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# Sitting and Watching the Others Being Active: The Experienced Difficulties in PE When Having a Disability

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The experience of participation in physical activity was explored in a qualitative study with twenty Norwegian adults with physical and visual disabilities. The interviews showed that more than 75% of negative experiences reported in this study originated from physical education (PE), suggesting that this was a particularly challenging arena. The negative experiences were centered in these common themes: experiences of not being included, experiences of failing, and experiences of not being listened to. The interviews were analyzed applying an existential-phenomenological approach. The participants with relatively minor degrees of disability and with the least visible disabilities were the ones who most often reported negative experiences regarding PE. This suggests the experiences were not generated solely by the actual physical or sensory limitations, but equally by how well the participants' challenges were understood by their teachers and to what degree adaptations were implemented.

Keywords: disability, embodiment, existence, phenomenology, physical activity

I never had PE at school . . . either I sat and looked at the others or I biked on an exercise bike. I found it very boring as I am quite an active person. . . . But I don't know, it did not seem to matter to them whether I took part or not. (Maria, born with a physical disability)

This quotation originates from a qualitative study (Bredahl, 2012). The aim of our study was to explore the experience of participating in physical activity while living with a physical or visual disability. We wished to illuminate what participants themselves found was of importance with regard to participation in physical activity by applying a phenomenological approach exploring participants' positive as well as negative experiences. The study did not concern any particular arena; however, it turned out that the majority of negative experiences related originated from PE. These accounts inspired reflections concerning critical issues regarding participation in physical activity in general and in PE in particular, as PE is an important arena that potentially introduces all children to participation in a variety of physical activities, as well as being a significant social arena (Sherrill, 2004).

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# The Experience of Participation in Physical Activity—Earlier Research

A broad variety of research approaches are advocated in the area of adapted physical activity (APA). Although applying a phenomenological approach in APA research may contribute valuable knowledge to the field, the use of this approach has so far been limited. Duesund (1993) was among the first to apply a phenomenological approach in APA while investigating children's experience of participation in PE. She found that although PE provided an important arena for developing physical and social skills, it also involved a risk of participants with disabilities feeling exposed, as their limitations became obvious and visible, resulting in PE potentially being challenging to their self-esteem. Among other phenomenological studies in APA, Goodwin, Krohn, and Kuhnle (2004) explored the experience of wheelchair dancing. Interviewing children with disabilities revealed that dancing had changed their experience of their wheelchairs' functions from mainly being tools for mobility to equally becoming tools for moving freely and for expressing themselves. In another study, the experience of participating in summer camps for children and youths with disabilities was explored (Goodwin & Staples, 2005). Findings highlighted participants' perceived benefits of meeting and learning from others with similar challenges to themselves. These findings pose questions concerning whether unilaterally promoting inclusion into mainstream settings risks overlooking the benefits participation in segregated settings might offer. In a third study Goodwin (2001) researched the experience of participating in PE while being dependant on help. Goodwin's research showed that the use of peer-tutoring in PE can be challenging for those dependant on help, and affect their experience of being participants of equal worth. While the studies mentioned all explored youngsters' experiences, a phenomenological study by Fitzpatrick and Watkinson (2003) explored adults' experiences. The adults recalled PE as being a difficult arena, providing experiences of failing due to activities not being adequately adapted to their being "physically awkward."

The above mentioned studies are pioneering in using a phenomenological approach in the field of APA; however, other researchers (e.g., Asbjørnslett & Hemmingsson, 2008; Coates & Vickerman, 2008; Fitzgerald, 2005; Grenier, 2007; Smith & Thomas, 2006; Spencer-Cavaliere & Watkinson, 2010) have also emphasized the importance of exploring individuals' experiences, as such research can contribute knowledge regarding critical issues concerning participation in physical activity in general and in PE in particular. It has also been stressed that when it comes to PE, the majority of research has focused on PE from the perspective of the teachers, the administrators, or peers (Smith & Thomas, 2006). In other studies (e.g., Brittain, 2004; Guthrie, 1999), adults have been interviewed about their experiences concerning participation in physical activity. In the analyses, however, a social model of disability approach has typically been applied, emphasizing empowerment and the importance of changes on a societal level to enhance participation. Questions regarding what is of importance to participants and in which ways participation in physical activity contributes positively and negatively to their everyday lives await exploration.

The recognition that adults' life situations and abilities to reflect on their experiences differ from those of children inspired the conduction of a phenomenological study focusing on the experiences of adults.

# **Conceptual Framework**

The analytical approach applied in the study was existential-phenomenological. Research-focused phenomenology has the lived human experience as the starting point and provides a descriptive, reflective, and engaged mode of inquiry in seeking to yield a more thorough understanding of people's experience of a phenomenon (Spinelli, 2005; van Manen, 1990). Applying this approach was substantiated in that it, in a particular way, opens participants' experiences for a broad and deep exploration, guided by participants' replies, pursuing essential aspects of their experiences that less explorative approaches risk neglecting (Spinelli, 2005; van Manen, 1990).

I will provide a brief introduction to three central issues in existential-phenomenology, which are of particular relevance for the topic being explored, and for the analysis of the findings. Because of its particular relevance to the study, the issue of embodiment will be described in the most detail.

#### Intentionality

The notion of *intentionality* (Husserl 1965) emphasizes our *directedness* toward the world, and focuses both on *the what* and *the how* of our experience. The combination of the two foci makes us, as individuals, interpret and experience the same 'thing' in different ways (Deurzen, 1997). It refers not only to *what* we see or experience but the relational way we see and experience: the attitudes, values, and aims we bring, and the emotional state we are in are always contained within the experience. When we remember something from the past, for instance, a particular swimming lesson, we do not just remember *what* happened, but also *how* it was experienced—or rather how we today remember what happened and how we experienced it. Intentionality refers to the relational element regarding lived experience, as emphasized in the second issue: the life world.

#### Life World

The term *life world* stresses the central assumption: that we as human beings are always engaged in and influenced by the world. Martin Heidegger's (1962) notion of *being-in-the-world* emphasizes how our experiences and reflections derive from our inevitable ongoing relation with the world (Cohn, 1997; Deurzen, 1997). Living with a disability affects (aspects of) a person's possibilities and ways of engaging with the world, as has been explored by Wendell (1996) and Thomas (1999). A person's ability to navigate in a wheelchair, for instance, is not just influenced by the person's physical strength and skills, but also by whether having to move on level pavement, in gravel, or in snow. The experience of our life world is not to be seen as a pure mental act. It is always grounded in the fact that we are in the world as bodily beings, which is addressed in the issue of *embodiment*.

#### **Embodiment**

Living with a disability means living with a body and abilities that (in some respects) differ from most other people's bodies and abilities. Theories regarding the issue of living-in-the-world with a (disabled) body have been developed by the philosophers Maurice Merleau-Ponty (1962) and Drew Leder (1990) especially. Central in their

theories is the notion of the lived body. This notion is in opposition to an understanding of the body in a Cartesian dualistic tradition, where the body is regarded as "a plenum of passive matter, driven by mechanical forces" (Leder, 1992, p. 20), as it has traditionally been examined in medicine, biomechanics, and physiology (Duesund, 1993, 2008; Leder, 1990, 1992; Merleau-Ponty, 1962). Merleau-Ponty emphasizes that we both *have* a body that can be studied and operated on and *are* our body. To be a subject means to be in the world as body; we perceive and experience the world through our body, as has been explored by Thomas (1999) concerning living with a disability. Leder expresses it this way: "the lived body is not just one thing in the world, but a way the world comes to be" (Leder, 1992, p. 25). Our body is directed toward and constantly interacts with the world. Leder (1990) examines the experience of living with a body in everyday life. When everything works smoothly, the awareness of our body tends to slide into the background of our attention. In other instances, the body might "stand out" and become present to us. Although the experience of the body standing out can be experienced both as positive and negative, as in pleasure versus pain, it may often be experienced as the body "getting in the way," disturbing our current activities. Leder describes this experience as the dys-appearing body. This notion is of interest when exploring living with a disability, as people with a disability may experience the body as dys-appearing more often than people without disabilities. This may be caused by the following:

- The body itself (for instance by pain or spasms)
- The environment (for instance stairs you can't climb or signs you can't read)
- Other people (who through their actions remind you of your disability)

Living with a body that may be experienced as dys-appearing might influence not only the way that one experiences one's own body, but one's being-in-theworld, as has been explored by Wendell (1996) and Thomas (1999). Having bodily capacities that differ from most other people's might influence the experience of participating in physical activity. How this might be experienced was explored in our empirical study.

#### Method

The study presented here is an existential-phenomenological explorative study based on interview as a qualitative method of research. The method was chosen as it allows for an in-depth exploration of participants' experiences in an open but systematic way (van Manen 1990). Twenty semistructured interviews with people with disabilities, verbalizing<sup>1</sup> personal experiences of participation in physical activity, formed the basis of the investigation.

# **Participants**

In selecting the 20 participants for the study, a purposeful sampling strategy (Creswell, 2007) based on specific criteria was applied:

- Physical and visual disability (at least 6 from each type of disability)
- Congenital disability, acquired abruptly or gradually (at least 5 from each category)

- Sex (at least 8 of each sex)
- Age (at least 5 from each age group: 18–23 years, 24–40 years, 41–65 years)<sup>2</sup>

This strategy was chosen to ensure variety among the participants, increasing the likelihood that the findings would reflect different types of experiences and perspectives. Although acknowledging the differences there could be concerning living with a visual or a physical disability, the decision to include both types was made to explore whether there might, in spite of differences, be some common themes in participants' experiences. The participants were involved in physical activity on various levels and in various types of activities, but all had experiences from the settings: PE, organized recreational physical activity, and unorganized arenas for physical activity. The inclusion criteria used for "physical and visual disability" were as defined by the International Paralympic Committee (IPC³) constituting the medical criteria for being entitled to compete in disability sports, thus ensuring that all the participants in the study had relatively comprehensive physical or visual disabilities (see Table 1, for the final sample of participants distributed according to the various inclusion criteria).

The participants were recruited through staff at Norwegian rehabilitation centers, organizations for people with disabilities, and organizations providing recreational physical activity for people with disabilities. Twenty-four letters of invitation were sent to get the study's target of 20 participants. The four potential participants who did not wish to take part all belonged to the youngest age group in the study. The mean age of the final sample of participants was 35.5.

#### **Data Collection**

Being an existential-phenomenological explorative study, a semistructured interview guide was developed. The interview guide was inspired by the theoretical framework. It focused on participants' lived experience (Leder, 1990) and their intentionality in relation to participation in physical activity. The issue of embodiment was emphasized in questions concerning the role of physical activity with regard to experiences of their own capabilities. Pilot interviews were conducted with two students with disabilities to refine and finalize the interview guide (Denzin & Lincoln, 1994; Kvale & Brinkmann, 2009). The interview guide consisted of questions like these:

Do you remember a particularly positive experience with physical activity? (Describe)

Do you remember a particularly negative experience with physical activity? (Describe)

Has engaging in physical activity influenced your experience of yourself and your capabilities? (How)

The interview guide, the letter of invitation, and letter of consent were submitted to, and approved by, the central Norwegian ethical committee (Norwegian Social Science Data Service). All participants signed a statement of consent. To ensure anonymity, pseudonyms replaced names of participants and locations.

Table 1 Inclusion Criteria and Distribution of Participants

		Sex		Age		Acqui	Acquisition of Disabilit	ability	
Type of Disability	Men	Women	18–23	24–40	41–65	Congenital	Acquired Abruptly	Acquired Gradually	Total
Partially sighted	-	3	1	1	2	1	1	2	4
Blind	2	1	1	1	1	1		1	3
Amputee	-	1	0	2	0	0	2	0	2
Spinal cord injury	_	1	1	0	1	0	2	0	2
Rheumatic disease	-	2	_	1	_	1	0	2	3
Cerebral Palsy	2	2	_	2	_	4	0	0	4
Congenital physical disability	_	2	1	1	1	3	0	0	3
Total	6	12	9	8	7	10	9	5	21*

\* The total: 21, is due to one participant having 2 types of disabilities

The data were collected 2005–2007.<sup>5</sup> Participants were recruited from different parts of Norway and the interviewer traveled to the location of the participants, where the interviews were carried out. One interview was conducted with each of the 20 participants. The interviews (lasting 70–110 min) were audio-taped and subsequently transcribed.

### **Analysis of the Interviews**

The analysis of the transcribed interviews was performed through "meaning condensation" (Creswell, 2007; Giorgi 1975). This entailed long statements being compressed into briefer statements containing the main sense of what was said in the interviews. The process allowed for themes to arise inductively from the interviews during analysis (Colaizzi, 1978; Giorgi, 1985; Kvale & Brinkmann, 2009). The process contains similarities to "open coding" as described in "grounded theory" research: The process of breaking down, examining, comparing, and categorizing data (Strauss & Corbin, 1990). The categorization of statements and categorization of emerging themes provided an overview of the data and also facilitated the possibility of quantification of the findings.

In the analysis process, each interview was read several times to get a feeling of it as a whole. This was followed by a detailed reading of each interview, where "meaning units," such as phrases, sentences, and segments, were identified and given descriptive headings.

The thorough readings and the significant statements formed the basis for composing an individual summary for each interview. To ensure rigor (Giorgi, 1975; Spinelli, 2005), the summary was sent to the participant concerned for approval. The approved summaries and the transcribed interviews were reread and headings were clustered into themes (see Table 2 for examples of meaning condensation as applied in the study).

# Validity

Validity was addressed by thoroughly accounting for methods and procedures applied in the study, such as the inclusion criteria, strategies for recruitment of participants, procedures for data collection, and methods used in analyzing the data. In phenomenology, as in other methods, these accounts inform the critical reader to bring plausibility to the captured experiences and authenticity to the findings (Denzin & Lincoln, 1994; Kvale & Brinkmann, 2009). To validate findings in this study, specific techniques were incorporated:

- A log was completed after each interview, capturing the researcher's immediate reflections, preserving impressions that otherwise may be lost in the transcription process, and due to memory loss.
- Member checks (Denzin & Lincoln, 1994) and "communicative validity" (Kvale & Brinkmann, 2009) were incorporated, which meant that the conducting researcher stopped during the interviews, rephrased, summed up, and asked for clarification.
- *Summaries* of each interview were composed and sent to the participant concerned. Participants' clarifications were added to the summaries before being approved.

Citation from the Interview	Heading	Theme
My worst experience ever was while I attended the 6th grade. We all had to jump over the vaulting horse I did not dare to, but I also did not dare to say that I did not dare either. So I ran toward the horse, ran into it and knocked it over so the horse and I rolled over, while the whole class were standing there laughing. It was awful! It is a really painful memory.	Stumbling over the vaulting horse	Failing in PE

Table 2 Example of Meaning Condensation as Applied in the Study

The data were approached from different angles: the transcripts, the logs, and the approved summaries, while applying the phenomenological-existential theoretical perspectives to assist the credibility of the analysis.

#### **Findings**

Participants were interviewed about their experiences of participation in physical activity, including which were their most positive and most negative experiences and what physical activity meant to them in their everyday lives. The participants were prompted to describe their experiences, elaborating on both what happened and how it had been experienced. Participants' most positive experiences were centered around the themes of "being capable" and "surpassing limitations," both originating from a variety of recreational settings for physical activity (Bredahl & Spinelli, 2012). Participants related how they had found activities where their abilities, rather than their disabilities, stood out. The vast majority of the negative experiences reported (13 out of 17), however, originated from PE. This finding appeared in spite of the questions asked not being directed toward any particular arena or type of physical activity. Analyzing the negative experiences, three common themes emerged: (a) experiences of not being included, (b) experiences of failing, and (c) experiences of not being listened to. The three themes will be described, exemplified and discussed below, while the more general discussion will take place in the following section.

**The experience of not being included.** The common theme of "not being included" is exemplified by Maria in the opening quotation of this paper. Similar experiences were related by five other participants. In addition, two participants reported how their level of participation had changed abruptly upon becoming disabled. One of these was Kim:

I was just exempt. From when I was eleven years old and lost my leg. There was no talk about that they could find other activities for me. Instead I went to the physiotherapist for training or I sat and watched [the others]. It was completely idiotic, as there are so many things I could have done. (Kim, acquired a physical disability)

Other participants related that their participation had varied over the years and that their degree of participation had little to do with changes in their disability.

One of those was Casper who described his participation in PE changing in parallel with him changing schools.

- Primary School (6–12 years): He participated in PE, but had to bring an assistant.
- Secondary School (12–16 years): He was excluded from participation in PE.
- *Upper Secondary School* (16–19 years): He participated in PE without an assistant.

Casper related that he had always liked physical activity and been motivated to participate in PE, that he was born with cerebral palsy, and that his level of ability had not changed over the years. He found, however, that his teachers' degree of motivation and willingness to adapt activities to make participation possible for him had varied greatly.

The participants who reported to have been excluded from participation in PE had typically had their PE converted into "individual training" separate from the rest of the class, or that they had been assigned the role of being a spectator. Only to a limited extent did the participants mention the physical training they had missed out on by not being included in PE; however, almost all accounts contained descriptions of the costs it had had socially, such as,

The fact that you constantly had to be taken away from the class to go swimming meant that I had to leave my classmates, which was irritating . . . and exactly in the seventh, eighth, and ninth grade where you actually need to be together with your friends. (Monica, acquired a progressive rheumatic disease)

Out of the participants who experienced not being included in the regular PE, one participant reported that she found it to be the best solution for her:

I needed my own program, adapted to me. . . . I learned to think that there are certain things I need to do and other things others need to do. They play football and I need another type of training. It was ok in a way. (Olivia, born with cerebral palsy)

Even though Olivia found that training separately from the others had been the best solution, she also expressed that she had missed out socially by not being with the rest of her class. Similar findings were reported in studies by Asbjørnslett and Hemmingsson (2008).

It might have been expected that participants with the more severe disabilities would have had reported to have participated the least in PE. This study, however, indicates differently. Table 3 provides an overview, relating participants' experienced degree of participation with their type of disability. As illustrated in Table 3, it seems like the participants with relatively lesser degree of physical disabilities<sup>6</sup> tend to report having participated to a *lesser* degree than the ones with more comprehensive disabilities. Those reporting to have participated in most activities and did not recall any negative experiences originating from PE all had more comprehensive disabilities. One of those was Kari, who, due to spinal bifida, is a wheelchair user. She recalled, "I do not remember any negative experiences in PE. I took part in what I wanted and was able to, and at the same time I was challenged."

	Participation in PE		
Type of Disability	Never or Seldom	Sometimes or Partially	Most of the Time
Problem with one limb	n = 3	n = 1	
Problem with two limbs	n = 2	n = 1	n = 2
Problem with more than two limbs	n = 0	n = 0	n = 2
Muscle disease	n = 0	n = 1	
Partially Sighted	n = 0	n = 1	n = 1
Blind	n = 1	n = 1	n = 0

Table 3 Participants'a Reported Degree of Participation in PE

The experience of failing. Central in other negative experiences was the opposite of exclusion, namely, having to participate, but on terms not adapted to their abilities, resulting in experiences of failing. This characterized six accounts from PE as well as three accounts originating from settings other than PE. One account was given by Alma (born with visual disability), who had attempted to join ordinary sports clubs, with little success. She recalled, "as you are usually the only one with a disability, most of the time you cannot keep up." Her negative experiences in many ways resonated with the ones reported from PE. Hannah, for instance, recalled:

It was awful! If I had been able to play truant, I would have. It was just so ridiculous that I had to participate in ballgames, as I could never keep up. . . . I distinctly remember how it was to stand in the middle of the field, just wishing for the lesson to finish quickly so I could get home. (Hannah, acquired a progressive visual disability)

Hannah described how her classmates got angry with her for not catching the ball and that it had meant that she had felt inadequate and begun to doubt her athletic abilities. Similar experiences of failing were described by other participants and illustrated in expressions like "It is not funny always to be chosen last!" and "I always lost, and I found that so depressing." Peter (born with cerebral palsy), recounted his particular negative experience:

I had to instruct [aerobics] . . . but to carry it out became too difficult, and I did not succeed. The focus on me as an instructor became too great and it completely "crashed" in my head, as I knew that an aerobics instructor has to be an example for others to follow, and I am not so stupid than to understand that the "example" I was able to show was not right. It became too big a challenge. I could not do it.

It had been a negative experience, both for him and his classmates. Peter had felt embarrassed over his difficulties with controlling his movements, while his classmates felt awkward as they, in attempting to follow his movements, had felt that they made fun of him without intending to. Concerning the experience, Peter

<sup>&</sup>lt;sup>a</sup> The 16 participants who were born with a disability or acquired a disability while still at school.

reflected: "I think this was completely unnecessary. . . . This became too personal and I felt I got completely stripped bare."

Embarrassment in relation to failing in PE was also central in Tanya's description of having had to participate in orienteering in PE in spite of being partially sighted. She recalled how she got lost in the forest: "I was only 12 or 13 years old . . . it was awful. I remember the feeling of having to go back, downcast that this was not possible for me." She had felt embarrassed over not accomplishing the task and that it had been her own fault. Tanya compared this experience to another incident, which also originated from PE:

I ran a 60 metre race and somebody had placed a manhole cover at the end that I stumbled over and broke my arm. Naturally it hurt, as I broke my arm, but it did not affect my self-confidence the same way, as everybody said that it was really stupid to place a manhole cover there and that we should never have run there! And then it was not really my fault.

The two negative experiences related by Tanya were experienced quite differently. While the latter experience, resulting in a broken arm, might seem more dramatic, Tanya recalled her failure in orienteering as being more painful than breaking her arm.

Among the negative accounts from PE, one participant recalled an incident originating from before he became disabled, having to do a somersault over a vaulting-horse:

I did not dare to, but I did not dare to say that I did not dare either. So I ran towards the vaulting-horse and I knocked over the vaulting-horse, so it and I rolled across the floor, while the whole class was standing there laughing. It was awful. (Daniel, acquired a visual disability)

The experience originating from before he became disabled stresses that participation in PE can also be challenging for people without disabilities, as has also been documented in other research (e.g., Cantell & Kooistra, 2002; Cantell, Smyth, & Ahonen, 1994; Fitzpatrick & Watkinson, 2003; Schoemaker & Kalverboer, 1994). Daniel's being the only one in our study recalling a negative experience originating from before he became disabled may suggest that people with disabilities are more prone to experiencing difficulties in settings like PE, which are typically organized in ways that accommodate participants who have different bodily capabilities to participants with disabilities. The accounts of failing underscore the relational element of experience, as they seemed not only to be based in "not succeeding" but also influenced by teachers' understanding of students' challenges.

**Experiences of not being listened to.** The third common theme that characterized seven of the accounts was the experience of *not being listened to*. Peter, for instance, who struggled with instructing aerobics, had suggested that he could have passed the exam by explaining what he would have done *if* he had had to instruct in aerobics. He found, however, that he had not been listened to, nor had his suggestions been considered. A solution was never found, which affected his final grade in PE. In similar ways Hannah reported not having been listened to. Her teacher had insisted that she take part in football in spite of not being able

to see the ball or the other players and had trouble with finding the goal. Hannah described her experience:

I had told my teachers about my sight problems and that I could not play ballgames. Still they were hell-bent on making me do them! I asked several times to be let off and do something different . . . perhaps I could kick ball with a friend or do something I could get a better grasp of. But, no, they just did not listen! It did not really fit with their plan or with the other students that I had to be there.

The teacher had rebuffed Hannah's suggestions, justifying this by claiming that it was stated in the curriculum that *all* students had to participate in football to graduate in PE.<sup>7</sup> Hannah's difficulties with participating in football had resulted in her getting a lower grade in PE than she normally got, which she found most unfair. Also Casper, whose participation in PE changed in parallel with changing school, emphasized frustration over not being listened to concerning his participation in PE. He stated "It was a decision made by the school. That is, I would definitely have chosen to be with my classmates, but it did not matter much what I wanted. They did not listen to me." Similar accounts of not being listened to were reported in studies by Fitzpatrick and Watkinson (2003) and by Fitzgerald (2005, 2009).

These accounts stand in contrast to the experience from Kari, who stated that she did not recall any negative experiences from PE and that she took part in what she wanted and was able to. This could indicate that her experience of being listened to involved both her abilities and intentionality being taken into account in a relevant way. The experience of not being listened to in some accounts seemed to be more significant than the practical difficulties regarding participating in given activities.

# **Discussion**

The purpose of the study was to explore participants' experiences of participation in physical activity, not focusing on any particular arena for activity. The number of negative experiences reported originating from PE, however, was so significant that it needed to be addressed. It might be argued that the number of negative experiences was not unexpected as all participants in the study had been exposed to PE. Following this reasoning, however, it would also mean that the majority of positive experiences with physical activity would be expected to originate from PE, but this was not the case. Even though all 20 participants recalled especially positive experiences, none of those originated from PE but from settings of organized sport or recreational physical activity (Bredahl & Spinelli, 2012).

In Norway, since the 1970s, the intention has been to include *all* students in the regular educational system in all subjects (Ekeberg & Buli Holmberg, 2004). Knowledge about and experience with including students with disabilities into mainstream schools has been gained over the years (Tripp, Rizzo, & Webbert, 2007; Wendelborg & Tøssebro). Taking this into account, it may have been expected that the participants in the study reporting the most negative experiences with PE would have been among the oldest participants. The relation was, however, not that unequivocal. The mean age for participants in the study was 35.5. While experiences of failing tended to be reported by the older participants (mean age

45.3), the mean age among those reporting experiences of exclusion and of not being listened to were 29.1 and 30.9, respectively. According to these findings, the development seems to have changed from the negative experiences tending to originate from compulsory participation in PE lacking adequate adaptation, to a greater degree of exclusion and experiences of being ignored. The findings stress that although legislation has been introduced in schools to support inclusion of students with disabilities, implementation takes time. Legislation is important to change attitudes and practice in the educational system, but research, like the current study, is required to understand how it has affected students' experience of participation (Fitzgerald, Jobling, & Kirk, 2003; Fitzpatrick & Watkinson, 2003).

#### **Embodiment and Experiences of Oneself**

The findings in the study bring out questions of embodiment: of not just *having* a body, but *being* a body (Merleau-Ponty, 1962) and the tensions that may arise for a person when the body he or she is *being* is not the body he or she is expected to have. This becomes particularly apparent in settings of PE (Duesund, 2003; Fitzgerald, 2009). The accounts illustrate how the experiences affect people: it is not just the "disabled body" that does not fulfill requirements, it is a persons' embodied "existential I" (Spinelli, 2005) that fails, gets excluded, or is not listened to. The effect was equally evident with regard to participants' most positive experiences (not originating from PE), where participants reported that embodied experiences of being capable and of surpassing limitations provided them strength to deal with challenges in life (Bredahl & Spinelli, 2012).

Recalling and relating negative experiences was challenging for many of the participants, and several shed tears during the interviews. Participants' strong wording such as: "embarrassment," "inadequacy," and "stripped bare" and statements like "the negative experiences are painfully embedded in you" underscore the emotions attached to the reported experiences. The experiences clearly constituted more than distant memories, but were experiences that had influenced participants' experiences of themselves and their abilities (Merleau-Ponty, 1962). This may also be supported by the fact that the four participants who declined the invitation to take part in the study were all among the youngest (18–23 years). In some interviews, participants were invited to reflect on why youths have hesitated to enroll in the study. Several participants replied that they probably would have hesitated themselves when younger, as they needed to mature before wanting to approach and reveal painful or troublesome experiences. As one participant expressed it, "You had quite a few negative experiences which mean that you probably need to become a grown up and get your life on track before you have the energy to rise above it and talk about it."

# **Ability Being Relational**

Accounts from the study draw attention to "experiences of being capable or not" being influenced, not only by being able to do certain things, but equally by to what degree these seem important and expected, as has also been stressed by Evans (2004) and Fitzgerald (2005). Leder's (1990) notion of the dys-appearing body may

contribute to an understanding of participants' experiences of living with a body, which sometimes appears to disturb opportunities to engage and participate in activities. Such experiences can be caused by the body itself, the physical surroundings, and other people. In this study, the negative experiences rarely centered on lack of physical abilities (e.g., doing a high jump or dribbling a ball as well as the others) or lack of accessible environments; rather, the negative experiences seemed to arise from (mainly) teachers, who participants found lacked understanding of their situation or did not take it into account in a relevant way. For some participants, this resulted in demands not being adjusted to their capabilities, causing experiences of embarrassment or failing. For others, their capabilities being overlooked resulted in exclusion. Central in the experiences was that being viewed as "not sufficiently capable" supported the experience of having a dys-appearing body. Interestingly, the participants who did not report any negative experiences from PE all tended to have more comprehensive disabilities, underscoring that the experiences of ability not only depend on the degree of disability but are also relational.

#### **Disability and Visibility**

Compared with the participants reporting negative experiences from PE, those who did not tended to have both more comprehensive disabilities and more visible disabilities, such as being wheelchair users. It could indicate that having a less visible disability, like being partially sighted or having a minor degree of cerebral palsy, constitutes a greater challenge in PE. It appears as if such disabilities may be overlooked and adequate adaptations not provided. Research by Duesund (1993) provided similar findings and stressed how lack of recognition can lead to a mismatch between what is required and what is actually possible.

Several participants in our study referred to PE teachers stating that adaptation was difficult as they felt constrained to follow the given curriculum. This, however, seemed almost exclusively to be the case if the participant had a "less visible" disability. There were no accounts of participants without arms having to play volleyball or participants using wheelchairs having to do long jumps with the justification of having to follow a given curriculum. In many ways, this could be equivalent to asking a partially sighted person to participate in orienteering, or a person with cerebral palsy to act as an aerobics instructor, as described by participants in the study.

PE constitutes an arena where one's capabilities and failures become clearly visible. Merleau-Ponty (1962) thematizes the potential vulnerability "being seen" involves. When we participate in physical activity, we jeopardize ourselves by being visible to others in a different way to taking part in, for instance, a Math lesson. If one does not understand the instructions given, or cannot execute a task, one can disguise this more easily in Math than in PE. When Daniel rolled across the floor with the vaulting horse, or Peter failed as an aerobic instructor, it was clearly visible to everybody. Having a less visible disability seeming to constitute a bigger challenge in PE might be due to it leaving the person's poorer performances visible, while the cause of it (the less visible disability) is less visible and obvious, both to others and the person him- or herself. The negative experiences reported by participants highlight common themes regarding the risks involved when dealing with the "lived body" of being particularly visible in physical activity.

#### Navigating in Life With a Disability

Accounts from the study show how participants actively navigate in life: they aim to take part, to pass an exam, or to avoid defeats. They reflect on their experiences and try to solve challenges. The term *intentionality* (Husserl, 1965), which stresses peoples' active engagement with the world, may help understand the difficulties people experience when they are not being listened to or are being prevented from using their potential. Kari's experience of "taking part in what she wanted and was able to" contrasts with other participants' accounts. It exemplifies how taking capabilities and intentionality into account can lead to more positive experiences in PE, in spite of not taking part in all activities. Not taking the participants' intentionality sufficiently into account in PE may contribute to negative experiences, just as much as the participants' physical or sensory limitations.

Merleau-Ponty (1962) states how the body one *has* and *is* influences the way one exists in the world. Equally, the world influences the experience of one's body and bodily abilities, as has also been strongly emphasized in the social model of disability (e.g., Oliver, 1996). Accounts in the study demonstrate how a disability is not just to be seen as "belonging" to an individual, but how disability reaches out into the world and how it is dealt with and understood "out there" affects the individual's experience. It is not just a person dealing with a medical condition or an individual difference; the experience of living with a disability is influenced by the world. Participants' accounts from the study illustrate the relational element of the life-world, this becoming particularly clear while participating in PE.

### Conclusion

Exploring the experience of participation in physical activity when living with a disability, suggests PE as being a particularly difficult arena. This is in accordance with previous research (Asbjørnslett & Hemmingsson, 2008; Bredahl, 1997; Duesund, 1993; Fitzgerald, 2005; Spencer-Cavaliere & Watkinson, 2010). The common themes revealed in our phenomenological study of experiences of not being included, of failing, and of not being listened to might indicate experiences of participants' intentionality (Husserl, 1965) and bodily capabilities (Leder, 1990) not being taken sufficiently into account. The fact that participants with relatively lesser degrees of disability more often reported negative experiences originating from PE might indicate that participation could be influenced equally importantly by how other people understand a participant's capabilities, rather than by the limitations a disability involves. It emphasizes the relational element of people's life world (Heidegger, 1962) and the importance of understanding a disability in its context.

As stated, the participants *did* all recall particular positive experiences with participation in physical activity (Bredahl & Spinelli, 2012). The fact that none of those originated from PE, however, might indicate that a context like PE tends to leave less room for experiences of "feeling capable" and of "surpassing limitation," at least for participants with disabilities. Phenomenological research captures individuals' experience while allowing for drawing out more general structures of experience, suggesting general critical issues. While participation in physical activity can provide enriching experiences, the findings demonstrate that physical activity can equally be an arena where embodied differences and shortcomings become exposed (Merleau-Ponty, 1962). Even though this might be especially

evident when participants have a disability, it probably applies equally to a number of participants with varied degrees of capabilities. The findings indicate critical issues concerning experiencing being included, succeeding and being listened to, which, when handled with care and consideration in practice, are likely to increase the chances of physical activity in general and PE in particular, providing positive experiences to participants both with and without defined disabilities.

### Limitations to the Study

It might be argued that recalling experiences retrospectively is a limitation with regard to trustworthiness of the findings. Practices in PE are likely to have changed over time, and findings based on experiences dating up to 40 years in the past might not reflect PE practice today. The aim of a phenomenological study, however, is to present some general critical issues based on subjective experiences. Such issues concerning participation in physical activity are likely to be relevant concerns in any practice.

The findings in the study also do not determine "disability" as being the only aspect causing the negative experiences in PE. Factors like gender, lack of ability, or being a minority may also have influenced the experiences. Of equal influence could be that the teacher had been in a bad mood, treated many students poorly, or simply was a poor teacher. It does not, however, change the fact that the majority of negative experiences reported in this study originated from PE, and not from other settings. The findings actualize the necessity of teacher training and continuing professional development (Sherrill, 2004).

#### **Further Research**

Further phenomenological research in the field can contribute knowledge concerning how participation is experienced in a variety of settings, including in which ways participants find that their participation can be improved. Such knowledge might assist practitioners and researchers to better understand challenges for participation, as well as the aspects that are of importance for participants to initiate participation.

#### **End Notes**

<sup>1</sup>This required that potential participants did not have too comprehensive a speech impediment, as the data collection depended on verbal communication.

<sup>2</sup>The choice of age groups aims to ensure inclusion of participants in different phases in life: transition period of establishing an independent adult life, establishing work career and family, being in a more established life situation, while not yet retired.

<sup>3</sup>As described at http://www.paralympic.org/Sport/Classification retrieved 24th of June 2010.

<sup>4</sup>This was to ensure enough data obtained through the interviews and a condition for the research grant.

<sup>5</sup>The 18 months time span was mainly due to invitations being sent progressively as interviews had been conducted to ensure they were sent to potential participants who contributed to fulfill the inclusion criteria.

<sup>6</sup>Such as having a problem with one limb or having a minor degree of spasticity.

<sup>7</sup>This reflected the teacher's interpretation, not the actual wording in the curriculum for PE in Norway.

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