathy, to a small degree, has been explored in explicit ways. More often it is dealt with implicitly, for example, in studies addressing the topic of communication (Griffiths & Smith, 2016). The attempt in the current study is closely connected to ethnographic research and its aim to get hold of the emic perspective—the insider’s view of reality (Fetterman, 2020). The emic perspective urges us to stay close to the empirical, letting what matters to the persons in regard be in the foreground (Hammersley & Atkinson, 2019). A similar concept to the emic, and one that might resonate with the case of persons with PIMD is that of thick descriptions. Fetterman (2020) points to thick description and verbatim quotations as the most identifiable features of ethnographies. The concept of thick description is put forward through the writing of Geertz (1973). He argues that producing thick descriptions is the main enterprise of doing ethnography. In this lies an expectation of the ethnographer to represent what is observed in ways that can distinguish between ambiguous meaning. The ethnography must engage with the multiplicity of complex conceptual structures, which are ‘at once strange, irregular, and

inexplicit, and which he must contrive somehow first to grasp and then to render' (Geertz, 1973, p. 10). Through thick description the emic perspective is aimed to be captured.

Through phenomenology accounts on humans as embodied has been argued, it is our bodies that expresses our existence (Merleau-Ponty, 1962/1998). Moran (2017) describes how the body can be experienced as a living, responsive organism (e.g., when I run and jump) or as a physical thing (e.g., when I fall and bang my knee). This is a demonstration of the phenomenological distinction on how we can experience and understand the body, between the lived body as subject, and the corporeal body as object, respectively termed 'Leib' and 'Körper' (Gallagher & Zahavi, 2021, p. 152), as also touched upon in Chapter 3. One must assume that all humans can experience their body in both of these ways, but when it comes to explicating it to another, persons with PIMD will have challenges in being understood. If a person with PIMD experiences pain or distress, it might be that the professional can see the distress but not understand what is causing the distress. Moran (2017) describes how phenomenology understands empathy to include a recognition of the other's lived body as expressive of his or her subjectivity that is lived through, but cannot be fully inhabited. This involves that the first-person perspective cannot be fully disclosed. But still, phenomenology will argue that empathy can provide us with some understanding of the other's body, and as such might be an entrance to get hold of the perspective of another, grasping the other's body-as-subject.

4.2 Design

With this background the ethnography was planned, involving methodological choice regarding sample and data collection procedures. Building on other ethnographies and observational studies in the field of profound disability (Vehmas & Mietola, 2021; Simmons & Watson, 2014) I deemed it important to recruit a rather small sample, to build trust and some degree of knowledge on the person's way of communicating. The topic under exploration that aimed to understand the phenomenon of self-determination, necessitated time for it to unfold, recognising that disclosing its many nuances might evolve gradually. By deciding to follow a few numbers of persons more extensively, time could be spent with each person, enhancing ability for closeness. It was planned to recruit 2–4 persons with PIMD, representatives of the person's family and 2–4 professionals per case.

Following the logic previously presented with the aim to represent the person with PIMD's perspective, observation was regarded as the main method. Participant observation characterises most ethnographic research, and is crucial to effective fieldwork (Fetterman,

2020). Observations can take several forms, depending amongst others on the role of the observer. In this study the intent was to explore what was going on in the relationship between the person with PIMD and the professional in the everyday context. Observations aimed to get hold of the mundanity of the person's life, participating in both more event-like situations, e.g., going to the pool or taking part in music lessons, but also situations where nothing special was on the agenda other than being at home, relaxing, eating, or training. It was important to find the balance between not interfering in the relation—thus keeping some distance—but still make the presence of an observer natural and thus interact with the participants when called for. Due to Covid-19, physical distance was planned by not touching the person. In addition to observation with the aid of perceptual skills, the use of video was also planned for in delimited situations. Observing complex interactions with the extensive use of non-verbal communication is demanding, and video might be argued to enhance the ability to capture the perspective of the person to a greater degree than exclusively relying on observations (Kaley et al., 2019; Rojas & Sanahuja, 2012). The writing down of observations was to include both descriptions of the relations, focusing on details regarding the different senses (Pink, 2015), and description of emotional reactions that could be sensed in both the participants and myself as a researcher, following the method of Infant observation (Bick, 2002/1946; Urwin & Sternberg, 2012).

As much research with persons with PIMD points toward, interpretation of others might be necessary, as also argued through the notion of mediation (Cluley, 2017). To include several voices, it was determined to include interviews with both family and several professionals, and facilitating a dialogue meeting (Hoppe et al., 2019) at the end of fieldwork. The aim of the dialogue meeting was two-fold: both to bring in important voices to add information (Watson, 2012) on understanding the thematic of self-determination, and for validating (Miles et al., 2020). By presenting my preliminary understanding, receiving instant feedback on its validity also informed further analysis. In both the formally planned interviews and dialogue meetings, but also in the more informal talks, phenomenological methods were of guidance, focusing on 'going back to the thing themselves' (Husserl 1950/1970b), aiming to get hold of the description of the phenomenon (Gallagher & Francesconi, 2012). The interviews were semi-structured (Bryman, 2016) consisting of three overall pre-defined topics guiding conversation:

I: How is self-determination unfolded within the relation?

II: What kind of knowledge, skills, and attitudes are described as essential in fostering self-determination?

III: What structural features in services are described to foster relations able to support self-determination?

Three datasets were planned: observational descriptions of the relationship; verbal accounts from family and professionals; and reflections upon emotional experiences during fieldwork.

Although I was aware that the unstructured data collection inherent in ethnographies does not adhere with implementing a fixed and detailed research design (Hammersley & Atkinson, 2019), the guiding ethical authorities, the Regional Ethical Committee (REC) still asked for overviews. A plan for activities was also important to provide to potential participants for them to consider participation. It was suggested that fieldwork in each case should be executed over nine weeks, distributed over two arenas, e.g., a housing facility and day-centre. Being present in close relations might be experienced as exhaustive for both the person with PIMD and the professional, and therefore observations were planned to have a rather short duration each time, in accordance with activity and the professional's recommendation. A short period of observing was also important in the process of writing fieldlog, making it possible to remember details. The observational period was to be divided into three sections, with a pause for a couple of weeks in between the sections, to reflect over previous activities and plan for the next period, thus stretching each case over the course of 3–4 months. Each section was to have a specific focus, guided by the three themes presented earlier. As will be demonstrated in the following, ethnographic work and perhaps in particular when conducted during a pandemic, needs to be flexible and relate to occurrences that happen, sometimes deviating from initial plans. The planning, though, was still experienced as a helpful guiding tool.

4.3 Recruitment and participants

I started recruitment through contacting leaders of health and welfare services in three municipalities. Two of these declined to participate, one due to few potential candidates (persons with PIMD comprise a relatively small group) and the other due to high pressure on the professionals at the time of recruitment, also involving high turnover in the services. The third municipality responded with enthusiasm. The contacted leader presented my request to leaders of housing facilities, which resulted in three possible residences. I received contact information of the leaders, and through dialogue and checking that we understood the target group to be the same, three persons with PIMD were identified. Via the leaders, next of kin

were approached and consulted, and each replied positively to participate. In this first approach with parents, reflections upon whether their child would react negatively to the suggested research activities were discussed.

The main persons of the study, the persons with PIMD, were anonymously called Vera, Erik, and Karen. Some of the details about them will be shared, but to keep anonymity this will be dealt with as an overall description, not disclosing who these details regard to. At the time of fieldwork, they were of the age of 11, 18, and 26. They are as different from each other as anyone else, and their functional profile varies regarding senses, although they all had some form of hearing or visual loss. Their communicative profile also differs, although common for them all were the dominance of bodily signs and gestures, not communicating in formal, verbal ways. They all depend on wheelchairs and assistance in all movement. One is tube-fed, whilst two eat with close assistance of professionals. Pleasure was found in different activities: varying from, e.g., relaxing in the soft waterbed, being moved around in the pool, listening to conversations, making music, interacting with others, being held in someone's lap, and listening to music. As like everyone else, they varied in their day-to-day form: some days being embossed in the need to sleep or relax, and other days being alert and participating in activities. They also varied on what might be understood as bodily tension, some days seemingly fine, and others in distress. They all lived in housing facilities organised as individual apartments located together with other apartments, and with day and night staff providing care. This was the base of the fieldwork, in addition to participating in the day-time activities they participated in, with two of them still being pupils at school, and one of them spending time at a daycentre. They interacted with professional caretakers throughout the day, in intimate situations of hygienic matters, dressing, feeding, and to move, or engaging in different activities or interactions.

Regardless of their living arrangement, whether in a family home or in a professional care setting, parents play a large, often lifelong role in the care of the person with PIMD (Kruithof et al., 2021). Parents, grandparents, and siblings—persons having known the person over time—are likely the ones most familiarized with the person's unique way of being and communicating, and as such represent important perspectives in the aim to explore the person's self-determination. One family member per case was recruited, participating in the initial interview, and a dialogue-meeting at the end of fieldwork. Occasionally family members were also present at times when I observed, visiting their child at the housing facility, allowing for a more informal interaction.

The different cases varied regarding how many professionals and which context they

represented. In Vera's case, five persons were recruited: two from a housing facility; two from a school; and one from a leisure activity. In the case of Erik, three persons participated: two employed at the housing facility; and one from the leisure activity. The two professionals from housing also accompanied Erik at the daycentre, and observations thus took place at two venues. In Karen's case, initially four professionals were recruited: two from a housing facility and two from a school. Due to the pandemic situation at that time of fieldwork, it was necessary to exclude the context of the school to reduce social contact to a minimum. Seven of the 10 professionals were trained as social educators, in addition to one musical therapist, one pedagogue, and one care worker.

4.4 Data collection

Data was collected during the period from September 2020 until June 2021. Although informed by the same methodological choices and design, all the cases evolved within their own context, necessitating flexibility regarding the initial plan.

4.4.1 Putting research on hold

When all the permissions to conduct the research were gained during the spring of 2020, and recruitment was done, the first thing that I had to do was to put the actual research on hold due to the pandemic. The first couple of months, when restrictions and demands for isolation were high, the entire project was experienced as losing its ground—would the situation change within a reasonable time, making the project possible to conduct? At some point, the thought to end the PhD crossed my mind. But due to pragmatic leaders at the Centre of Diaconia and Professional Practice and an opening at the bachelor programme where I worked as a teacher prior to the position as a PhD fellow, I was able to freeze the PhD period for 3 months and return to my teaching position. During this period the situation in the part of Norway where the project is situated gradually became more under control; infection rates were low, schools were opening, and restrictions on day-care activities and housing facilities were loosened. In close dialogue with family and professionals it was deemed acceptable to start the fieldwork. From June 2020 until December 2020, it was possible to start and finish data collection in two of the cases. The third case was supposed to start in January 2021. At this time the situation on a national level again got worse with higher infection rates, and new national guidelines made it difficult to proceed with fieldwork. It was therefore decided to postpone further data collection. Facing yet another delay in the project, I decided to start

working on the first article to keep progress, deeming that the two cases would provide sufficient material for the purpose. The situation changed again during spring, making it possible to start fieldwork, and observations and interviews were undertaken in the period between March and June 2021. Due to the uncertainty, however, it was considered that only one of the recruited institutions should be included to reduce the number of social contacts.

4.4.2 Building trust over time

Before starting observations, I met with the primary care workers and spoke with parents. These first encounters were important to orally inform on the study, in addition to the written information I had already sent them. Even though the meetings were important to prepare the professionals, they contributed just as much to prepare me on how to approach the person, what key communicative signs communicated, and other details in the lives of Vera, Erik, and Karen. Although I as a researcher hold the responsibility to conduct the research in ethical ways, it was in these first talks underlined the importance of the professionals to help guide me regarding assessing the person's possible distress or unease at my presence (Tuffrey-Wijne et al., 2008).

Likewise, it was important that the professionals experienced the situation as okay. In the initial phase, we thus put into words and recognised that to have a researcher observing closely could be experienced as demanding, and that it was important to have clear guidelines on what kind of situation to participate in, and for how long I should stay. Professionals were informed that I never would show up unexpectedly. During the first observations I did not bring a camera or notebook, intending to be present and start negotiating with the professionals what was okay and what was not. Some of them were very vivid in sharing that they found the project important, and that they wanted to contribute in all ways possible, gladly willing to participate in filmed sessions. However, one of them did not want to participate on video but was positive to the other activities. The professionals varied regarding how at ease they were experienced: some carried on with their activities in what seemed natural manners; others put into words that they felt a bit strange to conduct their job whilst I was there, expressing some anxiety having me present. To reduce stress and clear up misunderstandings regarding the project's intention, it was thus important in the initial phases to get to know the professionals, and I tried to spend moments where Vera, Erik, or Karen were relaxing to get to know the professionals.

4.4.3 The observational gaze—balancing verbal and bodily information

The observational approach was informed by the notion of being a ‘modest guest’ (my translation), a term suggested by Abrahamsen (2004, p. 29) in her application of the method of Infant observation, with an intent of not inferring in the participants’ daily activities. It took some time to get all the professionals into the idea that what was important to portray was the typical day, and I experienced that some of the professionals would rather have me present when eventful activities took place, describing that ‘nothing really happens’ when they just stayed at home.

I aimed to keep an open mind through my observational gaze, an important element in all ethnographic endeavours (Fetterman, 2020). In line with Zahavi and Martiny (2019) though, this does not imply that one should come totally without any background. The overall aim of the thesis is to explore the phenomenon of self-determination, and pre-conceptions on this were brought into the field, based on the definition of self-determination as congruence (Ryan & Deci, 2017). The dependent relationship between the person with PIMD and the professional were also recognised and served as the point of departure where self-determination was to be explored. The research was thus informed by a certain theoretical framework, although at the same time presenting to the participants an aim to explore and expand the concept, through the lived experience. With this background, close descriptions of all situations were recorded and written down, also including a researcher reflection log where emotional experiences were documented.

An essential part of doing an ethnography is the presentation. The data collected must somehow be displayed, and there are numerous ways one might do this, e.g., through an article, blog, info graphic, or data visualisation (Fetterman, 2020), to mention a few. Pink (2015) argues that conventional ways of reporting are limited in their capacity to communicate the directedness of the sensory and affective elements of the experience, and thus points to the use of arts and media as entrances to represent sensory knowing. Despite this, in this thesis, the ethnography has been presented within the frame of a thesis by publication, thus adhering to those guidelines. The chosen way of portrayal has been through the means of the written text, and the ambition has been to stay as close as possible to what could be observed, getting hold of the small and subtle details, and also using transcripts from filmed material and audiotaped interviews when presenting data. There is thus a paradox in the chosen format of this specific ethnography—portraying non-verbal living through the means of verbal words in the written text. This puts high demand on how the embodied living is portrayed, one that will be further reflected upon in the methodological section in chapter 6.

According to the method of Infant observation, writing should first occur after observations, but I experienced that writing down short notes (Emerson et al., 2011) was essential to preserve accuracy and detail. After clarifying with the professionals, I started to bring along a small notebook, where I could write down short descriptions that could help aid my memory on the embodied relations when writing the details afterwards. In this matter, both the suggestions from sensory ethnography and the different senses were of use, but also paying close attention to the different emotions that arose in me during observations.

Table 4: Overview of data material

Type of data:	Case 1: Vera	Case 2: Erik	Case 3: Karen	In total
Observations	26 sessions 62 hours	17 sessions 31.5 hours	13 sessions 31 hours	56 sessions 124.5 hours
Of which was filmed	7 situations: in total 1 hour and 16 minutes	5 situations: in total 35 minutes	4 situations: in total 31 minutes	16 episodes: in total 2 hours and 22 minutes
Interviews	1 family 5 professionals	1 family 3 professionals	1 family 2 professionals	3 family 10 professionals
Dialogue meetings	1	1	1	3
Written material	189 pages	114 pages	90 pages	396 pages

4.5 Analysis

Analysis has been a continuous process (Fetterman, 2020), starting when selecting topics to study and proceeding throughout field work; both in the active data collection and whilst recording and writing down. In addition, each of the three articles has undergone specific analysis that will be presented in more detail. What phenomenology can offer regarding analysis is not a specific procedure, but rather guidelines. Similarly, Hammersley and Atkinson (2019) state there is no formula to be followed for the analysis of ethnographic data, rather if one tries to follow a procedure, it is likely to lead to inadequate results. Still, both phenomenology and ethnography suggest some guidelines that have been helpful for the analyses comprising this thesis. A description of the overall guidance will be provided before explicating how this unfolded more practically in each of the articles.

4.5.1 Phenomenological attitude and analytical sensibility

The concept of the ‘phenomenological attitude’, as suggested by Finlay (2008; 2013) has informed analysis. This is understood as the process of retaining wonder and openness to the world while reflexively restraining pre-understandings. Although Finlay engages with the concept of the epoche (Finlay, 2008), the application of her suggestions in this thesis is done with the understanding from Zahavi (2021), suggesting that a strict adherence to such is not necessary, or perhaps not even possible in empirical research. Finlay’s concrete steps on how to approach data with a phenomenological attitude has still been useful. She describes this as a dance of improvised steps, shifting between bracketing pre-understandings and exploiting them as sources of insight (Finlay, 2008). This resembles the abductive process, starting out in an empirical basis, just like induction, but where theoretical preconceptions are not rejected and in that manner is closer to deduction (Alvesson & Sköldberg, 2018). Finlay’s (1999) steps are first suggested and applied to one case before moving on to the next. Some of the steps she suggests to undertake in each individual case are to: empathise with the material, take time and dwell, suspend belief and employ intense interest, reflect, and focus upon existential dimensions before aiming to formulate. A similar process is suggested when approaching the different cases as a whole: searching for general insights, comparing, being imaginative, establishing essential themes, testing, and formulating. These processes must be understood as floating into each other, and sometimes needing to stay longer on one step, or moving back and forth between steps. According to Finlay (2013, p. 172) the challenge and what distinguishes phenomenology from other methods is the special way of ‘seeing afresh’. This shift from a natural attitude into a phenomenological attitude of openness, is according to Dahlberg and Dahlberg (2020, p. 460) characterized by ‘bridling’. To bridle involves keeping an eye on, and keeping in check, our evolving understanding so that it does not happen randomly or too fast. The goal is to be open for many possibilities of understanding.

Literature on ethnography (Hammersley & Atkinson, 2019) points to the importance of analytical sensibility, arguing that ethnography is not just a set of methods but rather a particular mode of looking, listening and thinking about social phenomenon. Securing sensibility includes withholding from jumping onto quick conclusions and paying detailed attention to appearances, thus providing guidelines resembling the phenomenological attitude. Further, the analysis aimed to stay close to the emic view. According to Fetterman (2020), ethnographers interested in describing the emic perspective are often situated at the phenomenological end of the ethnographic spectrum, while researchers relying on ethically derived data first in their analysis stand in a more positivistic philosophical end of the

spectrum. Analyses aiming to get hold of the emic perspective are always embedded with challenges of validity—and in this study actualised through the interpretation and grasping of expressive behaviour (Klinke & Fernandez, 2022).

Table 5: Overview of overall intention, the three articles and factors guiding analysis

Intention:	What can we learn from persons with PIMD on self-determination and ethics		
The thesis research questions:	Question 1: How can the concept of self-determination for persons with PIMD be understood within the context of professional relations	Question 2: How can self-determination for persons with PIMD be practiced within professional relations	Question 3: How can knowledge be built on the topic in ways valuing persons with PIMD as individuals of knowledge?
Studies:	Article 1: On congruence	Article 2: On holding	Article 3: On empathy
Title:	Self-determination: What Can We Learn from Persons with Profound Intellectual and Multiple Disabilities	Holding and Professional Care—On Self-Determination for Persons with Profound Intellectual and Multiple Disabilities	Persons with Profound Intellectual and Multiple Disabilities as Subjects of Knowledge – Exploring the Possibilities of Empathy
Concretised questions in the article	How is self-determination unfolded in caring relationship between persons with PIMD and professionals and how can these processes contribute to a theoretical rethinking of the phenomenon of self-determination?	How is holding unfolded in professional caring relations with persons with PIMD, and can holding inform practices towards the realisation of self-determination?	What are the possibilities of recognising persons with PIMD as subjects of knowledge through empathy?
Design:	Ethnographic; close observations; and additional interviews with family and professionals		
Units of analysis:	The cases of Vera and Erik	The cases of Vera, Erik, and Karen	
Main theoretical lens:	Kittay	Lindemann	Stein

The same data material was applied in all the articles, although in the first article without the case of Karen. Analysis was undertaken in separate turns as will be explicated in the following.

4.5.2 Exploring congruence (article 1)

Aiming to stay close to the empirical data, the process started with reading the data material several times and watching the filmed material, intending to scope broadly situations possibly informing the concept of congruence. Watching the films helped bring back emotions and experiences from fieldwork. In this initial phase I worked with one case at the time, and I also started writing analytic memos (Hammersley & Atkinson, 2019), guided by the research questions. A log of the analytical process was tracked. In these logs, excerpts from field log were included, and temporary themes were suggested. In this first reading through a tendency started to prevail in the data: that the persons demonstrated self-determination through congruence on a continuum of degrees of independence-dependence, and where notions on closeness emerged as essential. These thoughts were presented and further discussed at a dialogue meeting with the professionals and family, where the aim of the presentation was to empathise with both Erik and Vera and the professionals, trying to grasp how they might understand and experience the situations. The intention was to see with an open and interested mind, turning into meaning and finding words that might capture the essentials. This process was undertaken in both cases, and afterwards Finlay's (1999) suggestions on analysing the general were done, suggesting categories that were understood to communicate essential themes cross-cases.

In the dialogue with supervisors, it was suggested to keep on working with the essential categories in ways even closer to the material, going back to data for further readings, aiming to find the basis for this relation and include suggestions on how congruence might unfold within the relations.

4.5.3 Exploring holding (article 2)

Starting out the analysis after finishing fieldwork in the third case, the same round of writing analytical memos of the case not included in article 1 started the process. Then a process of reading through proceeded, dwelling over the filmed material, guided by the analytical questions regarding factors that could be found to foster self-determination. Focusing upon practical aspects on how to ensure persons with PIMD self-determination within professional caring context, in this first round of analysis the understanding of Kittay

(2019) on caring practices as both labour, attitude and virtue were inspiring. Working with one case at the time, post it notes containing short descriptions from the fieldlog were produced, systematized under the headings of professional's competences: attitudes, skills, knowledge and systematic factors. The notes were allowed to hang on the wall for some months. After a while and during the writing of the draft analyses, the notion of holding another in identity unfolded as an essential of this relationship—suggesting an overall competence. At this point the post it notes were documented, and then taken down, aiming to free the mind and open to a new round of analysis, this time inspired by the concept of holding. This also led to the rephrasing of research questions guiding the article (see Table 5). In this second round of analysis the material were engaged with closely intending to uncover descriptions of holding. In this work creativity in combination with staying close to the data was of importance.

4.5.4 Exploring empathy (article 3)

The third article was initially planned as a methodological article, one focusing primarily on how to include persons with PIMD in research and ethical aspects of such inclusion. When starting to work on the manuscript the aim was broadened, as it was found that the inclusion of persons with PIMD could be expanded to include both research, but also regarding persons with PIMD's inclusion in society; it was then that the aim to explore how to position persons with PIMD as subjects of knowledge emerged. Dwelling over the data with the question of how we can understand the mind of the other, an intuition that these were processes hallmarked by an embodiment on both side of the relation emerged, and the need for theorisations that could highlight this were called for. The notion of empathy came as a guiding light through its aim to grasp the intent of another. Reading on the topic and participating on courses in phenomenology inspired towards the work of Edith Stein, and her understanding of empathy decidedly provided the framework that would guide further analysis. As such, it was decided on a phenomenologically informed analysis, where Stein's account on human existence provides an illuminating framework (Zahavi, 2019b). With this setting, engagement with data started, finding descriptions of Vera, Erik, and Karen, where both myself, as a researcher, and the professional aimed to empathically understand. This was done through descriptions from fieldnotes that was experienced as typical situations, demonstrating characteristics both when easy to understand and also when embedded with uncertainty. The data was then read with the purpose of finding demonstrations of empathic understanding from the professional and reflections from me as researcher, which could

explicate the theory of Stein. While the close observations of the persons with PIMD and the professional were important, in this article a close engagement with the interviews with professionals was just as important, as they were found to be able to shed light on understanding the empathic process.

4.5.5 Validity and reliability

In all research, it is of upmost importance to address questions regarding validity, or the soundness of the analysis. As this project includes persons who communicate non-verbally, validity became even more crucial (Boxall & Ralph, 2009). How can one be sure that the proxies are voicing the person's view, or that the researcher is able to understand the person's communication and grasping the intention? The latter, involving epistemic questions concerning the mind of others, represents one of the more challenging aspects regarding validity of this thesis. This will be thoroughly reflected upon in the methodological reflections in chapter 6.

In addition to the aim of grasping the intent of the other in more direct ways, one way of trying to address the challenge of validity is to involve multiple voices, and in that way, possibly counteract misguided interpretations. Liamputtong refers to the concept of 'polyphony' (from Marcus & Fischer 1986 in Liamputtong, 2007, p. 19), which involves the registration of different point of views in multiple voices in the representation. In the design, several people who knew the person was recruited, both family and staff, to gain several views, in addition to my own view, as the researcher.

It would be naïve to assume that I can get an in-depth knowledge through a period of 3-4 months together with the person, but I will argue that another gaze represented by a researcher might expand the knowledge on how to understand the person. To spend sufficient time in the field is thus one procedure a researcher can employ to check the accuracy of the findings (Creswell, 2018). In this study, the very design—involving few cases and staying a prolonged time in the field might be argued to enhance validity (Mietola et al., 2017; Simmons & Watson, 2015). In addition, REC also approved the use of video-recordings of clarified and defined interactions between staff and the person in regard. Video can be argued to ensure the perspective of the person to a greater degree than just the researcher's fieldnotes after doing observations (Kaley et al., 2019; Rojas & Sanahuja, 2012). But still, it is important to be sober regarding its use, as it should not be understood as presenting a direct view of the person's perspective; it is still seen from a perspective—from myself as a researcher holding the camera.

Respondent validation or member checking (Hammersley & Atkinson, 2019) has also been applied throughout the fieldwork, both during informal talks and interviews, and a more thorough check at the end of each case through the dialogue meeting. In these meetings my initial understanding of the person and suggesting of different ways to put these into words were presented and discussed together with both family and staff. These reflections included both validation and additional information regarding the person's way of being and communicating, and other descriptions of the phenomenon evolved in the dialogue, thus adding to the knowledge. The dialogue meetings invited the professionals and family to validate preliminary understandings and inform further analyses (Miles et al., 2020).

Ethnographers look for patterns, and patterns might be described as a form of ethnographic reliability (Fetterman, 2020). The included descriptions presented in the articles should thus contribute to providing the readers with these patterns. But still, it must be recognised that the representation is perspectival (Alvesson & Sköldbberg, 2018), and is very much influenced by my perspective.

4.6 Research ethics

The project has been evaluated by the Norwegian Centre for Research Data, NSD (ref. 472016) and Regional Ethical Committee, REC (ref. 107188), which means the project is found to answer issues regarding the handling of personal data, and the demands of the law of health research. This can be termed as the procedural ethics of the research (Guillemin & Gillam, 2004). Also, guidelines such as the declaration of Helsinki (2013), the European Code of Conduct for Research Integrity (ALLEA, 2017), and National Ethical Guidelines (NESH, 2021) function as a map for how to conduct a study in an acceptable manner, but they will not be sufficient for providing concrete rules of action. This leads us to ethics in practice, a dimension regarding how to solve and think about day-to-day ethical issues that arise in the doing of the research (Guillemin & Gilam, 2004). The research therefore needs ethical reflections throughout every aspect, from the preparation, fieldwork, analysis and understanding of the material, to communicating the findings. And in these successive processes, I was guided by normative ethics indicating what to do or not do in different situations (Israel & Hay, 2006). In the following, thoughts on vulnerability will be presented as a guide for the reflections on ethics in practice, touching upon the approval process, the inclusion of persons with PIMD, and some concluding remarks regarding researching during a pandemic.

4.6.1 Addressing vulnerability

The concept of vulnerability in research was first introduced in the Belmont Report in 1979, signalling the possibility that some groups may have a higher risk of harm or having wrong done unto them (Bracken-Roche et al., 2017). The Universal Declaration of Bioethics and Human Rights (UNESCO, 2005), article 8 stated that: ‘Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected’. Vulnerability, both in research and in life in general, implies that some special protection is needed, and in research it can be argued that persons who cannot consent should not be included (NEM, 2005). But at the same time, the risks are also underlined involving the exclusion of vulnerable groups (NESH, 2021). Exclusion might lead to additional marginalization; it is only through a better understanding of the conditions in the person’s life that treatment and care for people can be enhanced (NEM, 2005). The challenge for research involving vulnerable groups is to balance these guidelines; this includes both the need for protection with the potential benefit of including vulnerable people.

Persons with intellectual disabilities are often described as vulnerable, both in general theorizations (Lid, 2015; Scully, 2014) and when it comes to research ethics (Solbakk, 2015). Disabled people are among those commonly held to be especially vulnerable. Scully, an ethicist writing on disability, argues that the more vulnerable a person is believed to be, the less likely it is that others will treat the choices the person makes as worthy of respect (Scully, 2014). Bracken-Roche et al. (2017) found that the ethical guideline regarding vulnerability tends to reinforce stigmas about categories of individuals. They further point to the fact that there is too little attention to the importance of context.

One advocate for a view that vulnerability does not just apply to persons with disabilities—but rather that it is a universal human condition—is legal theorist, Fineman (2010). She argues that all humans carry an imminent possibility of harm. It is therefore wrong to attach vulnerability to specific subgroups. This also because the term has an air of victimhood attached and being labelled as vulnerable is thus stigmatizing (Fineman, 2010). Likewise, Mackenzie et al. (2014) presents a view where the universal perspective is important but where also features are incorporated from the view that some people are more vulnerable. They argue that this way allows for identifying possible responsibilities and interventions to mitigate effects of different forms of vulnerability. They suggest a taxonomy where both the universal and the contextual are incorporated.

Such a view on vulnerability as both an ontological human condition and as situational/contextual can be fruitful. Scully (2014) argues that vulnerability and disability

must be seen as a particular manifestation of something more general that all humans experience in one way or another. This should not be understood as rejecting the notion that people with disabilities have inherent vulnerability directly resulting from impairments, but that one should still take in the perspective of the contingent social or environmental factors that may have an influence. Scully also addresses the danger in extrapolating a genuine vulnerability in one area in a disabled person's life, to mean that they have global vulnerability stretching over their whole being. This can strongly harm the person's agency and lead to their exclusion from being considered a citizen (Scully, 2014). With this, the exclusion of persons with PIMD from research as a rule appears to contribute to further marginalisation.

The suggestion from Mackenzie (2014) that the duties that arise out of vulnerability are best met when the aim of fostering autonomy and promoting capabilities are involved, are also experienced as productive. This is important to avoid paternalistic and coercive practices under the discourse of vulnerability and protection (Mackenzie, 2014). Vulnerability must not be understood to be in opposition to autonomy, but rather reconceptualised to take in the relational aspects that are universal to all humans. This is important to achieve democratic equality (Mackenzie, 2014, p. 41), for instance through ensuring that people with profound intellectual and multiple disabilities are given enough support to enable them to be self-determined.

4.6.2 Reflections upon the approval process

The project has a social focus on aspects of self-determination and is not to collect any individual medical information, other than the inclusion criterion of having a profound intellectual disability. The project was thus initially thought to not be a health research-project. REC, however, experienced it as a case of doubt and since they regarded the persons included as a vulnerable group with extra need for protection, they favoured it to be regarded as a project under the regulation of The Health Research Act (2008). What views the committee have on vulnerability I cannot know, but they base their work on guidelines stating that the decisive point in including vulnerable people is that specific procedures and safeguards are in place (NEM, 2005). So, for the project to gain approval I had to address the committee's questions and demands. In this process I experienced a mismatch between the language in my original sketch sent to NSD and the demands from REC. I had to reply to comments difficult to meet due to the committee's application of medical language, for instance when they urged me to describe how I would *measure* self-determination. My aim,

however, is not to measure but to describe the phenomenon. I found myself trying to transform my project into a language I thought the committee would understand (Guillemin & Gillam, 2004). Similar experiences are also pointed to by other qualitative studies, where some argue that a social science project is treated unfairly by committees tied to medical models of research ethics (Ramcharan & Cutcliffe, 2001). What I found useful in this process though, set aside from it being very time-consuming, was that the committee urged me to be more explicit in my argumentation of including non-consenting participants. This raised my consciousness and reflections when it came to potential benefits and possible harm to the participants, being urged to think through, once more, potential situations that might emerge during fieldwork.

4.6.3 Including persons with PIMD

Informed consent has been positioned as the cornerstone principle of research ethics (Rhodes, 2005), and the Helsinki declaration (WMA, 2013) argues that if a study includes persons not capable of giving formal consent, then the benefits must outweigh the possible harms. If a person, after all means are conducted to facilitate information, is judged not able to give an informed consent, then the guideline in Norway requires that an informed consent by proxy should be obtained (NEM, 2005). The ethical guideline states that research including people who cannot consent to participation should only be done if: a) the research cannot be done with people who can consent; and b) where it is probable that the research will be of benefit for the included group.

I have already argued the case of including the persons not able to consent, to counteract further marginalisation. Furthermore, the study involved no direct treatment or intervention or altering of services and as such represented no apparent harm. But to be researched can create anxiety or worsen a stressful situation (Hammersley & Atkinson, 2019) and it is important to find ways to include consent in ways other than through the formal written one. Calveley (2012) argues that capacity to consent is a legal construct based on an individual's ability to meet some criteria. These criteria might seem to undermine the person's unique way of communicating, and it could be argued that even though persons with profound intellectual and multiple disability could be assessed to lack capacity to consent, they may be able to demonstrate capacity if their signals are assessed over time. This should be an ongoing process (Calveley, 2012). This can also be labelled 'process consent' (Tuffrey-Wijne et al., 2008), involving the continuous attention to whether a participant is happy or would rather not engage with the researcher. Other sensitive ways of assessing the person's ongoing

approval of research activities to evaluate possible harms (e.g. as described by Mietola et al., 2017; Simmons & Watson, 2015; Stefánsdóttir et al., 2018; Watson et al., 2017) have also informed the study. Prior to doing fieldwork I talked with close family to get a first-hand knowledge of potential participants. This is in accordance with the guidelines stating that one should consult with someone with good knowledge of the persons and their unique way of communicating (NEM, 2005). Also, the primary caretakers were consulted prior to starting observations. We agreed to have an ongoing dialogue regarding what situation I should partake in and not. I experienced that both the family and professionals were very inviting, and at the end it was up to me to decide what felt right to participate in. I chose to not engage in intimate situations of changing diapers and observing in the bathroom and instead to observe only in situations when clothed or covered by towels, perhaps reducing the person's vulnerability. Such a decision still triggered reflections upon whose vulnerability I was aiming to secure, my cultural experience of what was to intimate or the person's actual experience. It is a fact that the persons in regard were used to such intimate acts performed with a vast number of professionals, and thus my decision to withdraw might not represent an important ethical call for the person.

In two of the cases I experienced no distinct negative signals to my presence, and as such no indications that I should withdraw. I still chose to abort one observation in a situation where both the person with PIMD and the professional apparently expressed distress. I also withdrew from a situation with epileptic activity, to provide the space for the professional to attend to the person without my disturbance. In one of the cases I experienced that the person at times could be understood to react to my presence, and at one occurrence I was uncertain to whether her not wanting to eat was the result of me being in the room. I then decided to end the observation.

The professionals were invited to consent to the different activities in the projects, and all participants gave full consent, while one of them did not want to be filmed during observations.

4.6.4 Pandemic

Doing research during a global pandemic has added aspects concerning the demand that research should not expose the participants to any harm. When planning the project, prior to Covid-19, the aspect that the physical presence of the researcher could impose a risk was not an issue. The project was stopped momentarily in the period between March and June 2020, due to the globally uncertain situation. In these first months when institutions and

workplaces were closed and very strict social distancing was the new normal, persons with PIMD experienced even stricter regulations—not being allowed to have any visitors in their homes and not being able to attend the few activities they might have had in their lives (Patel et al., 2021). In the part of Norway where this study took place these first strict rules were changed, and during the spring, most activities had resumed. Adhering to the threat of the virus, however, and yet again pointing to all humans’ inherent dependency and vulnerability, I, as a researcher, still found it important to reduce contact—moving even beyond the national guidelines. During fieldwork, approximately two metres of distance was obtained, with no physical contact. During active periods of fieldwork, I reduced my social contacts to a minimum, choosing not to travel to my office, but rather to work from home, reducing visits to shops, social arenas, and so on.

CHAPTER 5: Findings

Given that this thesis is article-based, comprised of three articles, I will now present a summary of each article focusing on their specific contribution to the overall project. The articles can all be argued to explore the phenomenon of self-determination, putting the lens on how to understand, practice, and build knowledge (RQ 1-3). The context of exploration is within professional relations, and the thesis also contributes with insights relevant in informing philosophical issues regarding ethics connected to professional relations (RQ 4). This is done in more implicit manners in the three articles and will be more explicitly dealt with in chapter 6, Discussion, departing from the findings on self-determination presented in this chapter.

Each article departs from the ethnographic material and in this presentation demonstrations of these are included, hopefully to bring to the fore the persons in regard. The three articles' main significance will be presented, before synthesising the findings, suggesting perspectives from the persons in regard.

5.1 Article 1: on congruence

In the article 'Self-Determination: What Can We Learn from Persons with Profound Intellectual and Multiple Disabilities' (Skarsaune et al., 2021), an attempt to rethink the concept of self-determination in ways relevant for persons with PIMD is undertaken. The most outspoken contribution of the article is in regards to the theoretical understanding of the concept. But, as will be demonstrated, the article also contributes to more practical and methodological matters. The article suggests a foundation for the further thesis, trying to conceptualise self-determination in ways that incorporate the dependency inherent in everyone's life, and in particular, in the life of persons with PIMD.

Self-determination is often equated with independence and rational choice-making— aspects that make it of little relevance for persons with PIMD. Departing from the definition of Ryan and Deci (2017), stating that self-determination involves the experience of congruence between behaviour and preference, an attempt to broaden the concept was initiated—one that does not necessitate independence. Through an abductive approach, and moving from an ethnographic beginning toward a dialogue with self-determination theory before proceeding into theorisations guided by an ethics of care (Kittay, 2019), the concept was explored. The questions guiding the article were:

- How is self-determination unfolded in the caring relationships between persons with

PIMD and professionals?

- How can these processes contribute to a theoretical rethinking of the phenomenon of self-determination?

Departing from the ethnography, situations found to describe self-determination in forms of movement or action towards congruence are presented within the frame of the three following headings: ‘voicing and being voiced for’, ‘acting and being acted for’, ‘choosing and being chosen for’. These indicate that self-determination might occur on a continuum of independence-dependence, sometimes being able to reach congruence independently but more so in relations hallmarked with dependence. The following excerpt from the ethnography demonstrate how this might play out:

‘After a long, hectic day at school, Tiril places Vera in the beanbag to relax. Tiril turns on music, and Vera’s relaxed face and body signal her contentment. After a couple of songs, Tiril find the micro-switch and invites Vera to indicate that she wants more music by touching it with her chin. After a few somewhat reluctant efforts, Vera turns her head away from the switch. Sensitive to the situation, Tiril asks, ‘Is this not what you wanted?’. She moves the switch close to Vera’s chin to give her another chance, but Vera remains motionless. ‘You’re quite right, Vera. You should be able to listen to music without having to press the switch’ (Skarsaune et al., 2021, p. 323).

Here it might be argued that Vera, rather than communicate her will through a microswitch perhaps enhancing independence, demonstrated her preferences through Tiril’s close engagement with her body. Engaging with the data, the notion of closeness arose as a possible existential dimension in the material, suggesting that self-determination increases, along with the degree of closeness and possibilities for co-construction in a caring relationship. With dependency, though, comes asymmetry and relational power, issues that Kittay (2019) address in her suggestions on how to manage dependency. The ethnographic descriptions dialoguing with Kittay’s notions led to suggestions on how to understand self-determination in a more broadened way than merely as independent choice-making. For one thing, communication must be acknowledged as more than words. We all have communicative bodies, and we must free ourselves from the belief that meaning is best communicated verbally and be open to how meaning can arise through non-verbal ways. Furthermore, self-determination is much more than individualised acts of independence—the ethnography has given testimony on how congruence might unfold within partnership. For

this to happen, Kittay's (2019) fruitful suggestions highlight the importance of sensitive support in dealing with the dependency that such partnerships might include. The last point of discussion argues that self-determination moves beyond choice-making and should rather be viewed as ongoing processes of being understood. And these might be found in small moments of everyday living. With these suggestions on how a rethinking of the concept of self-determination might unfold, the article concludes with underlining the importance of remaining aware of the specifics of each person when searching for self-determination. There are no universalised insights in this matter, and a sensitive attention towards each person's singularity is of utmost importance. Hopefully, this broadening of the concept, demonstrated through the life of the persons in regard, will contribute to a belief and a view that the human right to be self-determined is relevant even for persons profoundly dependent.

5.2 Article 2: on holding

The article 'Holding and Professional Care – On Self-Determination for Persons with Profound Intellectual and Multiple Disabilities' (Skarsaune & Hanisch, 2023) moves from the theoretical approach toward the practical question on how to go about supporting self-determination within the professional relation between persons with PIMD and professionals. Building on article 1, the second article applies a view upon self-determination as something more than merely independent choice-making. Grounded on a social-ecological model of disability (Shogren et al., 2018), underlining the importance of determining and implementing the appropriate support, self-determination is understood as something that can unfold within caring relationships. The intention of the article is to fill the gap in knowledge regarding how to support self-determination in these contexts, focusing on details in the relationship.

The concept of grasping the person's identity emerged as essential in the ethnographic material, for the professional to be able to support self-determination, leading to the writings of Hilde Lindemann (2014) and her concept of *holding another in identity*. Her theorisation emerged as potentially fruitful to understand how to support self-determination within professional care relations. Lindemann (2014) emphasises the need to be supported in one's identity formation, a view that Ryan and Deci (2017) will agree upon. Lindemann has mainly explored holding within the field of dementia and within the care of the family, and in this article the concept is put up against a somewhat different context, aiming to add to the theorisation of the concept of holding. The questions guiding the article are:

- How is holding unfolded in professional caring relations with persons with PIMD?

- Can holding inform the realisation of self-determination within professional practices?

The lens of ‘holding in identity’ suggested two entries when engaging with data: one representing the spontaneous occurrences in everyday interactions; and the other displaying the more systematically planned facilitating efforts. The material demonstrates how the professionals assist the persons with PIMD through holding efforts: recognizing and responding to embodied expressions through everyday interactions, through facilitating for experiences believed to be preferable, through the exposure of familiar experiences and through moments of joint experiences. In the following excerpt, holding through a perhaps preferred experience is demonstrated.

Erik cries in the move from the changing room to the pool, signalling discomfort. While lowering his body into the water, floating on his back, his face changes into a gentle aspect. His eyes are open, he is making chewing movements. Carer Hanna holds him in her arms, his back against her chest. She tells me that she can sense him relaxing, while imitating the chewing movements he is known to make when content (Skarsaune & Hanisch, 2023, p. 30).

Hanna might in this instance be understood as holding Erik through engaging him in a preferred activity, his chewing movements perhaps suggesting that he is experiencing congruence when being in the water. The transfer from the changing room to the pool display the opposite, with Erik’s embodied communication of crying.

The material gives several demonstrations of situations where one might expect the person to experience holding, but holding efforts also come with the need to let go and situations of losing hold. To hold is an act of temporality and conditioned with a need to let go. Letting go can occur when the professional ends her shift for the day, or retires, demonstrating some of the many breaches that follow from professional relations. These are situations that are perhaps anticipated and planned for, while there are also several demonstrations of the professionals losing hold, e.g., through misrecognition. To hold another, and perhaps especially persons not able to contribute with their own verbal accounts, is embedded with uncertainty and the potential of losing hold is present.

These specific ways of holding in the professional care context are to some extent different from the already well explored field of holding within dementia, due to its consistent asymmetry and not being based within the love of a family. To deal with the profound dependency that always are present in persons with PIMD’s lives and the professional context, the work of Kittay (2019) has been of guidance. Through this work three aspects in

the relation are pointed to as relevant in the context of PIMD: caring practices must be facilitated in ways that support the professional's responsiveness to the other's need, one must be sensitive towards embodied non-verbal ways of being, and avoid attitudes that argue that human rights and moral worth is linked with independence and rationality. The article argues the case that if a professional cannot hold the other in identity, there are futile possibilities for self-determination.

Further, the article addresses three aspects of the professional relationship with implications for moving professional practices towards realisation of self-determination for persons with PIMD. The first being the importance of recognising the role of the professional—just as the professional can enable a person, that professional might also hinder the person's self-determination. This puts strong demands on the structure and leadership of professional services, where the professional must be capable to provide this kind of holding. This leads to one important competence of the professional, namely, to be able to grasp the other through embodied empathy. The ability to understand someone's body through empathy further points to a third aspect, namely that the professional must be enabled to be involved in the life of the person receiving support. To reduce risks of paternalism and neglect, it may be argued important to be connected to the person and in some ways feel for the person.

While many people will agree on the principle that all persons are entitled to human rights, like the right to experience self-determination, there might be uncertainty regarding how to practically go about supporting it. Hopefully, the suggestions from the concept of holding in identity (Lindemann, 2014) merging with Kittay's (2019) ethics of care will provide some practical pointers regarding details in the relationship that might foster possibilities of self-determination.

5.3 Article 3: on empathy

Building upon the two former publications, the article, 'Persons with Profound and Multiple Learning Disabilities as Subjects of Knowledge – Exploring the Possibilities of Empathy' (Skarsaune, 2023b) goes further into the question of how to understand the person with PIMD's identity through embodied communication and moreover exploring fundamental questions on how to recognise persons with PIMD as subjects of knowledge. This is an important topic both regarding how to include this perspective in research and in clinical practice, but also on a more philosophical level regarding ethics, and how to address challenging professional relations. To treat persons with PIMD as included members of

society involves treating them as subjects of knowledge—through their perspective. The main contribution of the article is thus regarding philosophical and methodological questions—how to value persons with PIMD as subjects, letting their lives inform knowledge. This is explored from both a theoretical perspective of empathy and engaging with the case of the ethnography, exploring relations between persons with PIMD and their professionals and conditions for self-determination, arguing that through the researcher’s time to focus and log what occurs, notions on empathy might be suggested.

The article sets out from the CRPD (UN, 2006) stating that all persons have the right to full and effective participation and inclusion in society. To achieve this right, it can be argued that all persons must be addressed as subjects of knowledge who are consulted regarding matters in their life. Perspective can be understood on different levels, both displaying a thorough view on a matter, and as reactions to a given situation, displaying preferences (Ware, 2004). How can we get hold of the view of persons not communicating verbally? Such questions lead to epistemological reflections on what we can know of others. Within philosophical debates, two main lines have dominated, arguing that such knowledge is inferential versus perceptual. The inferential view holds that the possibilities of understanding another must be based on either theories or self-simulation, while a perceptual view argues that through notions of intersubjectivity and empathy, there are possibilities of grasping another through a more direct engagement with the person in regard. Within the context of persons with PIMD, there have been several arguing a precaution in getting hold of the view of persons not verbalising, necessitating interpretations and inferences (Cluley, 2017; Ware, 2004). Although precautions are understandable, they might lead to attitudes that these are persons not able to state their perspective, and practices dominated of talking on behalf of the other, reducing persons with PIMD to objects (Simmons & Watson, 2015).

Starting out in the ethnography, three stories are presented. These are stories found to display characteristics of the process of understanding the other, e.g., represented by the story of Karen dancing to music:

Karen is standing in the Innowalker. Her arms hang down. She is moving her upper body rhythmically to the music playing. Carer Maria asks: ‘do you want the music to be louder? I know you like this song’. She turns the volume up; Karen lifts her head and laughs. She moves her left hand up towards her mouth and nods her head to the music (Skarsaune, 2023b).

Through the ethnographic material, some intuitions on the process of understanding

the other came forward, and where in particular the embodiment on both sides of the relation were experienced. Erik, Vera, and Karen clearly communicated some feelings, e.g., being happy as Karen demonstrates quite clearly in the included excerpt, feelings that were leading to affective responses in the other, either being able to grasp what might be the other's intention or in situations of uncertainty—an aim to understand. These instincts led to the field of empathy, as a possible lens to unfold the phenomenon that was playing out, aiming to answer:

- What are the possibilities of recognising persons with PIMD as subjects of knowledge through empathy?

Empathy comes with several understandings, amongst others diverging on what degree a cognitive and emotional component is dominant (Fernandez & Zahavi, 2021b). Stein (1989) presents an understanding that is found to be able to balance the cognitive and the emotional in ways able to avoid the pitfalls in an overly optimistic view in either. Due to her concise presentation (Zahavi, 2016) this was the chosen theoretical framework. Her writing is also providing innovations to ethics (Andrews & Calcagno, 2022), which might prove fruitful within the context of persons with PIMD.

She writes from the tradition of 'einfühlung', feeling into another. This involves a process of getting hold of what is expressed through embodied gestures, but also what is hidden behind these (Stein, 1989). This does not entail to feel as one with the other, but to be pulled into the other's horizon. Her understanding of empathy as initiated and accessed through feelings, as a process built on a relational framework and of being multidimensional, is unfolded through the demonstrations of the ethnography. With this as a backdrop, it is argued that there are hallmarks in the context of PIMD that might fuel the empathic process. This is firstly connected with the competencies of persons with PIMD regarding embodied being and affective language, contributing to the empathic process, motivating, and pulling the other in, thus enabling the process of feeling-in. Furthermore, persons with PIMD's sometimes ambiguous way of being might be found to motivate empathy to a larger degree than in situations of clarity. And in these situations, the misunderstanding comes with a potential of renewed understanding. The final point of reflection is the dependency that to an enlarged degree is portrayed in persons with PIMD's lives. Dependency relations, with the need of close and often intimate interactions, can be found to initiate an appeal in the other in strong ways. This further underlines the ethical dimension of empathy, and where the personalistic approach in Stein argues that the other is other, and thus can never be fully grasped (Urban, 2022). This otherness is what should guide our understanding of others.

The exploration concludes that empathy can take us further in including persons with PIMD, both in research and in society, holding the other's individuality high. Further, the exploration points to the ethical dimension in empathy, demonstrating how the appeal of the other is both impossible to ignore, but at the same time partly inaccessible, leaving some aspects of the other undisclosed. And, that the knowledge gained from empathy is temporary, based on the here and now, and should thus not be applied in static, fixed manners. This also has implications for the application of empathy as a tool in research. The presentation of an emphatic understanding of another should not be valued as a static fact, but rather as one possible understanding. It can be argued that empathy in research might counteract research that portray persons in objectifying ways due to the intention of engaging closely with the person in regard (Wharne, 2021).

Our ethical responses should be to always position another as subjects of knowledge. This is knowledge relevant both on how to address challenging professional relations within the context of persons with PIMD, but also as an entrance to how to ensure the right to be self-determined—empathy being one way of grasping the mind of another, not through their verbal words but through embodied communication.

5.4 Synthesising findings

The three articles all contribute with somewhat different perspectives on the topic of self-determination. But despite having a main area of focus, the articles still overlap and contributes on all the thesis' research questions. The articles were written in the order presented, as it was found relevant to start with an exploration regarding the conceptualisation before moving onto more practical questions and ending with philosophical and methodological aspects. But the process has not been linear, moving strictly from concept-practice-methods, but rather circular—constantly influencing each other, and as will be demonstrated in the following table, demonstrating the intertwinement.

Table 6: Synthesized findings

Paper	Perspective 1: How to understand (RQ1)	Perspective 2: How to practice (RQ2)	Perspective 3: How to build knowledge (RQ3)
1: On congruence	Congruence as an entrance; involving embodied processes of being understood within partnerships.	Listen to embodied communication, manage partnerships through sensitive support, and focus on moments of being understood.	Intersubjectivity as an entrance to share in another’s experience. The condition of mediation and co-construction of meaning.
2: On holding	Building on the concept of congruence: involving having one’s identity understood. This entails support from others, e.g., professionals.	A professional must be capable of holding the person in identity; recognizing the role of the professional, enabling embodied empathy and involvement.	Intersubjectivity and the co-construction of narratives.
3: On empathy	Unfolded through being understood on non-verbal communication—through empathy.	Empathy as a factor in professional relationships: Engage with the other as subjects of knowledge.	Empathy as an entrance, through feeling in and the act of perceiving and imagining.
Integration of findings	Self-determination, as congruence, understood as a relational and embodied phenomenon.	Self-determination can be practiced through empathy and holding relations.	Balancing elements of mediation, co-construction, and empathic understanding through close engagement with the lived experiences.

The overall premise of the thesis is to explore through the perspective of the persons with PIMD, valuing them as research subjects. The three articles thus suggest learning points regarding the thesis’ three first research questions, and possible perspectives from Vera, Karen, and Erik, which will be briefly summarized.

5.4.1 Self-determination understood as relational and embodied (RQ 1)

The lives of Karen, Erik, and Vera suggest a need to broaden the understanding of the concept of self-determination, involving it to move beyond independent choice-making. The ethnography gives several demonstrations of what might be understood as the experience of congruence, i.e., that their behaviours are in harmony with preferences. This is demonstrated to be possible within relations of dependency through embodied holding relations aiming towards grasping the others' identity. The belief that all self-determined acts must be based on verbalised and rational acts is contested and rather it is something that depends on the support and the co-creation of important others. The lived experiences give testimonies of how a broadening of the concept, hallmarking the relational and embodied aspects, necessitates reflections upon how to manage the asymmetry and possible power structures embedded. It is thus suggested that empathy is a vital component in such understandings of the concept. Although never being able to totally grasp another, it is found useful in guiding the management of the professional relations in sound ways and as a mean to grasp the embodied communication.

5.4.2 Ensure self-determination through empathy and holding relations (RQ 2)

Karen, Erik, and Vera demonstrate lives that are unfolded within caring relations. They give evidence on how they take active part in life through the sensitive support of their professional carers. The relational framework also sheds light on the fragility of experiencing self-determination, being dependent on the person caring for them. Recognising the important role of the professional, both in the construction of identity and in the actual facilitation of congruence, is thus important. To enhance the professional's ability to empathically grasp the other necessitates some form of involvement on behalf of the professional, setting them capable of feeling into the other. The act of empathy is one that sets the other person's alterity in the front, aiming to engage with the other as a subject of knowledge, an attitude important in holding relations. The persons with PIMD have given several demonstrations that caring cannot be done at a distance, and that rather closeness is called for.

5.4.3 Ground knowledge on lived experiences and the individuality of the person (RQ 3)

Karen, Erik, and Vera express their perspectives through embodied communication, and thus did not unveil their meaning through verbal, formal ways. This necessitates an

approach on the matter of including their views in innovative ways. The method of ethnography, informed by entrances like sensory ethnography and the method of infant observation, has proven useful in enhancing empathic understanding and thus perhaps being able to grasp embodied intentions. The thesis argues that identity and self is to be understood as constructed within relations, and further it has been argued that the support and mediation of the other is important in all meaning-making, thus underlining our interdependency. Attempts of including persons with PIMD thus often relies on significant others' understanding and interpretation, which has also informed this thesis. But additionally, the study has explored the phenomenon of empathy, as one potentially fruitful way of pushing inclusion further, arguing that one can also understand another without inferences. Such attempts call for the recognition of feelings as epistemic resources, and it is further demonstrated how persons with PIMD demonstrate competencies relevant for the process. Balancing the mediating role in the co-construction process and the possibilities of getting hold of the person's perspectives requires putting individuality at the forefront, holding on to the other's alterity. Karen, Erik and Vera demonstrate that they possess knowledge that should be taken account of, available if opening up understanding on how meaning is communicated and can be understood.

CHAPTER 6: Discussion and conclusion

In this closing chapter the overall intent of the thesis will be discussed: *What can we learn from persons with PIMD on self-determination and ethics on professional relations?* The first element of the question, regarding self-determination, has been addressed through the three articles engaging with the thesis' three first research questions. In this chapter the aim is to discuss the added value and scope of the overall contribution. This forms the backdrop for answering the thesis' fourth research question: How can the case of self-determination in the context of PIMD inform ethics on professional relations? This will be unfolded, making explicit a synthesised suggestion from the theoretical framework, as a response to suggestions from the ethnography. This leads to the chapter's third section, suggesting an ethics on holding as the thesis' contribution regarding self-determination and professional ethics. As the project came with an ambition to include persons with PIMD in research, a section discussing the methods applied are included, critically addressing the perhaps bold suggestion of grounding knowledge on the perspective of the person with PIMD. The chapter finishes off with some concluding thoughts, returning to the thesis' starting point—reflection upon humanity.

6.1 What can we learn on self-determination?

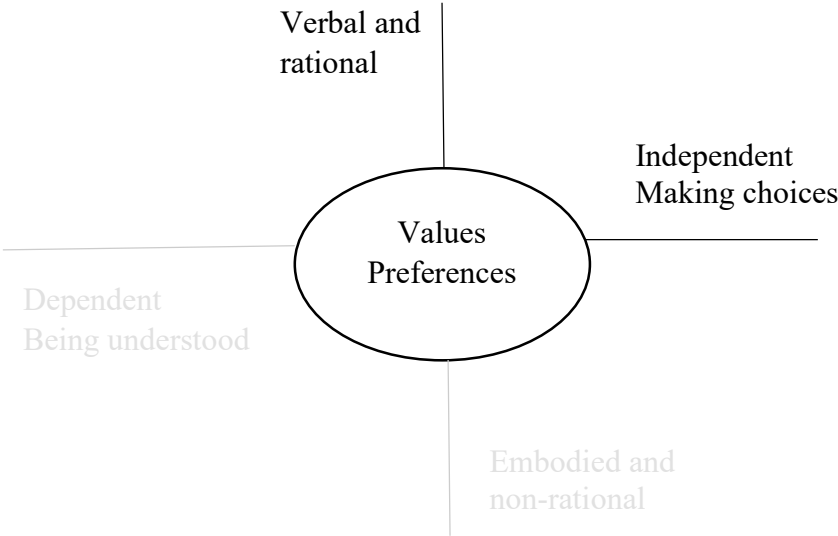
The thesis started out with the human right of self-determination, as described in the CRPD, article 3 (UN, 2006, p. 5) stating the principle of 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'. As demonstrated through the thesis, such understandings might come with challenges in the context of persons with PIMD, but still, it is the prevailing view on self-determination. Departing in this traditional scope on how to understand self-determination, the overall contribution on self-determination from this thesis and implications of these, will be discussed.

6.1.1 *The added value and implications*

Embedded in the human rights lies an understanding that self-determination comes to show through the individual's steadfast determination, communicated and understood through rational and verbal manners. The determination can unfold on different levels, both displaying the person's self through immediate responses to a situation, demonstrating preferences, and involving more thorough views on a matter, portraying the person's values (Ware, 2004).

Following the language in the human rights, self-determination is thus connected to independent choice-making, representing a person’s values and preferences.

Figure 2: The scope of a traditional understanding on self-determination



As this figure indicates, in addition to the suggestions emerging from what might be understood as a traditional understanding, there might be more to the picture, indicated by the blurry spots. The visualisation suggests that there are aspects of the phenomenon present but hard to grasp when informed by a traditional perspective. The main contribution from this thesis is a suggestion to move beyond traditional understandings emphasising choice-making and independence, but still the findings also relate to the language as suggested by human rights framework, as will be demonstrated. Departing from the framework of article 3 in the CRPD it will be discussed what is at stake and further implications of an expanded understanding of the phenomenon, thus perhaps enhancing possibilities of grasping the totality of the picture.

The understanding that self-determination is connected to the ability to make one’s *own choices* is the prevailing understanding today, both within research (Kuld et al., 2023) and practice, and as also demonstrated through the language applied in political documents. During fieldwork, such understandings were clearly present: some professionals were sceptical regarding the relevance of the concept of self-determination for the persons they

cared for because they only to a small degree were found able to make their own choices. This resonates with other studies demonstrating that the concept is experienced with little relevance for persons with PIMD (Voss et al., 2021). The ethnography demonstrates how professionals aim to secure the person's self-determination through making choices, for example, presenting different food choices, or responding to the person's gestures as an indication of their choices in a given situation. There are thus several demonstrations on self-determination unfolded in conventional ways, aiming towards the person's own choice-making. Through the demonstration of the lives of persons with PIMD, however, comes also other understandings, suggesting that the steadfast conviction on what one wants is not always the case, and rather than displaying self-determination through a firm decision, it is more often displayed as an ongoing negotiation on being understood, thus pressing forward the need for a rethinking. The thesis thus adds an understanding that contests the equalisation of self-determination to choice-making (Shogren et al., 2018). Such broadenings of understanding might be met with scepticism, regarding the concept being diluted and perhaps hard to evaluate. As an example, it might be easier to conclude that a person has been involved and exercised self-determination through making a decision regarding, e.g., how to spend money or what to eat for dinner, than through a person unable to verbalise signalling that they experience congruence through the professional receiving and responding to their embodied ways of being. But is the first example portraying the essence of being self-determined more than the latter? It is this thesis' ambition to suggest that both examples are linked to self-determination, but that the latter perhaps expresses the essence of self-determination.

Also, notions on *independence of persons* are found in the ethnography, demonstrated through efforts of professionals to secure self-determination through the facilitation of the persons independent acting, e.g., through Vera's use of the micro-switch to indicate wanting something more. The professionals argued that the person thus could put forward their meaning in ways not necessitating the professionals' interpretations, thus perhaps reducing misunderstandings. Although sympathizing with the intention, it was experienced that the switch acted more as a hearing aid for the professional, than a method for the person to communicate their wants. This is argued because the professionals demonstrated that they were able to understand the person without this aid when relying on the person's embodied communication. But still, some professionals were reluctant to confide in such. This might reveal an inclination for reality to be presented in vivid, unambiguous ways, and where verbal or at least independent ways of communicating might come forward as 'truer', not embedded

with the uncertainty or messiness of involving the aspect of understanding another through embodiment. To exhibit modesty when interacting with persons without verbal language, not presuming what the other is telling us (Kittay, 2019), comes forward as a sound approach, that also the professionals advocated. But if this modesty is taken to the extreme, the ability to include persons with PIMD in the discourse of self-determination will face challenges. The question on why Vera should communicate via a microswitch saying in verbal words, ‘I want more’, when she communicates her message perfectly well through her facial expression, is a valid one, pressing forward the understanding that self-determination can exist within dependency relations. The thesis is not opposing efforts of enhancing a person’s independence, e.g., regarding mobility suggested by Benford (2017), but to equalise self-determination with independence seems to present a narrow scope.

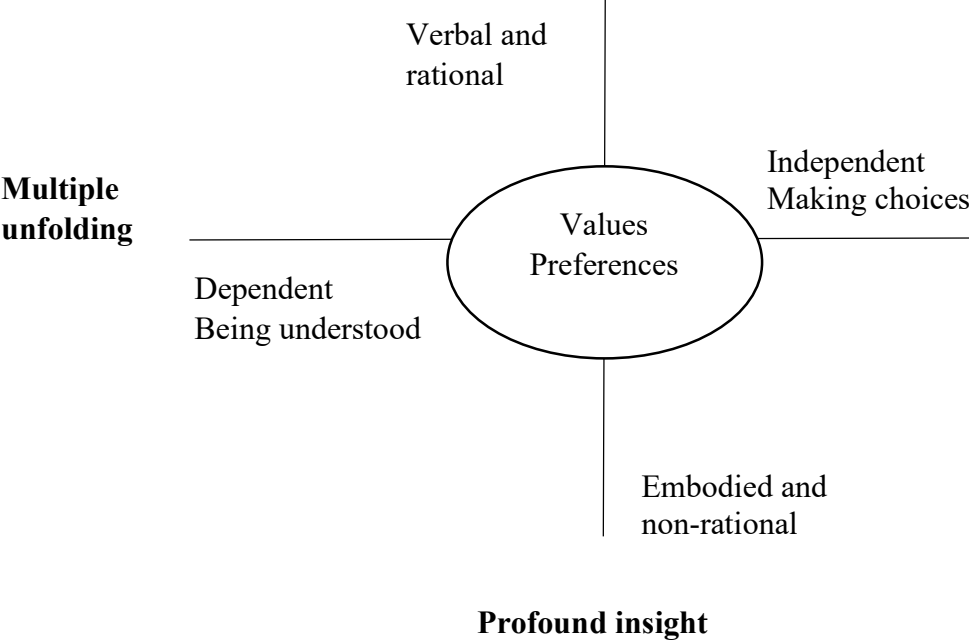
With this understanding on self-determination to not be merely about independent choice-making, comes a reliance on meaning as communicated in non-verbal ways. This is challenging though, as humans are very much set on favouring information given verbally, being reluctant to involve embodiment due to its alleged ambiguity. Thus, this necessitates the complicated task of challenging beliefs firmly rooted in at least Western philosophy, connected to the confidence in rational thought (Avramides, 2020). If we are to take the testimonies of persons with PIMD as valid knowledge, their ways of demonstrating congruence must be taken into account. The suggestion from this thesis is therefore to argue the awareness and status of dependent, embodied ways of being, and that we ought to put more effort and reliance in both the feelings displayed in the person’s embodied communication and in abilities to understand communication through other means than the verbal, through notions suggested by empathy and holding relations.

6.1.2 Self-determination as a multiple and profound phenomenon

The phenomenon of self-determination demonstrates the close interplay on how meaning is communicated and understood and how the phenomenon is experienced. The added value to the experience connected to dependent, embodied ways of both understanding and being understood thus suggests that the scope of the phenomenon involves something more, both in depth and in width, expanding the range of the phenomenon. Leaning on the suggestion from Simmons and Watson (2015) that more complex understanding is needed through what we listen to and how we listen to open for deeper understandings of the agency of persons with PIMD, this thesis argues that understanding on the phenomenon on self-determination requires both a profound and a multiple understanding. A figure displaying

these suggestions forms the basis for the further discussion:

Figure 3: Self-determination as a multiple and profound phenomenon



This thesis aims to take multisensory ways of being, including the role of feelings into account. It is argued that a traditional view steers understandings of self-determination into an over-emphasis on the verbal and/or rational act. The ethnography advocates that the many ways of being human must be considered. Hence, we must expand our view of how meaning is communicated and understood. Self-determination should thus be understood as a heterogenous phenomenon varying from verbal, independent choice-making as well as embodied, dependent processes of being understood, thus counteracting the more homogenic understanding of the phenomenon. The enlargement on how self-determination is unfolded relates to the several different situations that are embedded when both values and preferences are in action, and where the thesis argues that self-determination should be understood as a multiple phenomenon, also involving being understood within dependency relations. Such understanding is argued to represent a sounder way, for all humans, grasping self-determination within a continuum, thus being sensitive of the many ways to be human.

The ethnography provides several demonstrations on what one might call rudimentary forms of self-determination, e.g. when Karen is understood and facilitated for on her desire to listen to loud music. ‘Rudimentary’, in this context, simply means that self-determination

takes place without leading to what a traditional view would consider as self-determination through higher-level acts of independence. The thesis argues that such hierarchies of supposed higher-level and lower-level are superficial, and that any adequate understanding must consider that different forms are mutually interconnected. A philosophical approach to the phenomenon might argue that self-determination is a profound phenomenon. This involves that a person can hold both a steadfast view on a matter, communicated in clear and independent manners, and displaying more rudimentary preferences, perhaps emerging within a close partnership with another. In a traditional view, the first might be thought of as representing a higher level of self-determination—a position this thesis aims to counteract, suggesting that even more rudimentary and embodied ways of being can be embedded with notions on a person's views and values, thus relating to supposed higher-level acts. This relies, however, on the level of analytical insight the other part in the relation holds, and the thesis thus argues that self-determination is connected to the ability to engage with and understand bodily communication, both through a sensual and emotional level. This will involve insights both on a more rudimentary level, involving small moments in life where one can experience congruence through, e.g., being understood on one's preferences and also aiming to grasp the more complex understanding, e.g., through being able to facilitate according to the person's values and wishes.

All attempts to put understanding into figures and forms comes with the risk of oversimplifying, and the suggested visualisation (figure 3) is no exception. The visualisation should not be understood as representing a view that the traditional scope always presents a uniform and superficial understanding, but rather that the primary contribution of this thesis is the illumination on the multiple and profound aspects of the phenomenon. What is suggested is the complexities embedded in the phenomenon of self-determination.

When we approach and try to understand a phenomenon, we always apply a framework affecting experience. The more traditional lens highlights independent choice making, and that what should be conveyed by the other are clearly stated wishes and values, which risks losing hold of the entire picture. The traditional understanding might therefore be a hindrance to gaining a hold of the complexities of self-determination. The thesis would thus argue the importance of opening one's understanding, both regarding how meaning can be communicated and understood, and the ways the phenomenon might thus unfold. As demonstrated through the ethnography, there are several demonstrations of practices holding more traditional views on self-determination, but also combined with sensitive attempts of approaching the matter in ways more coherent with the way of being suggested by persons

with PIMD.

If such understandings are implemented within professional practices, it might contribute to professionals grasping the entire picture, including persons profoundly dependent. The advancement, though, involves a messier concept, including a wide range of situations and ways that self-determination might unfold. This puts high demand on the professional, thus leading us to the further exploration on ethics on professional relations.

6.2 What can we learn about ethics on professional relations?

The matter on ethics has been implicitly dealt with in the thesis' three articles: The different theoretical lenses applied suggest ways to understand the professional relations, in particular depending on the ethics of care as unfolded by Kittay (2019). The thesis also leans on other studies engaging with professional ethics in the context of persons with PIMD (e.g., Nieuwenhuijse et al., 2022; Jacobs et al., 2021) where ethical approaches is applied. But based on an understanding that ethics are what occurs in the actual encounter, the table might be turned—arguing that through these lives, ethics on professional relations can be understood. Ethics are what evolves through the encounter with the other, in this thesis through the engagement of an individual with PIMD, and thus the lens is on what we can learn about ethics from the persons in regard.

Guided by the ethnography suggestion will be made on what matters in the life of persons with PIMD, leading to extracting ethical, relevant reflections from the three contributing theories. Relevant ethical thoughts from Stein (1989), Lindemann (2014), and Kittay (2019) will be presented, aiming to demonstrate their specifics and the potential added value of merging their views. Relying on feminist ethic's sensitivity toward relations, combined with phenomenological insights regarding essentials of human nature, both potential insight and possible critics of the suggested guidelines will be addressed. The attempt is inspired by others who have indicated links between phenomenology and feminist ethics, as Vosman and Nortvedt (2020) demonstrating the kinship between phenomenology and ethics of care, and suggestions from Urban (2022) arguing the connection between Stein's theorisations and ethics of care. This thesis adds to these contributions through the context of persons with PIMD, suggesting guidelines for an ethics on professional relations.

6.2.1 Particular and complex

Through the exploration on self-determination, the unique identities and way of being of Erik, Karen, and Vera have been demonstrated. They portray specifics through various embodied manners, all having distinct ways of communicating through, e.g., a wrinkle over the nose, a gentle aspect in the face, or perhaps a high-pitched sound—gestures that might mean distinct things in different contexts. Their lives give strong testimonies, arguing that no recipe can be applied when providing professional services, and rather time must be spent to become familiarized with the embodied individuality of the person. When questions on how to act in a particular situation emerge, one must rely on the information in the here and now, rather than on some overall guideline. This might thus be an argument for ethics grounded on the particular.

Proponents of the opposite, arguing that ethics must be universal, state that to secure fairness and impartiality, ethics must be able to respond to all humans regardless of context. Such thoughts are grounded in the Kantian ethics, arguing through the categorical imperative that what applies for one person should apply for all (Hugman, 2005). The human rights, and the CRPD, which this thesis departs from, are founded on a universalistic perspective, following a view that we all have the same universal needs, for food and shelter (Hugman, 2005) and even self-determination. But the rights are demonstrated to come short in the more concrete case of persons with PIMD, as also prior research points to (Wilson et al., 2008). This has led to feminist accounts arguing that ethics should rather be based upon responsibilities on specific relations and the particularities rather than on rights (Kittay, 2019; Lindemann, 2019). Such views also come with critics, as already indicated in Chapter 3; the particular might make one oblivious to the broader concerns of social justice (Lindemann, 2019), and may lack reflections on questions concerning ethical partiality (Nortvedt et al., 2011), which might lead towards an ethics of universalism. Kittay (2019) describes this possible indifference to distant others and argues that although weaker than those close at hand, they are nonetheless morally significant. Stein (1989) agrees with several of the points from feminist ethics and opposes the view that ethics should be grounded on a priori, universal principles (Andrews 2022a). She might be found to provide argumentation on how to address challenges related to ethical impartiality: Rather than emphasising the context-related and situated nature of all moral knowledge, Stein underlines the idea of the absolute value of the human person (Urban, 2022), also involving those distant. But still, it might be challenging regarding how this is to unfold in practice—who distributes the care in, for example, a housing facility, if the very relationship should lead the direction? Another

challenge of grounding ethics on particularities is related to the messiness, or losing the tidier and more impartial universalism. To steer one's acting as a customized answer to the individual's specifics is perhaps more demanding, than abiding to some uniform principles. To this, Stein would argue the complexities of humans, thus anticipating elements from an ethics of care (Andrews 2022a). The attraction towards a belief that reality can be grasped without any messiness, that one can get hold of some tidy 'truth' that applies to all is understandable. But it is a perspective that fails to recognise the particularity and complexities and the many ways meaning and singularity can unfold. Without holding the specific individual highly, we may risk professional services lacking empathy and compassion (Nortvedt et al., 2011). The ethical encounter in the ethnography clearly demonstrates the importance of engaging with the particularity of the person, necessitating person-centred care.

Virginia Held (1995), a proponent for feminist ethics, problematizes the priority of care over principles of justice and argues that justice is important to avoid paternalistic and maternalistic domination. She suggests that care should be the wider moral framework into which justice should be fit. I am sympathetic to the importance of the responsibilities of the relationship, but still the universal principles in human rights are important in securing rights and regulating professionalism and counteracting challenges of a narrower scope from the care perspective. Leaning on Held's (1995) view, this thesis thus suggests that the ethical guidance from Kittay and Lindemann, with additions from Stein, might prove fruitful in guiding the broader concerns of justice. This would involve that justice, e.g., through the human rights, must be able to relate to the personalistic and more nuanced ways of being human, which include dependency and embodied being. The human right principles should thus be altered in ways that are more in sync with the actual ways of being human—underlining dependency and embodiment, notions that will be unfolded further in the upcoming sections.

6.2.2 Dependent and other

The lived experience of persons with PIMD have suggested essentials of human relations, and how these come with dependency. All humans depend on others, and in the case of Vera, Karen, and Erik, this condition is highlighted and enlarged. Through the exploration on self-determination, we might thus learn essentials on the dependency that we all, to some extent, experience during a lifespan, e.g., what is involved to need the support of others on intimate matters or being nurtured and living a life in congruence with one's own preferences and values. The interdependency in the ethnography is vivid and thus it might be argued that

it should be these relations hallmarked by dependency that should inform ethics.

Moral theories have a long history in arguing the opposite—that nurturing and advocating for independence is the ethical and sound thing to do. Modern theories of ethics, particular within Western cultures, generally begin with independent autonomous individuals (Kittay, 2019), strivings that arguably have been important to counteract oppressive systems. But still, to ground an ethics on such might ignore the actual elements of being human, if we try to convince ourselves that we are truly independent. This also resonates with the concrete case of self-determination, where the multiple and profound understanding of the phenomenon advocates implementing self-determination within dependency relations.

An ethics arguing dependency and relational aspects comes with challenges, though, and an ethics of care has been accused of possibilities of losing sight of the separateness of the person one cares for (Kittay, 2019). The enmeshment with others in dependency might lead to erasing the needs of the carer, but also to impose the need of the carer onto the other, leading to paternalistic services. Although not departing from disability, Stein’s writing is arguably relevant to all asymmetrical relations, suggesting ways to manage such challenges through the argument that the other is fundamentally other than oneself—or else it would not be two subjects displaying their particularities. And this difference is of utmost importance to hold onto. It involves that any account on humanity will always involve parts of another that is impossible to completely understand or explain due to the profound otherness of the two interacting parties. As Stein describes, ‘the other will always be other, the other and I will never be the same’ (Stein, 1989, p. 17). Jolly (2022, p. 41) states through her understanding of Stein that, ‘the more we engage with otherness, the more we understand what it is like to be human in a multi-faceted way, and this helps shape our understanding of humanity’. Jolly (2022) contends that Stein’s understanding of empathy might aid in developing better relationships. This she links to Stein’s way of urging us to be fully open and vulnerable to the other, thus allowing the other to remain different, contributing with theorisations relevant to the argument that dependency should guide in ethical encounters. To explore the dependency that hallmarks the lives of persons with PIMD might provide to be valuable insight for all humans.

6.2.3 Embodied and ambiguous

Karen, Vera, and Erik display their interests, their disagreement, and their happiness—their identity through embodied feelings. Persons with PIMD can be found to be highly effective in communicating through embodiment. When Karen lifts her head up high and

smiles, or Vera in silence wrinkles her nose, the feelings are strong and relatable, facilitating emotional understanding and responses to the professional. Although the professionals of course have rational information on the person who supports their caregiving (i.e., information on their communication, preferences, how they prefer to be transported), there are still several testimonies where professionals have been guided on how to understand the other, and thus how to act, through some emotional understanding. This demonstrated, e.g., when carer Hanna responds to Erik's cry, trying to inquire into his distress, or when carer Maria picks up on the positive spirit of Karen dancing. This might thus argue that ethics are to be guided by embodied feelings.

The opposite view—that rationality is what should guide—has several proponents. As Hugman (2005) describes, in modern times, philosophy has been built upon faith, not in gods or God, but in the capacity of human reason. Rationalism, seeking to understand the world through objective observations, is together with universalism the cornerstone of modernist thought. Emotions were deemed unreliable and unruly due to their subjective and particular nature (Hugman 2005).

Reason and principled thinking do play an important role in care practices, for example, reasoning over what our responsibilities are in each situation. But, according to an ethics of care, this must be done in ways where emotions are a part of the reasoning (Keller & Kittay, 2017). Emotions, and thus embodied communication, are thus a central motivation when acting on behalf of another, as an ethics of care argues (Kittay, 2019). Also, Lindemann describe how feminist ethics opposes the picture of rationality embedded in Kantian ethics, which excludes emotions. She argues that feelings should be acknowledged as playing a useful role in moral thinking (Lindemann, 2019). Stein is found to add valuable insights to feminist ethics: the ethical dimension of empathy as understood by Stein (1989) has demonstrated how a person's unique way of being, informed by feelings, is what should guide us in our interacting, arguing the case of interconnectedness and sensibility to the other's alterity. And this does not involve feelings only on the behalf of the person with PIMD, but also that the professional is constituted by feelings, and through the engagement with their own feelings one might be able to grasp the other.

The suggested arguments, that meaning can arise in complex ways including emotions as epistemic resources, might trigger stress or anxiety due to uncertainties and inherent ambiguousness. Critics hold that emotions are not a reliable source, but rather an impulse that can lead to cruel and irrational behaviour. These risks might be enhanced when putting forward a view that empathy involve an act of feeling the same as another, as e.g. Bloom

(2016) advocates, thus being sceptic to its relevance in moral reasoning. Stein (1989) counteracts this and argues that the role of feeling does not involve feeling the same, but to feel into the other, holding on to the separateness of the other. When engaging with persons with PIMD, this comes forward as an important point: that we allow the other's differences. Furthermore, Stein argued to enhance the complexities and ambiguousness of humans, through a perspective involving a broader grasp on what it means to be human, not just describing the physical, visible body, but also the elements of being human that one cannot rationally perceive. She unfolds a sensitivity to the aspects of being human that is not always visual by perception of embodied gestures, but by the ability to grasp 'what is hidden behind them' (Stein, 1989, p. 5). Stein might thus be found to put into words a more complex and possibly ambiguous understanding of humans, emphasising the role of feelings. Addressing the claim that emotions are unreliable, care ethics replies that these should be cultivated and modelled for the appropriate ethical use (Kittay, 2019). This thesis has suggested Stein's framework as a fruitful model to apply in the cultivation and practice of empathy, one that also underlines the many uncertainties in understanding another.

6.3 Suggesting an ethics on holding

So far, a profound and multiple understanding of the phenomenon of self-determination, and that professional relations should be guided by engaging with the particular, dependent, and embodied has been argued. Nortvedt (2020, p. 156) argues that 'the crucial issue from the perspective of phenomenology as well as care ethics, is that they both as ethical perspectives situate normativity not in impartial reason, but in relational and affective, intuitive experience'. This involves involving with the hallmarks of human nature as complex, other, and ambiguous. This further indicates another essential on the topic of professional relations—namely, that the work of caring for persons with PIMD is comprehensive and complex, both regarding the level and timespan of the care. It is intimate, thorough, and often involves the totality of a person's life, not having the aim of, e.g., reduced care, or regaining independence.

As a response to the comprehensiveness of the caring act, this thesis suggests an ethics on holding. The suggestion is a development of Lindemann's (2010; 2014) concept of holding another in identity. The far-reaching scope of the care of a person with PIMD demonstrates similarities of care within families, which Lindemann's theorisations departs from. An ethics adequate to meet the suggested demands will be suggested through different ways of holding another, enmeshing the already suggested notions on self-determination and professional

relations. Embedded in the act to hold another comes challenges related to issues on power, which will be discussed. The section ends with possible implications from an ethics on holding on professional practice, training and politics.

6.3.1 Emotional holding, embodied holding and holding-together

Lindemann's (2014) concept of holding is primarily understood as a metaphor: how one can support the others' identity through sensitive narration. This was an act found relevant when engaging with the ethnographic material, where the professionals held the person through several different acts they believed constituted essentials of that person, e.g., in ways they described the person, or how they facilitated the environment through preferable, recognizable situations. These are all acts that have an element of mental holding—holding the person's identity in mind, and allowing this to inform how one further facilitates the environment. When unable to communicate and inform verbally on how one prefers care, then the capacity of others to grasp one's intention, or holding one's views come forward as important. There are demonstrations that to hold in mind are fruitful within professional practices, e.g., in the work by Watson et al. (2019), arguing the relevance of using narratives as enabling caregivers' responsiveness. In the current study, it was demonstrated that during fieldwork, with a focus upon the topic of self-determination, the professionals became more conscious on the matter, perhaps demonstrating the sensitivity of situations that could be possibilities of self-determination. Following the writing of both Stein (1989) and Kittay (2019), this way of holding necessitates emotional aspects, informing on the other person through emotional engagement, perhaps grasping that individual's values. Through the thesis' emphasis on empathy as a fruitful way of getting hold of the other's identity, this way of mentally relating through holding will thus be termed emotional holding, involving being present, recognizing and acting upon the other person's feelings.

A dictionary understanding of the verb 'to hold' ('to hold', n.d.) comes with a more physical understanding than suggested by Lindemann, defining it as to grasp by some physical means. This depicts a concrete understanding of the word, describing the act of holding someone with the aid of one's own body. This is also touched upon in the theorisations of Lindemann (2014) arguing that the mental holding is connected to the involvement with the body of another. But even more so, the ethnography demonstrates this actual, physical encounter, providing several demonstrations of the practical, concrete handling and holding of the body, in the further termed embodied holding. To care for Karen, Erik, and Vera necessitates closeness—emotional but also in embodied manners—and how

this is acted upon should be an essential element of an ethics on holding. Psychoanalyst Winnicott (1965/2018) described the holding environment, characterizing the infant and the caretaker, consisting of an emotional but also physical element. When a mother physically holds her child, she takes care not only of the physical needs but also the psychological aspect. This demonstrates the importance of relating to the body of the other in sensitive, secure, and dignified ways. Vorhaus (2014) argues that this involves enquiring into what it is like for someone to live their life, and that must arguably also involve how bodies function and how a person prefers to be physically held. During a day the professional engages intimately with the person in several ways: transporting, clothing, feeding, and comforting, to mention just a few. And everyone varies on *how* they prefer to be touched, if there are body parts more sensitive and even hurtful, and whether they prefer to cuddle on the lap of the carer, or not. The intention of the thesis is not to state that the one or the other way of engaging with the person in embodied ways are more right, but to urge a sensitivity to what the other communicates is their preferred way, as the embodied holding constitutes one important way of holding the other. The professional must be close enough to engage in the negotiation on how to hold the body of another. And in these matters, there are arguably a close connection between holding emotionally and embodied, underlining the wholeness of the person.

A third suggested element of the holding act is connected to the element of holding the fragmented pieces of different relations and services the person experiences, one that can be termed holding-together. In the case of persons with PIMD the number of institutions and professionals can be numerous, and staff turn-over is a constant challenge of such services (Hatton et al., 2001; Murray et al., 2022), with potential of losing the overview. The profound need of care thus comes with a call to secure information flow in ethical ways, knowing what kind of information can and should be shared. The suggestions from the framework on supported decision making, as unfolded by Watson and Joseph (2011), demonstrate the importance of assembling significant persons together to reflect and make decisions together, through building supportive networks, thus demonstrating an element of holding-together. In the current study, the professionals and family members met for a dialogue meeting with the intent to validate and correct initial analyses and understandings. These meetings were experienced as valuable, and also beyond that, being a platform to connect the pieces, learning from each other about the person. It thus seems important that the act of holding also involves the different services and professionals providing services, securing cooperation and information flowing, thus advocating an act of holding-together.

In 2022, Norway implemented a right to be appointed a coordinator for persons needing complex services (The Patient and User Right Act §2.5b), the intention being that the coordinator is to secure the cooperation within services, and thus perhaps providing a person set to do the holding-together. This might be a person representing one of the institutions the person receives services from, and can be both professionals knowing the person well, e.g., if providing services on a daily basis in school or a housing facility, but also more peripheral professionals representing institutions the person has more seldom contact with. Without providing any conclusions, one reflective question may be: is the person most able to hold the person in emotional and embodied ways perhaps the person best fit of holding-together?

6.3.2 The aspect of power

To hold another comes with the possibility of doing injustice—one might hold the other in ways not recognising the person. This might come to show e.g. as misrecognising the person's likings in music (emotional holding) or positioning the person in the wheelchair in uncomfortable ways (embodied holding), or not passing important information from something happening at school forward to the professional taking over at the housing facility (holding-together). A related concept of holding is to control the other, a possibility that comes with the holding act. The theoretical framework applied in this thesis deals with aspects of power, and Kittay (2019) describes the potential vulnerability in asymmetrical relations. Adding to this, the ethical demand put forward by Løgstrup is found to be clarifying when aiming to put into words the aspect of power embedded in relations. He described the ethical act through the metaphor of holding parts of the other's life in one's hand, and how this can involve both small matters, 'but it may also be of tremendous significance, so that it is simply up to the individual whether the other person's life flourishes or not' (Løgstrup 1956/2020, p. 15).

Without going into depths of the ethical theory of Løgstrup, the extract from his ethical demand is useful to demonstrate the power embedded in relational ethics, where the act of holding another is enmeshed with power. In the context of caring for persons with PIMD this gets fortified, demonstrating the potential power of the professional in contribution to the flourishing of the person, or not. In Løgstrup's theory, trust is an important aspect, and with trust comes power; the trusting person gives the other power, and this is a demand on the trusted person to use his/her power for the good of the person who trusts (Stern, 2020). There is thus a delicacy in the relations, that must be managed.

An ethics of holding involves taking in the specifics of the individual. The embedded

condition of the complex and ambiguousness that comes from the aim of securing the peculiarity of the persons can only be overcome by an ongoing interest in taking in the other. In the case of persons with PIMD, this seems even more pressing, as they profoundly rely on someone attending to their unique ways of communicating. An ethics of holding further aims to stay tuned onto the particularities, not trying to be the same and thus meeting the condition of the otherness embedded in the understanding of humans as dependent. To stay sensitive to the other as a subject should always be of guidance in the encounter with others, but in the case of persons with PIMD it is even more essential, as they will have a harder time contradicting wrongdoings. Through the act of holding a heightened status of embodied meaning, responding to the understanding that humans are more than rationality is tempted. In the case of persons with PIMD it is a way of respecting their very way of being.

6.3.3 Implications of embroiling holding relations in practice, training, and politics

If professional relations are to be grounded on an ethics of holding, this puts high demand on the professional and the supporting system of the professional. Some might even argue that it is utopic to assume that a relationship between a paid professional and the person with PIMD can come with expectations of holding, due to its close and intimate callings. It is an ethics that puts the balance between involvement and distant professionalism at stake.

Similar reflections are also found in other caring professions, e.g., child welfare services, and where some argue the importance of implementing love, understood as compassion and recognition, in services (Thrana, 2016). The concept of love is also present in the theoretical framework of this thesis: Kittay (1999/2020) writes that the phrase ‘love’s labour’ is often used in caring for dependents. But she argues that love is neither necessary nor sufficient for well-done dependency work or care (p. 2). Still, she mentions love and compassion as important motivations when acting on behalf of another (Kittay, 2019). The aim of this thesis has not been to explore the concept of love within professional services, but clearly there are notions of similar affections in an ethics of holding. Without concluding on the matter, the thesis aims to put the lens on close, intimate holding relations, hopefully contributing to further discussions on the matter. These holding relations come with implications.

When it comes to the traits of the very relations within professional practices, this thesis argues the importance of skilled professionals being able to meet the conditions of the dependent and embodied human nature, recognizing what the consequences might be if not taken into account. If the professional does not hold the other in the suggested ways, then it

might lead to poor relations with the consequence of a degraded quality of life for the person, including scarce opportunities to experience self-determination. Although the current study has depicted moments of self-determination, it has also revealed practices of the opposite—hallmarked of the many routines that persons with PIMD endure during a day. If such gets to dominate, persons with PIMD risk leading ‘narrowed lives’ (Vehmas & Mietola, 2021) with little opportunities to engage in activities most of us take for granted. Several of the care workers participating in the study reflected over this, urging that fieldwork rather took place when something ‘exciting’ happened, e.g., going to the pool or attending music lessons, indicating that home life for the most part was filled with routines and slow living. During fieldwork it was experienced that the participating professionals critically scrutinized their own practice, perhaps triggering them to move beyond routines and mere custodial maintenance of the body (Kittay, 2019). One of the professionals put into words how she during the project was able to critically reflect and change her own practice, letting herself be informed by the person’s guidance rather than just follow a set of fixed routines. Such reflections might contribute to holding the other in more sensitive ways. Pointers related to the professional relations have been suggested in all of the thesis’ articles, demonstrating the importance of facilitating close relationships. A practical challenge though, regarding providing 24-hour services, is that the amount of staffing is often relatively high (Murray et al., 2022).

This indicates how an ethics of holding depends on professional systems that support such relations. Murray et al. (2022) found that professionals were more motivated to stay in their jobs if the structures allowed them to hold relations with the person they supported, with the reward of feeling that they contributed to that person’s life. This also resonates with what the professionals participating in the current study reported, being motivated by the possibility to influence positively in another’s life. How staffing is distributed among care receivers should thus be an issue of consideration, as also other studies on persons with PIMD have argued (Gjermestad & Skarsaune, 2022). The thesis argues the importance of close dependency relations being accounted for in the management of staff rotation. Also, the professional might experience conflicts on what one experiences as important to the person and possibilities to act on it, for example, regarding availability of different services like the pool or sensory rooms. Quality of services are thus connected to the entanglement of material and economic resources available, and skilled staff, all affecting possibilities to provide services in accordance with the person’s needs.

The most important factor, though, to ensure self-determination lies in the hand of the

professional, as Løgstrup (1956/2020) argues, and to train competent professionals is of utmost importance. Students in Norway training for, e.g., social educators, the primary group working together with persons with intellectual disability, must meet a curriculum and learning objectives that puts the focus upon competences fostering holding skills, through engagement with particularity and dependent and embodied ways of being. This thesis will suggest that more focus should be put upon ethical reflections regarding how to provide intimate care, and the close and intimate act of holding the other. Students should be trained in what is involved in holding; both emotional and embodied holding and on holding-together, thus training on the holding of the whole person. The need for knowledge specifically directed towards persons with the most profound needs is important. Several of the professionals reported that they were trained in intellectual disability, but mainly regarding those able to vocalise. This also reflects the status on research—there are rather few studies including persons with PIMD. Both the skilful handling of the other’s body, as well as engaging with concepts of empathy is important, and having an overview of the totality of services in that person’s life. When it comes to empathy, it is argued that this is a competence that can be improved through instruction and practice (Bas-Sarmiento et al., 2020; Fernandez & Zahavi, 2021a), and that such training should be incorporated in the curriculum. This thesis might contribute on how such training can be organized with suggestion of training students’ ability to act and reflect upon how to get hold of the particular emotional communication, how to secure the otherness, and not fusing them with one’s own preferences, following the guidelines from Stein (1989). From contemporary writings on empathy, following notions from Stein, it is argued important to train students in applying the attitude of empathic openness when engaging with others, addressing their individuality and their particular situation (Fernandez & Zahavi, 2021a; Zahavi, 2022).

To facilitate systems that nurture professional relations of holding, involves that such views must be recognized in political writings. Change is emerging also within the political domain regarding self-determination, expanding understanding to embed supporting structures (as, e.g., described in Arnstein-Kerslake et al., 2017). The thesis is sympathetic towards attempts in countries like Australia, the United States, Ireland, and Canada, moving from guardianship involving substituted decision making toward the notions of supported decision making, thus aiming to include persons with PIMD in policy. This is a call for change that pushes inclusion forward, and where methods like Circle of Support (Watson, 2016) are vital in ensuring the human rights for all. But still, a more sensitive engagement with the human condition of dependency is needed in the political language regarding self-

determination, moving beyond the ideal of choice-making and independence, broadening the understanding to involve both a multiple and profound understanding on self-determination.

Furthermore, politics and guidelines regulating practices ought to have ways of ensuring that the person's actual preferences are met. During fieldwork, great focus was experienced upon the attendance of the person's physical needs, sometimes perhaps overruling the focus on the person's psychological needs. This presented itself, e.g., in the many routines that the professionals are informed must be done regarding physical training or medical treatment. It is not this thesis' intention to suggest that such routines should be dropped in favour of facilitating the person experiencing congruence, but still the thesis aims to nurture reflections upon it. To experience self-determination and a life in congruence is a basic human need vital for thriving (Ryan & Deci, 2017). For this to be facilitated, there must be a raised awareness of this group of persons, making them visible as members of society.

These are persons that tend to be separated from others, living their lives in segregated rooms, with isolation and invisibility contributing to their exclusion from debates (Nind & Strnadova, 2020b). This might be one reason that political writings bear little notice of their specifics. And in this matter, it is vital to include and make these voices heard and listened to. As such this thesis might add to the important contributions of other researchers who have included the perspective of the person with PIMD in research (e.g., Evensen, 2018; Mietola et al., 2017; Simmons & Watson, 2015; Stefánsdóttir et al., 2018; Watson et al., 2017)—aiming to make the perspective of persons with PIMD known and further to make these count when making policies.

6.4 Methodological reflections

Leaning on other studies that engage closely with the lives of the persons with PIMD (e.g., Simmons & Watson, 2015; Mietola et al., 2017; Stefansdottir et al., 2018) this thesis comes with an aim to contribute with methodological explorations regarding how close one might come the perspective of a person not communicating in verbal, rational ways. To what degree can the suggested arguments of this thesis on self-determination and ethics on professional relations be argued to depart from the perspective of the persons in regard? And what might the way forward regarding the inclusion of persons with PIMD in research be?

To this latter question, de Haas et al. (2022) presents an optimistic position, arguing for the embrace of new possibilities of inclusion. But still, the critical aspects and challenges of inclusion needs to be addressed, which Maes et al. (2021) identifies as connected to,

amongst others, participant recruitment, analysis, and ethics. In the following, methodological reflections will be undertaken, including both the optimistic approach through innovations, and the critical perspective. It will be suggested what this thesis adds to the current knowledgebase, implications of such, and proposing a way forward. The reflections start out in the concepts of mediation, co-construction, and empathy, also unfolded in Chapter 4, demonstrating implications on epistemology, researcher skills, and research ethics.

6.4.1 Implications on epistemological understanding

Epistemological reflections in the thesis have been centred on possibilities on knowing the mind of another. Moving beyond epistemological paradigms of positivism engaging with science through what is believed is observable and measurable facts (Alvesson & Sköldberg, 2018), this thesis argues that knowledge must be understood as a relational phenomenon. The three concepts applied in this thesis—mediation, co-construction, and empathy—all take on a relations view upon knowledge. And as such, the incorporation of significant others and the use of multiple voices are relevant to include, as several other studies within the field of PIMD also have done (Haines, 2017; Mietola et al., 2017; Simmons & Watson, 2014; Stefánsdóttir et al., 2018; Watson et al., 2017). These studies share the view that meaning is not understood as an individualistic endeavour, a position this thesis also holds.

This thesis has obviously been informed by notions on the importance of being sensitive to the inferences embedded in attempt to grasp another, and thus the following suggestions from concepts like mediation (Cluley, 2017) and co-construction (Teachman et al., 2018) are relevant. All research should involve some precautions, being transparent on the subjective nature of knowledge, even when including persons who can verbalise their intention—all research is also mediated through a researcher (Alvesson & Sköldberg, 2018). The study's choice of presenting a 'best practice' (Benner, 1984) ethnography represents one such act of mediation—where I as a researcher determine which parts of the lived experience is presented in the written ethnography. This leads to delimiting the portrayal of characteristics of the relationships that the persons experience. This might contribute to portraying a more positive picture of the situation than if the design also included observations of other, less skilled professionals. It is not to be denied that persons with PIMD as a group risks several violations on their humanity, meeting professionals that hold negative perceptions on abilities to participate in e.g. decision-making (Voss et al., 2021). This is not highlighted in the current study, and it is thus important to communicate in transparent ways the choices made, and the mediating premises of the ethnography.

The more novel aspect of this thesis' methodological contribution is the exploration of possibilities to access knowledge through more direct means: through perception and empathy. This is an attempt to take inclusion one step further and explore if empathy might provide us with a tool in research that enhances our ability to grasp the other's body as subject, as 'Leib' (Fernandez, 2020). I will argue that on many occasions it was easy for me to understand the person: I could sense and perceive, e.g., whether the person was content or not. And there were many cases where there was more uncertainty. These lead me in partnership with both the person with PIMD and the professional, toward an aim to find out, engaging in emphatic acts of perceiving and imaging, and balancing both emotional and cognitive resources, engaging with processes similar to mediation and co-creation. At times I believe that I could feel into the other, grasping some salient features of the person, but still holding on to the understanding that to know exactly what that person meant and intended is impossible, and always presents with a challenge of misrepresenting the other (Vehmas & Mietola, 2021). According to Andrews (2022a, p. 237) 'Stein reminds us that what is given by apperception is given always along with what is *not* given'. Apperception includes what remains unseen, hidden, incomplete, or transcendent in the other. This point is also suggested by Moran (2017) who argues that although one might get hold of aspects of the others' lived body, the first-person perspective can never be fully disclosed. This should be relevant not just for embodied knowledge, but also information given verbally. An awareness of these aspects is important in the attempts of positioning another as the subject of knowledge and using these uncertainties as resources in further trying to understand.

So, with this background: how far can empathy take us regarding the inclusion of the perspective of the person with PIMD? Wharne (2021) argues that the application of Stein's account on empathy in research, leaning on emotions, might reduce risks of abusive forms of knowledge production, and of approaching the research participants as 'someone'. Surely, Stein's way of addressing the inherent value of all humans, might contribute to researchers being attentive to the person. The challenge, as Wharne (2021) points out, is that while we attend to how another person makes us feel, we must also be able to separate this feeling with what the research participant is experiencing. Also, if we are to follow the logic of Stein (1989), empathy is an act in the here and now, relying on the actual perception and feeling in, and thus of, temporary nature. To what degree is it then relevant to present a researcher's potential empathic understanding and portray in written words for others to rely upon? There are certainly challenges of such, and perhaps the best one might aspire is to provide thick descriptions of the lived experience, for the reader to ponder over self. The descriptions and

understandings on Vera, Erik, and Karen that I have presented must not be dealt with as facts, but as one possible understanding in that very moment (Magri, 2015). The suggestions I present as my empathic understanding cannot be taken for representing any truth, but rather to motivate others to engage directly with the lives of persons with PIMD.

With the attempt to grasp the person's perspective, the current study has also explored possibilities of enhancing reliance on knowledge beyond verbal accounts, through what can be perceived and sensed in a broader manner. This is in line with the suggestions from de Haas et al. (2022) that to assess the perspective of another does not necessitate words. This opposes the scientific belief in the rational and verbal, and rather argues for a messier understanding, involving a broadened understanding of epistemology. Such inclusion will add to the knowledgebase on persons with PIMD, as most research is based on the verbal reporting from proxies (Nind & Strnadova, 2020b). It might even contribute to the phenomenological research base: Although phenomenologist like Merleau-Ponty (1962/1998) and Stein (1989) argue that one can understand another from engaging with another's body, there still seems to be a rather small base of empirical studies exploring from the context of PIMD, where verbal accounts are not possible. Often phenomenological research aiming to unfold a first-person perspective relies on the phenomenological interview (Gallagher & Francesconi, 2012; Høffding & Martiny, 2016). This thesis might thus contribute with empirical material, arguing that even behavioural evidence is valid as subjectivity (Klinke & Fernandez, 2022). Through Stein's (1989) notion on empathy, the close engagement with the other, with openness to be affectively moved, might contribute to how to get hold of the first-person perspective of a person with PIMD. More reflection and exploration regarding the possibility to grasp the body as subject, rather than merely body as object, as corporeal, is thus needed.

6.4.2 Implications regarding researcher's skills and research ethics

Involving epistemological understandings as argued for in the former, including several ways that meaning can be communicated and understood, puts high demands on the sensitivity of the researcher. It involves reflections on how to deal with sense data in addition to visual information, and what can be experienced through listening, touching (though not in this study due to the Coronavirus Pandemic) and not least of which can emotionally be sensed.

Watson (2020) argues that through steering away from interpretation but rather reporting on what was seen, interpretations could be kept to a minimum. This was also

attempted in the current study, but still, the written word can never be a direct representation of the world; it seems to be an impossibility. The current study aims to give room to ethnographic descriptions rather than definitive conclusions and allow space to ponder the descriptions (Skarsaune, 2023a). Even though the study came with the guidance of methods arguing the importance of paying attention to the sensory (Pink, 2015) and emotional aspects (Hollway, 2016) of the researcher's experiences, this was found challenging. Despite preparations and intentions of taking in the sensual and emotional information, the domination of the verbal and rational was vivid when starting to write up fieldnotes. My experience is that, at least for me, this is a skill I need to practice and reflect upon. To do this with the aid of supervisors or others who one can critically reflect together upon what one is actually experiencing was found highly valuable, in addition to attending practical courses integrating phenomenological methods with empirical research.

Another essential experience during fieldwork was the importance of staying with the person over time. This was demonstrated through the field log reflections, where it became vivid that my understanding of the person, and my capacity to see the person's capabilities for self-determination enhanced during my stay. So, although I agree with Vehmas and Mietola (2021, p. 48) that it did not take that much time to build a general picture of the research participant's lives—due to their relatively narrow lives—the different relationships took time to properly grasp. When, e.g., comparing my first fieldnotes on Vera with later observations I can see how my understanding is much more nuanced in the latter ones, thus underlining the necessary time it takes to get a hold of these embodied relationships.

Although the thesis comes with an intention of moving inclusion further, it should not be argued in naïve ways, suggesting that what has been reported through the ethnographic descriptions are the truth according to Vera, Karen, and Erik. Agreeing with Simmons and Watson (2014) that identifying intentionality in another human is not about the discovery of absolute truth, the debate might continue regarding the level of interpretation versus the ability to understand the other through a more direct grasp—through empathy. Still, all research needs to be sensitive of the role of the researcher and the researcher's influence on what is reported from empirical data. When including persons with PIMD in research, these are aspects highly important to reflect upon. To recognize both what can be learned through one's own self, embodied and feeling-based human nature and the many challenges embedded are important, and as such represent skills and reflections important for researchers.

The intent of including persons with PIMD as subjects of knowledge also affects questions regarding research ethics. The first and most obvious being related to questions

regarding getting the necessary ethical permission and the related question of consent. As several researchers reporting from the field of PIMD have demonstrated (Haines, 2017; Mietola, 2017; Boxall & Ralph, 2011; Calveley, 2012), gaining ethical approval can seem challenging when designing research outside the scientific, quantitative paradigm. From the perspective of ethical research committees, persons with PIMD are likely to be viewed as vulnerable, and thus necessitating a strong case to demonstrate that benefits outweigh risks. What this thesis argues is the need for an expansion on the concept of vulnerability. Although sympathetic to the understanding that research should always address the inherent risks and recognize the asymmetry in relations, this thesis will still argue a view upon vulnerability that does not have an exclusionary effect. The current study has argued and acted on a view on vulnerability as suggested by Scully (2014), as both a human condition and as a state that is connected to context. This further puts high expectations on both the individual researcher designing a study to secure that the vulnerability of participants is reduced, and on ethical committees to become familiar with this field of research. Furthermore, the ethical competence of the researcher connected to the ability to empathise with the other, assessing the person's responses to research activities should guide in the matter of consent. Leaning on notions suggested by Tuffrey-Wijne (2008) on assessing process consent argues that such skills are highly relational. And as has been demonstrated in this thesis—relations and notions on empathy do not come without challenges and pitfalls. In situations of uncertainty as to whether the presence of the researcher is experienced as a burden, one should follow the guidance of the norms of securing that benefit outweighs risks—and abort the research activity.

6.4.3 Push inclusion further through the balance of being cautious and bold

This thesis agrees with opinions from Simmons and Watson (2014) that it is possible to articulate the life-worlds of persons with PIMD and that it is an ethically important thing to do (Vehmas & Mietola 2021). Maes et al. (2021) concludes that a pathway for the future inclusion in research involve the favouring of a comprehensive understanding of the person and their support system. In a similar line, de Haas et al. (2022) argue the importance of freeing ourselves of the preoccupation of the autonomous and verbal voice, and rather find ways to engage with the knowledge that persons with PIMD possesses. This is in line with the view of this thesis, arguing the reliance on the dependent ways of being and how meaning comes forward in embodied manners—and make that knowledge valid. Such attempts represent a fresh and evolving approach on research, and thus calls for both more theoretical

reflections and empirical studies, advancing the field further. The current study will hopefully contribute to the inclusion of persons with PIMD to be ‘for them and in some ways with them’ (Nind & Strnadova, 2020b, p. 10). It is much to be learned from other attempts to recognize the more sensory and emotional aspects in grasping the social world. The autoethnographic study conducted by Ikonen (2022) being one such demonstration, offers a strong description on how the use of listening and sonic analysis contributed to the understanding of emotionally challenging experiences. More examples of such are needed, demonstrating both possibilities and potential challenges.

To enhance professional services, the inclusion of persons with PIMD are necessary, and hopefully this thesis might inspire future attempts to include the persons in this regard, exploring novel ways of putting this perspective at the forefront. A balance must be found that embeds both a sound scepticism to involve persons not able to consent with attempts that are bold. To move inclusion further, creative, and imaginative suggestions must be made.

6.5 Concluding thoughts

Persons with PIMD are easy to exclude both in research and in society because of their subtle way of being, as they depend on others in all matters of life, unable to raise their voices in traditional ways. These are persons ‘at the margins of moral personhood’, as Kittay (2005, p. 100) states it. This thesis intends to contribute to the inclusion of persons with PIMD—through the concrete case of how to understand, practice, and build knowledge on the topic of self-determination, and how this might further inform on a more philosophical level regarding ethics on professional relations. Vorhaus (2018) states that there is much to be learned through the reflection on persons with PIMD, but also that ‘there are many problems which remain to be solved and which, in some cases, we are only now beginning to recognize’ (Vorhaus, 2018, p. 146). Hopefully this thesis might be one contribution in moving inclusion and understanding further.

By insisting on the inclusion of persons with PIMD, several others might be included in ethical discourse as well. By addressing the way persons depend on others in profound ways, the essentials of all persons’ lives have been touched upon. If dependency is treated as a human condition (Kittay, 2019), and we can embed our understanding on self and self-determination in ways recognising this, it will involve an awareness of the potential in persons formerly being devalued due to periods of dependency. Holding high the uniqueness of each person, and the many potentials and capabilities everyone possesses, if we are willing to

broaden our understanding of humanity, that might lead to sounder ways of interacting with each other. This involves a view that ethics should be based on the particulars, directed by the hallmarks of humanity as dependency and embodiment—in this thesis as suggested through an ethics of holding.

Kittay started off the thesis with reflections upon humanity. Following her lead that it must involve something other than rationality, the thesis will end with an excerpt from the ethnography, describing the interaction between Vera and her carer Line, perhaps contributing to a normative account on humanity (Vorhaus, 2021), arguing that the essence of being human is displayed through human encounters. By attempting to secure another human being's humanity one also constitutes one's own, or as put forward by Stein (1989, p. 116): 'By empathy with differently composed personal structures we become clear on what we are not, what we are more or less than others'.

In the included excerpt the challenge of understanding another is demonstrated, and how meeting such challenges necessitates holding the alterity of the other in high regard. The description might demonstrate the thesis' contributions, unfolding self-determination's profound and multiple nature through Vera being understood by her carer through acts of emotional holding, embodied holding, and holding-together. The encounter between the two demonstrates humanity through embodied interdependencies; Vera perhaps experiencing being treated as a human through Line's attempt to feel into her, and Line's desire to recognise and care for Vera being crucial for her own experience of being human.

Vera and her carer, Line, are on the floor training. Vera's body is stiff, which makes training difficult. She makes high-pitched sounds of distress; Line tries to comfort her and decides to bring her back in the wheelchair. Vera continues to make high-pitched sounds indicating discomfort, and they increase in intensity. Line says, 'Now you're trying to tell me something that I can't understand'. Line positions herself close to Vera and holds her hand. Vera makes another high-pitched 'aaa' sound, and she touches her chin to Line's hand that's firmly holding her own. With her chin against Line's hand, she closes and opens her eyes: the 'aaa' sound ends. She turns away from Line's hand for a few seconds, before returning her chin to rest on Line's hand (Skarsaune et al., 2021, p. 321).

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Appendices

Appendix 1: Ethical approval – Regional Ethical Committee



Region:	Saksbehandler:	Telefon:	Vår dato:
REK vest	Jessica Svård	55978497	07.04.2020

Vår referanse:

107188

Deres referanse:

Anita Gjermestad

107188 Selvbestemmelse uten ord Forskningsansvarlig: VID vitenskapelige høyskole **Søker:** Anita Gjermestad

Søkers beskrivelse av formål:

Selvbestemmelse er en grunnleggende menneskerett, fundamentalt menneskelig behov samt en rettighet som regulerer helse- og velferdstjenesten. Denne retten gjelder og personer med alvorlig utviklingshemning. Praksis viser at det er utfordrende å realisere, og store krav stilles til profesjonelle for å ivareta denne retten. Studien belyser følgende problemstilling: hva kjennetegner relasjoner mellom personer med alvorlig utviklingshemning og profesjonelle i helse- og velferdstjenester som fremmer selvbestemmelse? Studien skal fange perspektivene til personene det gjelder, nærpå personer og profesjonelle i tjenestene. Metodene som benyttes er observasjon i tjenestetilbud og intervju av ansatte og pårørende. Observasjon av komplekse samspill er krevende, og video som verktøy vil vurderes som supplement, da i avklarte situasjoner og med eget samtykke. Målet er å utvikle ny kunnskap om vilkår for selvbestemmelse og øke innsikt i rammer for livskvalitet for personer som mottar omfattende hjelp.

REKs vurdering

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK) vest i møtet 18.03.2020. Vurderingen er gjort med hjemmel i helseforskningsloven § 1

Forsvarlighetsvurdering

Prosjektsøknaden er en omarbeidet versjon av søknad om dispensasjon fra taushetsplikt med referansenummer 84545 som ble vurdert av REK vest i komitémøte 15. januar 2020. Den nye søknaden har en prosjektleder med PhD og bred kompetanse på tjenester til personer med utviklingshemming. Prosjektgruppen er også utvidet med ytterligere medarbeider med kompetanse på psykisk utviklingshemming.

I protokollen er det tatt hensyn til merknadene fra REK vest på søknad 84545. Det er godt gjort rede for prosjektets forskningsspørsmål. Prosjektet vil bidra til kunnskap om selvbestemmelse og til økt kompetanse hos tjenesteytere. Komiteen vurderer at prosjektet er til nytte for deltakerne og andre med samme lidelse slik det er krav om i hfl §18 for å kunne inkludere deltakere uten samtykkekompetanse. Rekruttering skjer via enhetsledere i kommunen. Det argumenteres for at den store variasjonen i tjenester til personen med utviklingshemming vil bidra til å gi nyttige data. Profesjonelle og pårørende skal samtykke til å delta i intervjuer og pårørende eller verge skal samtykke til observasjoner på vegne av personer med alvorlig utviklingshemming.

Komiteen vurderer at prosjektet er forsvarlig å gjennomføre slik beskrevet.

Deltakere

Personer med alvorlig utviklingshemming, deres pårørende og profesjonelle i helse- og velferdstjenester.

Totalt 24 deltakere: 2-4 deltakere med alvorlig utviklingshemming, 2-4 pårørende (1 pårørende pr deltaker med utviklingshemming) og 8 -16 ansatte (4 ansatte pr. deltaker med utviklingshemming).

Begrunnelsen for at det skal rekrutteres et forholdsvis lavt antall personer med utviklingshemming er at det vurderes at dybdekunnskap rundt færre personer vil bidra med mer nyttig informasjon og fylligere beskrivelser om fenomenet enn hva man kan oppnå ved å inkludere et større antall.

REK vest har ingen merknader.

Rekruttering

Rekruttering skal foregå via kontakt med enhetsledere i helse- og velferdstjenester. I søknaden er det forklart at det ikke finnes noen garanti mot at kommunen vil velge kandidater som reflekterer et godt bilde av kommunale tjenester. Det vurderes at selv om inngangen til feltet er via ledere i kommunen, så vil det fremkomme variasjon i relasjoner personen har med de profesjonelle.

REK vest har ingen merknader.

Samtykke

Profesjonelle som jobber i tjenester hvor personene med alvorlig utviklingshemming mottar tjeneste og pårørende samtykker til å delta i intervjuer. Pårørende/verge samtykker til observasjoner på vegne av personer uten samtykkekompetanse.

Informasjonsskriv

Informasjonen i vedlagte informasjonsskriv er god, men REKs mal burde vært brukt. Den er mer oversiktlig for den som får skjemaet, og den sikrer at nødvendig informasjon kommer med i skrevet. Her mangler logo til forskningsansvarlig institusjon, henvisning til behandlingsgrunnlag for personopplysninger og til REK-godkjenningsnummer. Skrevet er formulert som et brev i jeg-form og det er underskrevet med "vennlig hilsen".

Informasjonsskrivet bør kun ha saklig informasjon om prosjektet. I starten av skrevet kunne det også med fordel ha vært en tydeligere forskjell på informasjonsskriv til pårørende og til tjenesteytere.

Informasjonsskrivene må revideres etter ovennevnte merknader og sendes til REK vest via Rekportalen.

Metode

Metoder som skal benyttes er intervju og deltagende observasjon.

Intervjuer:

Strukturerte intervjuer med ansatte i tjenestetilbudene er planlagt i uke 0, 2, 5, 8 og 9. Intervjuer med pårørende utføres ved oppstart og ved dialogmøte.

Observasjon:

Deltagende observasjoner vil gjøres ved to tjenestetilbud, i økter mellom 2 og 4 timer. Video som verktøy vil vurderes som supplement i avklarte situasjoner og med eget samtykke. Det vil kunne være aktuelt å filme 3-10 samspillssituasjoner, og filmene vil være på 2-5 minutter hver.

REK vest har ingen merknader.

Helseopplysninger

Helseopplysningen "alvorlig utviklingshemning" er i denne studien et inklusjonskriterium for å delta. Denne informasjonen baseres på tjenestetilbudets kunnskap om personen.

Oppbevaring av data

Datamateriale vil bli aidentifisert og kryptert under lagring. Personopplysninger oppbevares separat fra datamateriale. Datamateriale i form av lydopptak og videopptak oppbevares på krypterte minnepinner. Datasett og personopplysninger vil bli oppbevart innelåst og kun være tilgjengelig for prosjektleder og PhD-kandidat.

REK vest anbefaler oppbevaring av data på forskningsserver, og forutsetter at retningslinjer til forskningsansvarlig institusjon følges.

Prosjektslutt og håndtering av data etter prosjektslutt

Prosjektslutt er 01.01.2023. Opptak av intervju slettes fortløpende etter de er transkribert, og innen prosjektperioden er ferdig. Alle data slettes eller anonymiseres ved prosjektslutt.

Vedtak

Godkjent med vilkår

Vilkår

Informasjonsskrivet må revideres etter ovennevnte merknader og sendes til REK vest.

REK vest har gjort en helhetlig forskningsetisk vurdering av alle prosjektets sider. Prosjektet godkjennes med hjemmel i helseforskningsloven § 10 på betingelse av at nevnte vilkår tas til følge.

Med vennlig hilsen

Marit Grønning Prof. Dr. med.
Komitéleder REK vest

Jessica Svärd rådgiver REK vest

Sluttmelding

Søker skal sende sluttmelding til REK vest på eget skjema senest seks måneder etter godkjenningsperioden er utløpt, jf. hfl. § 12.

Søknad om å foreta vesentlige endringer

Dersom man ønsker å foreta vesentlige endringer i forhold til formål, metode, tidsløp eller organisering, skal søknad sendes til den regionale komiteen for medisinsk og helsefaglig forskningsetikk som har gitt forhåndsgodkjenning. Søknaden skal beskrive hvilke endringer som ønskes foretatt og begrunnelsen for disse, jf. hfl. § 11.

Klageadgang

Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag (NEM) for endelig vurder

Appendix 2: Dispensation regarding duty of confidentiality



Region: Saksbehand Telefon Vår
REK ler: : dato:
vest Jessica 559784 27.05.20
Svård 97 20

Vår referanse:
107188

Deres referanse:

Anita Gjermestad

107188 Selvbestemmelse uten ord Forskningsansvarlig: VID vitenskapelige høyskole Søker:
Anita Gjermestad
REKs vurdering

Vi viser til endringsmelding for ovennevnte prosjekt innsendt 23.04.2020.

Endringsmeldingen er behandlet av REK vest i komitémøte 06.05.2020 med hjemmel i Helseforskningsloven § 11.

Det søkes om dispensasjon fra taushetsplikten for helseopplysninger om andre enn prosjektdeltakere som kan tilfalle prosjektmedarbeidere gjennom deltagende observasjon.

Vurdering

I endringsmeldingen er det beskrevet at prosjektets metode med deltagende observasjon i hverdagslivet til personer med alvorlig utviklingshemming kan medføre at den som observerer kan få informasjon om taushetsbelagte helseopplysninger om andre personer som ikke er inkludert i studien. Ingen opplysninger om andre enn de som har samtykket til å bli observert skal registreres eller på annet sett gjøres bruk av i forskningen. Dette kan være personer som bor i samme bolig, er elever ved samme skole, eller deltar på samme dagtilbud. Observasjonen skal skje i naturlige kontekster, og dette vil kunne foregå både i egne, avlukkede rom, men også i større fellesrom hvor andre mennesker oppholder seg.

Prosjektleder vurderer det som krevende å innhente samtykke fra alle potensielle personer som oppholder seg i samme rom som de som har samtykket til å bli observert. Ansatte og personer med utviklingshemming som ikke er inkludert i studien skal informeres om studien og forskers nærvær i tjenestetilbud.

REK vest forstår det som at det kun er personer som har samtykket til deltakelse som skal observeres i prosjektet og ingen opplysninger om andre personer skal registreres eller på annet sett brukes i prosjektet. Komiteen finner dermed at det ikke er nødvendig å søke dispensasjon fra taushetsplikt i prosjektet. Komiteen finner imidlertid at generelle forskningsetiske prinsipper tilsier at personer som oppholder seg i samme bolig, skole eller tjenestetilbud bør informeres om forskningsprosjektet slik at eventuelt pårørende eller ansatte til ikke-deltakere kan legge til rette for at ingen vil føle ubehag ved at det foregår en observasjonsstudie der de oppholder seg. Dette gjøres best ved god kommunikasjon og dialog mellom alle berørte parter.

Komiteen setter vilkår om at det utarbeides informasjon til "ikke-deltakere" som befinner seg på plasser hvor det skal observeres.

Vedtak

Godkjent

REK vest mener at det er forsvarlig at prosjektet gjennomfører deltagende observasjon i omgivelser hvor ikke-deltakere befinner seg, på betingelse av at disse personene får informasjon om prosjektet og at en har god dialog med alle berørte parter slik at det kan bli tilrettelagt for at heller ikke de som er ikke-deltakere vil føle noe ubehag ved at utenforstående observerer der de oppholder seg.

Med vennlig hilsen

Marit Grønning Prof. dr. med.
Komitéleder REK vest

Jessica Svärd rådgiver REK vest

Klageadgang

Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag (NEM) for endelig vurdering

Appendix 3: Evaluation from NSD

NSD sin vurdering

Prosjekttittel

Selvbestemmelse uten ord - utfordrende relasjoner mellom personer med alvorlig utviklingshemming og profesjonelle

Referansenummer

472016

Registrert

01.11.2019 av Synne Kristin Nese Skarsaune - synne.skarsaune@vid.no

Behandlingsansvarlig institusjon

VID vitenskapelige høgskole / Senter for diakoni og profesjonell praksis

Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Synne Nese Skarsaune, synne.skarsaune@vid.no, tlf: 41561292

Type prosjekt

Forskerprosjekt

Prosjektperiode

01.09.2019 - 01.04.2023

Status

03.06.2020 - Vurdert

Vurdering (1)

03.06.2020 - Vurdert

BAKGRUNN Prosjektet er vurdert og godkjent med vilkår av Regionale komiteer for medisinsk og helsefaglig forskningsetikk (REK) etter helseforskningsloven (hfl.) § 10 (REK sin ref: 107188). REK vest mener at det er forsvarlig at prosjektet gjennomfører deltagende observasjon i omgivelser hvor ikke-deltakere befinner seg, på betingelse av at disse personene får informasjon om prosjektet og at en har god dialog med alle berørte parter slik at det kan bli tilrettelagt for at heller ikke de som er ikke-deltakere vil føle noe ubehag ved at utenforstående observerer der de oppholder seg.

Deltakende observasjon vil avklares med den aktuelle institusjon. Det er NSD sin vurdering at behandlingen også vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet datert 03.06.2020 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD.

Behandlingen kan starte. MELD VESENTLIGE ENDRINGER Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde:

https://nsd.no/personvernombud/meld_prosjekt/meld_endringer.html Du må vente på svar fra NSD før endringen gjennomføres. TYPE OPPLYSNINGER OG VARIGHET

Prosjektet vil behandle særlige kategorier av personopplysninger om helseforhold og alminnelige kategorier av personopplysninger frem til 01.04.2023. LOVLIG

GRUNNLAG FOR UTVALG 2 og 3 Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake. Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a, jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2). LOVLIG GRUNNLAG FOR UTVALG 1 Utvalg 1 er personer med alvorlig utviklingshemming, som er ute av stand til å forstå informasjon eller samtykke til behandlingen. Samtykket vil derfor bli gitt av den registrertes verge, utvalget vil heller ikke ha nytte av tilpasset informasjon. Denne gruppen har i liten grad vært blitt inkludert i studier, nettopp grunnet manglende samtykkekompetanse. Det vil ikke være mulig å oppfylle prosjektets formål uten deres deltakelse. Det vurderes videre at opplysningene vil kunne komme gruppen som helhet til gode. I tillegg til stedfortredende samtykke vil forskere, tjenesteytere og pårørende som kjenner deltakerne godt fortløpende vurdere ubehag eller behag knyttet til observasjoner og forskerens tilstedeværelse. REK har også vurdert det som etisk forsvarlig å inkludere dette utvalget. Lovlig grunnlag for behandlingen vil dermed være den registrertes/nærmeste pårørendes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a, jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2). PERSONVERNPRINSIPPER NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om: - lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen - formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål - dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet - lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet DE REGISTRERTES RETTIGHETER Så lenge de registrerte kan identifiseres i datamaterialet vil de i utgangspunktet ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20). NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13. I utgangspunktet har alle som registreres i forskningsprosjektet rett til å få slettet opplysninger som er registrert om dem. Etter helseforskningsloven § 16 tredje ledd vil imidlertid adgangen til å kreve sletting av sine helseopplysninger ikke gjelde dersom materialet eller opplysningene er anonymisert, dersom materialet etter bearbeidelse inngår i et annet biologisk produkt, eller dersom opplysningene allerede er inngått i utførte analyser. Regelen henviser til at sletting i slike situasjoner vil være svært vanskelig og/eller ødeleggende for forskningen, og dermed forhindre at formålet med forskningen oppnås. Etter personvernforordningen art 17 nr. 3 d kan man unnta fra retten til sletting dersom

behandlingen er nødvendig for formål knyttet til vitenskapelig eller historisk forskning eller for statistiske formål i samsvar med artikkel 89 nr. 1 i den grad sletting sannsynligvis vil gjøre det umulig eller i alvorlig grad vil hindre at målene med nevnte behandling nås. NSD vurderer dermed at det kan gjøres unntak fra retten til sletting av helseopplysninger etter helseforskningslovens § 16 tredje ledd og personvernforordningen art 17 nr. 3 d, når materialet er bearbeidet slik at det inngår i et annet biologisk produkt, eller dersom opplysningene allerede er inngått i utførte analyser. Vi presiserer at helseopplysninger inngår i utførte analyser dersom de er sammenstilt eller koblet med andre opplysninger eller prøvesvar. Vi gjør oppmerksom på at øvrige opplysninger må slettes og det kan ikke innhentes ytterligere opplysninger fra deltakeren. Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned. FØLG DIN INSTITUSJONS RETNINGSLINJER NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32). For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon. OPPFØLGING AV PROSJEKTET NSD vil følge opp underveis (hvert annet år) og ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet/pågår i tråd med den behandlingen som er dokumentert. Lykke til med prosjektet! Kontaktperson hos NSD: Jørgen Wincentsen Tlf. Personverntjenester: 55 58 21 17 (tast 1)



Vil du delta i forskningsprosjektet «selvbestemmelse uten ord»?

Formålet med prosjektet og hvorfor du som pårørende blir spurt

Dette er et spørsmål til deg som pårørende om deltakelse i et forskningsprosjekt, hvor formålet er å utforske profesjonelle vilkår for å realisere selvbestemmelse for personer med alvorlig utviklingshemming. Vi ønsker både at du som pårørende deltar men og at den du er pårørende til deltar.

Prosjektet er en doktorgradsstudie (phd) finansiert av VID, Senter for diakoni og profesjonell praksis. Studien skal svare på tematikken: utfordrende relasjoner i profesjonell praksis, og mer spesifikt på relasjoner mellom personer med alvorlig utviklingshemming og ansatte/profesjonelle. Hvordan kan selvbestemmelse fremmes i relasjoner med profesjonelle hjelpere?

Selvbestemmelse er et grunnleggende behov og en rettighet nedfelt i menneskerettigheter og lovverk som regulerer helse- og velferdstjenester. Denne retten gjelder og personer med alvorlig utviklingshemming. Praksis viser at dette er en rettighet som er utfordrende å realisere. Personer med alvorlig utviklingshemming er en svært heterogen gruppe som deler det at de kommuniserer på andre måter enn verbalspråklig, og de er mottakere av livslang og nær hjelp gjennom livet. Dette stiller store krav til profesjonelle. Studien ønsker å belyse følgende overordnede problemstilling: hva kjennetegner relasjoner mellom personer med alvorlig utviklingshemming og profesjonelle i helse- og velferdstjenester som fremmer selvbestemmelse og medborgerskap? Målsetningen er å skape kunnskap som kan øke innsikt i rammer for livskvalitet og god helse for personer som mottar omfattende hjelp.

Denne kunnskapen skal skapes sammen med personer med alvorlig utviklingshemming, pårørende og viktige tjenesteytere. Via kontakt med aktuelle helse- og velferdstjenester (enhetsledere i skole, helse- og velferdstjenester) har de formidlet kontakt til aktuelle ansatte som jobber i tjenester der personer med alvorlig utviklingshemming mottar tjenester, og de igjen har kontaktet pårørende til aktuelle personer med utviklingshemming.

Hva innebærer PROSJEKTET for deg som pårørende og den du er pårørende til

Studien ønsker å fange perspektivet til personene det gjelder samt deres nærpå personer og profesjonelle som jobber i tjenestene. Metoden som skal brukes er observasjon, som innebærer at forsker er tilstede i tjenestene sammen med de som mottar hjelp og de som gir hjelp. Det å se hverdagslivet utspille seg tett på vurderes som en hensiktsmessig måte å legge til rette for forskning

hvor mennesker med alvorlig utviklingshemming skal bli hørt. Ved bruk av observasjon er målet å utforske hvordan de profesjonelle praksisene foregår og erfares med hensyn til selvbestemmelse, samt komme tett på personene det gjelder sin stemme. Observasjon er planlagt å foregå over 9 uker. For å få med seg detaljer i det som skjer i samspillet mellom den som mottar hjelp og den som gir hjelp vil det vurderes bruk av video-opptak i utvalgte situasjoner. Dette vil, dersom det vurderes som aktuelt å bruke, være i utvalgte og avklarte situasjoner. Anslagsvis vil det kunne være aktuelt å filme 3-10 samspillssituasjoner som vurderes å beskrive selvbestemmelse i relasjonene, og filmene vil være på omtrent 2-5 minutter hver. Det vil utarbeides en egen datahåndteringsplan. Du som pårørende må aktivt samtykke til at en slik metodikk kan brukes.

I tillegg til å observere vil forsker og gjennomføre individuelle intervju og gruppeintervju. Intervju som er planlagt er; et innledende intervju med pårørende, tre intervju med ansatte og et gruppeintervju/dialogmøte sammen med ansatte på tvers av tjenestetilbud og pårørende.

Dersom du som pårørende vil delta innebærer det at du deltar på et innledende intervju (tidsbruk ca 1 time) og et gruppeintervju sammen med viktige profesjonelle (anslått tid: 2 timer).

Dersom du samtykker til at den du er pårørende til kan delta innebærer det for vedkommende at forsker er tilstede i tjenestetilbudet til personen du er pårørende til i om lag 9 uker, fordelt over 3-4 måneder (totalt sett omtrent 60 timer fordelt på 15 dager).

Datainnsamling vil foregå i perioden august 2020 – august 2021 (oppstart må være forenlig med smittesituasjon i forbindelse med Corona-utbrudd).

I prosjektet vil vi innhente og registrere personopplysninger om deg og den du er pårørende til i form av navn og kontakinformasjon. Alle opplysninger som kan indentifisere deg skal lagres forskriftsmessig, navn vil bli fjernet fra samtaler (intervju og observasjonsnotater). Dette gjøres ved at intervjuer tas opp på bånd og skrives ut aidentifisert. Lydfiler og videofiler lagres på kryptert minnepinne, og oppbevares i låsbart skap. Lydfiler slettes fortløpende etter som transkripsjoner er gjort. Det vil skrives feltnotater fra observasjonene. Disse vil aidentifiseres og lagres forskriftsmessig. Alle navn og personopplysninger lagres atskilt fra datamaterialet. Det er kun forsker som har tilgang til lydopptak og personopplysninger. Veiledere har tilgang til aidentifisert datamateriale.

Mulige fordeler og ulemper

Det er rimelig å anta at prosjektets fokus på selvbestemmelse vil kunne medføre en økt bevissthet i praksisfeltet som kan ha direkte fordeler for personen med alvorlig utviklingshemming i form av at det i større grad fasiliteres for selvbestemmelse. Det er et mål at studien vil kunne bringe ny og relevant kunnskap til de profesjonelle og de pårørende som deltar. Studien innebærer ingen direkte intervensjoner og vil således i liten grad føre til noen ulemper for deltakeren utover mulig ubehag ved at forsker deltar i hverdagslivet. Hvordan forsker kan delta i praksis på en måte som reduserer ubehag/ulemper for både personen med utviklingshemming og de ansatte må avklares før oppstart.

Frivillig deltakelse og mulighet for å trekke ditt samtykke

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Det vil ikke ha noen negative konsekvenser for deg eller den du er pårørende for hvis du ikke vil delta eller senere velger å trekke deg. Dersom du trekker tilbake samtykket, vil det ikke forskes videre på dine opplysninger. Du kan også kreve at dine opplysninger i prosjektet slettes eller utleveres innen 30 dager. Adgangen til å kreve sletting eller utlevering gjelder ikke dersom materialet eller opplysningene er anonymisert.

Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder (se kontaktinformasjon på siste side).

Hva skjer med OPPLYSNINGENE om deg?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet under formålet med prosjektet, og planlegges brukt til 2023. Eventuelle utvidelser i bruk og oppbevaringstid kan kun skje etter godkjenning fra REK og andre relevante myndigheter. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene. Du kan klage på behandlingen av dine opplysninger til Datatilsynet og institusjonen sitt personvernombud.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger (=kodete opplysninger). En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun prosjektleder Anita Gjermestad og stipendiat Synne Nese Skarsaune som har tilgang til denne listen. De som vil ha tilgang til aidentifiserte data fra intervju og observasjon, samt videodata er Synne Skarsaune, stipendiat og veiledere: Anita Gjermestad, professor og Halvor Hanisch, førsteamanuensis. Doktorgradsarbeidet skal bidra med vitenskapelige artikler. I all publisering vil opplysninger fra observasjoner og intervju være aidentifisert.

Godkjenninger

Regional komité for medisinsk og helsefaglig forskningsetikk har gjort en forskningsetisk vurdering og godkjent prosjektet, saksnr. 107188.

VID Vitenskapelige høyskole og prosjektleder Anita Gjermestad er ansvarlig for personvernet i prosjektet.

Vi behandler opplysningene basert på ditt samtykke.

KONTAKTOPPLYSNINGER

Dersom du har spørsmål til prosjektet eller ønsker å trekke deg fra deltakelse, kan du kontakte Synne Nese Skarsaune, stipendiat, VID, Senter for diakoni og profesjonell praksis; synne.skarsaune@vid.no, telefon: 41 56 12 92 eller Anita Gjermestad, professor og veileder VID Sandnes, anita.gjermestad@vid.no, telefon: 51 97 22 87

Dersom du har spørsmål om personvernet i prosjektet, kan du kontakte personvernombudet ved institusjonen: personvernombud@vid.no

NSD – Norsk senter for forskningsdata AS kan kontaktes på epost: personverntjenester@nsd.no eller telefon: 55 58 21 17

Jeg samtykker på vegne av person uten samtykkekompetanse til å delta i prosjektet og til at vedkommendes personopplysninger brukes slik det er beskrevet

Jeg har mottatt informasjon om prosjektet *selvbestemmelse uten ord*, og har fått anledning til å stille spørsmål. Jeg samtykker til at:

 (navn på personen)

- Kan delta på gruppeintervju/dialogmøte (dersom det blir vurdert som hensiktsmessig)
- at intervjuene blir tatt opp på lydbånd
- at forsker kan delta i feltet (deltakende observasjon) sammen med _____ i prosjektperioden
- at forsker bruker video i feltarbeidet, i utvalgte og avklarte situasjoner (dersom aktuelt)

Sted og dato

Pårørendes signatur

Pårørendes navn med trykte bokstaver

JEG SAMTYKKER TIL Å DELTA I PROSJEKTET OG TIL AT MINE PERSONOPPLYSNINGER BRUKES SLIK DET ER BESKREVET

Jeg har mottatt informasjon om prosjektet *selvbestemmelse uten ord*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

- å delta på et innledende intervju og et gruppeintervju/dialogmøte
- at intervjuene blir tatt opp på lydbånd

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver



Vil du delta i forskningsprosjektet «selvbestemmelse uten ord»?

Formålet med prosjektet og hvorfor du som tjenesteyter blir spurt

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å utforske profesjonelle vilkår for å realisere selvbestemmelse for personer med alvorlig utviklingshemming. Prosjektet er en doktorgradsstudie (phd) finansiert av VID, Senter for diakoni og profesjonell praksis. Studien skal svare på tematikken: utfordrende relasjoner i profesjonell praksis, og mer spesifikt på relasjoner mellom personer med alvorlig utviklingshemming og ansatte/profesjonelle. Hvordan kan selvbestemmelse fremmes i relasjoner med profesjonelle hjelpere?

Selvbestemmelse er et grunnleggende behov og en rettighet nedfelt i menneskerettigheter og lovverk som regulerer helse- og velferdstjenester. Denne retten gjelder og personer med alvorlig utviklingshemming. Praksis viser at dette er en rettighet som er utfordrende å realisere. Personer med alvorlig utviklingshemming er en svært heterogen gruppe som deler det at de kommuniserer på andre måter enn verbalspråklig, og de er mottakere av livslang og nær hjelp gjennom livet. Dette stiller store krav til profesjonelle. Studien ønsker å belyse følgende overordnede problemstilling: hva kjennetegner relasjoner mellom personer med alvorlig utviklingshemming og profesjonelle i helse- og velferdstjenester som fremmer selvbestemmelse og medborgerskap? Målsetningen er å skape kunnskap som kan øke innsikt i rammer for livskvalitet og god helse for personer som mottar omfattende hjelp.

Denne kunnskapen skal skapes sammen med personer med alvorlig utviklingshemming, pårørende og viktige tjenesteytere. Via kontakt med aktuelle helse- og velferdstjenester (enhetsledere i skole, helse- og velferdstjenester) har de formidlet kontakt til aktuelle ansatte som jobber i tjenester der personer med alvorlig utviklingshemming mottar tjenester.

Hva innebærer PROSJEKTET for deg?

Studien ønsker å fange perspektivet til personene det gjelder samt deres nærpå personer og profesjonelle som jobber i tjenestene. Metoden som skal brukes er observasjon, som innebærer at forsker er tilstede i tjenestene sammen med de som mottar hjelp og de som gir hjelp. Det å se hverdagslivet utspille seg tett på vurderes som en hensiktsmessig måte å legge til rette for forskning

hvor mennesker med alvorlig utviklingshemming skal bli hørt. Ved bruk av observasjon er målet å utforske hvordan de profesjonelle praksisene foregår og erfares med hensyn til selvbestemmelse, samt komme tett på personene det gjelder sin stemme. Observasjon er planlagt å foregå over en periode på 3-4 måneder. For å få med seg detaljer i det som skjer i samspillet mellom den som mottar hjelp og den som gir hjelp vil det vurderes bruk av video-opptak i utvalgte situasjoner. Dette vil, dersom det vurderes som aktuelt å bruke, være i utvalgte og avklarte situasjoner. Anslagsvis vil det kunne være aktuelt å filme 3-10 samspillssituasjoner i hverdagslivet som vurderes å beskrive selvbestemmelse i relasjonene. Hver video vil være på omtrent 2-5 minutter. Det vil utarbeides en egen datahåndteringsplan. Du kan reservere deg for å delta på videofilm ved å ikke samtykke.

I tillegg til å observere vil forsker gjennomføre individuelle intervju og gruppeintervju. Intervju som er planlagt er; et innledende intervju med pårørende, tre intervju med ansatte og et gruppeintervju/dialogmøte sammen med ansatte på tvers av tjenestetilbud og pårørende.

Dersom du vil delta innebærer det at: forsker er tilstede i tjenestetilbudet hvor du jobber i en periode på 3-4 måneder. Dette vil innebære omtrent 60 timer fordelt på tilsammen 15 dager. Du som ansatt deltar også på tre intervju (enten individuelt eller sammen med kollegaer, tidsbruk ca totalt 3 timer) og et gruppeintervju sammen med andre viktige profesjonelle og pårørende (anslått tid: 2 timer).

Datainnsamling i form av observasjoner og intervjuer vil foregå i perioden august 2020 – august 2021 (oppstart må være forenlig med smittesituasjon i forbindelse med Corona-utbrudd).

I prosjektet vil vi innhente og registrere personopplysninger om deg i form av navn og kontaktinformasjon. Alle opplysninger som kan identifisere deg skal lagres forskriftsmessig, ditt navn vil bli fjernet fra samtaler (intervju og observasjonsnotater). Dette gjøres ved at intervjuer tas opp på bånd og skrives ut aidentifisert. Lydfiler og videofiler lagres på kryptert minnepinne, og oppbevares i låsbart skap. Lydfiler slettes fortløpende etter som transkripsjoner er gjort. Det vil skrives feltnotater fra observasjonene. Disse vil aidentifiseres og lagres forskriftsmessig. Alle navn og personopplysninger lagres atskilt fra datamaterialet. Det er kun forsker som har tilgang til lydopptak og personopplysninger. Veiledere har tilgang til aidentifisert datamateriale.

Mulige fordeler og ulemper

Det er rimelig å anta at prosjektets fokus på selvbestemmelse vil kunne medføre en økt bevissthet i praksisfeltet som kan ha direkte fordeler for personen med alvorlig utviklingshemming i form av at det i større grad fasiliteres for selvbestemmelse. Det er et mål at studien vil kunne bringe ny og relevant kunnskap til de profesjonelle som deltar. Studien innebærer ingen direkte intervensjoner og vil således i liten grad føre til ulemper for deltakeren utover mulig ubehag ved at forsker observerer og deltar i hverdagslivet. For å minske eventuelt ulempe/ubehag av forskningen skal forsker være i tett dialog med pårørende og praksisfelt, og delta i praksis på måter som reduserer ubehag/ulemper for både personen med utviklingshemming og de ansatte.

Frivillig deltakelse og mulighet for å trekke ditt samtykke

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg. Dersom du trekker tilbake samtykket, vil det ikke forskes videre på dine opplysninger. Du kan også kreve at dine opplysninger i prosjektet slettes eller utleveres innen 30 dager. Adgangen til å kreve sletting eller utlevering gjelder ikke dersom materialet eller opplysningene er anonymisert.

Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder (se kontaktinformasjon på siste side).

Hva skjer med OPPLYSNINGENE om deg?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet under formålet med prosjektet, og planlegges brukt til 2023. Eventuelle utvidelser i bruk og oppbevaringstid kan kun skje etter godkjenning fra REK og andre relevante myndigheter. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene. Du kan klage på behandlingen av dine opplysninger til Datatilsynet og institusjonen sitt personvernombud.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger (=kodete opplysninger). En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun prosjektleder Anita Gjermestad og stipendiat Synne Nese Skarsaune som har tilgang til denne listen. De som vil ha tilgang til avidentifiserte data fra intervju og observasjon, samt videodata er Synne Skarsaune, stipendiat og veiledere: Anita Gjermestad, professor og Halvor Hanisch, førsteamanuensis. Data fra doktorgradsarbeidet skal publiseres i vitenskapelige artikler. I alle publiseringer vil opplysninger fra observasjoner og intervju være avidentifisert.

Godkjenninger

Regional komité for medisinsk og helsefaglig forskningsetikk har gjort en forskningsetisk vurdering og godkjent prosjektet, saksnr. 107188

VID Vitenskapelige høyskole og prosjektleder Anita Gjermestad er ansvarlig for personvernet i prosjektet.

Vi behandler opplysningene basert på ditt samtykke.

KONTAKTOPPLYSNINGER

Dersom du har spørsmål til prosjektet eller ønsker å trekke deg fra deltakelse, kan du kontakte Synne Nese Skarsaune, stipendiat, VID, Senter for diakoni og profesjonell praksis; synne.skarsaune@vid.no, telefon: 41 56 12 92 eller Anita Gjermestad, professor og veileder VID Sandnes, anita.gjermestad@vid.no, telefon: 51 97 22 87

Dersom du har spørsmål om personvernet i prosjektet, kan du kontakte personvernombudet ved institusjonen: personvernombud@vid.no

NSD – Norsk senter for forskningsdata AS kan kontaktes på epost: personverntjenester@nsd.no eller telefon: 55 58 21 17

Jeg samtykker til å delta i prosjektet og til at mine personopplysninger brukes slik det er beskrevet

Jeg har mottatt informasjon om prosjektet *selvbestemmelse uten ord*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

- å delta på tre planlagte intervju og et gruppeintervju/dialogmøte
- at intervjuene blir tatt opp på lydbånd
- at forsker kan delta i feltet (deltakende observasjon) i prosjektperioden
- at forsker bruker video i feltarbeidet, i utvalgte og avklarte situasjoner (dersom aktuelt)

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Appendix 6 Guidelines fieldwork (interviews and observation)

Intervjuguide pårørende:

Intervju med pårørende skal skje i forkant av oppstart feltarbeid, og formålet er todelt; å forberede feltarbeid med relevant forhåndskunnskap ang personen med alvorlig utviklingshemming samt å få pårørendes perspektiv på selvbestemmelse.

Forsker vil innledningsvis beskrive studiens formål og gi anledning til å stille spørsmål.

Intervjuguide:

1. Hvem er NN? Vil du dele fortellinger fra NNs livshistorie som du vurderer at er relevant for nye mennesker å kjenne til for å bli bedre kjent?
2. Hvordan vil du beskrive NN sin kommunikasjon?
3. Kan du si noe om hvilke typer tjenester NN mottar? (dagsenter, bolig, skole).
4. Hvordan forstår du selvbestemmelse (evt. medvirkning, deltakelse, frihet, autonomi)? Hvordan kommer dette til uttrykk hos NN?
5. Har du eksempler på situasjoner hvor du erfarer at NN er selvbestemt? Eksempler på situasjoner hvor NN ikke er selvbestemt? Reflekter gjerne både ut fra egne erfaringer og erfaringer i forhold til ulike tjenestetilbud
6. I hvilken grad er selvbestemmelse aktuelt for NN ?
7. Hva tenker du er viktige forutsetninger for at NN skal oppleve selvbestemmelse?

Intervjuguide profesjonelle:

Fokus på å beskrive fenomenet, mer enn å tolke, tro og forklare.

Oppfølgingsssp: kan du fortelle mer om den erfaringen?

1. **Hvordan kan selvbestemmelse beskrives i relasjonen: hvordan kommer den til uttrykk.**

- kan du gi eksempler på situasjoner hvor hen erfarer å være selvbestemt? Hvordan kommer den til uttrykk i eksemplene?
- kan du gi eksempler på situasjoner hvor selvbestemmelse er vanskelig å få til for hen?
- hvilke erfaringer har du gjort når det gjelder din rolle som profesjonell i forhold til hens selvbestemmelse – har du eksempler på din rolle i samspillet ?
- jeg er nysgjerrig på hva som er hens ønsker og preferanser fra livet – har du eksempler fra levde erfaring som du tror er viktige ingredienser for at hun skal oppleve at livet er slik hun selv ønsker det skal være, etter hennes preferanser?

2. Hvilke kunnskaper, ferdigheter og holdninger hos profesjonelle erfares å fasilitere relasjoner som fremmer selvbestemmelse?

- Hvordan kan du som ansatt legge til rette for selvbestemmelse for hen?
Starte med å få personal til å reflektere over hvordan selvbestemmelse kan forstås for hen, situasjoner hvor hen er selvbestemt. Og hvilken rolle du har som personal til å fasilitere for dette.
- Kan du gi eksempel på kunnskap som du erfarer at du bruker i dette arbeidet?
- Kan du gi eksempler på ferdigheter du erfarer at er viktig for å legge til rette for selvbestemmelse?
- Kan du gi eksempler på holdninger du erfarer at er viktig for å legge til rette for selvbestemmelse?

3. Hva i tjenestetilbud erfares som å hemme og fremme relasjoner som fasiliterer selvbestemmelse

- Har du eksempler fra ditt arbeidssted som du erfarer bidrar til at du kan ha den type relasjon med hen som trengs for å fasilitere selvbestemmelsen hennes?
- Har du eksempler på noe i strukturen som kvalitetssikrer fortolkningen av hens kommunikasjon?
- Hvor mange ansatte jobber med hen?
- Har du eksempler fra ditt arbeidssted som du erfarer motvirker utviklingen av relasjoner hvor selvbestemmelse kan utfoldes?
- Felles for alle som deltar i denne studien er at alle kjenner hen godt, over lengre tid. Hvor mye av en gjennomsnittlig uke er hun sammen med folk som kjenner hen godt på din arbeidsplass? Jeg ønsker å fokusere på hva i relasjonen som fremmer selvbestemmelse, og det ville vært uetisk og gjort en studie hvor jeg bevisst plukket ut dårlig praksis, men tenk litt høyt – hva slags praksiser får jeg ikke se?
- Hva risikerer hen dersom hen ikke har disse nære relasjoner?

Guide for observasjon:

Fokus på det som utspiller seg i relasjonen mellom personen med alvorlig utviklingshemming og den profesjonelle – tett på. Hva gjør kroppene, gester, mimikk, bevegelser. Bruke alle sansene.

Feltlogger skrives fortrinnsvis umiddelbart etter observasjon. Inkluder følelser og refleksjoner erfaringene vekket i meg. Dersom avtalt med den profesjonelle – ha med liten notisbok for å skrive ned detaljer.

Bruk av kamera: etter skriftlig avtale om bruk, og muntlig tillatelse i hver aktuelle situasjon.

Paper 1

Persons with Profound Intellectual and Multiple Disabilities?. *Scandinavian Journal of Disability Research*, 23(1), p.317–327. DOI: <https://doi.org/10.16993/sjdr.830>

Abstract

Self-determination is often equated with independence and individual choices, which limits its relevance for persons with profound intellectual and multiple disabilities (PIMD) due to their dependency. This paper challenges the notion of independence by arguing for a rethinking of self-determination that is sensitive to lives characterised by dependency and non-verbal being. An ethnographic study informed by phenomenology emphasising embodiment shed light on how self-determination can unfold in the lives of persons with PIMD in relationships with professionals. These data are engaged in a theoretical discussion, dialoguing with theories of self-determination and ethics of care. We advocate that a rethinking involving embodied communication, partnership and ongoing processes of being understood can offer a sound way of grasping the phenomenon of self-determination, both for persons with and without PIMD.

Paper 2

Skarsaune, S. N., & Hanisch, H. M. (2023). Holding and Professional Care: On Self-Determination for Persons With Profound Intellectual and Multiple Disabilities. *Research and Practice for Persons with Severe Disabilities*, 48(1), 25-40. <https://doi.org/10.1177/15407969231153579>

Abstract

Persons with profound intellectual and multiple disabilities (PMID) are in danger of not being granted the human right to experience self-determination. Attitudes questioning the relevance of the rights of persons with significant support needs and a lack of guidance on how to practically go about ensuring self-determination might explain this. Providing knowledge about this matter, this article contributes through an ethnography highlighting the relationship between persons with PIMD and professionals. The concept of holding another's identity was found to be a possible, fruitful approach toward self-determination in this context. Descriptions of holding dialogues with an ethics of care suggest specific conditions for moving practices toward self-determination: recognize the role of the professional, emphasize embodied empathy, and enable involvement. The ethnography suggests a broadened understanding of self-determination, pinpointing the importance of sensitivity toward the other's particularity.

Paper 3

Skarsaune, S. N. (2023). Persons with profound and multiple learning disabilities as individuals of knowledge: Exploring the possibilities of empathy. *British Journal of Learning Disabilities*, 1–9. <https://doi.org/10.1111/bld.12550>

Abstract

Background

Persons with profound and multiple learning disabilities (PMLD) risk exclusion, both in research and as members of society. Because of their embodied communication, they face the challenges in being understood. Oftentimes, others speak on their behalf making inferences on what their perspective might be.

Methods

Empathy is suggested as an approach to grasp the perspective of a person with profound and multiple learning disabilities through engaging with embodied communication. The account of empathy suggested by Stein will be unfolded through an ethnographic study including persons with profound and multiple learning disabilities and their professional supporters. Given this background, the intent is to discuss the potential empathy can have in recognising persons with these disabilities as subjects of knowledge.

Findings and Conclusions

The characteristics of persons with profound and multiple learning disabilities provide energy to empathic situations in ways that advocate for the possibility of being recognised as subjects of knowledge. This is related to the competencies of the individual, ambiguous communication and the dependency relations in which they are involved. It is of utmost importance to respect the alterity of the other.

