

"My own way of Moving"
The Movement Experiences of Children with
disabilities

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Summary

This dissertation is about how children with various disabilities and chronic illnesses experience movement. Their experiences of movement are investigated in different contexts; daily life, regular follow-up programs within health and habilitation services and in a movement improvisation group. Phenomenology constitutes the theoretical perspective and the applied methodology, which indicates that movement is understood as both a personal and an inter-subjective phenomenon.

The empirical material stems from interviews and observations. Twenty-three children, all between four and 12 years of age (nine girls and 14 boys) and their parents participated in the project. The children were recruited from two different entities within the Norwegian specialist health services, one at a national level and the other at a county level. The inclusion criterion for children recruited from the national unit was that they be diagnosed with severe congenital heart disease (CHD). The inclusion criteria for children recruited from the county level unit were that they have motor function disability and a desire to participate in a movement improvisation group with other children once a week over a period of time.

The dissertation includes three papers. The papers illuminate how each of three different contexts offers different opportunities for the children's movement experiences and expressions. The three contexts are: children's daily life (Paper I), regular follow-up programs conducted by health and habilitation services (Paper II) and improvisational movement praxis (Paper III).

Paper I examines children's experiences with movement in play and familiar daily life activities. Interviews were carried out with 11 children and their parents. All children were diagnosed with CHD. In addition, observations of 10 of these children were recorded during one day at their school. One of the central discoveries revealed in this paper is that children move in different situations in ways that support them in the fulfillment of their primary wish: to be with friends and do what their friends do. Movement is shown to be a key to achieving this goal. The paper reveals that children's embodied movement strategies entail an awareness of their own physical condition, the characteristics of the

activity, the other children, cultural rules and the actual environment at a particular moment.

Paper II explores experiences of being tested when the aim is testing motor function by the use of standardized outcome measures. The material includes interviews with the same participants as in Paper I, as well as with nine additional children and their parents. An interview with a man in his mid-fifties with a lifelong medical condition is also included in the material. The paper shows that, for the children, the meaning of being tested is primarily related to the question of whether they pass the test requirements or not. The children often experience repeated testing as an ordeal they feel they are expected by others and also expect themselves to endure.

In paper III the purpose was to explore children's experience with movement improvisation. The research was framed as an inquiry into whether children with disabilities can be encouraged to develop and explore their own personal way of moving. A group of 12 children was invited to participate in a movement improvisation group over a period of one year. The central topic was to explore "one's own way of moving". Children's own capacities, kinetic repertoires and creativity in movement were clearly stimulated by an improvisational approach. Improvisation promoted an interest in moving and a desire to continue to move. However, the children needed time to become accustomed to movement improvisation and the new opportunities it afforded. One of the conclusions drawn in this paper is that improvisation can function as a pedagogical and therapeutic way of approaching movement training in child habilitation.

All three papers highlight how children with disability and chronic illness have the capacity to adapt and cope with challenges stemming from their environment and their bodily condition. The moving child and her or his environment share a reversible, dynamic and intertwined relationship. Performing movement in varied contexts showcases children's ability to take advantage of a situation as their bodily space appears to them through movement and action and thereby fulfills their primary goal. Additionally, the papers illuminate how children are capable of moving when they are engaged in an activity that is meaningful and social. Engagement in moving seem to be a key to adapting to different situations, as the children develop their movement capacity and participate in play. All three papers show how the children use their bodily awareness and the condition of the environment to support their actions. The results indicate that different children

perceive each other's bodily capacities and expressions and that these are a key factor in their play and participation. Consequently, an individual child's movement competence should not be linked to established, standardized forms of outcome; rather, it should be assessed in terms of movement expression and capability. The dissertation reveals that children with disabilities possess an innate awareness of how to balance their movements and activities with the demands of the environment and the actual situation. The three papers together discuss the validity of "normative based" expectations, including the tendency to regard some ways of moving as more skillful and successful than other ways, regardless of the experience of the mover. The dissertation sheds light on how children with disabilities have been defined historically and within medical/ social and hybrid perspectives of disability. Being "looked at" as different is a central experience in the lives of children with disability, but they are also viewers themselves. This situation of both being seen and see gives them "freedom" to engage in dynamic and changeable situations and activities with others. The research also shows that children who know each other as schoolmates or friends adjust their different ways of moving and acting according to the claim of the context and that their movements become habitual and familiar to them. However, every time a disabled child meets new people, he or she runs the risk of being perceived as "different". From the children's point of view, they incorporate these "differences" and treat them as the normal ways of playing, moving and acting together with friends. The dissertation argues that these are illustrations of co-existing-subjectivity—of mutual intercorporeality.

The children's specialized knowledge about themselves and their situation is a highly valuable resource. For professionals it would be particularly advantageous to become aware of the knowledge children possess about moving and how they use movement to adjust to play, to express themselves and to "throw" themselves into movement improvisation. The dissertation's conclusion is that phenomenological perspectives on movement experience have revealed movement as a rich resource in the lives of children with disabilities.

List of papers

The present dissertation is based upon the following original papers:

- I Wenche Schrøder Bjorbækmo and Gunn Helene Engelsrud. **'I am almost like a fish': an investigation of how children with congenital heart disease experience and perform movement in daily life**

Child: Care, Health and Development, 34 (2008) 781-788.

- II Wenche Schrøder Bjorbækmo and Gunn Helene Engelsrud. **Experiences of being tested: a critical discussion of the knowledge involved and produced in the practice of testing in children's rehabilitation**

Medicine, Health Care and Philosophy 2010; [DOI: 10.1007/s11019-010-9254-3](https://doi.org/10.1007/s11019-010-9254-3)

- III Wenche Schrøder Bjorbækmo and Gunn Helene Engelsrud. **"My own way of Moving" Movement improvisation in children's rehabilitation**

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1 Introduction

In one of the chapters of the book *Arguing about disability - philosophical perspectives*, Jackie Leach Scully describes her personal experience of deafness living in a “hearing world”. In particular she explains how she constantly orients herself with reference to the sources of sound and especially to light. The sources of light became “her ears”. She suggests, based on own experience, that her ways of orienting herself might be subtly unlike those of hearing people (Scully 2009, p. 68). The way she contextualized herself as a person with a “specialized way of living” in a world with hearing people made a strong impression on me.

Having a disability or a chronic illness from birth or early childhood is, according to Scully, to be a more or less “compromised” body. However, Scully does not describe her situation as a problem; instead she sees in it a possibility for the development of some “specialized capacity”. To regard a hearing problem or deafness as an opportunity to develop some “specialized capacity” inspired me. In my own life, I was diagnosed at the age of four with juvenile rheumatoid arthritis (JRA). In various periods of my life this disease has caused stiff and painful joints – especially in my knees. Thus, beginning at the age of four, my experiences with movement have been colored and shaped by living with this chronic disease. During my life and especially during my work on this dissertation, I have become explicitly aware of how my orientation to movement is rooted in my body condition connected to the disease. The disease has changed my body and movement possibilities in unpredictable ways, and thereby my orientation to the artifacts and physicality of the environment. In this way my experiences can be read in light of Scully’s text. One example from my childhood may illustrate what I mean.

I lived with my parents two minutes from a sandy beach and five minutes from one full of rocks. My friends and I often wanted to go to the beach. For us the beach was one of our favorite playgrounds. I longed for the beach and now as an adult I have strong memories of it. I wanted to go:

to the sandy one of course
that's the best. - more fun to play - better to take a swim.
easier to catch starfishes and crabs - cooler boys to look at¹

That the sandy beach was best seemed obvious and it was not something I wondered about or speculated on as a child and teenager. My reflection today might, however, shed light upon how this environment with the soft sand gave me an advantage in being able to move and become an equal participant playing with my friends. I used the sand as an environmental element to include myself and to do as my friends did:

Sand castles are just one thing you may make of sand
I know of sand-chairs and pillows too
putting a sand pillow between my bottom and my calves - and
I sit on my knees as easy as anyone
I love sandy beaches

Moving and especially sitting on the sand was easy. Since my knees often were stiff, the sand and water acted as a relatively supportive environment so did stones, stumps, curbstones, rugs, pillows, snow, handrails, etc. They were all environmental characteristics and artifacts which I took advantage of in order to move and participate.

Through my childhood and into adult life, movement has been something I connect not only to stiffness and pain but also to joy and fun. Even in periods of active illness, my interest in moving has been “kept alive”; through movement I developed and refined my alertness towards the environment. To make a long story short, these experiences influenced my choice to become a physiotherapist and devote my professional life to work with children. Through the years I have worked within different areas of what today is

¹ I have written this small “poem” while working on my PhD project.

known as the field and context of child habilitation². This means that I have been working with children who, like both Scully and myself, from birth or early childhood are “more or less compromised bodies”, as Scully puts it.

As already indicated, children with “compromised bodies” might find their own solutions to movement and action by the way they “cultivate” their perception of the environment and orientate themselves. In meeting professionals within habilitation, their specialized capacity of movement as well as social competence and participation with others can be both highlighted and hidden. My main research questions have grown from my experiences of assessing, treating and teaching movement in habilitation.

Over the years I have experienced that one of the most important knowledge and competence a child physiotherapist had to learn was to observe children’s movements in order to identify deviations in a child’s movements compared to what is understood and seen as “normal motor development and function”. Being an experienced physiotherapist for years I have developed an eye to distinguish between “normal” and what is understood as deviations from “normal” movements and movement development. This is an important competence and knowledge within a diagnostic context and also in terms of a child’s rights to health and habilitation services. During the 1990s I experienced that the use of standardized outcome measures to describe, distinguish and evaluate children’s movements or rather motor function increased and was considered as sign of good quality in habilitation services. However, I gradually began to doubt the major emphasis and great focus on describing children’s movements based on an understanding of “normal” and the deviance from “normal” as the most meaningful for the children themselves, and as the best approach to support them in their own effort to develop their movements.

This experience made me wonder how children with movement capacities that in different ways deviate from the current assumed norm or standard for movement, orientate themselves in daily life. How do they “solve” the differences that Sully points to? What do they like/dislike and find meaningful when it comes to movement? In my work as physiotherapist I have met children with “movement and body stories” that have touched and influenced me and also reminded me of my own story. The experiences outlined here has provoked my curiosity and inspired me to do research on certain topics. In particular

² Habilitation is the Scandinavian word and concept for children’s rehabilitation

my interest has been to investigate more closely how children develop and use their “specialized capacity” in moving. How do they invent or create ways of moving in different activities and situations? How do they account for their experience of moving? Do they “solve” their movement “limitations” as I solved my knee problems at the beach? Which movement strategies do children develop to cope with the environment?

When I proposed the PhD project my chief intention was, as indicated, to “pursue” and “satisfy” (to a greater extent) my interest in children’s capacity to orient themselves as creative movers. I wanted to examine how and in what ways movements and ways of moving are experienced and expressed by themselves in different situations in life. I was also interested in whether and how children’s own creativity and capacity in movement could be supported and strengthened within an institutional context like habilitation.

My interest to investigate children’s own perspective on movement connects to the growing body of research within humanistic health science³. Within this broad field I am especially inspired and affected by phenomenology and the writings of the French philosopher Maurice Merleau-Ponty⁴ (1968; 2005a⁵). Reading Merleau-Ponty’s philosophy has inspired me to pay attention to the value of the experiential side of movement. Through a phenomenological lens, movement can be regarded as a relational and inter-subjective bodily phenomenon.

Other sources of inspiration in the course of the PhD project has been the work of several scholars within qualitative health research, social science and humanities who emphasize children’s experiences as important in research concerning children themselves. Some of these researchers highlight the perspective of children with disabilities or chronic illness related to body and movement activities, and also recognizes the complexity and variety in the lives of children with disability (Mulderij 1996; Mulderij 2000; Davis et al. 2004; Guell 2007; Connolly 2008; Gibson et al. 2009). Also, research that examines “non-

³ <http://www.med.uio.no/ish/forskning/hhf/framework.xml>

⁴ Merleau-Ponty’s chief inspiration was the school of phenomenology that emerged in Germany in the early decades of the twentieth century with names like: Edmund Husserl, Martin Heidegger and Max Scheler (see: Carman and Hansen 2005 p. 1-23)

⁵ From now on onwards in the dissertation I use the abbreviation: PhP which refers to Merleau-Ponty’s Phenomenology of Perception and the reprint from 2005.

disabled” children’s experiences of movement have been sources of inspiration (Nilges 2004; Smith and Lloyd 2006; Smith and Fraser 2007; Nielsen 2008; Nielsen 2009). Several researchers have drawn attention to children’s participation and involvement in play and daily activities (Johannesen 2006; Eide 2008; Kirova and Emme 2009; Myrstad and Sverdrup 2009; Guldbrandsen 2010). Within the field of childhood studies the focus on children as social actors who find ways of creatively managing, negotiating and extending their possibilities has been of special inspiration (Prout 2000, p. 7; James 2000; Prout 2005, p 84).

What I so far have outlined is how experiences from different parts of my own life together with theoretical, philosophical perspectives and different research concerning children’s experiences has formed both the basis and been a continuous source of inspiration in my work with the dissertation. As already stated, a perspective that values the subjectivity of the mover is the main interest in the PhD project.

Thus, the overall aim of this dissertation is to gain insight into children’s movement experiences. My means of uncovering this knowledge is to explore how children talk and express themselves. More specifically, the aim is to examine the embodied movement knowledge—gained through and used during daily life activities and situations—of children affiliated to habilitation in the broad sense of its impact area. Secondly, my interest is also a practical one. I want to examine what kind of experiences can be expressed when children within the context of habilitation are invited to participate in an innovative movement group that allows them to explore and improvise in moving. This can be expressed in two research questions:

- *How do children with different disabilities or chronic illness experience movement and participation in different activities in daily life?*
- *What will come into light and happen when children are given the opportunity to explore and improvise their own ways of moving, together with others in a group, over a period of time?*

As mentioned these research questions have grown from my work in child habilitation. Those who use this institutional service are children who from birth or early childhood in different ways are compromised bodies, in the words of Scully (2009), and it is within this context I have derived most of my experience as a physiotherapist.

Habilitation - institution and research context

Norwegian contemporary habilitation service is rooted in a complex organizational model comprised of several different governmental authorities -- altogether regulated by four different political ministries: the Ministry of Health Care Services is responsible for medical and paramedical institutions. The Ministry of Education and Research has the responsibility for special education, educational and psychological counseling services, and educational specialty services. The Ministry of Labor and Social Inclusion⁶ is responsible for work and welfare administration. The child welfare service belongs to the Ministry of Children and Family Affairs⁷ (Hesselberg and von Tetzchner 2008, p. 85-87). This complex administrative regulation of the services illustrates how the lives of children referred to habilitation might, and usually does, include contact with many different professionals.

Professionals that, within this compound structure work variously at municipal, county, regional and national levels⁸. Sometimes even experienced professionals have to struggle in order to navigate and to get an overview of this “organizational jungle” (Hesselberg and von von Tetzchner 2008, p. 85). I have experiences from working both at municipal and county levels and have learned how children and parents are struggling to get an overview of who can and do what, where and when at different times.

Von Tetzchner et al. (2008, p. vi) explain this complexity and maintain that habilitation “in its nature” is interdisciplinary, and that no isolated professions possess the knowledge needed in habilitation work with children, youth and adults. This means that for children referred to habilitation services and their parents, several professionals often enter their lives almost immediately after the child is born (von Tetzchner et al. 2008, p. vii). What habilitation is meant to do is defined in “Forskrift om habilitering og rehabilitering”, where the aim of habilitation service is defined as:

[]timed and planned processes with clear goals and means, where several parties cooperate in providing necessary support to the consumer’s own efforts in order to

⁶ This refers to NAV which is not an abbreviation, but rather a name; see: <http://nav-norge.blogspot.com/2009/10/nav.html>

⁷ Also named; Bufetat

⁸ Forskrift om habilitering og rehabilitering (2001)

achieve optimal functional and coping skills, independence and participation in a social context and in society at large (Forskrift om habilitering og rehabilitering 2001⁹, kapittel 1, § 2)¹⁰

The stipulation named here aims to ensure that persons in need of habilitation are offered services to support their own learning and motivation, increase their functional and coping ability, secure equality and participation. The services offered are directed toward securing client participation, systematic planning and interdisciplinary, coordinated actions. Additionally, it is emphasized that the services offered have to be meaningful to the user her or himself, as well as being located as closely as possible to where the child and family live.

The children referred to habilitation and those who have “the right” to become users of this service are described as children with congenital chronic diseases or disabilities and those who during the first years of life acquire a chronic disease or disability. Additionally, children who are in danger of developing a permanent disability or chronic diseases are also eligible for habilitation services (Forskriften 2001 § 3; von Tetzchner et al. 2008). All children with reduced functioning who are in need of interdisciplinary habilitation are in the “target group” of habilitation services (von Tetzchner et al. 2008).

Von Tetzchner et al. (2008, p. 2) refer to the definition in the public law proposal (Stortingsmelding) nr. 23, 1977-78 as that which forms the basis for habilitation services in Norway today, and describes who is disabled. It says:

A disabled person is one who, due to permanent disease, injury or defect or due to social deviation, is substantially inhibited in the practical participation in society around him. This may refer to education, choice of occupation, physical and cultural activity (Public law proposal no. 23, 1977-78)¹¹.

⁹ <http://www.lovdata.no/cgi-wift/ldles?doc=/sf/sf/sf-20010628-0765.html>

¹⁰ [...] tidsavgrensede, planlagte prosesser med klare mål og virkemidler, hvor flere aktører samarbeider om å gi nødvendig bistand til brukerens egen innsats for å oppnå best mulig funksjons- og mestringsevne, selvstendighet og deltakelse sosialt og i samfunnet.

¹¹ Funksjonshemmet er den som på grunn av varig sykdom, skade eller lyte, eller på grunn av avvik av sosial art, er vesentlig hemmet i sin praktiske livsførsel i forhold til det samfunn som omgir ham. Dette kan gjelde utdanning, yrkesvalg og yrke, fysisk og kulturell aktivitet (Stortingsmelding nr. 23, 1977-78).

How disability is understood is important for how children with disabilities are seen and understood by their surroundings and also of importance to how they see themselves. I have briefly shown how Habilitation as context refers to an institutional organization, but it also refers to an emergent comprehensive research field with roots in social sciences, humanities and medical sciences, all of which provide different frameworks to the present understanding of disability (Albrecht et al. 2001, p. 2; Grue 2004). In the dissertation investigating children's experiences of movement through a phenomenological lens imply to regard the children as situated in a cultural and social world of meanings and understandings about the concept and the phenomenon of movement as well as that of disability.

Outline of dissertation

I have so far indicated that the theoretical perspective and research approach in the dissertation is based on phenomenology. In the following chapter I present this applied theoretical perspective with emphasize on movement experience as an inter-subjective phenomenon. In the same chapter I also present a limited sketch of the historical and contemporary understanding of disability. By doing this, my aim is to contextualize children in the PhD project within the structures of meaning and understanding of the concept and phenomenon of disability. Thereafter, in chapter three, I elaborate on phenomenology as research approach and describe the process of producing and analyzing the empirical material in the PhD project. Chapter four provides summaries of the three papers in the dissertation and their "findings". The dissertation ends with chapter five, where I discuss these findings in light of the theoretical framework described in chapter two, and suggest potential areas for future research. Before I go further, it is important to clarify that, since I am not a philosopher I do not use phenomenology in a philosophical sense. My approach can be described as practicing phenomenology based on empirical work (van Manen 1990, p. 7; Finlay 2009, p. 8). Thus, I have no ambition to make a contribution to phenomenology as philosophy.

2 Phenomenology - Movement - Disability

The phenomenological world is not the bringing to explicit expression of a pre-existing being, but the laying down of being. Philosophy is not the reflection of a pre-existing truth, but, like art, the act of bringing, truth into being (Merleau-Ponty PhP, p. xxiii).

The inter-subjectivity of experiences

As already mentioned, reading Merleau-Ponty's (PhP 2005) philosophy made a strong impression on me. Since then, Drew Leder (1990), Susan Wendell (1996), Hubert and Stuart Dreyfus (1999), Maxine Sheets-Johnstone (1999), Samuel Todes (2001), Richard Shusterman (2005), and David Abram (2005) have also contributed to my interest in and understanding of human movement as an expressive way of being-in-the-world. These authors emphasize a view of the human condition as experiencing bodily existence. I was deeply affected by this concept, and felt like I had been "woken up". This feeling was due to the importance this perspective placed on experience. It stimulated and enhanced my own experience, like my love for sandy beaches and fascination for children's inventiveness and creativity in movement, and, most of all, this theory recognized and valued the subjective, embodied and emotional expressiveness of human action and movement. Seen through this perspective, the movement of children with different capacities and competencies became valid, significant and important. I will elaborate on the use of phenomenology as a perspective for understanding movement. Before doing so, however, I would like to cite the opening sentence in Merleau-Ponty's major work, *Phenomenology of Perception* (PhP), where he asks: What is phenomenology? He answers that: "We shall find in ourselves, and nowhere else, the unity and true meaning of phenomenology (PhP, p. viii). He then describes how phenomenology emphasizes the significance of the individual and the individual's experiences in the creation of knowledge. He elaborates:

I am the absolute source, my existence does not stem from my antecedents, from my physical and social environment; instead it moves out towards them and sustains them, for I alone bring into being for myself [...] the tradition which I elect to carry on (PhP, p. ix).

The acknowledgment of the experiencing subject or individual as the creator of knowledge and understanding of different phenomena means that knowledge is always derived from the experiencing subject's particular point of view. Merleau-Ponty clarifies this when asking: "Is not to see always to see from somewhere?" (PhP, p. 77). He initially explains what being a person, an experiencing subject, is by stating what he is not: "I am not the outcome or the meeting-point of numerous causal agencies which determine my bodily or psychological make-up" (PhP, p. ix). Continuing, he points out that "I cannot conceive myself as nothing but a bit of the world, a mere object of biological, psychological or sociological investigation" (ibid). To be a person, a subject, a body, is then to be "a bit of the world". He elaborates on this in describing the phenomenological world, the world of experiences:

The phenomenological world is not pure being, but the sense which is revealed where the paths of my various experiences intersect, and also where my own and other people's [experiences¹²] intersect and engage each other like gears. It is thus inseparable from subjectivity and intersubjectivity, which find their unity when I either take up my past experiences in those of the present, or other people's in my own (PhP, p. xxii).

In this quotation Merleau-Ponty reveals the relationship between the experiencing subject and the world. The unity of subjectivity and inter-subjectivity and the recognition of how experiences and perspectives of different people can blend has been decisively important to me in exploring children's movement experiences in my dissertation. This perspective has led me to see movement as being created and performed in a dynamic interchange between a child and other individuals and objects—or, in brief, between that child and the world.

¹²My addition

The child--a person who moves, experiences, perceives and understands-- is a bodily being. Merleau-Ponty designates the body as “the vehicle” of our being in the world. Thus, to be and to have a body is to be constantly involved in certain environments and to continually identify with and commit oneself to certain projects (PhP, 2005, p. 94). Emphasizing the subject’s being as a bodily being is, according to Abram (2005, p. 54) the revolutionary contribution of Merleau-Ponty’s theory¹³. This is also noted by Shusterman (2005, p 151), who describes Merleau-Ponty’s work as a rigorous, systematic and persuasive argument of the “body’s primacy in human experience and meaning”, and therefore the crucial source of all perception and all action, as well as the basis of all expression, language and meaning.

Merleau-Ponty sees human existence as an embodied existence and argues that the root of both one’s subjectivity and one’s transcendence in relationship to others consists in “being given to oneself”. He writes: “*I am given*, that is, I find myself already situated and involved in a physical and social world [...]” (PhP, p. 419).

Merleau-Ponty goes on to assert that the relationship between the body-subject and the world implies the freedom, the fundamental power to be the subject of all one’s experiences (PhP, p. 419). Explaining this freedom, he says:

It is a fate for me to be free, to be unable to reduce myself to anything that I experience, to maintain in relation to any factual situation [...] and this fate was sealed the moment my transcendental field was thrown open, when I was born as vision and knowledge, when I was thrown into the world (PhP 2005, p. 419).

The relationship between the subject and the world, he emphasizes, means the individual being is “tied to a certain world” and the body is “of space” and not primarily “*in* space” (PhP, p. 171). Additionally, he explains that: “I am not in space and time, nor do I

¹³ Abram (2005) claims that even in the 21st century most people usually think of the self as something other than the body. He holds that dualism is still present in this understanding of the body. Even if some philosophers claim dualism is dead, it continues to be expressed in ideas and beliefs expressed in concept-couples such as body and soul, body and consciousness, and physical and psychic. The use of these dichotomized concepts reflects an understanding of the body as divided from consciousness. Merleau-Ponty, in contrast, maintains that the body is consciousness and consciousness is the body and one can’t be reduced to the other as they form an irreducible entity.

conceive space and time; I belong to them, my body combines with them and includes them”(PhP, p.162). This implies that the social is to be seen as a permanent field or dimension of one’s existence (PhP, p. 421). This concept makes it possible to see that time- space is a lived phenomenon that the children who form the subject of this dissertation experience and embody. Accordingly, the time and space that a moving child or anyone else inhabits at any moment is linked to, or, more precisely, is related to, the actual activity and situation that the individual child is involved in.

This inter-relationship of the subject and the world, Merleau-Ponty states, is a position of always being directed toward the world and simultaneously directed from it. He maintains that:

[...] the life of consciousness – cognitive life, the life of desire or perceptual life – is subtended by an ‘intentional arc’ which projects round about us our past, our future, our human setting, our physical, ideological and moral situation, or rather which results in our being situated in all these respects. It is this intentional arc which brings about the unity of the senses, of intelligence, of sensibility and motility. And it is this which ‘goes limp’ in illness. (PhP, p. 157).

The intertwined position of the subject and the world implies a position of continuous shifts between the body-subject as always directed inside-out and outside-in. Merleau-Ponty explains that these experiences of being directed both from within and without never exactly overlap. It is as if, he says, they “slip away at the very moment they are about to rejoin”. This everlasting “shift” and “slip” between inside-out and outside-in experiences occurs precisely because these reciprocal directions are properties of one and same body, one’s own body. Merleau-Ponty describes the property of the body as being to move in the world, to hear oneself both from within and from without, to see and to be seen, to touch and to be touched, etc. The body’s interconnection and interrelationship with the world includes this ongoing shift of inside-out and outside-in experiences and envelops these two entities or characteristics and makes them adhere to one another (VI¹⁴, 1968, p. 148). In the PhD project this has inspired me to pay attention to how children’s movements in different situations are related to the entire situation as well as to the kind of

¹⁴ VI, this abbreviation refers to Merleau-Ponty’s book *The Visible and the Invisible* 1968

body the individual child is and has, and to see that movements are never separated from their context.

Movement relations

In discussing movement and context, Merleau-Ponty asserts that: “Each voluntary movement takes place in a setting, against a background which is determined by the movement itself” (PhP, p. 159). Movement and background are in fact only “artificially separated stages of a unique totality” (ibid). He emphasizes that there is “no movement without a moving body which bears it uninterruptedly from start to finish” (PhP, p. 312). The moving body is both what children are and have and moves “in a space which is never “empty” or unrelated to them” (PhP, p. 159). Experience of movement provides the moving subject with “a way of access to the world” and to its objects. Merleau-Ponty adds that the bodily experience of movement has to be “recognized as original and perhaps also as primary” (PhP, p. 162). Once movement is recognized as both primary to the experiencing individual child and simultaneously blended with the situation that the child is part of and moves within, it becomes important to explore movement as a form of interactive, dynamic and changeable situational experiences and expressions.

In this sense the moving subject, as already noted, inhabits space and time, belongs to space and time and includes them (PhP, p. 161-162). Expanding on this concept, Merleau-Ponty emphasizes that “the synthesis of both time and space is a task that always has to be performed afresh” (PhP, p. 162). Movements are always movements at the moment. They are performed and experienced in specific times, places and situations. In this regard, Todes (2001, p. 58) explains that movements are produced and performed in the “spatiotemporal life-field of apparent circumstances, which we generate about ourselves by moving”. He describes his concept of “the spatiotemporal life-field” as “the field of our body needs in which things can appear only insofar as they are relevant to our needs by meeting them or failing to meet them” (ibid, p. 58). The moving child/person is then seen as creating her or his spatiotemporal life-field and based on her or his body needs sees different things, objects, situational aspects as relevant in relation to the actual movements at the moment.

In an approach similar to that of Todes, Merleau-Ponty says that the experience of our own body and movements teaches us to embed space in existence (PhP, p. 171). Moving

and acting imply a desire to achieve certain objectives or results and the relevant tasks or movements to achieve them are spontaneously and in different ways available to us “in virtue of their common meaning” (PhP, p. 172). To illustrate this, Merleau-Ponty writes:

That’s why, in their first attempts at grasping, children look, not at their hand, but at the object: the various parts of the body are known to us through their functional value only, and their co-ordination is not learnt. (PhP, p. 172).

Discussing the same concept, Todes (2001, p. 103) emphasizes that in making sense of a self-moved mover, we make sense of practical experience. In moving, the percipient self-moved mover relies upon “the *felt* unity of her or his active body in its freely directable activity” (ibid, p. 103). He goes on to declare that it is through such practical perception that the percipient finds herself in the world (ibid, p. 105). Phenomenology recognizes and appreciates movement as a decisive way for each of us to get to know ourselves or, more precisely, to get to know ourselves related to the world.

In a related argument, Sheets-Johnstone (1999, p.132) maintains that movement is the condition of all forms of creaturely existence. All of our knowledge originates in animatedness, she declares, since kinetic spontaneity is our point of departure for living in the world and making sense of it. Our animate being is the epistemological foundation of learning to move ourselves and the foundation of a developing repertoire of “I cans” (ibid, p. 136).

Sheets-Johnstone asserts that we literally discover ourselves in movement; by moving, we grow kinetically into our own body. In particular, she declares that to grow into our body is to grow into the distinctive ways of moving that come with being the body each of us is (ibid, p. 136). Accordingly, a child being the body she or he is in moving grows into her or his own ways of moving. However, I wonder if Sheets-Johnstone puts too much emphasis on self-directed animatedness as the basis for “growing into one’s own ways of moving”. I would suggest that children and everyone else develop under different conditions and with different opportunities related to their life circumstances. Moreover Sheets-Johnstone may be ignoring or underestimating the importance of environmental circumstances as interactive and interrelated factors in determining an individual’s movement creation and performance.

Merleau-Ponty maintains that to move oneself is what the subject, the individual person, does directly and differs in a basic way from moving others or other objects. He writes:

I move external objects with the aid of my body, which takes hold of them in one place and shifts them to another. But my body itself I move directly, I do not find it at one point of objective space and transfer it to another, I have no need to look for it, it is already with me – I do not need to lead it towards the movement's completion, it is in contact with it from the start and propels itself towards the end. The relationship between my decision and my body are, in movement, magic ones (PhP, p. 108).

Shusterman (2005, p. 164) agrees with Merleau-Ponty that the relationship between movement and decision is impressive and mysterious in its effective spontaneous intentionality. Shusterman, however, maintains that this alone cannot explain all of the ordinary powers of movement and perception, speech and thought (ibid, p. 164). He offers this example: "I can jump in the water and spontaneously move my arms and legs, but I will not reach my goal unless I first learned how to swim". Referring to Merleau-Ponty, he posits that the question is how learning movements can be explained. Shusterman maintains that we spontaneously do or understand a lot of things that were previously beyond our repertoire of unreflective performance, and they have had to be learned - but how (ibid, p. 164). I agree with Shusterman on this point, as I have experienced myself how learning to, for instance, ride a bike, and performing other sports activities or a dance have taken time and required more than spontaneous and direct action.

Movement learning - Movement habits

Regarding Shusterman's point, Merleau-Ponty describes learning movements as an acquisition of movement habits. A movement is learned when the body has understood it. A movement is learned and understood when the body has incorporated it into its "world". To move one's body, he says is to aim at things through it and to allow oneself to respond to their call – a call which is made upon it independently of any representation (PhP, p160, 161). According to this reasoning, my love for sandy beaches cited in the introduction might be seen as an example of the sand calling on me and me allowing myself to respond

by seeking to play with my friends. The sand “called” as I came to see its supportive potentiality for my action at the moment.

Merleau-Ponty also describes the way that movement learning, new understanding and the acquisition of habit takes place as the subject/individual acquiring “the power to respond with a certain type of solution to situations of a certain general form” (PhP, p. 164).

However, he emphasizes that situations may differ greatly. This implies that movement response varies and can involve different “operative organ(s)”. He emphasizes that what all movement cases have in common is a shared meaning, rather than a partial identity of certain elements (PhP, p. 165).

Merleau-Ponty declares that in learning and acquiring movements, it is the body that “catches (*kapiert*) and comprehends movement”. He argues that the acquisition of habit is the grasping of significance - a motor grasping of a motor significance (PhP, p. 165). Examples he offers are to get used to wearing a hat (with a big feather extending your height), driving a car or using a stick, which require the individual to “be transplanted into them or conversely to incorporate them” into the bulk of her or his own body. A habit expresses the individual’s power to expand one’s being-in-the-world or the power to change one’s existence by “appropriating fresh instruments” (PhP, p. 166). The only way for habits to be acquired and established is through bodily effort. Habit, Merleau-Ponty asserts, “is knowledge in the hands, which is forthcoming only when bodily effort is made, and cannot be formulated in isolation from that effort” (PhP, p. 166). Effort is visible as it is expressed in movement – an example is children’s efforts to learn to crawl. For days or weeks a child can be seen standing on her hands and knees and rock her body back and forth, sometimes falling on her nose but soon up on her hands and knees again, resuming her rocking– until one day she crawls for the first time. Without this effort, she would not learn to crawl.

Shusterman (2005, p. 164) describes Merleau-Ponty’s description of body habit as being learned through unreflective motor conditioning or somatic sedimentation in everyday life. According to Shusterman, Merleau-Ponty believes that body habits consist of two layers: beneath the spontaneous body of the moment lies “the habit-body” of sedimentation (ibid, p. 164). By emphasizing effort in the achievement of movement habits, Merleau-Ponty also declares trial and error as an important aspect in movement learning, in the establishment of habits.

Skillful self's – skilled movers

Todes (2001, p. 79) holds that the percipient comes to be characterized by the skills she or he acquires. For example, he maintains that movement skills are acquired through the discovery of determinate objects and voluntary self-movement. In this way the percipient creates her or his own determinate skillful self (Todes 2001, p. 79).

Similarly, Hubert and Stuart Dreyfus (1999, p. 104), referring to Merleau-Ponty, assert that people encounter and learn more differentiated challenges to act and refine their skills. They call attention to the specific shape and physical capacities of the human body - that it has arms and legs, a certain size, and certain abilities: what Merleau-Ponty calls *embodiment* (Dreyfus and Dreyfus 1999, p. 103). An individual's embodiment is of decisive importance to his or her freedom to, for instance, move and act in different situations (ibid, p. 104). They suggest that innate body structures, general acquired skills and specific cultural skills are the three factors that enable the individual body to determine what emerges in her or his world (ibid, p. 104). They maintain that Merleau-Ponty's notion of the intentional arc encompasses these three factors, as well as the interconnection between skillful action and perception (ibid, p. 105).

The Dreyfuses suggest that many abilities such as movement skills are developed at an early age through trial and error and by imitation, and later in life by instruction as well (Dreyfus and Dreyfus 1999, p. 105). People rely on experience, imitation and instruction to learn and become adept at new skills. They have to devise a plan, or choose a perspective that determines which elements of the situation should be considered important and which can be ignored (Dreyfus and Dreyfus 1999, p. 106-107). Gradually, they become more competent as well as more and more emotionally involved in the task and graduate from the "*detached* rule-following stance" of the beginner. -At that point, skills seem to take off. Dreyfus and Dreyfus suggest that reluctance to take the risk of engaging in learning- for instance, movement learning--can lead to stagnation and ultimately to boredom and regression (ibid, p. 107-108). They point out that experts do not solve *problems*, they simply do what "normally works" (ibid, p. 110).

Absorbed, skillful coping is experienced as a steady flow of skillful activity in response to an individual's sense of a given situation. When the situation deviates from an optimal

body-environment relationship, the individual will engage in activity designed to relieve the “tension” generated by the deviation by taking him or her closer to the optimum. The body is simply challenged by the situation to achieve equilibrium with it (ibid, p. 111). This seems to be close to what Todes (2001, p. 70) calls being in touch with one’s circumstances and poised. He defines poise as a way of successfully responding to and dealing with objects, and other persons around – “when successful, poise is its own effect” (ibid, p. 65). He argues that poise is not just “a matter of internal bodily coordination, but also of skill in handling things (and persons) about us” (ibid, p. 66). It involves skill in handling, not only body coordination but also things, persons and the situation within which a child moves. In my observations of the children participating in this dissertation I have found this concept particularly cogent.

An individual engaged in movement tends to make increasing fine discriminations in situations and respond with increasingly appropriate actions. This pattern continuously enriches and refines the intentional arc (Dreyfus and Dreyfus 1999, p. 114). To enhance a skill, the moving child must be involved, and also get a great deal of practice. Dreyfus and Dreyfus characterize this as the body’s tendency to acquire a *maximum grip* on the world (ibid, p. 114). With this concept, phenomenology opens up the possibility of seeing and exploring movement and movement-skills as a dynamic and relational phenomenon that involves far more than the physicality and physiology of the individual child.

Seen through the perspective of phenomenology of movement, children in movement are continuously engaged in an effort to get a maximum grip on their world. In the formulation of Edith Cobb (2004, p. 17) every child, independent of being seen as “privileged” or “unprivileged”, tries to structure her or his world. In this effort of structuring their world children are situated in a cultural and social world of meanings and understandings, about the concept and the phenomenon, both of movement and that of disability.

Disability - concept and lived experience

Privileged, unprivileged, compromised or disabled – the terms, understanding and definition of disability have changed through history. Consequently, thinking about proper treatment as well as language and concepts to address persons with disability/disabled

persons has also evolved (Grue 2004). Harry Hendrick (2000, p. 36) states that what historians do best is to make connections with the past in order to illuminate the problem of the present and the potential of the future. Relating this concept to how (disabled) children have been understood and are currently understood, I would say that history uncovers and contributes insights into how different paradigms of disability have changed and, to some extent, persisted through different historical periods up until the present.

During the few last decades disability studies have flowered and brought together scholars and activists from a variety of backgrounds and disciplines (Whyte and Ingstad 2007, p. 1). The literature they have produced shows a tendency to focus on disability/the disabled as a conceptual, discursive and linguistic phenomenon within a historical frame (see for instance: Braddock and Parish 2001; Grue 2004; Solvang 2006; Ingstad and Whyte 2007; Vehmas et al. 2009; Engebretsen and Solvang 2010). Lars Grue (2004, p. 113) maintains that even though researchers labeled as non-disabled have made valuable contributions to our understanding of disability, the most salient have been provided by researchers, scholars and activists who themselves experience disability¹⁵. In pointing this out, Grue suggests that personal experiences of disability can play a special role in research on the subject.

With this as a point of departure, I shall contextualize disability as a concept and lived phenomenon in time and space. From this perspective, I will elaborate on the most prominent understandings of how disability influences the circumstances and environmental conditions in which children and their parents participating in the PhD project -- as well as I, the researcher -- live, act and move.

Disability and disabled - concepts charged with history and meaning

In Classical Greece and Rome, life was nasty, brutish and short, according to David Braddock and Susan Parish (2001, p. 15), and infanticide was common. Babies born with

¹⁵ See for instance: Per Solvang and his book "Annerledes" (Different) (2002); Susann Wendell and her book *The Rejected Body – Feminist Philosophical Reflections on Disability* (1996), James Overboe (1999); Petra Kuppers and her book *Disability and Contemporary Performance- Bodies on Edge* (2004); Halvor Hanish, the chapter "Annerledeshet og dødelighet" in "Annerledeshet – Sårbarhetens språk og politikk" (2010); Jan Grue, the chapter "Annerledeshet og identitet" in "Annerledeshet – Sårbarhetens språk og politikk" (2010)

deformities were regarded as signs of the gods' displeasure. The reasons for putting babies to death, especially those with obvious impairments at birth, varied from economic (too many children to feed) to sacrifice to mollify the gods and secure the future of the species and the group (Braddock and Parish 2001; Grue 2004). But even though infanticide of babies with obvious disabilities was practiced, impairment was at least partly accepted in the ancient world as a natural aspect of life (Braddock and Parish 2001, p. 17).

The practice of infanticide in the ancient world has an analog in contemporary discussions of prenatal screening. Berge Solberg (2009, p.185) explores prenatal testing from a philosophical perspective, noting the ethical question underlying the decision to screen or not to screen. Donna Reeve (2009, p. 203) notes that prenatal diagnosis may reveal situations where it would be necessary to establish what constitutes a livable life, and Matti Häyry (2009) examines the ethics of identifying, for instance, deaf embryos. Referring to James Overboe, Reeve (2009, p. 207) notes that when society introduces laws regulating abortion of an impaired fetus:

[it] is not simply about the killing of a human being without legal punishment; [...] there is also the issue of the status afforded to the potential infant. The non-disabled foetus has an expectation of a 'political life' whereas this is far less certain for the disabled foetus, who, by the very interpellation of being labelled as disabled becomes abjectified (Reeve 2009, p. 207-208).

While discussions continue concerning medical procedures and how a livable life is to be understood, children with disabilities are growing up and living. Grue (2004, p. 99) calls attention to contemporary concepts like; "designer-baby" and "genetic lower class", and suggests that a future in which we could design babies and eradicate those with specific genetic variants is not simply possible but likely¹⁶. Wendell (1996, p. 156) points out that "elimination of differences that are feared, poorly understood, and widely considered to be marks of inferiority, easily masquerades as the compassionate desire to prevent or stop suffering". It is all too easy, Wendell notes, to make the leap from imagining that you would not want to live under certain circumstances to believing that no one would. She suggests that, even if voluntary, medical technologies such as genetic screening, prenatal

¹⁶ See for instance Aftenposten (Norwegian News Paper) 8th of February 2007; Jeg er en utdøende rase (I am a dying breed) av Bjørn Hatterud

diagnosis and selective abortion quickly become social necessities in complex consumer cultures (ibid, p. 156).

In my work and research with children with disabilities and my own experience as someone with a chronic disease I have often reflected on these issues and felt how charged with layers of meaning and attitude they are to me personally. In different situations I have encountered questions or rather statements like *No one wants a disabled child*. I have experienced and felt how easy it is to agree, as well as the feeling of discomfort, an ethical discomfort, that follows. I agree with Scully (2009, p. 57) who asserts that moral philosophy and ethics necessarily involves bodies, since morality concerns behavior, and behavior involves bodies. Individuals are vulnerable to each other through their embodied selves, she points out, and ethical theories and rules are abstractions that attempt to regulate what happens when embodied humans interact (ibid, p. 58). In addition, it is also important to keep in mind not only what Scully names the *general fact* of embodiment, but also *specifics* of embodiment that deviate from what one usually thinks of as "normal" embodiment. All of these issues should be significant elements of a sound moral understanding.

Disability – demonology and the natural order

In Europe from the Classical era through the Middle Ages, many disabling conditions were thought to have supernatural or demonological causes which led to attempts at cures based on religious ideas and exorcism (Braddock and Parish 2001, p.17, 18). But demonology was only part of the picture; disabled people were accepted as part of the natural order. This coexistence of understandings lent credence to the claim that there was no universal definition or interpretation of disability in this period of history (ibid, p.21).

From the fourteenth through the sixteenth centuries Humanism in art was accompanied by advances in anatomical and physiological studies. This led physicians to attempt new endeavors to cure illness and disability based on biological etiologies and treatment and signified a change from the prevailing belief that illness and disability were supernatural (Braddock and Parish 2001, p.21). This trend continued. In the seventeenth century and the Enlightenment period it formed part of the intellectual platform from which contemporary Western civilization developed. Changes in the care and treatment of

disability were related to a theoretical belief that experience and reason were the source of all knowledge, rather than innate ideas and divine punishment. This laid the foundation for bold new psychological and educational interventions. In addition, a growing belief in the power of natural science to advance the species began to influence and shape treatment and care for disabled (Braddock and Parish 2001, p. 24).

This discursive shift also represented a shift from seeing deviants from the physical norm as exotic/foreign and as entertaining curiosities to viewing them as suffering, ill and handicapped (Whyte 1994). The medicalization of deviations and defects and the construction of this as pathology have contributed to the characterization of people with disabilities as objects for examinations and evaluation by specialists (Smith 2008, p. 80). This revolutionary change in thinking in the field of disability stimulated extensive efforts to develop treatment interventions and led to the ascendancy of the professional class of physicians, as well as educators and other caretakers (Smith 2008; Grue 2004, p. 42). It also encouraged the development and proliferation of institutions and schools across Europe and subsequently North America. This trend toward institutionalization gained even greater momentum during the nineteenth and twentieth centuries (Braddock and Parish 2001, p. 29; Grue 2004, p. 42-43).

Thus systematic differentiation of people with disability is a product of the early modern period. The development of science provided a foundation for the establishment of formal organizations dedicated to making disabled people resemble the rest of the population (Grue 2004, p. 43). For the first time in history, people were capable of intervening in what had earlier been perceived as “the immutable natural order”. This concept was based on the new belief that both “society and human beings could be perfected” (Braddock and Parish 2001, p. 29). Interest in bodily differences and categorization of people, Alison James (2000, p. 23-26) maintains, gradually lead to a widespread cultural and social belief that children’s bodies were simply bodies growing up or growing out of childhood. The welfare of the nation was a consistent feature in the Western world of the nineteenth century social and political thought. Ensuring good nutrition and health for children was regarded as essential to the well-being of the future adults they would become.

Disability and the concept of “the normal”

During the time of the First World War the concept of “the normal” gained extensive cultural and social influence (Grue 2004, p. 43). The emergence of the concept of normality in European languages more or less coincided with Adolph Quetlet’s¹⁷ introduction of the concept of “the average man”, and the curve of normal distribution. The prevailing political environment played a decisive role in the establishment of statistics as a prominent aspect of scientific knowledge about the human body. The scientific and rational discourse based on normal distribution, on statistical normality, was based on the premise that human beings could be measured as objects to be controlled, evaluated and manipulated (Grue and Heiberg 2006, p. 235-237). Human beings deviating from the norm were categorized as *ab-normal*. The introduction of the concept of normal naturally led to the emergence of its companion, the ab-normal, as the two concepts are inseparably tied to each other and form a dichotomous couple (Solvang 2006, p. 169).

Currently, his dichotomy is a very much present and “useful” concept for the selection of children for treatment within habilitation. Ingunn Moser (2000, p.235) holds that normalization as strategy to integrate disabled persons into the community is actually an attempt to include by means of an exclusionary maneuver. These practices reflect the way disabled adults and children are measured, evaluated and compared to “the normal” or average healthy child or adult person. As I have already indicated, my own experience as well as my observation of practices related to deviations from the norm has inspired me to apply a broader understanding of disability than the phenomenological perspective alone provides. A practice will always reflect the cultural and social understanding at the time. Despite changes in the understanding of disability, as Tuija Takala (2009, p. 125) points out, they still reflect a definition of the “normal” or “gold standard” of the 21st century: “an able-bodied white (usually Christian) heterosexual man. She argues that women and disabled people--and I presume children and disabled children as well--are constantly placed in a position of the “other” when their achievements are assessed.

¹⁷ Quetlet was a Belgian astronomer, statistician and mathematician. For further reading about Quetlet see Grue and Heiberg 2006:234.

Disability as personal tragedy or environmental oppression

Within the medical paradigm disability, as already noted, came to be seen as a personal tragedy resulting from the individual's pathological condition (Vehmas et al. 2009, p. 2). The perception of people with disability as a series of individuals suffering different impairments implied seeing them as needing and belonging to the domain of medical and welfare professional services (Shakespeare and Watson 2001, p. 547). Several scholars have shown how this medical understanding has influenced and marked overall perceptions of disability in the 20th century (Wendell 1996; Grue 2004, p. 101; Kristiansen et al. 2009).

But as Simo Vehmas et al. (2009, p. 2) writes, this one-dimensional medical understanding has been fiercely attacked since the late 1960s. Critical voices have argued that medicine portrays disability in a biased manner that leads to practices and social arrangements that oppress people with impairments, and that interventions are solely aimed at the "abnormal" individual while the surrounding environment is left unrecognized. Resources have been directed at improving or repairing the impaired individual and only to a small degree directed at changing the environment (ibid). The social perspective on disability represents a displacement of the understanding of what leads to disability. Instead of focusing on the body and its possible "deficiency", attention needs to be paid to the social and cultural context which in different ways causes limitations and restrictions that restrict possibilities of participating in all aspects of life, including family life, education, work, social and cultural life, etc (Wendell 1996; Albercht et al. 2001; Grue 2004; Lutz and Bowers 2005; von Tetzner et al. 2008; Kristiansen et al. 2009). The movement for disability rights, like the struggles for race and gender equality has been an effort to achieve social justice; it has also had an important impact on, and been an inspiration for, rethinking disability and new research. In a sense, disability has been established as a political issue (Shakespeare and Watson 2001, p.546).

Disability and disabled – "handicap" or possible "talent"

Scully (2009, p. 57) portrays contemporary understanding and thinking about disability as a complex issue and phenomenon, This includes framing it as, "an emancipatory movement and minority-rights issue; a biomedical phenomenon; an emergent political

identity; a set of social relationships and practices; and [...], as a topic of philosophical and ethical inquiry”. The competing medical and social conceptions of disability are now more “accurately presented as archetypes of various discourses allowing for a range of interpretations between these two extremes” (Smith 2009, p. 15).

Steven Smith (2009, p. 16) argues that the medical and social understandings of disability still exist. Elaborating on these contemporary conceptions of disability, he asserts that policy and practical legislation throughout the industrialized world still reflect the medical concept (ibid, p. 16). This inevitably characterizes disabled people as passive and powerless targets of intervention through non-disabled expertise. In this way the disabled person experience is reduced to an essentially “abnormal” and “lesser-than” medical condition (ibid). However, this perspective has been rejected by contemporary policymakers and replaced by more social and integrated interpretations that combine elements from both the medical and social understandings of disability. These newer interpretations influence a variety of current policies and practices¹⁸ (Smith 2009, p. 17). Although this hybrid model has moved away from the “plain medical model” approach, it still “explicitly relies on a medical understanding of disability and cannot avoid an essentialist interpretation of normality” (ibid, p. 17).

Smith states that the Disability Rights Movement (DRM) rebuts the hybrid model by making a distinction between *impairment* and *disability*. An impairment is defined as a particular medical condition which may or may not lead to a disability. A disability is associated with various social, political restrictions that are often imposed upon people with impairments¹⁹. This interpretation challenges the medical understanding in many ways, but still adheres to the same myth of “ordinary” or “normal living”, as it relies on fixed assumptions concerning what is “normal” and “abnormal” related to “ideal” and “non-ideal” states of being (Smith 2009, p. 19). The value of functionality is accordingly

¹⁸ He points out that this understanding is implicitly used by the World Health Organization (WHO) in the Second International Classification of Functioning, Disability and Health (ICF) (WHO 2001) .

¹⁹ Smith refers to the following definitions of impairment and disability made by Union of the Physically Impaired Against Segregation (UPIAS) : Impairment is the functional limitation within the individual caused by physical, mental or sensory impairment. Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (UPIAS19 1976).

related to “ordinary citizenship” as a fixed ideal. It also portrays disabled people as looking forward to, as well as struggling to achieve, the ideal and normal state that the “non-disabled” are already supposed to enjoy (ibid, p. 19). This assumption demarcates rigid partitions between normality and abnormality, as well as between independence and dependence. Smith argues that it is a misconception to assume that all non-disabled people are independent and that independence is a desirable state of being for everyone (ibid, p. 19).

Like Smith, Bryan Turner (2001, p. 257) maintains that making a distinction between disability and impairment that leaves disability to the social sphere and impairment to the body constitutes a new form of dualism. A phenomenological approach, he argues, presents a powerful challenge to this dualism body-mind or body-world models. From a phenomenological perspective, both models err in assuming the subjective experience of the patient is irrelevant to treatment (Turner 2001, p. 254).

What I find especially interesting is the “new” interpretation and understanding of disability that Smith provides, in which he asserts that disabled people suffer discrimination in two types of social and political processes – on the one hand in social and political environments that exclude persons with certain medical conditions and on the other in social and political discourses that define what constitute talents and handicaps (Smith 2009, p. 20). As a result, a disabled person’s talents may easily be overlooked by the dominant medical interpretations of the impaired condition, which in turn leads to misjudgments of the person’s other talents or capabilities. Smith’s conception boldly permits and encourages disabled individuals to maintain a positive attitude toward themselves, including a conviction that their impairment is a positive part of their identity (ibid, p. 21). Possessing, an impairment might be seen, at least in some ways, as something a person may be glad to possess, and can perceive as a talent more than a handicap²⁰. This approach, which makes it possible to view impairments in new and enabling ways (Smith 2009, p. 21), is compatible with my suggestion in the introduction that compromised bodies can develop specialized orientations and coping strategies. This interpretation also challenges the dominant understanding of what might be seen as a

²⁰ Aimee Mullins: The opportunity of adversity, see:
http://www.ted.com/talks/aimee_mullins_the_opportunity_of_adversity.html

livable life and privileges the personal experiences of people with disabilities – remaining open to what ever they might reveal.

Phenomenology and disability

The phenomenological approach applied in the dissertation, based on my understanding of phenomenology, is more attentive to children as experiencing subjects, rather than emphasizing the concepts of “disability” and “normality”. Phenomenology goes beyond these concepts. Instead, it looks at children’s, and all people’s, experiences within a world where these and other conceptual understandings exist, change and develop. The circumstantial life-field, as Todes terms it, is the circumstances within which the children experience movement as the bodies they are, and as Merleau-Ponty wrote:

For many years, our knowledge of children and the sick was held back, kept at a rudimentary stage, []: the questions which the doctor or the researcher asked them were the questions of an adult or a healthy person. Little attempt was made to understand the way that they themselves lived; instead the emphasis fell on trying to measure how far their efforts fell short of what the average adult or healthy person was capable of accomplishing (Merleau-Ponty 2005b, p. 70-71).

This quotation is from one of the lectures Merleau-Ponty gave on French radio in 1948. In the introduction to the book containing these lectures, Thomas Baldwin (2005, p. 23) claims that even though Merleau-Ponty was showing respect for marginalized voices, his ideas still reflect the thinking of the time and betray vestiges of hierarchical thinking. He views “adult thought, normal or civilized [as] better than childish.” or what he terms “primitive people” (ibid, p. 22). However, Baldwin also notes that in PhP, when Merleau-Ponty discusses the existential significance of disability he bases it “on the continuity between the experience of the disabled and that of the normal”, rather than following the hierarchical model found in his lectures. This divergence found in Merleau-Ponty’s writings about how to address, how to understand disability and disabled is still common among writers in 2010, as I have attempted to show in this section pursued. The quotation from Merleau-Ponty’s radio lecture raises two issues of special interest and importance to this dissertation. One is his call for research that would enhance our understanding of the way in which, for instance, children with a disability themselves experience movement.

The other is his point that children and disabled are typically viewed according to how far their efforts fell short of what the average adult or healthy person is capable of accomplishing. Both of these issues are still highly relevant.

I have presented a selected synopsis of current prominent understandings and perspectives on the concept of disability. The history of disability (as a concept) provides an insight into the parallel discourses that have developed-- between which scarcely any cross-fertilization of ideas has occurred, according to Gareth Williams (1996; 2001). By presenting disability as concept I have tried to open up new horizons and suggest new dimensions and nuances for understanding it. My aim has been to illuminate and open up the complexity of disability as concept rather than to freeze, establish or prove an existing or new definition of the concept (Engelbreten and Solvang 2010, p. 12-13). Children with disabilities and their families must continue to live their lives in an environment colored by these divided and parallel understandings. Jens Qvortrup (2004, p. 79) maintains that “no child can evade the impact of [...] ideologies [...] they are born into [...] cultural circumstances which cannot be explained away”. And in the words of Susan Wendell (1996, p. 12), “Definitions of disability affect people’s self-identity”.

From a phenomenological perspective, Merleau-Ponty points out the importance and influence of language, of words and concepts in stating that:

As soon as man uses language to establish a living relation with himself or with his fellows, language is no longer an instrument, *no longer a means; it is a manifestation, a revelation of intimate being and the psychic link which unites us to the world and our fellow men* (PhP, p. 228).

Merleau-Ponty terms the way different phenomena are commonly understood and talked about within a given society and culture at a specific time “ready-made-meanings”. These meanings are the pre-understanding, the discourse that constitutes the general understandings of a phenomenon at a defined historical time and place. We live in a world where “speech is an *institution*”, he explains, and we possess “ready-made meanings in our commonplace utterances” (PhP, p. 213). Based on this insight, in my explorations of movement for this PhD project I have tried to remain attentive to the understandings and meanings of the concept of disability in the lived experiences of the participating children, their parents and myself. Within this complexity, deviances and more or less competing

ways of understanding disability the experiences of people with disability still, as Merleau-Ponty called attention to in 1948 have very little interest, space and significance within the professional field, as for instance in habilitation. From a phenomenological perspective, as elaborated on in previous paragraphs disabled children's views on themselves are not ignorant to the prominent and ambivalent view on disability at present time. To some extent this is shown in the three articles and will be further discussed in chapter five.

3 Methods

In this chapter I will describe my research approach. As already stated, phenomenology constitutes both the theoretical perspective and the applied methodology of this dissertation. Thus, phenomenology has been the guiding philosophy in the production of the empirical material and in the analysis and writing processes. The empirical material is the result of both interviews and observation.

Phenomenological research approach

The phenomenology of Merleau-Ponty, Abram, Shusterman and Todes has inspired me to reevaluate my own awareness of and experiences with movement, illness and disability. My intention is to value and see my own experiences as personal, while at the same time carrying some possibility of resemblance with the experiences of others. Merleau-Ponty argues that my own body is the fulcrum of all my experiences and knowledge (PhP, p. ix, p. 94, p. 239, p. 241) implying that I am co-creator in all parts of the work on this dissertation. Therefore, I also have to realize that I have my blind spots and be aware of any temptation to verify something I think I already know. Being engaged with phenomenology has led me to experience this research process as an absorbing process of slow, wondering cogitation interspersed with abrupt moments of insight.

Aside from the theoretical perspective of the dissertation and the phenomenologists already referred to, Max van Manen's book *Researching Lived Experience* has been another important reference point. Van Manen (1990, p. 27) makes a distinction between method and research methodology. He holds that methodology is "the philosophic framework, the fundamental assumptions and characteristics of a human science perspective". Thus, methodology is the theory behind the method, including the study of what method one should follow and why (ibid, p. 27-28). Hence, method is charged with methodological considerations and implications of particular philosophical or epistemological perspectives (ibid, p. 28). Based on this, van Manen (1990, p. 1) holds that research method is a way of investigating certain kinds of questions, and that the research questions and the way one understands these questions are more important than the method in itself.

Phenomenological research connects with the field of qualitative research, which Norman Denzin and Yvonna Lincoln (2005a, p. 3) describe as a comprehensive field in which situated activities always locate the researcher in the world at a certain cultural, social and historical time. Within this broad field, researchers deploy a wide range of interconnected, interpretive practices directed towards the studied use and collection of a variety of empirical materials. Denzin and Lincoln point out that each of these practices makes the world visible in a different way (ibid p 4). Thus, different methodological approaches influence what the research can discover.

Van Manen draws essential lines of distinction between the two research approaches of phenomenology and autoethnography. He maintains that while biography or autoethnography is oriented to the meaning(s) of an individual or private person's experiences, phenomenology is oriented to the existential and mutual meaning of experiences related to a certain phenomenon (van Manen 1990, p. 72). He emphasizes that in phenomenological research the point is to "borrow" other people's experiences in order to come to a deeper understanding of the subject matter, as for instance the phenomenon of movement. Van Manen holds that to "borrow experiences" from others allows us to become more experienced ourselves (van Manen 1990, p. 62). Taking into consideration experience as both a subjective and an inter-subjective phenomenon, van Manen writes:

It is to the extent that *my* experiences could be *our* experiences that the phenomenologist wants to be reflectively [...] aware of the structure of one's own experience of a phenomenon [as it] may provide the researcher with clues for orienting oneself to the phenomenon and thus to all the other stages of phenomenological research (van Manen 1990, p. 57).

I have used my own experiences with movement, illness and disability (as described in the introduction) as reflective sources and recourses in my work on this dissertation. Specifically, I have recalled and activated experiences from different situations and episodes connected to these phenomena in my life. I have written and re-written about these experiences. Some of the texts are like the small poem in the introduction and others are more like stories or anecdotes. In the process of writing, the hard work has been finding the "right" words and style of writing to bring the meaning of different situations and experiences into being. I have experienced Merleau-Ponty's assertion that "the process of expression brings the meaning into being" and also that "thought is no

‘internal’ thing, and does not exist independently of the [...] words”(PhP, p.213). The process of writing has forced me to reflect on my initial and pre-reflective understanding of these lived situations and experiences. It has made me see layers of meaning and also inspired new questions. In this way, writing my own experiences as well as the experiences “borrowed” from the participants has been a driving force in clarifying my questions and conceptions about the research.

The mode of working – stick to the topic and keep on questioning

As stated, questioning is fundamental throughout this dissertation. However, according to van Manen (1990, p. 44) a phenomenological question can not only be made clear and understood - it must be “lived” by the researcher. He explains this further by pointing out that to truly question something is to interrogate it from the heart of one’s existence, from the centre of one’s being (ibid, p. 43). In the introduction to this dissertation I gave a brief explanation of my deeply felt and living interest in movement as well as disability. Van Manen further argues that to live one’s research question is:

to question something by going back again and again to the things themselves until that which is put into question begins to reveal something of its essential nature (van Manen 1990, p. 43).

To me this has meant having a serious and deep interest in the subject matter of movement as an experiential phenomenon and to keep on asking: How do children experience their own movement in daily life? How do they invent or create ways of moving in different activities and situations? In what way and how do they account for their experience of moving? How do they “solve” their movement challenges? What movement strategies do they develop to cope with the environment in a broad sense of its meaning? How do they develop and use their own “specialized capacity” in moving? What is it like to move as an anomalous mover (Scully’s term)?

With these questions as both starting points and continual returning points, the research process has by no means been a linear ascending process—rather it has been a spiral, looping process of stating questions, returning to questions, gathering data, editing the

data, stating questions, analyzing the data and writing and re-writing the articles and the dissertation.

Participants

Twenty-three children, all between four and twelve years of age, participated in the PhD project. The children were recruited from two different entities within the Norwegian specialist health services²¹, one at a national level and the other at a county level. Inclusion criteria for children recruited from the national unit were that they be diagnosed with severe congenital heart disease. All of these children had undergone a surgical procedure during their first year of life involving multiple and complex corrections²². Eleven children were recruited from this unit. A copy of the information letter and consent form that they were given can be found in the appendix.

Inclusion criteria for children recruited from the county level unit were that they have a motor function disability and a desire to participate in an innovative movement group with other children every Monday evening from 6:00 till 7:30 over a period of time²³. The invitation letter offered information about the movement sessions, to be directed by two dance teachers with experience in movement improvisation and the researcher. Altogether, twelve children were recruited at the county level. Six were diagnosed with cerebral palsy, three with spina bifida or myelomenigocele, and two with hereditary spastic paraplegia. One child had no medical diagnosis and was not suspected to have any. This child participated with her twin sister. Copy of the invitation and information letter and consent form can be found in the appendix.

²¹ Specialist health services in Norway are included in the overall organizational model of habilitation as accounted for in the introduction.

²² Children with simple and moderate defects, such as single arterial septal defect, ventricular septal defect, coarctation of aorta, aortic valve stenosis, and pulmonic stenosis, were excluded.

²³ The invitation indicated half a year. Very soon after the movement praxis had started we decided to expand the time to one year.

Parents of 21 of the participating children have also participated in interviews for the PhD project. The following table provides an overview of the participating children and indicates whether they participated in an interview and/or observations.

Participants in the PhD project							
Children/ Gender		Year of birth	Child interview	Parent interview	School visit	Physiotherapy visit	Movement praxis Sept 2006-June 2007
01	F	1998	August 2006	2	+	+	+
02	F	1999					+ ½ year
03	F	1997	March 2007	2		+	+
04	M	1995	March 2007	(2)	+		+
05	M	1994					+ ½ year
06	M	1996	September 2005	2	+		
07	F	1996	May 2007	1	+	+	+ ½ year
08	M	1992	2005/2006	1	+		
09	M	2002	March 2007	2			+
10	M	2000	April 2007	2	+	+	+
11	M	1995	February 2005	1	+		
12	F	1998	Spring 2007	(1)			+
13	M	1993	April 2005	1	+		
14	M	1998	May 2007	1			+
15	M	1994	October 2005	2	+		
16	M	1995	October 2006	2	+		
17	F	1998	March 2007	2		+	+
18	M	1996	January 2005	1	+		
19	F	1995	February 2005	2	+		
20	F	1994	February 2005	2	+		
21	M	1993	May 2005	2	+	+	
22	M	1998	June 2006	2			
23	F	1998	2007	1		+	+
9F/14M=23			8F/13M= 21	31 parents of 21 children	14	7	12

Table keys: M= male, F= female, 2= both parents, 1= one parent (all interviews with a single parent represent the child’s mother in this PhD project) and (1)/(2)= indicates that they are parents of two children who participate in the PhD project.

The process of producing the empirical material

The empirical material was produced over a time span of 2 ½ years. In order to gather experiential data or to “borrow” children’s experiences of moving in daily life, I had to “enter their lifeworld” (van Manen 1990, p. 69.) To me this meant meeting children, being with them and talking with them and their parents and also perhaps most importantly, it meant moving with the children.

Van Manen (1990, p. 162) writes that concrete research plans are important, but maintains that a certain openness in human science research is required to allow the researcher to choose directions and explore techniques, procedures and sources that cannot always be foreseen at the outset of the project (ibid, p. 162). However, such openness does not release the researcher from the requirement to keep the topic and research question foremost in mind during the entire research process (ibid, p 166, 167). The combination of sticking with the subject matter and still being open to questions, associations and creativity, gave birth to the development and realization of the year of innovative and improvisational movement group/praxis (paper III).

In addition to the movement class for children, I had the opportunity to talk to and interview a man in his mid fifties who had lived with a congenital disease all his life (paper II). As an adult, one's childhood experiences are "long ago". My personal experience with childhood memories, for example those presented in the introduction, is that some past experiences are still as vivid "as if they were of today". Alan Prout (2000) maintains that, according to an understanding of childhood as a biological and social phenomenon, experiences from the past can never be retrieved as they were when they first occurred. This is a view supported by Merleau-Ponty (PhP, p. 162) who emphasizes that the body subject necessarily exists 'now' and can never become 'past'. But he also stresses that 'gaps in memory' merely express the temporal structure of one's existence. He maintains that; "I am not in space and time, nor do I conceive space and time; I belong to them, my body combines with them and includes them" (ibid).

Shaun McNiff writes in the foreword to Edith Cobb's book *The Ecology of Imagination in Childhood*²⁴, that Cobb "as an adult studying the child, [...] welcomed the bias of the adult memory" (Shaun McNiff 2004, p. xv). So, the gaps in memory that inevitably exist, and the bias that they might be seen to represent is what Cobb welcomed and, furthermore, it is what Merleau-Ponty claims that memory, present and past time are about – the past is always created anew and afresh without being false or untrue. Merleau-Ponty maintains that there is an unbroken chain of fields of presence, which guarantee access to one's past. One can only reflect on a certain period of one's past life "by unfolding it anew

²⁴ In her research Cobb combined observations of children in play and daily activities with an extensive collection of biographical and autobiographical material from artists, scientists and other creative people writing and telling about their childhood and life-story (ibid p. xiv).

according to its own *tempo*” (PhP, p. 491). This line of thought justifies my appreciation of memories, my own and others, old and new, as important sources in the understanding of movement knowledge.

Interviewing

[..] interviewing is one of the most common and powerful ways in which we try to understand our fellow humans (Fontana and Frey 2005, p. 697-698).

The interviews I carried out followed Andrea Fontana and James Frey’s (2005, p. 696) description of “empathic interviewing” and van Manen’s description of conversational interviewing. All interviews were audio recorded. Both empathic and conversational interviewing emphasizes partnership between the interviewer and the interviewee as a fundamental condition. Fontana and Frey also describe empathic interviewing as an approach that allows the researcher to take an ethical stance in favour of the individual(s) being studied (ibid, p. 697). This latter can be seen to be in harmony with van Manen’s description of phenomenological research as a “caring act”, which I have described earlier. Defining interviewing as taking an ethical stance and caring for the interviewee implied to me being attentive to what the individual child and parent consider important about movement experiences. It also demanded that I be attentive to their individual way of talking and relating different experiences, preferences, and dislikes regarding movement. During my conversations about the topic I aspired to be open and interested in what the children and their parents brought up. In the process of interviewing I experienced the interplay between pausing, being silent and inviting listening, as well as how fruitful it was to ask follow-up questions in an effort to unravel what I didn’t understand or was uncertain about. This allowed me to adapt to the talking and telling style of each individual and how we related to each other in our conversation. Sometimes I was a more active talker and other times a more active listener.

My research interest was to let the children talk and tell their stories in their own way. This implied that I waited to see where the story led, as the children often took the time to tell me a lot about different circumstances, such as who participated in different games, their names, where they lived, etc. Quite often, the children wanted to show me where the person they were talking about lived or where the hill they referred to was; one of them

wanted me to hear the music he liked to dance and move to. In these cases, I went with them to the window, the door or their own room to let them show me. Even though this practice might seem peripheral to my research topic, I found it fruitful to give space to the children's way of contextualizing their experiences and views and become attuned to their way of talking while walking or moving in other ways while telling their stories. Most of the time the core of their story concerned moving. They just guided me on a small trip before arriving at their point, and I experienced great pleasure in participating in their way of telling and talking. These experiences reveal that interviewing children may require an expansion of the interview space and engage the researcher in a more kinetic way of making conversation. This experience is in line with Lori Irwin and Joy Johnson's (2005, p. 826) experiences interviewing young children.

Adult interviewer and child interviewee

Doing interviews with children based on a phenomenological perspective and research approach implies seeing them as individuals in their own right who create their own meanings and understandings just as adults do (Davis et al. 2004, p. 203). At the beginning of the interviews I asked the children directly to help me in my research. I told them that I knew they had a medical diagnosis. I also informed them that I knew quite a lot of what the books said about the different diagnoses, but that I didn't know, and not many others did either, what it is like to be a child in their situation moving around with friends at home, at school, out playing, etc. I asked if they could tell me about these things. In this way I tried, as Berry Mayall has urged (2004, p. 122) to credit the children as knowers.

As an adult researcher, I had to be aware of and take into consideration generational issues, such as those briefly described above (ibid, p.121). At the same time, my experiences with interviewing children lead me to agree with Pia Christensen and Allison James (2004, p. 2), who maintain that to carry out research with children does not necessarily entail adopting any special or particular methods that differ from those applied to adults.

Another aspect of my interviews with young children was that their parents were always close by. The parents were important "gatekeepers". They also have extensive experience with and concerning their child's special life situations (Guell 2007, p. 886).

Interviews with parents about their child as a mover

When I asked the parents if they could tell me about their experience with their child's activities and movements they often gave descriptions like: "She is a strong girl; she tries to do whatever the other kids are doing and she never gives up. Sometimes we have to stop her from becoming so exhausted that she throws up". Others say: "She loves to run, but of course she is always the last one", or: "She wants to play handball, but we can't let her – it will be so bad for her as she can't keep up with the other children – I feel I have to protect her from that experience". Others comment: "He enjoys playing football, but of course he is the first to take a break and to sit down".

Parents talked about their child as a mover by evaluating the child's movement capacity compared to his or her friends. They didn't have much more to say about their child as a mover. Apart from this, they all talked a lot about the often dramatic circumstances around the child's birth, vital surgery during the baby's first months of life and all later medical and habilitation consultations. This relates to what Cornelia Guell (2007, p. 886-887) found in her study about the parent's voice as especially valuable in recollecting incidents in their child's early childhood. In the interviews with the parents I found that they took the opportunity to recall their lives with a chronically ill and or disabled child. This was not the topic of my research, but parents returned to this throughout the interview as a central experience in their life with the child. In this regard, from the phenomenological perspective of Merleau-Ponty, the parents' movement stories about their child from their point of view and from their bodily experience is as "out-side" observers of the child as a mover and as "in-sided" mum and dad living with a chronically ill and/or disabled child. Thus researchers interested in children's experiences have to talk with, be with, the children themselves. Parents have their own stories – stories which touch the story of the child, but never can be the story from the child's perspective; in this case, about experiences of moving.

[] grown ups cannot on their own understand the world from the child's point of view and therefore they need children to explain it to them (Christensen and James 2004, p. 7 the authors refer to Antoine de Saint-Exupery (1945) and his book *The Little Prince*).

Close observation

I conducted observations in three different contexts. As already mentioned, they were schools, physical therapy clinics (private and municipal) and a movement improvisation group – also called “The Monday Group”.

My role as close observer

The different close observation sites “invited” and allowed me to participate and observe in different ways. The term “close observation” helped me to define my role as a “school-day observer” and a “therapy session observer,” and more generally as an adult interested in visiting these sites. In the classrooms, all of the teachers invited me to sit at a desk at the very back. During the breaks I went out into the schoolyard with the child and her or his class, where I experienced being defined by the other children as one of the adults you may ask for help. For instance, to help tie shoelaces or fix a ponytail that had come undone. In performing this role, I was participating in schoolyard life. At the same time, I was observing the girl or boy I had come to watch. Some of the participating children seemed to take no special notice of me and played with their classmates, while others wanted to hold my hand and walk with me, or show me things like the climbing wall or the hut they had built with their schoolmates. Even those who seemingly didn’t take any notice of my presence sometimes made contact to tell some story, ask questions or present me to their friends, etc. According to van Manen (1990) close observing involves an “attitude of assuming a relation that is as close as possible while retaining a hermeneutic alertness” to the situation. This enabled me to relate to the children by willingly accepting their invitations to be with them, listening to them and talking with them as well as waiting and not aggressively attempting to participate in what they were occupied with. My attitude was to be open to noticing and observing situations as they occurred, as well as ready to accept invitations to take part in different activities.

My experience as close observer in the therapy treatment session was similar but also different. It was similar in that the children in varying ways and to varying degrees invited me to try out what they were doing. The difference was primarily related to the contextual condition, and the time span. Both schools and physical therapy clinics are professional sites, for either teachers or therapists. Schools, however, are everyday sites for all children throughout their childhood and into their adolescent years; not every child has personal

knowledge of physical therapy clinics. I will not elaborate on these contextual differences here, but simply note that it constitutes a significant difference in the lives of disabled versus non-disabled children. For both the children and their parents, disability implies entering and being involved in contexts unfamiliar to most of us.

The last observational context is the movement group. In this context I decided to adapt to becoming a “moving observer”. Van Manen’s (1990, p. 68) term close-observation encouraged me to play this role. Moving together with the group was an emotional, kinaesthetic and tactile body to body experience. I was participating fully with the children, although with a “little eye” on myself as an observer.

In all three contexts, I wrote up my experiences after participating in the actual events. I decided that writing during the events themselves would reduce my observational attentiveness and distance me from the children and the situations. After each session in the movement group I wrote about it in a logbook. I then traded logbooks with the dance teacher and my supervisor. This exchange of experiences contributed to the shaping and development of the content and approach that I took in the movement group throughout the year.

The weekly movement praxis was also video-recorded. Every evening the video camera was positioned on a tripod in the same corner of the gym. The camera ran by itself most of the time, since I was involved in the movement and improvisation activities with the children and dance teachers.

Working with the material

The empirical material consists of the audio-recorded interviews and the written transcriptions; observation notes, including my logbook from the movement praxis, informed by my exchange of logbooks with the dance teachers after each session; and the videotapes, with written transcriptions and some edited clips from the videos.

Before describing the analytical process, I would like to quote the words of Stacy Holman Jones, who calls attention to the importance and challenge of finding words that accurately convey the fruits of our research:

[...] texts point out not only the necessity of narrative in our world but also the power of narrative to reveal and revise that world, even when we struggle for words, when we fail to find them, or when the unspeakable is invoked but not silent (Stacy Holman Jones 2005, p.767).

In my reflective and analytical work, writing has held a central position, and I have followed van Manen (1990, p. 111) who maintains that writing does not enter research as a final step or stage, but characterizes and pervades the entire phenomenological research process. In my PhD project, this process has involved writing down different experiences, memories, thoughts and ideas that have seemed interesting and closely related to my research. In addition it has involved collecting pictures, poems, etc which in a variety of ways have seemed inspiring, interesting and important to the project.

Listening, reading and watching the empirical material to inform the process of writing have challenged me in several ways. Addressing and “meeting” this varied empirical material involved a process of reliving situations I had experienced. Re-experiencing these episodes and stories affected me, sometimes more strongly than the original experience did. Perhaps sitting alone, listening to the conversations and looking at the videos allowed me to let my own reactions and feelings flower in ways that were impossible during the actual conversations. While listening, reading, watching and writing up the experiences and analyzing them I often had to take breaks—make time to reflect and formulate the point(s) I perceived as essential and important in various parts of the material.

In writing and re-writing the perceived, experienced and in different ways lived-through situations and events, I found myself in a writing process that combined responsible reporting, writing what I had heard and seen, and writing to unearth the main point in the different situations. To write from experience was to relive movements heard of, seen and actually completed. In line with the dancers and researchers Mary Beth Cancienne and Celeste Snowber (2003, p. 243) I experienced the reflective and interpretive work of writing these movement stories and experiences as they engaged me corporally. I could feel the movements as if I was moving myself. I saw, imagined and relived different situations and often engaged in movement myself to express what I saw. Moving either “as if I had moved” or had actually moved was a way of reflecting. Maxine Sheets-Johnstone (1999, p. 147) argues that “in moving, we bring a certain play of forces to life” as an overall dynamic created by our movement and experiences in our kinaesthetic

consciousness of movement. She stresses that to think is first of all “to be caught up in a dynamic flow” and that thinking is itself kinetic. She explains that; “thinking in movement is not that the flow of thought is kinetic, but that the thought itself is” (ibid, p. 486).

According to van Manen (1990, p. 127): “Writing teaches us what we know, and in what way we know what we know”. Attempting to write what I experienced, saw and understood was an absorbing working process. In my reflective, interpretative and analytical work I tried to see beyond, in-between and underneath the spoken, told, written and seen. I searched for layers of meaning in the stories told and in situations observed and described, as well as in situations captured on videotapes. This process was similar to the point made by van Manen (1990) as well as Denzin and Lincoln (2005b, p. 911), who hold that writers interpret as they write. For me, writing was a form of inquiry and a way of making sense of what I heard, saw and read – of what I perceived in retrospective meetings after experiencing different situations.

In these retrospective meetings with the empirical material, I had to ask myself what I had understood in the actual interviews and observations and how that differed from the meanings I derived on further reflection. According to van Manen (1990, p. 77) the aim of the analytical work is to get a reflective grasp of the phenomenological structure of the lived meaning of different situations, utterances and performances. In keeping with van Manen’s (ibid) descriptions of reflective work, I sought to clarify and make explicit the structure of meaning I derived from hearing, seeing, reading and re-experiencing the recorded interviews, videos and observational notes.

In writing and re-writing these experiences, my aim was to reveal their layers of meaning. This process required me to be constantly aware of what van Manen describes as “the art of being sensitive [...] to the subtle undertones of language” (ibid, p.111). In the process of writing, as already mentioned above, I wavered between writing the actual words and sentences that the children and parents “spoke” and the “actual” course of events in the observed situations and writing experiential texts in an effort to unearth and make explicit the point and meaning of what was told and shown. I often played with words and wordings and movement to unearth the meanings of different stories and situations in the material. Applying my phenomenological and analytical perspective enabled me to accept this play and movement as a valid way of doing research.

In the process of writing I took particular inspiration from van Manen and his uses of anecdotal writing. He maintains that anecdotes are special kinds of stories that can make comprehensible ideas that are elusive in other writing styles (ibid, p. 115-121). My point of departure in writing anecdotes was episodes, conversations and situations from the empirical material that in some way stood out as especially interesting and meaningful in viewing movement as an experienced phenomenon. In writing these anecdotes, I tried to follow what van Manen (1990, p. 86) describes as the process of unearthing the initially “felt” or pre-reflective, lived understanding of the meaning of the experience--in this case, movement. This writing process helped me to catch and see points or themes concerning the meaning of movement.

The aim of anecdotal writing, according to van Manen (1990, p. 78) is to grasp and see meaning and formulate thematic understanding. This process, he argues, is not and cannot be rule-bound (ibid, p. 79). Writing anecdotes that grasp what van Manen describes as phenomenological *themes* or *structures of experience* makes these themes and meaning structures visible (ibid p. 79). Throughout the analytical work I have written poems and anecdotes. In writing I have tried to *write the experiences* rather than write “about” the experiences. A poetic style of writing, like the small poem in the introduction and also anecdotes as in paper III activated my reflections of different situations more vividly than writing about the experiences. I wanted to put *life* into writing, and found that a poetic writing style opened up to see meaning of experiences in more subtle ways than writing about and describing the experiences. I find, as already presented support in this way of writing within phenomenology and especially hermeneutic-phenomenology²⁵ (van Manen 1990; Henriksson and Saevi 2009). In the dissertation the text may be characterized as being in the borderland between different styles of writing. In phenomenological writing, the aim, as formulated by Cancienne and Snowber, (2003, p. 248) is: to write from the body so that “the deep listening to life actually spills over from blood to ink”. This is a wonderful goal, difficult to achieve.

In concluding this section, I will refer to Denzin and Lincoln (2005b, p. 909), who describe the analytical process as “always ongoing, emergent, unpredictable, and

²⁵ Especially hermeneutic-phenomenology and the literary style of the Utrecht orientation or Utrecht School is what, Henriksson and Saevi (2009) refer to. They point to the linguistic textures of hermeneutic-phenomenological writing and point to the close connection between lived experience and the ethical-aesthetic traits in interpreting and writing the experience.

unfinished”, like “a dance informed at every step of the way”, always embedded in an ongoing historical and political context.

Ethical considerations

This PhD project was approved by the regional committee for medical research ethics (REK-S) and the NSD²⁶ for confidentiality and anonymity of the research participants and data. Written informed consent was obtained from the children’s parents and from some of the children (see the appendix for a copy of the approval and for the information/invitation letter and consent form). Both parents and children were asked to complete the written consent form. For some of the children, writing their name was not easy. If the parents filled out a consent form, I did not insist that a form had to be filled out by the child as well.

When I met with a child for the first time, I always made sure to describe the PhD project, what I wanted and what participation would involve. In this way I aimed to make sure that the children were informed and could agree to or refuse to participate. Before I followed and observed a child on a school-day I asked the child for permission to visit the class and school. One of the children did not want me to visit his class; I did not. Before showing up in a child’s class I clarified with her or him what I could say to the class about my visit and the research project. I engaged in similar clarifications before observations at the physical therapy clinic. When the parents and children agreed that I could visit at school one day and/or observe a physiotherapy treatment session, the school and/or the physiotherapist received written information about the project. The date and time for all of these appointments was set in cooperation with the child’s parents, school and/or physiotherapist.

Historically, children have not been thought of as persons with a voice to be heard in research. Rather, they have been seen as objects of concern (Prout and Hallett 2005, p. 1). Their lives have been explored solely through the views and understandings of their adult caretakers (Christensen and James 2004, p. 2). However, in contemporary societies different visions of child and childhood have come into play, sometimes overlapping and

²⁶ Abbreviation for: Norges Samfunnsvitenskapelige Datatjeneste Datatilsyn.

sometimes conflicting with each other (Prout and Hallett 2005, p. 1). In this context, Astrid Strandbu and Renee Thørnblad (2010, p 28) call attention to some implicit understandings of the terms “vulnerable and exposed groups” present in research ethics guidelines in the social sciences and humanities, as well as medical science²⁷.

They (ibid, p. 27) point out that this attempt to unite two competitive views is also found in the United Convention on the Rights of the Child (CRC). On one hand children are viewed as vulnerable and in need of special protection according to their age and needs. On the other, they are described as “central contributors” to research on their lives and life situation.

Helen Roberts (2004, p. 225), however, maintains that the growing interest in listening to children and hearing their opinions on different matters (as a consumer group, through school-based surveys, by policy makers and the media) raises an important and basic question: “what is there to stop children becoming merely a tool in the adult armoury, with no opportunity for genuine participation”.

According to Denzin and Lincoln (2005b, 952-953), the question of children’s participation in research might be seen as an ethical and moral question, challenging models for research based on a generic, utilitarian and biomedical understanding of ethics that focuses almost exclusively on problems associated with deception and harm. They maintain that a collaborative research approach that makes the researcher responsible to those studied and stresses personal accountability, caring and the value of individual expressiveness would align the ethics of research with the politics of the oppressed – a politic of resistance, hope and freedom. They claim that by listening to indigenous storytellers, researchers may learn new ways of being moral (Denzin and Lincoln 2005b, 952-953).

A critical eye on the methodological approach

Linda Finlay (2009, p. 6-8) maintains that several variants of phenomenological methodology exist, giving rise to a debate about what may count as “appropriate”

²⁷ Forskningsetiske retningslinjer for samfunnsvitenskap, humaniora, juss og teologi, Publisert mars 2006 på <http://www.etikkom.no/retningslinjer/NESHretningslinjer/06 - 2006, p. 16>

phenomenological methodology. This debate concerns several questions. One is whether it is sufficient to strive for rich descriptions of lived experiences or a rigorous methodology requires additional facets, such as having a special phenomenological stance or attitude. Other questions involve the extent to which descriptions should include interpretation and whether researcher subjectivity should be set aside or brought to the foreground. Another question is whether the research objective should be to produce general (normative) descriptions or if idiographic analysis is a legitimate goal. Although a descriptive phenomenological approach has been demonstrated to be useful in uncovering essences of certain phenomena, an interpretive or hermeneutic phenomenological approach has proved useful in examining contextual features of experiences (Lopez and Willis 2004, p. 734).

This uncertainty and questions about what can be considered as appropriate phenomenological research contribute, according to Finlay (2009), to confusion in conducting such research and make it especially difficult for novices. Identifying myself as a novice in this respect, I think the best validation of my research is through the descriptions, presentations and interpretations of the steps I have taken in producing as well as analyzing the empirical material. This elucidation of my research process also contributes to the reliability and trustworthiness of the “results” of the dissertation as presented in the three articles and summarized in chapter 4. To the degree I dare use the terminology of van Manen and call my research a “caring act”, I do so based on my belief that children have an embodied movement knowledge derived from their specific life-situation that should be valued and respected.

4 Summary of the papers

Paper I

Paper I examines children's experience with movement in play and familiar daily life activities. To gain insight into children's lived movement experiences interviews with 11 children and their parents were carried out. Additional observations were undertaken with 10 of these children for one day at school. All 11 children have a chronic disease broadly defined as severe congenital heart disease (CHD). Due to significant medical advances in recent decades, most children with CHD survive into adulthood and participate in lifelong health care follow-up programs. One consequence has been a growing research interest in their physical abilities, exercise need and habits. The purpose of this paper is to give exposure to children's own experiences of what movement is like when living with and growing up with a diagnosis of CHD.

The paper shows that a key aspect of children's lived-movement-experiences while playing in the schoolyard, participating in sports activities, etc. is that movement enables them to be with friends and participate in the group. Being together with the others seems to be *the* most important issue for children. The paper explains how these children make use of their reciprocal inter-relational sensitivity to find ways of moving and acting that allow them to be with other children engaged in different activities. Their embodied movement strategies entail: being mindful of their own physical condition, the characteristics of the activity, the other children, cultural rules and the actual environment at that particular moment.

The paper also illuminates how children's experience of moving embraces movement as a vital force for mastering and coping, as joyful and desirable. It reveals that the children, during my interview with them preferred to talk about these kinds of movement experiences rather than discuss movement limitations or problems. The children have a ambiguous identity: a person, a child with a disease, disability or impairment and a person like everyone else. Their emphasis is on describing themselves as being like everyone else, but this doesn't mean they do not know or recognize that they have a disease or a disability. The heavy cultural and social pressure "to be seen as a normal subject" might promote the children's emphasis on this part of their own identity.

The discussion of movement experiences in daily life activities and the children's embodied competence in finding ways of moving and acting that enable them to achieve their primary goal of being with the others constitutes a stepping-stone to answering this question: How should these children be taught movement? Or, to put it another way, how should movement-treatment-programs within healthcare/ habilitation be designed? This question is pursued and explored in paper III.

Paper II

This paper explores experiences of being tested. The culture of standardized testing is increasingly permeating habilitation, as well as healthcare services in general. This paper's point of departure is the empirical material from interviews with 20 children and the children's parents designed to investigate the children's lived movement experiences in daily life. The material includes interviews with the same participants as in paper I, interviews with nine additional children and their parents and an interview with a man in his mid-fifties with a lifelong medical condition that affects his movements and actions in daily life. All of the children have a medical diagnosis that, in varying ways, influences their movements or ways of moving. Their distinct way of moving is more or less obvious and visible to an outside observer. In any case, all children have extensive testing experience, including tests of their "motor functions". During the analytical work, experiences of being tested were interpreted as a theme tied to the everyday movement experience of the children and their parent. Awareness of the participants' testing experience and viewing these experiences in the context of the great attention to and confidence in testing in the professional context of habilitation, impelled me to pursue this approach and write this paper.

The paper reveals how the children's experiential descriptions of being tested were brief, including very few details concerning the testing situation, the tasks to be performed and what being tested was like. The parents, however, showed more interest in talking about and relating situations when their child had been tested.

For the children, the meaning of being tested is revealed to be primarily related to the question of whether they pass or not. The test makes certain demands, and assessment of competence or incompetence is made based on the test standards. Given the symbolic

meaning of the test and the widespread use of testing, the paper suggests that children with a disability may experience repeated testing as an ordeal they feel that they themselves and others expect them to put up with.

The real purpose of testing is to evaluate what experts view as important, correct and admirable, and how closely a particular child fulfills the requirements of the predetermined standard of moving. The individual child's personal creative and sensitive management in performing different movement tasks has no real significance if it deviates from these predetermined requirements of standard movement performance.

Frequent, continual standardized testing is revealed to have serious flaws once the lived experiences of the test-takers is taken into consideration. The paper's contribution of knowledge from a first-person perspective offers an expanded background for initiating a serious discussion within habilitation concerning the possible benefits and negative aspects of testing. Such a discussion is decisively important in reaching well-balanced decisions on the use of testing in research and as part of ordinary clinical practice.

Paper III

Children's rehabilitation has a declared goal of assisting children's own efforts to develop and achieve the best possible coping and functioning strategies and the greatest possible degree of independence and social participation. In consequence, treatment or training approaches focus primarily on improving children's "functional status". During the last decade, several intensive intervention programs for children with a disability, both in Norway and elsewhere in the Western world, have been implemented with the goal of improving, for instance, children's "motor function". This paper questions whether such intensive treatment and training programs with pre-defined functional goals are the "best" and "only" way to assist children in achieving their potential, and in particular their movement potential. The purpose of this paper is to inquire why children with disabilities can't be encouraged to develop and explore their own personal way of moving. The question was: What will happen and come to light when children with different physical disabilities get this opportunity over a period of time. To answer this question, a group of children were invited to participate in an innovative, explorative movement praxis, developed and implemented in the PhD project, over a period of one year. During this

year 12 children participated²⁸. Two dance teachers with experience in movement improvisation were employed to lead the weekly movement sessions, which took place on Monday afternoons (6:00 – 7:30) in a small gymnastics hall at a county center for child habilitation.

In movement improvisation, bodily and functional diversity are seen as a resource rather than a problem. Within this improvisational movement context, my own kinesthetic experiences from moving with the children, carrying out close observation, the dancers and the researcher mutual logbook notes and the recorded videos from all the movement sessions constituted the research material. The paper presents, interprets and discusses experiential descriptions from five selected video-excerpts. All of these excerpts depict the same activity, performed on each of the weeks: *The Fellowship Dance*. To illuminate continuation, development and change in movement in the group, the selected excerpts cover the period from 29th of January to 4th of June.

The paper shows that children's own capacity, kinetic repertoires and creativity in movement seem to be stimulated by an improvisational approach. However, it also reveals that the children needed time to become accustomed to movement improvisation. Gradually, they felt secure enough to throw themselves into moving and to explore their own and collective movement resources and possibilities. Movement improvisation seems to promote an interest in moving and a desire to continue, rather than simply to complete movement tasks or exercises or bring them to an end.

The paper reveals that improvisation can function as a pedagogical or therapeutic "tool" or attitude in movement exploration. Improvisation might be a useful way of working in training and treatment approaches within child habilitation. An improvisational approach to movement training or treatment seems to have the potential to assist children in their own efforts to evolve and advance their capacity to explore their own ways of moving.

The paper indicates that the meaning of "my own way" of moving seem to be closely linked to the feeling of being in touch with one's circumstances, to being poised²⁹ while

²⁸ Nine of these 12 children participated all year and three half a year (two in the first half and one in the second).

²⁹ Poise and to be in touch with one's circumstances are a term and wording use by Samuel Todes (2001). The term is discussed in paper three and in chapter two in the dissertation.

moving. This requires that the therapist or teachers welcome and include body and movement diversity and are receptive to the unexpected.

5 Discussion

In this final chapter I will summarize the findings of the three papers. All three provide insight into children's experiences of moving in daily life as well as in institutionalized contexts. Paper III explicitly analyzes what I call "my own way" of moving. The scope of papers I and II is broader, where the children's personal moving strategies are highlighted. I have written about how "my own way" of moving contains various adaptations and adjustments that children use as they work on structuring their context of participation and using different activities and movements to engage with others and with the environment. I have illuminated how different contexts, such as regular follow-up programs within health and habilitation services (paper II), the children's daily life (paper I) and improvisational movement praxis, the Monday group, (paper III) give different opportunities for movement experience. When read in light of chapter two, all three papers indicate that the children in my material are confronted with varied definitions of the types of movement expressions that are valid and recognized by others and how "my own way" of moving might represent a challenge to the field of habilitation. In this final chapter I will examine the following challenges that the papers reveal. I will discuss the disabled children's experience in relation to four topics:

- the movement capacities in relation to the environment
- the perceiving process and its relation to movement
- the "normal" and the "disabled" child who are "strangers"
- the possibilities of exploring movement

Moving capacity and the environment

Children's capacity to adapt to and cope with challenges stemming from their environment and their own bodily condition have been revealed in different ways in the three papers. One central concept revealed in paper I is that the children move within different situations in ways that will help them to fulfill their primary wish; to be with friends and do what their friends do. The paper reveals that movement is a key to achieving this goal. It illuminates in different ways how children use their personal

physical capacity and strategies to adapt and attune their movements and ways of moving. In some situations their main goal is to participate in play and to be able to keep on playing. The participants in this paper are all children diagnosed with CHD. In the PhD project, children with other diagnoses do also participate, as described in chapter number three. Essentially, the empirical material as a whole reveals that being with friends and doing what they do is children's greatest wish and priority, independent of their defined medical diagnosis or disability.

From a phenomenological perspective, to move is always to move in "ones own way" and at the same time, movement is relational, inter-subjective and "shared". As Merleau-Ponty (PhP, p. 159) points out, movement is always performed "in a space which is not 'empty' or unrelated to [the mover], but which on the contrary, bears a highly determinate relation to them". The space or environment where a child moves bears several determinate relations to the mover and the movements performed, as "movement and background [...are] a unique totality" (PhP, p. 159). This perspective indicates that children's movements and movement expressions as intertwined with the environment. The three papers illuminate how the intertwined connection between the moving-subject and the environment is reversible and dynamic. Performing movement in different contexts (daily life, formal testing and movement improvisation) showcases the children's ability to take advantage of a situation as their bodily space appears to them through movement and action, thereby fulfilling their primary goal.

Perception and Self-Orientation

In order to understand children's movement experiences, it is necessary to first understand how they perceive their environment. In an everyday situations such as playing in the school-yard, children may make use of something like an imaginary mobile phone, or other, similar strategies that keep them in contact with friends who are more mobile than they are. Several of the participating children move within a small area when playing in the schoolyard, while their friends' movements and activities stretch out and consume large parts of the schoolyard. The outdoor landscape, as well as toys, and other people, all contribute to the experience of movement. This conception of moving and the creation of play are described by Todes (2001, p. 103). The percipient mover experiences the *felt*

unity of her or his active body in its freely directable activity (ibid, p. 103). Movement is directable and based on the felt unity of one's body. He further explains that it is through such practical perception that the percipient finds herself in the world (ibid, p. 105). In moving, one gets to know oneself in relation to the world and can begin to develop and create a personal way of moving and being a moving self-in-the-world. While involved and engaged in playing, every child uses past and present experience, as well as in-the-moment improvisation while the play/dance progresses and runs its course. All three papers illuminate how the way a child moves when engaging in an activity creates situational meaning. It is only by moving and adapting to different situations that children can develop their moving capacity and make movement habitual. When movement is habitual, the children's "spatiotemporal life field of apparent circumstance", as Todes (2001, p. 57-58) calls it, presents a realm of possibilities to the individual child to actively engage with and find their different ways to move within the actual activity at the moment, and to keep on playing. Todes emphasizes that the mover is able to see things in this field that might lead to possible satisfaction. According to him, the mover actively creates the spatiotemporal fields where movement happens. When seen through the lens of Todes' theory, children's strategies, such as using an imaginary mobile phone, hiding behind a hedge (paper I) or hopping back and forth on the only leg you manage to hop on, even though the task was to switch legs (paper II), can be seen as "possible things appearing" in the situations that the children inhabit, strategies that they can use to satisfy their needs at the moment. By using such strategies, children are able to satisfy their desire to keep on playing with their friends. Dreyfus's (1999, p. 104) analogy about embodiment, sheds light on the challenges that these children face, and their ability to overcome those challenges: "mountains are tall for us, and [] where they are passable and where not is not up to us but is a function of our climbing capacities". Consequently a child orients herself to the environment according to her own body capacity. The children find ways to adapt the body they have and are to the situation they participate in, the characteristic of the play and activity and the environmental conditions—mountains, schoolyards, beaches etc. Todes (2001, p. 103) writes that to understand a self-moved mover is to understand practical experience. Every child (disabled or not) has practical experiences with moving in different environments and situations. Todes' theory indicates that all children thus move in their "own way", act and play with each other in ways that make sense to them. As already stated, this seems to be the overarching goal of the children in my study.

In a discussion of what disabled children can and cannot do, my results here indicate that children with disabilities play with other children without moving, or acting in the same capacity as their friends (paper I). It appears that in playing the children adapted and attuned to each other and kept on playing, without paying any attention to the differences that are often given the most attention in habilitation. As addressed in paper III, when given a chance to play and improvise in moving, the children let themselves and each other into the dance or play, catch each other's contributions while continuing to move and play. This orientation towards action and their own adaptive abilities contributed to the children's engagement in playing. Thanks to this engagement, the children's self-inclusive movements kept up the continuity of the play.

Moving capacity and the moving self

As already stated, Todes (2001, p. 174-178) argues that practicing and moving at the same time is a way of seeing, experiencing and discovering ourselves. I have already discussed how Todes' theory contributes to our understanding of the children as practical percipients who move to meet their needs. One question along these lines is how other people can know what the needs of disabled children are. According to the issues raised in paper II, professional treatments are based on preconceived ideas of what the child needs. The question of what kind of needs disabled children are supposed to have should be discussed and possibly reassessed. Todes (2001, p. 175) writes that, "[in] the case of the practical percipient [...], self-activity helps to *make* the active self. It transforms the active self from a creature of needs into a creature of capacities to satisfy these needs". By moving and being active, one develops the capacity to satisfy, for instance, one's wish and need to move and play with others. The children's ways of moving can then be seen as an expressed capacity to orient themselves, to see possibilities in the surroundings that might support them in their effort to do what they want. As I have shown in all three papers, what the individual child uses to support her or his action varies according to their personal and individual awareness, the environment and the child's bodily condition. This indicates that for different children, with differing movement capacities and in different situations, movements have varied expressions. Consequently, recognition of a particular child as a competent mover cannot be linked to established and predetermined forms of

movement expression, even though this is standard practice in testing, testing motor function (paper II).

According to Todes (2001, p. 175), capacity is always a “capacity *for* something” - something that can “be realized by making use of that capacity” (ibid). The personal and individual capacity to move oneself and orient oneself in moving is a capacity that both allows and is realized by moving oneself in different situations. In describing this responsiveness, Abram (2005, p. 58) portrays people as open forms continually improvising their relationship to objects, other people and the world. Clarifying this, he asserts that the body’s actions and commitments are never fully determined, but must always adapt to a world and a terrain that is itself in perpetual flux. This indicates that there is a dynamic variation of movement and environment, a concept that informs all three of the papers. Thus, to adjust one’s movement is to discover oneself, the world and the others. Todes maintains that what we perceive is “what we discover,” that perception “in some measure create[s] the perceiver” (Todes 2001, p. 175), and that this process of self-creation requires “self-movement”. When the children move within a certain situation they are both responding to it and expressing their capacity to move in it. When they use their capacity for movement and play, they simultaneously discover and create new capabilities in moving and playing. Such a practice involves a dynamic exchange between the child, the play and the surroundings. My results indicate that children with disabilities have a certain awareness of how to balance their movement and activity against the demands of the environment, the actual situation and their own bodily condition in order to distribute their energy and to be able to continue to play and move with their friends as long as the game last or throughout the whole break etc. (paper I).

Movement capacity and the notion of success

I have often, when presenting anecdotes from the empirical material, been asked questions such as these: Wouldn’t the child want most of all to run as fast as the others, as her friends? Is he happy with just being in and near a playhouse playing with friends in the schoolyard? In the Monday group, the dance teachers and I discussed similar questions. We asked if the children that could not manage to perform certain movements would be unhappy to see others, for instance the dance teacher, perform a variety of movements that

were impossible for them. If one applies a perspective of movement as observed from the outside this question might be easy to answer. However, as I have shown in the three papers, movement is lived from a first person perspective and always situated in an actual situation. In this respect, being in touch with a situation does not in itself mean that the movements have to be performed in certain ways. Although testing situations put certain limits on the expressivity of those being tested, while on the other hand, the improvisation group opens up new ways of moving. The children are brought out of their habitual ways of moving to gain new experiences of weight, space, time, flow and each other. Given the strong emphasis put upon learning predetermined/normative skills in many of the children's lives (and all the children in the Monday group), being "open to" improvisation sometimes presents a huge challenge. The children often ask themselves if they can manage—will they be able to do and perform certain movements, tasks, dance or skills? What do the diagnoses given to them by the professionals say about how they will be able to move? These questions raise some important issues concerning which movement expressions are seen as desirable and successful ways of moving. It also raises the question of whether a child can be happy despite not having the same capacity for performing movements that most children have. These questions illuminate the reality that different embodiments of movement are not purely personal and inter-subjective; they are influenced by a social and cultural system of hierarchical values.

In describing embodiment, Dreyfus and Dreyfus (1999, p. 103) refer to Merleau-Ponty who defines it as the actual shape and innate capacity of the human body. To embody the capacity for moving means to embody it as the individual human body that anyone at any time in life is. When some ways of moving, within certain social, cultural and professional domains are seen as more successful than others, the risk is that personal ways of moving are underestimated and overlooked. This is revealed in paper II where hopping back and forth on one leg during a test of hopping skills did not count as a successful solution from the professional perspective of standardized testing. Instead, it was described as a hopping problem. The child's personal and creative solution to the task and the way he talked about it afterwards both show that he saw his own way of hopping as a way of coping, but was also aware of how it was devalued in the situation. What paper II reveals is that dealing with one's circumstances, as Todes (2001) names it also means dealing with the expectations of others. The professional's expectations about movement expression in a standardized test situation highly limits a child's ability to make use of their specialized

moving and coping orientations and situational adaptation skills. A combination of normative and non-normative skills would allow a different potential for self-discovery. Self-discovery is seldom an active goal in the habilitation of children with disabilities. However, to refer once more to Todes, “[s]elf-movement is required in order to transform the *need* for self-discovery into the *capacity* for it.” In other words, moving oneself is crucially important for the development of the self. The child that moves develops a capacity for self-discovery and creatively discovers her or himself as a moving self. The driving idea behind the improvisation group was for each child to explore who they are when they move alone and with others. By moving and gaining practical experiences in a variety of situations, children get to know themselves, their environment and the people around them. I have not yet discussed the concept of “normality”, since my focus has been on the children’s experience. However, in the field of habilitation, the question of normality and its relationship to self-discovery is crucial.

Normal, disabled —who are the “strangers”

In order to pursue and further discuss the above issues and questions I will first draw the reader’s attention to what Taylor Carman (2005, p.70) writes about the ease with which we “overlook the normativity” of our own bodily orientation when viewing other people. Along these lines, I would argue that it is easy to overlook one’s own expectation of how children “normally” move and act when they are playing together, attending gymnastics lessons or working on various physical and sporting activities.

Carman points out the human tendency to transfer expectations about the movements of others based on what he names our own bodily “normativity”. When considering the questions mentioned above about how children will react to seeing other people perform actions that they cannot do themselves, we seem to be unable to escape our own expectations. If expectations are unavoidable, then we must look more closely at what kind of expectations we do meet disabled children with. To connect the question to our bodily normativity as well as cultural views about how children “should” or “usually” move and play might illuminate our own expectations and how these expectations might be projected on the disabled child. Carman argues that precisely because certain ways of moving are basic, expected and familiar to us, any action that differs to some extent stands out as strange and alien (ibid). If we go back to paper II, the testing situations seem to be

interpreted by a gaze that is predetermined by "normative based" expectations. Normative based expectations about children with disabilities are characteristic of most people in my profession, including myself. We tend to focus on problems and deviance compared to a standard or norm, forming ideas about moving in general rather than basing our research on the experiences and knowledge of the child that moves. In the Monday group, the adults were initially concerned about whether it would upset the children to see someone move in ways that were far from their own "achievements". My and the dance teachers embodied wondering on this theme revealed that "normative based" expectations include a tendency to regard some ways of moving as better, more skillful and successful than other ways, regardless of the experience of the mover.

Such normative based expectations are the source of Julia Kristeva's (1991, p. 3) question in her book *Strangers to ourselves* where she asks, "are there any happy foreigners?" She argues that, when encountering differences and deviations, one is struck by the foreigner's "peculiarity" and also by all that distinguishes her or him from what is familiar, which "reminds one that there is *someone* there". Inga Bostad (2010 p. 229) gives an example of this process as she observed it in her own life. She describes the way that people change behavior when they meet her daughter, who is multi-handicapped and moves her body in ways that are not expected of a pretty, smiling teenager. She portrays this change in people's behavior as understandable, because they are encountering a type of behavior and movements that they do not expect. Because of the strength of cultural norms, meeting "strangers" can activate expressions of insecurity and lack of understanding in general. According to Bostad, an inherent distinction between what is seen as normal or orderly and what is uncommon, deviant, other, disorderly is kept alive (Bostad 2010, p. 229). The definitions of normality and disability are debatable and in flux, and in this respect Bostad considers it as important to be open to "the stranger", to expand our concepts and ways of thinking, to break up stereotypes and rigid notions of normality and deviance. We must understand that people are different, sometimes unknown and alien to each other and also that they have different needs which ought to be recognized in society. Bostad also argues that people suffer from a lack of understanding of what it would mean to live a different life. People living with a disability, as well as their families, have significant and important experiences and knowledge that they can share with the rest of the community (ibid, p. 233). The difference that Kristeva and Bostad describe has a more "positive" role in society. They "normalize" difference, in contrast to the exclusion from participation in

schools and society that disabled people have often been subjected to because they are “different.” This exclusion has historically been a heavy burden for people with disabilities (chapter 2). As a possible remedy to this often unthinking prejudice, in my introduction I referenced Scully’s (2009, p. 65) argument about the importance of using a first person perspective in order to understand the experience of people with disability. Her concept of “compromised bodies” functions as a criticism of medical perspectives. Scully also criticizes the field of phenomenology’s neglect of the gendered body³⁰. She claims that this neglect also applies to ‘phenomenologists’ treatment of other phenotypic variance. Even though Merleau-Ponty was engaged with impaired embodiment, she argues that it was mostly with a view to clarify “the normal state” of being-in-the-world. She holds that Merleau-Ponty (and I would add Leder as well) refers to illness as a circumstance in which “the intentional arc goes limp”, in other words, as disruption or breakdown. Scully points out that, for someone who has had a compromised body from birth or early childhood, their body is still their body, and it is for them what the “normal” body is to anybody else. She asserts that philosophical work on disability still lacks knowledge about what it is like “to live as anomalous” bodies (ibid, p. 70). She qualifies her statement by saying:

It is worth emphasising that my argument is *not* that having/being an unusual embodiment means that people with bodies that are morphologically or functionally unusual inevitably develop completely unique frameworks of understanding, incommensurable with those of ‘normal people’ (Scully 2009, p. 70).

With regard to Scully’s criticism of Merleau-Ponty, I believe that he himself saw some of what she refers to as he maintains: “It is impossible to deduce the normal from the pathological...” (PhP, p 123). Like Scully, I believe that the mirror image of what Merleau-Ponty says is also true—namely, that it is impossible to deduce the pathological from the normal. Knowledge of life as a “normal” body cannot help us to fully understand what it is like to live as what Scully calls an anomalous body. It is well worth reconsidering the assumption that the one may reveal and illuminate the other. Especially in the fields of habilitation and health care, it is necessary to be aware of this issue in order to support the children in their effort to function and live their lives.

³⁰ About the lack of gendered body in phenomenology see, among others, for instance: Simone de Beauvoir and her book *The Second Sex*; Toril Moi and her book *What is a Woman?*

Carman, Kristeva, Bostad and Scully reveal in various ways the inherent normative reasoning that occurs when meeting and understanding otherness, foreigners, or deviance. Paper I reveals how children with serious heart diseases find strategies to include themselves in play with others and present themselves as being “like everyone else”. However, just because they emphasize being like everyone else doesn’t mean they do not know or accept that they “suffer” from a heart disease. Scully’s position is that being similar to other children or being different from them are experienced from the child’s first person perspective. Sometimes the children’s first person perspective might reveal “brute facts,” as Simo Vehmas and Pekka Mäkelä (2009, p. 47-49) call the challenges disabled children might experience. Even if “brute facts” might be part of the experience of children in the PhD project, they showed no interest in discussing limitations concerning their disease or disability (as shown in papers I and II). Paper II reveals that children regularly experience habilitation/health care standardized testing of qualities like motor function as an ordeal. The tests are ordeals that they perceive they are expected—and expect themselves—to endure. During the interviews the children preferred to talk about what they did and what they liked to do. On these topics they had a lot to say. The great social and cultural importance of being considered “normal” seems to affect the children’s desire to portray themselves and identify as being-like-everyone-else.

Children express a need both for “being-like-everyone-else” and also to be seen as “special and unique.” One of the questions raised by my research is: how are disabled children’s movements judged and valued? Is their movement valued as alternate ways of moving with talent and specific personal expression³¹?

To sum up; how a child’s movements are seen, understood and evaluated by others is influential in how the individual child sees her or his own self, way of moving and identity as movers. Historically, children with disabilities have had to deal with an understanding of disability that is embedded in the medicalization of deviations and defects. Deviations in body and function has been defined as pathology and contributed to an institutionalized practice of viewing children/people with disabilities as objects for examination and evaluation by specialists (Braddock and Parish 2001; Grue 2004; Smith 2008). Despite

³¹ See for instance CandoCo Dance Compagny:
http://www.dailymotion.com/video/x7m1v9_candoco_people and
<http://vids.myspace.com/index.cfm?fuseaction=vids.individual&videoid=2031179429> etc.

changes in the understanding of disability, as Takala (2009, p. 125) points out, people with disabilities are still largely defined by the ways in which they depart from the “normal” or “gold standard” of the 21st century: “an able-bodied white (usually Christian) heterosexual man.” Accordingly women and disabled people as well as children and disabled children are consistently placed in a position of the “other” when their achievements are assessed. One wonders whether being “the other” leads to exclusion, and loss of accessibility to full participation in society. Several researchers have contributed to this discussion and Smith (2009, p. 27) is one of those who maintains that “the discriminated position” of disabled people in addition to “social and economic structural injustice” is also caused by what he calls “identity exclusion” (ibid, p. 25). He describes identity exclusion as “when the diversity of the response to the experiences of ‘the disadvantaged’ are effectively ignored or marginalized in favor of more dominant constructions” (ibid, p. 25). Smith is suggesting that society place more emphasis on a particular conception of individual agency and what he calls a “productive tension” in human relations. This tension would reflect the individual as unbounded by contingent-determinism, whether it be medical or social, and at the same time serve as a critique of social structures which systematically exclude people with medical impairments. Smith’s main claim is that—a person’s capacity for agency allow active engagement with experience and provides her or him with the ability to step back from her or his circumstances and conditions and respond to them—often, as he writes, in surprising ways³² as surprise is born from the human agency itself (Smith 2009, p. 25). This sort of active agency would allow an individual to radically buck expectations about dominant norms in favor of an emphasis on own experiences and own circumstances in forming their own life (ibid, p. 26). The children who participated in the Monday group gradually began to oppose being compared to expected or normative ways of moving. They showed both confidence and pride in their own solutions. One example is Charlotte, who, together with Jenny one evening was to show the whole Monday group the various movements in the Fellowship dance presented in paper III. When they finished, Jenny commented that Charlotte had not done everything right, whereupon Charlotte replied, “Yes I did—I did it my way.” The ability to step back to consider, re-consider and explore alternative ways of acting and handling one’s

³² See also Ingunn Moser’s article: “On becoming disabled and articulating alternatives. The multiple modes of ordering disability and their interferences.” *Cultural Studies*, 2005 19 (6), pp 667-700.
<http://www.informaworld.com/smp/ftinterface~content=a738567881~fulltext=713240930~frm=content>

circumstances and situation, will, from a phenomenological perspective always be intersubjective and can't be freed from the subjects being-in-the-world.

Merleau-Ponty had this to say on the matter. No matter how great or small the differences between people may be,

There is no way of living with others which takes away the burden of being myself, which allows me to have an opinion; there is no 'inner' life that is not a first attempt to relate to another person. In this ambiguous position, which has been forced on us because we have a body and a history (both personally and collectively), we can never know complete rest. We are continually obliged to work on our differences, to explain things we have said that have not been properly understood, to reveal what is hidden within us and to perceive other people (Merleau-Ponty 2005b, p. 86-87).

In this quote Merleau-Ponty ascribes to our bodily being-in-the-world a commitment to work with our differences and to perceive and understand each other.

According to this phenomenological obligation, we must constantly examine and revise our own understandings, misunderstandings and prejudices in the attempt to appreciate differences in body and movement. Carman writes that the tendency for differences in bodily ways of being to rise up in front of us and draw our attention is something we need to be aware of. The "normativity" of our bodily orientation in the world and towards other persons is engraved with the "normativity" of our own bodily orientation and capacity, for instance concerning movements. These will most likely come to mask what the other person does, what stands out is only their difference. What they do and what they deal with is overshadowed by what they don't do, what they not are. Habilitation professionals have learned and incorporated observation skills in order to uncover differences in body and movement. As my preceding arguments suggest, the risk in having specific skills to identify the "problems" is that the individual, expressive sides of movement will be ignored. Since my results indicate that the knowledge the children have of themselves is extensive, such knowledge could contribute new insight to the professionals. Paper II reveals how the predominant use of standardized testing within habilitation can be seen to emphasize discrimination between "normal/standard" and "not normal/not standard." Furthermore, it showed that a child's capacity to discover personal solutions and capacities embedded in her or his bodily features has no significance and value within

such a perspective if the child's movements do not match up to the "normal" standard. Given a situation within health care where discussion about normality and deviance is inevitable, what kind of opportunities for movement are children with disabilities offered?

The possibilities in exploring movement

Paper III treats my efforts to develop an improvisational way of approaching children that aims to support them in their own effort to explore movements. An improvisational attitude that appreciates and welcomes individuality and difference (Steinsholt, 2006) allows one to see children's movements, movement orientation, movement strategies and coping skills from another point of view than the immediate "normative" way of viewing others that Carman warns against. As a pedagogical and a therapeutic way of approaching movement, improvisation made it possible to make a shift—not a turnaround—but a shift that emphasized really seeing the children's ways of moving—ways that I had to work on myself in order to see and apply them. As the paper illuminates, this applied to the children as well. They needed time to adjust their habitual ways of viewing movement – their own movement as well as the movements of others.

One question throughout the research process was what the benefits of the movement class would be for the children themselves. When the participating children in the PhD project were "put in a situation" where they were being looked at, they also experienced themselves as viewers. Karel Mulderij (1996, p. 315-316) writes that being looked at is a central experience in the lives of disabled children. He claims that the gaze of others constantly reminds the children that they are different. Along the same lines, Carrie Sandhal and Philip Auslander (2008, p. 2) maintain that disability is a performance that is the lived, embodied experience of people with disability. I think, however, that these authors overlook a central phenomenon that became clear to me during my research: the importance of regarding the children themselves as viewers with the "freedom" to have a dynamic and changeable view of themselves and others. For a disabled child to place her or himself in a co-existing-subjectivity with others is different from being trapped in the position of being defined by other people's gaze. Leder (1990) illuminates my point here when he describes a walk in the forest with a friend where they have a friendly chat about what they see, pointing out to one another the colors of the leaves and a passing bird. Both

of them are adjusting to one another and experience “being-with-another” in a way that supports “transcendence” (Leder 1990, p. 94). Leder is talking about the transcendence of co-existing-subjectivity, of a kind of intercorporeality where the two friends supplement each other. Leder writes “We transcend together to a common world, sharing the forest in which we walk.” This example points to one of the benefits of the children in my group’s play and movement. Regardless of whether their ways of moving deviate from each other, they can benefit from interacting with each other’s capacity for movement.

On the other side of the coin, there is a need to discuss the “reality” of the differences. When children know each other, when they are schoolmates or friends, their different ways of moving and acting are familiar to each other—even the differences are habitual and familiar. However, every time a disabled child meets people new to her or him they run the risk of being perceived as “different”³³. My argument in this dissertation is that we need to learn to open up our view of disabled children so that we can learn to value the way they play, move and act together as an illustration of co-existing-subjectivity – of mutual intercorporeality. Just as importantly, the children’s own individual perspectives on the world, through their co-existing-subjectivity, can be extended. As Leder maintains: “Mutuality is impossible in the absence of distance” (Leder 1990, p. 95). In other words, reciprocity between persons requires that there is a positive difference between them, a distance to overcome. Reciprocity in this respect can stimulate an interest towards the other and her or his way of moving as a significant, personal expression.

³³ An example of such an ambiguous position is revealed in Tone Saevis online article *The Experience of “Being Seen” for Persons with Disability* (<http://www.phenomenologyonline.com/articles/saevi.html>). Here she refers to the Norwegian author Finn Carling who in the preface to his autobiography “And yet we are human” describes what it was like to speak for the first time on radio about his experience of being physically disabled: “Dripping wet from sweat I sank into the seat of the car, waiting for me outside the television building at Marienlyst, leaned back and tried to light a cigarette. Again and again I thought: My God, what have I done! My God, I have told that I am a cripple! Despite the fact that I knew that this was something that everybody who knew me had already learned and connected to me; something that in their eyes had to be a significant aspect of my identity, still I felt as if I had undertaken an irrevocable disclosure” (Carling 1962, pp. 8, 9).

Final remarks and future research

The starting point for my research was the current and historical situation of disabled children. I began by referring to Scully as well as my own experience. As I conclude the discussion of my results, I am reminded of when Scully (2009, p. 68) refers to Mark Johnson, and maintains that “everyday *moral* thinking” is organized through metaphors and semantic frames rooted in bodily processes. There are embodied values that are connected in our culture to being vertical and upright rather than horizontal or low to the ground. These physically based values are metaphorically and morally perpetuated through phrases like upright person, high-minded, stands on her own two feet, etc. For those who fail to embody these value-loaded metaphors because they cannot stand on their own feet, cannot stand as straight as demanded, those who can’t run or climb like most others do, etc. will not be afforded the positive connotations that go along with such approved terms. Implicit layers of meaning contained within certain words and phrases are potent, because commonly used terminology carries unspoken assumptions about our own or others’ moral status or competence (ibid, p, 69). However, even though these metaphors and semantic frames rooted in bodily processes have a strong impact on society, the children who I have met during my work have contributed experience and knowledge that help to transform these cultural values and hierarchies. Even though the power structures and health systems have a decisive influence over how children with disabilities are viewed, I have illuminated how the children still manage to use their specialized bodily orientation to move, cope with and participate in everyday life activities, included regularly being tested and assessed. Furthermore, it is evident that, given a chance to improvise, the children seize the opportunity to explore and expand their movements and ways of moving. It is clear that they use specialized strategies and ways of moving and acting that help to include them in play with others. The knowledge contributed by the three papers is particularly relevant to professionals within habilitation. My hope is that the children’s specialized knowledge can be understood and valued as a resource. I believe it is crucial for professionals to become more aware of the knowledge children possess when it comes to moving—and to shift their focus away from “otherness” as problematic condition. Regarding further research, it will be of particular interest to investigate more ways that children with disabilities can be given opportunities to develop their own movements and movement capacities. The approaches applied in the

improvisation group were only a beginning, and my hope is that they will stimulate other researchers and practitioners to organize new studies and programs.

Finally, I agree with van Manen (1990, p. 163) that phenomenological research has a transformative effect on the researcher. My experience of working on my dissertation has influenced me not only as a researcher, but also as a person, as I have become more aware of the capacity of each individual child to create her or his own best situation.

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PAPER I

Wenche Schrøder Bjorbækmo and Gunn Helene Engelsrud.

**'I am almost like a fish': an investigation of how children with
congenitalheart disease experience and perform movement in daily life**

Child: Care, Health and Development, 34 (2008) 781-788.

PAPER II

Wenche Schrøder Bjorbækmo and Gunn Helene Engelsrud.

**Experiences being tested: a critical discussion of the knowledge involved
and produced in the practice of testing in children's rehabilitation**

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PAPER III

Wenche Schrøder Bjorbækmo and Gunn Helene Engelsrud.

“My own way of Moving”- Movement-improvisation in children’s

rehabilitation

Phenomenology & Practice (submitted)

“My own way of moving”

Movement improvisation in children’s rehabilitation

Abstract

This article illuminates how children with different motor disabilities perform movements in an improvisational context. As part of a research project we developed and implemented a one-year long movement improvisation praxis/program, in which 12 children with different motor disabilities participated in weekly sessions under the practical leadership of two dance teachers and the researchers. In the praxis/program movement was emphasised as personal, relational and expressive. Using the researchers’ kinaesthetically lived experiences combined with video observations from the weekly movement improvisation sessions, we present and reflect upon five episodes from one of the activities regularly performed. The article contributes with insight into how movement improvisation over a period of time can offer children with motor disabilities a freedom and opportunity to move and explore their own way of moving. The analysis presents how the children gradually felt secure enough to throw themselves into exploring their own movement possibilities and how improvisation promoted their desire to keep on moving.

Keywords:, Children, disability, improvisation, movement, phenomenology

Introduction

Children with defined disabilities have a legal right to health care and (re)habilitation services¹. In Norway a stated aim of children's rehabilitation is to *assist* the children in their *own efforts* to develop and achieve; the best possible coping and functioning strategy and the greatest possible degree of independence and social participation.². Accordingly current approaches within the field mainly focus on improving the phenomenon called "functional status". To improve the children's "functional status" they are instructed to move, often through intensive interventions that are supposed to result in "better" achievements and improved "functional status" (Muldrej 2000; Gibson et al 2009). We have started to doubt this approach, and our question in this article is: why can't children with disabilities be encouraged to develop and explore their own personal way of moving? In order to illuminate this question we invited a group of children with defined disabilities to explore moving in their own way. We wanted to introduce movement improvisation and inspire the children to achieve an "inner" relationship to moving.

Why movement improvisation?

Steinsholt and Sommerro (2006) describe improvisation as a form of reflective practice that is not only applicable to different artistic expressions but also to other areas such as education, consulting and management. A central perspective in movement improvisation is that the participant is regarded as an active mover and the situation and the environment are regarded as elements of the movements created and performed. One improvisational dance form is called "contact improvisation" (Novack 1990), and has given people with disabilities access to dance as both creative and performing artists (Østern 2006). In movement improvisation each person is viewed as unique, with their own specific movement possibilities, and the individual possibilities are seen not only as valuable but as decisively important for the individual and thus also for the collective movement expressions (ibid, p. 199). In movement improvisation, bodily and functional diversity are seen as a resource rather than a problem.

As already mentioned, Steinsholt and Sommerro (2006) maintain that improvisation is a form of reflective practice applicable to many different professional areas. In educational research it has been shown that in teaching, improvisation is a vital force in propelling children's learning processes (Sawyer 2004, p. 17) and that it also promotes deep learning through inductive discovery (Berk and Trieber 2009). Østern (2009) has explored dance improvisation with *differently bodied* dancers, as she names them, and describes dance improvisation as a learning space where all the participants experience, learn and change in an individual, uncategorised way.

Regardless of what professional practice improvisation is a part of, Steinsholt (2006, p. 17-18/29) emphasises that during improvisation it is impossible for the improviser to escape from the imprint of the past. He points out that although improvisation challenges clichés, habits and preconceptions, it always builds on existing knowledge and experiences. It is in the tension between individuality and tradition, between innovation and structure that improvisation takes place (Steinsholt 2006; Jurow and Creighton 2005; Sawyer 2004). Improvisation can thus open the field of movement and be a driving force in exploration of the possibilities of performing individual expressivity in a context with others.

Method and Material

As already stated, we invited a group of children with defined disabilities to move with us, as a one year long movement project³. The project was situated at a county centre for children's rehabilitation⁴, and information about the project was given beforehand at a meeting for all professionals at the centre where the project was implemented.

The researchers organizing the program followed ethical procedures in recruiting⁵ the group of children in autumn 2006⁶. A total of 12 children (seven girls and five boys, all between four and eleven years of age) participated. Eleven of the children had a medical diagnosis and one had no diagnosis⁷. The children had various kinds of walking and locomotion aids, including ankle-foot orthosis,⁸ crutches, walkers, walking sticks and/or manual or electric wheelchairs.

Two dance teachers with experience in movement improvisation were employed in the project. Their task was to lead the weekly sessions, which took place every Monday evening from 6 o'clock till 7:30. All together we were 12 children, two dance teachers and one researcher that met every week, with a second researcher attending the meetings one evening every month.

The sessions were held in a small gymnastics hall that was usually emptied of all apparati that was not built in, in order to provide plenty of space for movement. Our research material was derived from the movement sessions that ensued. Since our interests were in the exploration of movement itself, our participation in the movement is a central methodological approach. This methodological approach was inspired by what Max van Manen calls close observation (1990, p. 68). He claims that the best way to enter a person's lifeworld is to participate in it (p. 69). As van Manen predicted, by moving along with the children we gained personal experiences and considerable anecdotal material that would have been inaccessible to us in the capacity of outside observers.

In order to preserve, "keep" and recollect the living movement session, the dance pedagogues and the researchers made and exchanged logbook notes. The logbooks served as a space in which to take a step back and reflect on the main points and meanings of the various lived-through situations in the session. Writing in the logbooks became an essential resource for further developing the activities and for further interpretation and reflection after the end of our one-year project period.

Another tool to preserve, "keep" and create the research material was video recording. The video camera was positioned on a tripod in the same corner of the gym at every session. We did not use a zoom and the camera was unmanned most of the time, since we were involved in the improvisation activities. An important point here is that, as van Manen points out, all recollections of experiences, reflections on experiences, descriptions of experiences and even, as in our case, life or movements captured directly on magnetic or light-sensitive tape are already transformations of those experiences (van Manen 1990, p. 54). Lived experiences

have a temporal structure and can therefore never be grasped in their immediate manifestation but only reflectively as “past presence” (ibid, p. 36).

As close observers, the material we produced is clearly dependent on our own bodily kinaesthetic experience of moving with the children. We were also reflective writers in the logbook dialogue and viewers of the videotapes.⁹ Watching the videotapes reminded us of lived experiences and enabled further reflection on episodes and situations that stood out as significant in our moving together.

Structure and frames in the movement improvisation sessions

In the movement sessions we used an improvisational approach that built on knowledge gained from modern dance and especially from contact improvisation. Since improvisation involves a productive tension between innovation and structure (Jurow and Creighton 2005), we included some movement in each session. For instance, we repeated the same opening and closing activities in every movement session. Another regular feature of each session was a break to have a drink of water, go to the bathroom or just relax. These two repetitive activities functioned as a frame around a number of different activities within which the leaders set different tasks.

We made use of every part of the room – the floor, the walls, the corners, the door handles, the wall bars – in the different activities. One of the central elements was allowing the children to feel comfortable in relating to their environment. For example, using the floor to sense how it supported their bodies without sitting or lying on gym mats was difficult for them at the beginning of the year but became gradually easier. Music and stillness were also used. Working in pairs and groups, we explored ways of moving with each other that focused on how to give and receive bodily support. The participants were regularly invited to put on a show and to watch one another moving, for example when working in smaller groups and in pairs. One example of a frame activity was called “crossing the floor”. All the participants gathered at one of the short walls of the gym, and the activity was to cross the floor to the opposite wall. At the beginning of the activity the leader told the participants to move for example at the same level as a tiger or a dog would and to stop at intervals and make marks or imprints in imaginary sand on the floor. When everyone had reached the opposite wall and

was returning, the leader might add that the tigers/dogs were to move slowly from one mark in the sand to the next. In this way the same activity incorporated different tasks relating to tempo and alternation of tempo, space and body level above the floor. Thus the children were asked to move from lizard level to bird level, to move in imaginary sand, snow, water or slime, or to move as if they were made of lead or feathers.

At the end of every session, and just after “a show”, we reserved time for discussing what we had seen and what it had been like to watch the others moving and to put on a show. By including reflections and adjusting the activities based on what was said, the sessions gradually came to consist of several activities that were dynamically organised and continually reshaped and further developed. Week by week the dance came to consist of an increasing number of movements, each supplied by one of the participating children. Within the frame of the activity, each participant could perform all the different movements in their own way subject to two conditions: everyone had to stay in the same position in the room throughout the dance and no movement should raise us higher than our own height when sitting on the floor. Inspired by van Manen (1990, p. 78), we analysed and reflected on the thematic layers of these episodes and situations by writing and rewriting about what we saw in the videos combined with our memory of these episodes and with reading and consulting our logbook notes. The episodes we present below are all from the same activity, but from several different sessions. The reason that we chose to select episodes from a single activity that was performed at every session is that we wanted to focus primarily on the movements and not the activities. This focus on the movements developed and performed by each participant and the whole group together allowed us to follow, in time and space, the children’s evolving process of moving when they were offered the opportunity to move and explore their individual as well as collective movements and ways of moving. The episodes within this frame activity were those that struck us as especially interesting in the context of our research aim, both in the actual performance situations and in retrospect when watching the video tapes. When writing down these episodes we bore in mind Henriksson and Saevi’s (2009, p. 36) emphasis on the potential for language to give expression to the meaning of recollected lived experiences and what they describe as the “methodological significance of *writing the experience* rather than writing *about* the experience”. The experience of being

there and moving about with the children, and then afterwards watching the episodes on video, challenged us when writing these experiences to try to combine the perspectives of participant and observer.

Result from movement improvisation - “my own way of moving”

Below we present situations from the improvisations sessions. The episodes are all from an activity we called “the fellowship dance”, which was performed at every session. For “the fellowship dance” the leader invited one child to suggest one movement. The movement that was chosen by the child should first be performed by the child who had invented the movement and then be performing it for the group. After the child had shown his or her movement, the whole group together performed the movement together.

In the following episodes we have given the children fictional names in order to stress their individuality. This is not intended to limit the point(s) or theme(s) of the episodes to a specific child, but to underline the participants as subjects in the improvisation activity.

Giving and receiving movements

Showing and receiving movements was the main element in the “the fellowship dance”. “The fellowship dance” was considered suitable to promote relational attentiveness in the group and the awareness of our shared space of individual and collective movement contributions.

Ten children and three adults are sitting in a circle on the floor. The welcoming opening activity has just finished and we are preparing for the fellowship dance. In order to perform this dance we need more space, so all the participants move about until they have enough elbow room. Then we look at Emma. She is the one who is going to make and show her movement contribution this evening. Emma sits quietly. Everyone is waiting, including Christopher and Phillip, even though they have already started performing the initial movement of the fellowship dance. Shortly afterwards they sit down too. All the time the leader is attentively facing Emma. Emma still sits quietly, slightly stooped over and looking down. Then she raises her head, slowly shrugs her shoulders, stretches out and lifts both arms with her palms upwards, tilts her

head and lifts her eyebrows and with a cautious smile looks at the leader. The leader waits for a while and then asks “Is this what we’re going to do?” and imitates Emma’s movement. Emma nods approvingly. Then it is decided that we are all going to make Emma’s movement. We make her movement three times. The fellowship dance now consists of seven movements, all of which we each perform in our own way. (Episode from video-tape, 19th of March)

Our first impression is that Emma is expressing that she does not know what to do. Her body language expresses insecurity. Seen through the lens of Merleau-Ponty (2005, p. 214, 215), Emma’s movement expressed pure *insecurity* and that she did not know what to do. According to Merleau-Ponty, the meaning of a gesture is given in its expression – there is nothing behind it, it is “intermingled with the structure of the world outlined by the gesture” (ibid, p. 216). Emma expresses herself in the situation and the rest of the group have all their attention focused on Emma. At that moment, she is in a position of “not knowing”. This “not-knowing” situation fills the group with a tension that mirror’s Emma’s and is an expression of the interconnection and interrelation of the body and world as Merleau-Ponty explains it (Merleau-Ponty 1968, p. 148). Merleau-Ponty’s concepts of chiasm, interconnection and intersubjectivity can be highly relevant to understanding the relation between Emma and the rest of us in that particular “waiting” moment. Feelings and understandings float between us as osmotic processes so that we recognised and understood that Emma did not know what to do and could not at that moment think of a movement. From a phenomenological point of view, her body (itself), however, knew about the not-knowing and expressed it in a movement. In this way Emma’s embodied knowledge became visible to us.

Emma’s “I don’t know” movement left the group for some seconds with a question mark, since we initially interpreted it as a movement that was not meant to be included in the fellowship dance. For some seconds we wondered: what now, what next, what will the leader do? The leaders waiting attitude indicated an assumption that Emma might do more, make another movement or make the movement meant to be included in the dance.

When Emma made no further movements, the leader suggested in the form of a question whether to use the movement she had performed, and Emma took a risk and nodded. This turned the situation around. Emma’s nodding confirmed that her movement was the

movement to be included. Steinsholt (2006) maintains that in improvisation a *mistake* or, as in our case, a movement not meant to be a contributed movement is seized and invited in and becomes part of the creative development of the activity. Jørgensen (2006, p. 46) describes the improviser as someone continually challenged to use her or his sensitivity to the context in order to respond; it is through sensitive dialogue that companionship is built and meaning created in improvisation. The leader's thoughtful wait and resourceful response illustrates also what van Manen (1990) calls pedagogical tact. Emma's nod welcoming the leader's suggestion makes this dialogue and companionship happen. So far two themes can be abstracted from the above interpretation. We have called the first "the agony of having to make a contribution" and the second "the virtue of waiting".

The agony of having to make a contribution

In the above situation we all expected Emma to perform a movement that would contribute to the fellowship dance. Steinsholt (2006, p. 41) argues that in the context of improvisation such situations challenge the person, in this case Emma, to throw themselves into movement, to take a risk and let go. He maintains that this throwing oneself into, for instance movement is one of the main aspects of improvisation, and emphasises the importance of liberating oneself from fixed ideas and giving oneself up to the unknown, risky and hazardous aspects of a situation, which in this case was the creation of a movement within a landscape of possible movements and ways of moving.

From a phenomenological perspective Emma's hesitation and bodily expressed insecurity can also be understood as illustrating how "being my body for me and my body for others" may be relevant; Emma's behaviour might seem conspicuous in her being her body for others at that moment (Merleau-Ponty 2005, p. 122). The ordinary, taken-for-granted way of moving as a response and attunement to daily life and actions was displaced at this moment. By having a disability, Emma as the body she is, and also like the rest of us, does not "weld together individual movements and individual stimuli but acquires the power to respond with a certain type of solution to situations of a certain general form" (Merleau-Ponty 2005, p. 164). According to Sheet-Johnstone (1999, p. 516) her habitual being was characterized by

non-separation of thinking and doing as well as a non-separation of sensing and moving. Thinking, sensing and moving are qualities absorbed by the moving mindful body as a whole when everything is as usual, but if the above situation appeared unusual, unfamiliar or uncomfortable to Emma, this would hamper her in the task to think of a movement at that moment.

As the situation turned out Emma's movement was given value as communication. Her movement expressing "not knowing" was taken as a significant expression of the situation. The freedom to let oneself blossom that according to Steinsholt (2006) is what improvisation invites one to do, is not automatically easy to understand and apply

Merleau-Ponty points out that movement is always created or performed in a space that is not empty, since movement and background or environment are not separate but are two elements of the same totality (2005 p 159). Since improvisation is concerned with dialogue, what the leader as well as Emma does and how they respond and interact in this situation are vital to the outcome of the situation.

The virtue of waiting

The leader wondered how she should meet Emma's movement. Her attentive focus on Emma and her patient waiting had made Emma's movement possible. As already discussed above, such a movement or a gesture does not make us *think of* "I don't know", it *is* "I don't know" (Merleau-Ponty 2005, p. 214). However, instead of confirming that Emma does not know what movement to make, the leader welcomes her movement as a significant contribution by asking her "Are we going to do it like this?" As Steinsholt (2006) maintains, the leader follows a fundamental principle of improvisation as she seizes and welcomes Emma's movement, and thereby lets her in. Emma is treated with respect. Her movement is as good as anyone else's movement and as any kind of movement. According to Steinsholt and Sommerro (2006), approving what has actually happened is at the core of improvisation.

Sheet-Johnstone (1999, p. 488-489) argues that in dance improvisation movements are not limited to what is culturally identified as "dance movements", but also incorporate

movements and gestures from everyday life that have certain culturally recognised meanings. Østern (2006) also points out that this is a characteristic of improvisation, especially contact improvisation. Sheet-Johnston adds that performing such movements does not make the dance symbolic or the particular movement symptomatic. Emma's contribution is not a contribution about "not knowing", but about knowing who she is at that moment. As Sheet-Johnstone says, in dance improvisation every movement is filled with the movement's range, rhythm, power and intricacy that are fundamental for the experience of self and others. Emma's movement in that particular session was a new contribution that was permitted and welcomed. The movement was welcomed for its own perceptual dynamic and kinaesthetic expression.

The moment during which we waited for Emma's movement illustrates how, as Steinsholt (2006, p. 41) says; in improvisation one have to be prepared for spontaneous confusion and the torment of insecurity. The improvisers are required to accustom themselves to the torment of insecurity by departing from fixed rules and cultivating waiting and passivity, and to have the courage to throw themselves, for instance into movement. This makes the participants susceptible and thus also vulnerable. If group members are to meet the condition that they depart from fixed rules and place themselves in a vulnerable position, there must be mutual trust within the group. The point of heteronomy is to say yes to the other's request as an ethical obligation and responsibility and by this create mutual trust and surrender one's freedom to the freedom of the other without losing oneself and one's own freedom (Steinsholt 2006, p. 42;. Alterhaug 2006, p. 90-91).

As we have indicated, an improvisational approach allows room for movements to express themselves. In Emma's case this involved seizing what actually happened there and then. The episode revealed how a welcoming and approving attitude made Emma comfortable enough to throw herself into accepting her own movement, to feel that her own movement as it happened was good enough and was a significant contribution to the fellowship dance.

Performing given movements

Sharing movements with each other and performing them in our own way was another central element of the fellowship dance. The episode below is the continuation of the one above.

Now that Emma has given her movement contribution and we have all tried it, we are ready to perform the whole dance as it now stands. Each movement is to be done twice, and the child who “owns” the movement has to count aloud: one, two. Susanne’s movement is the first one and she spins round and round on her hands and knees – once and then a second time. The whole group is moving around. Some spin sitting on their bottoms, others by turning their heads from side to side. Most spin on hands and knees. After Susanne’s movement comes Gustav’s. Gustav is ready. He raises both arms up in the air, turns slightly to the left and then flings himself sidewise to the right. His left leg raises a little as he reaches the floor with a muffled bang. “One” he counts loudly. Several participants are flinging themselves sidewise onto the floor while others remain sitting or fling themselves half-way down, slapping one or both hands on the floor. Gustav raises himself to a sitting position. “Two” he says as he flings himself down onto his right side. He does this a third time as well, and one of the adults enthusiastically follows him this time too.

(Episode from videotape 19th of March)

When Gustav showed his movement contribution for the first time, Phillip said; “I can’t do it. I’ll hurt my head.” The leader answered: “Then you have to make sure you don’t do that.” Soon afterwards she added: “Maybe you can stop yourself with your hands or maybe not throw yourself so vigorously or so fast.”

(Episode from videotape 29th of January)

Performing Susanne’s, Gustav’s and the others’ movements called attention to the performance of the others. Even when everybody are allowed to make all the movements in their own way, performing them seems to involve questions concerning ones own competence and performance possibilities. To compare oneself with others is unavoidable in social situations. In this situation it becomes quite clear that there are huge differences in how one movement shown by its “owner”, is received as when others, here Phillip, indicated that he cannot perform the movement without hurting his head.

When everybody perform Susanne's spinning movement and Gustav's side-fling, the different personal bodily expressions may be perceived as pictures of our different kinetic repertoires, to quote Sheet-Johnstone. She claims (1999, p. 136) that: "our individual repertoires are ultimately a measure of how far we have grown into the bodies we are". When some of the participants spin sitting on their bottom or make spinning movements with their neck while most of us are spinning on hands and knees like Susanne, this could be interpreted as evidence that some were being more creative by spinning in their own way or as if they do not have the capacity or kinetic repertoire to spin on hands and knees. The question of capacity or kinetic repertoire and creativity may also be linked to a question about courage. Steinholt maintains that the courage to "put oneself at risk" is required in improvisation. An intermingling of, capacity, creativity and courage was shown to be a vital theme in our performance of the all the movements in the fellowship dance.

Capacity, creativity and the courage to put oneself at risk

With regard to capacity and capacity building, Sheet-Johnstone argues that in moving oneself the one that moves discovers more and more "I cans". She describes this realm of kinetic "I cans" as an open-ended realm of possibilities (p. 136). We performed Susanne's, Gustav's and the others' movements both as the bodies we are and with the movement repertoire each of us possess. In relation to our movement repertoire of "I cans", the episodes can also be perceived as revealing a repertoire of possible "I cant's". This "I can't" seems present when Phillip says "I'll hurt my head", and when other children said they could not perform the movement or went frequently to the bathroom or momentarily become extremely tired when some movements were being performed.

We performed the fellowship dance as the bodies we are, and according to Merleau-Ponty (2005, p. 157) our performance was rooted in our ever-present reciprocal directedness or "motor intentionality" or, as Todes calls it, our "poise". This sensing, sentient body-subject is what Abram (2005, p. 58) describes as an open form continually improvising its relationship to objects, other persons and the world. Thus in performing the fellowship dance we

committed ourselves to adapting and attuning ourselves to the environmental landscape of this dance from moment to moment. Merleau-Ponty claims that every individuals

[]-cognitive life, the life of desire or perceptual life, is subtended by an ‘intentional arc’ which projects round about us our past, our future, our human setting, our physical, ideological and moral situation, or rather which results in our being situated in all these respects. It is this intentional arc which brings about the unity of the sense, of intelligence, of sensibility and motility (PhP 2005, p. 157).

Thus in performing these movements and being allowed to do so in our own way, our previous movement experiences – of participating in previous sessions, in therapy, school activities, gym lessons, playing with friends – mingled with our performance in the present situation, as we carried out Susanne’s spinning movement and Gustav’s side-fling. Todes (2001, p. 65) calls this “being in touch with our circumstances”, and states that: “To be poised is to be *self*-possessed by being in touch with one’s *circumstances*” (p. 65). Dealing with one’s circumstances is about responding, and as Steinsholt (2006) emphasises, participating in improvisation is about taking risks.

Children with disabilities have a great deal of experience of dealing with and taking risks in moving. They also have extensive experience of failure in this area and of cultural and social devaluation of their movements. Todes states that failure of response results in the experience of a loss of poise, which is the experience of a gap between oneself and one’s circumstances. He says:

It is only in failure of response, and loss of poise, that a distinction appears between what I was trying to do and what I did. When I act in an effective, poised way, it is not merely that what I was trying to do is in agreement with what I did do. Rather, there is no gap at all between my own action and what it made of my surroundings, so that no agreement or disagreement could be noticed; there were no two things to compare, but only the perfect fit of me-in-my-circumstances. (p. 70)

The perfect fit of me-in-my-circumstances might be better served by leaving the room to go to the bathroom, by claiming that “I’m so tired that I have to rest” instead of participating in the movement, and even better served by declaring my lack of ability or talent to perform certain movements. Moving in my own way and the question of my own capacity or ability to make a movement like Gustav’s side-fling is also a question of my creativity in finding solutions to coping with my circumstances and not only coping with my body and its movements. However, Steinsholt (2006) holds that an essential characteristic of improvisation, besides individuality, creativity and personal expression, is fellowship. He points out that improvisational practice has always been concerned with building fellowship and developing new ways of thinking about what it means to participate in human relationships (ibid, p. 34).

According to Berk and Triber (2009), the building of trust is of decisive importance in improvisation in order to build fellowship and as a basis for participating and daring to be creative in ones own way. They emphasise the need for time to establish and provide an environment where the participants can feel free to explore and create their own way of performing for instance movements like Susanne’s spinning movement.

The capacity and creativity required to perform the other children’s movements in “my own way” depended on the children feeling secure enough in that particular situation to put themselves at risk when dealing with all the different movements of the fellowship dance. We found that the children’s own capacity, kinetic repertoires and creativity seemed to be stimulated by trying out and playing with the movements of the fellowship dance. The meaning of “my own way of moving” in improvisation is rooted in the attitudes expressed in the actual environment. My own way of moving is related to a feeling of security, desire to be in touch with ones circumstances, coping with performing a certain movement shown, whether by mimicking, duplicating or in some other way transcending the movements of others. Performing the fellowship dance required each participant to weigh the possibility of success against that of failure, which in this case involved crucial bodily, relational and situational considerations.

Playing with the movements of the dance

We used many weeks to create and develop the fellowship dance. Before the end of the year all the children had contributed a movement and we had performed the whole dance several times. We then loosened up or changed the rules in terms of space, time, succession of movements and our position in the room. This was intended to challenge the participants to further explore the movements, the dance itself and their own ways of moving and dancing it.

After having performed the fellowship dance as usual, the leader said: "Now we're going to do it differently. We're going to play with it." After a short explanation of the new rules we were split into two groups. For more than half an hour each group moved, tried out different ways of performing the movements and talked about movement. While moving, the members of each group focused intently on playing with the movements within their own group. After a while the leader told the two groups to show each other how they had been working with the movements of the dance. The first group consisted of three children and one adult.

Anne, Johannes and the group leader are standing with their backs against the wall while Emma is sitting on the floor facing them. The audience, the other group is sitting on the floor a little behind and to the right of Emma. There is complete silence. The music starts and the dance begins. Slowly arms, bodies and legs move against the wall, making smooth sweeping sounds. The performers stretch out and bend their arms and twist their bodies, first in one direction and then another. Johannes stops. He stands still. Anna rolls herself against the wall, stops and bends over with her arms above her head. Johannes looks at Anna and the leader. Then, facing the wall, he stretches his arms very high and starts to swing his body from side to side. At the same moment Gustav, who is in the audience, does his side-fling movement and Jenny, also in the audience, gets up on her knees, stretches both arms high up and swings her whole body. Emma's arms are moving like wings in the same rhythm as the bodies against the wall. Arms, legs and bodies move towards, away from, over and under each other. Suddenly the smooth, slow rhythm is interrupted by rapid repeated up-and-down movements, first with one leg, then the other. The show comes to an end when the leader of the other group slowly turns off the music. Emma turns her head towards the audience. All the performers are looking at us and smiling. We, the audience smiles and applauds.

(Episode from video-tape 4th of June)

What especially attracted our attention in this episode was the concentration and commitment we experienced and observed in the two groups while we were trying out different ways of performing the movements of the fellowship dance. While playing with the movements everyone seemed deeply present and relationally engaged in the activity of moving. We were all absorbed in moving in ways that differed from how it had been at the beginning of the year. Then, when exploring ways of moving in response to the various tasks the children had often stopped the activity quite soon, saying: “I’ve finished,” “I’ve done it,” “I’ve tried all the movements.” At the end of the year, movement seemed to stimulate more movement and new and different ways of performing the same movements over a continuum. The participants were no longer just performing and completing the movement or the dance but seemed almost possessed by moving for the sake of moving. As shown in the above episode, the performers did not stop until the leader of the other group turned off the music. In playing with the fellowship dance, in improvising on the movements of the dance, moving and dancing seemed to become what we wanted to do and keep on doing instead of completing moving or the dance.

The desire to move and to keep on moving

The process of keeping on moving that we experienced and observed may be related to what Sheet-Johnston describes as “kinetic intelligence forcing its way” in the immediate situation into moving and shaping and re-shaping given and known movements (1990, p. 489). She maintains that in movement improvisation moving is not about making explicit choices about movements or specific ways of moving, but that moving as one does calls forth new kinetic circumstances that in turn call forth the individual’s way of moving in an actual situation. In playing with and improvising on the fellowship dance everyone kept on moving in their own individual way as well as in a collectively driven continuum of movements that arose there and then.

In playing with the fellowship dance and keeping on moving, our bodily “kinetic intelligence forced its way” into the movements and ways of moving we created and improvised. This is also related to what Gendlin (1992) calls “coming” as a characteristic of the body. He says:

[] appetite comes, also orgasm, tears, sleep. You recognize the bodily nature of such comings. Emotions also come in this way. You can feign joy or anger but to *have* them, they must come. So also does muse come, when she is willing and not otherwise. And new ideas, the lines of a new design, and steps of therapy come in this way” (Gendlin 1992, p. 202).

During the show the performers kept on moving, and the movements seemed to just come, to arise of themselves, even though they also stopped as when Johannes stood still at the wall. At the moment of not moving he seemed contented and not disturbed by his own stillness as he watched his companions moving. Nor did the others seem to be disturbed by Johannes not moving. They continued with their own movements and accepted Johannes’s stillness, so that his stillness became an element of their collective movement.

Steinsholt (2006, p. 25) describes improvisation as an activity or a practice of waiting for the moment when what happens, happens – a moment that happens in a state of “not-knowing” or through a reinforcement of the tension arising from not knowing what will happen in what does happen. When Johannes suddenly started moving again it was as if other performers’ movements were being transmitted. Anna’s movements seemed to inspire him to stretch his arms higher and higher as she stretched hers. This alternation between not moving and moving had an effect, it created a tension and as Steinsholt puts it, it also created an expectation in the audience. Improvisation is playing together, and in performances it is at its best when the audience joins in. Steinsholt (2006, p 36) refers to Gadamer when he emphasises the importance of the audience’s primed attention as an important contribution to improvisation as a complex dialogical play that is essential for grasping the meaning of the moment.

With respect to “keeping on moving”, Merleau-Ponty (2005, p. 125) maintains that every stimulus applied to the body¹⁰ arouses a potentiality of movements rather than an actual movement. Thus seeing the display of others’ movements and moving themselves aroused a

potentiality of movements in all the participants, both the performers and the audience. It was as if the individual movements slowly drifted and floated into each other, not only between the performers but also into and between those in the audience. As the episode shows, this caused members of the audience like Gustav and Jenny to throw themselves into visible movement. The boundaries between the performers and the audience fluctuated and dissolved. This dissolution of boundaries between performers on the one hand and the audience on the other is what Østern (2006) calls as a characteristic and quality of dance improvisation as opposed to the built-in distance between the disciplined stage dance and its audience. In moving together, the distance between the children, the leaders and the researchers disappeared in our improvisations. In movement improvisation everyone *is able* to move, since diversity and differences are accepted, welcomed and seen as a productive resource rather than a problem. Improvising and playing with movements seem to stimulate the desire to move and keep on moving.

Reflecting on movements seen and performed

As mentioned above, talking about movement expressions and movements expressed was an integral part of the sessions, since we wanted to provide time and space for reflecting on watching others' movements and performing movements for an audience. Thus after the show in the above episode the leader asked the audience:

“Did you see what the performing group has been working with?” “Yes,” Gustav replied. “I saw you were doing my movement, but (he hesitates a little) you didn’t imitate me ... you should (he stops, then continues) it’s a difficult movement.” “Yes it is,” replies the leader. Gustav is asked what he thought about the performing group making their own version of his movement. He does not answer directly, but says: “I saw Johannes was working really well.” Susanne is next and says: “I think it looked very good with someone standing and others sitting.” Lisa, also one of the audience, says: “I thought the slow movements were very nice.” She adds: “I use to move fast.” And shortly afterwards: “I think it’s difficult to move slowly.”

The performers are also asked to say what it has been like to put on the show. Smilingly Anna explains: “I think it was a bit strange. It was strange to do it like this.” Emma agrees with Anna,

and added: “It was fun and fine – my movement became so strange and different” (Episode from videotape 4th of June).

This episode shows how the children paid attention to each other and also commented, not only on what they had seen, but also on what it had been like to see the others' movements and ways of moving. When Gustav says “Yes, I saw you were doing my movement”, this could show how observing the performance made him recognise and feel in his own body the performers “doing his movement”. He also recognised and felt bodily that they did not imitate him exactly or made the movement “his way”. In this sense the experience is linked with the question of “my own way” and “the other's way” of moving. Gustav's hesitation and stopping himself after saying “you didn't, you should...” indicates that he had to some extent adopted an attitude of appreciation, the attitude that what is being shown is significant and good as it is. His reaction shows how challenging it is to act in accordance with different cultural understandings of movement – the everyday social understanding, that of the health services and that implied in improvisation. In this context Gustav's approving statement “I saw Johannes was working really well” is a good illustration of this intermingling of different discourses and understandings about movement. Susanne's and Lisa's comments also seemed to arise from their bodily felt experience of the performance. When Susanne says that the different positioning of the performers is nice and good, the pattern of the performer's positions might have meant something special to her or she might have been mainly expressing appreciation of the difference between Emma sitting on the floor and the others standing against the wall. Lisa's comment on the speed of the movements, when she says that she thinks slow movements look nice and at the same time says that she herself usually moves fast and that she feels moving slowly is difficult, shows how looking at and attending to others' movements is about bodily felt experiences related to the actual situation, previous experience, one's own body and possible movements and the movements and bodies being observed. The children's comments and reflections gave greater significance to the other children's movements and the bodily felt transfer of movements between the performers and the members of the audience. Movement improvisation seems to promote the felt and seized qualities of movements and moving, and as shown above to promote a desire to keep on moving.

Movements felt, transmitted and desired

In playing with the movements of the fellowship dance the children threw themselves into moving and gradually began making use of what they heard, saw or felt inside themselves in their body and in their movements. Wigerstrand (2006, p. 129) considers this to be a significant element of improvisation. Daring to put oneself at risk by moving in accordance with what one feels inside comes from confidence that one's movements, ways of moving are accepted and welcomed as they come and as they are. According to Gendlin (1997), the "felt sense" is a capacity and characteristic of the body. The body feels and knows. Block and Kissell (2001, p. 10) also maintain that this is vital in improvisational dance. They describe improvisation as an awakening of the body as knower. The body knows what it wants to do as it senses and feels our impulses. In the show and in the episode where Emma showed her movement for the first time, the children's bodies knew what they wanted to do both when Johannes stood still and when Emma shrugged her shoulders and stretched her arms forward with the palms turned upwards. Movements come when given time and space, since the body knows what it wants to do.

While Gendlin talks of *coming* as a characteristic of the body, Todes (2001, p. 68) talks of the body's *need*. He defines this as our field of experience, and states that our needs can appear definite only to the extent that fulfilling them appears possible. The closing of the gap between oneself and the field of one's experience is about satisfying needs – a spatiotemporal life-field in which "finding is the satisfaction of seeking", which in turn is moved by need (ibid, p 67). In playing with the fellowship dance and all the other improvisation activities we all needed to find different ways of moving, performing the different movements and dancing the dances. In the fellowship dance this process made it possible to close the gap between need and satisfaction, and thus to be poised. When poised there is no gap at all between ones own actions and what they make of ones surroundings, so that there is no agreement or disagreement: "there were no two things to compare", but only the perfect fit of the performers putting on the show and their circumstances, which were performing the dance for the audience (ibid, p. 70). The performers' smiles at the end of the show seemed to express

satisfaction with their performance. Emma's momentary turn towards the audience, the performers' smiles and Anna's and Emma's smiles and comments that doing the show had been "fine", "fun" and "strange" may indicate that they felt in touch with the circumstances of putting on a movement show and of having found satisfaction in the ways they moved. When in touch with one's circumstances in movement improvisation, the improvisation is in Steinsholt's words (2006, p. 25) a playful experience that is almost magical, that produces a feeling of being "on the other side of nowhere". As the show indicated, the improvisation sessions gave the participants the opportunity to seek and find ways of moving and of letting movements come as they came. It also showed how movement improvisation facilitates the desire for movement and stimulates a need to move, and in doing so allows for the possibility of finding satisfaction and experiencing a feeling of being "on the other side of nowhere", where moving for moving's sake is the driving force.

Our year of movement improvisation sessions was a year-long journey of exploring movements in moving. Steinsholt holds that creativity in finding ways, as for instance of moving, ones own way", of moving is a question of luck, which is related to struggle and frustration in the process of trial and error (Steinsholt 2006, p. 35). Thus being creative and trying out and exploring one's own way of moving is not only closely linked with the moving subject's own body but is also to a large extent a question of contextual attitude.

Final remarks

In this article we have discussed the phenomenon "my own way of moving" from several different perspectives. The analyses from movement sessions with children with a defined disability have uncovered how the children contributed to fill the space with improvisation and discovered new movements that they seem to take advantage of. By presenting and reflecting on episodes from one activity, the fellowship dance, the article illustrates how the children needed time to adjust to the improvisational praxis. When they discovered the "new" possibilities for moving they gradually felt more secure in exploring movements and their "own way of moving." Providing each other with the freedom and opportunity to move the way we moved created trust and helped the children to throw themselves into exploring ways of moving and movement possibilities. When they felt increasingly secure in the

improvisational context they trusted that their performing movements were “good enough”. When they felt “good enough” they were less likely to be caught up in “I can’ts” and showed more confidence in their own ways of moving. They increasingly moved in the space with a growing satisfaction and pride in their movements and bodies.

Over one year of improvisation sessions the children proved to us that they possessed a large variety of movement possibilities. We learned that improvisation can function as a pedagogical tool in the creation and exploration of moving. During the year, the children improved their “functional ability” and also increased their movement competence. The movement competence became particularly visible in a desire to keep on moving in a continuous and exploratory way. The meaning of finding “my own way of moving” seemed to be closely linked with the feeling of being in touch with one’s circumstances while moving. When the children’s way of moving was welcomed and regarded as significant, they found satisfaction in moving and seemed to be inspired to keep on moving and to enjoy moving in their own way.

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Endnotes

- ¹ World health organization (WHO) about health and human rights: <http://www.who.int/hhr/en/>. Norway L02.07.1999 nr. 63 Lov om pasientrettigheter. The UN Convention on the Rights of the Child, see; point; 23 and 24: <http://www.regjeringen.no/en/dep/bld/Documents/Guidelines-and-brochures/2000/barnekonvensjonen-engelsk.html?id=419254>
- ² “Children’s habilitation and rehabilitation are *planned, time-limited* processes with clear *goals and methods*, where several actors *participate* in providing the necessary *assistance* to the *user’s own efforts* to achieve the best possible coping and functioning strategy and social participation.” (Chapter 1, section 2 of the Norwegian regulations of 2001).
- ³ This was part of a research project in which we explored how children with different disabilities experience moving in daily life, in play and activities with their friends and family, including how children experience moving in the movement improvisation concept we developed. Before carrying out the project, approval was attained from the regional committee of medical research ethics.
- ⁴ A county-level centre located in the south-eastern part of Norway.
- ⁵ Written information and invitations to participate were handed out to the professionals to pass on to their clients. An invitation accompanied by information was also published in the bi-annual course catalogue dispatched by the centre to all its users, which included children and their families and other relevant professionals in all the municipalities in the county.
- ⁶ All those who gave a positive response received written information together with a consent form. Eleven children started in the autumn of 2006. Two of them decided to leave the project after the first half year. One child started in January 2007 and participated in the last half year. We decided in the first autumn that the project should run for a full year.

⁷ Eleven of the participating children had a medical diagnosis. Six were diagnosed with cerebral palsy, three with spina bifida or myelomeningocele, and two with hereditary spastic paraplegia. One child had no medical diagnosis and was not suspected of having one. This child participated with her twin sister.

⁸ http://en.wikipedia.org/wiki/Ankle-foot_orthosis.

⁹ The video material consisted of 29 videos representing about 40 hours of recording. The logbook consisted of 69 A4 pages.

¹⁰ He added “of the normal person”

APPENDIX

Information forms

Forespørsel til foreldre/ foresatte om å delta i forskningsprosjektet: "Bevegelse som erfaring hos barn og unge med medfødt hjertefeil"

Da dere allerede deltar i prosjektet "Motoriske ferdigheter hos barn og unge med medfødt hjertefeil", spør vi om dere også kan tenke dere å stille opp til et intervju

Dersom dere sier ja til å bli intervjuet, gjelder dette både barnet og foreldre/ foresatte. Som bakgrunn og utfyllende informasjon til intervjuene spør vi om å få være sammen med barnet en skoledag, på en fritidsaktivitet eller lignende. Hensikten er å kunne observere hva barnet gjør sammen med andre i kjente aktiviteter og omgivelser. Det skal ikke tas spesielle hensyn til at vi er tilstede. Hvilke aktivitet vi blir med på, avtaler vi med dere senere

Intervjuene vil foregå separat, og dere bestemmer sammen med barnet om dere skal være til stede når barnet blir intervjuet. Tid og sted for intervjuene avtaler vi slik det passer best for dere. Intervjuet med foreldrene vil vare ca 1 – 1 1/2 time og intervjuet med barnet ca 1/2 - 1 time. Intervjuene vil bli tatt opp på lydbånd. Alle opplysninger vil bli behandlet konfidensielt. Datamaterialet vil bli anonymisert, og lydopptak slettet innen 31.12.08.

Hensikten med prosjektet er å få mer kunnskap om hvilke erfaringer barn og unge med medfødt hjertefeil har med bevegelse. Med bevegelse tenker vi her spesielt på bevegelse knyttet til det å delta i ulike aktiviteter, lek med jevnaldrende og ulike former for trening. Det er også av interesse å få kunnskap om erfaringer og opplevelser som foreldre/ foresatte har med dette. Resultatene fra prosjektet vil bli presentert i form av fagartikler i internasjonale, vitenskapelige tidsskrift. Kunnskap fra prosjektet "Motoriske ferdigheter hos barn og unge med medfødt hjertefeil" og dette prosjektet vil til sammen kunne gi et bredt og utfyllende bakgrunnsmateriale for å videreutvikle behandlingstilbudene til barn og unge med medfødt hjertefeil

Deltakelse i prosjektet er frivillig, og dere kan når som helst trekke dere uten å oppgi grunn. Om dere sier nei til å delta eller trekker dere fra deltagelse, vil ikke dette få følger for videre behandling eller for forholdet mellom dere og Rikshospitalet. Dersom dere ønsker å delta, ber vi dere underskrive samtykkeerklæringen nederst på siden. Da barnet er under 18 år må dere underskrive både på vegne av barnet og dere selv. Barnet har likevel fått et eget informasjonsskriv med egen samtykkeerklæring.

Prosjektet er meldt til Personvernombudet for forskning ved Norsk samfunnsvitenskaplig datatjeneste AS, og er forelagt regional komité for medisinsk forskningsetikk.

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Inger Holm
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Skriftlig samtykke

Jeg samtykker med dette på vegne av meg selv og mitt barn.....i å delta i prosjektet "Bevegelse som erfaring hos barn og unge med medfødt hjertefeil". Jeg er kjent med hva prosjektet går ut på, at det er frivillig å delta og at jeg når som helst kan trekke meg fra prosjektet uten å oppgi grunn.

Dato

Navn

Vil du være med i forskningsprosjektet:

”Bevegelse som erfaring hos barn og unge med medfødt hjertefeil”?

Vi arbeider med et prosjekt der vi skal finne ut hva slags aktiviteter og trening barn og unge med medfødt hjertefeil liker og har behov for.

Derfor spør vi om å få være med deg en dag på skolen eller på en fritidsaktivitet for å se og høre hva dere gjør der. Dere skal ikke gjøre noe annet enn hva dere pleier å gjøre. Vi vil også gjerne snakke med deg (intervjue deg). Du og foreldrene dine bestemmer om de skal være sammen med oss når du blir intervjuet. Intervjuet vil bli tatt opp på lydbånd. Etterpå er det bare vi som arbeider med prosjektet som vil høre på opptakene. Når prosjektet er ferdig vil lydbåndene bli slettet slik at ingen som ikke har noe med dette å gjøre kan høre opptakene.

Det er frivillig å bli med i prosjektet og du kan når som helst ombestemme deg dersom du finner ut at du ikke vil bli med likevel. Om du sier ja til å bli med skal du skrive navnet ditt på slippen nederst på arket.

Fordi du er under 18 år må vi også spørre foreldrene dine om det er greit at vi er med deg på skolen eller på en fritidsaktivitet, og at vi kan intervjue deg. Foreldrene dine får et eget brev om dette.

Med vennlig hilsen

Wenche Bjorbækmo
Vit.ass, Seksjon for helsefag
Universitetet i Oslo

Inger Holm
Professor
Fysioterapiavdelingen Rikshospitalet

Skriftlig samtykke

Jeg sier ja, til å være med i prosjektet ”Bevegelse som erfaring hos barn og unge med medfødt hjertefeil”. Jeg vet hva prosjektet handler om. Jeg vet at det er frivillig å delta og at jeg når som helst kan ombestemme meg hvis jeg ikke vil være med likevel

Dato

Navn



UNIVERSITETET I OSLO

DET MEDISINSKE FAKULTET

Forespørsel om deltagelse i forskningsprosjekt

Høsten 2006 starter et forskningsprosjekt som handler om bevegelse (Bevegelsesprosjektet). Bevegelsesprosjektet er et samarbeid mellom Universitetet i Oslo og Habiliteringstjenesten i Østfold, seksjon barnehabilitering. *Bevegelsesprosjektet* vil inngå i Wenche Bjorbækmos doktorgradsprosjekt med tittelen: *Bevegelse og trening som erfaring hos barn og unge med cerebral parese, og barn og unge med medfødt hjertefeil*.

Bevegelsesprosjektet innebærer at vi vil sette i gang bevegelsesgruppe for barn og unge med ulike typer bevegelsesvansker, uavhengig av hvilken medisinsk diagnose barna har. Derfor spør vi barn i alderen 6 til 10 år som har en tilknytning til Habiliteringstjenesten i Østfold om å delta i en bevegelsesgruppe en gang i uken. Gruppen vil møtes på Habiliteringstjenesten på ettermiddag/kveldstid og vil være av 1 ½ times varighet. Tanken er å starte med en gruppe på ca ti barn. Om det er mange som melder sin interesse planlegges utvidelse med flere grupper. Starttidspunktet for den første gruppen er i begynnelsen av september 2006.

Bevegelsesprosjektet vil legge vekt på å anerkjenne det enkelte barns uttrykk og kreativitet. De bevegelser barna bruker og gjør vil bli tillagt betydning i utformingen av opplegget. Utvikling og utforming av bevegelse vil foregå som et oppdagende prosjekt for alle deltagerne. Hensikten med tilbudet er å få fram et materiale som kan si oss mer om hvilke erfaringer barn gjør seg dersom de får anledning til å arbeide utforskende med bevegelse. Kunnskap om dette anses å ha stor betydning for å kunne realisere et habiliteringstilbud til barn og unge som bygger på og utvikler barnas egen erfaring med bevegelse og det å uttrykke seg og samhandle gjennom bevegelse.

To pedagoger med dansefaglig bakgrunn, Guro Anna Wyller Odden og Anne Synnøve Skogstad, vil være ansvarlige for gjennomføringen av Bevegelsesprosjektet. Professor Gunn Engelsrud har det overordnede faglige ansvar for prosjektet. Wenche Bjorbækmo er stipendiat og vil som ledd i sitt doktorgradsprosjekt få data fra bevegelsesgruppen. Det som skjer i bevegelsesgruppen vil bli videofilmert og benyttet som datagrunnlag i prosjektet. Videoene vil bli slettet når doktorgradsprosjektet er fullført i løpet av 2009.



Guro Anna Wyller Odden



Anne Synnøve Skogstad

Guro Anna har utdanning fra Skolen for Samtidsdans i Oslo og Teater Tango Danseteaterskole i København. Hun har også erfaring fra ulike forestillings- og undervisningsprosjekter, blant annet fra kulturskole og kunstfaglige undervisning med den kulturelle skolesekken. Hun er til daglig tilknyttet Rom for Dans i Oslo som underviser, veileder og kunstnerisk ansvarlig for ulike grupper barn, unge og studenter ved Skolen for Samtidsdans.

Anne Synnøve har utdanning fra Teater Tango Danseteaterskole i København og er for tiden student ved Skolen for Samtidsdans i Oslo. Hun har pedagogisk erfaring fra ulike kunstfaglige undervisningsopplegg for barn, ungdom og voksne. Blant annet har hun vært på turné med Riksutstillinger og den kulturelle skolesekken.

Wenche Bjorbækmo

Doktorgradstipendiat, Institutt for sykepleievitenskap og helsefag, Seksjon for helsefag, Universitetet i Oslo

Er dette av interesse ta kontakt med: Habiliteringstjenesten, Seksjon barnehabilitering tlf: 69366700, eller med: Wenche Bjorbækmo, mobil 41200854, E.post: w.s.bjorbakmo@medisin.uio.no

Skriftlig samtykke

Dersom dere ønsker at barnet deres skal delta i Bevegelsesprosjektet tilknyttet prosjektet *Bevegelse og trening som erfaring hos barn og unge med cerebral parese, og barn og unge med medfødt hjertefeil*, ber vi dere skrive under på denne samtykkeerklæringen. Slik samtykkeerklæring er nødvendig da Bevegelsesprosjektet inngår i et doktorgradsprosjekt. Deltakelse i Bevegelsesprosjektet er frivillig, og dere kan når som helst trekke dere uten å oppgi grunn. Om dere ikke ønsker å delta eller trekker dere fra deltagelse, vil ikke dette få følger for forholdet mellom dere og Habiliteringstjenesten. Prosjektet er meldt til Personvernombudet for forskning ved Norsk samfunnsvitenskaplig datatjeneste AS, og er forelagt regional komité for medisinsk forskningsetikk.

Jeg samtykker med dette på vegne av meg selv og mitt barn at kan delta i Bevegelsesprosjektet i forbindelse med prosjektet "Bevegelse og trening som erfaring hos barn og unge med cerebral parese og barn og unge med medfødt hjertefeil".

Jeg er kjent med hva Bevegelsesprosjektet går ut på, at det er frivillig å delta og at jeg når som helst kan trekke meg uten å oppgi grunn.

Dato og navn

Dato og navn

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