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“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 in ordinary school settings. Yet usually their schooldays are organized differently from those of their non-disabled peers. In this paper the authors aim (1) to 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 and the phenomenological methodology the authors acknowledge movement as fundamental for the students' possibilities to express their perspective. Their 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, they have applied Goffman's interactionism.

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 cause 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 education in segregated classes or schools (Wendelborg & Tøssebro, 2011). Tendencies identified by Ytterhus and Tøssebro (2005) illustrate that the number 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 & 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 (Lancioni et al., 2004; Mulholland & McNeill, 1989; Sigafos et al., 1993). A typical example is a case study by Lancioni et al. (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 mouths of two participants, where camera-based optic sensors measured eyelid closure and mouth and eyelid opening. If responses were comprehensive enough, students

received their favoured stimuli. Researchers have also approached the education of students with SMD through a literature review followed by an experimental stimulus-response approach (Logan et al., 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 behaviouristic 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, and so on, 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 favour 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 et al., 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 machine¹ 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 Velcro. 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 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 1949–52. 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 behaviour 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' behaviours 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, fully worthy, yet qualitatively 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 symbolic 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 programmes). The principal positions, values and beliefs, 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 in 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 a perspective other 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 emailed to principals in eight public schools that on their web pages stated that they had students with severe and multiple disabilities attending 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 8 and 15 years old, attending 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, 10-year-old fourth grader Oskar and 12-year-old sixth grader 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 the help of a teacher who 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 30–60 minute intervals, usually following one student at a time.

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

Ethics

Including students with SMD in 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 author's 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) 7 April 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 the 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’ perspectives as possible.

Through all steps of the research process, we paid attention to how pre-understanding as a result of our vocational backgrounds within rehabilitation, nursing, sociology, and pedagogy could influence interpretation. All authors have worked directly with children with extensive need 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 Velcro; 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 moving too much.

“I will start the machine at three. One. Two. Three.” Maria shows Oskar that she is counting by raising 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 would bring the device out of position if it were 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 breathes 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 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 qualitatively different, yet of equal value as emphasized by Merleau-Ponty [2010, 2014]), opens up for recognizing this other as a fully 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 degree

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 while 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 a 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 point 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 the use of assistive equipment is embedded in a dichotomy of disabled–not disabled and an individual deviation approach (Lancioni et al., 2004; Logan et al., 2001; Mulholland & McNeill, 1989). Findings in disability studies based on social and relational models of disability, technology, or education (Östlund, 2015; Söderström, 2016; Söderström & Ytterhus, 2010) 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-bodiedness, 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 animator–author–principal triad, 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 staff's relational competence and capability in attending to a child-centred pedagogy when acknowledging students with SMD as first and foremost children. Pedagogical tact and sensitivity towards students' 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.

Note

1. <http://madeformovement.com/products/innowalk/>.

Disclosure statement

No potential conflict of interest was reported by the authors.

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