

Kristin Vindhol Evensen

## **Give me a thousand gestures**

Embodied meaning and severe, multiple disabilities  
in segregated special needs education

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## **Sammendrag**

I denne avhandlingen undersøker jeg subjektive kroppslige erfaringer hos elever i grunnskolen. De åtte elevene som deltar i studien har alle diagnosen multifunksjonshemming, men til tross for dette har de ulike interesser, meninger, sosiale bakgrunner og erfaringer. For å utvikle kunnskap som tilfører noe annet enn hva de dominerende medisinske og sosiale forståelsesmåtene av funksjonshemming har gjort har jeg benyttet persepsjonens fenomenologi slik den er forstått av Maurice Merleau-Ponty. På denne måten har jeg kunnet nærme meg elevenes perspektiver. Grunnet funksjonshemmingens kompleksitet uttrykker elevene som deltar seg gjennom før-symboliske, kroppslige gester. Derfor, i tråd med Merleau-Pontys filosofi som tilfører noe annet enn hva empirisisme og intellektualisme har gjort, anser jeg bevegelse som en tredje vei mot forståelse av menneskelige erfaringer. Merleau-Pontys persepsjonsfenomenologi har gitt rom for å forstå bevegelser og kroppslige gester som ikke-symboliske uttrykk som skiller seg kvalitativt fra symbolsk språk, dog uten å være mindreverdige som uttrykksform.

For å nærme meg de subjektive perspektivene til elevene i den praktisk-pedagogiske hverdagen har jeg utført nærobservasjoner ved å ta del i hverdagslivet i tre spesialgrupper tilrettelagt for elever med multifunksjonshemming. Nærobservasjonene har frembrakt data som beskriver levd erfaring i livsverdener hvor uttrykk er direkte, uten filter eller manipulative intensjoner. Jeg har også foretatt fenomenologiske intervjuer med det pedagogiske personalet for å inkludere beskrivelser av hvordan elever og personale skaper situasjoner sammen. Kombinasjonen av observasjoner og intervjuer fremmer et bilde av elever med multifunksjonshemming som barn som erfarer en særegen sårbarhet og relasjonell avhengighet i skolekonteksten.

Avhandlingen består av fire selvstendige artikler som er bundet sammen av en introduksjon, et teoretisk kapittel, et metodologisk kapittel og en avsluttende refleksjon. De fenomenologiske eksistensialitetene romlighet, materialitet og relasjonalt er benyttet som analytiske virkemidler når jeg har undersøkt hvordan kroppslig mening viser seg hos elever med multifunksjonshemming. I tillegg til disse fenomenologiske begrepene har jeg tilført analysene i artikkel to og tre begreper fra sosial-konstruktivisme og poststrukturalisme.

Avhandlingen krediterer bevegelse som fullverdig bærer av subjektive meninger. De fire artiklene indikerer at relasjoner mellom mennesker som anerkjenner kroppslig mening kan overkomme en forståelse av funksjonshemming som et binært være- eller ikke være, et ha- eller ikke ha. I avhandlingen beskrives ikke disse levde erfaringene som polariserte punkter sammenliknet med levd erfaring uten funksjonshemming, men som erfaringer som er

sammenflettet, oppsummert og uttrykt på ikke-deterministiske måter av en fenomenal kropp.

### **Summary**

In this dissertation I investigate subjective embodied experiences of students in primary and secondary schools. The eight students participating in the study all have the diagnose multiple disability, yet they have a variety interests, meanings, social backgrounds and experiences. To develop knowledge that goes beyond the prevailing medical and social understandings of disability, I have applied phenomenology of perception as understood by Maurice Merleau-Ponty to attend to the students' perspectives. Due to the complexity of the disability, the participating students express them self through pre-symbolic, embodied gestures. Thus, in line with Merleau-Ponty's aim to provide a philosophy that extend empiricism and intellectualism, I have accredited movement as a third path towards knowledge about human experiences. Merleau-Ponty's phenomenology of perception has provided a possibility to attend to movements and embodied gestures as non-symbolic expressions that are qualitatively different from, yet not inferior to symbolic language.

To approach the subjective perspectives of the students in pedagogical everyday life, I have conducted close observations, taking part in everyday life in three special needs education units. The study's focus has been the subjective perspective of the students. Hence, close observations have provided data about lived experiences in lifeworlds where expressions are direct, without filters or manipulative intentions. I have also conducted phenomenological interviews with pedagogical staff members in order to shed light on how students and pedagogical staff co-create situations. The use of both observations and interviews has shed light on the particularly vulnerability and relational dependency in being a student with severe and multiple disability in the educational context.

The dissertation consists of four independent papers that are overarched by an introduction, a theoretical chapter, a methodological chapter and a chapter of reflection. The phenomenological existentials spatiality, materiality, and relationality are utilized as analytical insight cultivators in the investigation of embodied meaning and severe multiple disabilities. In addition to these phenomenological concepts, concepts from constructivism and post-structuralism are applied for analytical purposes in paper two and three.

This dissertation accredits movements as fully worthy carriers of subjective meanings. The four papers imply that relations between humans that acknowledge embodied meaning can dissolve a binary understanding of disability. Thus, movements of students with severe

and multiple disabilities are described as lived experiences. I have not attended to these experiences as polarized points compared to lives without disabilities, but as experiences that are intertwined, summed up, and expressed in non-determinate ways by the phenomenal body.

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## 1- Introduction

This dissertation's title "Give me a thousand gestures. Embodied meaning and severe, multiple disabilities in segregated special needs education" is inspired by Lithuanian-Swedish-Syrian feminist rapper Silvana Imam. October 4<sup>th</sup> 2017 Imam will meet journalist Yohan Shanmugaratnam for a talk called "Ge mig tusen röster" [Give me a thousand voices] at Litteraturhuset in Oslo. Imam's diverse background, her approach to sex, gender, sexuality and racism gives resonance to how this project questions established truths. Yet, an emphasis of "voices" could implicitly place perspectives expressed without words as inferior expressions that constantly are measured towards symbolic language as an undebated standard. As this project embraces gestures, "give me a thousand gestures" it is.

The purpose of this study is to investigate how embodied meaning unfolds in segregated educational contexts. Hence, the research question overarching the dissertation as a whole is *how does embodied meaning of students with severe and multiple disabilities unfold in school?* Enveloped by this question, various shades of embodied meaning are investigated in the four papers.

Paper one is called "'I guess that the greatest Freedom...' A Phenomenology of Spaces and severe, multiple Disabilities". The paper investigates embodied meaning by asking the research-question *what is the meaning of spatiality for students with severe, multiple disabilities in the context of special needs education?*

Paper two is called "Golden Paper, a Chain and a Bag: A Phenomenology of Queer Things in a Special Needs Education Unit". The paper sheds light on how embodied meaning emerge when queer things are put to use in the context of education. The research-question asked is *what is the meaning of things that are put to use in practical pedagogical work in special needs education units?*

Paper three is called "'He is not crying for real'. Severe, multiple Disabilities and embodied Constraint in two special Needs Education Units". The paper addresses how embodied meaning unfolds when bodies are under constraint by asking two research-questions; i) *what are the embodied meanings unfolding when students with severe and multiple disabilities are fastened in assistive technical devices?*, and ii) *How are students' gestures recognized and included in interactions by staff-members?*

Paper four is called "Phenomenology of professional practices in education and health care: an empirical investigation". The paper investigates embodied intersubjectivity in professional practices within education and health-care by asking *what is the*

*interaction/connection between professionals and patients/ students like in education and health care encounters?*

Since its fragile beginning, this project has been driven by curiosity. This curiosity is rooted in my occupational background within practical pedagogical work as well as in my academic development within sports pedagogy and special needs education. Embodiment as pedagogical resource has captured my attention for many years. The quiet expressions of a hand's small gesture, as well as loud outbursts of joy or anger have expressed perspectives that have reached far beyond communication as equivalent to the ability to speak or perform other kinds of symbolic exchanges of perspectives.

The dominant perspective in disability research "is framed within special education or rehabilitation, often taking a biomedical and individualistic approach. The dominant perspective has been medical, viewing disability as an abnormality of the individual child" (Egilson, Ytterhus, Traustadóttir and Berg, 2015, p. 3). In my search for knowledge that does not provide more of the same perspectives that Egilson et al. (2015) describe, I turn to movements as lived experiences in educational everyday life. To come closer to an understanding of what embodied meaning might mean in special needs education, this project employs phenomenology in order to bring forward the students' perspectives.

The project's initial title was "A qualitative study of students with intellectual disability and their experiences in physical education". My point of departure as kindergarten teacher, and later on as special needs educator with a particular interest for embodiment influenced the initial sketch. Despite the project's aim to investigate intellectual disability in general, the first period of my PhD scholarship revealed an unanticipated gap of knowledge in the field of intellectual disabilities.

### **From intellectual disabilities and physical education to severe and multiple disabilities and embodied meaning**

To approach intellectual disabilities and physical education, I conducted a literature overview during summer 2013. I found papers that addressed intellectual disabilities and physical education in 17 different journals<sup>1</sup> in the research databases ERIC, ISI Web of science, and

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<sup>1</sup> Acta Universitatis Palackianae Olomucensis. Gymnica; Adapted Physical Activity Quarterly; Archives of Pediatrics & Adolescent Medicine; European Journal of Adapted Physical Activity; Journal of Applied Research in Intellectual Disabilities; Journal of Developmental and Physical Disabilities; Journal of Policy and Practice in Intellectual Disabilities; Journal of Teaching in Physical Education; Medicine and Science in Sports and Exercise; Ovidius University Annals, Series Physical Education & Sport/Science, Movement

SPORTDiscuss. The papers showed that there was a need for knowledge that could shed light on movement experiences of students with intellectual disabilities in physical education in new ways. Thus, I searched for an approach that did not consider disability as medical deviation, as behavioristic results of cause and effect nor as constructed by social arrangements. The literature overview also showed that the more severe the intellectual disability, the less research attention was received. Thus, this project's aim changed. To include students who had received restricted amount of research attention, I chose to investigate the experiences of students with severe and multiple disabilities in physical education.

Yet, the aim to investigate physical education took another turn when I entered educational everyday life in three special needs education units. I realized that all observable expressions, sounds and emotions of the eight participating students emerged into a shared world through movement. Hence, it turned out that demarcating embodied experiences to physical education appeared to be artificial and limiting. Several staff members stated that movement was foundational in the students' way of expressing them self. Movements crossed constructions defined by time schedules, school subjects, curriculums and individualized educational plans. It also crossed my pre-defined research assumption, saying that embodiment primarily belonged to the structures of physical education. Thus, there were two turns while developing this study: first, including only students with severe and multiple disabilities in particular rather than students with intellectual disabilities in general, and second, investigating embodied meaning as a human existential rather than physical education as construction.

### **A brief outlining of inclusion- and segregation tendencies**

In the foreword to *Childhood and Disability in the Nordic Countries. Being, Becoming, Belonging*, Shakespeare states that "the Nordic countries are about the best in the world in achieving the welfare framework necessary for inclusion" (Shakespeare, 2015, p. x).

Historically, the Norwegian law for special schools came into being in 1951. The law ensured students with disabilities the right to education in segregated educational arrangements. While

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& Health; Pennsylvania Journal of Health, Physical Education, Recreation & Dance; Perceptual and Motor Skills; Physical Education and Sport Pedagogy; Research Quarterly for Exercise & Sport; The Journal of Physical Education, Recreation and Dance; The Journal of Physical Education, Recreation & Pediatrics; Timisoara Physical Education & Rehabilitation Journal

ensuring some students the right to education, the law did not recognize the students with the most severe disabilities as educable. These students were not officially included into the Norwegian educational system until 1976, when the law of special schools was terminated.

From 1976 on, the concept of what counted as education was expanded. Education was ascribed to include more than it traditionally had done, thus, students that earlier were seen as unable to learn were included into the educational system. Since 1998, all Norwegian students with special educational needs have had the right to be included at their local school. Today, The Norwegian Directorate for Education and Training (UDIR, 2015) states that inclusion is an overarching principle, and that all students shall belong to a class and take part in a school community.

Internationally, The Salamanca Statement and Framework for Action on Special Needs Education (United Nations Educational, Scientific and Cultural Organization UNESCO, 1994) emphasized the importance of "recognizing the necessity and urgency of providing education for children, youth and adults with special educational needs within the regular education system". In a recent Norwegian report on special needs education and research, Ekspertgruppen for spesialpedagogikk [The expert group for special needs education] (2014), pointed out that between 2007 and 2010, there was a 19,3% increase in kindergarten teachers and teachers that attended further education to develop a more comprehensive competence in special needs education. Yet, despite national and international guidelines and the increase in staff's competence in special needs education, researchers describe that 75 % of children with severe disabilities still attend to education in segregated classes or schools in Norway (Wendelborg and Tøssebro, 2011). Tendencies identified by Ytterhus and Tøssebro (2005) illustrate that the amount is higher in the capital area of Oslo and surroundings than in the rest of the country. There also seems to be huge shifts of increasing numbers from kindergarten to primary school as well as increasing numbers from primary school to secondary school (Wendelborg and Tøssebro, 2011).

The expert group for special needs education (2014) states that a medical understanding of disability was ubiquitous in special needs education for many years. Gradually, such an individualistic understanding was seen as inadequate as it did not include social and contextual influences. Further, the expert group (2014) states that some fields within special needs education have received a fair share of attention, while other fields have not. The group states that several researchers within special needs education are occupied with language, reading- and writing difficulties, and socio-emotional difficulties, and that investigations in visual impairments, intellectual disabilities, and disabilities across the lifespan are more rare.

To conduct research that provides knowledge to the practical field of special needs education, the expert group (2014) recommends some future methodological approaches. Systematic reviews and meta analyses, methods that shed light on correlations and causal connections, and qualitative case studies investigating rare disabilities like severe and multiple disabilities are requested. Also, Traustadóttir, Ytterhus, Egilson and Berg (2015) and Tøssebro and Wendelborg (2015) have requested future research to direct attention to children's subjective experiences when they are enrolled in education that is ideologically inclusive. The way this dissertation sheds light on embodied meanings of students with severe and multiple disabilities within the frame of special needs education is a phenomenological reply to these proposals.

### **Phenomenology: searching for the first person perspective**

Phenomenology implies striving to understand phenomena as they are lived. Van Manen (2014) describes how Heidegger "carefully unpacks his provisional ontological formulation of the etymological meaning of the Greek word *phenomenology*. He points out that *logos* means "to let something be seen", and *phenomenon* means "that which shows itself in itself" (van Manen, 2014, p. 27. Italics in original). This leads to Heidegger's famous claim:

Hence phenomenology means: to let what shows itself be seen from itself, just as it shows itself from itself. That is the formal meaning of the type of research that calls itself "phenomenology". But this expresses nothing other than the maxim formulated above: "To the things themselves!" (Heidegger, 2010, p. 32, cited in van Manen, 2014, p. 28).

*Turning to the things themselves*, or in Husserl's words, *zu den Sachen selbst* (Ricoeur, 1967, p. 102. Italics in original), is the path to access experiences as they are lived. Lived experiences take place in everyday life in the flow of pre-reflective moments. Thus, to attune phenomenologically to experiences is to be open to enigmas of everyday life. Phenomenologists searching for knowledge ought to accept that the answers to these enigmas are glances of meaning rather than determinate conclusions (van Manen, 2014).

The phenomenon I turn to in this dissertation is the embodied meaning of students who attend to education in segregated arrangements. Turning to their experiences means taking part in their lifeworld when entering into their educational everyday life. By including self-experienced embodied interactions as well as felt resonance when observing embodied

interactions, this dissertation first and foremost investigate students' perspectives. Aiming to explore their first person perspective makes this approach diverge from an investigation of the experience of the experiences of others, as would have been the case if the words of the staff members were the most prominent. Yet, the first person perspective of the staff members are included to broaden the students' perspectives. Also, my perspective permeates through the dissertation, situating it in a hermeneutic phenomenological approach to special needs education.

### **Special needs education and phenomenology as philosophy and methodology**

As we have seen, phenomenology gives credit to embodied meaning as lived in a first person perspective. As such, the phenomenological approach provides something different from what the prevailing medical-, behavioristic-, and social approaches to severe and multiple disabilities have done. This project attends to a group of children whose perspectives seldom are visible to others than those already involved with them in personal or institutional contexts. Thus, to include students' subjectivity without presenting them solely in light of medical, behavioristic or social understandings, I have applied phenomenological philosophy and phenomenological methodology. As an alternative to objectifying approaches to human existence, phenomenology does not rest on objective and measurable descriptions of deviations. Rather, the dissertation's phenomenological objectivism is attended to by keeping close *zu den Sachen selbst* (Ricoeur, 1967, p. 102. Italics in original): to the embodied meanings of the student participants.

The divergence between phenomenology as philosophy and phenomenology as humanistic research method including empirical material is distinct to phenomenological researchers, as "the application of philosophical ideas to the empirical project provokes both uncertainty and controversy" (Finlay, 2009, p. 6). There exist projects of pure phenomenological philosophy as well as phenomenological projects based on empirical material gathered by the application of various phenomenological research methods. Thus, projects that carry the hallmark of being phenomenological are developed in a field that is in debate about what counts as true and trustworthy phenomenology and what does not.

This project includes empirical material from the educational lifeworlds of eight students with severe and multiple disabilities. Meanwhile, I claim that it is phenomenological. In educational research, this project is not alone in crossing lines of phenomenological philosophy and phenomenological methodology. It follows other projects that have combined



phenomenology as philosophy and empirical material from educational contexts, for example van Manen and Li (2002), Sævi (2005), Smith (2007), Foran and Olson (2008), and Robinson (2015). Van Manen (2012) describes how phenomenology and pedagogy relate in pedagogical moments. In these moments, children's first person perspectives emerge and can be acted upon in the blink of an eye:

Sometimes, if not usually, in our daily living with children we are required to act in the spur of the moment. The usual case is that we do not have time to sit back and deliberatively decide what to do in the situation. And even when there is time to reflect on what several alternatives are available, and what best approach one should take in the pedagogical moment itself, one must act, even though that action may consist in holding back (van Manen, 2012a, p. 9).

Philosophically, this dissertation is rooted in a phenomenological direction that accredits human movements as intentional carriers of meaning. Merleau-Ponty's *Phenomenology of Perception* (2014) has provided philosophical possibilities to inquire into how embodied meanings unfold when students have severe and multiple disabilities. Methodologically, van Manen's *Phenomenology of Practice* (2014) has provided methodological guidelines that are suitable when including perspectives that are expressed without words into research. It is important to point out that this separation of philosophy and methodology is done for clarification- and epistemological situating purposes. In the dissertation, philosophy and methodology are intertwined, both providing valuable contributions to the project.

### **I, a phenomenologically inspired pedagogue**

Placed within a hermeneutic phenomenological tradition, this dissertation carries traces of my presence, where an intertwining of practical pedagogical work and academic development has influenced the written material. My experiences with intellectual disabilities, autism spectrum disorders, and severe and multiple disabilities have framed an interest in understanding how embodiment can bridge and even overcome qualitative differences in expressions and communication.

Academically, I was briefly introduced to phenomenology when in the last year of kindergarten teacher education. Later, phenomenology re-appeared when I studied a minor degree called "physical activity and disability". After starting education at master level, I re-

attended to phenomenology. The master program, which provided specialization in intellectual disabilities, paid attention to history of intellectual disabilities, cognition as a measurable variable, language development and diagnostic criterions. The intentional, perceiving, and meaning-seeking body was barely addressed. Thus, my master dissertation turned out to be a counter-reaction to what I understood as a determinant, objectifying and instrumental understanding of intellectual disabilities. To address what I considered a neglect of embodiment in higher special needs education, I undertook a critical, theoretical discussion of the body of persons with intellectual disabilities as a resource rather than as an expressional hindrance (Evensen, 2011).

Yet, this project's fragile start was my personal-professional meeting with a five year old boy in kindergarten. He showed me an enigma that I, 22 years later, have been unable to provide a definite answer to. How can it be that communication can be complete and fluent, even when there is a seemingly huge difference between those involved? How can it be that deviations fade into background when personality comes forth? What is this "something" that covers the gap between pre-symbolic and symbolic expressions? Is there a gap after all, if communication is about adapting in mutual relationships?

## 2- Theory

To see is always to see from somewhere, is it not? If we say that the house is seen from nowhere, are we not just saying that it is invisible? And yet, when I say "I see the house with my eyes", surely I am not saying anything controversial, for I do not mean that my retina and my crystalline lens, or that my eyes as material organs are operational and make me see the house. With only myself to examine, I know nothing of these things (Merleau-Ponty, 2014, p. 69).

### **Phenomenology-beginnings and divergences**

Edmund Husserl (1859-1938) is called the father of phenomenology. Unsatisfied with positivist scientific approaches when studying psychology, he developed a radical approach that had reinstatement of subjective dimensions of experience as its goal (Allen-Collinson, 2011). Husserl's claim was that human phenomena best could be understood by transcending natural attitudes like preunderstandings and tacit presuppositions that stood in the way of the phenomenon. Thus, he developed a descriptive phenomenological method, in which epoché and reduction were key-concepts. In order to reach his goal to return to the things themselves, "*zu den Sachen selbst*" (Ricoeur, 1967, p. 102. Italics in original), Husserl claimed that phenomenologists have to suspend their preunderstandings and tacit presuppositions by putting them into brackets, which means removing them so that they do not disturb the investigation of the particular phenomenon.

Husserl's method of bracketing the subjectivity of the investigating philosopher can thus be seen as a "step out of the world to grasp the meaning from above" (van Manen, 2014, p. 220). Where Husserl's approach implies grasping meaning from above, van Manen describes the phenomenology of Martin Heidegger (1889-1976) as one that "stays in the world of beings to understand their modes of being from within the world" (2014, p. 220). Heidegger agreed with Husserl that epoché and reduction should be attended to provide sound, phenomenological research. Yet, he could not accept that reduction could ever become complete (van Manen, 2014). He also doubted that the phenomenologist's subjectivity could be suspended by being put into brackets. Rather than following Husserl's descriptive approach, Heidegger promoted phenomenology as hermeneutic. His solution was that philosophers should stay true to reduction and epoché by making their subjectivity visible. By doing so, what belonged to the philosopher and what belonged to the phenomenon should turn visible to the reader.

According to Heidegger, Husserl's descriptive phenomenology was impossible to carry out in a complete way. Rather, Heidegger found his place in the line of phenomenologists acknowledging perception as always situated. Van Manen addresses Heidegger's temporal position among phenomenologists:

As we regard the history of phenomenology—from the early Husserl through Stein, Heidegger, Merleau-Ponty, Levinas, to Blanchot, Derrida and Henry, and now to contemporaries such as Lingis, Agamben, Marion, Figal, Serres, Chrétien, and Nancy—we notice an increasing awareness that the phenomenality of human experience cannot be adequately captured with the clarity of analytic concepts, objectifying theme, the purity of philosophical prose, the laws of logic, the abstractions of theory, the codifications of scientific method, and the traditional rationalities of philosophical systems. Instead, there is an acknowledgment that inquiries into the phenomenality of human experiences and truths require the full measure and complexity of the language of prose and the poetic, the cognitive and the pathic (van Manen, 2014, p. 29).

Heidegger turned attention towards humans' practical involvement with the world, yet, he has received critique for neglecting the role the human body plays in this involvement (Breivik, 2008). This leads us to the theoretical hub in this dissertation, the embodiment phenomenology of Frenchman Maurice Merleau-Ponty (1908–1961) and how he acknowledges subjective situatedness, where perceiving is always perceiving from somewhere.

This dissertation is developed and written in a hermeneutic tradition, aiming to stay true to the complexity of prose and poetic language, as well as the cognitive and the pathic. To get closer to lived experiences of others, I have used the phenomenological method reduction, which consists of the epoché and the reduction. I have attended to the epoché by making my identity visible to the reader. Thus, I aim to make clear what belongs to me and what belongs to the project in order to brush away what is not related to the phenomenon. I have also attended to the reduction by leading attention towards the phenomenon. This is done by keeping language close to the experiences as they were lived in order to emphasize students with severe and multiple disabilities as active participants and creators of embodied meaning.

### **Merleau-Ponty: acknowledging movement**

Merleau-Ponty engages with philosophy in a time where, as Landes describes it in the translator's introduction to *Phenomenology of Perception*, "any acceptable philosophical anthropology would have to synthesize incompatible sciences: those of the human being's physical nature and those of our thinking substance" (Merleau-Ponty, 2014, p. xxxiii). Merleau-Ponty (2014), in his usual style, unfolds empiricism and intellectualism before he describes phenomenology of perception as a third path towards understanding. He describes the schism between physical nature and thinking substance as quite natural due to the incompatibility of these directions. As Landes refers to, Merleau-Ponty points out that the results of the schism stems from "the discordance between the view man might take of himself through reflection or consciousness, and the one he obtains by linking his behaviors to the external conditions upon which they clearly depend" (Merleau-Ponty 2014, p. xxxiii).

Merleau-Ponty studies a wide range of phenomena. In his investigations of the body as expression and speech, the body as a sexed being and intersubjectivity and movement, he searches for an alternative way of understanding basic structures of human experience. Turning to the first person perspective rather than relying on the third person perspective that had dominated research until then, Merleau-Ponty follows the phenomenological call of returning to the things themselves.

To question critically whether empiricism or intellectualism understands perception in ways that can give credit to the rich intentionality of the human body, Merleau-Ponty turns to movement. In the first edition of *The Structure of Behavior [La Structure du comportement]* (1942) and *Phenomenology of Perception [Phénoménologie de la perception]* (1945), he acknowledges perception as the hub of the relation between subject and the world. In dualism, empirical–physical and intellectual–psychological analyses of perception have separated the sensible given from significant sensations. Turning to movement in a first person perspective, Merleau-Ponty emphasizes that phenomenologically, movement experiences are embodied, indivisible and thereby full-worthy.

In *Phenomenology of Perception*, chapter I: The Body, part III: *The Spatiality of One's Own Body and Motricity*, he uses his own embodiment in the introduction to spatiality of positions and spatiality of situations:

If my arm is resting on the table, I will never think to say that it is *next* to the ashtray in the same way that the ashtray is next to the telephone. The contour of my body is a border that ordinary spatial relations do not cross. This is because the body's parts

relate to each other in a peculiar way: they are not laid out side by side, but rather envelop each other. My hand, for example, is not a collection of points (Merleau-Ponty, 2014, p. 100).

Merleau-Ponty does not separate perception into pure body or pure mind. Nor does he attempt to apply an obscure fusion of empiricism's description of humans as objects among objects and bodies as mechanical constructions composed by atoms and externally related points with intellectualism's description of memories, emotions, and desires. Revealing how the perceiving subject and its perceived world co-create experiences that are larger than the sum of their parts, Merleau-Ponty will not stay within a dichotomized understanding of empiricism and intellectualism, physiology and psychology, the body as pure object or pure subject. Hence, his phenomenology of perception gives credits to the body as intentional, meaning-seeking, and fully worthy.

When emphasizing movements as carriers of experienced meaning through which humans can be understood, Merleau-Ponty points out that empiricism and intellectualism ought to be rejected in order to foreground lived experiences. He will not accept the classical understandings as indisputable, and writes "We must, then, reject as abstract any analysis of bodily space that considers only figures and points, since figures and points can neither be conceived nor exist at all without horizons" (Merleau-Ponty, 2014, p. 103). Thus, it is not until figures and points are rejected as explanations that it is possible to turn to the experiencing body as substantiate in itself.

As a magnifying glass, movement provides Merleau-Ponty possibilities to emphasize what dualism annihilates and makes invisible. Dualism has mislead humans to think that understanding only can be achieved by attending to experiences as either body or mind. Merleau-Ponty attends to an initial meaning of existence when he turns to the moving body as an existential, belonging to the lifeworld of everyone. He states:

How the body inhabits space (and time, for that matter) can be seen more clearly by considering the body in motion because movement is not content with passively undergoing space and time, it actively assumes them, it takes them up in their original signification that is effaced in the banality of established situations (Merleau-Ponty, 2014, p. 105).

In some of his earliest writings from the interwar period, Merleau-Ponty makes it clear that humans carry their perception somewhere with them in every situation they participate. Thus, he disapproves that causal explanations applied to relations between humans and their world can give a fully worthy picture of experience. In order to persuade that his arguments are trustworthy, he scrutinizes what he in the language of his time calls morbid motricity. In this, he includes impairments, disabilities, and illnesses, all in order to elaborate the insufficiency inherent in empiricists' and intellectualists' explanations of human perception.

### **Disability underlines possibilities in *Phenomenology of Perception***

Merleau-Ponty points out how dualism has approached disabilities by rendering causes and effects. In particular, he points to the phenomenon of the phantom limb, where a person who have lost a limb still experiences it to be present. Empiricism and intellectualism explain this phenomenon *either* by a peripheral theory *or* by a central theory, implicitly saying that if the empirical, peripheral explanation of the phenomenon cannot provide an explanation, a central, psychological explanation must be given. The physiological explanation of empiricists explains the phantom limb "as the mere suppression or the mere persistence of interoceptive stimulations" (Merleau-Ponty, 2014, p. 82) and that "the phantom limb is the presence of a part of the body's representation that should not be given, since the corresponding limb is in fact absent" (Merleau-Ponty, 2014, p. 82). On the other hand, the psychological explanation of intellectualists states that the phantom limb "becomes a memory, a positive judgment, or a perception". Hence, physiological explanations treat the phantom limb as "the actual presence of a representation" (Merleau-Ponty, 2014, p. 82), whereas the psychological explanations treat it as "the representation of an actual absence" (Merleau-Ponty, 2014, p. 82).

Treating the phantom limb as an actual presence of representation or as the representation of an actual absence, dualistic approaches have not been able to escape from categories that are already known. Merleau-Ponty points out that even a fusion of empiricists' actual presence and intellectualists' actual absence does not provide an alternative to already established categories, as presence and absence have no middle ground. To describe the phenomenon of the phantom limb from a phenomenological perspective, Merleau-Ponty states that:

This phenomenon – distorted by both physiological and psychological explanations – can nevertheless be understood from the perspective of being in the world. What refuses the mutilation or the deficiency in us is an I that is engaged in a certain physical and inter-human world, an I that continues to tend toward its world despite

deficiencies or amputations and that to this extent does not *de jure* recognize them (Merleau-Ponty, 2014, p. 83. Italics in original).

Merleau-Ponty claims that "The phantom arm is not a representation of the arm, but rather the ambivalent presence of an arm" (2014, p. 83). When experiencing this ambivalent presence of a limb, a person that is actively engaged in the world might try to use it, even though it is no longer there. Hence, the person might try to walk with a leg that is no longer there and "is not even discouraged by a fall" (Merleau-Ponty, 2014, p. 83). Here, an ambiguity shows. On the one hand, the person through his attempt of walking seems to be unaware of the absent limb, while on the other hand, this person:

describes the particularities of the phantom limb quite well – such as its strange motricity – and, if he treats it in practice as a real limb, this is because, like the normal subject, he has no need of a clear and articulated perception of his body in order to begin moving (Merleau-Ponty, 2014, p. 83).

Through elaborations of the phantom limb when experienced as an ambivalent presence in the world, Merleau-Ponty addresses how refusals of the phantom limb are not deliberated decisions nor are theythetic consciousness. Experiences of health and disease are not of the order of the "I think that..." (Merleau-Ponty, 2014, p. 83). Rather, Merleau-Ponty turns back to the moving body in a world with things in continuous reciprocal interactions where each engagement carries something new. He states that:

the body is the vehicle of being in the world and, for a living being, having a body means being united with a definite milieu, merging with certain projects, and being perpetually engaged therein. In the evidentness of this complete world in which manipulable objects still figure, in the impulse of movement that goes toward it and where the project of writing or of playing the piano still figures, the patient finds the certainty of his [bodily] integrity (Merleau-Ponty, 2014, p. 84).

Merleau-Ponty then turns to the gaze as an example of how bodies have "natural instruments" (2014, p. 154) available to reach out in the world. "The gaze obtains more or less from things according to the manner in which it interrogates them, in which it glances over them or rests upon them" (2014, p. 154). Thus, he can claim that by obtaining lived significations through



motor and perceptual powers, movements and perceptions integrate into motor and sensual entities. As a perpetual process of fresh experiences:

our natural powers suddenly merge with a richer signification that was, up until that point, merely implied in our perceptual and practical field or that was merely anticipated in our experience through a certain lack, and whose advent suddenly reorganizes our equilibrium and fulfills our blind expectation (Merleau-Ponty, 2014, p. 155).

When fundamental motor- or perceptual functions delimit fields of action and perception, objects can expand the person's outreach in the world through an inter-corporeal meeting between person, object, and world. To exemplify, Merleau-Ponty turns to the blind man's cane. He states that when the cane becomes a familiar instrument:

the world of tactile objects expands, it no longer begins at the skin of the hand, but at the tip of the cane. One is tempted to say that the blind man constructs the cane and its various positions through the sensations produced by the pressure of the cane upon his hand, since these different positions in turn mediate an object to the second degree, namely, an external object (Merleau-Ponty, 2014, p. 153).

Merleau-Ponty acknowledges that certain objects can open possibilities for extending into a world that would not be experienced in the same way without this object being at hand. He finds that the world consists of certain kinds of spaces in which some bodies are entitled to reach out, whereas others are restricted. In these reciprocal relations between subjects and worlds, certain kinds of objects enhance outreach. Still, application of objects shall not be done in order to create an equilibrium where a given normality is the standard towards which everything ought to be measured. In fact, Merleau-Ponty claims that procedures employed to replace "the normal functions that have been destroyed are themselves pathological phenomena" (2014, p. 110). Normality can not be deduced from what is pathological, neither can deficiencies be deduced from their substitutions. Turning to subjective experiences of persons that use these objects rather than turning to how these objects direct their user towards a pre-defined normality is what will reveal embodied meaning. Thus, directing a subject towards a given normality should be subordinated acknowledging this subjects' way of being in the world. He writes:

The substitutions must be understood as substitutions, as allusions to a fundamental function that they attempt to replace, but of which they do not give us the direct image. The genuine inductive method is not a "method of differences," it consists in correctly reading phenomena, in grasping their sense, that is in treating them as modalities and variations of the subject's total being (Merleau-Ponty, 2014, p. 110).

In this, a principle challenging a given normality as the one and only standard against which all deviations should be measured is presented.

To pinpoint that life consists of periods and states of being that are qualitative different from adulthood or from life without disabilities, Merleau-Ponty turns to childhood in general and disabilities in particular. He claims that these life stages and states of being are not inferior to the adult life of a person without disabilities. Rather, childhood is the fulfilled way and time of being a child, adolescence is the fulfilled way and time of being in youth and being a child having a disability is the fulfilled way of being a child having a disability.

### **Pedagogy in the light of Merleau-Ponty**

Merleau-Ponty held a position as chair of psychology and pedagogy at the Sorbonne from 1949 to 1952, from which his work is documented in detail by his review of student notes (Merleau-Ponty, 2010). At the Sorbonne, Merleau-Ponty continues his elaboration of the intentional and meaning-seeking body. He is critical towards adults that approach children as if they are obliged to develop in a causal, straightforward manner, where causes and effects are determinate, undebated and natural. He also criticizes rules of pedagogical actions when these are asymmetrical, communicated *from* the adult *to* the child in order to lead the learning child towards an unavoidable state of adulthood (Merleau-Ponty, 2010).

Merleau-Ponty's roads crosses with developmental psychologist Jean Piaget's when the latter takes a professorship at Sorbonne in 1952. Merleau-Ponty frequently refers to Piaget, elaborating and sharpening his critical approach towards behavioristic and determinant stage thinking. Merleau-Ponty is critical to how Piaget reduces the child to an "achiever" of developmental stages, while ignoring social, cultural and historical situations. The result is a negative interpretation of children where they are measured towards adult capabilities, resulting in an over-evaluation of subjective language that underestimates artistic, expressive and childhood language (Merleau-Ponty, 2010).

Merleau-Ponty illuminates how pedagogy usually is approached as the unnoticeable background of child psychology. Thus, he questions a pedagogy that rests on a science of causes, consequences and employed techniques as means and ends that are transformed into rules of actions. In the relation between psychology and pedagogy, it appears that presuppositions subordinate pedagogy to psychology and morality (Merleau-Ponty, 2010). A quote that is especially interesting to this dissertation as situated in an educational landscape where medical considerations are present in everyday educational life is found in *Child Psychology and Pedagogy. The Sorbonne Lectures 1949–1952* (Merleau-Ponty, 2010), chapter 2; *The Adult's View of the Child (1949–1950)*. Merleau-Ponty states: "(For instance, the kind of implicit assumptions that medicine postulates—is life more valuable than death?) We must ask if this kind of double dependence is tenable" (2010, p 68. Brackets in original).

Merleau-Ponty points out how pre-established values are applied to pedagogy, where pedagogues do not acknowledge how these values speak to the child's real situation. This creates an artificial conservation of old customs, as "a moral imperative only emerges in contact with a situation" (Merleau-Ponty, 2010, p. 68). Following Merleau-Ponty, Standal (2009) addresses how learning connects to relations of meaning, as "the situation taken as a whole is not something merely attributed to the compound of stimuli, because these stimuli are integrated into structural processes that play a regulating role" (Standal, 2009, p. 60).

Merleau-Ponty's phenomenology of perception (2014) and child psychology and pedagogy (2010) provide a unique theoretical background for understanding embodied meaning in pedagogical contexts without searching for the adult in the child, without directing disability towards a given normality and without disallowing unique child-experiences.

### **Phenomenology and severe, multiple disabilities**

Merleau-Ponty's phenomenological philosophy has provided this project possibilities to approach the perspectives of students with severe and multiple disabilities as fully worthy. In fact, phenomenology aims to grasp and describe experiences as they are lived, before they are reflected upon and translated into symbolic language by thought. As such, being a perceiving human does not presuppose an ability to form symbolic language. Inferring from movements, gestures and postures makes it possible to get closer to an understanding of students with severe and multiple disabilities from the inside.

I have described how Merleau-Ponty in line with Husserl and Heidegger acknowledged the first person perspective as the appropriate approach to understand human experiences. Yet, Merleau-Ponty was the first phenomenologist that placed the body as the hub around

which all experiences gather. Acknowledging corporeality as an existential constantly intertwined with the other existentials spatiality, temporality, materiality, and relationality, he found support in movement and disability when making his point of view substantiate. Atmospheres that are characterized by dichotomies like "obedient-authority, cleanliness-dirtiness, virtue-vice, masculinity-femininity" (Merleau-Ponty, 2010, p. 242) will not create possibilities of experiencing ambiguity and possibilities to orientate towards disability as lived experiences rather than a dichotomous state of having or not having.

As both research literature as well as the empirical material presented in this dissertation shows, a medical perspective seems to be deeply rooted in the education that students with severe and multiple disabilities attend to. Thus, to get hold of the students' first person perspective, severe and multiple disabilities are understood as experiences shaped within the present world in continuums. In the continuums described, students' experiences are not dichotomous states of categories like medical or social considerations, experiences of wellbeing or pain, or by being able or unable. Rather, human experiences are transcendental and crossing categories. Thus, experiences of students with severe and multiple disabilities are expressed with the same value as any other human expressions as:

We never move our objective body, we move our phenomenal body, and we do so without mystery, since it is our body as a power of various regions of the world that already rises up toward the objects to grasp and perceive them (Merleau-Ponty, 2014, p. 108).

Merleau-Ponty's phenomenology has provided a philosophical platform for reflecting upon a given normality as a standard that severe and multiple disabilities ought to be measured against in educational contexts. As the papers will show, Merleau-Ponty, Ahmed, Goffman, and to part also Nancy, have provided perspectives that all shed light on experiences as first and foremost embodied.

## 2.1- Existentials. Bodies experiencing space, time, things and others

Nå kan du det

Nå kan du det, nå kan du det, jeg holder ikke nå

jeg stopper opp, du ruller vekk, og himmelen er blå.

Der sykler du, du sykler nå! Blant lavblokker og stein

i junisol, med vinglefart, og tynne, brune bein.

Jeg står igjen på asfalten, litt anpusten og svett

med merker inni hendene fra ditt bagasjebrett.

Der ruller du så fint av sted

så svinger du, du klarer det

og smilet ditt er veldig bredt

alt ble med ett så veldig lett:

En mandagskveld, en sykkel og en plastflaske med vann

en jente og en asfalt plass og brennesle og sand.

Og ikke visste vi at man kan bli så glad og fri

på en parkeringsplass rett bakom Moltzau trykkeri<sup>2</sup> (Rishøi and Kaltenborn, 2011, pages without numbers).

As this project follows the methodological guidelines of van Manen (2012; 2014), it includes what is pathic, poetic and artistic in relation to the explored phenomenon. Thus, I introduce existentials; space, time, things and others by including poems and excerpts from prose.

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<sup>2</sup> [You can do it now

You can do it now, you can do it now, I do not hold you anymore  
I'm standing still, you roll away, and the skies are blue  
You ride your bike, now you are riding! Among apartments and rocks  
in June-sun, with unstable speed and with thin and brown legs.  
I stand behind on the asphalt, short of breath and sweat  
with marks inside my hands from your bike rack.  
There you roll so neat your way  
You turn around, you are making it  
and your smile is very wide  
all of a sudden, it all was so easy:  
Monday evening, a bike and a plastic bottle of water  
a girl, a space with asphalt and stinging nettle and sand  
and we surly didn't know that one could be so glad and free  
on a parking lot behind Moltzau printing office] (author's translation).

Poems and prose are presented in their original languages; Bokmål, Nynorsk<sup>3</sup>, Swedish and German. This is a conscious decision made in order to make parts of my identity as a Norwegian, Scandinavian and European kindergarten teacher visible. The excerpts express the project as situated in a hermeneutic phenomenological tradition. English translations are available in footnotes.

Corporeality, spatiality, temporality, materiality and relationality are "existentials in the sense that they belong to everyone's life world—they are universal themes of life" (van Manen, 2014, p. 302). Body, space, time, things and others do not form a complete and saturated list of existentials. Yet, van Manen (2014) acknowledges these five as fundamental, as they in addition to belonging to every lifeworld occur repeatedly in phenomenological literature. In particular, van Manen points out how Merleau-Ponty in *Phenomenology of Perception* "has major sections on body, spatiality, things or world, others or relations, and temporality" (van Manen, 2014, p. 302-303).

The moving human does not address movement experiences to pure mind dominated by an "I think that" (Merleau-Ponty, 2014, p. 139). Rather, movements, voluntary or not, are inter-sensory units of the person and a milieu of existentials. In this dissertation, I have understood the body under analytical lenses provided by Merleau-Ponty. Also, Ahmed (2004; 2006) and Goffman (1981; 1991; 2008), both taking up various aspects of existentials, have provided important analytical tools. Ahmed (2004, 2006) addresses queerness by discussing queer phenomenology of things. She also discusses how subjects are limited or entitled to reach out in spaces that shape and have taken the shape of some bodies over others. She points to Heidegger's descriptions of material things, and sheds light on how things that surround us function as orientation devices. Goffman (1981; 1991; 2008) addresses relationality in interactions as expressed through embodied signals like gestures and mimicry in segregated institutional contexts where relations are asymmetrical.

### **Body and space**

Tonje Glimmerdal

Om du går av båten nede ved kaia, då kjenner du vinden frå dalen med ein gong. Til  
og med no når det er kald vinter, kjenner du den. Berre lat att auga. Furu luktar det. Og

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<sup>3</sup> Bokmål and Nynorsk are official written standards of Norwegian. Bokmål is derived from Danish, while Nynorsk is derived from Norwegian dialects.

gran. Det er berre å begynne å gå.

Du skal følgje den vegen som går rett fram, forbi den nedlagde kiosken, butikken og frisørsalongen til Theo, og vidare framover langsmed elva.

I starten er det nokså flatt, og nokre hus. Eit av dei siste husa står det ei gravemaskin utanfor. Der bur Peter og mor hans.

Så vert det meir og meir snø og skog, og mindre og mindre hus. Vegen vert halvparten så brei og dobbelt så bratt. Det kan godt hende du begynner å kjenne deg litt skeptisk, då, dersom du ikkje har vore der før, og kanskje du lurar på om du har gått feil. Men det har du ikkje. For akkurat når du har tenkt det, då ser du eit skilt.

"Glimmerdalen" står det. Og så veit du at du har gått rett likevel<sup>4</sup> (Parr, 2015, p. 11-12).

This section addresses spatiality as an existential that unfolds between lived space and objective space. Merleau-Ponty (2014) points out how objective directions like up and down "breaks down and rebuilds itself before our eyes" (2014, p. 255). He describes an experimental case where a person's retinal images are turned upright by the use of glasses. Thus, space is experienced as unreal and inverted, and the person will feel that the body itself is affected. Yet, as time passes by, the body - particularly when in motion – is experienced as being normally positioned in the inverted space once again (Merleau-Ponty, 2014).

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<sup>4</sup> [Tonje Glimmerdal.

If you step out of the ferry down by the harbor, you feel the wind from the valley at once. Even like now, when it is cold winter, you can feel it. Just close your eyes. It smells spruce. And pine. Just begin to walk.

You shall follow the road that leads straight ahead, pass the disused kiosk, the grocery-store and Theo's hair-salon, and further along the river.

In the beginning it is pretty level, and some houses. One of the last houses has an excavator on the outside. That's where Peter and his mom lives.

Then there is more and more snow and forest, and less and less houses. The road becomes half as wide and double as steep. It might be that you begin to feel a little skeptical, then, if you have never been there before, and maybe you wonder if you have lost your way. But you have not. Because, in the moment that you have thought the thought, you will see a sign.

"Glimmerdal" it says. And then, you know that the road you have been walking is the right one] (author's translation).

In the introduction to part II (2014, p. 253, italics in original) in *Phenomenology of Perception*, Merleau-Ponty asks "*Is space a 'form' of knowledge*". Yet, spatiality has caught his interest even earlier. In *The Structure of Behaviour*, he describes a football field to pinpoint how humans act in their spaces. Merleau-Ponty depicts how movements in spaces take place in between "lines of force" like "the yard lines", the "penalty area" and "the 'openings' between the adversaries" (1967, p. 168) in a field constituted by official or unofficial rules that encourages or limits the actions the player can execute.

According to Merleau-Ponty, spaces are not objective, nor are they acts of connection between the subject and the subject's spaces. He finds that the essences of spaces are already constituted, and spaces thereby bestow in landscapes "without itself ever appearing" (Merleau-Ponty, 2014, p. 265). In this relation between space and subject, spaces wrap subjects' particular focuses into a general project that is constituted by the body. Alternations between parts and wholes are made possible by the body itself.

Merleau-Ponty (2014) accredits corporeality when subject, space, and perception meet as a communication more ancient than thought, made possible by a subject that is placed at the origin of everything. Orientations in spaces do not carry contingent properties as described by empiricists and intellectualists. Rather, orientations are what makes perception possible, claims Merleau-Ponty. In his view, if the perceiving subject does not orientate towards A rather than B, perception will not exist at all, as no contours, shapes, backgrounds or objects will stand out.

Acknowledging spaces as bestowing landscapes without appearing, Merleau-Ponty sees each meeting between subject and space as a continuous, yet hardly graspable birth. In *The Prose of the World [La Prose du monde]*, which was first published in 1969, Merleau-Ponty (1973) describes how each subjective perception in spaces creates the state of a self being born again and again, understanding the gestures of the subject as meanings in genesis. Merleau-Ponty (2014) enhances that these spatial experiences are sequential, where each experience returns to previous experiences as well as passing forward on a spatiality that is already acquired. In these sequences where spaces eclipse movements and make them possible, the relation between space and movements unfolds, as "Space is not the milieu (real or logic) in which things are laid out, but rather the means by which the position of things become possible" (Merleau-Ponty, 2014, 253-254). Spaces are thus not given to the one immersed in them, rather, spaces are intrinsically present through the person's practical intentions with them. Hence, certain kinds of spaces call for certain kinds of actions from persons that have a variation of interests, meanings, backgrounds, and experiences. Acting in



these spaces, persons and environments relate dialectically and leave reciprocal imprints that affect future movements.

To Merleau-Ponty spaces offer irreducible multiplicities of the body's concrete relations to up, down, right, left, near and far in a physical space. Spaces also offer unique capacities where moving subjects can conceive the contrast between spatiality of positions and spatiality of situations. According to Merleau-Ponty (2014), this distinction is hard to grasp. Yet, in contrasts that are revealed and made recognizable through movement, moments of reversibility unfolds. In sequential moments between objective spatiality of positions and subjective spatiality of situations, movement makes a gestalt of the perspective of the subject. In a spectrum of possible ways to move in spaces, the actual movement expresses how the person co-creates spatiality with the space he or she is immersed in. This happens as the person turns back towards what is already known or acts upon an interruption that brings in something new.

Merleau-Ponty turns to movement within spaces as carriers of knowledge and being. As such, movements are formative in understanding human existence. The distinction between positions and situations can be confronted by using technical instruments in modern physics or by turning to substitutional dimensions assuming that the change of space will not "modify the moving object in any way" (Merleau-Ponty, 2014, p. 254). Dismissing that the relation between person and space is purely objective, I follow Merleau-Ponty's thesis of movement and argue in favor for attending to the experiential dimensions when a person moves in space when aiming to attend to embodied meaning and severe, multiple disabilities.

### **Body and time**

Happy Sally

Du ligger med ryggen till under filtarna. Det är på vinden. När jag kommer uppför trapporna vänder du dig om.

-Hej, säger du och öppnar filtarna och drar in mig.

Där är det mörkt och sött och huden på dina armar är så het att jag bränner mig när jag drar med händerna över dem. Vi ligger där tysta och tittar på skuggorna som flyttar sig över rummet. Skuggorna är tiden och jag vill att tiden ska gå långsammare.

Till slut är det bara några vita ljusfläckar kvar borta vid trappan<sup>5</sup> (Stridsberg, 2004, p. 27).

Objective time is measurable, lived time is not. Merleau-Ponty (2014) describes lived time as the moving milieu we inhabit, like the way the distant landscape appears to move slowly while the railway attendant "whizzes by" (Merleau-Ponty, 2014, p. 443) when a passenger looks out of the window of a train.

Mensch (2010) points out an indivisible intertwining between body, space and time, and claims that "my being spatially in the world is not, in fact, distinct from its temporal analogue. This cannot be otherwise, given that it takes time to move from one place to another" (p. 455). Yet, as Taylor Carman states in the foreword to *Phenomenology of Perception* (Merleau-Ponty, 2014, p. xiii): "It is nevertheless possible to draw a distinction for analytical purposes in that primitive middle ground between two aspects of perception that arguably underlie and motivate all subsequent distinctions between subjective and objective, inner and outer, mental and physical".

Even if temporality has not been applied as an independent existential for analytical purposes in this dissertation, temporality has permeated through spatiality, materiality and relationality as analytical concepts. Thus, temporality seems to be an existential that climbs analytical walls when lived experiences meet existentials. Approaching the body as a temporal point zero (a point of "now" in time) and its spatial situatedness as a spatial point zero (a point of "here" in space), are two sides of the same coin. The now-point between a given past and a given future appears to have similar features to the here-point between possible orientations of up, down, right, left, near, and far in a physical space. The now-body moves within a world in which future, past, and present experiences create the body's horizons. The phenomenological experience of touching and being touched, would not be experienced if it did not take place as progressively unfolding in a certain order (Mensch, 2010).

Phenomenological time is not linear and actions in time are proactive. Breivik (2008) describes how skilled football players

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<sup>5</sup> [Happy Sally.

You are lying on your back under the carpets. It is on the attic. When I come up the stairs, you turn around. –Hi, you say, open the carpets and drag me in. In there it is dark and sweet and the skin on your arms is so warm that I am burned when I move my hands over them. We are lying there quietly, looking at the shadows that move across the room. The shadows are time and I want time to pass slower. In the end, there are just some white spots of light there by the stairs] (author's translation).

are able to read the situation before the ball is played. Therefore the best players tend to be at the right place at the right time. And more than that: they are ready for the action that the situation demands (Breivik, 2008, p. 342).

In such moments of phenomenological time, movements in the now can align to previous experiences or to the expectations of experiences that are to come. Thus, phenomenological time is not linear, but rather a non-linear state of being tossed between present, past, and future.

The body touching and the body being touched has temporal aspects, as past, present, and future are determined in inseparable, muddled, and hardly graspable moments of lived experience. Merleau-Ponty's phenomenology ceases in attending to temporality as linear, determinant relation of cause and effect (Mensch, 2010). Acknowledging perceptions as parts of perpetual cycles instead of lining perceptions up as temporal determinations implies a non-linear relation between a past that proceeds through the present and continues into the future. Hence, perceptions have their point of departure in any of these three temporal dimensions, where each temporal dimension contains signals reaching out for the two others through the subject.

In the resonance of recalled past-, situated present- or imagined future perceptions lies the importance of foregrounds and backgrounds as contrasts that makes perception possible. Contrasting distinctions are foundational for expressions, as one distinctions turn meaningful only when seen in light of the other. Adams (2008) describes how Merleau-Ponty situates real expression as temporal contrasts:

Somehow, that is, expression must occur in the transition between old and new, between text and interpreter, between past and present, between the already spoken and the speaking of the yet to be expressed. For if expression involved only the perfectly faithful transmission of some original meaning, this would not constitute real expression, only repetition and reproduction. On the other hand, if expression involved a wholly new meaning, created just in and for the present, this also could not constitute real expression, only a kind of mute utterance or private language (Adams, 2008, p. 156).

Expressive contrasts are not possible to detect if movements are seen as pure "now". Adams (2008) points this out as a paradox of expression, as movements in the now are what we can infer from, yet expressiveness of movements will not be captured if they do not appear as contrasts towards a known past and an unknown, yet expected, future. Analyses of perception are ever renewed and not mere repetition of previous expressions or mere utterances of private language. Thus, temporality is what makes contrasts visible to others.

In the foreword to *Phenomenology of Perception*, Lefort turns to the visible and the invisible as equally important temporal aspects of appearance. He writes:

This is not a *de facto* invisible, deduced from our being subjected to the here and the now, nor is it an invisible that would merely be the lining and the reverse side of the visible. Leaving a place for the invisible does not compel one to modify the definition of consciousness; the invisible becomes the structure of the visible, or that which never will appear from any perspective – the pivots, the dimensions, the levels of the field, which are absolutely beyond our grasp; and yet there is no sense in saying that they are concealed from the seer, for they are just as much the inner framework of seeing, and they are no more on the outside than they are on the inside of seeing (Lefort in Merleau-Ponty, 2014 p. xxviii, italics in original).

Thus, temporal orientation is an invariant structure, making phenomenology transcendental. Transcendental temporality is beyond categories, constituting possibilities and impossibilities for the person moving, and thus, through movement continuously expressing experiences in the un-linear interrelation between past, present, and future.

### **Body and thing**

Hvem skal trøste knøttet?

Så gikk det lille knøttet ut på stranden  
og fant en musling som var stor og hvit.  
Han satte seg forsiktig ned i sanden  
og tenkte: Å, så skjønt at jeg kom HIT!  
Og han la vakre stener i sin hatt,  
og havet var så smult og det ble natt.

Langt borte var hemulene med store, tunge skritt,  
og hufsa var forsvunnet-inn i hufse-huset sitt.  
Vårt knøtt tok av seg skoene og sukket litt og sa:  
Hva er jeg så bedrøvet for når allting er så bra?  
Men hvem skal trøste knøttet: Du må vise til en venn  
din musling. Hvilken glede kan du ellers få av den<sup>6</sup> (Jansson, 1998)?

Merleau-Ponty (2014) describes relations between humans and things that surround them in the world they carry themselves towards. Using the die as an example, he describes how a thing expresses its "ness", like the way the die expresses cubeness through its mere existence. When it becomes a part of a personal history, the die ceases being solely a die. When interacting with the world, the human "I" "throw my perceptual intentions and my practical intentions against objects that appear to me", Merleau-Ponty continues (2014, p. 84). Yet, where the "I" and the object are situated in the presence of each other, intentions are directed towards objects only insofar that the object "arouse thoughts and desires in me" (Merleau-Ponty, 2014, p. 84). When the object and the user correspond and the object is used, it might be incorporated and habitual, prolonging the user's outreach in the world. As examples, Merleau-Ponty (2014) depicts how the cane of a blind man becomes a prolongation of his embodied outreach in the world, as does the feather on a woman's hat when she bows to avoid the feather from breaking when the woman enters a door.

Merleau-Ponty's writings on how things and bodies relate dovetail with Heidegger's writings about how relations between things and users make objective things into equipment. Heidegger takes a step out of a dualistic, Cartesian understanding and investigates the basis of existence. Hence, he turns to materiality, and addresses material things as existentials. Things are foundational for the creation of a self, as human use of things creates possibilities to understand ourselves and our existence. According to Heidegger (Dreyfus, 1991), objective

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<sup>6</sup> [Who will comfort Toffle?

Toffle picks up his case and makes his way towards the beach.  
He sees a big white shell. What luck-it's just within his reach!  
He pulls his shoes off, feels his toes sink into soft white sand  
As he admires the pale blue sky, the sea, the rippling land.  
'How wonderful', thinks Toffle, 'I can rest or dance or shout  
Or fill my hat with pebbles.' Even so, he can't work out  
Why he is still not happy. There is no-one in his way,  
No Hemulen or Groke nearby. He ought to feel okay.  
So WHO will comfort Toffle and remind him that a shell  
Is nicer when there's somebody to show it to as well?] (Jansson, 2003)

equipment is an impossibility. Rather, it is first when the thing is used that it becomes what it is. When picked up and used by *someone*, the what-ness and how-ness of the thing emerges hand in hand with the what-ness and the how-ness of the user. Then, thing and user take shape in reciprocal interactions.

Ahmed (2006) follows Heidegger's reflections on things. In *Queer Phenomenology. Orientations. Objects. Others*, she states that things are orientation devices that allow some bodies to reach out in the world, while other bodies are restricted. Things present in immediate socio-cultural environments will be within reach for some bodies, making it possible for these bodies to act with comfort and ease. For other bodies, the same things will present a what-ness underlining the user's incapability, making the use uncomfortable and uneasy.

Ahmed (2004; 2006) points to how things that correspond to its users easily can become invisible. This is because the privileges of things that correspond to the bodies using them are hard to notice. Ahmed points to how homosexuality turns distinct when the world is shaped by and for heterosexuality. Gender turns distinct when a female rejects expectations by appearing in ways considered boyish or when a male appears in ways considered girlish. Being black stands out in a world of whiteness and disability turns distinct in a world where ability seems to be an undebated mirage.

Ahmed further leads our attention towards the presence of some things over others, presenting an alternative to a mechanistic and causal relation between thing and user. Emphasizing how things are carriers of a "can", Ahmed (2006) in line with Heidegger, pinpoints that the usefulness of a thing is not instrumental. Describing how the wheel can (but do not have to) roll, the pen can (but do not have to) write and the jug can (but do not have to) pour, Ahmed (2006) highlights that the capacity of a thing depends on how it is used by the person reaching out for it.

To explore the meaning of capacities in things, Ahmed (2006) turns to queer things. Queer things have lost their place. When these things are put to use without carrying expectations on how they are supposed to be used, they present new possibilities for those having them near. Queer things then turn into resources that carry a certain kind of openness, enhancing users' subjective possibilities to show their perspectives and to express their views.

The openness of queer things is relational and contingent. Turning to how humans move towards, with, and away from materiality reveals the intentional and reciprocal relation between mover and things. In this relation, the moving person is enrolled in a continuous becoming of a self when perceptual and practical intentions are directed towards the things

present. This means that things that have lost their place and arrived in other places than where they were originally expected or intended to be are things that can be approached more open and without expectations than things carrying preunderstandings and presuppositions.

### **Body and others**

#### Der Hase und die Maus

Ein besonders kleiner Hase hatte eine besonders große Maus geheiratet. "Das kann doch nicht gutgehen", sagten die Leute. "Der eine ist besonders klein, und die andere ist besonders groß, das paßt nicht zusammen, das ist paradox". Aber dann führten die beiden eine schöne, glückliche, lange und lustige Ehe zusammen, bis ans Ende ihrer Tage<sup>7</sup> (Janosch, 1991, p. 58-59).

Merleau-Ponty (2014) describes how he and his friend Paul share details in a landscape when Paul points his finger towards a steeple. Maurice and Paul do not conceive the steeple from the same point of view, rather, their seeing is analogue from two different starting points. From these different starting points, they now share a history of a steeple in a landscape.

In *Child Psychology and Pedagogy. The Sorbonne Lectures 1949–1952*, Merleau-Ponty describes how humans relate to each other. He addresses asymmetry as immanent in all human relations, and writes:

The relations with the other are always complicated. Even in an objective discussion, the triumph of reason is always felt as a personal triumph. Moreover, situations are rarely completely equal. Even if we make an effort to respect the autonomy of the other, even if we grant the other freedom, the other will never feel completely free since he receives his freedom in a partnership (Merleau-Ponty, 2010, p. 83).

Adult relations, Merleau-Ponty (2010) states, can renounce the asymmetry by instituting situational equality through marriage or friendship. In asymmetrical relations, however, turning to the parent and the child, Merleau-Ponty addresses how "the triumph of reason"

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<sup>7</sup> [The hare and the mouse.

A particularly small hare married a particularly big mouse. "This cannot end well" people said. "One is particularly small, and the other is particularly big, this do not fit, it is a paradox". But then they both led a nice, happy, long and fun marriage, until the end of their days] (author's translation).

(Merleau-Ponty, 2010, p.83) emerges from the tension between authority and reasoning. If an adult lose sight of what happens in the present situation in which the child is involved, but rather turns to "past traumas" (Merleau-Ponty, 2010, p. 83), an encroachment of the child's freedom is the result. Encroaching the freedom of the child is unavoidable, claims Merleau-Ponty (2010). Yet, he sees it as an adult duty to reduce encroachment to what is strictly necessary in order to keep the child safe in the world.

The adult that turns to the child's present situation has to accept that total adult control over the child is possible only if the child is attended to as an object. Objectification through total control will establish an inhuman gaze, where the actions of the other are not taken up and understood. Thus, the present actions are not included in future reciprocal interactions (Merleau-Ponty, 2010).

Still, objectifications of others are communicative acts, as objectifications of other humans annihilate their worlds. Merleau-Ponty states:

A dog's gaze upon me hardly bothers me at all. The refusal to communicate is still a mode of communication. Protean freedom, thinking nature, the inalienable background, or the non-qualified existence, which in me and in others marks the limits of all sympathy, certainly suspends communication, but it does not annihilate it. If I must deal with a stranger who has not yet uttered a word, I might well believe that he lives in another world where my actions or thoughts are not worthy of appearing. But should he utter a word, or merely make an impatient gesture, then he already ceases to transcend me: so that is his voice and those are his thoughts, and there is the domain I believed was inaccessible (Merleau-Ponty, 2014, p. 378).

Accepting the child as a competent actor in situations in which it might experience a relational disequilibrium diminishes the adult's possibilities of putting the child in disgrace. Merleau-Ponty (2014) points to how human beings cannot be placed as objects within the social world. Nor can society be placed within the human subject as an object of thought. To understand human relations, we must turn to the social world we are in contact with through existence, Merleau-Ponty (2014) continues. This social world is already there, and its appearance is a result of how personal existences take up pre-personal traditions. Pre-personal traditions are ancient conventions, where subjects that have entered the world in the past have marked out new subjects' social world.



To elaborate on asymmetrical relationships between adult staff members and children with severe and multiple disabilities in segregated educational contexts, the work of Canadian sociologist Erving Goffman has made an important contribution to this dissertation. According to Crossley (1995), Goffman elaborates on Merleau-Ponty's work by acknowledging movement as foundational for expressing perspectives in segregated contexts. Much of Goffman's work is conducted in asylums and prisons. In these institutions, he identified "the roots of social life in carnal interchange. Face-to-face, body-to-body, seen-seer: an intertwining, a chiasm" (Crossley, 1995, p. 145).

In segregated contexts inmates' expressed perspectives can be accredited or overlooked, depending on how ritual practices specify what idealistically should be done and what is actually done in the institution (Goffman, 2008). This corresponds to how Merleau-Ponty (2010) turns to the importance that the adult gives value to the expressions of the child in their asymmetrical relations. The adult immanently has to accept that children experience disequilibrium. Within a disequilibrium, the child has possibilities for acting competent if the adult does not attempt to perform a totality of control. Goffman (2008) also assigns to dissonance as positive challenges in social encounters. When those interacting turn to and accept the dissonance rather than ignoring its presence, future interactions might be right.

Yet, for dissonance to carry possibilities, non-verbal acts like gestures, mimicry, and movements have to be met as valuable expressions rather than as attention-claiming impediments (Merleau-Ponty, 2014, Goffman, 2008). If attention is turned towards impediments rather than towards movements as fully worthy embodied expressions, embarrassment as a dislikable feeling is due to strike. Goffman (2008) considers embarrassment as cause of feeling confused or flustered, feelings that should be covered over. Feeling confused "is considered evidence of weakness, inferiority, low status, moral guilt, defeat, and other unenviable attributes. And, as previously suggested, flustering threatens the encounter itself by disrupting the smooth transmission and reception by which encounters are sustained" (Goffman, 2008, p. 101–102).

Reciprocal relations are threatened when embarrassment take place. According to Goffman (2008), to restore the relation, every human has an obligation to overcome the embarrassment and to show deference towards others and self. Such obligations count even in asymmetrical relations like those between teacher and student. This makes both parties potential givers and deniers of deference. Goffman points out this mutual possibility for success or failure in giving or receiving deference:

In general then, when a rule of conduct is broken we find that two individuals run the risk of becoming dis-credited: one with an obligation, who should have governed himself by the rule; the other with an expectation, who should have been treated in a particular way because of this governance. Both actor and recipient are threatened (Goffman, 2008, p. 51).

Deference is attended to through ongoing, versatile, mutual relations where both parties have possibilities to see them self in the acts of the other. Thus, deference is present only when humans regard them self when being well regarded by others (Goffman, 2008).

To attain to deference in situations of embarrassment, the embarrassed person will try to conceal his or her embodied expressions by turning towards the verbal or non-verbal expressions of the other. Otherwise, the embarrassed person can create an alternative foreground, against which the embarrassment becomes the non-attention claiming background. By turning to embodied expressions, both the self and the embarrassed other can be brought back into interaction. Yet, this does not always happen, as willed gestures can conceal the immediate embodied expressions. Thus, if pretending to know what should be done to reestablish the relation without including the perspective of the other, the person granted authority in segregated contexts might attend to deference on his or her own part while diminishing the deference of the interactional partner (Goffman, 2008).

It can be challenging to bring embodied expressions into interactions when one of the parties is deprived of movement possibilities. Goffman (2008) points out the importance of possibilities to mobilize muscular and intellectual resources that suits the task present. If not even the smallest possible movement is attended to as carrier of an expressed perspective, deprivation of embodied freedom by the application of internal or external constraint blocks the line of relation. Constraint turns the person that could have been a fully worthy party in interaction into a person present with the others, but "he is not 'in play'" (Goffman, p. 101). According to Goffman, if a person is constricted in his possibilities to move in the ongoing relation:

the others may be forced to stop and turn their attention to the impediment; the topic of conversation is neglected, and energies are directed to the task of re-establishing the flustered individual, of studiously ignoring him, or of withdrawing from his presence (Goffman, 2008, p. 101).

Thus, turning attention to embodiment may retrieve mutuality in relations. If not, the interactional party given superiority in the asymmetrical relation leaves the other out of play.

### **3- Methods**

Each of us lives his or her life in an immediate, concrete, and personal manner that a different person may share or be aware of, but this difference can never be erased for the simple reason that we are corporeally, temporally, and spatially separate and singular beings (van Manen, 2014, p. 60).

As a philosophical discipline, phenomenology in general and phenomenology of perception in particular arose as a counter reaction to empiricism and intellectualism. Hence, phenomenological investigations of human experiences cannot rely on instrumental, positivistic research approaches (Martínková and Parry, 2011). Even though phenomenological directions have acknowledged embodiment as a common ground (Finlay, 2009), a divergence between the descriptive phenomenological philosophy of Husserl and the interpretive phenomenological philosophy of Heidegger has developed. This has resulted in a plethora of phenomenological methodological approaches, like Descriptive Phenomenological Method in Psychology (Giorgi, 2009), Interpretive Phenomenological Analyses (Smith, Flowers and Larkin, 2009), Phenomenology of Life-worlds (Schutz and Luckman, 1973) and Phenomenology of Practice (van Manen, 2014).

I have used Phenomenology of Practice (van Manen, 2014) as methodology to approach lived experiences of students with severe and multiple disabilities. I will give accounts of how I conducted close observations in order to attend to students' perspectives as well as accounts of phenomenological interviews conducted to gather staff-members stories about students' embodied meaning. The process of analysis and its significance to the compilation of phenomenological anecdotes will be described by giving an account of meaning condensation and emerging of themes. I will describe formal procedures, recruitment of participants, and practical considerations.

In this chapter, you will meet descriptive accounts addressing contexts and participants. Yet, these descriptions do not provide information that can stand alone when attending to students' embodied meaning. I describe the students' individuality and their pedagogical climate in phenomenological anecdotes and excerpts from phenomenological interviews in the four papers. These phenomenological devices carry the dissertation.

I have chosen phenomenological philosophy and methodology as there has been a call for research investigating subjective perspectives of students with disabilities. A contemporary Norwegian special needs education research report has requested future projects to pay attention to children's subjective perspectives (Ekspertgruppen for spesialpedagogikk, 2014).

Traustadóttir, Ytterhus, Egilson and Berg (2015), and Tøssebro and Wendelborg (2015) have proposed that disability researchers should pay attention to subjects with severe disabilities enrolled in an educational context that is ideologically inclusive. They have pointed out that subjective perspectives take shape in a social world, and that perspectives of caregivers provide important, yet different knowledge, especially when the children are unable to communicate their views in symbolic language (Wendelborg and Tøssebro, 2011, Traustadóttir, Ytterhus, Egilson and Berg, 2015).

The phenomenological approach to disability diverges from prevailing medical-, and social approaches, where disability is dominantly understood as placed within the individual child or as placed in the child's social environment. Based on a literature overview that revealed that researchers within the field of intellectual disabilities had paid minor attention to students with severe and multiple disabilities, we wondered what knowledge was to be found if we turned towards the perspectives of students with severe and multiple disabilities.

As students' perspectives are embodied and thus interchange from one body to another, this project is situated in a hermeneutical tradition following the early phenomenological philosophy of Heidegger. The subjectivity of the researcher and teachers being bodily close to students are thus present throughout the text. A withdrawal of subjectivity of one of these partners could undermine the project, as this kind of research is made possible through closeness of bodies that are seen as having equal value.

Phenomenology of perception as understood by Merleau-Ponty (2014) is the dissertation's philosophical framework. Phenomenology of practice as understood by van Manen (2014) has provided the methodological framework for investigating students with severe and multiple disabilities as actively situated and in reciprocal relations to their educational life-worlds. Van Manen (2014) describes phenomenology of practice as an interpretive meaning-giving method where research attends to lived experiences as they take place in everyday life in professional fields like education and health sciences.

### **Recruitment of participants**

The project started up April 1<sup>st</sup> 2013, and the study was approved by Norwegian Center of Research Data (NSD) April 7<sup>th</sup>, 2014 (see appendix). In cooperation with my main supervisor, I prepared a short enquiry that gave information about the study. This enquiry was e-mailed to principals in eight public schools that stated on their web pages that they had students with severe and multiple disabilities attending to special needs education units. An attachment that described the purpose of the study, the method that would be used, a brief literature review

and information telling that all participation in the study was voluntarily was applied to the enquiry.

Three out of eight schools responded positively, one responded negatively, and four did not respond. Two special needs educators from two schools contacted me by phone to ask questions about the project. In both cases, we agreed that I should make a visit in order for us to meet and discuss how the purpose of the project could be situated within the practical pedagogical everyday life in the specific unit. In these meetings, staff reflected on which of the unit's students they thought could be participants, excluding students that would react negatively when relating to the researcher as a stranger visiting for a limited period of time. I made all initial contact with the third school by e-mail. Further, the teachers conveyed written information about the study to the students' guardians, who then returned their consent to the teachers. All guardians that were asked approved their child's participation.

### **Contexts and participants**

The eight students participating in this study take part in education in special needs education units. The total number of students in each unit are less than ten. The staff have various practical and professional backgrounds like pedagogy, musical therapy, occupational therapy, childcare, youth workers, and assistants without professional education.

Physical surroundings in the units vary. In one of the units, most students have access to a separate room adapted to their personal needs in addition to common areas. The two other units consist of different theme-rooms that are used by all students, but none of them has a separate room for individual work. Common for all units are assistive devices like wheelchairs, trolleys, standing aids, walking aids and lifts, which occupy space in common areas like corridors, wardrobes and stairs.

One unit is located in the end of a long corridor on the first floor, and upper primary level students mainly without disabilities are based on the second floor, sharing the entrance and first meters of the corridor with the special needs education unit. The second special needs education unit is located in a building separated from the rest of the school. The building was raised temporarily in the 1980s, and house different special needs education units. It has an enclosed schoolyard, yet some students attend to recess-time in the main schoolyard. The third special needs education unit is located in the same building as one of the school's special rooms. All other age groups in the school are located in small houses that surround a yard.

The three girls and five boys participating in the close observations of this study have

been accredited place in the units because of their common diagnoses of severe and multiple disability, and because guardians have applied for the school place and had their applications confirmed by school authorities.

Student's name	Grade during close observations
Emma	6 <sup>th</sup> grade
Filip	10 <sup>th</sup> grade
Jakob	6 <sup>th</sup> grade
Oliver	2 <sup>nd</sup> grade
Oskar	4 <sup>th</sup> grade
Sara	7 <sup>th</sup> grade
Sofie	7 <sup>th</sup> grade
William	6 <sup>th</sup> grade

Practical-pedagogical work is organized in different ways in the different units. Some students participate in daily group-activities like morning-greetings with song and music, while others mainly attend to individual lessons or lessons with just a few students present.

The duration of lessons varied, depending on how the staff organized their work and on the students' condition of the day. In two units, staff switched responsibility for the students every 30 minutes to an hour, meaning that the students re-related to staff-members several times a day. In the third school one staff member followed the same student through the whole day.

Some staff members were present in the close observations, but have not taken part in phenomenological interviews. Yet, all staff members that appear in the dissertation were informed about the study orally and through a written form (see appendix). All staff members that were asked gave their written consent to participate.

Staff-members are all female. They have varied professional and practical experience, ranging from two to 27 years in working with students with severe and multiple disabilities. They all take part in practical-pedagogical tasks in daily work, yet the pedagogues are the ones formally responsible for planning and organizing teaching and supervising the rest of the staff.

Staff member	Title	Years in current job position
Anna	Teacher	27

Anne	Teacher	9
Berit	Assistant	4
Elizabeth	Teacher	16
Eva	Assistant	15
Hilde	Assistant	3
Ida	Assistant	2
Inger	Teacher	10
Karen	Assistant	10
Liv	Assistant	18
Maria	Teacher	4
Marit	Teacher	20

### **An introduction to attending to lived experiences of others**

By utilizing the phenomenology of practice (van Manen, 2014), it has been possible to acknowledge the students' being in the world as fully worthy. The method has provided important reflections and practical advices that have opened up for my visit to the lifeworlds of children with severe and multiple disabilities in their educational everyday life. Van Manen (2012, p. 57, italics in original) states: "It is to the extent that *my* experiences could be *our* experiences that the phenomenologist wants to be reflectively aware of certain experiential meanings". He continues by writing "phenomenology always addresses any phenomenon as a *possible human experience*" (2012, p. 58, italics in original). His phenomenological approach underlines that existentials are present in the life-world of everyone. Subjective experiences borrowed from students with severe and multiple disabilities are thus possible general experiences, breaking down categorical hallmarks of identities.

Reflecting over how wordiness of articulated staff-members easily can overthrow the bodily expressed perspectives of the students, close observations stand out as a linchpin in attending to lived experiences in lifeworlds where expressions are pre-symbolic. Yet, as disability is approached as how-ness of subjective beings rather than as what-ness of disability as a category, phenomenological interviews provide important stories about students' embodied meaning as it emerges when students and teachers relate corporally to each other, with things, and in spaces that are present. Thus, the perspectives of the teachers are important



contributions in understanding disability phenomenologically in a world where medical-, behavioristic-, and social understandings of disability create almost invisible backgrounds.

### **Close observations: approaching lived experiences and wordless perspectives**

Phenomenology of practice (van Manen, 2014) does not provide strict methodological guidelines for how to conduct close observations. Rather, van Manen compares the close observer to the storyteller embedded between nearness and distance to the participants, always looking out for a story to tell or an incident to remember. In this project, stories collected through close observations emerged in a span where my relations to the participating students and staff members were as close as possible within the time limit of the project. Meanwhile, I kept a hermeneutic vigilance to attend to how the embodied meaning of the students unfolded.

Van Manen (2014) describes close observation as an explorative method suitable when collecting experiential material from young children or very ill people, as gaining written descriptions or taking part in oral interviews can be difficult. Utilizing close observations to grasp lived experiences as they appear before they are reflected upon and transformed into symbolic language, the researcher can gain access to experiences that can be overlooked if more behavioristic or experimental observation techniques are applied.

Close observations carried possibilities for me to engage in embodied exchange of perspectives with the students as well as to observe how perspectives were exchanged between students and between students and staff. As I had been engaged with the students myself, observing students and staff provided experiences of resonance. Taking joyful part in mutual eye contact and a shared smile as well as having felt the force of severe spasticity when having a student on my lap provided me with pathic, embodied experiences that shaped my gaze when I observed others.

Attending to how different perspectives unfold in more or less long-lasting, reciprocal, embodied dialogues, close observations challenged an understanding of communication as belonging to the ability to articulate symbolic language. Attending to perspectives of students as evolving when bodies met, close observations provided a breeding ground for understanding lived experiences in pre-symbolical lifeworlds as fully worthy exchange of subjective perspectives. Observing and experiencing reciprocal exchange of embodied perspectives was possible when students', staff-members', and the researcher's bodies were close to each other. When the interacting parts gave value to the expressions of the other, they overcame requiring the ability to speak or write as necessary for having a perspective worth

acknowledging.

### **Conducting close observations**

I participated in everyday life in three special needs education units located in Norwegian public primary-, and secondary schools. The period of close observations lasted two weeks in each unit. During six weeks all together, I followed students and teachers in their daily doings from when the students arrived in the morning until they left for home or for an after-school program. Each period of close observations was followed by a two weeks period of planning and conducting phenomenological interviews based on what was observed before a new period of close observations started.

Having my professional background in special needs education in kindergartens and schools, in particular with children with intellectual disabilities, autism spectrum disorders and severe and multiple disabilities, being directly involved with students and staff-members was familiar to me. Yet each student, each staff member and each unit was new to me. By taking part in various everyday tasks, a wide range of students' experiences unfolded. Examples of these tasks are daily morning greetings, looking at pictures and reading books, singing, dressing, swimming, horse-back-riding, breaks, meals, forming salt dough, bending, stretching, and use of technical assistive devices, playtime and peak-a-boo.

Being a close observer for a limited period, I was constantly reflecting over what was acceptable involvement, and what could be a violation of the subjective limits of each student. Most of the students are severely restricted in their possibilities to avoid or to move away from unwanted situations. As well, they are severely restricted in expressing symbolically their subjective limits of which involvements and interventions towards their bodies that they accept. These ethical questions will be discussed in the reflections.

### **Creating field notes**

This study is conducted in segregated contexts in an educational everyday life that is partly hidden from the gaze of others. Most of the student participants arrive and leave school by taxi, few have recess time with the other students, and they attend to education in buildings or units separate from the rest of the school, all factors making them more or less invisible to peers, general staff, school management and guardians. By approaching segregated contexts that are unfamiliar to most, I have stressed to write field notes that give credits to details and

the vividness in lived experiences, in order to be able to create anecdotes that can create resonance also outside the specific context of special needs education.

Fangen (2011) emphasizes that field notes should be written down as immediately as possible after observations are conducted. The shorter the time from observation to written material, the more detailed and the less stereotypical descriptions are possible. Even thinking of the field notes will according to Fangen intensify the researcher's possibility to remember what was observed.

Each day, immediate after school day was over, I sat down in teachers' office, on lawns, at the beach or in my car, writing down occurrences from the day and drawing sketches of objects and assistive devices used. The time schedule I had followed that day turned into valuable support when making notes, as the details of experiences were remembered when one thought was followed by another. Despite my attempt to recognize what had happened chronologically, each day provided me with information that did not suit into the straightforward chronological arrangements. These descriptions and reflections were organized in a separate accumulative section.

Scrawling down notes at the end of the day and not during school day was a conscious choice. If I had turned attention to a notebook rather than to how the embodied meaning of the students unfolded, gestures, mimicry, movements, smells, sounds or tactical impressions could have been overlooked and lost. Being able to notice these small signs by taking active part in everyday life was valued over the risk of forgetting what was not noted down immediately. Frequent interruptions in my relations to the students or interruptions when observing the constant flow of interactions between students and teachers or between students could make important information slip away.

In my relation to the staff, I also found it beneficial to have my hands free to participate and contribute in the practical pedagogical work. If I had been taking notes while conducting practical tasks, I would have been occupied with something else than the present moment. On the other hand, identifying too strong with the pedagogical staff might have made me "going native". I tried to solve this challenge by staying a perpetual beginner that stayed for no more than two weeks in each special needs education unit.

### **Phenomenological interviews: experiencing the experiences of others**

The students are the source of a possible answer to the project's research question. Yet, the voices of staff-members are present throughout the thesis, not only as participants in the anecdotes created from close observations, but also through quotes, and excerpts from

phenomenological interviews. Students and staff co-create situations where different existentials turn into foreground and background when students' embodied meaning unfolds. This makes staff-members' verbal stories important contributions to highly subjective, embodied expressions as created in asymmetric relations in professional educational practices.

### **Conducting phenomenological interviews**

The interviews were carried out after each period of close observations. Different students, different staff, different arrangements and different approaches to disability made a wide spectrum of experiences stand out in the three units. Hence, the interview-guides (example in appendix) were different from school to school. Each interview-guide consisted of six to ten questions. The questions took their point of departure in the unique close observations in the particular unit. The interviews were shaped by the space and time available. Yet, all interviews pivoted around the project's common feature: the unfolding of students' embodied meaning.

When conducting the interviews, participating staff members were informed that questions were rooted in what I had observed, but that they were free to bring other issues to the table. All interviews took place on school premises. The shortest interviews took place during school time. As consequence, the time the staff members could spend was limited, as the students were still the staff's responsibility. These interviews were carried out in a classroom that is ordinarily used for teaching, but where the doors were closed for the occasion. In this environment, staff pointed to the room itself, things, and persons that had been present to describe factual situations in which the students had been engaged. The longest interviews were conducted after school days were over. Thus, the staff members had no obligation to take care of the students, as they at this time had entered their after-school program. These interviews were conducted in a meeting room. Here, the surroundings were neutral, and descriptions tended to be less situated to the present environment. I transcribed all interviews myself.

### **Process of analysis**

Van Manen (2014) claims that a proper phenomenological analysis never should be conducted by relying on codifications, conceptual abstractions or empirical generalizations, as these can never produce phenomenological insights founded in the phenomenological

tradition. Yet, he addresses that in order to examine reflective methods for finding meaning in phenomenological research, some specific questions can be asked. He states:

When we examine a paper or a dissertation that claims to have used a phenomenological method, it may be helpful to ask: Does this "look like" any of the phenomenological studies that one encounters in the more primary literature? This does not mean that one has to test oneself against the great texts of the original thinkers, but one should be able to recognize the presence of a phenomenological attitude and the presentation of phenomenological insights in a study (van Manen, 2014, p. 319).

In a phenomenological project where lived experiences are worked into the form of written material, thematic analysis is the process conducted to recover meaning structures found in field notes and transcriptions of phenomenological interviews. Yet, thematic analysis is too often understood as "an unambiguous and fairly mechanical application of some frequency count or coding of significant terms in transcripts or texts, or some other breakdown of the content of protocol or documentary material" (van Manen, 2014, p. 320). Rather than relying on strict and mechanical ways of handling the text for analytical purposes, the researcher should conduct phenomenological seeing to discover meanings embedded in the given text. This act of proper phenomenological seeing shall be driven by epoché and reduction by brushing away what is not related to the phenomenon and continuously leading back to the towards it.

### **Meaning condensation and the development of phenomenological anecdotes**

The development of phenomenological anecdotes followed three steps. First, observation notes based on close observations shaped the questions that were asked in the phenomenological interviews. Second, when the interviews were transcribed, units of meaning were detected through meaning condensation. Third, I turned back to the field notes to find stories that could shed light on students' experiences with the units of meaning that was detected.

Kvale and Brinkmann (2014) describe meaning condensation as a process suitable to analyze transcribed interview texts. Van Manen (2014) states that when exploring themes and insights, "we can treat texts as sources of meaning at the level of the whole story; at the level

of the separate paragraph; and at the level of the sentence, phrase, expression, or single word" (p. 320). Following van Manen, I initially read the transcribed interviews holistically. Then, I placed utterances of the participants into units of meaning, like in the following example, which is a direct excerpt from an interview with Anna, a teacher in one of the special needs education units:

That's why it is important that they get to experience different materials, like metal, woods, plastics, knotty, glass, rough, like all, with holes, because then one can comment about those things. And then, one can create consciousness about the things that also they are surrounded by. I am not saying that she understands that this was a ball with holes in it, but the more often she gets to hear it, well, yes. It is not for sure that she has concepts telling her "this is a ball with holes in it, it looks like this", not necessarily, but, like pure physically, she gets to experience it... Like recognition.

In the process of meaning condensation, one unit of meaning was placed in a column, meanwhile a condensed text describing the utterance was formulated in another column. In this example, the condensed text where the teacher describes the importance of students various experiences' with different textures was "When the student is presented to and recognizes different sensual impressions, the teacher gets possibilities to respond to the lived experiences of the student". When all interviews were condensed, each unit of meaning was explored by asking the research-question "*how does the embodied meaning of students with multiple disability unfold in school?*" Units of meaning that did not address the question were excluded before themes that remained were united in descriptive accounts.

Using MaxQDA, a software program for arranging extensive interview texts, I structured the excerpts from interviews and units of meaning by placing them in columns where excerpts and units of meaning were linked to each other. Then, I grouped different structures of experiences across the different interviews. Further, these structures were discussed with the main supervisor of the project. These discussions ended up with superior themes; embodied meaning/learning/teaching, relations/empathy, pedagogical objects and the body as subject/object. Then, the raw material was examined once more in order to see if some of what was rejected as irrelevant turned out to be relevant in light of the superior themes.

Finally, when working out themes that stood out in the embodied meaning of the students, I found insight cultivators in sources of philosophy, in human sciences, in prose and in picture books. Insight cultivators are aids in the reflective interpretive process. As van

Manen states "we find insight cultivators in reading the reflective writings of philosophers and other scholars of the arts, humanities, and human sciences. Insight cultivators give us the sense of, 'oh, now 'I see!'" (van Manen, 2014, p. 324).

When the empirical material and insight cultivators like Ahmed's descriptions of things as orientation devices and Goffman's descriptions of embodied constraint and relationality met, phenomenological anecdotes came into being. Van Manen (2014) describes phenomenological anecdotes as specific kinds of narratives that stir and create understandings that go further than what the reader can grasp intellectually. Anecdotes are short and simple stories, describing single incidents, keeping close to central moments of experiences, containing concrete details, several quotes, they close quickly and ends with a punctum— not the dot at the end of the sentence, rather, a certain concluding phrase that makes the anecdote a compelling one (van Manen, 2014).

### **Phenomenology of perception in practice: my certain uncertainty**

When attending to a practical pedagogical field that I used to think that I was familiar with, I utilized a method that appealed to my vocational foundation in special needs education. In practical pedagogical work in kindergartens and schools, I used to consider students' subjective ways of moving as important pedagogical resources. Now, four years of PhD-scholarship have passed, and I consider myself to be more attentive to my insecurity than I used to be. I hope that this makes the novice in me more reflected and humble than it initially was.

A bothersome, yet quiet phenomenological revelation has been lurking around throughout four years of scholarship, and when confronted by the inevitable end of the PhD-period, it was forced to show me parts of its face. Despite my conviction that I have been an advocate for the value of movement on the subjective premises of children with a wide range of disabilities throughout my vocational and academic development, I now have to acknowledge that these premises have rested on an understanding of body and soul as incontestable separate entities. When reading Merleau-Ponty (2014), I eventually found that he consolably describes this divergence as quite natural, as it has its origin in how I have a view of myself through reflection and consciousness and the view I obtain by linking my behavior to external conditions.

I have been in a process where I have tried to grasp that it is not until perception is attended to in its own right that it provides knowledge about the intentional body, where lived experiences are more than the sum of identifiable parts. Lifeworlds of students with severe

and multiple disabilities have prevalingly been understood as placed within the individual body as a medical impairment or within the social environment as lack of adaptations. Phenomenology of perception, when properly conducted, refuses to rely on a binary understanding of the body. As well, it refuses attempts to fuse body and mind. Phenomenology ascribes embodied subjective perspectives as expressions, qualitatively different from symbolic expressions, yet carrying the same value. When our students' perspectives are recognized and included into the world of everyday practical pedagogical life, phenomenology as philosophy is utilized, not purely as a tool for thought, but also as a guidance for actions that are ethically defensible in lifeworlds that are without words, yet not without perspectives.

I have felt reading Merleau-Ponty as a process of understanding gained, just to feel it slip out of my hands in the next moment. When letting go and trying to regain a grasp, I was at regular intervals thrown back and immersed in the confirming possibilities of classifying and placing deviations in the individual or the surroundings as part of prevailing understandings of disability. Time and time again, staying true to the idea that subjective movements carry an overlooked scientific- and practical-pedagogical approach to special needs education, I have re-attended to the students' subjectivity. Phenomenology has provided what was foundational for this project from its very beginning: an acknowledgement of different bodies reaching out in the world. No matter how different these outreaches might be from what is expected from the person, phenomenology is what made my visit into these lifeworlds possible. In this, aiming to stay true to phenomenological philosophy and methodology, I have felt like being caught between wonder and never-ending curiosity and the search for definite answers. This has sometimes made me feel insufficient and untrue towards the phenomenological approach that I claimed to have. Yet, the times when I have managed to keep close to the perspectives of the students, even when applying analytical tools from feminism, queer-theory and sociology, students' lived experiences in lifeworlds that are partly hidden and seldom seen have come to life. At the core of this process, phenomenology's acknowledgement of embodiment and perception provided all I could ask for.

### **Trustworthiness and validity**

All research must be subject to critical discussions about quality and trustworthiness. The Norwegian National Research Ethics Committees state that "research activity is a quest for new knowledge, with critical and systematic verification and peer review. Honesty, openness, systematicness and documentation are fundamental preconditions for achieving this goal"



(The Norwegian National Committees for Research Ethics [NESH], 2014). My phenomenological project is subject to the same demands regarding trustworthiness and validity as any other research project. Trustworthiness and validity in a phenomenological project has to be assessed on criteria of suspension of personal and systemic bias, on originality of insight and scholarly treatment of sources (van Manen, 2014). According to van Manen, this causes a challenge for phenomenological researchers, especially when "external concepts of validation, such as sample size, sampling selection criteria, members' checking, and empirical generalizations are applied to phenomenology. These are concepts that belong to the languages of different qualitative methodologies" (van Manen, 2014, p. 347). Thus, assessment of a phenomenological project presupposes that the reader is scholarly competent in reading a phenomenological text.

Phenomenological validation is attended to when the study is based on a phenomenological question rather than a question investigating causality or theoretical explanations (van Manen, 2014). A valid phenomenological study is situated in primary phenomenological philosophy, creating research in which phenomenological attitude and phenomenological insight should be recognizable. Humanistic research is rational when it promotes faith in a shared world that can be understood by thought, insight, and dialogue, van Manen continues. Still, what is considered rational has to be seen in an extended perspective where rationality does not link to standards of objective research, nor to a denial of rational foundation (van Manen, 2012). Phenomenology does not reject objectivity, rather it addresses objectivity as a matter of keeping close to the phenomenon- "*zu den Sachen selbst*" (Ricoeur, 1967, p. 102. Italics in original).

Van Manen (2014) disavows applications of checklists of rational and technical procedures in order to evaluate the quality of knowledge gained by the utilization of phenomenology of practice. He also discredits:

practitioners of human science research in education who disdainfully disclaim any need for criteria or standards; they claim that theirs is not a "rational" science, that to be rationalistic is to be intellectualistic, positivistic, scientific and insensitive to intuitive and more experiential dimensions of truth and understanding (van Manen, 2012, p. 16).

Even though van Manen provides important reflections for discussing what creates validity and trustworthiness in phenomenological projects, he provides few guidelines, making

openness, systematism and documentation challenging when addressing a project as valid and trustworthy.

This project investigates lived experiences of a certain group of students in a special needs education context. Thus, it is qualitative. As Brantlinger, Jimenez, Klingner, Pugach and Richardson (2005) state, qualitative research in special needs education "is a systematic approach to understanding qualities, or the essential nature, of a phenomenon within a particular context" (Brantlinger et al., 2005, p. 195). To address the validity and trustworthiness of this project, I will follow their credibility measures for qualitative research. In line with the caution made by Brantlinger et al., I avoid using credibility measure checklists in a rigid and unreflective way. Rather, I will use their strategies to describe the choices that are made in continuums between standards of objective research and rationality in an extended perspective. By addressing how this project answers to the strategies described by Brantlinger et al. (2005), I aim to make this project honest, open, systematic and well documented. Doing so, I attend to general guidelines for research ethics.

Triangulation of data, theory and methods strengthens a project's credibility, as convergences and consistencies within data sources may show (Brantlinger et al., 2005). In this project, I have conducted a theoretical triangulation by applying Goffman's interactionism to Merleau-Ponty's phenomenology of perception. This doctoral dissertation is my work. Yet, throughout the process, I have found support in other researchers in general and in my supervisors in particular. As main-supervisor and co-supervisor, they have followed the project closely from its initial beginning to the very end. I have conducted close observations and phenomenological interviews. My main supervisor also visited one of the special needs education units during the period of close observations.

In article one, two and three, I and one or both of my supervisors have been involved in analyses through holistic, detailed, and selected reading of the empirical material. In article four, five researchers, myself and my main supervisor included, collaborated when analyzing the empirical material. I have applied concepts from phenomenology, constructivism, and post-structuralism in order to address how our students' embodied meaning relates to power and normativity. All four articles have been subject to double- or triple blind peer reviews. The use of external auditors like peer reviewing may confirm that inferences are logical and that they are grounded in the findings (Brantlinger et al., 2005).

A search for disconfirming evidence within established themes will strengthen a project's credibility (Brantlinger et al., 2005). We looked for field notes or excerpts from interviews that would make contradictions to the categories that had emerged from the initial analyses.

Thus, discrepancies and different shades of meanings were detected and addressed. As an example, a member of the pedagogical staff emphasized how she had learned to read the student's body language in an interview, while observations showed the same teacher overruling tears of a crying student.

Throughout the project, the researcher should outline his or her personal-professional situatedness within the frames of the project. In this hermeneutic phenomenological study, I have outlined my professional background within special needs education, as well as how I have situated myself within the hermeneutic rather than the descriptive phenomenological tradition. This is a result of how I have searched for knowledge in lifeworlds where embodied meaning emerge between humans that are bodily close to each other.

Member checks are done if the researcher let participants review and confirm transcriptions, field notes or analyzed empirical material (Brantlinger et al., 2005). The students participating in the project will due to their complex disability not have possibilities for attending to retrospective member checks. Yet, the pedagogical staff could have been asked to look through the written material in order to confirm or dismiss it. I have not done this in this project, a decision that according to Brantlinger et al., (2005) may challenge the project's trustworthiness. Smith and McGannon (2017) challenge this view as they have assessed whether member checks are important in qualitative research. They conclude that member checks are problematic as means to secure rigorous research for three reasons. First, there is no possibility for researcher and participant to find an external reference point. Second, neither can evidences that confirm the value of member checks be found. Third, conducting member checks might be followed by practical challenges regarding contradictory claims, power relations, time and personal and political interests (Smith and McGannon, 2017).

To most of us, verbal expressions are tied to lived situations in a more spontaneous, direct and immediate way than written expressions are. Thus, transcriptions making verbal interviews and what I observed into text might make what was expressed in one context appear helpless without the references to the actual situation. Considering what we say and do as contingent to situations, I will argue that I have attended to trustworthiness by not conducting member checks. Applying member checks might have resulted in research where the staff participants would draw back written information that could not withstand scrutiny. In some cases, the combination of what I had observed, and what staff members said in the interviews co-created stories that crossed the borders of ethical sound education. Of course then, this project's validity presumes that I as researcher have treated the written material with

respect and followed the methodological guidelines given. To make verification possible, I have kept track of transcriptions of interviews as well as dated field notes.

Additionally, Brantlinger et al., (2005) emphasize that observations shall be multiple and that interviews shall go in depth. This dissertation rests on three times two weeks periods of close observations followed by interviews. Extended periods in each unit as well as multiple phenomenological interviews would have provided a larger amount of empirical material. The empirical material presented in the articles is especially chosen to shed light on students embodied meaning. Thus, there is an amount of field notes and transcribed interviews not included in the dissertation. The anecdotes are rooted in close observations of our students' educational everyday life, and their meanings are broadened with the excerpts of interviews.

Eventually, qualitative projects ought to tell stories that readers can use to determine whether the project can be transferrable to their own situation (Brantlinger et. al., 2005). This project finds its empirical material in segregated contexts that might be recognizable to persons working with persons in other segregated contexts, like the descriptions of embodiment in dementia care as described by Käll (forthcoming, 2017). Also, by applying existentials as analytical and philosophical concepts, my aim is that the thick descriptions presented might shed light on phenomena that create resonance also to readers unfamiliar with severe and multiple disabilities and segregated educational contexts.

Brantlinger et al., (2005) relate credibility to an assessment of how the reader experiences transferability to his or her own situation. Credibility as created in the crossing of reader and text is given a touch of phenomenology by van Manen (2014). Van Manen does not list a set of criteria towards which credibility is measured. Rather, he points explicit and sensitive to the insecurity that might emerge when the reader and the phenomenological text meet. He addresses how a phenomenological study shall be assessed on premises of whether reflection and insight is gained when you, the reader, include your subjectivity. Do you wonder about the appearance and presence of the phenomenon of the study? Do you experience that rich descriptions create resonance with your background? Does the text offer you possibilities to reflect over the phenomenon reaching further than the level of everyday life common sense? Does the researcher provide self-critical questions that enhances the meaning of the phenomenon? Does your embodiment and your history as a meaning-seeking embodied human being occur to you? Does the language of the text contribute to your own lived experiences as they appeared to you even before you reflected over them? Has the text provided you a deeper insight in the phenomenon, and has this insight illuminated ethics and

commitments in professional practices in a new and deeper way? These are questions that may be addressed to challenge the validity of a phenomenological text (van Manen, 2014).

### **Ethical considerations**

The guidelines for Norwegian research ethics outline that research shall be grounded on respect, fairness, integrity and good consequences (NESH, 2014). Thus, all research participants shall be treated with respect. Research projects shall be designed and implemented fairly. Researchers shall conform to norms and behave responsibly, openly and honestly towards colleagues and the public. They shall pursue consequences that are good, as well as ensuring that negative consequences are acceptable for those involved. To oblige this project to answer to the ethical guidelines, an application was submitted to Norwegian Center of Research Data, NSD, March 27<sup>th</sup>, 2014. The application described the study's purpose, participants, and methodology, and was approved April 7<sup>th</sup>, 2014 (see appendix).

Severe and multiple disabilities imply complexity. As students have several diagnostic hallmarks that most often do not concur, each student's appearance is unique. Thus, they are easily recognizable at individual level, and anonymization of student- and staff participants has been important. Throughout the project, all names are changed. Diagnostic hallmarks are, when they are considered as necessary to include in the written material, described in general terms like epilepsy or spasms. Geographical localization is never stated.

Delicate presentations of results to attend to student's dignity has been of importance. As this study approaches severe and multiple disabilities phenomenologically, crude empiricism (Tøssebro and Kittelsaa, 2004) resting heavily on attention-claiming descriptions of bodily fluids or marked bodily differences are avoided. Such differences might attract and fascinate, yet they might lead attention away from the phenomenon that the project aims to investigate. Yet, I have attempted to describe the heavy complexity of severe and multiple disabilities in a straightforward manner that does not underestimate students' experiences of illness, pain and discomfort.

Ellingsen (2010) points out that researchers that investigate intellectual disabilities experience dilemmas when they attend to ethical principles like confirmed, free consent and when giving information about the study. In this project, in law, the principles of free consent and information is attended to, as parents or guardians were the ones approving the students' participation. Thus, the ethical challenge is addressed to how the study includes students with severe and multiple disabilities in a way that attends to voluntariness. As Ellingsen (2010)

points out, a consequence of this challenge is that persons with severe intellectual disabilities are more or less systematically excluded as research participants.

Including students' perspectives has demanded specific ethical considerations in order to protect their interests. Because they are children and because of their complex disabilities, their possibilities to give informed consent for participation are reduced. Prior to the study, staff members and guardians received information about the study's aim and its methods. In this information, I emphasized that if a student expressed discomfort with my presence, my observations would cease. When I entered the units as a stranger, the embodied and highly subjective expressions of each student were new to me. This lack of a shared past made it challenging to address if expressions communicated discomfort at all or if an expressed discomfort was due to my presence. This dilemma is discussed by Mietola, Miettinen and Vehmas (2015) in a project where they conducted participant observations of adults with severe and multiple disability in an ethnographical study. They underscore the importance of including interpretations of significant others in order to translate subjective signals as well as to sort out which signals are related to the presence of the researcher and which are everyday signals not related to the researcher at all.

#### **4- Summary of the papers**

##### **Paper one: "I guess that the greatest Freedom..." A Phenomenology of Spaces and severe, multiple Disabilities**

Paper one begins with a wonder about how bodies moving towards, between and within different spaces can lead towards an understanding of embodied meaning in lifeworlds where expressions are embodied and pre-symbolic.

The paper accredits spatiality as decisive for persons' possibilities to express perspectives through a wide range of movements. Movements take place in the continuum between spatiality of positions as objective bodily sensations and spatiality of situations as embodied interactions with others and the world. To explore the intertwining between bodies and their spaces, we turn to lived experiences of eight year old Oliver and twelve year old Sara as they move in different spaces. The empirical material is collected through close observations of the students and phenomenological interviews of two teachers. Applying spatiality as an analytical lens, we find that recognizing relations between the students' subjective movements and the spaces they move within create embodied meaning. This takes place in an educational context where moving in spaces includes the spatial "here" and the temporal "now" that are closely related to the spatial "there" and the temporal past or future.

Oliver's and Sara's complex disabilities constrain to various degrees their possibilities to approach or avoid spaces. Thus, staff's pedagogical arrangements when including some spaces and rejecting others are formative for the students' lived experiences of spaces.

##### **Paper two: A golden Paper, a Chain and a Bag. Phenomenology of Queer Things in a Special Needs Education Unit**

This paper explores materiality of queer things. Queer things are things that are taken out of their intentional context. To explore the phenomenology of queer things in a special needs education unit, we turn the embodied meanings that emerge when ten year old Oskar and twelve year old Sara use things that are produced without pedagogical intentions. The empirical material consists of close observations of Sara, Oskar and staff-members Hilde and Maria, as well as phenomenological interviews of teachers Anna and Maria.

In paper two, we investigate how queer things provide a certain kind of openness that allows the students to reach out in the world in ways that express how they relate to others. Sara's way of using a worn-out golden paper that used to cover a box of assorted chocolates and Oskar's way of using a chain of red plastic pearls and an IKEA-bag sheds light on things

as phenomenological existentials. When moving towards, with or away from things, the relational readiness of our students are expressed without words or symbolic acts.

When bodies meet and perspectives are acknowledged, they can be taken up and included into further pedagogical arrangements. The presence of things that provide open ways of utilization are thus things that by their mere presence in educational contexts can include or exclude the subjectivity of students with severe and multiple disabilities.

This paper's contribution to knowledge is to offer a framework for questioning the use of things that might direct students with severe and multiple disabilities towards a given standard of normality. Rather, we emphasize that when staff members bring things that let students reach out into practical pedagogical everyday life, the students' are included as competent participants.

**Paper three: 'He is not crying for real'. Severe, multiple Disabilities and embodied constraint in two special needs education units**

This paper investigates how relations between students with severe and multiple disabilities and their staff are challenged when students are under embodied constraint. The paper describes lived experiences of ten year old Oskar and twelve year old Jakob when they use an assistive technical device. The empirical material consists of close observations of students and pedagogical staff, as well as of phenomenological interviews of staff members.

The dominating scientific approaches to severe and multiple disabilities have seen disability as an abnormality placed within the child. Treatments and remediation of problems has been the focus, not only in research, but also in educational contexts. Assuming that there are standards of normality, the picture of standing and walking students seem to be an undebated mirage.

In this paper, we turn towards one specific assistive technical device that directs the two boys towards the norm of their standing and walking peers. Oskar and Jakob are at regular basis lifted into a technical walking aid, in which they are fastened with bows, straps and Velcros in order to assure safety and lead their movements in technical standardized ways. The use of straps and Velcros brings about external embodied constraint to children that are also under internal constraint due to their disability.

The purpose of this paper is to make visible a particular vulnerability when persons that communicate through gestures are deprived possibilities of free movement. The paper points out that relational sensitivity and embodied closeness is foundational if the expressions of the



students are to be acknowledged and included. We question an undebated normality towards which every person seems to have an obligation to endure medically based interventions. We promote a pedagogy where staff-members turn to and acknowledge the expressions of the students rather than to credits given by medical professionals when searching confirmation for their choices.

**Paper four: Phenomenology of professional practices in education and health care: an empirical investigation**

Paper four is developed in the close cooperation between five researcher with interest in phenomenology. In this paper, wondering if and what kinds of common features that can appear in research applying phenomenology of practice as methodological approach, we have brought together phenomenological anecdotes from different professional practices.

Drawing on van Manen's work, the paper aims to explore professional practices in education and health care from a phenomenological perspective. Three different anecdotes describe experiences from a nutritionists' office, from a special needs education unit and from a physiotherapeutic intervention context. When we bring the anecdotes together, some common issues are detected, breaking down or enhancing human differences.

For that purpose, we have analyzed practice experiences generated through close observations and interviews in research projects concerning special needs education, physiotherapy and consultations with a nutritionist. By drawing on the notion of pathic knowledge as well as Nancy's ideas about existence as always co-existence, we develop phenomenological insights about interaction in professional practice. More specifically, these qualities are captured in the dimensions of pushing–being pushed, pulling–being pulled. These dimensions are constituted by two poles, but in-between these poles, we argue, lie the possibility for acting and interacting between professional and student/ patient.

In the paper we point to how professionals are powerful actors when deciding to keep or give up the idea of control in asymmetrical relations. Professionals can displace their position by giving up a totality of control and create a togetherness with their student or their client without giving up their position of being a professional practitioner.

## **5- Reflections**

So, in cases when consciousness itself is the object of consciousness (when I reflect on my own thinking process), then consciousness is not the same as the act in which it appears. This also demonstrates that true introspection is impossible. A person cannot reflect on lived experience while living through the experience. For example, if one tries to reflect on one's anger while being angry, one finds that the anger has already changed or dissipated. Thus, phenomenological reflection is not introspective but retrospective. Reflection on lived experience is always recollective; it is reflection on experience that is already passed or lived through (van Manen, 2014, p. 94).

### **Main Findings- a brief overview**

The combination of phenomenology of perception (Merleau-Ponty, 2014) and phenomenology of practice (van Manen, 2014) has resulted in four papers, where different existentials have shed light on the meaning of various lived experiences after the moments in which they were lived. In the papers, the existentials are separated for analytical purposes. Yet, to the project as a whole, some main findings cross the structure of the dissertation that consists of an overarching framework and four papers that can be read independently. Thus, these main findings stand out as important for future professional practice and research.

Accrediting movement as expressions of subjective meanings in lifeworlds where words are not an option, specifically in the field of children and disabilities, has provided knowledge aided by my application of Merleau-Ponty's philosophy. Embodied expressions when seen as fully worthy challenge symbolic language as given standard. A social-cultural emphasis on symbolic language easily fosters an impression of students with severe and multiple disabilities as humans trapped in tacit, silent lifeworlds. This dissertation challenges this view. Even if the participating students do not speak words, point to pictures or perform symbolic signs, they are not tacit or silent. Yet to have their perspectives acknowledged they depend on how those surrounding them are attentive to what bodies express in close relations. In daily life in special needs education, staff member's ways of considering movements like the change of breath, the gaze, the slant of the head, a pouting lip and a smile sum up embodied meaning in ways that embraces the body's different facets.

Following Merleau-Ponty's phenomenology, this dissertation sheds light on how bodies are objective, social and lived at the same time. In between medical, social and subjective needs, students as well as staff-members seek and find confirmations of their gestures and their intentional acts in relations that are asymmetrical. To convey the dissertation's findings

to those relating to children with severe and multiple disabilities in educational contexts, I have highlighted the possibilities of realizing perceptual phenomenological philosophy in practical acts. Movements are foundational for medical, social and subjective meaning making, and provide a powerful expressivity that includes the perspectives of those living in lifeworlds where gestures are what express perspectives.

### **Empirical reflections**

In lived moments, existentials are intertwined. Thus, my attending to them in the professional practice of special needs education shows that they are not hierarchically ordered. Rather, they are continually present as hardly separable foregrounds and backgrounds, where the presence of one partly constitutes the other. Hence, it might be challenging to point out where one existential begins and another ends, and there will probably be as many nuances of lived experiences as the number of persons experiencing.

So when does a table end as a thing and become a room under which a child can hide? When does a bike cease to be a piece of sports equipment and become a prolongation of the rider's body? How does the experience of time alter between the slow wait for something longed for and the desire to get through with something that one has been dreading? When does relational attunement towards another person's embodiment bridge and overcome differences? In the following reflections upon the results from the four papers, I will address such fluid embodied experiences of existentials by attending to how they have appeared in the papers.

In a Merleau-Pontyan understanding of embodied relations between children and adults, relations in educational contexts are asymmetrical, as there is an adult duty to keep the child safe (Merleau-Ponty, 2010). Educational asymmetry is also confirmed by O'Loughlin (2013). She investigates authoritative pedagogy and corporeal subjectivity in the light of Merleau-Ponty by applying phenomenology to race and gender in school. Yet accepting that relations are asymmetrical does not itself make it legitimate for the adult to infringe on the child (Merleau-Ponty, 2010). Due to the participating students' severe, multiple disabilities and the internal and external constraints they experience, their vulnerability in asymmetrical relations is highly visible. Approaching or rejecting spaces, things and embodied relations as well as deciding upon the time spent are a matter of choices others have made on behalf of the students. Thus relationality as practiced in everyday educational life takes shape from the ways in which pedagogical staff members attune themselves to their students.

By attending to professional practices, this project sheds light on embodied meaning as a

transcendental human phenomenon. Being transcendental, relationality crosses demarcations of ability-disability. This requires staff members who are willing to move towards the student and include the student's perspective when the student is ready to relate. When things, spaces and persons meet, spectrums of reciprocal human relations are revealed. In this dissertation, a variety of things and spaces are present: a golden paper that used to cover a box of assorted chocolates, a blue IKEA-bag, an assistive technical walking device, a Christmas chain of shiny, red plastic pearls, a pool, a gym, a schoolyard. The meanings that unfold when things and spaces are made reachable and put to use take shape from the relationality enveloping students and teachers as embodied beings, being sensitively aware of the other's next move. Thus, it is not solely the materiality of an objective thing or a space that creates embodied meaning, nor is it the subject's use and the expressions following the use alone. Rather, embodied meaning unfolds and takes shape when the student's expressed subjectivity is met in a continuum between being valued or discredited by another person.

Existentials are intertwined and hardly separable in lived experiences. Yet they are noticeable, distinct and essential in phenomenological analysis. Separating existentials for analytical purposes has made visible the nuances of lived experiences. An example might be the application of spatiality in paper one, where lived experiences of disability are shaped by the spaces the students move to, from and within.

Even if none of the papers attends to temporality as an analytical concept, temporality permeates through other analytical concepts when spatiality, relationality and materiality meet the empirical material. Throughout the papers, temporality frames and shapes possible nuances of embodied meaning in general and relationality in particular when students engage with things and in spaces. Thus, temporality is hardly dividable from the unfolding of students' embodied meaning. Shared time is foundational to detect and then acknowledge more or less contrasting presences and absences of embodied gestures. To be able to include perspectives expressed through the presence or absence of tiny or more distinct signals like the sweat in a palm, the slant of the head, the increase of breath, the smile, the increasing or diminishing grumble or the lip pouting out, shared space and time make the contrasts in expressions detectable.

How students and staff share time and space in practical professional everyday life are structural choices. These choices bring about practical pedagogical consequences regarding organization of staff-members work tasks, planning and accomplishing of time-schedules, and the practical and economical choices of bringing students into some spaces over others. Applications of things, time and spaces express how staff members give the students'

perspectives value in a wide spectrum between recognition and rejection. Thus, choices about which things to use and how to use them, time to spend and spaces to tread into are choices that express views of humanity.

In educational lifeworlds where medical considerations are part of everyday life as matters of pain, well-being, life and death, the intertwining of medical and experienced perspectives are undeniably and legitimately present in daily activities. As stated by Toombs (2001), a phenomenological approach to disability includes medical aspects. Phenomenology includes the relation between body, consciousness, emotions, intersubjectivity and empathy in professional practices to attend to subjective experiences. Thus, turning to embodied meaning as understood by Merleau-Ponty does not dismiss the importance of objective, medical knowledge in special needs education. Rather, sensitive staff members facilitate situations in which the medical, the social and the subjective interact.

### **Theoretical reflections**

Rorty described the challenges in addressing some philosophies of science as more superior than others when it comes to describing truth. He states: "We cannot, I think, imagine a moment at which the human race could settle back and say, 'well, now that we've finally arrived at the Truth we can relax'" (Rorty, 1991, p. 39).

In a field of research that has been dominated by medical, social and behavioristic approaches, I have sometimes wondered whether my project provides knowledge that counts as truth. In the last months of the project, Merleau-Ponty (2014) provides a sudden consolation to my worries. My feelings of being insecure, of not being finished, my feelings that this project is only inchoate and that it in despite of more than four years of work still is incomplete are not signs of failure. Contrary, "the philosopher is a perpetual beginner. This means that he accepts nothing as established from what men or scientists believe they know" as Merleau-Ponty writes in the preface to *Phenomenology of Perception* (2014, p. lxxviii). Thus, as phenomenology's nature is to be unfinished, my feelings are inevitable. Phenomenology's task is to reveal mysteries that empiricism and intellectualism have tried to solve by dichotomizing human experiences as belonging to body or soul. My experienced insecurity is not a sign of being an inferior researcher; it is a relieving sign of a phenomenological attitude. As long as I have stayed true to Merleau-Ponty's notion that perceptions and actions never have causal outcomes and that the perspectives of the research participants, the researcher, and the reader are always perspectives from somewhere, uncertainty is not a sign of weakness. Uncertainty is a strength if the researcher embraces it

and makes it visible rather than turns away from it to find support in one of the sides of the distinction of total physiological and intellectual knowledge.

To broaden the understanding of severe and multiple disabilities, I have applied phenomenology in order to give credit to embodiment as fully worthy and intentional. This is done to write a text about the subjectivity of students with severe and multiple disabilities, a text that provides something different from what medical, social and behavioristic projects have intended to. Yet I have chosen to apply concepts from social-constructivism in order to attend to the specific lived experience of embodied constraint in segregated contexts. This is a choice that may disrupt the project's phenomenological direction.

This dissertation combines different epistemological and ontological philosophies of sciences. To reflect on whether the application of concepts from different philosophies of science strengthens or weakens the dissertation, I will point out some conformities and omissions in Goffman's social-constructivist interactionism as related to Merleau-Ponty's phenomenology of perception. Ahmed's post-structural queer phenomenology, which also appears in the dissertation, will not be addressed as comprehensively, as her point of departure is phenomenological with a queer twist, and thus does not depart from Merleau-Ponty in the same way as Goffman does.

Crossley addresses how Goffman's sociological interest in embodiment has provided researchers with possibilities to gain new knowledge. Addressing embodiment, Crossley writes: "We have been able to view our history in a new light and to identify and question hitherto unnoticed and unquestioned presuppositions regarding the body which have shaped that history" (Crossley, 1995, p. 133). Goffman's descriptions of embodiment in general and embodied constraint in particular include concepts that create resonance with phenomenology, like reciprocal possibilities, freedom of movement and the meaning of mimicry and gestures. As Smith (2006) points out, phenomenological resonances are found in the ways Goffman uses terms that give phenomenological echoes as well as in his vivid descriptions of lived experiences of subjects interacting with each other.

Goffman's stringent and specific descriptions of embodied constraint make relationality stand out as foundational for how this dissertation has described the participating students' embodied meaning making in situations where their bodies are constrained and moved mechanically by external forces. The meaning of relationality when students' bodies are held comprehensively in place has provided insight in how relational and medical needs shift between being foregrounds and backgrounds in segregated units. As Goffman points out in *Interaction Ritual. Essays on Face to Face Behavior* (2008), actions in segregated

arrangements are hidden and non-transparent to others than those let on the inside. This dissertation shows that by including or ignoring students' embodied gestures, staff members' way of relating to their students carry meanings that reach far beyond the medical advantages ascribed to the students' objective bodies. The findings in the paper "He is not crying for real'. Severe, multiple disabilities and embodied constraint in two special needs units", show that an acceptance of the medical perspective as compulsory and undebatable in education takes place when a students' pouting lip and whimper are gestures not accredited as worth listening to. Other findings in the same paper illuminate contrastive occurrences, showing that the medical perspective per se can be included into education when small movements like the change of breath are accredited and included into future interactions between staff and students. To confirm their position as pedagogical employees, some staff-members seek acknowledgement in the students' expressed subjectivity, whereas others seek acknowledgement elsewhere, discrediting the students' expressed perspectives.

My application of Goffman's interactionism as analytical tool sheds light on the dilemma in applying concepts from non-phenomenological approaches to a project that claims to be phenomenological. According to Smith (2006, p. 404), Goffman was determined to work with "minimal philosophical, moral or political mandates". Thus, "There is a tension between the temper of Goffman's approach and the open, questioning outlook characteristic of the phenomenological tradition" (2006, p. 404). Thus, Goffman's eye for interactions may have resulted in a paper that to some points moves away from the subjectivity of the students.

Combining Merleau-Ponty and Goffman in a phenomenological project has created advantages and disadvantages. Goffman's elaboration of embodied constraint has made an important contribution when I address what can happen with relationality when an assistive technical device produced and implemented with medical intentions severely limits students scope for possible subjective expressions.

Goffman (1981; 1991, 2008) and in part also Ahmed (2004; 2006) have contributed with concepts of embodied constraint and queerness. These concepts have worked as insight cultivators, pointing out specific experiences. On the one hand, as insight cultivators pointing towards issues of power and able-bodiedness, these applications have certainly provided perspectives that might draw attention away from the lived experiences of the students and towards structures of normative powers in their surrounding world. On the other hand, these applications have provided concepts that have made it possible to spot, acknowledge and address the practical acts of everyday life as formative for how embodied meaning unfolds in light of perceptual phenomenology. These acts are performed upon the students' bodies, in

situations from which they have no possibilities to escape. As such, these situations touch upon subjective experiences in asymmetrical relations.

Philosophical and methodological challenges when combining different philosophies of science have emerged throughout the process of writing. This might result in what Martínková and Parry (2011), perhaps rightfully, describe as a confusing, misleading and presumptuously derived phenomenology. Yet, it is important to remember that the aim of this project is to understand the embodied meaning of students with severe and multiple disabilities. Hence, this project is situated in pedagogy, and meaning of pedagogical situations are sought with *Phenomenology of perception* (Merleau-Ponty, 1968; 2010; 2014) as the project's philosophical platform. I have let pedagogical professional practice, which is no phenomenological philosophy, meet the phenomenology of perception. My aim is to provide scientific as well as practical research-based knowledge that might inform future approaches of researchers and practitioners. *Phenomenology of practice* (van Manen, 2012; 2014) is the substantiate methodology that made it possible to enter lifeworlds where subjective embodied expressions are what communicates perspectives. When empirical material, philosophy and methodology cross, this project with all its hallmarks, strengths and weaknesses becomes what it is, anchored in a hermeneutic phenomenological tradition where meaning unfolds when existentials intertwine.

### **Sample reflections**

As a hermeneutic phenomenological project, this dissertation makes no claim to rest on quantifications. It might thus appear as a paradox that I choose to lead attention to how parts of the empirical material are given weight. Out of the eight students participating in the study, only Jakob, Oliver, Oskar and Sara are comprehensively present in the written material. William is present indirectly once in an excerpt from a phenomenological interview. This does not mean that the perspectives of Emma, Filip, Sofie and William are dismissed, but that the perspectives of Jakob, Oliver, Oskar and Sara shed light on the main research question in a striking way. There is also a real possibility that I would not have been able to craft the anecdotes with Jakob, Oliver, Oskar and Sara without having met and observed the lifeworlds of the other students in the material.

Out of the three units that I visited, only two are present through the anecdotes. Even if each unit, each student and each of the staff members were new to me, I initially felt closer to the role of the pedagogical employee rather than to the role of the researcher. Yet, during the periods of close observations, I became more and more secure in my new role. This might



have been avoided if I had conducted a pilot for the project. Still, I will argue that a pilot alone does not educate a researcher. In hindsight, I acknowledge that my proposal for the first unit's participation had been more honest if I had asked if they would like to participate as a pilot unit. Yet I recognize that such dilemmas cannot always be seen in advance.

I would also like to address that the students participating in the study are both boys and Girls, and that a wide range of ages are represented. This does not mean that age and gender does not matter if students are treated in a certain way because of their biological sex, or when a student has lived as long as any teenager, has the bodily maturity of a teenager, yet some needs that might resemble the needs of an infant. Such issues have been left out of this study in order to keep close to the transcendental phenomenon of embodied meaning as a phenomenon that overarches socially constructed categories.

Van Manen states that "even though phenomenology employs empirical material, it does not make empirical claims. Phenomenology does not generalize from an empirical sample to a certain population, nor draw factual conclusions about certain states of affairs, happenings, or factual events" (2014, p. 249). In a qualitative dissertation like this, a counting of the times a person has been heard should be unnecessary, as

it is important to emphasize that phenomenological inquiry cannot strive for empirical generalization—from a sample to a population. And so, it does not make much sense to ask how large the sample of interviewees, participants, or subjects should be (van Manen, 2014, p. 352-354).

The main research question began with a wonder about how different bodies can overcome the ability to perform symbolic language as foundational when communicating reciprocally as equal worthy partners. Thus, I have included empirical material that sheds light on a multiplicity of embodied meanings unfolding. I found contrasts when students' experiences were shaped by the attentiveness of the pedagogical staff in the different special needs education units. Organizations and the ways daily tasks that were performed were seen in close observations. Further, contrasting or confirming statements from pedagogical staff members shed light on what I had observed.

Also, an even wider range of contrasting findings might have been investigated if I had attended to inclusive educational contexts where students with severe and multiple disabilities are enrolled. It is plausible to think that an educational organization where the presence of a variety of other students, parents, staff-members and school leaders secures transparency and

leads to constructive challenges of the practical pedagogical work. The fact that this study is conducted only in segregated contexts may be seen as a methodological weakness, as there may be shades of embodied meaning that have slipped my investigation. Yet, the aim of this project is not to generalize, but to give rich and vivid descriptions of existential structures of lived experiences. As such, it sheds light on how everyday life unfolds in segregated contexts that exist despite political, ideological and special needs educational rhetoric enhancing inclusion.

### **Ethical reflections**

I have described vulnerable relations between body and world in situations where institutional cultures are inescapable for the students. This vulnerability and dependency unfolds in a continuum between being denied as a person that has a perspective worth accrediting and being a person who can be confident that even the smallest embodied signals in all likelihood will be taken into account. This inescapability became an ethical issue several times during my presence as a close observer. As a close observer, I experienced a dilemma of being both a visitor and a contributor in everyday life. One moment was of particular importance for my recognition of my new position as researcher and the impact my presence might make when being in embodied contact with the students. The described situation took place at a moment when there were no staff members present to support my interpretation:

Jakob sits alone in his wheelchair in the middle of the room. He is securely strapped to the chair with bows and Velcros. As I enter the room, I feel a sudden need to do something in order to show him that I have seen him, to let him know that I know that he is there. I walk towards him and let my fingers run down his chin as a greeting gesture. Feeling the soft skin of the child and the budding hairs of a beard to be, I immediately feel that I have crossed a border of acceptable involvement.

Jakob, 12 years old, is soon to be a teenager. I, a woman, am soon to turn 40 and I touched his face without knowing him. He had no possibility to escape from the situation, nor to express symbolically whether he was comfortable with my touch or not. I did not know him well enough to infer whether he approved or disapproved my touch, and his reactions to my touch did not reveal an answer. Every relation has its point of departure, and most relations have a first embodied meeting. Touching Jakob's chin and my reflections thereafter made me aware

of the fine line between acceptable involvement that creates a relation through shared embodiment and the possible violation of each student's subjective borders.

As seen in the description of the situation where I touched Jacob's chin, dilemmas when being a close observer inside and outside of lived experiences occur. When I visited the educational everyday life of Emma, Filip, Jakob, Oliver, Oskar, Sara, Sofie, and William, I reflected constantly over what was acceptable involvement and what could be a violation of their personal limits, and how this related to my role as a researcher. As described above, these limits were difficult to detect in the lived moment. Sometimes staff's proactive choices made me aware of my role as researcher rather than as a pedagogical staff member in everyday life, as was the case in the following story:

I am about to join teaching assistant Eva and 12-year old Jakob to the bathroom for a session of massage, stretching, and touch of Jakob's bare skin. The session is to be enveloped by dimmed lights and the easy altering of colored fiber optics.

When Eva has lifted Jakob onto the adjustable changing table, she reckons that he is in need of new diapers. Then she turns towards me and asks if I have had my cup of morning-coffee today. I am a bit surprised by the question as the time is far beyond morning-coffee-time to me, and confused I answer "no".

"I think you should go to the kitchen and make yourself a nice cup of coffee", Eva states and leaves no room for refusal of the offer. I do as I am told, and while drinking my warm cup of instant coffee, it occurs to me that Eva is not being concerned about my daily coffee intake. In fact, she is taking care of Jakob's integrity. A twelve year old does not need to have an audience while having his diapers changed.

This situation contributed to my understanding of my role as a researcher, involved in practical pedagogical life, but meanwhile very aware of my presence as close observing guest just for a period.

Throughout the research process, some experiences have been formative to my recognition of the field of severe and multiple disabilities as a field that wakes emotions in people. I have also recognized that this field, which is familiar to me, is unknown to many. When I have presented papers at conferences abroad, listeners have cried because they have experienced the project to describe human dignity. On the other hand, listeners with

professional backgrounds in other scientific traditions have been provoked, for example, when I described the practical employment of a technical device in school that deviated from what was the medical intention of the device in the first place. Such experiences have illuminated that the shape of this project might evoke stronger emotions in its audience than what I expected.

As the empirical material describing student experiences has the shape of phenomenological anecdotes, it has been given literary shape in ways that make it ideally stringent and to the point. Such stringent presentations of the students may cause readers to experience the emotionality of the empirical material as blocking the way for further exploration of the students' embodied meaning. Consciously, there has been left little room for the anecdotes to provide information that can relieve the tension created when subjective experiences are described in a field that usually rests on medical, social and behavioral understandings of disability. Thus, by holding up what is common for all humans rather than keeping up categorizations that manifest an "us" and a "them", this project may provoke by touching upon essences of subjective perception rather than resting upon traditional understandings of disability.

This project investigates lived experiences of persons in vulnerable situations; not only are they children, they have severe and multiple disabilities that make their appearance, behavior, size and mobility diverge from an assumed state of able-bodiedness. Due to cultural representations, able-bodiedness might seem hard to debate. Yet, it is a state of being that during the life span is a mirage for all of us. With intention, this dissertation diverges from understandings shaped by cultural representations describing children with disabilities as pitiable, brittle, innocent, brave little fighters, striving their way or being directed towards the mirage.

### **The enigma: Is there a phenomenological special needs education?**

Retrieving Merleau-Ponty's descriptions of movements, childhood and disability, I will emphasize how he refrains from acknowledging given standards of equilibrium as final human destinations. In fact, he states that acknowledging subjective possibilities is more important than overcoming difficulties, and that applying substitutions in order to reach a destination of a presupposed normality will harm rather than do good.

Duesund (1994) and Sævi (2005) touch upon the relation between body, disability and pedagogy, Duesund by investigating the relation between body and special needs education, Sævi by investigating diversity in a pedagogy that is supposed to include a variety

of needs. Sævi states and questions:

[S]tudents and teachers at various levels and in various kinds of education share space, time and effort to learn and teach. But what are the indispensable elements of pedagogy? What cannot be taken away from or added to the pedagogical situation without making pedagogy not-pedagogy? What indeed makes pedagogy pedagogical? The simple and complex answer might be the pedagogical relation (Sævi, 2005, p. 7).

Reindal (2007) too touches upon how the body is accredited or discredited in special needs education, pointing out some foundational problems with disability, body and subject. She touches briefly on the values communicated by Merleau-Ponty, and points out how special needs education traditionally has been occupied with difficulties. Reindal (2007) further describes how disability, body and subject are shaped by the relations within which they exist.

This project is a continuing of the work of Duesund (1994), Sævi (2005) and Reindal (2007) in the means that it accredits lived, embodied experiences of students with severe and multiple disability in educational arrangements. Applying phenomenology of perception to a project that investigates lived experiences of children having their everyday life organized as result of specific diagnostic hallmarks has challenged the way special needs education is oriented towards difficulties rather than possibilities. The dissertation holds up a mirror that reflects severe and multiple disability as a way of being human in general, in which we all live our lives in continuums between possibilities and restrictions.

At the end of this stage of my academic journey, an enigma has struck me: If meaning is experienced when embodied subjects share situations, is there such a phenomenon as a special needs education after all? This enigma frames the questions that I asked in the introduction: How can it be that communication can be complete and fluent, even when there is a seemingly huge difference between those involved? How can it be that deviations fade into background when subjectivity comes forth? What is this "something" that covers the gap between pre-symbolic and symbolic expressions? Is there a gap after all, if communication is about adapting in mutual relationships? This enigma takes me back to the kindergarten lifeworld that I shared with a boy with severe and multiple disabilities in the nineties, as well as to the moment when I questioned academics on why the experiencing body of humans with intellectual disabilities was hardly addressed in higher education.

The enigma is my reply.

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# PAPER 1



## **Paper one: 'I guess that the greatest Freedom...' A Phenomenology of Spaces and severe, multiple Disabilities**

Evensen, K. V. and Standal, Ø.F. Accepted and forthcoming in Indo-Pacific Journal of Phenomenology.

### **Abstract**

This paper expresses a wonder about how bodies in motion can lead towards an understanding of embodied meaning in silent lifeworlds. In such lifeworlds, expressions are embodied, pre-symbolic and without words. To address the wonder, we have attended to phenomenological philosophy and phenomenological methodology to outline an approach that accredits lives with disabilities as qualitatively different from, yet not inferior to, lives without.

The paper accredits spatiality as decisive for persons' possibilities to express perspectives through a wide range of movements. Movements take place in the continuum between spatiality of positions as objective bodily sensations and spatiality of situations as embodied interactions with others and the world. Thus, to attend to the perspectives of students with severe and multiple disabilities, we turn to transitions between and movements within different spaces.

We approach an educational everyday life where students are restricted in their possibilities to move in and out of spaces. This paper points out the importance of recognizing relations between subjective movements and the spaces enveloping them as what creates a spatiality that is meaningful to the subject. Thus, we suggest that choosing which spaces to include in educational contexts are formative choices that express a view of humanity. The paper also emphasizes the importance of recognizing temporality as a pedagogical resource when detecting and acting upon student's changing expressions.

### **Introduction**

Inclusion is a wide concept that carries many nuances in the educational system (Qvotrup, 2012). The idea of inclusive education is widespread and in many countries embraced as an ideology for the educational system (Standal and Rugseth, 2015). In this paper, we investigate lived experiences in segregated educational spaces adapted for students with severe and multiple disabilities. To explore the meaning of spatiality as phenomenological existential, we turn to movement as a possible hub in perception and expressiveness for the students that participate. To acknowledge their expressivity, we follow French phenomenologist Merleau-



Ponty's emphasis on the moving body as purposeful and active. Merleau-Ponty's phenomenology of perception (2014) thus offers a framework for understanding disabilities as total ways of being. Yet it is important to point out that not all bodies have equal possibilities to inhabit spaces that correspond to their point of departure, as the world has already taken shape of and for some bodies, and thus leaving other bodies out of place.

Research projects including participants with severe and multiple disabilities have prevalently applied other perspectives than the phenomenological. In a medical perspective, Mulholland and McNeill (1989), and Foley, Harvey, Chun and Kim (2008) apply objective medical standards for measuring bodied reactions. In a behavioristic perspective, Lancioni, Bellini, Oliva, Singh, O'Reilly and Sigafoos (2010) describe behavior as cause and effect, and in a social perspective, Östlund (2015) describes how educational organizations are formative for students' participation. Thus we find that a medical perspective describes disability as an impairment created by objective traits of individuals; a behavioristic perspective describes disability as measurable behavior deviating from a given norm, and a social perspective describes disability as shaped by social constructions. As a consequence of these dominating approaches to disability, the subjective perspectives of the students are often left unexplored.

A paradigmatic shift appeared in childhood studies in the beginning of the twentieth century. While earlier research approached childhood as a transition to adulthood, more recent approaches consider childhood as a fullworthy state of being (Spord Borgen and Eriksen Ødegaard, 2015). This position is also found in contemporary childhood disability research, where Traustadóttir, Ytterhus, Egilson and Berg (2015) criticize a narrow understanding of childhood and disability. They suggest that future research should aim to bring forward perspectives of children and youth with disabilities. Yet, Traustadóttir, Ytterhus, Egilson and Berg (2015) underline the importance of including the perspectives of the children's significant others, especially when the children cannot speak or articulate their points of view symbolically. Therefore, in line with the described development in disability research, the research question for this paper is *what is the meaning of spatiality for students with severe, multiple disabilities in the context of special needs education?*

### **Spatiality, a phenomenological Perspective of Space**

Van Manen (2012; 2014) describes spatiality as an existential that, in its different modalities, is part of every person's lifeworld. There is a difference between space as the objective presence of geometrical points, and spatiality as experienced space. Spaces might be

geographically close, yet, due to hindrances, they might be experienced as far away if they are difficult to approach (van Manen, 2012).

In *Geography of the Lifeworld* (1979), Seamon turns to bonds between persons and places by retelling stories about how body-subjects experience spaces they inhabit in everyday life. Giving examples from a variety of spaces, like the bus, the bakery that is no longer there, the neighborhood, and the transition from a long night's drive and to falling asleep in one's own bed, Seamon searches for meaning in the ways in which persons relate to their spaces. His aim is to establish that the phenomenological notion of spatiality might awake interest, and provide tools and frameworks for a wide range of decision-making; for the reader's interest in his or her own movements within spaces, for policy makers, as well as for subjects' possibilities to engage in specific spaces that correspond to their point of departure.

Toombs (2001) reflects on the ways in which spaces relate to medicine and lived experiences of disability. She contests the position that a medical description of disability as "specific physical incapacities" (p. 247) can capture subjective experiences. Rather, she describes how disability relates to a disruption between lived body and space. She writes:

Locomotion opens up space, allowing one freely to change position and move towards objects in the world. Loss of mobility anchors one in the Here, engendering a heightened sense of distance between oneself and surrounding things.... Loss of mobility illustrates in a concrete way that the subjective experience of space is intimately related both to one's bodily capacities and to the design of the surrounding world (Toombs, 2001, 249).

Referring to her subjective experiences of living with MS, Toombs states that her lived experience of disability as constraint emerges when she approaches spaces that do not correspond to her present point of departure. These experiences are spatial and emerge through "the impossibility of taking a walk around the block, of climbing the stairs to reach the second floor in my house, of carrying a cup of coffee from the kitchen to the den" (Toombs, 2001, p. 247).

Merleau-Ponty underscores how bodies and spaces relate, as "space is not the milieu (real or logical) in which things are laid out, but rather the means by which the position of things become possible" (Merleau-Ponty, 2014, p. 253-254). In some spaces, possibilities of

movement emerge, and humans move with such ease that body and space co-create an experienced unity. In these spaces, boundaries between the experienced body and its world are blurred. Yet, if interrupted by an event that destroys the experience of easy movement and spatial interplay, the attention of the moving subject is due to change. Weiss (2015) draws on Merleau-Ponty, Young and Butler when she states that movements are meaningful whether they are reflected upon or not. Actions are related to an "I can" rather to an "I think that", thus, movements constitute an intentionality that is prior to thought.

Merleau-Ponty rejected an understanding of the body and its spaces as solely an object among objects or a coordinate in objective spaces, because "my entire body is not for me an assemblage of organs juxtaposed in space" (Merleau-Ponty, 2014, p. 100). Rather than being an object, the body is non-atomistic, an active, purposeful hub of perception embedded in its world. Merleau-Ponty describes this intertwining of body and space when he addresses his flat as a space familiar to him:

My flat is, for me, not a set of closely associated images. It remains a familiar domain round about me only as long as I have 'in my arms' or 'in my legs' the main distances involved, and as long as from my body intentional threads run out towards it (Merleau-Ponty, 1962, p. 150).

Yet, persons do not usually inhabit only one familiar domain over time. Merleau-Ponty (2014) describes humans' engagement with a wide range of spaces, from the spatiality of the night, the sexual space, the mythical space, and the lived space. When humans alter between spaces, spatial distinctions emerge. Such distinctions make possibilities to move in one space appear even clearer when seen in light of possibilities to move in another space. Merleau-Ponty describes the relaxed environment of a holiday village as a place that is qualitatively different from the city of Paris. He feels at home in the village as long as he is not reminded by the existence of the city. If reminded of Paris, his spaces alter, making one space foreground against the background of the other. He writes:

I arrive in a village for the holidays, happy to leave behind my work and my ordinary surroundings. I settle into the village. It becomes the center of my life. The low level of water in the river, or the corn or walnut harvest, are events for me. But if a friend

comes to see me and brings news from Paris, or if the radio and newspapers inform me that there are threats of war, then I feel exiled in this village, excluded from real life, and imprisoned far away from everything. Our body and our perception always solicit us to take the landscape they offer as the center of the world (Merleau-Ponty, 2014, p. 299).

The village in which he holds holiday, or the city of Paris as it is manifested to him through "the cafés, the faces, the poplars along the quays, the bends of the Seine" (Merleau-Ponty, 2014, p. 294) are spaces accessible through Merleau-Ponty's subjective body inhabiting them in past or present. Factual or imagined alternations between here; the village in which he is now, and there; Paris as it occurs to him when something creates resonance with his former experiences thus blur the lines between body, time and space.

Movements express relations between space and subject, where actions are temporal and exist in continuums between objective positions and subjective situations. Merleau-Ponty states:

How the body inhabits space (and time, for that matter) can be seen more clearly by considering the body in motion because movement is not content with passively undergoing space and time, it actively assumes them, it takes them up in their original signification that is effaced in the banality of established situations (Merleau-Ponty, 2014, p. 105).

Different bodies' presence in spaces are constructed since "we literally are what others think of us, and we are our world" (Merleau-Ponty, 2014, p. 109). The embodied subject relates to others, and together, the subject and its others inhabit spaces in ways that foster spatiality. The quotes above shed light on expectations as socio-culturally manifested situations. Merleau-Ponty addresses how expectations are formative when the shape of environments as well as subjects' presence in these environments, are planned, as "the customs of our milieu or the arrangement of our listeners immediately obtains from us the words, attitudes, and tone that fits with them" (Merleau-Ponty, 2014, p. 109). Thus, due to customs, we might easily turn attention towards expected hallmarks of groups rather than towards subjective identities.

## Method

Our methodological approach is inspired by van Manen's (2014) phenomenology of practice. van Manen describes this approach as "the practice of phenomenological research and writing that reflects *on* and *in* practice, and prepares for practice" (2014, p. 15, italics in original). In the educational everyday life of students with severe and multiple disabilities, students' expressions are essentially embodied and pre-symbolic. As phenomenology accredits moving bodies as presenting direct access to human engagement with the world, phenomenological philosophy and methodology provides this project the possibility to attend to disability as a state of being that is not inferior to a state without.

In a medical perspective, severe and multiple disabilities are recognized as complex conditions where cognitive difficulties are combined with motor-, somatic- and health-related difficulties, and loss of sensory functions such as vision or hearing. This results in conditions where one difficulty exacerbates the other, causing a mismatch between the person and the socio-cultural environment. It is important to note that while we make use of the diagnostic term "severe and multiple disabilities", our methodological aim is not to make medical descriptions, but rather to search for lived experiences.

We investigate lived experiences of eight Norwegian students with severe and multiple disabilities that attend segregated education in a country where education is ideologically inclusive. 75 % of children with severe disabilities still attend education in segregated classes or schools in Norway (Wendelborg and Tøssebro, 2011). Tendencies identified by Ytterhus and Tøssebro (2005) illustrate that the amount is even greater in the capital area of Oslo and surroundings. There also seem to be huge shifts of increasing numbers of children being segregated between kindergarten and primary school and from primary school to secondary school (Wendelborg and Tøssebro, 2011).

All eight students attend education in segregated special needs units organized in separate buildings or blocks in local schools in suburban areas. The two students that appear in this paper take part in the same special needs unit. Oliver is eight years old, and in second grade. Sara is twelve years old, and in sixth grade. Where Oliver walks, runs and skips unsteadily around in school, Sara is severely limited in her possibilities to seek some spaces and to avoid others. Where Oliver receives nutrition and fluid through a gastric peg, and often vomits slime, water and semper, Sara eats her yoghurt with muesli and her birthday muffin with good appetite. In non-determinant ways, they shed light on subjective likes and dislikes, different medical needs and different ways of reaching out for relations with others. Hence, Sara and Oliver show in flesh how lived disabilities are part of general human continuums.

In order to search for the participants' lived experiences, we follow van Manen's (2014) recommendation of using close observations. The closely observing researcher takes part in the participants' life-worlds. Close observations take place between proximity and distance, and involve "an attitude of assuming a relation that is as close as possible while retaining a hermeneutic alertness to situations that allows us to constantly step back and reflect on the meaning of those situations" (van Manen, 2014, p. 318). Van Manen claims that close observations are particularly suitable when the researcher wants to generate experiential material from "young children or very ill people, [because] it is often very difficult to generate written descriptions or to engage in conversational interviewing" (2014, p. 318). Conducting close observations, the first author spent two weeks in three special needs education units. She experienced and observed embodied relations and wordless dialogues between students, between students and pedagogical staff, as well as when being in close embodied contact with the students herself when giving nourishment through gastric peg, washing hands in lukewarm water, singing, lifting, dressing, or when a student sat in her lap. Through these involvements, the students and first author were accessible to each other, offering engagement in reciprocal, embodied dialogues.

During observations, close embodied involvements included a continuous, conscious aim for ethically acceptable involvement in order to minimize involvement that transgress the subjective borders of what each student accepted as invasive. The students mainly guided this process, the staff guided it partly, as did the first author's professional background in special needs education in general and in severe and multiple disabilities in particular.

The first author wrote field-notes at the end of school days. This was a conscious choice made in order to attend to students' gestures, mimicry, movements, smells, sounds or tactical outreaches. If the first author had focused on writing notes rather than paying attention to the students, she could have overlooked and lost embodied expressions. What was observed and noted down after close observations formed themes for the phenomenological interviews of staff-members, which were conducted when each period of close observations was over.

When we interpret the student participants' gestures, movements, and expressions, we construct their possible experience of spatiality from an outside perspective. Thus, following van Manen's guidelines for phenomenological writing, we have attempted to keep a sensitive and evocative language throughout the paper. In particular, we have aimed at acknowledging Oliver and Sara as active subjects who express their perspectives through movements. Our access to their experiences is what we can infer from the way they move and gesture, their mimicry, and the ways in which they position their bodies in space. In other words, we

approach spatiality from the outside rather than the inside, which is not a weakness in this kind of study. In a similar vein, Simms (1993) has investigated preverbal expressions in the light of Merleau-Ponty and Stern. She concludes that preverbal can coexist with verbal, as embodied gestures express a direct engagement with the world.

The field-notes and interviews were analyzed by both authors, who read the raw-material holistically and in detail to locate units of meaning. Further, they returned to the field-notes, where experiential structures were shaped into phenomenological anecdotes: short stories, concisely describing a single incident, opening near the central moment of the experience, including important details only, often containing several quotes, and ending promptly after the incident has passed (van Manen, 2014). Investigating wordless perspectives, we have continuously reflected on how embodied expressions easily can be overthrown by wordiness of pedagogical staff and researchers. Being aware of the asymmetry in relation between adult and child, we have still chosen to include teachers' verbal statements excerpted from phenomenological interviews. These excerpts are linguistically honed in order to attend as close as possible to the students' perspectives.

As stated, we make use of the diagnostic term "severe and multiple disabilities". Yet our aim is not to make medical descriptions, but rather to develop a phenomenology of how the two participating students act in spaces. As pediatrician Beets claimed, phenomenological pedagogy has its own special character that differs from psychological and medical approaches to divergence. Phenomenological pedagogy turns to the child itself, in the child's particular situation, and in relation to particular others (van Manen, 2014).

In our search for lived experiences in the silent lifeworlds of students with severe and multiple disabilities, we have found support in Merleau-Ponty. Thus, we have striven to acknowledge and describe the two student participants as fully worthy persons with varieties of interests, meanings, social backgrounds, and experiences.

## **Findings**

Practical pedagogical decisions about which spaces to include into Oliver's and Sara's immediate educational environment are formative for their possibilities to move freely. Through the following phenomenological anecdotes, we describe how the students express spatial experiences when they move. We will also present excerpts from interviews with staff members that provide interpretations of how Oliver and Sara move within different spaces.

*It is Monday morning. Oliver walks, runs, and skips with one foot in front of the other around a very warm, small gymnastics hall on the ground floor. He has a keen eye, seems eager and glad, and changes direction continuously; a bit this way, a bit that way, unsteadily, yet he never bumps into anything that might bring his elegant and hardly predictable moves out of balance. Oliver chews eagerly on a chewy-toy made of green, knotty, hard rubber, he salivates intensively before spitting the toy out again. When not chewing, he blows spit-bubbles that make bubbly sounds as they burst through his pouted mouth.*

*Oliver is light on his feet, skipping towards a low window with a view towards the schoolyard. He holds on to the window frame and squashes his tiny nose flat towards the glass. On the outside, students about his age play in ponds of water in the pouring autumn rain. For quite a while, Oliver stands by the window. Apparently concentrated he watches what happens just a few meters away.*

*Teaching assistant Hilde carries a laminated strip of pictures in her hand as she approaches Oliver by the window. She takes his hand, and Oliver accepts that she guides him towards the trampoline that is depicted on the top of the strip. Standing unsteadily on the trampoline, holding Hilde's hands, Oliver abruptly drops his short, light and slender body down with a wham, and sits sunken with his legs in the shape of a W.*

*"Stand up, Oliver", Hilde says. Oliver stays down. Hilde takes his hands, leads him up, and sways carefully. Oliver stands still before he lets go of Hilde's hands. He climbs down from the trampoline and runs unsteadily, yet purposeful back towards the window.*

*Oliver stands by the window for a while, also this time with his nose squeezed firmly against the glass. When Hilde approaches him there, he turns his head towards her and accepts the picture that she places in his hand. Yet, he walks towards the entrance door, puts the lights out and grabs the doorknob. Once again, Hilde takes his hand. From now on, with extensive hand-leading and encouragements, Oliver carries out the activities depicted; a balancing installation, a big, peanut-shaped ball, a bobath ball, wall-bars, a crash-mat, a slide.*



*Oliver has carried out all the activities, and now there are no more pictures left. He moves around the room in several directions before he returns to the window. He salivates, rubs his tiny fists intensively in his eyes, and presses his nose towards the window once more. The students on the outside are gone. A man with a big German shepherd walks across the school-yard. Oliver turns his head and follows the man and his dog with his gaze.*

Oliver walks, skips, and jumps apparently unconstricted around in the gym. As Toombs (2001) states, locomotion makes spaces emerge. When moving out of, into and within spaces, the moving subject can turn towards as well as away from the space itself, as well as towards or away from objects and others present in that particular space.

Oliver moves a number of times towards the window and once towards the door. The door and the window carry promises of a world outside the gym. The way he reaches towards the outside where other children play and a man walks his dog, and the way he walks towards the entrance door and puts the lights in the gym out, expresses his perspective saying "I am done here". Thus, it appears that he has an agenda on his own. This agenda corresponds to his newly gained possibility to walk, and is expressed to his surroundings by the way he moves in the gym.

Where Toombs (2001) relates her experienced disability to her limited possibilities to bring her cup of coffee to the den, we might recon that Oliver's lived experience of disability emerges when his reaches for the outside are limited by Hilde's agenda to keep him in the gym in order to perform certain tasks. Special needs educator Maria addresses the intertwining between the moving subject and spatiality, as well as the importance of acknowledging subjective wants when she observes Oliver's joy of walking. In the following excerpt from an interview, she describes how Oliver's newly gained movements intertwined with spaces that were new to him when he started school last year:

*So, I thought, "well, what would a person that just has learned to walk like to do? Of course, you would like to walk. Walk, walk, walk, walk. A completely new world unfolds.*

*In kindergarten, Oliver had been crawling around, dragging himself around, he needed lots of help at that time. While now... He manages to move around on his own. And he is so happy with himself!*

*He still walks unsteadily. Yet, in the beginning, he did not fall or stumble that much, even though I thought that he would, because there are a lot of assistive devices to stumble into around here. But he did not, actually.*

*Still, he came to a place that was all new to him just after he had learned to walk, and it appeared that he found this new place a bit scary. There were new grown-ups, the building was new to him, new school-yard, everything was new. This seemed to make him a bit unsure, and then he sat down. Unsure. Often, he sat down when he entered a new place. What he managed at first was the hall and the classroom. That was what he investigated first.*

By turning to how Oliver walks unsteadily into his new environment in school, Maria does not place movement and space in a hierarchic relationship where one rests upon the other. Rather, she attends to space and movement as reciprocal and equally important. Yet the institutionalized asymmetry between student and teacher shows, as it is she as a special needs educator who opens up for his possibilities to "walk, walk, walk, walk". Oliver moves light-footed and eagerly when he walks, skips and runs around in school. As recognized by Maria, his possibilities to enter and move around in spaces make him happy with himself. Yet school is a place for expectations not only for being, but also for becoming. Assuming that Oliver's agenda is to walk into the spatiality of the social world of the schoolyard, his reiterated approaches towards the exits of the gym might express his longing for the outside. Yet his agenda apparently does not correspond to the agenda of teaching assistant Hilde, who represents the professional actor in the educational context. Hilde, as member of the pedagogical staff, has expectations regarding Oliver's education. In a calm, yet leading way, she takes Oliver away from what caught his attention on the outside and guides him towards certain tasks and objects on the inside.

The strip that visualizes the activities he ought to perform in the gym sheds light on the ways in which education takes place in a wide span between Oliver's present being and his future becoming. An individualized educational plan formulated by the pedagogical staff states that an aim for Oliver is to gain new communicative skills, and thus, specific

interventions are utilized. In the following excerpt, Maria describes a tension between including her student's subjectivity while aiming for him to achieve certain skills in an unknown future:

*The strip, it is kind of a pilot project. In kindergarten, they used to work a lot with symbols. I think that was far above his possibilities to understand. Hence, I started on ground level, and took his body language as my point of departure. So, what we are investigating with those pictures is in fact if he understands the connection between picture and activity.*

To deepen our understanding of how movements in spaces express perspectives, we turn to Sara as she enters a warm-water pool. Sara's movements constitute her dwelling possibilities to move in some spaces over others.

Sara is the size of any 12-year old. She sits with some support, but prefers to lie on her back with her legs drawn up towards her belly. She actively resists staff's attempts to make her lie belly down. On good days, when not too interrupted by epileptic activity, she moves her legs carefully back and forth when supported by her weight bearing assistive device, "jolly jumper". To give some examples, she expresses herself when she gives eye contact or not, when she slants her head, when she ends or continues movements supported by song and rhymes, and when she increases or diminishes sounds of complaint.

*The long, tiled hallway from the shower room to the pool is cold, moist, draughty, and smells of chlorine. Sara sits in her wheelchair, which is pushed by teaching assistant Hilde. Over Sara's hips go straps that secure her from toppling out. She bends her upper body all the way down to her thighs, and crosses her legs in the seat. Over her shoulders and her back lies a terry cloth towel. She complains continuously; "ehhhhhh, ehhhhhh, ehhhhhh".*

*When they reach the pool, Sara still curls up in the chair, while she continues to complain in a deep tone. "You are going swimming Sara. Yes you are". Hilde talks slowly and in a bright tone as she takes the towel away, places her hands carefully on Sara's shoulders and leads her upper body slightly towards the backrest. Hilde grabs a slim, yellow life vest and leads Sara's arms through the openings one by one before fastening straps in the front. Carefully, she pulls orange inflatable arm rings on Sara's*

*upper arms before she rolls the wheelchair as close to the pool as possible. Sara still grumbles, and her continuous sounds are monotonous and persistent. At the count of three, Hilde and special needs educator Maria take Sara in tow and lift her from the wheelchair into the warm water.*

*Once in the water, Sara unfolds her curled-up body and her grumble diminishes. She lies down on her back, stretches and bends her legs and her arms and moves around the whole of the pool with slow movements.*

*Sara is all quiet now. For quite a while, she is not interrupted by anyone and moves around, kicks her legs and flutters her arms, and occasionally she turns around her own axis.*

*All of a sudden, moving around on her back, Sara collides with a teacher who is walking backwards while playing with one of the other students. Sara straightens up and grabs the upper arms of Maria who happens to be nearby. For a while, Sara grumbles, while she holds on to Maria. Then she lies down in the water again, continuing her quiet voyage around the pool.*

Sara experiences constraint due to internal and external forces that are part of her disability. To various degrees, medical conditions like epilepsy, scoliosis, and low muscle tonicity limit what she can do. For safety reasons, she is strapped to the wheelchair, yet, when in the water she moves unconstricted. Thus, her movements magnify how spaces support or delimit subjects' possibilities to reach out.

When we follow Sara's transition between spaces, the way she unfolds her body when she enters a certain space express her perspective. She used to curl herself up when in the wheelchair. Yet, in the warm water, she stretches out and leaves this curled up position as she folds out the soft side of her body. In this, she leaves her stomach, chest and abdomen unprotected. When Sara enters the pool, she accepts being immersed in an element in which she interplays with pressure, buoyancy, and temperature. She leaves the curled up position that might resemble the position of a fetus when the warm water that might resemble being in utero envelopes her. Thus, we can infer that the properties of warm water counterbalance what Sara misses when being in other kinds of spaces, where gravity limits her possibilities to

move. Thus, from Sara's contrasting expressions, we gather that the "here" of the pool corresponds to her point of departure in way that to part liberates her from her constraints.

Another distinction, through which Sara expresses how she experiences the "here" of the wheelchair, emerges through the sounds she makes when the "here" of the wheelchair turns into a "there" when she enters the pool (which in order turns the "there" of the pool into a "here" the moment she enters it). Her absent grumble in the pool is as communicative as its presence in the wheelchair when seen in the flow of time, not as singular spatial occasions. Without the former grumble, Sara's quietness could have been unnoticeable quietness and not the attention-claiming absence of sound. In these contrasting moments lies the possibility to attend to movements as distinct, where one is constituted by the presence and absence of the other.

As Merleau-Ponty (2014) describes his holiday village and the city of Paris as alternating foreground and background related to a "here" and a "there", spatiality constitutes comfort and pain as foreground and background. As Sara grumbles and curls up, we can assume that she expresses dissatisfaction with her "here". When the wheelchair turns into Sara's "there" as the pool becomes her "here", attending to her contrastive movements give us a possibility to interpret her expressions as manifestations of experienced comfort and pain, as well as expressions related to joy, self-determination and happiness. Anna, Sara's teacher through six years, describes the relation between space, movements and humanistic values:

*I guess that the greatest freedom... The pool, it is the space where Sara is occupied with herself and her own body and her movements. It is the place where she shows joy and activities based on her own free will, activities combined with happiness, not duty and expectations. She can be active in other situations as well, but those are activities combined with our expectations. Our only expectations when she is in the pool is that she shall use the water, and that is kind of unavoidable. In the water, she does not need to use her hands to anything else but to move them, in different angles, open, twist and stretch.*

Anna's interpretations of the relations between movement, space and values of freedom are carried out in practical pedagogical arrangements. When Sara engages with the warm water, the subjective ways she moves are not coincidental. The staff's active involvement when bringing Sara to the pool is replaced by active disengagement when she reaches the water. No one prompts Sara in order for her to perform specific movements aiming to attain

physiological or psychological goals. No singing games or rhymes are performed, no specific objects to manipulate are provided. Sara leads the situation, and her movements express her subjective horizons to the pedagogical staff-members.

### **Conclusion**

Acts and absence of acts are formative practical pedagogical means when staff attunes to movements as expressive. Returning to Merleau-Ponty's (1962; 2014) and Toombs' (2001) outlining of disability and space, we can acknowledge that movements express medical, personal, social and emotional aspects of lived experiences of severe and multiple disabilities.

As Merleau-Ponty (2014) points out, inhabiting even familiar spaces like one's own flat presupposes intentional embodied outreaches. Thus, a space only becomes familiar when a person moves into it. Meanwhile, turning towards one space always includes turning away from another. When Oliver moves from the window to the trampoline, the window as his "here" turns to his "there" when the trampoline that used to be his "there" turns to Oliver's "here". Being anchored in a "here" due to disability seems to be shaped by different shades of inescapability, as described by Toombs (2001) when she addresses how she and her spaces do not correspond. Turning to the empirical material, we can reckon that Oliver's lived experience of disability as inescapability is anchored in the situational "here". What turns into his "here" is not a limitation of the objective spaces that he can reach, rather, it takes the shape of constrictions placed upon him due to the educational agenda. This agenda overrides his subjective wants, and causes him not to attend to the social world on the outside. Sara is anchored in the positional "here" to a larger degree than Oliver, yet the approach of those surrounding her creates possibilities for her to move freely and thus to express a wide spectrum of satisfaction and dissatisfaction, and of comfort and pain, all dependent on how she corresponds with the spaces she is placed into. When Oliver and Sara move from "here", another qualitative different "here" unfolds, in which they and their spaces redirect in a continuously ongoing process. The moving subject "*reckons with the possible*" (Merleau-Ponty, 2014, p. 112, italics in original) in a continuum between total situatedness and total imagination. Thus, moving from "here" to "there" includes the possibility to turn towards what is new as well as the possibility to turn back towards the known.

Embodied expressions are, as Merleau-Ponty has stated, a path towards understanding human meaning that extends the type of knowledge provided by empiricism and intellectualism. Sara and Oliver move in spaces in which their "maybe I can" is continually thrusting towards a "maybe I can't". If confident experiences of "I can" are frequent, and

embodied expressions are accredited as fully worthy, traditional expectations that challenge limits of what bodies of minority groups can do are challenged.

In line with Seamon (1979), we argue that spatiality might provide tools and framework for decision-making in the practical-pedagogical everyday life of students with severe and multiple disabilities. Even if we have attended to movements in spaces as formative for perception, thought, and language as described by Merleau-Ponty (1968; 2014), we acknowledge that movements in spaces are also temporal when movement in one space appears in light of another. As an original moment is irretrievable (Weiss, 2000), every moment will form a more or less distinct contrast to moments of the known past or expectations of an unknown future. When paying attention to contrastive embodied expressions as they unfold in spaces, temporal continuity in human relations stands out as foundational. Thus, we suggest that human relations should be sustained over time in special needs education, as they are valuable in detecting and accrediting contrastive movements that express the silent perspectives of students with severe and multiple disabilities.

Phenomenology offers a framework that challenges prevailing understandings of disability as a deviation from a given normality. Paying attention to how transitions between spaces make expressions and absence of expressions recognizable, we emphasize movements as important per se when including embodied and pre-symbolic perspectives of students with severe and multiple disabilities in educational decision-making. Finding and inhabiting spaces that correspond to students' subjective points of departure are matters of seeing them as beings in their own right, confident in the knowledge that being will walk side by side with becoming in education.

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# PAPER 2



## **Paper two: A golden Paper, a Chain and a Bag: Phenomenology of Queer Things in a Special Needs Education Unit**

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### **Abstract**

All children seem to be attracted to play with things that can be used in numerous ways; a stick, a spoon or a chain of pearls all seem to contain a goldmine of possibilities for the child as a subject with predilections and dislikes.

Some children, like Sara and Oskar who we meet in this paper, are due to severe and multiple disabilities restricted in their possibilities to approach certain things and to reject others. In this paper, we explore the existential meaning of queer things as foundational in the way our two students reach out in a space where they relate to themselves as well as to others.

*Keywords:* Severe and Multiple Disabilities, Queer Phenomenology, Education, Things

### **A golden Paper, a Chain and a Bag: Phenomenology of Queer Things in a Special Needs Education Unit**

Lived material things are existentials along with lived self and others, lived bodies, lived spaces and lived time (van Manen, 2014). Existentials are present in the world of every human being, and are suitable to guide investigations of human phenomena. In this paper, we are interested in the existential of materiality as it is experienced in the educational everyday life of two students with severe and multiple disabilities. By exploring the research-question *what is the meaning of things that are put to use in practical pedagogical work in special needs education units?* we are interested in what happens when things are put to use in other ways than what was expected. Thus, we are brought to the agenda of queer phenomenologist Sara Ahmed. Ahmed (2006) describes things as anchoring points that shapes bodies reaching for things present. She claims that queer things are things that have lost their place, and when put to use they present new spaces for the persons having them near. Pointing to phenomenologist Maurice Merleau-Ponty, Ahmed acknowledges how queer things are shaped by purposeful bodies. When these bodies are labelled as having disabilities, Merleau-Ponty (2014) challenges disability as a binary state of having or not having. He claims that disability exists in a continuum where it is experienced in relation to how it is embedded in its involvement with things, relations, bodies, spaces and time.

Ahmed (2006) claims that use of things deviating from what was expected makes both the thing and its user queer. In this, she introduces an alternative way of thinking about how humans turn to some things over others. The term “queer” is often related to sexual orientation, where humans are defined by whom they are attracted to and towards whom they orient. In this paper, however, we use the term queer as an insight cultivator and analytical support, aiming to approach understanding of the meaning of things in special needs education.

The work of Ahmed is clearly related to Martin Heidegger who was also engaged in how humans are involved with things. Breaking out of a Cartesian understanding where “thing” is understood as separate from “user”, Heidegger described our involvement with things as a matter of existence. He proposed that situated use of things is prior to perception of things, and that “in everyday terms, we understand ourselves and our existence by way of the activities we pursue and the things we take care of” (Heidegger, 1982, p. 159 as cited in Dreyfus, 1991, p. 61). “To exist then means *relating to oneself by being with beings*” (Heidegger, 1982, p. 157 as cited in Dreyfus, 1991, p. 61, italics in original). To be involved with things is an existential matter of being related to others as well as being related to oneself.

In Dreyfus’s (1991) exposition of Heidegger’s *Being and Time* (1962) he claims that things of everyday life are not available and close until there is a human subject present. Further, availability of some things as well as absence of others depends on actions related to certain orientations. In Ahmed’s words, “spatial relations between subjects and others are produced through actions, which make some things available to be reached” (2006, p. 52). In her understanding, things, available or not, are orientation devices. Things let bodies extend in ways that can create new livable spaces for humans to inhabit. Things can also keep bodies in expected places in everyday life.

In Heidegger’s understanding, the perceived but unused thing does not offer the perceiver knowledge about its function. This perceptual mode of access is addressed by Heidegger stating that “No matter how sharply we just *look* at the ‘outward appearance’ of things in whatever form this takes, we cannot discover anything available” (Heidegger, 1968, p. 98, as cited in Dreyfus, 1991, p. 64, italics in original). What makes us discover the availability of a thing is in its use:

The less we just stare at the hammer-thing, and the more we seize hold of it and use it, the more primordial does our relationship to it become, and the more unveiledly is it

encountered as that which it is-as equipment. (Heidegger, 1968, p. 98, as cited in Dreyfus, 1991, p. 64)

Through involvement with things that are available “Dasein takes a stand on itself” (Dreyfus, 1991, p. 61), and includes its subjectivity into the relation between thing and user. This relation, where the subject’s point of departure meets the capacities embedded in the thing can be understood as occupation, not in terms as having a certain profession, but as a mode of being busy with existence. According to Ahmed (2006), occupation is to inhabit space, to make use of things in this space, and to work and have an identity through the actions one performs.

When a person uses a thing, capacities are revealed. Ahmed (2006, p. 46) states that “the pen can write... [but] the capacity is not so much ‘in’ the tool, but depends on how the tool is taken up or ‘put to use’”. What makes equipment reveal its functions is the recognition of the thing as being part of an equipmental nexus, where each piece points to a whole. Ahmed (2006) highlights how things relate to each other when turning to things surrounding the philosopher. As equipment like the writing table points to other tools such as paper, inkwell and pencils, every item is part of an equipmental nexus where the philosopher is also part (Ahmed, 2006). In this nexus, the thing is defined by what it is used for and how it points to other things (Dreyfus, 1991).

Usefulness of equipment is not only instrumental (Ahmed, 2006). Rather, its capacity depends on how it is apprehended as open towards the future of the user. When user and thing meet, the user turns to the thing as a person with meanings, predilections and previous experiences. As things are recognized by an un-instrumental “can”; the wheel can roll and the pen can write, the person using it is the one revealing its’ capacities. Even if the thing is a carrier of cultural expectations on how it ought to be used, it can appear and be approached in unexpected ways. In the end, what the thing can do depends on how it is approached and how it encourages or restrains the user’s extension into the world. This taking up of objects is a matter of the orientation of the user, who perceives and approaches the object in a certain way, by liking it, admiring it or hating it.

Bodies are orientated to some things over others in ways depending on where they are located, what is brought near and which values inhabit institutions as collective or public spaces. By describing how humans turn to some things over others, Ahmed (2006) emphasizes relation between body and things that bodies act upon. Even though human orientation is normative in the sense that attention is expected to be directed towards what is

considered straight related to body, sex, gender, or race, attention can be directed towards what is considered queer, and new possibilities unfold.

### **Method**

In this paper we explore the meaning of things by utilizing phenomenology of practice (van Manen, 2012; 2014). Van Manen (2014) describes phenomenology of practice as “the practice of phenomenological research and writing that reflects *on* and *in* practice, and prepares for practice” (p. 15, italics in original). In line with Husserl’s and Heidegger’s student Patočka, we argue that practice “lies at the proto-foundation of thought, of consciousness, of the being of human being” (van Manen, 2014, p.15).

In the educational everyday life of students with severe and multiple disabilities in special needs education, student’s expressions are essentially embodied, without words or symbolic signs. Van Manen (2014) recommends close observations when the researcher wants to get closer to student’s perspective to generate experiential material from ‘young children or very ill people, [because] it is often very difficult to generate written descriptions or to engage in conversational interviewing’ (p. 318).

Taking part in practical-pedagogical tasks as a close observer, the first author experienced embodied relations and wordless dialogues between students, between students and teachers as well as through close embodied contact when involved with the students herself when feeding through gastric peg, washing hands in lukewarm water, singing, lifting, dressing or providing a lap. These involvements made students and first author accessible to each other, offering engagement in reciprocal, embodied dialogues. The first author’s experiences of close embodied contact with students with severe and multiple disabilities enhanced what was ordinary rather than deviating and due to the research-question, what was subjectively expressed rather than what was medically or diagnostically defined turned into foreground. Close embodied involvements included a continuous, subtle balance between ethical acceptable involvement which the students were comfortable with, and involvement that desecrate the subjective borders of what each student accepted as invasive.

While continuously reflecting on how student’s embodied perspectives easily can be overthrown by wordiness of the teachers, we have chosen to include quotes from interviews of two teachers in this paper. The two students Sara’s and Oskar’s experiences with queer things are experiences shedding light on disability created as how-ness in fluent continuums rather than as what-ness connected to specific deviations. In an educational field where what-ness of diagnoses has been prevailing, the how-ness emerging in the unit of Sara and Oskar

depends on the way students and teachers are bodily close to each other. Yet, being aware of the asymmetry in this relation between adult and child, we have chosen to include teachers' reflections. Their reflections are honed in order to attend as close as possible to the students' perspectives.

### **Creating Possibilities Together**

Sara has been a student in the same special needs education unit for six years. In the following quote, special needs educator Anna describes how Sara's preferences of things were decisive when she and the staff carefully approached and got to know each other when Sara arrived from another country in second grade.

*She used to curl up like a little ball all the time, but when we approached her with things that would crackle when touched, we discovered that we made contact.*

Anna points to the importance of acknowledging Sara's subjective experiences with things of a certain kind in order for student and staff to make contact. When approached with things that crackle, Sara moves from being "curled up like a little ball all the time" to a state of being where she reaches out in space. Six years after their first cautious meeting, we turn to what happens in the relation between Sara and Hilde when Sara approaches a crackling, golden paper.

*Twelve-year-old Sara is in the seventh grade in the special needs education unit. She is the size of any twelve-year old, lying on her back in furniture that looks like the fusion of a baby's bed and a playpen.*

*Teaching assistant Hilde walks slowly towards Sara, greets her, puts on Sara's corset, climbs into the furniture, and asks Sara to sit up, supporting her student firmly as she raises her upper body. Hilde steps out of the furniture, lifts Sara with her, sits down on an office-chair with Sara in her lap, and together they roll towards a wooden resonance box<sup>8</sup> placed on the floor nearby. Carefully, Hilde lays Sara down on the resonance box. Hilde then finds her place with her back against the wall, takes a firm*

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<sup>8</sup> The resonance box is used to amplify sounds created by a moving body or by things touching it. It is made of wood measures approximately 2x2 meters and two centimeters high.



*grasp under Sara's armpits, raising her up and lifting her close onto her own sitting body. Sara slides down in Hilde's lap.*

*Hilde places a low table with two plastic boxes filled with toys and various plastics in front of Sara. Sara raises her upper body, but slides quickly back into Hilde's lap.*

*"Oh, Sara. You are tired today. Yes, you are. You are a tired girl today. We have plenty of time. No need to rush, Sara." Hilde is talking in a low voice and slowly, sitting steadily, supporting Sara's body. The minutes go by when Sara suddenly straightens up, reaches out and chooses a well-worn, thick, gold colored paper which is used to cover a box of assorted chocolates.*

*Hilde stands up, lifts Sara close to the wall and withdraws. Sara sits by herself, legs crossed like a tailor, back leaning steadily against the wall. She rubs the golden paper in her hands, it crackles. Sara starts breathing forcefully, rhythmically, in through her mouth, out of her nose, head slanted.*

Sara's severe and multiple disabilities confine her possibilities to reach certain things in certain spaces, making availability a matter of others bringing things within her reach. Yet, she chooses the golden paper and rejects other available toys and plastics when her moving body is recognized as fully worthy and patiently supported by Hilde's body and voice. In the anecdote, Hilde's considerations frames Sara's possibilities of subjective movement. When Hilde supports her outreach, Sara can grasp the paper, rub it and change the way her breath goes. Relating to Sara through close body-to-body-contact when sitting behind her, talking slow and in a low voice, Hilde recognizes Sara's possibilities to reach out towards the golden paper as potential rather than as deviation from a given norm.

Hilde contributes to Sara's direction of attention towards the paper by lending her body to Sara. Yet, Hilde is not conducting the situation, as Sara's acceptance of their bodies being close is a presupposition for what happens when Sara chooses and grabs the golden paper. When this close contact is created, neither Sara nor Hilde are left untouched by the expressions of the other's body. Being reciprocally engaged in what this other body in all its sameness and difference expresses enhances an understanding of the other as qualitatively different, yet of equal value as emphasized by Merleau-Ponty (2014). This does not mean that disability does not exist, rather that all human experiences are shaped in a continuum of things, spaces, relations, bodies and time. In such a continuum, all bodies carry possibilities

for attending to things through competent movement and well-being as well as through pain and shortcoming.

The golden paper, well worn, with a stiff core and a smooth surface, is available to Sara in the space co-created by bodies. Sounds and vibrations of Hilde's voice coming from the immediate background of Sara's body as well as her low and slow utterings, saying Sara's name over and over again tells Sara that she should use the time she needs. Covering the back, the left and the right of her student with the warmth of a well-known body, the sound and vibrations of a familiar voice, Hilde frames Sara's attention towards the boxes with things, making them available for Sara's choice. Sara contributes to the situation by sliding down in Hilde's lap and staying there for a while, before suddenly raising her upper body, reaching out for the paper and from there playing with it in her own way. The situation is a shared situation, where Sara's accepts the close, embodied contact offered by Hilde, an acceptance that in Sara's everyday life in school is not be taken for granted.

### **Me, You, We**

Special needs educator Maria emphasizes how characteristics of certain things can form a point of departure when she introduces new things to ten-year-old Oskar. She tells about this in an interview.

*He likes to touch certain things, different consistencies. He is not very fond of soft things; he likes things that are hard, a bit crackling, so I try to find different nuances of those. He likes it either this way or that way, those nuances in the middle, he just doesn't find them interesting; they are more like "touch them a bit and then I'm done".*

*Then, some things are interesting to him all the time. Plastic bags of different consistencies, he likes any kind of plastic bag actually, but those that are a bit thicker, they give another sound that is more exciting. What I try to do is to use his favorites as a point of departure. Then I find variations to it, and sometimes I try something completely new that can turn out either this way or that way.*

Oskar has some favorite things and takes part in decision-making about which things that are to be brought to his reach. Acknowledging and taking point of departure in the things he prefers, Maria describes how these things might point to other things. Yet, when including

new things into school, Maria might make Oskar's experience with handling new things stumble. If so, Maria can try to change what can be changed to support the way Oskar puts the thing to use; if the thing is a sticky, yellow rubber chicken, perhaps it should be changed into the green dragon teddy with the glossy nose worn out from several of Oskar's kisses. Perhaps sitting restrains how Oskar can use the dragon teddy, whereas the oblique pillow supports it. Perhaps Oskar is hungry or thirsty and thereby unable to attend to the dragon; perhaps he is tired and in need of a nap. Perhaps he is in need of being by himself for a while, or perhaps he is in need of having his teacher bodily close, supporting and reacting to his use of things. This relation between thing and subjects underlines the unpredictability in how students, teachers and things relate in the ever-changing everyday life in school.

The significance of embodied closeness as enveloping possibilities of relations between Oskar, Maria and the things in their presence is further explored in the following anecdote.

*Oskar sits on the floor and Maria supports his back. Oskar drivels and smiles to his reflection smiling back at him in the mirror on the wall.*

*Oskar topples forward and seizes a Christmas chain of shiny, red plastic pearls. He shakes his arm, everything from his shoulder and down to his closed fist moves. Maria stretches towards a big, blue IKEA bag made of thick, woven plastics. She places it under Oskar's leg, and he starts to move his knee eagerly back and forth. The more the bag crackles, the wider Oskar smiles. He lifts his head, searching for the look of his teacher in the mirror. He catches her glance and smiles to her. She smiles back at him.*

As in the anecdote of Sara, where Sara and Hilde co-created a space where Sara could extend her body, Oskar turns towards the Christmas chain in a situation created by him and Maria. As the chain grabs his attention, Oscar topples towards it. As he makes use of the chain in a way that suits his possibilities to reach out, he extends his body. When Maria gives Oskar the IKEA bag, the same thing happens. Oskar's moves his leg and creates a crackling sound, the blue plastic reflect light and shadow when he moves his knee back and forth.

From here, Oskar's use of things makes an important turn. Oskar reaches out towards Maria and expresses his experience. In the mirrored glance of the shared experience with the chain and the bag, a new confirmation of relations takes place. Oskar lifts his head, his eyes search for the look of the other, Maria, in the mirror. As he smiles, he confirms what she already seems to know; that he is a fully-worthy contributor in their relation. When she smiles

in return, she confirms that she knows what he knows. As queer things appear in a context where they were not expected to be, offering possibilities of movement, they turn into hubs in human experiences of being related, seen, and acknowledged as well as to relate, see and acknowledge the other; there is a me, a you and a we.

### **Giving What I Can When Relating to You**

The story of Oskar, the red chain and the blue bag differs from the story of Sara and the golden paper by the presence of the mirror. As Maria sits behind Oskar, both of them facing the mirror, she extends the meaning of the things he uses. Reflecting his mimicry, his gaze and her reply, the mirror makes Oskar's expressed experience available to Maria. Further, Maria's experience of his experience is reflected back to him. As Oskar lifts his head, he finds his teacher's glance and smiles to her in the mirror. In the mutual glimpse of two pairs of eyes, they acknowledge each other as persons who have something to tell, as persons worth listening to. They share attention, and in this attention he expressions of the other are continuously reflected. Oskar and Maria are thrown back at each other as continuously contributing partners.

When Sara rubs the golden paper in her hand and starts breathing rhythmically, Hilde withdraws. Sara continues moving; her hand rubs paper, she draws air in through nose and lets out through mouth, she slants her head. It seems like Sara is attuned towards the play with the thing in her hand, introvert, directed towards herself. The way Sara rubs the paper, and the way she creates a rhythmic expression by breathing in a new way, she leads our attention back to disability as understood by Merleau-Ponty (2014). Understanding Sara's disability in a continuum, her way of directing towards herself may communicate her possibilities right here, right now. In line with this, Hilde's withdrawal can be understood as an expression of respect for Sara. If Hilde's approach to Sara was recognized by understanding education as becoming rather than being, Hilde could have pushed Sara beyond her subjective state of being, and even Sara's relating towards herself could have stranded, leaving her as an incomplete deviation rather than as actively engaged subject.

The two experimental episodes trod the same path in the way students and teachers reciprocally find and give support in each other. Students and teachers hold up what happens next by letting bodies co-create spaces, spaces that contains things that carry a certain kind of openness. Through embodied contact, neither Sara, Oskar, Hilde nor Maria are untouched by what is expressed by the other. Rather, their bodies, being close to each others, leave imprints that envelopes what is to happen next in relations where each subject contributes.

When Hilde withdraws from Sara, the two stories differ in how things, persons and pedagogy are interwoven. Hilde supports Sara on her way to play with the golden paper. Sara directs to her play rather than reaching out. She directs her attention towards the thing she has in her possession, and Hilde withdraws, leaving the question of what could have happened if she had continued being close to Sara, either as interactional possibility or breakdown, unanswered. Still, Hilde's sensitivity towards Sara as fully worthy subject opens up for re-learning and extending knowledge about a life-world where experiences prevailingly has been understood in terms of medicine.

### **Concluding Comments**

Children seem to be attracted to explore and play with things that provide openness in intention or utility. These actions indeed seem more ordinary than unordinary in the life of most children. From Sara's and Oskar's stories, we see that things that provide open, multi-sensory possibilities are things letting our two students play with them in their own way. The paper, chain and bag are things that create possibilities to reach out in space and, maybe, create possibilities to reach out towards others. On the other hand, Maria mentions "pedagogical things sold in toy stores" such as sorting cubes or play-kitchens as things restraining the students' possibilities to reach out. These things are of little interest to our two students. Relations between children's ways of being in the world and the closed way of putting pre-defined things to use can break down, either by the thing demanding specific motor capabilities or by demanding the child to have an ability to pretend.

As Ahmed (2006) points out, things present double-edged swords. Reachable things measure competence and capacities, defining persons as able or unable. Things can communicate that the world is a place in which being active implies possibilities of understanding, of choosing preferred sensual impressions or as possibilities of including and to be included in relations. Yet, things can also communicate that the world is a place where being active implies shortcoming, pain and relational rejections. In a continuum, things that communicate openness consolidate all human movement as potential rather than as deviation. In the use of queer things, possibilities unfold. Sara's rubbing of the golden paper makes her turn her actions towards herself and her subjective possibilities. Oskar's rattling with the chain and his kicking of the bag makes him reach out and relate to others, creating reciprocity if these others are sensitive and responsive.

Pedagogical decisions about which things to bring into an educational context where

students are severely constrained in their possibilities to move around are moral decisions. If Sara and Oskar had possibilities to move freely in spaces we could reckon that they would seek things corresponding to their subjective way of being, as the toddler seeks the wooden ladle in the kitchen drawer. Where the toddler might experience constraint due to the ladle being out of reach due to the kitchen drawer having a child-safe hook for the child's safety or the adult's convenience, Sara and Oskar experience internal and external constraint directly connected to their bodies. Internal constraint like spasticity and epilepsy as well as external constraint like the use of assistive devices restrain Sara's and Oskar's embodied freedom, and in this, a particular vulnerability in relation between student, teacher and things evolves.

Students and staff co-create spaces where queer things let bodies reach out and values of childhood and disability unfolds. When staff-members bring queer things into special needs education as result of reflection, they carry out practical acts bearing pedagogical meaning. Turning to Sara and Oskar for advice and confirmation on the choices they make, Hilde, Maria and Anna shows a deliberate humbleness. Their recognition of the students' severe and multiple disabilities and their possibilities for qualitative different, yet fully worthy movements, implies that they do not consider the students to be empty blackboards, "tabula rasa", which the staff-members are to fill with pre-defined wisdom and competence. Rather, Sara and Oskar are acknowledged as beings already immersed in a world where subjective preferences and dislikes are experienced and expressed by lived bodies. By recognizing their students' possibilities to choose and to act upon things brought to them, the staff contribute in challenging disability as a binary state of being.

More specifically, Hilde and Maria seek confirmation in their pedagogical decision-making by relating to what the students express rather in what is communicated in the prevailing medical perspective to disability. The golden paper, the chain and the bag are things that allow our two students to experience ability in a world where severe and multiple disabilities are dominated by things present with medical purposes. These things constrain embodied freedom and are used with therapeutic ambitions directed towards future participation and active contribution in education. The active subjects Sara and Oskar appear even clearer when we let their way of using the paper, chain and bag form the foreground, where the medical approach to disability is understood as a contrasting background. This means that things that have lost their place and arrived in other places than where they were originally expected or intended to be are in the right place after all when they correspond to those making use of them.

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# PAPER 3





**Paper three: 'He is not crying for real'. Severe, multiple disabilities and embodied constraint in two special needs education units**

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**Abstract**

Students with severe and multiple disabilities are according to official Norwegian policies to be included into ordinary school settings. Yet usually their schooldays are organized differently from those of their non-disabled peers. In this paper we aim to 1) identify how embodied meaning unfolds when students with severe and multiple disabilities are fastened in assistive technical devices and 2) to identify how staff respond when students make gestures. Applying the phenomenological philosophy of Merleau-Ponty (2010; 2014) and the phenomenological methodology of van Manen (2012; 2014) we acknowledge movement as fundamental for the students' possibilities to express their perspective. Our empirical material describes how possibilities for making gestures are severely limited when students are fastened in devices. To shed light on the staff's recognition and response as fundamental for interactions when students are under embodied constraint, we have applied Goffman's interactionism (1981; 1991; 2008).

**Keywords**

Assistive technical devices, constraint, embodied meaning, interactions, severe and multiple disabilities

**Introduction**

The aim of this paper is to identify how embodied meaning unfolds when students with severe and multiple disabilities (SMD) are fastened in assistive technical devices and to identify how staff recognize and respond to students' gestures. Gesturing is understood as subjective movements and embodied expressions such as breathing, blushing or sweating, that is, visible expressions of human intentions (Ahmed, 2006; Merleau-Ponty, 2014). Following how Merleau-Ponty described gestures as direct carriers of meaning as "I do not perceive the anger or the threat as a psychological fact hidden behind the gesture, I read the anger in the gesture. The gesture does not *make me think* of anger, it is the anger itself "(Merleau-Ponty, 2014, p.

190. Italics in original), we consider gestures of students with SMD as direct, non-manipulative embodied expressions. Awareness towards subjective movements is important in face-to-face encounters between individuals because both awareness and lack of awareness causes social consequences for those involved. This paper pays special attention to embodied encounters in educational settings where one party is a student with SMD.

The Salamanca Statement and Framework for Action on Special Needs Education (UNESCO, 1994) emphasized "recognizing the necessity and urgency of providing education for children, youth and adults with special educational needs within the regular education system". Yet in Norway 75 % of children with severe disabilities still attend to education in segregated classes or schools (Wendelborg and Tøssebro, 2011). Tendencies identified by Ytterhus and Tøssebro (2005) illustrate that the amount is even greater in the capital area of Oslo and surroundings. There also seem to be huge shifts of increasing numbers from kindergarten to primary school and from primary school to secondary school (Wendelborg and Tøssebro, 2011). Because of this educational organization and our ambition of studying children with SMD, this study is carried out in segregated settings.

### **Existing research**

The predominant approach in existing research regarding SMD has viewed disability as an abnormality of the individual child, and thereby focused on the treatment and remediation of individuals' deviations and problems (Mulholland and McNeill, 1989; Sigafos, Elkins, Couzens, Gunn, Roberts and Kerr, 1993; Lancioni, Singh, O'Reilly, Oliva, Scalini, Vigo and Groeneweg, 2004). A typical example is a case study by Lancioni, Bellini, Oliva, Singh, O'Reilly and Sigafos (2010). They investigated how camera-based optic sensors could detect the closing of eyelids or the opening of the mouth without providing participants with devices such as spectacles. The researchers placed green marks on the eyelids and mouth of two participants, where camera-based optic sensors measured eyelid closure and mouth- and eyelid opening. If responses were comprehensive enough, students received their favored stimuli. Researchers have also approached the education of students with SMD through a literature review followed by an experimental stimulus-response approach (Logan, Jacobs, Gast, Smith, Daniel and Rawls, 2001).

Measurable responses to stimuli are part of important medical and psychological research describing how students with SMD can respond. Yet there is a challenge involved in understanding persons predominantly through medical and behavioristic discourses. Here, researchers run the risk of describing participants as objective representors of diagnoses

where actions are seen to relate to impairments or to stimulus-response. Thus the subjectivity of the participants as actors with personal experiences, preferences and interests in a social context may become invisible and the medical perspective continues to be undebated.

There are increasing numbers of social scientific studies where attention is directed towards assistive technical devices in classrooms. Through qualitative interviews, Söderström and Ytterhus (2010) investigated how students with visual impairments/blindness experienced assistive technical devices as representing competence, belonging and independence as well as restriction, difference and dependency. Söderström (2016) undertook an observational study including conversational interviews. She found that socio-material practices presented double-edged swords, where students moved between social participation and social isolation. Östlund (2015) collected empirical material through observations and video recordings, researching interactional patterns between 20 students with SMD and pedagogical staff. Through conversational analyses, he found students to be attentive, responsive, engaged, autonomous, exploring and playful, suggesting future approaches to emphasize these characteristics to create inclusive environments.

Barron (2015) challenged the medical approach to disability in education by describing experiences of persons recalling how emphasis on training and rehabilitation denied them social inclusion in school. Barron's research is in line with other contemporary childhood disability researchers' urgings that future researchers should direct attention to subjective experiences (Egilson, Ytterhus, Traustadóttir, Berg, 2015). Traustadóttir, Ytterhus, Egilson and Berg (2015) and Tøssebro and Wendelborg (2015) propose that future disability research should pay attention to subjects with severe disabilities enrolled in an educational context that is ideologically inclusive.

As an important critique of the medical and social approach to disabilities, both Shakespeare (2006) and Moser (2006) question dichotomies embedded in these approaches. Shakespeare (2006) sheds light on how disability is an intrinsic factor in impairments and an extrinsic factor in environment, support systems etc., and that equalizing will never happen merely by adjusting the extrinsic factors. Existential aspects, as for example related to pain, cannot be removed by structural reorganization alone. Thus, Shakespeare (2006) promotes a relational understanding in favor of a social or medical model of disabilities. Moser (2006) draws attention to how technologies empower or undermine the differences they intend to diminish, and thus reproduce disability as binary, placing disability either within the individual or within the socio-material environment. When used for compensation purposes,

technologies aim to replace what is lost in undebated standards of compulsory normality. Technology, Moser (2006) claims, continues to reproduce disability as binary to normality.

In line with Shakespeare's and Moser's ambitions to exceed research on disability as binary, we apply phenomenology and ask '*What are the embodied meanings unfolding when students with severe, multiple disabilities are fastened in assistive technical devices?*' and '*How are students' gestures recognized and included in interactions by staff-members?*'

### **Severe and multiple disabilities, interactions and assistive technical devices**

In a medical perspective, SMD are described as complex conditions where cognitive, motoric, somatic and health-related difficulties co-appear with loss of sensory functions, resulting in conditions where one difficulty enforces the other. In a social-relational perspective, however, disability in general is understood as a mismatch between person and environment, in different situations and contexts, shaped by how cut-off points related to impairments are seen as definitional (Traustadóttir, Ytterhus, Egilson and Berg, 2015). In this phenomenological paper, we understand disability as lived experiences where the active body is enveloped in space, time, with things and in relation to others. Phenomenology keeps close to the subject's lived experiences (Merleau-Ponty, 2014), but to only a limited extent reflects the social consequences. To be aware of these social consequences we rely on sociologist Erving Goffman's interactionism and his conceptual framework, including gestures, mimicry and movements as interactional expressions (1981; 1991; 2008).

Assistive devices are understood as adaptations supplementary to those securing general accessibility in society through universal design. Where universal design involves students' physical accessibility as well as accessibility to curriculums, information, teaching approaches and assessments, assistive devices are individualized items, equipment or products applied to support students' possibilities to participate and learn in school (Söderström, 2016). In this paper, we turn to a machine<sup>9</sup> that leads the bodies of persons who are not able to walk independently into a walking pattern. Due to the severity of students' disability, comprehensive constraints are performed by use of bows and Velcros. Constraint ensures safety and leads bodies through technically standardized movements. However, it limits users' possibilities to make gestures.

The perspectives of our two participants are expressed through smaller and more distinct

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<sup>9</sup> <http://madeformovement.com/products/innowalk/>

embodied expressions in situations where their possibilities of making gestures are challenged due to the constraint performed. It is important to note that constraining the students is undertaken with therapeutic ambitions, and that the assistive device described is part of everyday life in school for our two participating students.

### **Merleau-Ponty meets Goffman**

Our study addresses embodiment and disability by attending to perception as the hub in human existence as described by Merleau-Ponty (2010; 2014). Merleau-Ponty held a position as chair of psychology and pedagogy at the Sorbonne from 1949-1952. He is critical towards adults who approach children as if they are obliged to develop in a causal, straightforward manner, where causes and effects are determinate, undebated and natural. He also criticizes rules of pedagogical actions when these are asymmetrical, communicated *from* the adult *to* the child in order to lead the learning child towards an unavoidable state of adulthood (Merleau-Ponty, 2010).

In asymmetrical relations, Merleau-Ponty addresses how "the triumph of reason" (Merleau-Ponty, 2010, p.83) emerges from a tension between authority and reasoning. Thus, Merleau-Ponty claims that encroaching on the freedom of the child is unavoidable. Yet, he sees it as an adult duty to limit the encroachment to what is strictly necessary in order to keep the child safe in the world. The adult who turns to the child's present situation has to accept that total adult control over the child is possible only if the child is treated as an object. Objectification through total control will establish an inhuman gaze, where the actions of the other are not taken up and understood (Merleau-Ponty, 2010).

Despite different scientific positions within phenomenology and interactionism, Merleau-Ponty and Goffman acknowledge the scope for movement as fundamental for expressions to exist in a world where their expressive value is accredited or overlooked. Merleau-Ponty (2014) explains how being close to another human body, experiencing what it in sameness and difference expresses when reaching out in shared corporeal space, leaves no-one untouched by the other. Goffman (2008) underlines that every person involved in face-to-face encounters has to define what is going on in the situation through behavior that finds place, and by doing so evaluates and validates both her/his own self and the self of the other. To be exact, we claim that while Merleau-Ponty describes bodily agency from inside into a shared world, Goffman describes individuals' behavior and expressions through interpretation and meaning construction.

In *Phenomenology of perception*, Merleau-Ponty (2014) considers subjective

movements as matter for potential rather than limitation when humans make gestures. He challenges deviation as a category of able-unable as well as a viewpoint of objective truth directly linked to embodied stimulus-response in everyday life. He points to impairments, disabilities and illnesses as total, full worthy, yet qualitative different ways of being in the world, a world in which all humans experience well-being and pain in degrees of ability and dis-ability. Merleau-Ponty (2014) describes deviations as continuums rather than as binary states of impairment situated in the individual body or as handicap situated in the surrounding world. Still, emphasizing difference as qualitative variation rather than inferiority in human diversities, he acknowledges that some bodies are more entitled to reach out into the world than others, as "we literally are what others think of us, and we are our world" (Merleau-Ponty, 2014, p. 109). What others think of as hallmarks of sex, gender, race, sexual orientation, class or disability is formative for how bodies take shape in the world and how they shape the world in which they reach out.

Goffman often studied people in socially marginalized positions in segregated units, for example patients in mental hospitals. Turning to constraint within these arrangements, Goffman states:

In any case, a completely flustered individual is one who cannot for the time being mobilize his muscular and intellectual resources for the task at hand, although he would like to; he cannot volunteer a response to those around him that will allow them to sustain the conversation smoothly (Goffman, 2008, p. 100).

If possibilities of gesturing through movement or symbolical acts are constrained, humans turn to primary adaptations by acting in embodied, verbal or non-verbal ways expected by the social group (Goffman, 2008). If primary adaptations are unrecognized or ignored, the person will turn to secondary adaptations. Secondary adaptations create possibilities for reaching self-defined goals by applying self-defined means like swearing or playing truant, dissociative acts serving the purpose of keeping the person self-determined.

Turning to institutionalized contexts, Goffman (1981) describes the danger for staff members becoming the tools of the establishments. He introduces a triad of institutional actors: animator, author and principal. The animator is the one that follows a given agenda (here: pedagogical assistants, teachers or special needs educators). The agenda is created by the author (here: special needs educators working out students' individual educational plans or physiotherapists working out individualized training-programs). The principal positions

values and believes, statements, plans and scripts in which animator and author seek confirmation (here: the prevailing perspective as performed by politics or economy). All actors assume their specific positioning as correct. With reference to their authority at different levels, they further attempt to include their partner into interaction, expecting that the other will take the position they describe.

### **Research methods**

Merleau-Ponty (2014) lays the foundation for a reform of methodology to present disability in another perspective than mechanical physiology or classical psychology. To realize phenomenology in this pedagogical field where expressions are immediate, pre-symbolic and honest, we have applied the phenomenology of practice (van Manen, 2012, 2014) as meaning-giving method to approach lived experiences in lifeworlds where communication is essentially embodied and pre-symbolic.

### **Recruitment, context and participants**

In May 2014 an enquiry was e-mailed to principals in eight public schools that on their web pages stated that they had students with severe and multiple disabilities attending to special needs education units. Three schools responded positively, and contact was established between the first author and the pedagogical staff. All staff members who were asked gave their written consent to participate. The teachers conveyed written information about the study to the students' guardians. All guardians who were asked approved their child's participation.

The eight students participating in the overall study are between eight and fifteen years old, attending to second to tenth grades in segregated units in Norwegian public schools. Nine staff-members participated in interviews. In the interactions described in this paper's anecdotes, two students are chosen to explore how constraint added by the use of an assistive technical device illuminates the ways and degree to which gestures are included in interactions.

The students, ten-year-old fourth grade Oskar and twelve-year-old sixth grade Jakob, attend different special needs education units. *Oskar* sits with some support. On good days, he moves around independently, supported by an assistive device that gives some weight bearing, or with help of a teacher that holds, supports and easily leads his body in a walking pattern. He communicates by nodding and shaking his head, as well as through embodied signals like blushing, sweating or smiling, signals taken up and included in interaction by the



pedagogical staff. In Oskar's unit, one staff-member follows the same student throughout the whole school day.

*Jakob* can sit only with extensive support. If subject to a distinct sound nearby, he can slowly turn his head towards its origin. His joints are stiffly bent due to spasticity. When given extensive time, *Jakob* returns an 'ehhhh' when asked if he would like an activity to continue. In *Jakob's* unit, staff alternate at 30 to 60 minutes intervals, usually following one student at the time.

Staff-members *Elizabeth*, *Karen* and *Maria* possess different professional qualifications from special needs educators to teaching assistant.

### **Ethics**

Including students with SMD into research demands specific ethical considerations. Because they are children and because of their complex disabilities, they have reduced possibilities to give informed consent (NESH, 2014). Thus, when staff members and guardians received information about the study, the first author emphasized that if a student expressed discomfort with her presence her observations would cease. In this relation, including the knowledge of staff members was crucial in order to sort out whether gestures of discomfort related to the first authors presence or whether they related to other aspects of educational everyday life. An example can be how assistant *Eva*, when providing *Jakob* with new diapers told the first author to "go to the kitchen and make yourself a nice cup of coffee". This can be accredited as a pro-active decision protecting *Jakob's* integrity even if he did not show signs expressing that he experienced the presence of the first author as uncomfortable.

Severe and multiple disabilities imply complexity. As diagnostic hallmarks do not concur, each student's appearance is unique and the students are easily recognizable at individual level. Diagnostic hallmarks are, when considered as necessary to include in the written material, described in general terms like epilepsy or spasms. Students and staff members are called by pseudonyms. Geographical localization is never stated. These precautions and our dialogue with the staff members and the students' guardians made our study in line with the national ethical guidelines (NESH, 2014) and approved by the Norwegian Center of Research Data (NSD) April 7<sup>th</sup>, 2014.

### **Data and analyses**

During autumn 2014, the first author entered everyday life in three special needs education units in Norwegian public schools, staying for two weeks in each unit. She established

relationships with eight students and their pedagogical staff and conducted close observations in practical pedagogical everyday life. Close observations are recommended when researchers want to generate experiential material from "young children or very ill people, [because] it is often very difficult to generate written descriptions or to engage in conversational interviewing" (van Manen, 2014, p. 318). While taking part in practical-pedagogical tasks, the first author observed embodied relations and wordless dialogues between students and between students and teachers. She also experienced close embodied contact with the students when giving them their meals through a gastric peg, when washing hands in lukewarm water together, and singing, lifting, or dressing. These involvements made students and first author reciprocally accessible, offering engagement and possibilities to establish embodied dialogues. As well, the first author's direct experiences of the force of spasticity and the joy in mutual eye-contact and a reciprocal smile created resonance when observing student-teacher interactions.

In addition to the students' expressed embodiment, phenomenological interviews of staff members are included, as they provide important interpretations of the students' gestures. After each period of close observations, the first author developed an interview guide directed towards the staff. Questions related to what was observed, and in line with van Manen's (2014) guidelines they were based on when, why, how, what and whatever. The first author carried out and transcribed the interviews.

Following van Manen's guidelines, all three authors analyzed observation notes and interview transcriptions through holistic reading, selective reading and detailed reading in order to explore themes and insights. Through meaning condensation and discussions, the main themes relationality, spatiality and materiality were identified.

Phenomenological anecdotes are central in analyses and presentations of results when applying phenomenology of practice. Anecdotes are methodological arrangements used to describe what commonly slips minds and words (van Manen, 2012, 2014). They are short, simple stories, describing single incidents, beginning close to moments of experience, including important details, containing quotes, ending rapidly when incidents have passed, bringing the story to a closure with a *punctum* intended to nurture the reader's sense of wonder (van Manen, 2014). We wrote and re-wrote field notes describing situations where students' bodies were constrained in one specific device. By honing texts, sorting out what was not connected to constraint, we aimed to keep as close to students' perspective as possible.

Through all steps of the research process, we paid attention to how pre-understanding

as result of our vocational backgrounds within rehabilitation, nursing, sociology and pedagogy could influence interpretation. All authors have worked directly with children with extensive needs of assistance in institutions where various approaches to disability have been prevailing. This has been discussed and addressed throughout the writing process.

### **Findings**

The students' lived experiences described in this paper are introduced by two situations. These situations represent the extremities of our data, and most situations identified are somewhere in between. We have made a Goffman (2008) turn and unveil the examples where the interaction totally breaks down or flows smoothly to be able to understand the ordinary interaction and interaction rules here based on bodily expressions. This is also in line with Adams (2008) and the addressed interpretation of expressions as dependent on a contrasting background of expectations.

To legitimate our interpretations of the students' gestures, we follow Grue (2016) and Garland-Thomson (2009), and their claim that experiences of ability and disability are contextually dependent and defined by the majority. Thus, interpretations will always be manifested in cultural contexts. Our claim finds support in Merleau-Ponty and his statement saying that gestures are not signs of experiences, they are experiences in their very being. Thus, we interpret gestures as embodied signs of subjective experiences enveloped by a cultural context.

The findings will be introduced with Oskar's and Jakob's everyday life in school and the assistive devices they use to attend to physical needs. Oskar's and Jakob's experiences are extreme points. Thus, we touch upon the thin line between education that includes the students' movements as expressive gestures and practices where fastening students in assistive technical devices challenges expressiveness and self-determination severely. Yet we would like to point out that our phenomenological approach implies that the experiences described in this paper frame a continuum of possible experiences when the walking device is used.

### **Being exercised! Fastened, gesturing and interacting**

Investigating how small gestures can be included in future interactions, we turn to Oskar and special needs educator Maria in this phenomenological anecdote.

*Oskar lies on a mattress on the floor; he has been horseback riding, and is in need of a rest.*

*'Do you want to exercise, Oskar?' Maria, who took him riding this morning, looks at Oskar, who nods slowly. She lifts him up and places him on the seat of the walking device. His feet are placed on platforms and fastened by Velcros; his legs are fastened with padded bows just below his knees, padded bows and a broad Velcro stretch over his chest. Maria raises the device by pushing a wired remote button, and when Oskar is upright, she fastens another broad Velcro between the padded bows and over his hips. She fastens a transparent table covered with a blue, sticky rubber sheet in front of him. The device stands on an even larger sheet of sticky rubber in order to avoid it from moving too much.*

*'I will start the machine at three. One. Two. Three.'* Maria shows Oskar that she is counting by rising three fingers one by one, then pushing the start-button. Directed towards a mirror on the wall, Oskar sees his whole body. He rocks steadily back and forth, and even if his body is under constraint, he rocks with a force that that would bring the device out of position if it was not placed on the sticky rubber sheet. Pop-music plays from his CD-player, and the device moves his legs in a walking-like pattern. Oskar lifts his head, looks at himself in the mirror and smiles and laughs occasionally.

*Ten minutes of being walked has passed as Maria tells Oskar that she will stop the device at three, once again visualizing the counting with her fingers. When the device has stopped, she asks him if he is finished walking. Pop-music still fills the room, yet Oskar switches from rocking back and forth to rocking from side to side. Maria counts once more; 'one, two, three', and puts the device into walking mode. Oskar is walked for five more minutes when Maria stops the device at the count of three. She releases the Velcro over his chest, the bows over his legs and the transparent table before she lowers the device.*

*Suddenly, Oskar's breathing changes. He moans weakly. Maria puts her hand on his forehead; he breathes audibly faster than before. She looks at him and discovers that the hip-Velcro is unfastened, pressing against the lower part of his stomach and his abdomen. Swiftly, she tries to raise the device, but nothing happens. She fumbles with the Velcro, succeeds and releases Oskar.*

*Carefully, Maria lifts Oskar out of the device and lays him on his back on the mattress on the floor. He ceases the quick breathing, and seconds after the moment when Maria lifts him onto the mattress he breaths calm and quiet. Maria removes his shoes, ankle cuisses and cuisses socks, and discovers a small red mark on the inside of his left ankle. She brushes her hand carefully over this. Oskar winces once, a short movement of his entire body that disappears almost in the moment that it occurs.*

When severe disabilities limit what bodies can do, comprehensive external constraints are performed in order to ensure safety and lead bodies through technically standardized movements. The walking device creates physical distance between bodies, obstructing embodied closeness. This entails that small, yet decisive embodied expressions can be concealed. The smaller the gesture due to internal constraint like spasticity or apraxia, the more wholly it is hidden due to the external constraint of the device.

When staff members pay attention to students' bodies, presence or absence of embodied signals are included in their relation. Maria acts upon Oskar's nodding, head shaking and his change of breath and includes his expressions into reciprocal interaction. In these crucial moments, where Maria gives up the possibility of a total control she seeks and finds a deference that includes them both. Maria tells about this in an interview:

*To do justice, to make that assessment, it is demanded that we know that student that well, and that you are observing pretty much in advance and by the way, that you know which signs you should look for.*

*The signs can be many. His pupils, how you feel Oskar's body; is it tight and tensed or relaxed, shades of color, are his cheeks red or not. Pretty small signs. So, we talk a lot about those little signs, those very small signs, signs that are decisive, telling us what we should do and what we should look for.*

When being bodily close to another human, experiencing what this other expresses of sameness and difference, being left untouched is impossible. Relating to another body as qualitative different, yet of equal value as emphasized by Merleau-Ponty (2010; 2014) opens up for recognizing this other as a full worthy contributor in interactions, even when arrangements are asymmetrical. When turning to Oskar rather than upwards in the animator-

author-principal hierarchy as described by Goffman (1981), Maria's approach, when seen in the light of interactionism and phenomenology, secures mutual deference and continuous interaction. Yet, recognition and physical closeness do not secure every interaction to be harmonious and straightforward. Maria continues:

*Oskar, he can indeed get frustrated, but he does not show it explicitly to his surroundings. Therefore, knowing how he relates to what is happening is difficult, as he puts on a mask that turns him inexpressive if there is something he does not like.*

*Sometimes, we make mistakes. That is unavoidable. That is a part of our learning, to try, to fail and then to do one's best the next time. So, I follow my gut feeling, and the better I know my students, the easier it is for me to trust my gut feeling.*

In the anecdote and the quotes, we see that interacting with Oskar by relating to his expressions is by no means linear and determinant like tossing a ball back and forth. Interactions depend on relations close enough to experience and acknowledge communicative absence of expressions as well as expressive signs like nodding or more laborious breathing.

### **Being exercised! Exercised body and obliterated self**

To move towards boundaries of freedom of expression when being fastened in assistive technical devices, we turn to Jakob and assistant Karen in this phenomenological anecdote.

*Jakob has really grown lately. He looks short and thin for a twelve-year-old, but has stretched a lot, the staff says. Because of his growth, he has not used his assistive walking device for quite a while. Recently it was refitted, and Karen received instructions on how the device should be used.*

*Monday morning, Jakob has an epileptic seizure when students and staff are together for their daily morning greetings. Jakob sits in his wheelchair, comprehensively fastened, and trembles under internal forces. The seizure passes, and Jakob blushes, his face is inflamed and swollen.*

*An hour later, Karen lifts Jakob from the wheelchair and into the walking device. She fastens his sandal-covered, slender, pointed feet to platforms with thin Velcros. She*

*places padded metallic bows under his knees, padded bows and a broad Velcro covers his chest. Two Velcros straighten his shoulders backwards, and attached to his forehead, keeping his head upright, are two padded bows. Karen fastens a transparent table supposed to give support to Jakob's arms in front of him, but as he holds his arms stiffly with closed fists across his chest most of the time, they seldom reach the table anyway.*

*Karen takes hold of a wired panel and pushes a button that makes the device elevate Jakob from sitting to standing. She fastens another broad Velcro over his hips. Then, she pushes the button that is supposed to put the device into walking mode.*

*Nothing happens. Karen unfastens the hip-Velcro and lowers the device, placing Jakob into sitting position once again. Then, she pushes the button that should make the device elevate. The device rises, but only half way up. Then it abruptly stops, and Jakob finds himself in neither a sitting nor a standing posture. Jakob whimpers and makes small, rhythmical whines. His upper lip pouts out.*

*'He is not crying for real. Let's continue. Jakob gets stronger and more flexible when being walked' Karen says. She lowers the device once more, and all of a sudden, the movement of walking starts while Jakob sits. She stops the walk and raises Jakob in the device into a standing position, fastening the hip-Velcro once more.*

*Jakob is now crying audibly, tears run down his cheeks. Karen releases the hip-Velcro, lowers the device and unfastens bows and the other Velcros. She lifts Jakob and places him on his back on a physiotherapy-mat on the floor nearby. His knees point towards the roof, his legs bend in 90 degrees angles, and his thin, thin leg-bones and pointed knees tremble intensely.*

When embodied primary adaptations express self-determination and sensitive animators include these adaptations in relations, mutual interaction continues. Jakob's expressions of self-determination, his rhythmic whimpering and pouting lip, are subjective expressions of how he experiences the situation. Yet, overlooking his whimper and pouting lip is justified when references to medical benefits are rated as more important than Jakob's gestures and thus, his deference is threatened. In Goffman's (2008) terminology, primary or secondary adaptations are

out of his reach, and thus, he is left out of play. When Jakob is left out of play, consequences affect both parts in the asymmetrical interaction. Mutual embarrassment is the result, as neither Jakob nor Karen finds deference in the other.

A lack of temporal continuity seems to affect Jakob's and Karen's opportunities to experience continuous, reciprocal interaction. The first day of the week, Karen accomplishes one of her work tasks, a task with therapeutic intentions, when she makes sure that Jakob gets to use the assistive device. The use of the walking device takes place an hour after Jakob's epileptic seizure. Jakob has not used the assistive device for a long time, and in a temporal sense it is new to him. As the staff in the unit changes every 30 minutes to an hour, lack of continuity influences staff members' possibilities to detect and act upon the students' continuous or changing expressions.

When Karen raises Jakob in the device in order to attend to medical aspects of his SMD, the technology goes awry. Karen directs attention towards the device that covers Jakob's body, still, his mimicry and sounds are accessible to her. Yet, his expressive pouting lip and his whimper are gestures not taken into consideration. Karen's approach towards the device as a means directed towards Jakob's future possibilities rather than towards his expressions in the present moment creates physical as well as relational distance.

As secondary adaptations such as swearing or playing truant are out of Jakob's reach, his self is at risk of obliteration due to lack of deference. Karen, the person granted intellectual authority in the institution, can attend to her need for deference, either by including Jakob's expressions, or by turning to values communicated in his individual educational plan and in directions prepared by physiotherapists. In an interview, a discrepancy between acknowledging students' body language meanwhile seeking deference elsewhere creates dissonance between what is said and what is done. Karen says:

*These children, none of them have a language. So, in a way it is body language where each have their special thing. So in a way it's like 'okay, it's like that, yeah'. You learn to read them in a way that I actually did not know was possible. It is hard to explain....*

*So, what is really fun is that I have been working lots and lots with William (one of the other students in the unit), being supervised by a physiotherapist. So, like William has become very, very much, stronger, in..., in..., in his legs, and in a way, he has managed to stand a couple of seconds all by himself. Because we have been training a*



*lot. The physiotherapist gave me very good feedback, like this was something that was good for William, and that he really benefited from what I did, so that was really fun.*

Karen acknowledges body language as the language the students have at hand. Yet, as the anecdote shows, acknowledgment does not mean inclusion. Representing the animator in the triad (Goffman, 1981), Karen seeks deference in a medical approach to disability by referring to the physiotherapist. She omits a critical perspective which could have provided possibilities for discussing how the device could have been used in ways where Jakob's expressions were not overlooked.

In the following quote, special needs educator Elizabeth explains how the assistive device has medical advantages that also include pedagogical aspects. Elizabeth points to the device as means to increase Jakob's possibilities for future achievements:

*The walking device has opened up for Jakob being strong enough in his neck to use a head-switch. So it has been of great importance to Jakob. In his life, actually. To his possibilities to affect his environment. Many times, physical things, physical training, can be so important to create physical development that further opens up for new possibilities.*

*He likes the walking device. And it provides him wonderful exercise. He receives very good training when he walks in it; he gets his body straightened up, and he gets to use muscles that he usually does not get to use. To Jakob, all this has provided very positive side effects. For instance, he can control his head now, and he has been able to control it for many years. But that did not occur until he started to use the walking device; he was walking in it for about a year, and then all of a sudden, he could control his head pretty well.*

Elizabeth claims that Jakob likes the walking device. She emphasizes medical effects like claimed ability of head-control as means that points towards possibilities in Jakob's future. Still, Jakob's possibilities to make gestures in the present moment are challenged by overall constraint and a lack of acknowledgement. As his pouting lip and his whimper are seen but not acknowledged, Karen's reflections in the concrete situation and Elizabeth's overriding comments about the effect of the walking device confirm that the medical perspective is given superiority in Jakob's unit. In the segregated institution, animator, author and principal assume

that their position is the right one. Without receiving confirmation from Jakob, a possible questioning whether the device is used as intended is unaddressed.

### **Discussion**

Most of the existing research about children with disabilities and use of assistive equipment is embedded in a dichotomy of disabled – not disabled and an individual deviation approach (Mulholland and McNeill, 1989; Lancioni et al 2004; Logan et al, 2001). Findings in disability studies based on social and relational models of disability, technology or education (Söderström and Ytterhus, 2010; Söderström, 2016; Östlund, 2015) identify students using assistive technical devices as competent, attentive and responsive, and are thus partly in line with our study. However, these studies do not include students with severe disabilities and do not give special attention to bodily expressions and existential dimensions to the same extent that we do and Moser (2006) and Shakespeare (2006) recommend.

Our attempt to apply phenomenology by giving attention to gestures and embodiment has revealed a way of moving disability towards a continuum. Such an understanding depends on students' embodied expressions and gestures being recognized as fully worthy in face-to-face-encounters. To shed light on this, we have presented one specific external force applied by the use of an assistive technical device.

Maria seeks confirmation by turning to Oskar as an expressive and competent subject in a vulnerable social position. Turning to Jakob's experience, it seems to be affected by the way Karen sees, yet overlooks his expressions as she seeks confirmation upwards in the hierarchic triad. In this case, Jakob is attended to as a medical deviation that should be led towards a considered norm of able bodiness, and his expressions are overruled.

Maria turns to Oskar and acknowledges his changing breath. Thus, he is a recognized group-member allowed to be no more or less than what he was prepared to. As school days in Oskar's unit are recognized by continuity, detecting changes in embodied expressions is possible. Continuity and acknowledgement of subjective gestures create promising educational spheres that touch upon Merleau-Ponty's understanding of movements when living with disabilities is seen as qualitatively different, yet not inferior.

Karen turns towards Jakob and claims that "he is not crying for real", before she turns away from his pouting lip and his whimper, leaving his tearful cry to be his next possible expression. According to Goffman (2008), a person like Jakob, constricted and deprived of possibilities to show subjective bodily and intellectual resources, causes embarrassment to himself and to his interactional partner. To attain deference on her own part when recognizing

that Jakob is uncomfortable, Karen acts on the embarrassment by continuously directing Jakob towards the appearance of a standing and walking 12-year old. She seeks confirmation for her actions from author and principal instead of turning towards Jakob himself.

Representing different paradigms, Merleau-Ponty and Goffman dovetail in how they acknowledge the body as a source of experience, expression and interaction if movements and gestures are regarded as resources, not inferior deviations. In the light of Merleau-Ponty (2010), we acknowledge that encroaching on the freedom of a child is unavoidable, but that it is an adult duty to limit the encroachment to what is strictly necessary to ensure safety. Adults who pay attention to the lived experiences of the child as these are expressed in the present situation attend to this duty.

With support in Goffman's (1981) elaboration of the triad animator-author-principal, as well as in the way Merleau-Ponty addresses "the triumph of reason" (Merleau-Ponty, 2010, p.83), we find that staff members have opportunities to include medical considerations into ethically sound practice when students are under constraint. Yet this presupposes that a binary understanding of disability as well as the apparent superiority of a medical understanding is questioned in a special needs education that accredits the individuality of the child as well.

## **Conclusion**

We have considered the research questions "*What are the embodied meanings unfolding when students with severe, multiple disabilities are fastened in assistive technical devices?*" and "*How are students' gestures recognized and included into interactions by staff-members?*" We describe how interactions are challenged when students are subject to physical separation due to constraint. We stress the importance of sensitive staff-members turning to expressive subjects rather than predominantly to the assistive device and its medical advantages.

Goffman (1991; 2008) accredits how detection and acknowledgement of embodied gestures are acts that have wide-reaching consequences. Detection and acknowledgement of gestures cause immediate practical consequences when interactions persist, and even more important, they avoid obliterations of the selves of those interacting with each other. We have found that such detections and acknowledgements depend on temporal continuity, as a gesture always has to be seen in relation to the presence or absence of other gestures to carry meaning. This has important implications for practical-pedagogical arrangements in the everyday educational life of students with SMD.

We have not paid attention to what could have happened in inclusive educational

contexts, and we do not know if our findings would have been different where everyday life is due to be observed by others than those already belonging to the segregated institution. However, since most students with SMD attend to education in segregated organizations, the wide span of experiences presented in our findings belongs to the dominant educational organization.

Conducting phenomenological research, our aim is not to create comparable, reproducible projects. Yet the fact that we present one assistive technical device used by two different students may mislead readers to think that the anecdotes are comparable. Due to the complexity of SMD, Oskar and Jakob experience different degrees of constraint when fastened in the device. Their opportunities for gesture are shaped by this, and so are the results. Yet, the phenomenon of constraint is general in human experience.

Approaching Oskar's and Jakob's lifeworlds through phenomenology and interactionism provide possibilities to re-learn and extend knowledge about a segregated life-world usually understood in terms of medicine. We have found students expressive and competent in affecting their situations, but also students who experience their embodied expressions as neglected. Challenging understandings of SMD as situated in a compulsory, undebated striving for able-bodiedness, we contribute to a research-based critical discussion. We leave the ontological idea of disability as what-ness of certain identities to reach towards continuums where how-ness of subjects shape experiences.

Our findings underscore the importance of the staffs' relational competence and capability in attending to a child-centered pedagogy when acknowledging students with SMD as first and foremost children. Pedagogical tact and sensitivity towards student's initiative and communication as fully worthy embodied expressivity is fundamental in the development of institutional cultures where staff supervision is part of practical pedagogical everyday life. Acknowledging that sound ethical decisions depend on professional competence is important for future policy-making and curriculums in higher education, as these decisions affect environments surrounding students who can hardly protest on their own.

Methodologically, this paper contributes to research investigating lifeworlds where communication is wordless and pre-symbolic. Applying phenomenology and interactionism to address constraint of embodied freedom within segregated contexts provides possibilities to address embodied meaning making which is hidden to others than those already within the institution, displacing the undebated striving towards a given normality. We stress that there is a need for acknowledging the moving body to open up for new approaches in professional practices as well as in future research projects.

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# PAPER 4



**Paper four: Phenomenology of professional practices in education and health care: an empirical investigation.**

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**Abstract**

Max van Manen's conceptualization of phenomenology of practice is based on a research interest aiming for phenomenological insights into the meaning(s) of different phenomenon relevant for various professional practices. Therefore, there is also a knowledge interest in his work that seeks to understand and further a sensitive and caring professional practice. Drawing on van Manen's work, the purpose of this paper is to explore professional practices in education and health care from a phenomenological perspective. The question that has orientated our study has been *what is the meaning of interaction in encounters of education and health care?* For that purpose, we have analyzed practice experiences generated through close observations and interviews in research projects concerning special needs education, physiotherapy and consultations with a nutritionist. By drawing on the notion of pathic knowledge as well as Nancy's ideas about existence as always co-existence, we develop phenomenological insights about temporal, embodied and relational qualities of the phenomenon of interaction in professional practice. More specifically, these qualities are captured in the dimensions of pushing–being pushed, pulling-being pulled. These dimensions are constituted by two poles, but in-between these poles, we argue, lie the possibility for acting and interacting between professional and student/ patient.

**Introduction**

This study has grown out of cooperation between researchers with practical, professional backgrounds in the health sciences and education who all share an interest in phenomenology. In particular, Max van Manen's writings on phenomenology and professional practice (e.g. van Manen, 1977; 1991; 2014) has inspired us. As we see it, there is a clear and visible line throughout van Manen's work from his early conceptualization of education and phenomenological pedagogy (van Manen, 1977, 1982) via his methodological best-seller *Researching lived experience* (van Manen, 1990) to his recent book *Phenomenology of practice* (van Manen, 2014). This line is among other things made up of a *research interest*:

... that address[es] and serve[s] the practices of professional practitioners as well as the quotidian practices of everyday life. More specifically, this phenomenology of practice is meant to refer to the practice of phenomenological research and writing that reflects on and in practice, and prepares for practice (van Manen, 2014, p. 15).

As the latter part of this quote suggests, there is a strong link between this research interest and professional practice. There is thus also a *knowledge interest* in van Manen's work that seeks to understand and further a sensitive and caring professional practice that

... depends on the sense and sensuality of the body, personal presence, relational perceptiveness, tact for knowing what to say and do in contingent situations, thoughtful routines and practices, and other aspects of knowledge that are in part prereflective, pre-theoretic, pre-linguistic (van Manen, 2007, p. 20).

Research exploring the experiences of individuals attending health care or education is fairly commonplace. In the field of special needs education, Sævi (2005) investigated lived experiences of students with intellectual disability and their significant others in pedagogical encounters. Through analyses of being seen, Sævi offers telling insights for pedagogues working in this context. Goodwin (2001) has approached the perspectives of students with physical disabilities, investigating the meaning of help in elementary school physical education. By analyzing the various meanings that were assigned to being helped, Goodwin provided a nuanced picture of students' experiences. In a similar vein, Vagle (2010) has investigated teachers' perspectives in moments where they apprehend that there was something students did not understand during teaching.

In the context of health care research, the experiences of people living with different medical conditions have been researched. Examples are the experiences of living with fibromyalgia (Råheim and Håland, 2006), children with serious congenital heart disease experiences of motion in everyday life (Bjorbækmo and Engelsrud, 2008), or children's experiences of being hospitalized with a newly diagnosed chronic illness (Ekra and Gjengedal, 2012). Furthermore, Gjengedal (1994) examined the experiences of having been a critical ill respirator patient, as well as careers' experiences of taken care of them. The experiences of living with obesity (Rugseth, 2011; Rugseth and Standal, 2015) and the long-term bodily changes after weight-loss (Groven, Råheim and Engelsrud, 2015) or bariatric surgery (Groven, Galdas and Solbrække, 2015; Natvik, 2015) have also been studied.

Bjorbækmo and Engelsrud (2010) have investigated the experiences of children with physical disabilities and their parents' experiences regarding of testing within healthcare settings.

While the selected empirical research we have referred to here is situated in different professional contexts, each study is also situated to only one professional discipline, such as education, nursing or physiotherapy. Within each professional discipline, the studies have mainly been directed to clients' or students' experiences and some have focused on caregivers' and teachers' experiences. However, few studies have investigated the meaning of interaction in these professional encounters (but see Bjorbækmo and Mengshoel, 2015 and Ozolins, Dahlberg, Hörberg and Engelsrud, 2011) for exceptions.

Therefore, the purpose of this paper is to explore the meaning of interaction in education and health care encounters from a phenomenological perspective. To examine relational aspects of a phenomenon is to ask how people or things are connected (van Manen 2014, p. 303). The specific question that has orientated our study has been *what is the interaction/connection between professionals and patients/ students like in education and health care encounters?*

### **Professional Practices and Pathic Knowledge**

A phenomenology of practice “aims to open up possibilities for creating formative relations between being and acting, between who we are and how we act, between thoughtfulness and tact” (van Manen, 2007, p. 13). In his early work, van Manen developed the notion *tact*, which has three central meanings (van Manen, 1993). First, the etymology suggests that tact refers to the sense of touch or feeling. In this sense, tact is related to touching or being in touched, as in the word tactile. Second, in music tact is used to describe the orchestration of several instruments. Third, tact has connotations to an ability to deal carefully with delicate situations. In a relation to both education and health care, tact can therefore refer to a practitioner's ability to be in touch with the professional situation, to find the rhythm of the students or patients, and to co-create situations in ways that are suited to the needs of the students and patients. According to van Manen, tact is an ability to see and understand situations, understanding the meaning and significance of the situation and then to act by knowing and doing. Finally, it is incumbent on phenomenological practitioners to act ethically right (van Manen, 1993).

One aspect of practical knowledge, which is of particular relevance for our purpose, is *pathic knowledge* (van Manen, 1996; van Manen and Li, 2002). Pathic knowledge is, as the word suggests, knowledge related to sympathy and empathy, i.e. it is a form of inter-

subjective relationship. The practitioner's knowledge is pathic in the sense that it depends on "presence, relational perceptiveness, tact and other aspects of pre-reflective, pre-theoretical, pre-linguistic knowledge" (van Manen and Li, 2002, p. 217). It is this kind of knowledge that helps practitioners to become attuned to professional situations and the experiential dimensions of the persons with whom they are interacting. Pathic knowledge is, according to van Manen and Li (2002) embodied knowing, which in addition to providing a corporeal sense of ourselves, things and others, can be described in several forms:

- *Actional knowing*: knowledge expressed for instance through personal styles of teaching, habits and kinesthetic memories.
- *Temporal knowing*: humans are temporal beings in the sense that the present now is a projection of past knowledge towards the future. Temporal knowing is expressed through intentions, inclinations and orientations.
- *Corporeal knowing*: just as humans are temporal, we are also corporeal beings who come to know in and through our bodies.
- *Situational knowing*: all knowledge, including knowledge of ourselves is distributed and relational, residing to some extent in the world around us and the way we interact with it.
- *Relational knowing*: practitioners' knowledge also resides in the relationships they form with others.

Although these aspects of pathic knowledge are interwoven, we are particularly interested in the situational and relational aspects of professional practice. In this article, we are primarily interested in the shared elements of the interaction in professional practices described as inter-personal practices.

### **Method**

Van Manen outlines a methodology of researching lived experience in order to generate human science knowledge that can inform phenomenological practices, such as education and health care (van Manen, 2007; 2014). The means by which this knowledge is generated are the same as those van Manen suggests are necessary for developing pedagogical tact in teachers: using personal experiences, being sensitive to language (for instance by tracing etymology and idiomatic expressions), interviewing or closely observing others, and attending to experiential descriptions in literature. In this article, we draw on experiential anecdotes

from three different research projects. The anecdotes are developed from close observations and interviews done in education and health care settings. In line with van Manen's (2014) recommendations, our aim is to explore and understand possible human experiences.

As all authors of this article are either educators or health care professionals, our research has involved a basic challenge of digging into and confronting our own presuppositions and prejudices about the practices we have been studying. In order to see the practices afresh, we have sought to reveal our habitual ways of thinking about the practices involved in the paper, the role of the practitioners, the student, the patient and of the researcher (Finlay, 2002). The collaborative nature of this project, where we subjected each other's individual work to scrutiny, aided the process of the epoché in a manner that individual work cannot do. The epoché is a central component of phenomenological reflection and analysis, parenthesizing or bracketing various assumptions that might stand in the way of opening up and being able to see the "living meaning" of a phenomenon (van Manen, 2014).

Phenomenology is the science of examples. The "phenomenological example" is as van Manen (2017, p. 814) puts it "the example of something knowable or understandable that may not be directly sayable". The "phenomenological example" provides access to a phenomenon in its singularity and makes the "singular" knowable and understandable. Consequently, for an anecdote or example to be powerful it should bring experience vividly into presence –so that the reader can unreflectively recognize the experiential possibilities of human life (van Manen 2014, p. 241). The example should "let the singular be seen" (van Manen 2017, p. 815).

In phenomenological writing the challenge or problem is not about "how to get from text to meaning but how get from meaning to text" (van Manen 20017, p. 813). To do phenomenological research is to write. Writing and rewriting is a process of systematically exploring meaning structures of the actual phenomenon, situation or event. Additionally, it is about trying to find expressive means to grasp the pre-reflective substrata of the actual experience. In the phenomenological research process generating data, analysis and writing is intertwined. The basic and complementing moves of epoché and reduction are employed in the activity of phenomenological writing and rewriting. It involves the researchers to attend an attitude that involves a fascination with the moment, with the uniqueness of an experience or event. Reflecting on the moment, on the event that has made us wonder, has demanded our patience, our ability and willingness to see, to understand and to discover the unexpected.

Below, we present three anecdotes from three various and specific professional situations that we have researched. In developing, creating and writing the anecdotes, we have sought to



show rather than tell, the meaning of the various experiences and situations. For that purpose, we are fictionalizing or anecdoting factual empirical accounts in order to reach a more plausible description of it. Needless to say, we do not believe such editing makes an anecdote less trustworthy.

### **Findings**

In this paragraph, we present three anecdotes. They follow a similar structure in that first, the research context from which the anecdote is taken is briefly presented by the researcher (the I person). Second, the anecdote is presented (italicized text). Here we use fictive names both for the professional and for the patient or student. The intention is to evoke the particular, the singular of the events among the readers, even though we acknowledge the potential that one person's experience might be the possible experience of the other, and vice versa. Each anecdote is then followed by our reflections exploring lived experiences of interacting in educational and health professional encounters.

#### **The Nutritionist and Dora - to interact is to confront and being confronted**

The following anecdote has its origin from a larger research material about how it is experienced to be fat (author). Dora is one of 16 participants, recruited from a lifestyle treatment program that takes place at a hospital. Dora is married, has three kids and works part-time as a cook at a nursing home. I interview her about what she calls her `lifelong struggle with being fat`. The interview takes place in her living room. She serves me her favorite tea and delicious homemade scones. During the interview Dora invites me to join her the following week at one of her monthly 20-minute consultations with a nutritionist engaged in the treatment program. She is expected to send her food-diary from the week before to the nutritionist, and adds jokingly that she has to write down the homemade scones we have shared.

*Dora is in the nutritionist's office. She sits upright on the chair, her back is straight, and her face expression is like frozen. The nutritionist reads on her computer and does not pay attention to Dora. Then she looks up and greets Dora with a hasty smile. "You made pasta for dinner last Thursday", the nutritionist states. "Too many carbs could be a problem if you want to lose weight". "I know"; says Dora, "but I watch the portion size". "What about the sauce", the nutritionist continues. "Do you add a lot of cream to it"? "No, of course not", Dora answers. "I work as a cook, I know a lot about*

*how to make pasta sauce without too many calories". The nutritionist looks at Dora, pauses for a second and says: "If you knew a lot about making food without too many calories Dora, you wouldn't be here trying to lose weight, would you"?*

What is the interaction like, in this situation? What constitutes the inter-acting dimensions in the situation? How is the connection between the patient and the professional? Is there a connection, or is it a dis-connection?

From the very beginning, there is a felt tension in the room. A tension felt through the patient's bodily expression. A bodily expression of being on the alert. On the alert for something to come? The professional has initially turned all her attention towards the computer screen. Bodily approaching the computer screen, she is turned away from the patient, and the relational space between them is open – open as waiting for possible actions, connections and interactions. At the very beginning of the session the contact between them is on hold, while both seem to bodily notice each other's presence.

When the nutritionist finishes reading and looks at her patient - she confronts her with having eaten pasta last Thursday. The patient avoids responding directly to what she is confronted with; to have eaten pasta. Instead, she focuses on the size of the portion she has eaten. Does she oppose the confrontation? The professional resists in a similar way by not responding to the importance of the size of the pasta portion, and instead turning the focus towards the pasta sauce, and if there was a lot of cream in the sauce. The situation is reminiscent of a kind of battle. It is more like a battle than a jointly cooperation towards a shared goal.

The situation develops to be more and more confrontational from the nutritionists' side, and at the end the nutritionists' words take up all space, fill the room, and at that moment freeze or stops the interaction between the two. The space in-between the professional and the patient is by the nutritionists' words a demand to stop. The words being said hang like a shadow over the situation, over the relationship between the professional and her patient. To be confronted, to confront is like pushing and being pushed. And to push and being pushed when "hard enough" brings the relational situation into a stand-still, a vacuum. We are stopped by surprise, rebellion, humiliation, wonder and after some time maybe with a wondering feeling of possible reorientation. To interact in professional encounters, either within education or different health-care situations, always implies to engage in an interaction about topics of common interest. However, the common interest between professionals and patients in for instance a weight loss program, implies at least two perspectives. The one who

is to lose weight and the professional aiming to support the other to lose weight are understood to share an interest in succeeding to achieve an assumed shared pre-decided goal. To the person expected to lose weight when joining the treatment program, this becomes part of what Dora herself names her “life-long struggle of being fat”. An utterance we easily might come to understand as “a lifelong struggle to lose weight”, but are these utterance equivalent?

The inter-dependency between professional and patient in achieving the presumed shared goal of the treatment, challenge them to connect, to get in touch with one another and to cooperate. In the encounter, the professional is expected to provide proper care and service that helps the patient or student to achieve what they want, aim at and hope for. We do know that attending a treatment program or an educational setting not in itself can tell what the patient or the student want and desire to achieve, even not when someone join a treatment program for losing weight. Might the lived experience of being fat as a lifelong struggle and participation in a weight reduction program be experienced to be in conflict?

To confront someone with not having acted according to, as in the example above, professional advices (eating pasta for dinner, even though being aware of the portion size) and the lack of professional success in convincing the other to act as recommended and to follow provided professional advices creates a tense situation. A situation in which both parties becomes visible to themselves and each other as “unsuccessful”. Nevertheless, the professional has a special responsibility to establish an atmosphere and interaction in order to achieve a collaboration so that the patient succeeds and thereby she herself succeed as well.

In an interaction, both the professional and the patient become visible for one another. They become visible through gestures, bodily presence and spoken words. Becoming visible in the world, imply that the world which we become visible in, gives meaning to the things we both do and say. Behavior and utterances carry meaning into our shared situation. The meaning of a gesture (behavior as well as spoken words) is not behind it, but intermingled with the structure of the world outlined by the gesture (Merleau-Ponty 2005, p 216).

In the example, the interaction and conversation takes place within the frame of a weight-loss treatment program at a hospital, a professional context. A context that contains “ready-made-meanings” (Merleau-Ponty 2005, p. 213) about what it, for instance, takes to lose weight, how to act and what to do to lose weight. What we say and how it is said bears meaning and makes our understandings and knowledge visible. “Language bears the meaning of our thoughts as a footprint signifies the movement and effort of a body” (van Manen 2014, p. 29 - referring to Merleau-Ponty). What the professionals, students and patients say, the way

they say it in a situation reveal the thoughts and knowledge that for instance the professional base her practice on. Our knowledge does manifest itself in practical actions and it involves the tone of our voice, the way we smile or not smile and the way we look the other in the eye etc. (van Manen 2014, p. 270).

A professional perspective grounded in a medical understanding focusing on gnostic insights cannot produce pathic experiences (van Manen 2014, p. 281). And, it might neither produce a mutual interaction between professional and patient as mutual interaction and togetherness in achieving a stated goal requires both to move towards the other with a specific demand on the professional to move towards her patient, to displace herself so as to try to see the situation from the perspective of the other, not as if being the other, but as a fellow human wanting and aiming for an understanding and for caring for the other.

In the space in-between the professional and the patient their interaction and communication, in the example, show the lived experience of being confronted and of confronting. Confronted with being one who do not comply with the “rules of the game”, but instead deviates from following the professional’s advices. Confrontation, being confronted – being pulled and pushed into confronting oneself with a certain view on a “reality” - is it only based on gnostic knowledge, is it bad, cruel and untactful - or is it more to it? Is pathic practice never about to confront or being confronted? In this example, we do not get any answer of what happened after the climax when the interaction between the professional and the patient stopped and the situation came to a stand-still. The lived experience of confronting and being confronted, of pulling and being pulled to face your lack of complying to treatment or teaching as provided and expected is an open space for possible experiences as well as for possible further actions, interactions and re-orientation.

### **Sara and her Teacher – To interact is to wait for action to react**

In an ongoing project, I explore how embodied meaning unfolds in school when students have severe, multiple disabilities (author). I have created the following anecdote from close observations conducted in a special needs education unit that is part of a Norwegian primary school in a suburban area. The unit consists of less than eight students that all have severe cognitive and sensory difficulties as well as somatic and health-related difficulties.

Twelve-year-old Sara lies in a corner in the largest classroom. At this time of day, the other students are occupied in other rooms or in the other end of the classroom, and the space around Sara is calm and quiet. Sara lies in a solid wooden furniture which looks like the fusion of a baby’s bed and a playpen. Her dad has made it for her to use in school. It is

approximately 1,5 meters above the floor and 2x2 meters wide, mattress-covered, and contains blankets, soft toys, teddies, pillows and a feeding bottle.

*Sara lies on her back with her feet pulled all the way up to her belly. She makes long-lasting and deep toned, wailing sounds. Anna, Sara's teacher, climbs up in the furniture and sits down. She faces Sara, stretches her legs out, gestures that she wants Sara to sit up. Then she grasps Sara's hands and tries to drag her upper body towards her own. Sara resists - she withdraws her hands, stays down and continue wailing. After a couple of minutes, Sara stops wailing. Anna takes a firm grasp under Sara's armpits, and leads her up until she sits. Anna lies backwards, and tries to drag Sara with her so that she can lie belly down on Anna's body, stomach to stomach, chest to chest, face to face. Sara resists, turns her face away, lies down on her back again and continues to wail monotonously. The minutes pass by. Anna waits quietly. All of a sudden, Sara stops wailing and sits up in Anna's lap. Their faces are close, Sara slants her head. With low voice Anna starts slowly to sing:*

*"Row, row, row your boat,  
gently down the stream.  
Merrily, merrily, merrily, merrily,  
life is but a dream".*

*Sara sways from side to side following the rhythm of Anna's song. Anna sings the verse over and over again and then stops. Shortly after, Sara stops swaying. Sara sits still for a while. Then, she continues to sway. Immediately, Anna starts to sing.*

In this example, the student and her teacher are enveloped by an educational context where the professional is obligated to attune to her student in order to ensure a relation that is meaningful to both of them. While the teacher several times attempts to include her student into interaction, the student actively denies her invitations. The close bodily approach the teacher use trying to start an interaction with her student is not accepted by her student. The student denies to be enrolled in an interaction this way. After having tried several times the teacher accepts her student's denial and sits still, and waits. From actively trying to pull her student into a relational interaction with her, the teacher changes her approach into waiting. While sitting and waiting she is still bodily close to her student. They are still near each other.

The teachers waiting is an active waiting. Her attention is still directed towards her student. The teacher waits for her student. Waiting for someone while being physically close and quiet creates the space for the other to act. It is a push on the student to act, to respond to her teachers waiting and to their shared situation. A push to act that the student eventually accepts by getting up into her teacher's lap. From then on, their interaction takes off in another form. A form of doing together, stopping, waiting, taking the initiative to continue the activity they share.

The situation embraces different bodies that try to relate to another in sameness and in difference. Yet, the relation rests upon the teacher's approach that allows the student to accept the invitation of close embodied contact when she is ready.

The interaction between them alternates between engagement and (active) disengagement, where they both change in being in the lead of what happens. The teacher's active retention opens up for her student to tell that she wants their acting together, their interaction to continue. Her want is expressed not only in the presence of the swaying, but in the situation as a whole, where movements and absence of movements, co-created and incorporated by bodies being close to each other, creates a relation where they both are included in an embodied exchange of perspectives. There is an embodied interaction and conversation in which patient waiting or maybe it rather is an active waiting, seems to be of value in pushing and pulling the other into actively engaging in a mutual interaction and a shared activity at the moment.

### **The Physiotherapist and Tracy – to interact is to take risks**

The following anecdote is part of a research project exploring physiotherapists' experiences helping patients diagnosed as obese to change lifestyle, particularly aimed at weight loss (author). Most of the activities are group based in which patients are encouraged to participate.

In my interview with Ingvild, one of the participating physiotherapists, she recalls a situation she had experienced as challenging concerning whether her professional decision had been wrong or not when she encouraged Tracy (one of the participating patients) into joining the rest of the group on a long outdoor walk. Ingvild recalls the situation:

*Today we will go for a long walk. Tracy is eager to participate, but also concerned about the problem of having pain in her knees and feet. Tracy shares her concern with*

*me (her physiotherapist), claiming she might not make it all the way back and forth so perhaps she could rather go for a shorter walk. "The trip is not that long, and the terrain is OK", I assure her. I continue and say; "I do think you should join the rest of the group". Tracy agrees, nodding that she will have a try, and we start walking. When we are halfway and about to return, Tracy confronts me. "How could you" she says. "I cannot understand how you could recommend this trip to me. It is not ok for my legs and my feet. It is very painful and I do not understand how I will manage to walk all the way back. This is by no means a good experience for me."*

*Despite this- Tracy walks all the way back. Yet, my thoughts are like "did I assess her capacity correctly" - "I am no longer sure that my professional decision was right". One day, or maybe two days afterwards I meet Tracy again, and she tells: "I became very tired during the long walk. My legs and feet ached a lot, but the pain did not last for long, and it has not got any worse after the trip". She continues "I want to thank you for believing in me, for believing I could manage the trip".*

When a professional encourages and recommend us to do something and assures us that we will manage to do it. The experience of being trusted to be able, to be capable of, and to have the capacity to do for instance a long walk is a call to do as recommended. And, even if we doubt our own capacity, the professional's assurances and encouragement will be of great importance to our decision. A decision that might overrides our own judgments and opinions, as the feeling of being seen and considered to be able by a professional is an invitation to see ourselves capable of performing for example, the long trip and to trust the professional's judgment concerning our capability. The feeling of being trusted to have the needed capacity make us believe that we can, we can manage to walk the walk. We are pulled to believe we can, and therefore we dare to do as recommended. We take, as Tracy, the chance and put ourselves at risk.

In professional practice to support and to convince the student, to convince the patient is part of teaching, caring and of a treatment process. A paradox is that we may come to believe that to be able to do as recommended is simpler than it is. So, if and when we experience it as hard to do and complete the task we may get angry, upset and see the professional as not capable of giving the right recommendations, and by this for not seeing us as we are, not seeing our capacity as well as our concerns and problems – then the feeling of being not seen, of being misjudged come to the forefront. It might leave us with a sense of being cheated.

From encouraging her patient to go the walk, to being confronted to have made completely wrong recommendation and thereafter to be acknowledged for having trusted her patient to be able to complete the trip - the relation between the physiotherapist and Tracy moves from trust to mistrust, from stated certainty to uncertainty about own judgment skills and finally to thankfulness for being believed in and for the relief of not having made a complete wrong decision.

The interaction between a professional and a patient or student seem to be an experience of continuous negotiations. Negotiations characterized by exchange between supporting and letting oneself be supported, between to convince and to be convinced, between to confront and to be confronted, between actively acting and waiting for the other to act and likely there is several other possible characteristics too. Interaction is about the experience of a continuously back and forth, forth and back motion in the relational space in-between persons. In the inter-personal sphere of interacting the experiences of pushing, being pushed and pulling and being pulled is a more or less prominently lived experience.

To the professional recommending and encourage the patient to push her limits it's about taking "chances". Taking the chance of pulling and pushing what the individual can handle and tolerate. To the patient or student, it is also about taking chances. To take the risk to do as recommended even if you feel uncertain about whether you may manage or not, it is about trusting the professional, and to experience a felt; "I can" – and a felt confidence that make you take the chance to rely on the other, relying on the professional judgment, but also to rely on yourself.

### **Concluding comments**

The findings of our study touch on possible meaning structure of interaction in professional encounters like education and health care. Meaning structure that might be characterized as a back and forth motion orientated within the experiences of pushing and been pushed, of pulling and been pulled. Involved in the push/pull and pushed/pulled experiences are various nuances of inter-related lived experiences. Interaction is shaped and unfolds in time and space as a dynamic counterbalancing embodied co-existence enveloped within these meaning structures. Occasionally the parties may experience moments of togetherness and co-existing harmony – an experience of equilibrium and flow in communicating, acting and doing whatever they do at the moment. Other times there are moments and situations where interaction and co-existence is experienced as dis-attuned and towards a possible break down.

In professional encounters the professional and the patient/student co-exist, and as



Merleau-Ponty (2005) holds “Co-existence must in all cases be experienced on both sides” (p. 416). Hence, experienced from both sides – the experience of each individual is personal as well as shared. In professional encounters the interworld of the professional and patient/student when being experienced as shared involves the parties to continuously displace, to move themselves for collaboration to be maintained and developed. In displacing oneself one shift positions and move towards the other.

Elaborating on the meaning of being together, togetherness and *Being with* Nancy (2000) says: “‘With’ does not indicate the sharing of a common situation any more than the juxtaposition of pure exteriorities does (for example, a bench with a tree with a dog with a passer-by)” (p. 35). In this sense, “with” is the sharing of time-space and nothing more. With and being together does not indicate a sharing of a common situation more than merely appearing in the same place at the same time. It is the dis-position in between people, things and the environment that opens a possibility—or not—for the sharing of a situation and for togetherness. Thus, Nancy argues that togetherness implies to be in contact, and to get in contact demands displacement.

However, in a situation involving two individuals in contact, neither can take the other's space, place or perspective. Rather, their sharing of a situation demands both individuals to shift position. Establishing contact implies that both parties have to be willing to move towards one another. Displacing oneself towards the other may involve both forward, backward, sideways, up and down movements. It is about adjusting one's “steps” according to the placement and displacement of the other.

While conducting this study writing up this paper we have challenged ourselves in trying to involve in phenomenological reflections. We have sought to attend phenomenological writing to create a text that show pathic, emotive, embodied, and relational understanding of the experience of interacting in health-care and educational encounters. Our findings offer some insights into the lived experiences with taking part and interact in interpersonal professional practices within healthcare and education. Ultimately, we hope these findings may inspire professionals to bring about more thoughtful and tactful encounters within education and health care.

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## Appendix



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Vår dato: 07.04.2014      Vår ref: 38333 / 3 / LT      Deres dato:      Deres ref:

#### TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 27.03.2014. Meldingen gjelder prosjektet:

38333      *En kvalitativ studie av elever med utviklingshemning og deres erfaringer i kroppsøvingstimer*  
*Behandlingsansvarlig*      *Norges idrettshøgskole, ved institusjonens øverste leder*  
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Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

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Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 31.03.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Lis Tenold

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Forespørsel om deltakelse i forskningsprosjektet

***”En kvalitativ studie av elever med utviklingshemning og deres erfaringer i kroppsøvingsfaget”***

**Bakgrunn og formål**

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Forespørsel om deltakelse i forskningsprosjektet

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**Bakgrunn og formål**

Formålet med studien er å undersøke hvordan elever med utviklingshemning erfarer kroppsøvingsfaget. Studien skal undersøke og beskrive hvordan elevene gir uttrykk for sine erfaringer med faget slik det er definert i læreplanen eller i elevens individuelle opplæringsplan (IOP). Prosjektet er en doktorgradsstudie ved Norges idrettshøgskole, Seksjon for kroppsøving og pedagogikk.

Du forespørres som lærer for elever med utviklingshemning eller multifunksjonshemning om å delta i studien, da din kjennskap til elevenes måte å kommunisere på er viktig for å utdype det eleven kommuniserer om erfaringene i faget.

**Hva innebærer deltakelse i studien?**

Deltakelse i studien innebærer at eleven blir observert i kroppsøvingstimene. Observasjonene vil ha fokus på det eleven kommuniserer om sine erfaringer i faget, enten via lyder, kroppsspråk, gester, tegn, symbolutveksling, verbalspråk eller annen kommunikasjon. Du som lærer intervjues slik at din kjennskap til elevens måte å kommunisere om erfaringer på utdyper elevens perspektiv. Data vil bli registrert med lydopptaker.

Det er også ønskelig at forskeren gjennom skolen får tilgang til elevens individuelle opplæringsplan (IOP) i faget kroppsøving der dette er aktuelt, dette for å få vite elevens individuelle læringsmål, innholdet i opplæringen og hvordan det skal arbeides for å nå målene.

**Hva skjer med informasjonen om deg?**

Alle personopplysninger vil bli behandlet konfidensielt. De eneste som vil ha tilgang til opplysningene er doktorgradsstipendiat Kristin Vindhol Evensen og veilederne Gunn

Engelsrud, Øyvind Standal og Borgunn Ytterhus. Det vil ikke lagres personopplysninger som for eksempel navn, fødselsdato, bosted, skoletilhørighet eller annet som kan identifisere elev eller lærer. Ved publisering vil ingen enkeltpersoner kunne gjenkjennes.

Prosjektet skal etter planen avsluttes mars 2017. Personopplysninger og lydopptak som beskriver barnets erfaringer med kroppsøvingfaget vil da anonymiseres.

### **Frivillig deltakelse**

Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert

*Dersom du ønsker å delta eller har spørsmål til studien, ta kontakt med doktorgradsstipendiat Kristin V. Evensen på mobil 90591285 eller på mail [k.v.evensen@nih.no](mailto:k.v.evensen@nih.no), eventuelt hovedveileder Gunn Engelsrud på 23262407 eller på mail [gunn.engelsrud@nih.no](mailto:gunn.engelsrud@nih.no).*

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

### **Samtykke til deltakelse i studien**

Jeg har mottatt informasjon om studien, og er villig til å delta

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(Signert av prosjektdeltaker, dato)

### Aktiv læring

Hvordan styrer elevens utviklingsstadier de aktivitetene dere velger når dere arbeider med aktiv læring? Er det noen dilemmaer knyttet til dette?

Hva betyr samspillet mellom deg og eleven når dere jobber med aktiv læring?

Hvilke objekter og miljøer støtter aktiv læring for eleven?

Eleven brukte «det lille rom», og var aktivt utforskende, samtidig som hun suttet iherdig på fingrene. Hvis tyggeleken hun pleier å bruke var blitt gitt til henne som alternativ til hånda, ville det da kunne forhindre henne i å være aktiv med objektene i rommet? Blir egen kropp som kilde til stimuli noe annet enn det stimulerende objektet?

### Hjelpemidler

Hvordan påvirker bruk av hjelpemidler eleven sin mulighet til å vise initiativ og å delta i samspill?

Noen hjelpemidler skaper aktivitet uten bevegelse, for eksempel ståstativ. Noen skaper passiv bevegelse, som for eksempel Innwalk. Noen skaper aktiv bevegelse, for eksempel hoppsa. Hvordan brukes de ulike typene hjelpemidler for å fremme elevenes læring?

Har du selv prøvd noen av de hjelpemidlene elevene bruker? Har denne erfaringen hatt betydning for hvordan dere bruker hjelpemidlene i hverdagen?

Kan et hjelpemiddel tre i forgrunnen slik at eleven selv blir mindre synlig for omgivelsene? Påvirker bruken av hjelpemidler slik sett relasjonen mellom lærer-elev og elev-elev?

### Pedagogikk og medisin

Hvordan påvirker en livshistorie med mye smerte tilretteleggingen av bevegelseserfaringer i skolen?

Hvordan «snakker» det medisinske fagfeltet med den pedagogiske skolehverdagen?







