



## “I Guess that the Greatest Freedom ...”: A Phenomenology of Spaces and Severe Multiple Disabilities

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### Abstract

*This paper expresses wonder about how bodies in motion can lead towards an understanding of lived meaning in silent lifeworlds. In such lifeworlds, expressions are without words, pre-symbolic, and thus embodied. To address the wonder, phenomenological philosophy and phenomenological methodology were employed to frame an approach that acknowledges lives with disabilities as qualitatively different from, and yet not inferior to, nor less imbued with meaning than, lives without.*

*The paper focuses on spatiality as decisive in determining possibilities for persons to express their perspectives through a wide range of movements. Movements take place in the continuum between the spatiality of positions as objective bodily sensations and the spatiality of situations as embodied interactions with others and the world. Thus, in order to access the perspectives of students with severe and multiple disabilities, transitions between and movements within different spaces are examined.*

*Approaching an educational everyday life where students are restricted in the possibilities available to them for moving in and out of spaces, the study reported points to the importance of recognizing the relationship between subjective movements and the spaces enveloping them as what creates a spatiality that is meaningful to the subject. It is accordingly suggested 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 students' changing expressions.*

### Introduction

Inclusivity is a wide concept that carries many nuances in the educational system (Qvortrup, 2012). The notion of inclusive education is universal and, in a number of countries, embraced as an ideology for the educational system (Standal & Rugseth, 2015). In this paper, we investigate lived experiences in segregated educational spaces adapted for students with severe and multiple disabilities. In order to explore the meaning of spatiality as phenomenological existentiality, we focus on movement as a possible hub of perception and expressiveness

for the participants. To acknowledge their expressivity, we follow French phenomenologist Merleau-Ponty's emphasis on the moving body as purposefully active. Merleau-Ponty's phenomenology of perception (1945/2014) therefore offers a framework for understanding disability as a total way 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 around and for some bodies, thus leaving other bodies out of place.

Research projects including participants with severe and

multiple disabilities have generally applied perspectives other than the phenomenological. Proceeding from a medical perspective, Mulholland and McNeill (1989), as also Foley, Harvey, Chun and Kim (2008), apply what are upheld as objective medical standards for measuring bodily reactions. Applying a behaviourist perspective, Lancioni, Bellini, Oliva, Singh, O'Reilly, and Sigafoos (2010) view behaviour in terms of cause and effect; and, adopting a social perspective, Östlund (2015) focuses on educational organization as shaping students' participation. Accordingly, we find that, while a medical perspective views disability as impairment caused by inherent traits of individuals, a behaviourist perspective views disability as measurable behaviour deviating from a given norm, and a social perspective views disability as socially constructed. Due to the predominance of these approaches to disability, the subjective perspectives of those affected have tended to remain unexplored.

A paradigmatic shift occurred in childhood studies at the start of the twentieth century. While earlier research approached childhood as a transition to adulthood, more recent approaches regard childhood as a "fully fledged" state of being (Spord Borgen & Eriksen Ødegaard, 2015) in which children are independent actors in their own right (Ytterhus, Egilson, Traustadóttir, & Berg, 2015, p. 17). This stance is also upheld in contemporary childhood disability research, where Ytterhus, Egilson, Traustadóttir, and Berg (2015) criticise the traditional "narrow and limited" understanding of childhood and disability. While they thus suggest that future research should aim to foreground the perspectives of children and youth with disabilities, they nevertheless underline the importance of also including the perspectives of the children's significant others, particularly when children can neither speak nor articulate their points of view symbolically. In line, thus, with recent developments in disability research, the research question formulated for this study was as follows: *What is the meaning of spatiality for students with severe multiple disabilities in the context of special needs education?*

### Spatiality: A Phenomenological Perspective on Space

Van Manen (1990/2012, 2014) describes spatiality as an existentiality 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 subjectively experienced space. Spaces might be geographically close, and yet they might be experienced as far away if, due to hindrances, they are difficult to approach (van Manen, 1990/2012).

In *Geography of the Lifeworld* (1979), Seamon looks at bonds between persons and places, recounting stories about how body-subjects experience spaces they inhabit in everyday life. Including examples from a variety of spaces, like the bus, the bakery that is no longer there,

the neighbourhood, and the transition from a very long night's drive to falling asleep in one's own bed, Seamon searches for meaning in the ways in which persons relate to their spaces. In the process, he points to the value of understanding the phenomenological notion of spatiality as inhering not only in inspiring conscious awareness of the nature and meaning of individuals' own encounters with the environments, places and spaces in which they live and move, but in providing tools and frameworks for a wide range of decision-making: whether for policy makers and environmental designers, or for individuals to shape their own possibilities to engage with 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 view that the medical description of disability as "specific physical incapacities" (p. 247) can capture subjective experiences. Rather, she describes disability as relating 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, p. 249)

In describing her subjective experience of living with multiple sclerosis, Toombs points to her own experience of disability as constraint as emerging in relation to spaces that do not correspond with her present point of departure. These experiences of spatial restriction are lived as "impossibility": "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 (1945/2014) underscores how bodies and spaces relate in his definition of space as "not the milieu (real or logical) in which things are laid out, but rather the means by which the position of things becomes possible" (pp. 253-254). Movement possibilities emerge in some spaces, and humans move with such ease within them that body and space co-create an experiential unity. In these spaces, boundaries between the lived 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 set to change. Weiss (2015) draws on Merleau-Ponty, Iris Young and Judith Butler in identifying movements as meaningful whether they are reflected upon or not. Actions are related to an "I can" rather to an "I think that"; as such, 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 co-ordinate in objective spaces, because “my entire body is not for me an assemblage of organs juxtaposed in space” (Merleau-Ponty, 1945/2014, 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 reflects on his flat as a familiar space:

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. (1945/1962, p. 150)

Yet, persons do not usually inhabit only one familiar domain over time. Merleau-Ponty (1945/2014) describes human beings’ engagement with a wide range of spaces, from the spatiality of the night, the sexual space, the mythical space, and the lived space. When people alternate 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 of the existence of the city. If reminded of Paris, his spaces alter, foregrounding one space 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 centre 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 centre of the world. (1945/2014, p. 299)

The village in which he holidays, 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, 1945/2014, p. 294) are spaces accessible through Merleau-Ponty’s subjective body’s inhabiting of 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 resonates 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. (1945/2014, 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, 1945/2014, p. 109). The embodied subject relates to others, and, together, the subject and its others inhabit spaces in ways that foster spatiality. The quotations 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, 1945/2014, p. 109). Due to customs, therefore, we might easily turn attention towards expected hallmarks of groups rather than towards subjective identities.

## Method

The methodological approach of this study 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). In the educational everyday life of students with severe and multiple disabilities, their expressions are essentially embodied and pre-symbolic. Given that phenomenology perceives moving bodies as presenting direct access to human engagement with the world, phenomenological philosophy and methodology provide this project with a means of approach to disability as a state of being that is not inferior to a state without.

Within the medical perspective, severe and multiple disabilities are recognized as complex conditions where cognitive difficulties are combined with motor-, somatic- and health-related difficulties, as well as possible 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 arrive at medical descriptions, but rather to search for the essential meaning structure of lived experiences.

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

All eight students included in the study attend school in segregated special needs units organized in separate buildings or blocks in local schools in suburban areas. The two students focused on in this paper are placed 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 around unsteadily in school, Sara is severely limited in her physical freedom to seek out some spaces and avoid others. Where Oliver receives nutrition and fluid through a gastric PEG<sup>1</sup> tube, and often vomits slime, water and Semper<sup>2</sup>, Sara eats her yoghurt with muesli and her birthday muffin with a healthy appetite. In non-determinate ways, they shed light on subjective likes and dislikes, different medical needs and different ways of reaching out to relate to others. Both Sara and Oliver therefore show in the flesh how lived disabilities are part of general human continuums.

Van Manen (2014) views close observation as eminently suitable for collecting experiential material from “young children or very ill people, [in which cases] it is often very difficult to generate written descriptions or to engage in conversational interviewing” (p. 318). Given that the conventional methods of data collection were not feasible with the participants in the present study, the method of close observation was therefore used to access the participants’ lived experiences. This required that the researcher involved in closely observing the participants enter their lifeworlds. Close observation takes place between proximity and distance, and involves “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). In conducting close observation of the participants, the first author spent two weeks in three special needs education units. She both experienced and observed embodied relations and wordless dialogues between students, between students and pedagogical staff, as well as when in close embodied contact with

the students herself, for instance while feeding through a gastric PEG tube, washing hands in lukewarm water, singing, lifting, dressing, or when a student sat on her lap. Through involvements of this nature, the students and researcher were accessible to each other, offering reciprocal engagement in embodied dialogues.

During observations, close embodied involvements were contained by constant consciousness of the limits of ethically acceptable involvement in order not to risk transgressing the subjective boundaries of what each student regarded as invasive. While the students mainly guided this process by their embodied responses, the staff guided it partly, as did the researcher’s professional background in special needs education in general and in severe and multiple disabilities in particular.

The first author, as participant researcher, wrote field notes at the end of each school day. This was a choice consciously made in order to attend as fully as possible to the students’ gestures, mimicry, movements, smells, sounds, or tactical outreaches. If the researcher 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 after the conclusion of each period of close observations.

When we interpret the student participants’ gestures, movements, and expressions, we construct their possible experience of spatiality from an outside perspective. Thus, in accordance with van Manen’s guidelines for phenomenological writing, we have attempted to adhere to sensitive and evocative language use throughout the paper. In particular, we have aimed at acknowledging Oliver and Sara as active subjects who happen to 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 similar vein, Simms (1993) investigated the preverbal expressions of infants in light of the theories of Merleau-Ponty and Daniel Stern. She concluded that the pre-verbal can coexist with the verbal, since embodied gestures express direct engagement with the world.

The field notes and interviews were analyzed by both authors, who read the raw material holistically and in detail in order to locate units of meaning. They then 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 verbatim quotations, and ending promptly after the incident has

<sup>1</sup> Percutaneous endoscopic gastrostomy.

<sup>2</sup> A Scandinavian brand of infant food.

passed (van Manen, 2014). In investigating wordless perspectives, we have continuously reflected on how embodied expressions easily can be overthrown by the wordiness of pedagogical staff and researchers. While being aware of the asymmetry in the relation between adult and child, we have nevertheless chosen to include teachers' verbal statements excerpted from interviews. These excerpts are linguistically honed in order to attend as closely as possible to the students' perspectives.

As previously stated, we make use of the diagnostic term "severe and multiple disabilities", and yet not with the aim of arriving at medical descriptions. Rather, our aim is to develop a phenomenological account of how the two participating students act in spaces. As paediatrician Beets claimed (in van Manen 1996, p. 12; 2014, p. 207), phenomenological pedagogy has its own special character that differs in both essence and focus 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.

In our search for lived experiences in the silent life-worlds of students with severe and multiple disabilities, we have found support in Merleau-Ponty. Thus, we have striven to acknowledge and describe the student participants as fully fledged human beings, each with their own unique personalities, preferences, interests, meanings, social backgrounds, and experiences.

## Findings

Practical pedagogical decisions about which spaces to include in Oliver's and Sara's immediate educational environment are formative of the possibilities that exist for them to move freely. Through the following anecdotes we describe phenomenologically how the two students respectively 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, and 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 copiously 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 school-yard. He holds on to the window frame and squashes his tiny nose flat against the glass. On the outside, students about his age play in pools of water in the pouring autumn rain. For quite a while, Oliver stands by the window. Apparently captivated, he watches what happens just a few meters away.*

*Teaching assistant Hilde carries a laminated strip of pictures as she approaches Oliver at the window. She takes his hand, and Oliver accepts that she guides him towards the trampoline that is depicted at 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, draws 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 purposefully, 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, switches the lights off 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 intently in his eyes, and presses his nose against 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.*

In the gym, Oliver walks, skips and jumps around apparently unconstrainedly. 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 the promise 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 switches off the lights in the gym, expresses his perspective, saying "I am done here". Thus, it appears that he has an agenda of his own. This agenda corresponds with his newly gained ability to walk, and is expressed to those surrounding him by the way he moves in the gym.

Whereas Toombs (2001) relates her lived disability to the impossibility for her of carrying her cup of coffee to the den, we might conclude that, in Oliver's case, his lived experience of disability as constraint emerges when his reaches for the outside are limited by Hilde's agenda to keep him in the gym in order to perform his scheduled tasks. Special needs educator Maria points to the experiential intertwining between the moving subject and spatiality, as well as the importance of acknowledging subjective desires, in her empathic observations regarding Oliver's joy in 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 the year before:

*So, I thought, "Well, what would a person that has just 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, at first 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 hierarchical relationship

where one rests upon the other. Rather, she attends to space and movement as reciprocally intertwined and equally important. Yet the institutionalized asymmetry between student and teacher shows, as it is she as a special needs educator who opens up possibilities for him 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 new possibilities to enter and move around in spaces make him happy with himself. And yet, school is a place for expectations not only of being, but also of 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 own agenda apparently does not correspond with the agenda of teaching assistant Hilde, who as such represents the professional actor in the educational context. Hilde, as a member of the pedagogical staff, has expectations regarding Oliver's education. In a calm, and yet leading, way, she takes Oliver away from what caught his attention on the outside and guides him towards certain tasks, objects and objectives on the inside.

The strip that pictorially illustrates 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 level to understand. Hence, I started at 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 heated pool. Sara's movements constitute her dwelling possibilities to move in some spaces in contrast to 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 stomach. She actively resists staff members' attempts to make her lie on her stomach. 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

or “jolly jumper”. To give some examples, she expresses herself when she makes 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 prevent 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 incessantly: “ehhhhhh, ehhhhh, ehhhhh”.*

*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 gently on Sara's shoulders and guides her upper body slightly towards the backrest. Hilde grabs a slim, yellow life vest and guides Sara's arms through the openings one by one before fastening straps in the front. Carefully, she pulls orange inflatable arm rings onto 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. On the count of three, Hilde and special needs educator Maria draw Sara forward and lift her from the wheelchair into the warm water.*

*Once in the water, Sara unfolds her curled-up body and her grumbling 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 completely 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 clings to Maria. Then she again lies back in the water, continuing her quiet voyage around the pool.*

Sara experiences constraint due to internal and external forces that are part of her disability. To varying degrees, medical conditions like epilepsy, scoliosis and poor muscle tone limit what she can do. For safety reasons, she is strapped to the wheelchair. Yet, when in the water, she moves unconstrainedly. The extreme contrast, thus, between Sara's constrained experiential norm and her freedom of movement in the water magnifies the way in which 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 expresses her perspective. She curls herself up when in the wheelchair. Yet, when in the warm water, she stretches out and leaves this curled up position as she unfolds 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 foetus 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 can gather that the “here” of the pool corresponds to her point of departure in a way that in 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 turn, 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 sequential flow of time and not as singular spatial occasions. Without the former grumble, the presence of Sara's quietness could have been unnoticeable quietness rather than an attention-claiming absence of sound. In such contrasting moments lies the possibility to attend to movements as distinct, where one is constituted by the presence or absence of the other.

Just as Merleau-Ponty (1945/2014) describes his holiday village and the city of Paris as alternating foreground and background related to a “here” and a “there”, Sara's spatiality constitutes comfort and pain as alternating foreground and background. As Sara grumbles and curls up, we can assume that she is expressing dissatisfaction with her “here”. When the wheelchair turns into Sara's “there” the instant the pool becomes her “here”, paying attention to her contrasting movements provides us with the possibility of interpreting her bodily expressions as manifestations of, respectively, experienced pain and comfort, as well as expressions related to joy, happiness

and self-determination. Anna, Sara's teacher for 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 just 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 expectation when she is in the pool is that she will use the water, and that is kind of unavoidable. In the water, she does not need to use her hands to do anything else but to move them, at different angles, open, twist and stretch.*

Anna's interpretations of the essence of the relations between movement, space and values of freedom are implemented pedagogically in practical arrangements. When Sara engages subjectively with the warm water, the self-determined ways in which she moves are not coincidental. The staff's active involvement when taking Sara to the pool is replaced by active disengagement when she reaches the water. No one prompts Sara to perform specific movements aimed at attaining specific physiological or psychological goals. No singing games or rhymes are performed, no objects to manipulate are provided. Sara leads the situation, and her movements express her subjective horizons to the pedagogical staff members.

## Conclusion

Acts and the absence of acts are formative practical pedagogical means when staff members attune to the expressiveness of bodily movements. Returning to Merleau-Ponty's (1945/1962; 1945/2014) and Toombs's (2001) outlining of disability in relation to space, we can recognise that movements express medical, personal, social and emotional aspects of lived experiences of severe and multiple disabilities.

As Merleau-Ponty (1945/2014) points out, inhabiting even familiar spaces like one's own flat presupposes intentional embodied outreaches. While a space thus only becomes familiar when a person moves into it, turning towards one space always includes turning away from another. When Oliver moves from the window to the trampoline, the window as his "here" becomes his "there", while the trampoline that used to be his "there" turns into 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 the lack of correspondence between herself and her spaces. Turning to the empirical material,

we can conclude 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 he can reach; rather, it is shaped by the constrictions imposed on him by 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 greater degree than Oliver, and yet the intervention of those surrounding her creates possibilities for her to move freely and thus to experience and express a wide spectrum of satisfaction and dissatisfaction, as well as of comfort and pain, depending on her correspondence with the spaces she is placed into. When Oliver and Sara move elsewhere from their "here" of the moment, a qualitatively different "here" unfolds as they and their spaces redirect in a constantly ongoing process. The moving subject "reckons with the possible" (Merleau-Ponty, 1945/2014, p. 112) 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 pathway 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" thrusts constantly towards a "maybe I can't". If confident experiences of "I can" are frequent, and embodied expressions are validated as fully worthy by being acknowledged and responded to as such, conventional expectations regarding the limits of what the bodies of those with severe and multiple disabilities can do are challenged, and a marginalised minority group empowered to have its own embodied expressing of its perspective attended to.

In line with Seamon (1979), we argue that spatiality provides tools and a framework for decision-making in the practical-pedagogical everyday life of students with severe and multiple disabilities. Even though we have here attended to movements in spaces as formative for perception, thought, and language as described by Merleau-Ponty (1945/1968; 1945/2014), the temporal dimension of movements in spaces is acknowledged in the perception of movement in one space in light of another. Given that 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 contrasting embodied expressions as they unfold in spaces, temporal continuity in human relations stands out as fundamental. Thus, we would suggest that human relationships should be sustained over time in special needs education, given the value of long-term interaction in detecting and acknowledging contrasting movements that express the wordless perspectives of students with severe and multiple disabilities.

Phenomenology offers a framework that challenges prevailing understandings of disability as incapacitating in its deviation from a given normality, and provides a means of giving silent lifeworlds a voice and say in matters affecting those that inhabit them. In paying attention to how transitions between spaces make both expressions and absence of expressions recognizable, we emphasize the importance of movements *per se* when including the pre-symbolic and wordlessly embodied

perspectives of students with severe multiple disabilities in educational decision-making. Facilitating the finding and inhabiting by students of spaces that correspond to their subjective points of departure is founded on an attitude of seeing them as fully fledged human beings and active agents in their own right, confident in the knowledge that, if their unique self-expressive needs are attended to, being will walk side by side with becoming in the educational context.

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## References

Barron, K. (2015). Social inclusion as a theoretical concept and a social practice. In R. Traustadóttir, B. Ytterhus, S. T. Egilson, & B. Berg (Eds.), *Childhood and disability in the Nordic countries: Being, becoming, belonging* (pp. 133–148). Basingstoke, UK: Palgrave Macmillan.

Foley, J., Harvey, S., Chun, H.-J., & Kim, S.-Y. (2008). The relationships among fundamental motor skills, health-related physical fitness, and body fatness in South Korean adolescents with mental retardation. *Research Quarterly for Exercise and Sport*, 79(2), 149–157. doi: 10.1080/02701367.2008.10599478

Lancioni, G. E., Bellini, D., Oliva, D., Singh, N. N., O'Reilly, M. F., & Sigafoos, J. (2010). Camera-based microswitch technology for eyelid and mouth responses of persons with profound multiple disabilities: Two case studies. *Research in Developmental Disabilities*, 31(6), 1509–1514. doi: 10.1016/j.ridd.2010.06.006

Merleau-Ponty, M. (1962). *Phenomenology of perception* (C. Smith, Trans.). New York, NY: Routledge. (Original work published 1945)

Merleau-Ponty, M. (1968). *The visible and the invisible* (A. Lingis, Trans.). Evanston, IL: Northwestern University Press. (Original work published 1948)

Merleau-Ponty, M. (2014). *Phenomenology of perception* (D. Landes, Trans.). Oxford, UK: Routledge. (Original work published 1945)

Mulholland, R., Jr., & McNeill, A. W. (1989). Heart rate responses of profoundly retarded, multiply handicapped children during closed-skill fine motor and open-skill gross motor activities. *Adapted Physical Activity Quarterly*, 6(1), 68–78. doi: 10.1123/apaq.6.1.68

Östlund, D. (2015). Students with profound and multiple disabilities in education in Sweden: Teaching organization and modes of student participation. *Research and Practice in Intellectual and Developmental Disabilities*, 2(2), 148–164. doi: 10.1080/23297018.2015.1085327

Qvortrup, L. (2012). Inklusion – En definition [Inclusion – A definition]. In T. Næsby (Ed.), *Er du med? Om inklusion i dagtilbud og skole* [Are you with us? About inclusion in childcare and school] (Vol. 5, pp. 5–16). Aalborg, Denmark: UCN Forlag.

Seamon, D. (1979). *A geography of the lifeworld: Movement, rest and encounter*. New York, NY: St. Martin's Press.

Simms, E.-M. (1993). The infant's experience of the world: Stern, Merleau-Ponty and the phenomenology of the preverbal self. *The Humanistic Psychologist*, 21(1), 26–40. doi: 10.1080/08873267.1993.9976904

Spord Borgen, J., & Eriksen Ødegaard, E. (2015). Barnekultur som forskningsfelt – Et interdisiplinært vitenskaplig emne [Children's culture as field of research – An interdisciplinary field]. *Barn*, 33(3–4), 5–18.

Standal, Ø. F., & Rugseth, G. (Eds.). (2015). *Inkluderende kroppsøving* [Inclusive physical education]. Oslo, Norway: Cappelen Damm.

Toombs, S. K. (2001). Reflections on bodily change: The lived experience of disability. In S. K. Toombs (Ed.), *Handbook of phenomenology and medicine* (pp. 247–261). Dordrecht, Netherlands: Kluwer Academic Publishers.

Traustadóttir, R., Ytterhus, B., Egilson, S. T., & Berg, B. (Eds.). (2015). *Childhood and disability in the Nordic countries: Being, becoming, belonging*. Basingstoke, UK: Palgrave Macmillan.

Van Manen, M. (1996). Phenomenological pedagogy and the question of meaning. In D. Vandenberg (Ed.), *Phenomenology and educational discourse* (pp. 39–64). Durban, South Africa: Heinemann Higher and Further Education.

Van Manen, M. (2012). *Researching lived experience. Human science for an action sensitive pedagogy* (2nd ed.). London, ON: The Althouse Press. (Original work published 1990)

Van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. Walnut Creek, CA: Left Coast Press.

Weiss, G. (2000). Écart: The space of corporeal difference. In F. Evans & L. Lawlor (Eds.), *Chiasms: Merleau-Ponty's notion of flesh* (pp. 203–218). Albany, NY: State University of New York Press.

Weiss, G. (2015). The normal, the natural, and the normative: A Merleau-Pontian legacy to feminist theory, critical race theory, and disability studies. *Continental Philosophy Review*, 48(1), 77–93. doi: 10.1007/s11007-014-9316-y

Wendelborg, C., & Tøssebro, J. (2011). Educational arrangements and social participation with peers amongst children with disabilities in regular schools. *International Journal of Inclusive Education*, 15(5), 497–512. doi: 10.1080/13603110903131739

Young, I. M. (2005). *On female body experience: "Throwing like a girl" and other essays*. New York, NY: Oxford University Press.

Ytterhus, B., & Tøssebro, J. (2005). *En skole for alle? En studie av organiseringen av opplæringa til barn med generelle lærevansker eller utviklingshemming i norsk grunnskole* [A school for everyone? A study of the organization of the education of children with learning difficulties or intellectual disability in Norwegian primary and lower secondary school]. NTNU/ISH Report No. 58. Trondheim, Norway: NTNU, Institutt for Sosialt Arbeid og Helsevitenskap.

Ytterhus, B., Egilson, S. T., Traustadóttir, R., & Berg, B. (2015). Perspectives on childhood and disability. In R. Traustadóttir, B. Ytterhus, S. T. Egilson, & B. Berg (Eds.), *Childhood and disability in the Nordic countries: Being, becoming, belonging* (pp. 15–33). Basingstoke, UK: Palgrave Macmillan.