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2008

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Citation for published version (APA):

Flodin, E. (2008). *To move ahead - the extension of a life-world*. [Licentiate Thesis, Certec - Rehabilitation Engineering and Design].

Total number of authors:

1

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To move ahead - the extension of a life-world



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Licentiate Thesis Certec 1:2008



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Lund 2008

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CHAPTER 1: PROLOGUE

Hanna's and my place in the process

My connection to the topic of this thesis is threefold. In November 1982 our daughter Hanna was born, who at 13 months of age was diagnosed with Spinal Muscular Atrophy. At this point in life I was a recently examined nurse, but Spinal Muscular Atrophy (SMA) was something I had never heard about, let alone different types of the status, I, II, III. During the last eleven years I have spent my time in the academic world, first as a student starting off at 34 and then as a teacher in pedagogy after my master's degree. Through these three different perspectives, the parent, the nurse and the university teacher, I have found that the understanding of a child growing up with a disability, as for instance SMA II, differs a lot depending on from what perspective you look at it. Knowledge from all three worlds can help paint a sharper picture of the landscape of Hanna's growth and development given the condition of SMA II.

The fact that I as a researcher use the knowledge and experience I have got from the parent in me, spending hours, days, months and years in the company of my daughter, is of course a somewhat unorthodox way of research and not an unproblematic one. Still the knowledge I have got as a mother is the very core of the material creating this licentiate thesis. There is a longitudinal aspect of the research that would have been impossible if I hadn't been a close relative. As I have been a natural part of Hanna's life I have been able to be with Hanna almost continuously through her life, in a natural way that would have been impossible for someone else. I would also like to stress that the knowledge that comes out of this is somewhat different from the kinds of knowledge obtained in other ways. I might have been able to write a thesis on the same topic without being a mother of a child with SMA II. I could have been a physiotherapist, joining the family on a regular basis a few times a week and observing the progress and training methods. I could have been a psychologist meeting parents and children with SMA II and other conditions, talking to them about their experiences. Still it would have been different stories and I think this parental dimension of mine will add a knowledge of this topic that could not have been obtained otherwise.

In medicine SMA is referred to as a disease and this is the common way of referring to it in literature as well. (See Appendix no 1.) However, in daily life Hanna and our family consider SMA II as a condition under which Hanna was born. Svenaeus (2003) distinguishes three dimensions of a disease or an illness¹; the biological/physiological, the phenomenological dimension based on the experiences and the cultural dimension based on language. In this licentiate thesis I will focus on the phenomenological dimension using the experience obtained in Hanna's early life-world to develop new knowledge on what it can mean to exist under the conditions of SMA II. My doctoral thesis will encompass also later parts of Hanna's development, and to elaborate these I will use the phenomenological experience-based dimension, together with the cultural dimension, based on language.

¹ In the Swedish language we only have one word for both illness and disease i.e. sjukdom. Hence we can not make the literal distinction between the condition from a biological/physiological point of view, a disease and the condition from a personal/experiential point of view, an illness. See Svenaeus, 2003 p. 27.

Today Hanna is 25 years old. She is a university student and as such fully capable of self analyzing her present situation and the years back as far as she can remember. From the beginning she has been highly involved in the process of creating assistive technology helping her overcome her physical disability and be able to lead a normal life. She has always been able to make explicit what she wants and how she wants it. Now as an adult with the academic education she has, she is able not only to reflect on her situation, but also to analyze it from a variety of theoretical perspectives, thus being an invaluable source of inspiration, correction, learning and feedback for me when writing this thesis. I must say we have made this journey together. The experiences described, the analysis made, are my responsibility as well as the errors in them, but Hanna's love, sparkling personality and bright intellect have been the source of inspiration throughout the whole process, both in real life and in research. Thank you Hanna for everything, you mean the world to me!

Hanna has given her point of views in a number of discussions and she has read most parts of the text. Our mutual aim with this licentiate thesis is that our experiences can help someone else to see the possibilities and not only the obstacles if born with SMA II or similar diseases. This is why Hanna has given her consent to this story and why I have written it.

Finally, through my contact with the academic world I have been acquainted with, and interested in ontological and epistemological questions. I have also got interested in the theoretical perspective of phenomenology, highlighting experience as a source of knowledge. I have found the life-world phenomenological perspective highly interesting and fruitful when it comes to study humans and their life conditions, development and growth. The fundamental structure of its reality is that it is shared by us. I can up to a certain point, through my experiences obtain knowledge of the lived experiences of my fellow human beings (Schutz and Luckman, 1973). Thus there is an intersubjective dimension of the life-world perspective. We are not so much individuals but omniduals, that is, we are more alike than different; we are our relations (Tjellander, 2004). My interactions with Hanna and my experiences when our life-worlds have been intertwined have made this clear to me.

Acknowledgements

I would like to thank:

My friends and family who have supported me in different ways throughout the process. You know who you are and how much you mean to me. I try to tell you face to face now and then, because I believe it is important to say it in everyday life and not only on an occasion like this.

My supervisors, Bodil Jönsson and Ulla Tebelius: Bodil, for everything you have taught me. Ulla, for believing in me.

Jan Bengtsson, who has supported my phenomenological efforts with expertise and kindness.

Last but not least, thanks for the music, always the music; Release the Stars! I have told you before and I hereby tell you again: thank you!

CHAPTER 2: SUMMARY, OVERVIEW AND DISPOSITION

This licentiate thesis is a monography complemented with one published article: “*Interactive Design – the desire for autonomous upright mobility: A longitudinal case study*, *Technology and Disability* 19 (2007) 213-224”. The article differs from the monographic part in a number of different ways:

- It has a more explicit focus on the actual design process than on Hanna herself.
- It refers more to Spinal Muscular Atrophy type II, from now on called SMA II, in general than to Hanna’s experiences of SMA II and more to child development in general than to Hanna’s development.
- There is no “I” in the article. I made adjustments to accomplish the passive form preferred in “*Technology and Disability*” (“the frame was redesigned”).
- The fact that Hanna is my daughter is not made explicit in the article, but it was evident in the original text that I sent to the journal. It is also evident in this monography. I chose to exclude that information after a strong suggestion from one of the referees arguing for the anonymous approach. This does not mean that I consider the fact that we are mother and daughter to mean nothing when it comes to the longitudinal design process.

My hope is that the combination of the monographic part (with its phenomenological tone, personified and situated), and the more unbarked “*Technology and Disability*” article (with its orientation towards the general rather than the personal aspects) will contribute to dialogues on different scientific approaches. Although the main focus of the licentiate thesis is on the monographic part, I appreciated the opportunity to present part of my work also through the article. Some aspects of the process were easier to present clearly and concretely there, than they would have been in a phenomenological and pedagogical presentation.

Let me also introduce the disposition together with short summaries of the chapters:

In Chapter 2 I have situated Hanna and myself in the process and given a brief introduction to the base of the thesis by telling our story in short.

In Chapter 3 the purpose and the research questions of the thesis are presented, divided into four questions that are the overall aim of it.

Then I present my theoretical frames (Chapter 4); the phenomenological perspective is discussed from an ontological and epistemological point of view. The phenomenological life-world concept, defined as everything that is possible to experience and do (Bengtsson, priv com). This is followed by a short presentation of some aspects of the developmental theories by Daniel Stern and Jean Piaget used in this thesis. Finally I give a short overview of contemporary articles highlighting aspects important to the thesis.

Chapter 5 is the methodological implications given by the life-world phenomenological approach.

In the next chapter, chapter 6, we make an early visit to Hanna’s life-world, to the first 18 months of Hanna’s life. Hanna’s life-world is made explicit in the form of episodes, showing

among other things, how she communicated her wishes to explore herself and the world. The episodes also address the interactions in her life-world. I use the phenomenological life-world concept and the concept of the lived body elaborated by Maurice Merleau-Ponty together with the theory of Daniel Stern and Jean Piaget to analyze the events in the life-world. To own your motor act and to explore and conquer are the main focal points of this chapter.

Chapter 7 is a visit to Hanna's life-world during the second year of her life and onwards. In focus are the upright independent locomotion and Hanna's way to find out the splendor of it. I mirror her experiences to theories on independent locomotion, powered mobility and skills acquired to manage this at an early age. Incorporating the walking aid in her existence and how this affected her life-world are the themes of this chapter.

Chapter 8, "Discussion and conclusion", sums up this work and points forward towards the next themes to be highlighted.

CHAPTER 3: PURPOSE AND QUESTIONS

The overall purpose of this thesis is to develop new knowledge on child development under the conditions of SMA II. As I use a life-world phenomenological approach my first quest is to highlight and make explicit what appeared in Hanna's life-world and how these experiences have contributed to her overall development.

I also want to put forward how Hanna's motility and mobility were supported, guided by what she expressed and strived for, in order to promote a healthy physical, psychological and social development. A special focus is on independent locomotion and how this was accomplished for Hanna. By using technology in a new way it was possible to enhance Hanna's access to the world through the medium of her lived body, thus changing her life-world by widening her life-world horizon. The second quest of this licentiate thesis is to make this journey explicit.

The questions posed in this thesis are as follows;

1. What appeared in Hanna's life-world, growing up with SMA II?
2. What did it mean to Hanna?
3. How could her motility and mobility be supported?
4. What impact did these experiences, interactions and interventions (the latter with special focus on autonomous upright mobility) have on her life-world and her overall development?

I have already mentioned Hanna's and my mutual aim to inspire other persons facing the conditions of SMA II to widen their life-worlds too.

Our story in short

Hanna was born in November 1982. During her first six months we didn't notice anything different from what was expected. I enjoyed the company of the sparkling Hanna who was such a joy to be with. When Hanna was about six months old she, just like other kids more and more wanted to explore and conquer the world. We didn't suspect Hanna to be different to any other child although she didn't sit unsupported when she was 8 months old and she didn't make any attempt to crawl either. In the autumn of 1983 the healthcare raised the question if something was unnormal, and at Christmas 1983 Hanna got her diagnosis, SMA II. When this happened we were thrown into another world, a world we didn't recognize. No more regular check-ups at the children's healthcare department but visits to the doctors and visits to the physiotherapists, training programmes, and so forth. From my diary: *"In everyday life I am so used to Hanna being the way she is in her body, I can't think of it as something that is wrong, it is simply Hanna!"*

We strenuously embarked on the voyage of training, mostly to fight the somewhat pessimistic forecast given in medical books. We were encouraged by our physiotherapist to help Hanna to a standing posture in order to strengthen her body and her skeleton and if possible avoid contractions of joints. From this upright posture accomplished by a training device, Hanna and I began to understand the power of the upright posture. When Hanna was about two years old she got her first motorized walking aid and this was a milestone in her life. For some years she

altered between the upright posture and the sitting one in a manual or electronic wheelchair. One day at the age of about six and a half years, when her father was building a new walking aid, she decided that she didn't want the seating options in it. She wanted to stand all the time when moving around.

I noticed that she was to some extent a different girl when standing in her walking aid. I also noticed that her interactions with others were different when standing up compared to sitting or lying down. In other words, the way she took on the world was different and the way the world took on her was different too. This was an unexpected side effect of the upright locomotion that rapidly turned out to be just as important as the bodily benefits. The locomotion in an upright position influenced her development in a positive way; helping her to develop to the person she is today.

Over the years Hanna developed a feeling for what her walking aid was supposed to be, and what it was supposed to look like. It was to be small, easy to maneuver and as discrete as possible. Hanna early became involved in the design process of the walking aid, as we continuously developed it by rebuilding, updating the details etc. She is now, as an adult, still using her walking aid as her only assistive technology for locomotion and she considers herself a walking person. Hanna has no ability to hold her body in an upright posture due to her lack of muscular strength, but existing in the upright posture is as natural to Hanna as to anyone without any motor impairment.

CHAPTER 4: THEORETICAL FRAMEWORKS

Alfred Schutz, 1899-1959, more than any other phenomenologist, attempted to relate the thoughts of Edmund Husserl to the social world and the social sciences

[.http://plato.stanford.edu/entries/schutz/#LifInf](http://plato.stanford.edu/entries/schutz/#LifInf) Schutz stated that the sciences that aim to interpret and explain human actions and thoughts must begin with the description of what is prescientific, that is the reality which seems self-evident to the human being. This reality is the everyday life-world (Schutz and Luckman, 1973). *“The everyday life-world is the region of reality in which man can engage himself and which he can change while he operates in it by means of his animate organism”* (Schutz and Luckman, 1973 p. 3). It is in this world the human being can be understood and work together with his or her fellow human beings, taking them and the entire reality for granted. They have This means that My life-world is not only my private world since they have a consciousness that is essentially the same as mine. Up to a certain point, I can obtain knowledge of the lived experiences of my fellow human beings, such as the motives of their actions for instance. The same goes for them, and objects of the outer world are more or less the same to my fellow human beings as they are to me.

Phenomenological life-world approach

The concept of the life-world and the lived body might at first seem like an abstract construction. However, put in the context of Hanna’s childhood, growing up with SMA II, I find it fruitful and it gives new perspectives to the conditions of the human being with SMA II. Svenaeus writes on the topic of studying sickness from a phenomenological perspective; *“The credo of phenomenology is to go back to ‘the things themselves’ and what can, next to self being sick, be a better strategy than to seek the company of those who have experienced the illness or to those who have as their profession to deal with it?”* (2003 p.17 my translation).

I don’t have SMA II myself but I have been part of Hanna’s life-world every day for many years now, and our life-worlds have been that intertwined that I can use my experiences as the empirical base in the research process. My point of departure lies in the instantaneous experience and mediated understanding of illness as described by Svenaeus (2003 p. 17).

Phenomenology is considered a philosophy of experience (Bengtsson, 1993). Through the experience the things will appear, but nothing can appear without having someone to appear for. Hence, the concept of phenomenon means a reciprocal dependence between the subject and the object or between the subject and the subject as another lived body (Bengtsson, 1999). The way we can get access to everything we want to study is through our experiences of them. The task of phenomenology is therefore to make justice to the experienced network of connections that exist between the subject and the object (Bengtsson, 1993 p. 30). Experience is from a phenomenological point of view the fundament of knowledge. We can not ignore personal experiences of phenomenon and a science which ignores them will be guilty of: *“suppressing evidence and will end with a truncated universe”* (Spiegelberg, 1982 p. 689). We can only understand and apprehend our world and the things around us with ourselves as experiencing subjects through our lived bodies. The subject is situated in the world (Bengtsson, 2007, priv com).

Emotion as knowledge

One of the epistemological perspectives in phenomenology is that emotion is an important source of knowledge. In a “Sketch for a theory of the emotions” (1976) Jean Paul Sartre elaborates emotions as a phenomenon, and analyzes its importance. Sartre claims that emotional consciousness is primarily a non-reflexive consciousness of the world. Fear for instance is not primarily consciousness of me being scared but rather a reaction to the thing that has frightened me. A conscious awareness may arise, but always later. Sartre (1976) also claims that it is impossible to talk about emotions without mentioning the objects creating the feeling within the subject. In other words: the emotional subject and the object/subject creating this emotion are inseparably connected to each other. This makes emotion a specific way of apprehending the world. The feeling precedes the emotion and is the natural predecessor of it. The feeling is connected to the act of perceiving (it also contains the tactile dimension). The emotion is a deepened form of feeling that transplants itself throughout the body. The feeling also creates a certain way of acting. We can act both on a genuine feeling and on a feeling that does not have a genuine character. The difference will be that the (re)action on a non-genuine feeling will be possible to shut off on demand whereas the genuine feeling will fade out by itself when the time is right. Prior to that it will be impossible to quit the state of mind and the actions this state of mind brings. For instance; you might stop running when scared but you can’t make your knees stop shaking. Emotion is therefore, from a phenomenological point of view, an important source of knowledge.

The Life-world

The life-world is the arena where we act; it is presupposed and taken for granted as an implicit background of all different activities. It can be defined as the world of everything that is possible to experience and do. The life-world is both affected by us and affects us. We are connected to the life-world in an interdependent way, making the life-world both prereflexive and prescientific. By being both prereflexive and prescientific the life-world is the predecessor of both philosophy and science, even though we don’t always acknowledge this. The life-world is neither a pure objective world in its own right, nor is it a subjective world. It is something different, it is rather an ambivalent world in-between.(Bengtsson, 1999)

The life-world is surrounded by a horizon, but that is not an absolute border. The life-world horizon is a border that can be displaced (Bengtsson, 2006). The life-world can grow, expand, and the life-world horizon will then move outwards if you gain ability and/or discover new talents. The life- world can shrink if you, for instance, lose the ability to do something.

The Lived Body

The French Philosopher Maurice Merleau-Ponty elaborates a theory of the body in his book *Phenomenology of Perception* (1999). *“The body is the vehicle of being in the world and having a body is for a living creature, to be involved in a definite environment, to identify oneself with certain projects and be continually committed to them.”* (p. 82). In this well-known quotation Merleau-Ponty talks about “having” a body. Later in his texts he takes these thoughts further when he claims; *“I am not in front of my body, I am in it or rather I am it* “(ibid p. 150).

Merleau-Ponty also says: *“I am conscious of my body via the world, that is my body is the unperceived term in the centre of the world. Towards this centre all objects turn their face, it is true for the same reason that my*

body is the pivot of the world: I know that objects have several facets because I could make a tour of inspection of them, and in that sense I am conscious of the world through the medium of my body” (ibid p. 82).

Thus, Merleau-Ponty states that the body is the general medium for having a world. I apprehend the world through my body and the word “here” applied to my body means to identify the first coordinates. Sometimes the body is involved in, and restricted to, the actions necessary for the conservation of life, and at those times “*it posits around us a biological world;*” (1999 p. 146). At other times it gives the actions a new core of meaning, actions that we will call habits, such as dancing. Sometimes “*the meaning aimed at can not be achieved by the body’s natural means; it must then build itself an instrument* (1999 p. 146). The body is my beacon from where I get access to the world and without my body there would be no perspectives. This means that every change of the body means a change of the world. Through the body I get access to the world and the capacity of my body will determine the way I perceive my world. This makes the body a double existence, it is both body and subject, or “the lived body”. (Bengtsson, 1999, p. 22) Accordingly there is no contradiction between body and soul, it is instead an integrated whole.

“Consciousness is being-towards-the-thing through the intermediary of the body. A movement is learned when the body has understood it, that is, when it has incorporated it into its ‘world’, and to move ones body is to aim at things through it ; it is to allow oneself to respond to their call, which is made upon it independently of any representation. Motility, then, is not, as it were, a handmaid of consciousness, transporting the body to that point in space of which we have formed a representation beforehand” (Merleau-Ponty, 1999 p. 139).

The body is the subject of all objects (and other subjects) we can experience whatsoever. We can incorporate things with our own body, for instance the blind man’s stick (Merleau-Ponty, 1999) and after a while they stop being things and will become means to extend and transform our world (Bengtsson, 1993). The lived body is the actor on the arena of the life-world – both are at the very core of our existence.

The Intersubjectiveness of the Life-world

We coexist with our lived bodies in a natural way with other human beings through their lived bodies (Bengtsson, 1993). “*If my consciousness has a body, why should other bodies not ‘have’ consciousnesses?*” (Merleau-Ponty, 1999 p. 351). We never experience other human beings as merely physical objects; we always experience them as psychophysical entities (Bengtsson, 1993 p. 72). We apprehend the gestures and the facial expressions of another human being, another lived body, in a pre-predicative way. The meaning is not somewhere behind the gesture, but incarnated in it (Merleau-Ponty, 1999 p.186). Put in other words; “*The gesture does not make me think of anger, says, “it is anger itself”* (Merleau-Ponty, 1999 p. 184). When a friend comes towards me in the dark there is something about him or her that makes me apprehend that it is my friend, not by adding certain features to establish the recognition of a friend, but by the nonverbal entirety of the experience (Bengtsson, 1993 p. 84). When I understand the mood of another person it will be by his or her overall expression of his or her being-in-the-worldness. Through taking over and passing on the meaning expressed in the other person’s being-in-the-worldness a dialogue will unfold. When I confirm the other and the other person confirms me, when I correct the other person and the other person corrects me, we will find ourselves in a spontaneously working interaction and communication (Bengtsson, 1993 p. 86)

The Lived room

Another concept that is an important phenomenological concept is the “lived room” (Bengtsson, 1998 b). The human beings’ relation to the room is a complex matter. Room in this context does not mean the room as we normally think of it; an enclosed area defined by its walls, ceiling and floor. Instead the room is to be understood as the sphere in space that a human being as an experiencing subject can perceive. Human consciousness is always directed towards something which is the theory of intentionality (Merleau-Ponty, 1999). The intentional room is the room she as a subject is directed towards; it is edified around the perceiving human-being in motion. Thus it will assign the position of the human being as the centre of that room (Bollnow, 1994) i.e. the room has a connection to human life that will make the position and the posture of the human body the natural pivot of the room. This phenomenological understanding of the room is defined as the “lived room” (Bengtsson, 1998 b).

The room is furthermore limited by the human horizons, making an outer limit in relation to her, and when the human being moves, the horizon will move too. There are also different dimensions within the same room, defined by the different ways humans perceive it and act in it (through vision, hearing, smell, taste and perception of touch) and act in it (it will be structured according to what we focus on, the reasons for this and how we display our will). All these dimensions of the room will be coordinated by the own lived body; the natural 0-coordinate of the room (Bollnow, 1994). Hence, this is not a point possible to regard from the outside but a *here* that can be related to a *there*, or to an *over there* (Bollnow, 1994). There is no room as such, only the thousands, millions of rooms experienced from every possible 0-coordinate position. From this will follow that the lived room is a system for the things’ relations to the moving body, a system that will follow the moving body.

Every lived room has also its special mood, temper or atmosphere. These dimensions are determined by the different activities in the room as well as by the persons executing them. Hence the atmosphere is not an objective quality of the room but rather a mix of the above mentioned qualities. The human being is influenced by the atmosphere of the room and the atmosphere in the room is influenced by the human beings. Noteworthy is that the subject will not be in the room as an object in a box, instead the subject will constitute the room by relating to the environment, to claim the room, to inhabit it. The human being, as a lived body, a bodily subject, is therefore to her inner existence spatial (Bengtsson, 1998 b).

Merleau-Ponty uses the word “inhabit” to describe the intimate relation between the incarnation of the soul and a spatial formation. He also talks about the possibility for a human being, by feeling and insight, to inhabit the body of another person, i.e. that the meaning instantly will manifest in the experienced expression of the other (Bollnow, 1994).

Inhabiting is about expressing a special intimacy with which something spiritual merges with something spatial (Bollnow, 1994). There is a circular relationship between the (lived) room and life that makes it impossible to reduce the room to merely a psychological (inner) entity. It also makes it impossible to reduce the (lived) room to merely a physical (outer) entity. From a life-world phenomenological point of view the appropriate denomination of this expanded understanding of the room is the lived room (Bengtsson, 1998 b).

The Lived Time

In the same way as with the lived room, one can look upon time as lived time. Chronological time, with points replacing each other in a uniform and objective way, is the most common way of looking at time (Bengtsson, 1998 b). But the time we experience as lived bodies or subjects, the lived time does not flow in a uniform way. Instead it has a different rhythm depending on what we do and how and when it is done. In lived time the time is structured with the lived now of the subject at the center, and from this point of view, dimensions of time will unfold backwards and forwards. The concept of horizons, described above, moving with the subject, is also applicable when talking about time (Bengtsson, 1998).

Provinces of meaning

Schutz talks about different worlds that we participate in, worlds that are all included in our life-world. They are provinces of meaning (Schutz and Luckmann, 1973 p. 23) and a human being is able to transcend from one province of meaning to another. This is done through a leap from one province of meaning to another, i.e. from one regional world to another. A regional world is only a part of the life-world (Bengtsson, 2006). The regional worlds are all the different worlds a person moves between in her life. Regional worlds do not exist in isolation; they have always references to other regional worlds. The life-world though, includes all the regional worlds in the existence of a human being. We might move in and out of our regional worlds, such as our work, our leisure activities, our travels, our visits to the hospital when sick etc. As the human being moves between her regional worlds she takes experiences with her (Bengtsson, 2006). That means that experiencing something in one regional world will become an experience that we can take with us into another regional world and use in a different setting. As an experiencing subject, the human being might enter and leave and re enter different regional worlds, they are interchangeable, but the life-world is not.

Developmental theories

The core self

A theory I have found useful with its focus on interplay between the child and its caregiver, is the theory of Daniel Stern on child development (1998) with special focus on the points where Stern elaborates the motor activities. Unfortunately Stern only in a limited way explicitly talks about the motor development, its meaning and significance for the psychological processes and development that he so vibrantly describes. His explicit focus is on emotions, perception and the interaction. When reading his texts, however, I have assumed that he presumes an average motor and intellectual capacity within the child and that this goes without saying. Still on some occasions he explicitly talks about the motor activities of the child and how this competence is interacting with the overall development. Stern calls his book a “working hypothesis about infants’ subjective experience of their own social life.”(Stern, 1998 p.4) As such his theory is highly applicable to the purpose of this licentiate thesis.

The interplay between a child and his or her caregiver is a delicate matter as described by Daniel Stern in “The interpersonal world of the infant”. A functional interplay is characterized by mutual sensitiveness, ability to attunement and amodal perception, i.e. transmitting perceptions from one sense to another, and so forth (1998). A healthy relationship is based on the mutual attunement between the caregiver and the child although the caregiver in many aspects thinks he or she is the person controlling the interplay. The child, is according to Stern (1998), from the beginning a competent person capable of interacting actively with his or her caregiver, able to affect as well as be affected by the interplay situation. If the caregiver is recipient to the child’s expressions the interplay becomes just that, interplay between two persons, in a mutual give and take situation. *“I can enter into interrelations and reciprocal actions with my fellow men”* (Schutz and Luckmann, 1973 p. 5). This is one of the fundamentals of a natural attitude and this condition is applicable even to a small child, a baby. As mentioned above Stern (1998) states, opposed to the opinion of many earlier psychodynamic orientated researchers such as for instance Mahler (Mahler et.al.1990), that the child is born with an innate competence for interaction. The primary task for the child is connecting to the caregiver instead of separating from a symbiotic relation.

In the center of his theory Stern places the sense of self and divides it into four parts, or four domains in the development of a human being: the sense of an emerging self, the sense of a core self, the sense of a subjective self, and the sense of a verbal self. Important to understand, in order to understand the theory, is that *“Once formed the domains remain forever as distinct forms of experiencing social life and self.”* (Stern, 1998 p. 32) The formative phase for each sense of self is to be regarded as a sensitive period but none of the senses of self will become developmentally obsolete or will get left behind. The formative period of the sense of emergent self is between birth and two months of age, the formative period for the sense of a core self is between two and nine months of age, the formative period for the sense of the inter-subjective self is between 9 and 15 months of age, and finally the formative period for the sense of the verbal self is around 15 months (Stern, 1998).

Stern divides the first year in life in three parts with different focuses for the baby. The period from birth to two months is a period of regulating physiological needs such as sleep and hunger. The period roughly from two to six months is perhaps the most exclusively social period in life, where the child is a highly social partner.

“After six months the infant transforms again and becomes fascinated by, and proficient in, manipulating external objects; coordination of limbs and hand-to-eye has improved rapidly, and an interest in inanimate objects sweeps the field. When in physiological and affective equilibrium, the infant is relatively more engaged with things than with people.” (Stern, 1998 p.72).

The first organizing perspective of self is at a fairly basic level, and experiences needed to form an organized sense of a core self are of four different types. Stern describes these four invariations (islands of consistency as he calls them) of a core self and calls them self-agency, self-coherence, self-affectivity and self-memory. These four self-experiences together constitute a sense of a core self. The sense of a core self is the foundation for all the other senses of self added later. The sense of self is not a cognitive construct, but an experiential integration. In this part of the thesis I will focus on the first one, *self-agency*.

“Self-agency, or authorship of action, can be broken down into three possible invariants of experience: (1) the sense of volition that precedes a motor act, (2) the proprioceptive feedback that does or does not occur during the act, and (3) the predictability of consequences that follow the act.” (Stern, 1998 p. 76-77).

These three components are connected to motor skills. The first invariant of self-agency, *the sense of volition that precedes a motor act* is the one invariant Stern describes as maybe the most fundamental invariant of core self experience (1998). Stern refers to Lashey (1951) who states that all movements by striped muscles (organized on a level above reflexes) are preceded by the elaboration of a motor plan, a plan later carried out by the muscles. This can be described as a mental registration of a motor plan before an action is carried out. Stern continues by writing: *“The existence of the plan can reach awareness quite readily when its execution is inhibited or when for some reason the motor execution misfires and fail to match the original plan.....* (1998 p.77).

The next of the invariances Stern talks about in addition to self-agency, invariance number two, is the proprioceptive muscular feedback present during the time of motor action (1998). This is something that, according to Stern, characterizes the motor actions regardless if they are initiated and carried out by the person her/himself or is manipulated by someone else (ibid). I interpret this as the sensory feeling the individual gets when performing a motor action. Stern also claims that we have every reason to believe that the proprioceptive muscular feedback has an important role to play, is developmentally a constant invariant of self agency, even when the child is not moving but only fighting gravity. The last of Stern’s steps, the third invariant, is the predictability of consequences following the act. This is the ability to predict what will follow and control the results that follows are relevant to the performed act (1998).

Stern has also classified three different patterns of movements causing different experiences in the child. He calls them: *“other-willed action of other”*, where someone else is bringing a thing to the child and neither volition, nor proprioception is experienced, *“self-willed action of self”*, where the child wants to grab a thing and does it. Here the child experiences both volition and proprioception. The third possible outcome, *“other willed action of self”*, (1998 p. 80) is when someone else does something with the child’s body, i.e. takes the child’s hands and claps them where the volition is lacking but the proprioception is there for the child to experience. Self-agency in the sense of authorship of one’s own actions, and nonauthorship over the actions of others; having volitions and having control over self-generated actions and expecting consequences of one’s actions is of utmost importance for the development of the sense of self.

Stern does not, as mentioned before, speak about motor activities often, but on a few occasions he does. One of them is when he claims that it seems reasonable to suppose that the capacity and ability to crawl or cruise the environment, is crucial for the discovery of different and alternative perspectives (1998).

Stern states that: *It seems reasonable to assume that, even prior to pointing the infant's beginning capacity to move about, to crawl or cruise, is crucial in discovering alternative perspectives as is necessary for joint attention. In moving about, the infant continually alters the perspective held on some known stationary sight. Perhaps this initial acceptance of serially different perspectives is a necessary precursor to the more generic "realization" that others can be using a different coordinate system from the infants own.* (Stern, 1998, p. 130-31)

This ability is developed at about 9 months of age. The sign of this capacity in the child is among others the child's ability to follow a pointed finger with the gaze of the eyes, looking in the direction of the finger, not at the finger itself. The discovery of different perspectives may be necessary for the child's ability to acquire the understanding of other people having different perspectives than the child, i.e. using another coordinate system than the child's own (Stern, 1998). This is the starting point of inter-attentionality (Stern, 1998). Stern also stresses that the ability to share focus of attention is one of the evidences of a developed intersubjective relatedness. Sharing intentions and sharing affective states is the two other signs of this.

I will also use some aspects developed by Jean Piaget in this part of the thesis. Jean Piaget wrote his theories focusing on cognitive aspects of human development and human existence; that is the development of intelligence and the ability of abstract thinking. He stresses these functions as central when it comes to individuals mastering their world and understanding it. The actions and experiences of the individual is a fundamental condition for development, where the action is defined as the individual's opportunity of practice, to be able to master the things in order to understand them, their characteristics and the situations in which they are included. During the time Piaget refers to as the sensory-motor stadium reaching from 0 to 2 years, the intelligence of the child is characterized by a practical nature and the child discovers the world by his or her muscles and senses (in Shaffer, 1994). When the secondary circular reaction becomes a natural part of the child's repertoire at about 4 to 8 months and the child is getting an interest in the effects of his or her motor (re)action on the external things, the motor actions themselves becomes more and more precise and effective. The child hits the rattle, a sound emerges, and the child wants to repeat this and repeats the motor action. Being the cause of an action is a source of great pleasure to the child (Piaget, 1999). Piaget also highlights the importance of the growing radius of action the child conquers for him- or herself first by crawling and later by walking. This expanding radius of action gives a bigger potential of new experiences of the world and the objects in it, humans as well as things. These accumulating experiences create the schemes and inner representations that constitute the representations of the world (in Shaffer, 1994). This process is a complicated learning process and takes place between 8 and 12 months of age and leads to a deepened understanding of cause-and-action connections (Piaget, 1999).

Stern's and Piaget's theories use a different vocabulary for human conditions in general, compared to the life-world phenomenological approach. Stern talks about child development from a psychodynamic point of view, using the vocabulary common in these traditions. Important concepts in this part of the thesis will therefore be: relation, interaction, explore and conquer. Piaget talks about it from a cognitive point of view. A fruitful result might be the outcome of putting Stern's approach and Piaget's approach in relation to the phenomenon in Hanna's life-world. In this part of the thesis I will also use some contemporary articles written in different traditions with different vocabulary but they have one thing in common; they all have something important to say about life conditions that can be used to understand and get a deeper meaning of what appears in Hanna's life-world.

Bodily aspects

Bodily Benefits

There are a lot of research articles on the bodily benefits that can be gained by achieving an upright standing position for people with different kinds of disabilities. These gains are for instance reduction in loss of bone mineral density. Here static loading has proved to be less efficient than dynamic loading in prevention of bone mineral density. (Fritton et al. 2000) (McLeod et al., 1998) (Lanyon et al., 1986) (Lanyon and Rubin, 1984) (Rubin and Lanyon, 1984) Prevention of osteoporosis and the consequent risk of fractures (Martin and Houston, 1987) (Martin and McCulloch, 1987) (Erlish and Lanyon, 2002) is another benefit from standing; just like improved bowel function/reduced constipation (Hoenig et al., 2001). To the benefits scientifically proved is also prevention/delays of contractures (Trudel and Uthoff, 2001)(Trudel, 1999) and reduction in respiratory and gastrointestinal complications (Eng et al., 2001). Children with SMA II are no exception.

The importance of independent locomotion

“Independent mobility is crucial to the intellectual, social and emotional development of disabled babies and children” (Durkin, 2002 p.170).

Locomotion is crucial to the child’s ability to explore the environment and socialize with others (Jones et al. 2003). It is important that *“development of the mind and body presents a special window of opportunity to correct (note, not cure) errors that occur early in life and that novel treatment for paediatric disorders should fully take advantage of these periods in ontogeny in order to achieve maximum gains.”* (Andersen, 2004). Independent mobility in early childhood is said to be associated with various developmental skills such as cognitive skills and psychosocial skills. For children with physical disabilities there is a risk of delays in these areas (Tefft, Guerette, Furumasu, 1999). Durkin states that: *“Disabled infants who are unable to move themselves independently around their environment are set on a slow and disadvantaged developmental spiral”* (2002 p.163). The use of powered pediatric mobility devices or powered wheelchairs may be beneficial to children who are unable to move independently (Tefft, Guerette, Furumasu, 1999).

Children may learn how to maneuver a powered mobility device at an early age through trial and error play with the mobility device and by experimenting with the joystick (Furumasu, Guerette, Tefft, 1996). The opportunity for practice should not be limited to times when the physical therapist is visiting two or three times a week for an hour (blocked practice) but should be incorporated in daily activities (random practice) (Jones et al 2003). In some way or another the child’s aspiration for motor action must be noticed and taken into consideration by people around a disabled child, so that the urge of the child can be made expressible by use of assistive technology suitable for the purpose.

Perspectives on impairments

A person with SMA II has an inborn motor impairment that from the start will affect the life-world of that person. A new philosophical framework has emerged in pediatric rehabilitation in recent years focused by Wiart and Darrah (2002). This change of perspective challenges the traditional paradigm which is based on the thought that the primary goal is acquisition of normal movements through changing factors within the child to attain the highest level of

independent movement possible without the use of assistive devices. The old neuro maturation theory encouraged intervention strategies that aspired to normalize movement patterns by changing the child. Lately, a new way of looking at the problem has emerged. Normal movement patterns may not always be the most efficient for children with physical disabilities. Successful movement can be accomplished by modifications of factors external to the child (Viart and Darrah, 2002). This means that there are currently two different paradigms, the traditional and the contemporary, that exist in the rehabilitation management of children with physical disabilities. The contemporary models mentioned in the article take similar standpoints; optimal motor activities may be achieved by movement patterns that may not be considered normal. For instance, children should be provided with an array of movement options in order to be able to participate in different meaningful activities (Butler, 1991). There is nowadays a biopsychosocial view on development that recognizes both intrinsic and extrinsic factors to understand the difficult interaction between biology/genetics and the environment shaping the developmental processes. There is also a need for follow-up from childhood to adulthood as there are some functional limitations from childhood disorders whose consequences will only be fully expressed in adulthood (Helders et al 2003). My study is to some extent such an effort.

CHAPTER 5: METHOD

Underlying every research project is an ontological assumption about the reality that is to be studied and also an assumption about what knowledge is and how to obtain knowledge about the world and the things in it, an epistemological starting point. These assumptions lead to a practical research strategy. It is of importance that these standpoints are made explicit in order to make the research process transparent and possible for others to evaluate (Bengtsson, 1999). Phenomenological life-world research can not put forward a unanimous methodology regarding how to carry out phenomenological life-world research. Instead it is up to the researcher carefully to consider, create and account for his or her chosen path. This calls for certain creativity.

I will use a phenomenological life-world approach and such research can be described as a way to understand the lived relations that human beings have to their world (Berndtsson, 2001) and her fellow human beings. The demand put on the method is that it is based on the part of the life-world, regional ontology, that is at the centre of the project. The method must be chosen depending on its ability to make justice to the life-world in focus and that will allow the phenomenon under study to appear on its own premises. By doing so the researcher gains closeness to the life-world in focus of the investigation and a responsibility for the knowledge created. (Bengtsson, 1999) In this study I will make my experiences in Hanna's life-world explicit. Through my experiences of her experiences I have tried to understand what her experiences meant to her and how these experiences have contributed to her development as a person. I will present the different steps of the analyzing process used in this thesis, to make the process transparent for others to evaluate.

The encounter: interactions and relations

To enable something to happen between a human being and her world some kind of encounter is necessary. Bengtsson states that *"to be able to enter someone's life-world some kind of meeting is required"* (1999 p. 35 my translation) and refers to Merleau-Ponty who claims that it is through the communicative and interactive meeting we can get hold of other people and things in the world. The effort to get access to experience from somebody else's life-world, is described by Svenaeus as he tries to understand the meaning of disease from a phenomenological point of view: *"I have tried making a virtue of this everyday perspective, by seeking environments where patients and personnel meet and discuss disease, illness and healing"* (2003 p. 17 my translation). As researchers, we must expose ourselves to the risk of participating with our own life-world (Johansson, 2003). I had a natural access to Hanna's life-world as our life-worlds have been intertwined so this was nothing exceptional to me. In my case the difficulty rather was to distinguish beyond the familiar and the obvious. Self-reflection (Bengtsson, 1998a p.107), can be used as a way to create distance to your own self and as a tool to create a distance to your own activities. I have tried to be self-reflective as a way to see other things than just the familiar and the obvious.

My process resembles the participatory ethnographic approach used by Moore (Goodley, Lawthon, Clough, Moore, 2004) when entering the life of her distant relative David, let alone that she never uses the word life-world in her work. Moore first entered the life of her relative at this close range in order to help David. I was in Hanna's life because I was her mother. Later Moore used the knowledge she had obtained from their meetings and her encounters with David and his world, to tell his story because *"David said he wanted his story told"* (Goodley,

et.al. 2004 p. 78) and because Sheila, David's mother wanted it told "*because David wanted it told and because she came to believe that the telling of David's story might help to alleviate tragedy in the lives of other families*" (ibid). Hanna and I have decided to communicate parts of her life-world in order to, if not alleviate tragedy, inspire others and point out alternative roads to travel.

Experiencing versus experience.....

Phenomenology is considered a philosophy of experience (Bengtsson, 1993). We can get access to the things through our experiences of them. A distinction I find necessary to make is the one between the act of experiencing and an experience. I would like to claim that *experiencing* is an act that takes place between the subject and the world (the things and persons in it) and that the *experience* is something each subject acquires and carries with him or her. This means that whereas the act of experiencing is something that happens between people and is a shared entity, an *interpersonal* act, the experience on the other hand is something *intrapersonal*, something the experiencing subject can, and to a great extent will, bring with him or her. As the human being moves between her regional worlds (see also Schutz and Luckmann, 1973) she brings experiences with her (Bengtsson, 2006). Interactions and the responses we get, such as reactions from our fellow humans, form the experiences that each person carries with him or her. Human existence and human knowledge-making is thus an intertwining of these components. I was experiencing events in Hanna's life-world, and this has formed my experience of it. Through these experiences I could get important knowledge of what was important to Hanna's development.

....and the experience of whom?

Another dilemma is the one concerning whose experience is the fundament of life-world research. To be in another person's life-world is, to some extent, to be exposed to the reality of that person. The researcher's life-world will meet the life-world of her fellow human beings. Through the encounters with their life-worlds, the researcher will be confronted with other perspectives (Bengtsson, 1999). The optimal result would be if the researcher understood the world of the other the same way he or she understands it him- or herself. This is in my opinion impossible to accomplish. Instead we have to accept the more realistic outcome – the researcher's experience of the other person's life-world and through systematic studies of these life-worlds we can enhance our understanding of them (Bengtsson, 2007 personal conversation). In this licentiate thesis my life-world was exposed to Hanna's life-world and I was confronted with the perspectives in it. I tried to experience the world from her horizon but as we never can understand the world as someone else understands it, it will be my experience of her life-world, my experience of Hanna's experience.

Sources of knowledge

My experiences are available through three different sources. There are the diary texts I was writing at the time, there are the pictures taken during Hanna's childhood and there are my memories of the events and situations we encountered. The first two sources have the advantage that they are there explicit for others to see, read and interpret although the interpretation can differ from person to person. But what about memories?

This licentiate thesis is a longitudinal study over Hanna's first 7 years. Since then, almost 20 years have passed by, and during most of the time I didn't have any thoughts of elaborating the experiences. Still I reflected a lot over our situation and I have a lot of vivid memories both from the first 7 years and later from the reflections upon them. The possibility to evaluate the correctness of a long time memory, sometimes called the archival memory is discussed by Hoffman and Hoffman

www.google.com/search?q=cache:ATsijskgDYkJ:www3.baylor.edu/Oral_History/Hoffmans.pdf+reliability+and+validity+in+oral+history:the+case+for+memoryandhl=svandgl=seandct=clnkandcd=1

Two questions are highlighted in this discussion; How reliable is human memory? How valid is it? In this context reliability can be defined as the consistency with which an individual will tell the same story of the same event a number of different occasions. Validity on the other hand, refers to the conformity between the report of the event and other reports of the event such as; diaries, documents, letters or other oral reports. Hoffman and Hoffman talk about what they call archival memories. Some impressions are stored in the archival memory, stable over time; and often the result of a first encounter with something. Some differences between the memories and the reports from other primary sources could be noticed though. The memories of events and situations used in this thesis are of the kind archival memories.

From experience to episode

The process also contains a selection process; I had to choose what events from the life-world I would use in the thesis. The question I had to answer was; which events and encounters were to be used? Some of the events and encounters had a striking impact on me when they occurred and later when I in retrospect was to decide which episodes to use, they again stood out as pregnant. All events used do not have this origin though. In some cases it was the repetitive aspect of an event that made me realize that this might be something important, due to the reoccurrence of sequences it and recognized as being of importance after a while.

What I have experienced in the encounter with Hanna's life-world have to be transformed to texts for others to share. I have tried to describe the events, feelings, interactions and so forth as thoroughly as I possibly can in the form of episodes where my aim is to make justice to the diversity of Hanna's life-world. Every time we try to describe the life-world, we will automatically reduce it because we can never make justice to the complexity of it (Bengtsson, 2007 personal conversation) still when writing the episodes I have tried to make justice to the life-world by writing a kind of text that is sensitive to the atmosphere, tone and events I experienced in it, in an attempt to at least try to make justice to Hanna's life-world. Such a text is, in my opinion, brilliantly written by Langeveld (1983) (1984) in his phenomenological description of the secret place in the life of the child. This is a kind of text that links directly to my inner room where the feeling from my long ago lost secret places still lingered on, and to my delight was easily retrieved. This kind of text, speaking to the inner room of a human being and the feelings she carries there, is the kind of text I have tried to write when creating the episodes using a narrative form.

If we wish to understand the deepest and most universal of human experiences, if we wish our work to be faithful to the lived experiences of people, if we wish for a union between poetics and science, or if we wish to use our privileges and skills to empower the people we study, then we *should* value the narrative (Richardson, 1990 p.133-4)

In order to make the episodes vivid I have also chosen to write in the present tense, to include details and describe the events and situations in full, making an effort to recreate the situations as I experienced them in an attempt to make it possible for the reader to feel, think about and turn the perspectives of every episode. Still, in the word recreate lies a clue to what it really is to write a narrative of this kind; you (re)create something; that is you are creating it even though you do it as thoroughly you can. By reading the episodes from Hanna's life-world it will be possible for others to get a grip of events and interactions that was important to Hanna and that would have been impossible to get access to but through me.

The episodes have some items in common;

- 1) They are all true in the sense that they are what I experienced happened. They are based on my memories, pictures and diary texts. It is my experience of Hanna's life-world, my experience of the encounter with her life-world that is put on paper.
- 2) The episodes are to be seen as a way of making a small part, a moment in time of Hanna's life-world, explicit in order to make it vivid and apprehensible to the reader. They are not to be seen as examples of some specific entity put together in order to make an analytic point clear.
- 3) The words are, in this context, to be looked upon only as tools to make the life-world explicit for someone not there to experience it. Writing down the events using words to fixate it will inevitably mean a reduction of the life-world and that some aspects of it will be lost. This is also true for the mere act of perception that precedes the writing of the story.
- 4) The theoretical analyses performed later in the thesis are not an analysis of the text but an analysis of the events in the life-world described in the text and made explicit as narratives.

Hanna's regional world is all I can say something about in this project, but these structures and their meaning might also have something to say about the conditions of humans in general, disabled or not. There are at least three levels of understanding my empirical material:

Three levels of understanding

Descriptive life-world level: The first level is a narrative, a detailed story with the aim to give the reader a possibility to visit Hanna's life-world for a while. The experiences during the many times Hanna's and my life-worlds where overlapping is reconstructed and displayed rich in detail in an attempt to cover as much as possible of the multiple dimensions of Hanna's life-world.

Systematic life-world level: The second level of understanding I look at, and compare, experiences from different situations in the life-world. My aim is to detect patterns that can generate a more systematic understanding of the contents and structures of the experiences in it. By looking at many situations such patterns will be possible to detect. I also try to take a step back and reflect over what I have experienced in our intertwined life-worlds, to be able to see beyond the familiar and the obvious, to differentiate between being in the life-world and writing about it.

Meta-reflective theoretical/life-world level: The third level of understanding is where my experiences in Hanna's life-world are put in relation to different theories and research relevant for my research question. My aim is to understand in what way the experiences in Hanna's life-world can be understood in the light of the knowledge presented in the theories and articles.

I have tried to make the research process as transparent as possible in order to make it possible for each person reading this to evaluate my statements and the conclusions I draw from my material in my analyses. The strength of the life-world approach is, from my point of view, that it retains the contact between the everyday world (such as it is perceived by humans in it) and science with its urge for knowledge in different forms. This is all to avoid that the knowledge obtained is distanced from lived life.

CHAPTER 6: THE FIRST YEAR

What happens between a human being and her world is the fundament of her development and being. During the first period in life the interplay with the caregiver and other important persons is almost all that is possible to experience and do for the child, hence her life-world unfolds in the interaction with her caregiver. As time goes by the child will be more and more able to widen her life-world horizon, to explore and conquer the world around her with the help of new capacities in the lived body, in other terms called cognitive, emotional and physical aspects of the human being. This will make a change in the lived body that will change the life-world and its horizon. Theories and relevant research have been selected according to their theoretical capability to make an interesting and creative resonance to the episodes.

In her first six months Hanna related to the world in the way that was to be expected. She was able to do what any child that age does, maybe a little less intensely. During the second part of the first year the signs of her SMA II condition slowly occurred although we didn't know about them.

To own your motor act and be the author of action

On her own on the blanket July 1983

Hanna is 8 months old

Hanna is on a blanket on the floor. Her toys lie shattered all around her so that she will be able to amuse herself. She doesn't have full stability when sitting yet, so I bend down and put a rolled towel round her hips to support her in the sitting position. This makes her a little more stable and she slowly bends forward a little and stretches for the nearest toy, the yellow doll that looks like a mix between a doll and a mouse. Her little hand is a few centimetres from it when she tires and seems bored. I put the doll a little bit closer so that she can grab it and this captures her interest for a short while. Then she lets it fall. I try to make her interested in some of the toys around her and she grabs them if I stick them in her hands or hold them a little bit in front of her so that she can grab them without moving. She makes no attempt whatsoever to move around or change her position when I leave her in the sitting position. I feel a little sting of worry but then I think about her father who was a slow starter and didn't learn to walk until he was 18 months old and never learned how to crawl. I tell myself this as I see my daughter sitting still in the middle of her toy collection.

I fetch some more toys and place them around Hanna on the blanket. The usually ever smiling Hanna looks sad and there is a different expression on her face, an expression I don't recognize and don't like. I watch her and feel distressed when doing so. Something about her cries out to me that she is not satisfied and content. She just sits there, she doesn't cry or anything, just sits there on the blanket, her back a little bit bent, her face reflecting utter inactivity. It feels like she becomes extinct when sitting on the floor. It is a stomach feeling in me and it transplants throughout my whole body. I can't stand it so I bend down and pick her up. In front of my eyes she transforms, the light in her eyes is back, she starts to babble and use the words she can, moving her body up and down on my hip. Her movements are transmitted into my body and I can feel her wishes in my bones. I smile and start walking towards the thing she is focusing on.

The practical nature of the intelligence in the Piagetian sensory motor stadium is characterized by the world being experienced by motor actions. This was an obstacle for Hanna as it is for any child with SMA II. Left at her own devices, she had limited possibility to take any action to master the world. On the blanket on the floor Hanna's lived room was affected by her lack of muscular strength. The intentional room, she as a perceiving subject was directed towards, edified around her as a perceiving human being in motion (Bollnow, 1994) but Hanna was not in motion. Her senses were fully at her service, so the perceiving part she was able to carry out satisfactory, but her striped muscles were not, making the "in motion" part impossible. This made her lived room narrow and dull when she was left to her own physical capacity.

Hanna tried to overcome this as she had a large amount of motor plans i.e. the sense of volition that precedes a motor act (Stern, 1998). These motor plans often resulted in one or two attempts to accomplish something but when left alone relying only on her own motor capacity; she often failed in executing a motor action. This made her fail to widen the horizon of her life-world. Her failures seldom resulted in her crying which would have made her negative experiences evident. Instead she often resigned and became passive "bodily numb" in these situations, as described above. This numbness could have been mistaken for contentment, leaving any person in her close environment to believe she was satisfied, but as we have the ability to understand the meaning incarnated in the gesture (Merleau-Ponty, 1999, p.186) I had, what I in the episode called a "stomach feeling". This feeling was about what Hanna was communicating. I was able to understand these body expressions without words in a direct manner. Merleau-Ponty states that:

It is through my body that I understand other people, just as it is through my body that I perceive 'things'. The meaning of a gesture thus 'understood' is not behind it, it is intermingled with the structure of the world outlined by the gesture, and which I take up on my own account. (Merleau-Ponty, 1999 p. 186).

I strongly felt her bodily numbness as some kind of resignation although not in a way that made her aggressive with frustration. Instead it was some kind of tranquility that scared me even more. If we use the theory of Merleau-Ponty on human existence, i.e. *we are our body* (1999), this will mean a different scenario for Hanna compared to a child with strong muscles. The lack of muscular strength will then not only affect what she *can do*, but also determine *who she will be*. I also experienced a tendency in Hanna to stop wishing instead of to stop trying. What she did was that she was content with what she could do, however restricted, and showed no signs of anger, frustration and distress. What she could do was her life-world, as the life-world is everything that is possible to experience and to do (Bengtsson, 1999). If you for instance see a ball and don't have any experience of its ability to bounce if you interact with it, a ball will be nothing but (maybe) a bright coloured stone. Hanna could on her own never discover the magic with a bouncing ball because with her limited muscular strength she could not make it happen. Furthermore there is a difference between trying to bounce a ball, yelling and kicking in frustration because of the inability to do so, but being aware of the fact that the ball has bouncing potential, and not understanding there is such a thing as bouncing a ball and be content with it. Hanna did the latter and this I found frightening. Put in phenomenological terms her consciousness directed itself towards the things the way her body was able to, and a lot of the magic of the world was lost to her. I felt her go out like a candle in the wind when left on her own devices, for instance on the blanket on the floor. The meaning of a gesture is incarnated in the gesture (Merleau-Ponty, 1998) and what I saw in her bodily expressions and gestures were, I think, a picture of her life-world at that moment.

Hanna transformed when sitting on my hip. As she got access to my muscles and the strength of my body was put at her disposal, she suddenly got another physical capacity and according to

this physical capacity she could be another person. This showed in her state of mind as she suddenly expressed other wishes and desires, she became vibrant and alive. I wanted her to be aware of the magic of the world, how it was, and is, able to manipulate, make her experience things that were out of her reach, and so forth so that her consciousness could direct itself towards a wider range of things in the life-world, making the horizon of the life-world expand. So I used my body to support her, continued our walks with Hanna on my hip, continued to add strength and support her body, because it made her glowing and alive, interested and exploring in a way she never expressed when she was left to the capacity of her own lived body.

When Hanna was 6 to 8 months old her diminished motor repertoire became more apparent. Firstly her ability to reach and get hold of things in her environment was restricted, thus diminishing the world within her potential reach. Secondly, the things within her reach, or the things made accessible to her by the help of others, were less maneuverable in her grasp because of the lack of strength in her arms and hands.

Sitting in the sofa: August 1983

Hanna is 9 months old



We have just had breakfast. Hanna is happy and ready to start the day. I know she is not content by sitting on the floor, so I put her in the corner of the sofa, leaning her back against the corner between the back support and the arm support. She likes to sit in this position, she smiles and looks around her with light in her eyes, waving her arms, saying “da, da” at the guitar

lying next to her. I put the instrument over her knees and she bends forward a little and pulls the strings. When the sound reaches her ear she laughs and pulls the strings over and over again, making happy sounds as she “plays”. She continues for quite a while but sometimes casts a glance at me as I move around in the room minding my chores. I keep an eye on her too because I know she will eventually fall when trying to grab something placed a bit away from her, and I want to be ready to support her in order to prevent her from falling.

Suddenly she gets tired of playing and looks at me. “Da” she says looking at the big box in which you are supposed to put differently shaped bricks through holes the same shape, standing beside her in the sofa. I get up to her, take the guitar and place it on the floor. Then I take the box and place it in front of Hanna instead, at the same time shattering the bricks around her in the sofa as close as I can so she will have a chance to reach them. The issue at hand here is to match the shape of the brick with the shape of the hole. This is not a problem for Hanna. She can spot the right form quickly and precisely, the challenge she is up against is to reach the bricks around her legs and pick them up from the sofa. I can see she is struggling with her balance trying to bend forward without falling. The more she leans forward the more she tilts her head backwards to keep her balance. It makes me feel utterly bad to watch her trying so hard so I place my hands round her chest and stomach. As she bends forward I follow, thus providing her with a flexible torso support. Given this assistance Hanna is able to free her arms and stretch out towards the red brick closest to her left foot. She grabs it and I can feel her swinging her torso backwards in order to gain the straight sitting position again. I support her movement adding strength and tone to her torso making it possible for her to regain her balance with the brick in a firm grip of her hand. She smiles and puts it in the right hole as soon as she is in the straight sitting position again. Then she bends forward again and I follow her movements with my hands around her upper body. We repeat the activities over and over again and Hanna seems satisfied.

Hanna constantly had to adapt her motor activity to her limited strength. Being as limited as Hanna was in the dimension of independent motility, was of course determining for the horizon in Hanna’s life-world. Normally the ability to perceive and act will to some extent go hand in hand but to Hanna the gap became bigger because of her lack of motor capacity. One

dimension of the lived room is defined by the way we perceive the room with our senses and the other dimension defined by the way we act in it. These dimensions are coordinated by our own lived body, the pivot of the room (Bengtsson, 1998 b). In the above episode Hanna's perception of the objects around her was excellent and this together with her cognitive capacity made it easy for her to decide in what hole to put the bricks before she even grabbed them. Once she got hold of them she hardly ever tried them in different places, she just put them in the hole with the appropriate shape right away.

The dimensions of the room as defined by the way we act in it, was of course the dimension where Hanna's lack of motor capacity became most evident. To her there was a big discrepancy between the dimensions of the room as perceived and the dimensions of the room as acted in. When I helped Hanna bend forward by holding her torso, she used the strength I added to acquire the ability to bend forward against the object, stretch out her arms and grab the brick. The dimensions of the room defined by the way we act in it, (Bengtsson, 1998 b) changed for Hanna as she was able to act in a more competent and forceful way. To Hanna this was a noticeable improvement.

In retrospect it is apparent that Hanna had difficulties in developing an unsupported sitting appropriate for her age. One reason for this was that the stability of her torso was too insufficient for her to be able to use her arms in a free and rewarding way. In order to maintain her balance she had to keep her arms close to her body, thus enabling her sitting position but disabling any interesting action, like playing with toys in an unreflected way. She couldn't let her arms out in well coordinated movements when sitting unsupported. So much of the magic of the world was lost to her as she was so restricted in manipulating it. Because of her inability to make things happen with physical strength, her life-world became a duller place to be in. Merleau-Ponty states that our bodily experience of movement is a way to get access to the world; *"it provides us with a way of access to the world and the object, with a 'praktognosia' which has to be recognized as original and perhaps as primary"* (1999 p. 140).

When Hanna sat in the sofa and I gave her a flexible torso support she was able to manipulate the world to a greater extent. By supporting Hanna immediately in bending forward my aim was that her consciousness toward-the-things (Merleau-Ponty, 1999) should have an immediate output in so far she could respond to the call from the things without thinking about it. This demanded a high level of interaction between Hanna and me as I wanted her to just perform the motor act without having a chance to reflect on it as an obstacle. By this interplay it was possible for Hanna to be able to manipulate the environment in a more natural and rewarding way. Through this she could acquire experiences natural for her age. She could have the joy of causing the action. This is of utmost importance for developing intelligence (Piaget, 1999).

Perspectives of the world

On the hip: September 1983

Hanna is 10 months old

I lift up Hanna and put her on my hip as usual, her back against my body, face out. Hanna starts smiling while looking around with curiosity in her eyes. In front of my eyes she transforms to an active child. Her eyes start to sparkle and she waves her arms as much as she can. Her whole body feels active against mine and I can feel her excitement spreading through my bones. She is happiest and most at ease when she sits on my hip and I start to move around minding my chores using only one hand and arm as the other one is occupied by Hanna. She is following everything I do with utmost interest as I mind my tasks. Suddenly I can feel her moving her centre of gravity outwards, she is bending from my body. When I first felt these movements of hers I thought that she lost her balance and took a firm grip of her body, but now I know it is an expression of her wish to get close to an interesting object she has spotted. I look in the direction she leans and see the sun shining at one of the plants with big green leaves. "Do you want to go there Hanna?" I point at the plant and she looks in the direction of my finger towards the plant and nods. I walk up to the plant, moving sideways so that Hanna can retain her focus on the plant. I can feel it in her body that she is excited as it gets the sparkly feeling and I can hear her breathing more intensely. When this is accompanied by the happy gurgling she produces I also know she is content.

When we get close to the plant she reaches for the leaves in her characteristic way, her arm a little bit bent, and she grabs it. She likes grabbing and feeling. When she gets hold of the green leaf she smiles with joy. My mother who is visiting us mocks me. "You spoil her by carrying her around all day" she says "she will never learn to move around if you do that. Leave her be for a while and she will make an effort to move on her own" she tells me. Hanna has lost interest in the leaf and bends in a new direction. "There" she says and aims at the TV in the corner. I start walking in the direction desired by Hanna. I know my mother means well and that she is probably right. Maybe I am spoiling her but I don't feel at ease when Hanna is on her blanket on the floor. I can feel it in my bones that she is not happy almost the same moment I put her there, although she is not screaming or crying, but she is happy while sitting on my hip. She wants to sit there most of the time. So our walks with Hanna sitting on the hip continue.

At this time Hanna was nearly 10 months of age and she could sit on her own although not totally stable, but she didn't make any efforts to move around at all. Still she had a huge need of exploring the world and to get a constant change of perspective. Hanna directed me to take her to different places in the room. The room has a natural centre; it is edified around the perceiving human being in motion (Bengtsson, 1998 b). Children with normal muscular strength often learn to crawl or move around in some way or another at this point in life, thus being able to satisfy the desire to explore the room. Through this capacity they will get the ability to change the horizon of the room all by themselves. To Hanna this was totally impossible. The room has a connection to human life that will make the position and the posture of the human body the natural pivot of the room (Bollnow, 1994) and Hanna on her own sitting on the floor was of course also the pivot of her room but it was a room with a fixed horizon. The room is limited by the human horizon and when the human moves, the horizon will move too, but Hanna could not move when left to her own devices. The room is dependent on the subject (as the subject is the pivot of the room) but the subject will also be affected by

and dependent on the room in which she lives and acts (Bengtsson, 1998 b). When Hanna was carried around sitting on my hip, her lived room (Bengtsson, 1998 b) changed and expanded, and she expressed satisfaction in a direct and bodily way that I think was her way of acknowledging the circular relationship that exists between the human being and the room, i.e. the lived room. When we moved around in the room together Hanna was able to experience the room edifying around her as the human being in motion and it pleased her to have this dimension added to her life-world. This made our walks around the house and in the environment outdoors more frequent and longer as time went by.

To Hanna it was impossible to accomplish a change of perspectives on her own. Her physical motor capacity was never big enough for her to move around in any way without assistance of some kind. In Stern's way of thinking, this put her at risk of not being able to understand the concept of different and alternative perspectives (Stern, 1998). When sitting on my hip, face outwards from my body, she was totally absorbed by the world around her, getting close to objects, grabbing them, touching them and so forth and I strongly felt it was this, rather than the contact with me, she wanted. I was at this point a tool to accomplish the intentional act in which she was involved. The more I carried her around the more she craved this mobile dimension in life. Her lived room unfolded because of our joint efforts in such a way that after a while it was totally impossible for me to put her on the floor on her own. The human being inhabits the room (Bengtsson, 1998 b) and from her position on my hip Hanna got a wider horizon, a change of perspective and she was able to answer the calls from the things surrounding her in her lived room in a different way to what she would have been able to without my help. Her intentionality, the way her consciousness was directed towards the things, was different compared to what she expressed without the option to move around in the room. Stern states that the ability to understand inter-attentionality (1998) is dependent on the ability to experience different perspectives, and this is something the child will master as it learns to crawl. From this follows the notion that there are different perspectives and to follow the direction of a pointed finger is a way to express this. Hanna had no problems to understand the meaning of the pointed finger at this age; to crawl and thereby take different perspectives on her own was, on the other hand, something she could never do. My interpretation of this is that she got the change of perspective partly from her walks on my hip. I would like to state that it is not the ability to crawl or cruise that is crucial but the "*initial acceptance of serially different perspectives*" (Stern, 1998 p. 130). Any way to achieve the experience of serially different perspectives will probably do for the children who (for instance because of decreased motor capacity) are unable to crawl or cruise on their own. Important to Hanna though, was also that she was able to conduct these changes of perspective. This will lead to the hypothesis, that a child with a disability inhibiting the motor capacity, such as SMA II in Hanna, should be given the opportunity to experience these serial changes of perspective and control where to go, at the appropriate age (i.e. at the age of natural onset of the skill) in order not to lose pace in the developmental process, concerning these skills, compared to his or her able-bodied peers.

She also had an urge to touch things, to feel the surface and texture, and it was important to her that I moved in close to all the exciting objects she wanted to look at. This Piaget talks about as typical for the sensory-motor stage (in Shaffer, 1994) and it was a strategy that enabled her to be involved in age-appropriate activities as described by Butler (1991). To Hanna, as to other children, it was important to have the growing radius of actions the increased mobility provided, and we have every reason to believe that this made her ability to create inner schemes, i.e. constituting representations of the world this way (Piaget, 1999), increased.

Hanna was also able to use her position on my hip to accomplish the learning process that is needed to enable a child to differentiate between the action (getting close to an object and

grabbing it) and the object itself, as opposed to the way a child understands the world at an earlier age where the action and the object is closely intertwined (Piaget, 1999). From the position on my hip, Hanna was able to get straight ahead from the exploring position to the investigating position. The exploring position refers to the position when she sat on my hip, facing the world and something caught her eye. The investigating position refers to the position when she was close to the object that had caught her eye, and was able to explore it up front grabbing it, feeling it, eventually tasting it and looking at it closely. To explore and investigate thus craved two different positions; to explore Hanna needed a good overview; to investigate she needed a close contact with the object in order to examine it closely in detail, both visually and tactically. When I was able to provide these different positions it meant that the horizon in Hanna's lived room (Bengtsson, 1998 b) could constantly shift and moreover Hanna herself could accomplish a change in her lived room, due to her different activities and perspectives, by using my body as the means to do it. She used the same technique humans have done for ages when riding horses, making them move in the direction and at the speed desired, using the horses' bigger bodily capacity to our benefit. She insisted on going forward towards the chosen object by swaying her body back and forth like you do when you ride a horse to make it move.

This way she could also see the connections between cause and action, she experienced what she wanted, what she did and the feedback from the body and the senses on this action. She was also able to predict what her action would lead to as I tried to accomplish what she strived for. This made it possible for Hanna to experience all three invariants of experience constituting what Stern (1998) calls agency or authorship of action: volition, proprioceptive feedback and the predictability of consequences following the act. When she didn't get up close it created a strong frustration in Hanna. This became obvious when I, mostly because of lack of time, tried to skip the up-close and stop-part and just walked by the chosen object at some distance.

This way of supporting Hanna's motility and mobility resulted in that she expressed increasing physical dependency on me, the provider of these skills, at a time when able-bodied children decrease theirs. This was the subject of many discussions stating that Hanna and I were moving towards an unnatural symbiotic relationship. My point is that it also can be interpreted in a different way; as a sign of normal development in Hanna, aiming at exploring the possibilities of her lived body and the world, thus expanding her life-world. In retrospect I say that the latter was the case. It might be useful to consider this possibility meeting other children with known or suspected lack of muscular strength. The possible disadvantages with this way of motor supporting the child during the time prior to normal onset of walking, must then be put in relation to the advantages of being able to explore the world and create a more vivid and colourful life-world. To use the strength of the caregiver could be one way to help the child take important developmental steps. To Hanna both motility and mobility interventions were important. Assisted motility made it possible for Hanna to make interesting things happen to external objects in her life-world, assisted mobility made it possible to change perspectives by moving around and experiencing the objects and subjects in her life-world from different angles, thus changing her lived room and expanding the horizon of her life-world (Bengtsson, 1999). The assisted motility and mobility could also help Hanna build a bank of physical and tactile experiences that she could use to develop an understanding of herself and of the world in a way that to some extent resembled the experiences made by able-bodied children of her age. The experience of her body as a more capable lived body was beneficial to her. I see a huge gain for children with SMA II, if you can secure such sensory experience to broaden the ground of experiencing the self and the world.

Hanna's first birthday: November 8th 1983

My mother tells me that Hanna on her first birthday was entertaining the guests by sitting on her blanket and letting herself fall on the side, landing on the soft towel draped around her hips. I can't remember this myself, or I have repressed it. Maybe I was in the kitchen, washing up the dishes. Every time she falls over she laughs and so does the audience. Hanna seems amused and is bending over time after time, letting herself fall and the others put her back up again as this is something she can not do by herself. On the way home an old friend of my mother's spontaneously says; "This can never be right!" My mother says she knows this in her heart already.

To bend over to the extent of falling sideways with the help of gravity was something Hanna could manage on her own, and this gave her a sense of motor mastery within herself. To be able to execute a motor activity, experimenting with the lived body, and through the activities of that same lived body affect the lived room and accomplish a change of perspectives, is natural for most of us. To be able to make an impact and make a change in our immediate surroundings is so too. We are used to extend our world, our life-world, and push the horizon in new and exciting directions. As Hanna was extremely happy when she could accomplish this, my interpretation is that this total control over the action added a quality to Hanna's existence. Self-agency, being the author of one's movement (Stern, 1998), is an essential part of the core self, and self-agency was extremely difficult for Hanna to achieve because of her SMA II.

Hanna and the Lego-bricks: February 1984

Hanna is 14 months old



It is 11am. Hanna stands on her knees in the U-shaped cushion the physiotherapist has given us and she has a lot of toy-bricks in front of her. This exercise is done to stretch her hips and trains her to use her arms in a more efficient way. Through the full arm support from the cushion under her arm she can slide with her arm over the cushion thus getting a wider range of her arms. Hanna smiles as she carefully reaches for the yellow Lego-brick at the end of her range. I can see that she is focusing, working hard to keep her balance while reaching the desired toy. Hanna has accepted the different bodily positions initiated by the physiotherapist but

the mission for me is to keep her occupied with something that really fascinates her otherwise she easily gets bored. She grabs the brick with her left hand and pulls it towards her. Everything points to the fact that she will be left-handed. Hanna's eyes sparkle when she pulls the Lego-brick towards herself. Two more times she stretches for bricks and pulls them over. Then, with a big effort, she piles two of them on top of each other and turns to me. "Da" she summons me, pushing with all her force on the upper red Lego-brick. I put my hand over hers and give her the power she needs to press her bricks together. After three pieces on top of each other she is satisfied. She has obviously a clear picture of how she wants it to be because she stretches for another Lego-brick just within her reach, grabs it and places it in front of herself. She does that once more but now she puts the brick on top of the one beside the tower we just finished. The same procedure is repeated once again, she puts her hand on top of the two Lego-bricks and looks demandingly at me saying; "Da together". It is not hard to understand what she means so I put my hand over hers and we push the pieces together in a joint effort.

The sense of volition that precedes a motor act and the existence of such motor plan can reach awareness when its execution for some reason is inhibited, something that happened to Hanna quite often when she failed to accomplish what her consciousness, i.e. her being-towards-the-thing (Merleau-Ponty, 1999) aimed at. When she put Lego-bricks on top of each other but didn't have the strength to push them together she experienced motor plans that crashed. The body was not attuned to her consciousness and this made it difficult for Hanna. Her body did not have the capacity to be the executor of her directedness towards the things. Merleau-Ponty writes: "*To move one's body is to aim at things through it; it is to allow oneself to respond to their call, which is made upon it independently of any representation*"(1999 p. 139). In Hanna's case it was not a matter of *allowing* herself to respond to the call from the things, instead it was impossible for her to do so. Initially I could see that she "heard the call", tried to answer to it and often failed if left to her own devices. When this happened she became "bodily numb" as I call it, (see also episode "On a blanket on the floor"). This bodily numbness can be interpreted in at least two ways; one is that Hanna stopped responding to the calls from the

things; the other is that the things stopped calling her. The latter is maybe more in line with the Piagetian thought that at this age wish and motor action are the same (1999), thus when Hanna couldn't answer; she *experienced* no call to respond to. This is also in line with what I experienced when I was part of her life-world; Hanna stopped wishing instead of stopped trying. Yet, Hanna and I found a way out of this dilemma before she resigned to inactivity. She summoned me to add the strength she needed. She didn't ask me to take over; she kept her motor act her own by letting her hand stay on top of the Lego-bricks only asking for additional pushing strength.

If "*Consciousness is being-towards-the-things through the intermediary of the body*" (Merleau-Ponty, 1999 139) consciousness is intimately intertwined with, and dependent on, the body. In Hanna's case her body had limited muscular strength. This implies that her diminished body strength had an impact (probably a negative one) on her consciousness as her body was a non efficient intermediary to get access to the world. This was a risk we had to overcome one way or the other. Hanna also had difficulty with the next step in Stern's concept of self-agency, the proprioceptive feedback (1998). By holding her hand under mine when pressing the bricks together, it was possible for her to get that proprioceptive feedback i.e. getting the sensory feeling in the hand of the pushing-together act, even though the power was from my hand above hers. As the proprioceptive feedback tells us what is done and allows us to predict the consequences of the motor act and is an important dimension in the experience of a core of self this was important (ibid). To Hanna many of these sensations, these experiences of proprioceptive muscular feedback, were few because her motor capacity was so limited, despite the fact that she had and has no dysfunction in the sensory nervous system. This means she had and has a fully developed ability to experience her body, its movements and positions. To Hanna it obviously was important to feel the movement in her hand and arm when the act was performed maybe because it is through my body I can perceive the world (Merleau-Ponty, 1999).

Hanna could also, by this participation in the whole act, easier take part of the last of Sterns steps, the third invariant, i.e. the predictability of consequences following the act (1998). It was important for me to assist Hanna so that the intention she initially had with her motor activity was achieved. This allowed Hanna to experience her self as agent throughout the motor activity, from the sense of volition that precedes a motor act, via the muscular feedback that told her what happened, to the predictability of consequences that she finally could experience. Of importance was that Hanna could not only see the result, but also *feel* it in her body. All these parts of the motor activity, i.e. to own a motor act, were a big challenge to Hanna and of course this was affecting the experiences she made. Merleau-Ponty claims the "*various parts of the body are known to us through their functional value only*" (1999 p.149). Given this Hanna risked to know her body in a different way to children with functioning muscles.

Hanna had trouble with her balance due to her muscular weakness, and there was a risk of her falling all the time if I placed her hand too far away from her body to help her being able to grip a toy. This meant that many times I had to perform the bigger part of the motor action with Hanna watching me after that she had taken her motor action to the limit of her body strength even with support. This probably resulted in the kind of movements Stern (1998 p. 80) calls "*other-willed action on self*" i.e. I made a motor action Hanna didn't desire, thus counting out volition, although the aim was for every act to be one that Hanna initiated. To Hanna many of her actions risked being failures as she didn't manage executing what she had "planned" resulting in fewer actions that could be referred to as "self-willed action of self" (Stern, 1998). I tried all the time to be as sensitive as I could to the gestures of Hanna's and the way her consciousness, her being-towards-the-thing-through-her-intermediary-of-her-body (Merleau-

Ponty, 1999 p. 138), was oriented. This was an effort of mine to catch the action Hanna herself initiated, a kind of action Stern refers to as “*self-willed action of self*”(1998). The aim I had was to make it possible for Hanna to experience that it was her consciousness that ruled. So, when I tried to help her succeed in handling her own body it was done with the mere purpose to help Hanna get the experiences of motility, of her own body, thus of herself, so that she could make use of the experiences from the sensory nervous system to experience her lived body in a more dynamic way than she otherwise was able to. This I think made it easier for her to understand life, widen her life-world horizon (Bengtsson, 1999) and successfully take part in the process described by Stern (1998) as developing the sense of core-self.

CHAPTER 7: SECOND YEAR AND ONWARDS

When Hanna was 13 months old she got her diagnosis. Her lack of motor skills was not due to the fact that she was a slow starter, but to the fact that she had a neuromuscular disorder. At this time in a child's life focus is often on the expected motor development just ahead, the walking ability. One of the main topics for the medical staff after Hanna had got her diagnosis was discussing whether or not Hanna would be able to walk.

From the diary just after we had got the diagnosis, December 1983: *In everyday life I am so used to the feeling of Hanna when lifting her and handling her, that it is difficult when the doctors all focus on the fact that what Hanna feels like when I hold her is a symptom of her muscular weakness and what she feels like is something that is **wrong**. To me it is simply Hanna and I couldn't imagine her in any other way. The way I feel her in my bones is Hanna, not a sign of a disease. If Hanna will be able to walk nobody knows.*

The upright posture

Shortly after Hanna had got her diagnosis we got a standing aid from the rehabilitation centre to strengthen her body and avoid contractions of the joints. This was part of the physiotherapeutic treatment. Hanna quickly got used to standing in the standing aid. After a short period of time when she physically and mentally got used to the standing experience, we noticed that other things happened to Hanna when she was in her standing aid.

An extended view of the world: February 1984

Hanna is 15 months old



Hanna has been standing in her standing aid for almost half an hour. She plays with some plastic animals on the table in front of her. Suddenly she gets tired of them and looks around. "There" she says and points her finger at the flowers in the window in her characteristic way with her arm bent. "Do you want to go there Hanna?" I ask her and point my finger as well. Hanna is smiling all over her face and repeats her "There". She bends over in the standing aid with small, careful movements not to lose her balance but yet so obviously showing me how desperately she wants to reach the blue flowers in full bloom on the window-sill. I grab the two sticks (supporting Hanna in the standing aid) from behind and lift her in the standing aid over the

floor in direction of the flowers. I want her to see the "journey" so I carry her facing the flowers. I put her down in front of the window-sill and she smiles happily. She reaches towards the flowers but since she has not the strength to stretch her arm straight forward she can't get hold of them. I lift the standing aid once more and place it as close to the window-frame as I can. Now Hanna is just in front of the flowers and she can, with her frequently used tweezers

grip, get hold of one of the petals of the flower. She squeezes the petal between her fingers and then puts her nose in it and smells it with a happy smile on her face. I feel warm inside at the sight of her joy. With caution Hanna strikes one of the hairy leafs with her index finger. Then she looks around once again and points her finger at the television set in the other corner of the room. The same procedure takes place, I grip the standing aid from behind, walk with Hanna across the room, put her down in front of the television as closely as I can and Hanna can reach the desired buttons. Hanna is happy and pushes the buttons, especially the loud control which is a button easy to move up and down. Next stop is our dog that has just entered the room. He is a black spotted Dalmatian and he calmly accepts Hanna sticking her fingers into his mouth. The room is getting darker as the twilight hour closes in. Suddenly the timer in our aquarium clicks and the light is on. This catches Hanna's eyes. "There" she says and I pick the standing aid up once again as I realize, she is using her wider upright view to explore the world.

The first part of the lesson Hanna gave me was that with the upright position she got an extended view of the world, i.e. her lived room changed again, just as it did when I lifted her from the blanket to my hip. Her lived body, the pivot of the room, (Bengtsson, 1998 b) also changed as she was standing upright, and from this new here-position she suddenly had a better overview. From this upright position Hanna was able to experience a lot of there-positions (Bengtsson, 1998 b) and objects occupying those there-positions which had previously been hidden from her. These there-positions and the things in them brought a new world to Hanna, and the room became a place different from all she had experienced before. The things called her (Merleau-Ponty, 1999) in a way they had never done before and put her in an exploring mode. Hanna's eyes scanned the surroundings until she found an object that caught her eye. It was obvious that she wanted to reach the desired object and she told me so both orally and by gestures, bending over in her standing aid in the direction she wanted to go repeatedly summoning me to lift her standing aid in different directions. As she had a small motor range due to her muscular weakness it was a modified gesture but never the less totally clear to me, as the intention of her gesture was not behind it but incarnated in it, as described by Merleau-Ponty (1999 p. 184).

The natural thing for Hanna to do at this age was to become involved with things through her body (Merleau-Ponty, 1999 p. 185). On a perceptual level she did it in a new way when she was in the upright position, as she got a better overview of things, and she used this new posture to detect interesting objects in her lived room. On a mobility level on the other hand, she was unable to get involved with the things through her body as she was unable to move around while standing in her standing aid. When I, at her command, started lifting her around in her standing aid Hanna could maintain the upright posture while exploring the world. The upright posture was also a posture that seemed natural considering her age, and this made me determined to try to maintain it. With my help it became possible for her to use the upright posture not only to get an expanded visual experience of the environment, but also to get acting potential based on this extended view. Because of this the "walks" in the standing aid became the natural successor to the walks on my hip.

When combined with the exploring activities the standing aid quickly became Hanna's favorite assistive technology device and the time spent in the upright posture steadily increased. We had instructions from the physiotherapists that the upright position was to be maintained 10 minutes a day at first and then to increase it to desirably 30 minutes two times a day. This was a part of the physiotherapists' training program to maintain, and if possible enhance, the strength and capacity of Hanna's muscles. The obvious bodily benefits, initially the reason for using the standing aid at all, were combined with psychologically important benefits that slowly became

evident. The ability to have an upright posture made a difference to her as every change of the body makes a change of the world (Merleau-Ponty, 1999). This combination of upright posture and moving around added a new dimension to Hanna's life, the *dimension of being an upright person*. Still the standing aid could not provide her with independent locomotion in order to be able to withdraw from her primary caregiver (me), stated by Mahler (1984) as important. Yet, when using the standing aid we took one step in this direction as she had the opportunity of *being* away from me while exploring her world as opposed to when she had been sitting on my hip.

Hanna constantly wanted to get up close to the objects she was interested in, and in a distinct way directed me to carry her in her standing aid every inch of the way to the desired object. When I lifted her from behind Hanna could see which way she was going. This way she was able to experience the feeling you get when you move towards an object desired and in this sense she could respond to the call from the things by means of her body. Merleau-Ponty (1999) defines this as the natural relationship between an experiencing subject and her world, and I would like to add that the upright posture also was important as it is the natural posture for a human being when she is active and engaged in her environment.

Due to Piaget, the ages from 0 to 2 years are characterized by the fact that the intelligence of the child has a practical nature and the child discovers the world by his or her muscles and senses (in Shaffer, 1994). Piaget states: "*Compensation, fulfillment of wishes, liquidation of conflicts, etc., are continually added to the mere pleasure of mastering reality, which is a continuation of the pleasure of being the cause inherent in sensory-motor practice*". (1999 p. 112) To Hanna her natural capacity to manipulate and master her world by help of her motor skills was limited, but as "*[...] I am conscious of the world through the medium of my body*" (Merleau-Ponty, 1999 p. 82) we realized that both the option of a wider overview of the environment, the lived room as perceived (Bengtsson, 1998 b) and the possibility of getting up close to things, the lived room as acted (ibid) was a valuable, and from a developmental perspective, interesting outcome of the standing procedure. Still, Hanna couldn't get about on her own in her standing aid and this was an obstacle we had to overcome because the locomotive part is also essential for the development of a human being. Merleau-Ponty writes on the topic; [... ..] "*and to move ones body is to aim at things through it ; it is to allow oneself to respond to their call, which is made upon it independently of any representation.*" (1999 p.139).

Up, up and away: March 1984

Hanna is 16 months old

I have put Hanna in her standing aid and I am just about to put her in front of the table to play with some toys when she forestalls me. "There" she says pointing with her little finger at the window. "Do you want to walk there?" I ask her and she nods and repeats her "there". I pick up the standing aid and carry her away over the floor and put her down in front of the flowers. For about twenty seconds she is satisfied standing there. Then she raises her little finger again and points in a new direction. "There" she says and looks at me with determination in her eyes. When I don't react as fast as she wishes she pats her cheek (which means "I" since she hasn't started using pronouns yet) and only occasionally calls herself by name. Then she repeats her "there" and adds a "walk there" and points again. I pick up the standing aid and walk with her in her new direction. I hardly have time to put her down before she points again. "Walk there" she says and looks at me with a totally happy face. It's impossible not to notice her enthusiasm, she is glowing. I execute the change in position she desires. So we continue, round and round, her little head spins of eagerness not to miss anything. She is quickly learning how to talk and she uses this new capacity of hers to make me take her where she wants to go. It seems that the view she has got from the upright position gives her an unstoppable urge to explore the world and Hanna is enjoying herself and the fact strikes me that Hanna's desire is no longer a special position but the locomotion between two points. Then suddenly the idea strikes me; if we put wheels on the standing aid I can push her around. It would feel even more like walking and I won't have to lift the standing aid all the time. Walk is what she calls it, walk is what she wants!

It was obviously fascinating to Hanna to see the world from different perspectives, and this discovery of different perspectives may, according to Stern, be necessary for the child's ability to acquire the understanding of other people having different perspectives than the child, i.e. others are using another coordinate system than the child's own and this is the starting point of inter-attentionality (Stern, 1998). Hanna also showed me that the extended view her upright posture gave her enhanced her ability to decide where to go. Hanna was content while in her standing aid, especially when I lifted her around according to her wishes, probably because she found that position rewarding for the urges she had and for what she, in an unconscious way, wanted to accomplish. This made me realize that the essential part many times was the locomotion between two points. These factors all contributed to Hanna's delight when standing in her standing aid. This made her stand in the standing aid until she had used all the strength in her body every standing session, and every day she highly exceeded the desired and anticipated standing time set by the physiotherapists. This perception of time, as something that passed quickly as the upright position was so rewarding, made it possible for her to maintain that posture longer and longer each day and this made her lived time (Bengtsson, 1998 b) change. If I lifted her around she would stand almost until she dropped and she was persistent when she wanted to move from place to place. Probably this strive of Hanna's to move around in the upright position, making me lift her and the standing aid from place to place, was the same that would have spurred her to constantly train her ability to walk if she had had strong muscles. To meet her desire to move we decided to put wheels on her standing aid thus making the locomotion between points quicker and smoother and if possible avoid that Hanna got frustrated. Without me lifting her and the standing aid her movement also would become more like walking.

The first wheels - To dance: April 1984

Hanna is 17 months old

It's done! Hanna's father and a technician at the children's rehabilitation centre have put wheels on Hanna's standing aid, ball-shaped wheels that are able to roll in any direction. I place her in her standing aid as usual and she smiles happily at me. As expected she starts by pointing and telling me "walk da" looking enthusiastic as usual when doing so. "I will show you Hanna" I tell her and start pushing her in the desired direction. Hanna first looks a little afraid but this expression soon gives place to a surprised look as I slowly increase the speed over the floor. We have a rather big living room and this means that the distance I can push her is quite long until we reach the yucca plant she initially pointed at. At this time her facial expression has changed once more from surprise to delight. "Walk there" she says the moment I stop the standing aid. We go off in the new direction. "Is it too fast Hanna?" I ask her while pushing her at quite a high speed towards the window this time. I look at her face for guidance as to how she perceives this. She looks happy, her little face is glowing. I think she has misunderstood my question or she chooses just to listen to part of it because she replies; "Walk there, fast, fast" and points forward. Suddenly she begins to laugh. We get to the other side of the room and before I have stopped the standing aid Hanna points again; "walk there, fast, fast". I move my hands from her back to the top of the sticks that is a part of the standing aid and which keeps her upright. Then I push her forward once again. Now Hanna is laughing out loud. She laughs so intensely I fear she will lose her head balance altogether by pure excited joy. "Is it fun?" I ask her totally unnecessary. "Yes" she replies "fun, fun" and then she laughs even more. "Do you want to dance Hanna?" Hanna nods; "dance" she says. So I take a firm grip on one of the strates holding Hanna upright and start spinning her around in some kind of slow jive. A bit forward, a bit round a kind of improvised dance. I just have to keep an eye on her head balance and neck as she is not used to movements like this. Hanna's hair whirls around her. At this moment I think both of us are totally happy.



This event showed me a new dimension of the locomotive power. It was obvious that Hanna enjoyed the feeling of moving fast over the floor with her own body as the contact to the ground, although through the standing aid. I had danced with her before, holding her in my arms turning her around and making all kinds of moves and I had danced with her in the wheelchair, turning her around in the sitting position. She had always enjoyed that too, but there was a qualitative difference for Hanna between these patterns of movement. For the first time it was her body encountering the spinning and moving feeling on her own, with her feet on the ground so to speak. Once again the lived room changed (Bengtsson, 1998 b) as another capacity was added to her body, and this changed the way she was relating to her world. Our body inhabits time and space (Merleau-Ponty, 1999 p. 139) and this new capacity provided

her with a new way of inhabiting time and space. It was the first time she was moving over the floor in a standing upright position without me lifting her standing aid.

Standing “au naturel”: July 1984

Hanna is 20 months old

It is a summer's day in July and Hanna and I carry out today's training on the lawn. She has already been standing in the standing aid but this is not to her satisfaction today because she wants to “walk” on the lawn. Hanna is not content even though I have taken a small table out on the lawn and filled it with toys for her to play with, while standing. “Walk there” she says and points her little finger in the direction of the redcurrant bushes growing beside the lawn. But I can't push her around as the grass is too thick to allow the wheels to roll. I lift up the standing aid and walk on the lawn up to the bushes with Hanna as I used to do before we put wheels on the standing aid.

“Do you want to taste the berries Hanna?” I ask her as we approach the end of the lawn. I glance at her face from the side. I can tell from her facial expression that it annoys her that she can't walk the lawn. And I am right; she is not content at all when I put her down in front of the bushes. So we walk back to the table and I pick her out of the standing aid. Just as I am on the way to put her on a blanket on the grass she protests loudly. “No” she says, “up, up” and taps her chin, referring to herself. She is frustrated and she wants up. She stretches her arms as high as she can towards the edge of the table. The table is just as high as her shoulders. I lift her up again and place her feet on the grass. Slowly I raise her up and help her to grab the edge of the table. She is wearing her corset and it provides an extra stability to her back and torso, a stability she needs as she leans forward and supports herself by the chest at the table holding on to it with all she has got. She is keeping her arms bent and curves her back inwards so that she gets a sway-back. She is able to keep her knees straight. I can feel that she is fighting, she is breathing faster but I can't tell if it is because she is strained or if it is because she is excited by the experience of standing on her own. Probably it is both. Slowly I loosen my hands from her hips, all the time prepared to catch her if she would totter, but Hanna stands. Fascinated she stands on her own against the table, the whole girl glowing with determination. Something in this position makes her extremely satisfied.

Hanna initiated standing by herself for a long time after she experienced the standing position “au naturel” against the table for the first time, even though she, as a result of her increased bodily weakness, was less and less able to accomplish it. Could one understand this urge of Hanna's to stand up as a result of biology and genetics, as the human being is known to operate from an upright position or as a result of the environment encouraging her to stand despite her physical difficulties to do so? There is nowadays a biopsychosocial view on development that recognizes both intrinsic and extrinsic factors to understand the difficult interaction between biology/genetics and the environment shaping the developmental processes (Helders et al 2003). At this time in life Hanna tried out different kinds of motor behavior, pushing her abilities to the limit and in some sense giving the try-out of the neuronal networks her own personal touch. To Hanna this was an additional way of experiencing her body as the 0-coordinate (Bollnow, 1994). She was able to experience the body as being the pivot of the world (Merleau-Ponty, 1998) without anything supporting it, the body totally on its own. Something in the upright position seemed to be highly desirable to Hanna and once she had got the taste of it by using her standing aid she tried to accomplish the same position on her own.

The fact that we tried to imitate what can be called “normal bodily expressions” and postures calls for a thought on how to relate to the concept of “normality” and to explain how I use the word in this thesis. Here the term “normal” is defined as motility and mobility that resembles the motility and mobility of children the same age with no disability. But is it of any good



striving for a normal motility capacity and a normal mobility capacity for a person with some kind of disability and what does earlier research have to say on the matter? There has been a change in perspective in recent years challenging the old paradigm where the primary goal is acquisition of normal movements by changing factors within the child, with the thought that successful movement can be accomplished by modifications of factors external to the child (Viart and Darrah, 2002). Even if there are strong reasons for the contemporary standpoint that successful movement may be achieved by modulating factors external to the child and the focus of *achievement of a task*, there is a gain for a child with SMA II in imitating a “normal”, movement pattern and postures at least initially i.e. early in the life of the child. My argument for this is that the opportunity to experience the same feeling in her body as others do when performing a certain movement was important to Hanna

as she expressed her delight over it on so many occasions. As she had, and has, no loss of function in her sensory nervous system, this was possible to achieve from a neurological point of view. The aim was to make it possible for her to, to some extent, have the same frame of reference for bodily sensations as others, as these sensations seem to play an important role in the developmental process.

The idea of standing in a new way: August 1984

Hanna is 21 months old

It is late morning and Hanna is hungry. She likes to sleep late in the morning and I hurry a bit as I put her in her standing aid not to make the breakfast too late. Hanna has increased the amount of activities she likes to perform standing and eating is one of them. I am happy about this as it gives her the opportunity to be in the standing position (the position she likes the best) for a longer time each day. That's why the day starts with breakfast in the standing aid. She happily eats her sandwich while I feed her the porridge. Fifteen minutes later she is almost finished. Baby brother Johan is in his baby lift watching the procedure. He is now nine weeks old and he has been awake since a quarter past five and is soon going to have his nap. I can see he is getting sleepy, he is kicking his legs less and less and his eyes are slowly closing. I feel his diaper; it is wet and needs to be changed before he falls asleep. Now Hanna is finished and ready for action. "Walk there" she says as usual and points her finger at the other side of the room. Johan starts crying, I think he is discontent with the wet diaper. "Walk there" Hanna repeats, her hunger is gone and she is ready to face the world that is in front of her eyes. Suddenly it strikes me like a light from a clear blue sky; we have to motorize the standing aid so that Hanna can "walk" where ever she wants to, whenever she wants to!

This was a critical incident in our process as it was at this point in time I clearly understood a "new" urge that Hanna was expressing. From her expressions I had already understood that the upright posture was an exploring posture to her and it was natural for her to use the upright posture when she wanted to interact with her environment. Her determination to get up to the desired objects, suddenly made it clear that she needed more than just the upright posture. She needed the opportunity to move in the direction desired and it was insufficient for her to have to wait for me to do it. Given her age, 21 months, she would already have been on her way, had she been equipped with strong muscles. The lived room as acted in (Bengtsson, 1998 b) craves two skills from the agent, one is motility, i.e. the ability to move ones own arms, legs hands, head in order to be able to handle things in the life-world. The other is mobility or locomotion, i.e. the ability to relocate ones body in order to get closer to what is desired, whether it is objects or other living creatures. It is also important to be able to leave things and places in your lived room to which you want some distance. At this point in life Hanna had some capacity for motility that could be used to manipulate the world, but she totally lacked independent locomotion and it was in the upright posture she wanted it. There were two issues at hand here; one was the bodily benefits gained from the upright position, and the other was Hanna's desire for, and benefits from, independent locomotion, especially from the time she would normally gain access to walking using the window of opportunity present for doing so. In the journal Pediatric Rehabilitation is written:

It is important that "development of the mind and body presents a special window of opportunity to correct (note, not cure) errors that occur early in life and that novel treatment for paediatric disorders should fully take advantage of these periods in ontogeny in order to achieve maximum gains." (Andersen, 2004, p. 229)

This was a crucial point in our process as it raised the question of how to combine the two factors most important to Hanna at the time, the upright position and the independent locomotion. From this moment on we started to work with the autonomous upright mobility in focus. By adding the powered engine to the standing aid we were able to add an important competence to Hanna in her life, the independent locomotion in an upright position. While we were experimenting with the motorized standing aid, Hanna still used her manual wheelchair

combined with the standing aid During some time we alternated between the two as we were advised by the physiotherapists to make her use the manual wheelchair in order to exercise her arms and torso although Hanna found this utterly boring. I realized that if we made Hanna's locomotive capacity dependent on her own muscular strength there was a risk of slowing down her intellectual, social and emotional development as independent locomotion is crucial to optimal development in these areas (Durkin, 2002)

Not being able to reach things: February 1985

Hanna is 2 years and 3 months old



Hanna is sitting in her wheelchair. She has laid her eyes on one of my plants and this plant she wants to get hold of. She is slowly driving forward. Hanna is a very determined young lady and I control my impulse of pushing the wheelchair. I am still skeptical of the thought that she must work so hard to move forward in her manual wheelchair but the electric one we have is so big it is an even worse option. Finally she reaches the palm planted in a pot on the floor; that is to say her foot support touches the pot. Hanna makes faces with all her little two-year old face. It is easy to tell she is frustrated. "Hanna have flower" she says and leans forward as far as she dares. I can see she interrupts the movement almost immediately and bends her head backwards in order to stabilize her body. By this maneuver she manages to keep her balance and remain sitting. She has a limited ability to lean forward because of her poor torso stability. To lean forward and at the same time stretch her arms forward is impossible for her. This means she can't accomplish her mission, to feel the soil in the pot. She is

fond of watering the flowers and often wants to feel the soil to explore if the plant needs some additional water. I can see that she gets sad. The glow in her eyes fades and her lower lip starts trembling and is pushed forward. I can see how she tries to maneuver the wheelchair and gain access to the pot from the side. This is something I have seen her do when driving her electric wheelchair as well and in the electric wheelchair she doesn't have to work so hard but the possibilities of getting hold of the things she wants is just as poor. I help her by placing my hands around her ribcage and support her so that she can stretch her finger down in the pot and feel the soil. "Dry" she says and her sad face lightens and suddenly she smiles. This makes me even more determined to continue our project with motorizing the standing aid.

The difficulties she experienced when trying to use the wheelchair, made her prefer the standing aid. She never initiated sitting (in any of her wheelchairs) as she did with the standing position both in her standing aid and "au naturel" as described earlier. The inability to get close to the objects she desired was probably another reason why the wheelchair never got popular with Hanna, and this applied to the manual one as well as to the powered one. One other reason is the fact that a child with SMA II has limited strength of the torso and this made it hard for Hanna to bend forward from her sitting position in order to be able to grab desired objects. This equals the description made by Jones et al.(2003) who observed that Molly, the girl in their case study, affected with SMA II, had difficulty gripping objects positioned to the right or to the left sides of her body. Hanna had the same difficulty. She never possessed the torso strength to lean sideward and stretch out her hand at the same time. Sitting in the wheelchair required all her strength to maintain her balance. We became more and more aware of the fact that the sitting posture was somewhat of a dead end for Hanna if we wanted to maintain some kind of active posture in adulthood as well. Hanna's inability to move independently made her one of the children who would benefit from the use of powered pediatric mobility devices or powered wheelchairs as stated by Tefft, Guerette, Furumasa (1999) but the difficulty Hanna experienced while driving her wheelchairs made us realize the sitting posture may not be the optimal for her. This made us intensify the efforts to make her standing aid motorized.

Autonomous upright mobility

The first motorized standing aid: February 13th 1985

Hanna is 2 years and 3 months old



Finally it is built, the first prototype of the motorized standing aid for Hanna. The standing aid she will be able to drive herself. It is time for her to try it for the first time and we are very excited. Hanna is now two years and three months old and it is high time she gets the opportunity to “walk” on her own. We have been waiting eagerly but it has taken time to get all the parts for the motorized walking aid, some of them from England. I put Hanna in it. It takes a little bit longer than usual because of the somewhat changed construction. Hanna has now an arm support where she can rest her arms in order to be able to relax and lower her shoulders. I help her putting her arms in the right position and she grabs the joystick. She starts experimenting with her movements. In the beginning we can see rests of the manual wheelchair driving technique in her hand

and arm movements as she pushes the joystick forward, lets it go and pushes it forward again as she is used to in order to maneuver her manual wheelchair. Of course this results in the standing aid starting and stopping, starting and stopping.

It doesn't take long though, until she changes her technique and pushes the joystick with an even pressure making the machine move away steadily over the floor. The speed is limited in order to make sure Hanna can maneuver the standing aid and slowly she moves over the floor. Hanna smiles and her face expresses pure joy. She pushes the joystick harder and a touch of impatience strikes her face. “Do you want to move faster?” I ask Hanna and she nods. I turn the speed regulator up and as Hanna rapidly learns how to get a steady and constant pressure on the joystick, her locomotion becomes more and more distinct. She begins to move from place to place but she doesn't stay many seconds at each place and the whining sound of the motors rises and falls.

*Suddenly she aims at the door and disappears out in the corridor. I can hear her moving down the corridor and turning back. I am a little bit worried because she has never driven in a standing position before but she is learning rapidly and I take a deep breath and swallow the words of instructions I have on my tongue. This is the first time she can leave me in her upright position and I will **not** spoil it for her. Suddenly she re-enters the room, makes a u-turn and disappears out in the corridor again. I see her face for a short moment before the u-turn is complete and she looks so happy, her little face is glowing. And so she continues, she goes round and round, out in the corridor and back again, each time she goes further down the corridor, I can't see her but I can hear the sound of the motors and realize she is as far off in the corridor as she can get and then I hear her turning and moving back through the corridor. Then she is in the doorway entering the room once again. “Hey” she says and her facial expression of total happiness and excitement is telling me; now she is really walking!*

After a short period of time, less than an hour, Hanna was able to maneuver her powered walking aid. During the first hour she learned the skills of turning, moving forward and stopping through her own trial and error play with it, and to experiment with the joystick as described by Furumasu, Guerette and Tefft, (1996). Hanna had no difficulty whatsoever to get

hold of how to maneuver the motorized walking aid and of course her fast cognitive comprehension of the mechanisms was partly due to her age, she was two years and three months (27 months) at the time. This supports the findings of Jones et al. (2003) who observed 20-months old Molly who learned how to maneuver a powered wheelchair within 6 weeks. This implies the intervention could have been done earlier, giving Hanna the opportunity to independent upright locomotion at an earlier age, but the process that led to the idea and to the actual prototype had to take its course. The question of when a child is mature enough to drive a motorized wheelchair has been discussed and the process with Hanna supports the findings of Butler (1986) who have suggested that children with severe motor impairments should be provided with means of independent mobility at an early age, preferably when other able bodied children are crawling and walking to explore their environments. The experiences from Hanna's first afternoon in her motorized walking aid told us she had a huge urge for this kind of possibility and it was as if she was trying to compensate for months of relative immobilization within one single afternoon.

The timing for giving Hanna the opportunity to "walk" in her case independent locomotion in an upright position, was set out from the perspective of natural development although Hanna was older, than the usual onset of walking, when she got her first walking aid. Nevertheless I think it was important that Hanna got the opportunity of locomotion in an upright posture at a fairly appropriate age. Mahler (1984) states that the child by developing the ability to walk takes the biggest step on the road of individuation and even if the issue for the child may not be individuation but relatedness (Stern, 1998) the importance of independent locomotion still remains.

You can not overestimate the importance of being able to walk for the child's emotional development. It gives the child an enormous increased knowledge of the world and to try out the world on its own and to get a magic power over it (Mahler, 1984 p. 88).

The ability to try it (the world) out on her own, and get a magic power over it, i.e. to be able to manipulate it, was something Hanna wanted but had difficulties to accomplish. When she got the opportunity of upright independent locomotion, the time she spent in her upright posture was once again dramatically prolonged. Just as Hanna's lived room (Bengtsson, 1998) changed, her lived time (ibid) did too. The exceeding time she spent in the walking aid indicated to me a change not only in the experience of the lived room (Bengtsson, 1998) as discussed before, but also a change in her lived time (Bengtsson, 1998). In her walking aid a world full of exciting objects within her reach opened to her, and this made her go on standing, go on exploring, long after she would normally be tired. Time flies when you are having fun and this highly applied to Hanna when in her walking aid. I don't think she felt fatigue. "*Consciousness is being-towards-the-things through the intermediary of the body*" (Merleau-Ponty, 1999 p. 139) and the extended competence of her body made it possible for her consciousness to reach out, to direct itself, to the world in a new and rewarding way. Her mind was directed towards the things in her environment in such a way that, as a side effect, she prolonged her time standing immensely. The impact on her in everyday life was prominent both from a physiological point of view and from a psychological one.

Incorporating the walking aid in the existence

Combining the upright posture with the independent locomotion transformed the upright posture from a training activity performed at isolated times to a way of presenting herself to the world in play and other activities, an existential habit. *“The acquisition of a habit is indeed the grasping of significance, but it is the motor grasping of a motor significance.”* (Merleau-Ponty, 1999 p.143). To Hanna this was what changed her into an erect and walking person. The walking aid became more and more the centre of her being, and it was crucial whenever she was to present herself to the world. Hanna wanted to be in the upright posture as much as possible and I could even detect a change of mood in her depending on whether or not she was in her walking aid or not. She seemed happier, and more at ease when she was in the walking aid. It was as if it filled her with self-confidence.

It is easier to stand and be a Lucia: December 1987

Hanna is 5 years and 1 month old



We have celebrated Hanna’s fifth birthday only a month ago. The children are to go to the local old folk’s home and “lussa”² Hanna, like most children preparing for this, is very excited. “We have prepared a special program” she tells me, “the songs are to be sung in a special order while we are walking round the house and I must have a nice Lucia gown.” I nod. “Everyone is allowed to be Lucia” she continues “and everyone is supposed to have a red ribbon round the waist” she adds. I assure her I will provide the required items. Then she is silent, thinking for a brief moment before she continues; “It’s a good thing that I have got my walking aid” she says “it’s easier to be a Lucia if you can stand and walk around”.

During the first four years when she had the powered walking aid, Hanna totally incorporated it in her existence, growing and developing as a standing and walking person. Merleau-Ponty explains the phenomenon of the instruments we humans use in our daily life and how we make them part of our being (Merleau-Ponty, 1999). The walking aid was to some extent, no longer

² i.e. the Swedish tradition where you walk around in white gowns, singing Christmas Carols with electric lights in hair and hands.

perceived as an object by Hanna. It was the locomotive capacity of her body. To maneuver the walking aid she no longer needed to compare the walking aid to other objects, for instance whether or not it was possible for it to pass through a door or a gate, it had “ [...] *the demand for a certain amount of free space*” (Merleau-Ponty, 1999 p. 143). Merleau-Ponty states that to get used to technical devices at our disposal is to “ [...] *be transplanted into them*” (Merleau-Ponty, 1999 p. 143). This is highly applicable in the case of Hanna and her walking aid. Using the walking aid had become a habit to Hanna which “ *expresses our power of dilating our being-in-the-world or changing our existence by appropriating fresh instruments*” (ibid p. 143). Whenever Hanna presented herself to the world she did it in her walking aid, in the upright position and it was a way for her to change her existence by appropriating the walking aid, the instrument. Somehow this posture made her feel comfortable and at ease, not only from a physiological point of view, but more importantly from a psychological one. It was her natural way to live when she was at home playing with her friends, and it was an absolutely necessary condition to Hanna when she was to take part in any activity at nursery school, or later school, as for instance the celebration of Lucia. Therefore she was always hesitant to participate in activities if she couldn't use her walking aid and by being hesitant she expressed what she preferred. Presenting herself in the walking aid became a well-known habit to Hanna.

The phenomenon of habit is just what prompts us to revise our notion of ‘understand’ and our notion of the body. To understand is to experience the harmony between what we aim at and what is given, between the intention and the performance-and the body is our anchorage in the world. (Merleau-Ponty, 1999 p. 144)

From a psychodynamic perspective Mahler states that you can not overestimate the importance of being able to walk for the child's emotional development (1984). The statement above from Hanna; “ *it's easier to be a Lucia if you can stand up and walk around*” indicates that if you can extend the meaning of the word “walk” as Hanna did, to also mean the upright bodily posture combined with independent locomotion, this was something utterly important to her. To Hanna the locomotion in the upright position was important as it gave her some kind of self esteem when meeting the world something the wheelchair did not. Maybe it had to do with the fact that it was important to her to present herself in the same body posture as her peers, especially in situations like this, walking around singing Christmas carols.

When Hanna was 6 and a half years old, we started to build a new walking aid. The old one was to be replaced with an improved one in time for Hanna to start school. We had talked about some improvements and Hanna's father had started to build the under frame. Hanna herself was somewhat skeptical.

The new walking aid; late spring 1989:

Hanna is 6 ½ years old



We are constructing a new walking aid. Hanna's face is resolute and closed, she who almost always smiles and looks happy has a dark glow in her eyes and her otherwise ever laughing mouth is closed with lips firmly pressed together, when looking at the steel skeleton of the new walking aid. It

gives her a feeling of unease just to think about changing her walking aid or some of its parts. "Don't you think it looks nice? I throw out a feeler. Hanna doesn't answer me she just looks at me with a resolute look. The otherwise happy Hanna looks at me with seriousness in her face and blank eyes. I feel bad about the whole situation.

At this time Hanna really needed some improvement of her walking aid. She had become tall and heavy and she wanted to move faster than the old one was capable of. We also thought she would benefit from stronger motors and bigger driving wheels. This last aspect was something she agreed on, because she wanted to be able to move faster, but accepting the change was hard for her. The walking aid was the only assistive technology we had that could make Hanna worried about changing any parts or modifying it. None of the others, and we had quite a few, could awake the same fear in her. It was like changing a part of her. Using the walking aid to some extent had dilated her being-in-the-world (Merleau-Ponty, 1999 p. 143). The upright independent locomotion had become such a part of her existential conditions (and the walking aid was the means to accomplish this) that the mere risk of losing some feeling or function within it, was threatening to Hanna. At the end of the summer before Hanna was to start school we were at the end of the design and building process of Hanna's new walking aid, the third in her row of prototypes. We wanted it to be ready by the time school started.

The choice: August 1989

Hanna is 6 years and 9 months old

The garage is fully lit as the last work is to take place tonight. Hanna is now a little more at ease with the thought of changing the walking aid provided that we keep the standing device (the part of the walking aid that keeps her body in the upright position) exactly as it is. So we have promised her to make the new frame compatible to the old standing device. This promise makes Hanna in a good enough mood to participate in the design process of her own free will. The frame is ready, painted in the chosen colour; the old standing device is adaptable; now the fixing points for Hanna's sitting device remains. Urban, Hanna's father turns to her and holds up the seat in front of her. The seat is the same as well, we are just to adapt it to the new frame, in order to make it possible to sit and move independently even in the new walking aid as a complement to the standing possibilities. "I think I will make the fixing points here" he says, pointing at the base of the seat, showing it to Hanna. Hanna walks around her father in her old walking aid as he starts measuring the fixing points of the seat. "Daddy" Hanna suddenly says; "never mind this, I just want to stand up and walk, I don't want to sit in the seat at any time".

The decision to do without a seat was something that felt natural and of course we approved of this her demand. At this time in life Hanna strongly resented anything that had to do with a different lifestyle because of her disability. To Hanna the upright posture combined with independent locomotion was something meaningful as it added a dimension she wanted to get access to in life, not just adding a dimension of physiotherapy. To Hanna the world of physiotherapy and other parts of life related to her disability was a province of meaning (Schutz and Luckmann, 1973) she resented to enter. At this age it was not primarily because she resented being different, this knowledge didn't really hit her until she was in the first grade. Rather it was that there were a lot of other things that attracted Hanna in life. These things were all part of other provinces of meaning, such as life with peers and her brother, summers on the beach, playing with our dogs, listening to daddy reading books and so forth. These things belonged to provinces of meaning in which she gladly dwelled.

When Hanna was a bit over 7 years old she started having trouble holding her head upright, especially when in motion and gravity affected her body. This was something that affected her independent locomotion in the walking aid as she experienced difficulty in keeping her head up straight while running, turning, starting and stopping. To solve this problem we developed a neck supporting device and put it on the walking aid. This was done in the autumn of 1989.

The neck support: October 1989

Hanna is nearly 7 years old



Hanna is growing. She is now a girl in the 2:nd grade and the class is on an outing to town. We are supposed to visit the church and the market square and talk about the history of our town. Today Hanna is using her neck supporting device in public for the first time. She is not overwhelmed with the thought of needing such a device but this time I have insisted because I have seen the difficulties she has in keeping her head straight and I am afraid she will hurt her neck. So I am quite tense when putting her in her walking aid inside the church and even more tense when I put the neck support behind her neck before we enter the inner parts

of the church. Hanna walks away. She doesn't say anything to me just walks and joins the group around the teacher. They all start to move down the aisle. I watch Hanna closely from the corner of my eye. She looks a little bit tense at first, walking with a certain stiffness in her posture. Her class-mates gather around her. Nobody seems to notice the new part of the walking aid. I can see Hanna relax and the stiffness in her posture slowly declines. She starts moving more aggressively, taking sharp turns, stopping and starting, following the group as it moves around in the church.

Hanna's perfection in moving was improved almost instantly after she got the neck support and she immediately started using her new neck stability to expand her moving capacity. The main issue here was Hanna's decreasing control of her own body. The capacity to be the author of actions (Stern, 1998) is important to promote a healthy development. To be able to own your action you have to be able to control your body, the vehicle of being in the world to speak with Merleau-Ponty (1999) and this means to have muscular strength enough to be able to keep your body in a steady state, ready for action. This steady state was difficult for Hanna to maintain as it got harder and harder for her to control her head, even to hold it upright. To Hanna it was impossible as she had to direct her consciousness towards herself and the project of keeping control of her own body. When she slowly lost her head control she was unable to aim at things through her body. She could not direct her senses towards the call from the things because she was preoccupied with handling her body, which is supposed to be the unreflected "medium for having a world" (Merleau-Ponty, 1999). To Hanna the body was not the unreflected medium, as she had to adapt her motor actions a lot to what she was and wasn't able to do. Therefore there was a big gain in helping her handle her body without unnecessary effort and the neck support was one way of doing this and to do it in a way that resembled the way her able-bodied peers handled their bodies.

Not only striving for accomplishment of a task, but sometimes also aiming at imitating a normal movement pattern for Hanna, I wanted to plant into her lived body the experiences of motility and mobility, i.e. bodily memories. This way she got an extended knowledge of her

lived body that would be beneficial to her developmental process as the lived body is the means to get access to the world. Merleau-Ponty states that every change of the body will mean a change of the life-world (1999). This implies that **if** Hanna's experiences of her being and her life-world were somewhat similar to the experiences other children had of their beings and their life-worlds, it would be easier for her to participate in human interactions and relations, furthermore to understand and to be understood. Important to note is that I am not talking about being understood on a personal level, or even on a cultural level, but on an existential level.

In one way the action can be seen as conforming to the new paradigm, i.e. helping the child to successful movement by modifications by a factor external to the child. On the other hand it can be seen as an act using the old paradigm as I was helping Hanna to achieve what can be seen as a normal movement pattern. The latter standpoint opposes the argued point of view in a lot of contemporary research described by Viart and Darrah (2002) saying that normal movement patterns may not always be the most efficient for children with physical disability. The motor support Hanna got can be seen as supporting both paradigms because focus is somewhat different if you look at what we did from a life-world phenomenological point of view. Then the motility and mobility support Hanna got must be seen with a life-world phenomenological aspect in focus; her experiences in her life-world.

CHAPTER 8: TO SUM UP AND TO PROCEED



The upright posture has influenced not only the bodily but also the existential and social conditions for Hanna. As a school child, as a teenager and now as a young adult, the meaning and importance of not only family connections but also relations outside the family have been ever increasing (“we are our relations”, Tjellander 2004). In all this, her sense of self-agency as well as her sense of core-self (Stern, 1998), her radius of action as well as her ability to learn different perspectives have played important roles.

Her walking aids may have been mute but they have been with her all the time, and by now, the aids and their influences on Hanna’s development are inseparable from her. The two of them is one. *The* Hanna, the one and only, is a Hanna *with* her walking aid always available. How a “Hanna stand-alone” would have grown up and developed is an impossible question, but it is noticeable that although Hanna’s impairment has increased during the years (due to the progressivity of SMA II), the consequences of it, her disabilities, have decreased over the same period. Many of the consequences of functional limitations from childhood disorders will only be fully expressed in adulthood (Helders et.al., 2003) and in this study, the follow up on Hanna’s development, there is reason to believe that the walking aid to a great extent have contributed to this positive outcome.

In the next part of my doctoral thesis, I will follow Hanna all the way until the present now. Her own voice and her own memories will be even more influential than here, and her presence will be obvious and steering not only orally but also through the intended implementation of her insights. She will enter a design process together with a PhD student (an industrial designer) at Certec in a joint effort to elaborate the appearance and functioning of an *ideal* new walking aid, fulfilling its purposes as an integrated part of the future life of Hanna.

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Appendix 1

What is Spinal Muscular Atrophy?

A short medical presentation

When relating to bodily conditions such as Hanna's we are used to talk about it in a medical way. SMA and other different(dys)functions of the body are often first and foremost looked upon from a medical point of view, defined from a medical point of view as a disease called this and that. Is it really necessary to include a medical description of SMA II in this thesis as it is not from a medical point of view, not as a disease, I have written about it? I have decided to do so for your convenience, as the medical aspects of SMA II is the conditions Hanna have to deal with in her everyday life.

SMA is a motor neuron status. The motor neurons affect the voluntary muscles that are used for activities such as crawling, walking, head and neck control, and swallowing. SMA causes weakness in these muscles, although the proximal muscles (those closest to the trunk of one's body - i.e. shoulders, hips, and back) are often most severely affected. Involvement of respiratory muscles (muscles involved in breathing and coughing) can lead to an increased tendency for pneumonia and other lung problems. Weakness in the legs is generally greater than in the arms. Involvement of respiratory muscles can lead to an increased tendency for pneumonia and other lung problems. The skeleton is often affected because the muscles cannot support it and the vertebral column develops a scoliosis that twists the ribcage. This increases the risk for pulmonary dysfunction. Sensation and the ability to feel are not affected. Intellectual activity is normal and it is often observed that patients with SMA are unusually bright and sociable. It is a relatively common "rare disorder": approximately 1 in 6000 babies born are affected, and about 1 in 40 people are genetic carriers.

<http://www.fsma.org/booklet.shtml#whatis>

Patients present symptoms including: hypotonia (i.e., loss of postural tone), flaccid weakness, and atrophy. Patients with SMA present with weakness and muscle wasting in the limbs, respiratory, and bulbar or brainstem muscles. They have no evidence of cerebral or other CNS dysfunction. Patients with SMA often have above-average intelligence quotients (IQs) and demonstrate high degrees of intelligence.

<http://www.emedicine.com/neuro/topic631.htm>

The above written is mostly a description of the SMA disease. Displayed like this it is a list of different symptoms that can be seen in a person with SMA. But at the same time it is the conditions given to this person, the biological conditions of life for the person with SMA II and in this case it is the conditions of Hanna's.

Interactive Design – the desire for autonomous upright mobility: A longitudinal case study

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Abstract. When a child is born with a motor disability, making it difficult or impossible to acquire independent locomotion, a challenging task is to find assistive compensating technology. This study addresses the motor needs of a child, Hanna, with Spinal Muscular Atrophy (SMA II). She participated in the development of her assistive technology, with a focus on her independent locomotion and posture, during her infancy, childhood and early teens in a longitudinal and interactive design project. From the very beginning, she expressed a strong attraction to autonomous upright mobility, in contrast to the more common sitting posture in a wheelchair. She has used different versions of the resulting powered walking aid ever since. The upright independent locomotion it has afforded has been of major importance for her self-image, independence and physical development.

Keywords: SMA, standing posture, design process, walking aid, case study

1. Introduction

This design process emerged from the needs and desires of Hanna, who was born with the motor neuron disease, Spinal Muscular Atrophy II (SMA II). The process was highly situated [16]: needs and desires were captured where Hanna lived and acted. It was also an iterative process [31], with solutions invented through repeated acting and reflecting on the ideas expressed by Hanna as useworthy [7]. SMA II is characterized by visual onset around six months. The child with SMA II may pass motor milestones slowly and often concerns are not raised until a child is not sitting independently by 9 to 12 months or is not standing by one year of age [14]. For these children the standing posture is mostly impossible to acquire on their own. This study revisits the time of the situated [4,15] and iterative design process and the development of its technical outcome: the powered walking aid.

2. Earlier research

There are several physiological benefits to be gained from the upright position for people with different kinds of physical disabilities. This includes reductions in the loss of bone mineral density through dynamic loading [8,10,19,23,28], prevention of osteoporosis and the consequent risk of fractures [8,24,25], improved bowel function/reduced constipation [13], prevention/delays of contractures [35,36], and reduction in respiratory and gastrointestinal complications [5,9]. Thus, physiotherapists and doctors often prescribe standing as a means of training for people with physical disabilities, and children with SMA II are no exception. Persons with dysfunction in the motor neurons present flaccid weakness, hypotonia and muscle atrophy [37] and standing can help diminish these negative effects of SMA II.

There are commercial standing devices on the market, preferably for children [30] and some powered wheelchairs are constructed with the standing posture as a complement to the seated one. This is achieved by a seat that can be raised, positioning the body supporting features behind the body [21] and is used mostly for

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adults. The seat is dominant and its construction determines the conditions of the standing support. A supporting unit positioned in back combined with a standing shell, a plastic mould that fits the bodily contours, casted from the back of the child's body, is the basis of the assistive technology often used when providing a young child with the opportunity to stand.

2.1. *Independent locomotion and psychological development*

Durkin [6] highlights the need for a child-led assessment tool for powered mobility users. She states that disabled children (of many diagnoses) who are unable to move themselves independently, often are set on a slow and disadvantaged, downward developmental spiral. She also states that the lack of independent locomotion denies these infants a key experimental process which allows them the opportunity to undergo changes in their perceptual, cognitive and socio-emotional behaviour [6]. One way of providing these children access to the world is through a powered wheelchair. Hayes [12] identified 4 categories of children who would benefit from powered mobility: children who will never walk, children who cannot efficiently manoeuvre a manual wheelchair, children who lose their ability to move due to traumatic injury or progressive neuromuscular disorder, and children who require temporary assistance for mobility, most often due to surgery. Powered mobility is believed to promote independence and prevent functional limitations that these children might otherwise encounter [12]. Self-produced locomotion is an organizer of psychological changes in typically developing infants involving emotions, social understanding and spatial cognition [3]. Locomotion also influences the development of social behaviours and physical play according to Gustafsson [11]. Psychodynamic theorist Margaret Mahler addresses the significance of upright mobility in learning to walk. The ability to walk gives, according to Mahler, the child an enormous increased knowledge of the world, to try it out on its own and get a magic power over it. [22].

McDermott and Akina state that if certain impulses for movement essential for physical, emotional and intellectual processes are blocked for an extended period the child will become restless and angry, wanting to overcome the helplessness which is overcoming him or her [26]. Wright-Ott [40] describes the GoBot, the transitional powered mobility aid that is both an educational and therapeutic tool. It is a mobile standing aid

intended to provide means for children with physical disabilities to explore the environment. This may facilitate development in areas of language, socialization, self-esteem, visual-motor and upper extremity function. The GoBot is not intended to replace a powered wheelchair but is seen as a transitional aid.

2.2. *Ability to manoeuvre a powered wheelchair*

Many studies have explored the age at which a child is able to manoeuvre powered wheelchairs. In the 1980s, Butler et al found that children can learn how to drive a powered wheelchair with minimal professional involvement and that they learned more quickly and at a much younger age than what was initially considered possible [2]. Jones, McEwen and Hansen found in their case study that Molly, a 20-month old girl with SMA II, learned to manoeuvre her powered wheelchair in difficult situations in 6 weeks. She showed developmental gains in other domains as well and was reported much more independent after receiving the powered wheelchair [17]. During Piaget's sensor-motor stage, from 0 to 2 years, the intelligence of the child is practical in nature; the child discovers the world through his or her muscles and senses [33]. Children with severe musculoskeletal or neuromuscular impairments should, as well as their able-bodied peers, be given this opportunity; otherwise their ability to explore and socialize is often limited because of their difficulty in moving around on their own as noted by Tefft et al. [34] and Verburg et al. [39]. McEwen [27], Butler [1] and Kangas [18] have suggested that these children should be offered a means of achieving independent mobility at an early age. Other studies highlight that practice should not be limited to the two or three times a week the physical therapist is visiting for an hour (blocked practice) but should be incorporated into daily activities (random practice). The difference between blocked and the random practice is that the former may be beneficial for initially acquiring skills and competencies but the latter is necessary for learning, retention and refinement [20,32].

3. **Project background**

Technical solutions have to be adapted to the humans using them. When it comes to persons with disabilities, this is even more important as they cannot always compensate for the shortcomings of technology as others usually can [16]. Traditionally technicians have devel-

oped AT and the users have been given an AT already in production. User input can then only be used in retrospect. Today, more voices are being heard that stress the importance of user participation when designing and constructing AT. It is important to make assistive technology useworthy. Useworthiness is the individual user's assessment of the extent to which the technology meets his or her high-priority needs [7]. Another important point is how the aid is experienced by the one who is to use it. To make the final product optimal, the user should take part in the developmental process in a situated manner; in the context where the technology is to be used [16]. This study shows that even a quite young child can take part in such an endeavour and contribute significantly to the design process. The study addresses the following issues:

- How can AT providing independent locomotion be constructed to meet the demands and desires of a child affected by SMA II?
- How can a child / young person affected by SMA II contribute to the development of such AT?

4. Method

This is a longitudinal case study of an interactive process, a process where Hanna participated in the creation and design of her assistive technology. A case study "investigates a contemporary phenomenon within its real-life context" [41]. This is a single-case design, built around Hanna alone as she falls under the category of being a unique case [41]. The process here investigated went on actively on a daily/weekly basis during the first thirteen years of her life and was situated [4,15]: It took place in Hanna's daily life. One of the sources of information in a case study is participant-observation [41] and this is used in this case-study. Interaction with and sensitivity to Hanna's expressed desires was the basis of the design process in the early years. As she grew, she was able to verbally express her points of view and this resulted in her increasingly becoming the director of the process. Another source of information in a case study is documents [41] and this process was also documented by photographs and journals from 1983 to 1995. The interactive meetings, and the experiences derived from them, resulted in knowledge about what Hanna desired and benefited from; they were the basis for designing and constructing a powered walking aid prototype. This AT has subsequently been developed according to Hanna's wishes over the years, to what she considered useworthy [7] from her experiences. Its impact on Hanna's life in many dimensions has been observed and analyzed.

5. Result

5.1. Where the action was – everyday life with Hanna

The starting point for this design process was when Hanna was diagnosed with SMA II at the age of 13 months, Christmas 1983. She had been a slow starter, late in achieving motor milestones and lacking the physical stability usually found in a child during the first year of life. When she was diagnosed, a physiotherapist started Hanna on a daily training programme including standing in an upright position which was considered beneficial [8,13,24,25,28]. The standing position was achieved by the use of a standing aid called *Patric*, provided by the Child Habilitation Team of Halmstad, Sweden. The standing aid was incorporated into Hanna's daily routine.

5.1.1. February 1984, Hanna is 1 year, 3 months

Hanna rapidly got accustomed to the upright position in the *Patric* standing aid and after a short period of time she began enjoying the erect position. The overview thus attained was highly attractive to her as well and the options that were available around her. The latter enabled her to decide where to go and she constantly wanted to be lifted in the standing aid from one place to another. By changing perspectives, the child finds new ways of understanding the world and of controlling it as stated by Piaget [33]. This would have been possible for Hanna by crawling and later walking, the latter by Mahler stated as one of the most important developmental factors [22], if she had had normal muscle development. With increasing age locomotion between two points became more and more important to her.

5.1.2. April 1984, Hanna is 1 year, 5 months

Figure 1 shows the first actual modifications made to the *Patric* standing aid, adding wheels to it. The standing aid was the one Hanna had used from the start, only the castor's were added. They could roll in any direction to make the moving sensation as vivid as possible. By the help of someone pushing the *Patric* standing aid around, Hanna was now able to get access to locomotion in her environment from a standing position. Being able to stand up and move around at the same time was highly attractive to her and she expressed her delight in every way possible. By referring to the action using the word "gå" (in English "walk") she expressed what she considered her locomotion to be: walking. In her wheelchair she referred to her locomotion as "köra" the Swedish word for "drive". This proved important later on.



Fig. 1. First modified standing aid with wheels.

5.1.3. August 1984, Hanna is 1 year, 9 months

At this point Hanna strongly expressed what she wanted and that the upright posture was an exploring posture to her. Her determination to get to the desired objects suddenly made it clear that she needed more than just the upright posture. Given her age, 21 months, she would already have been walking on her own had she been equipped with strong muscles and she needed the opportunity to move in the direction desired on her own. It was insufficient for her to have to wait for someone to push her in the direction desired. Hanna was more than ready for independent locomotion and it was in the upright posture she wanted it.

5.2. The sitting posture and its limitations

5.2.1. February 1985, Hanna is 2 years, 3 months

At this time Hanna had a manual wheelchair for independent locomotion. Doctors and physiotherapists pre-

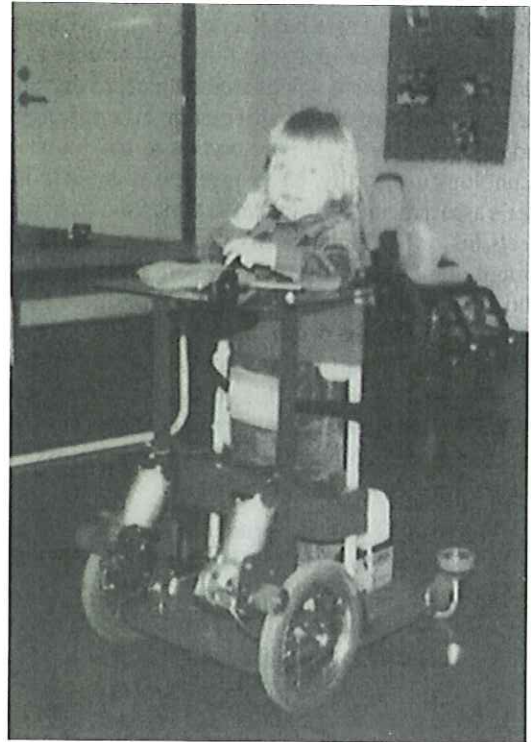


Fig. 2. First motorized walking aid.

ferred to start out with manual wheelchairs. Paulsson and Christofferson writes that the unfounded beliefs of health care professionals in Sweden in those days was that the provision of an electrically driven wheelchair would diminish the children's motivation for physical training or even make them lazy [29]. After some time, though, Hanna was able to try a powered wheelchair as well; she had it for several years but only used it occasionally, and the manual wheelchair she used even less.

To Hanna (and other children with SMA II) the limited muscular strength made it almost impossible to combine the physical training with the urge to explore and conquer the world. Her mind always outstripped the body making her frustrated. One reason for this is that a child with SMA II has extremely limited torso strength and this makes it hard to bend forward from a sitting position to grab desired objects. This is similar to the description of Jones et al. [33] who observed that Molly, the SMA II girl in their case study, had difficulty gripping objects positioned to the right or to the left of her body. Hanna had the same difficulty, and she therefore failed to grab objects even when she drove up beside it to keep the feet supporters from getting in the way. She did not possess the torso strength to lean side-

ways and stretch out her hand at the same time and all her strength was required to maintain her sitting balance if the posture was to be somewhat active, i.e. sitting up straight. The inability to get close to the objects she desired was another of the reasons wheelchairs, manual or powered, never were very popular with Hanna. It became increasingly apparent that the sitting posture was somewhat of a dead end for Hanna if she was going to maintain any kind of active posture in adulthood. Her eventual loss of muscular strength over time as well as greater demands on strength to manoeuvre as she grew had to be taken into consideration [38]. Maintaining an active posture was, of course, of utmost importance for her quality of life and this was much easier to accomplish if Hanna was in a standing position. The standing posture was also less energy consuming and balance demanding for her than a sitting one.

5.3. Combining the two: Upright posture as a basis for independent locomotion

5.3.1. February 1985, Hanna is 2 years, 3 months

This was a crucial point in the process; the issue of how to combine the two factors most important to Hanna right then – the upright position and independent locomotion. Until now, it had been either/or: the upright position (Hanna being moved, with the help of someone else, from one point to another in her *Patric* standing aid) versus the sitting position when driving the wheelchair (in many aspects frustrating for Hanna) exploring the world from a sitting posture. So the two issues involved were: the physical and psychological benefits gained from the upright position, and Hanna's desire for and benefits from independent locomotion. From this moment on, the focus was on working with autonomous upright mobility. At first, the old *Patric* standing aid was used as the basis for the prototype, motorizing it so that Hanna could move around independently and control it with a joystick. This made her gain access to independent locomotion in an upright position and not in the conventional wheelchair manner (see Fig. 2).

The combination of upright posture and independent locomotion transformed the upright posture in the standing aid from a training activity performed at isolated times *to a way of being*. Combining the upright posture with the independent locomotion was crucial as interventions recommended and performed by physiotherapists (such as contraction prophylaxis) on their visits once or twice a week for an hour or two, would make *no* real difference unless Hanna was able

to continue performing the activities in her daily life with assistance from parents. The combination of upright position and independent locomotion prolonged the time spent in standing position in a way that highly exceeded the time recommended by the doctors and the physiotherapists in order to gain the bodily benefits anticipated.

Furthermore, Hanna had no difficulty learning how to manoeuvre the motorized walking aid and her quick comprehension of the mechanism was probably partly due to her age: she was two years, three months (27 months) at the time. This supports the findings of Jones et al. [17] who observed 20-months old Molly who learned how to manoeuvre a powered wheelchair within 6 weeks. This implies the intervention could have been accomplished earlier but the process had to take its course; it took quite some time from idea to actual prototype. The question of when a child is mature enough to drive a motorized wheelchair has been discussed [34], and the experiences from Hanna's first afternoon in her motorized walking aid support the findings of McEwen [27], Butler [1] and Kangas [18]. They have suggested that children with severe motor impairments should be provided with a means of independent mobility at an early age to explore their environments. Hanna tried it was like she was trying to compensate for months of relative immobilization in one single afternoon.

5.4. Redesigning the walking aid: Prototype 2

5.4.1. August 1986, Hanna is 3 years and 9 months old

In the autumn of 1986, the construction of a new walking aid resulted in a project incorporating Child Habilitation in Halmstad and the newly established University of Halmstad. The project aimed at developing and redesigning Hanna's walking aid according to her needs and wishes. Thus she was a natural part of this design process all along, and with three students from the Developmental Engineering Programme, a new concept for an improved walking aid was outlined. We outlined a concept for an improved walking aid. It was a completely new construction and was built by habilitation personnel and Hanna's father (see Fig. 3). The main changes were:

- 1) A new body-supporting device constructed to make the upright position as energy saving and comfortable as possible.



Fig. 3. Hanna's hips were tilted backwards to prevent overstretching of the hip joint due to Hanna's wish to tilt her pelvis forward, resulting in a sway-backed posture to maintain balance.

- 2) All parts connecting directly to Hanna's body, were easily detachable in order to be able to change them and adjust them to follow the growth of her body.
- 3) All parts connected to Hanna's body were adjustable in height, independent of each other, in order to make her standing position as comfortable as possible.
- 4) A totally new construction of the frame.
- 5) The ability to run the motors at normal (quick) walking speed and not have to reduce the maximum speed because of the upright position as in many powered wheelchairs with standing capacity.
- 6) Direct motor transmission with a gear to each wheel to optimize speed and power.
- 7) Change to back wheel drive.

5.4.2. The body supporting device

The issue at hand here was to design and construct a totally new walking aid according to Hanna's wishes. In this process the upright posture was taken as

the starting point because it offered totally different options when constructing the body supporting details compared to starting from a sitting position leaving all wheelchair based solutions behind. Many wheelchairs, constructed with a seat you can raise, place the supporting structures behind the body [21,30,40]. The human body has a greater curvature in the back, though, and this made it more difficult to give Hanna optimal support this way. When she tried such solutions already on the market, she had great difficulty in finding her balance supported from behind due to her overall low muscle tone. Thus, all attempts to support her from the back failed as it became increasingly difficult to maintain a straight knee position and prevent her from tilting forwards. As the whole body is affected by the weak muscles due to SMA II, especially in the torso and legs [37], quite a lot of pressure has to be put on certain crucial points to stabilize the body and make it possible for a person with SMA II to maintain balance. It was necessary to support her body from the front. It was also found that Hanna had a better and more energy saving posture by having only one strut placed in front of her body. Then the fixation points for hips, knees and torso could be placed so that they better followed the body contours, thus giving better ergonomic support. The old *Patric* standing aid was also abandoned as a starting point for the construction, having too many disadvantages.

So the construction process had to start from scratch and Hanna was the guide telling what was comfortable. It was also possible to get a clue from how long she would be able to maintain her upright position without fatigue and the overall resemblance to the posture of an able-bodied person, when deciding how to construct the body supporting device. The hips were the most important stabilization points, fixating them to the strut with a hip supporter. At first, this was accomplished by measuring her hips and making the diameter of the supporter fit them; later a moulded frame was constructed with the help of the orthopaedic engineer, shaped to fit her hips exactly for greater comfort and stability. The second fixation point was at the knees, and to put the supporting device just above the kneecap at the lower part of the thighs avoided direct pressure on the joint. By fixating the major joints of the lower body, the hip joints and knee joints, Hanna achieved a comfortable and stable supporting area with the pressure of her weight equally divided between her feet and legs. This saved power and strength for her to control her upper torso, arms and neck. The hip and knee supports were made adjustable and detachable to adjust in height as



Fig. 4.

Hanna grew. This even made it possible to acquire new supporting devices without having to change the entire construction. She also needed to be a little swaybacked in order to keep her balance and save energy. The benefits of changing the bodily supporting part of the walking aid succeeded in promoting a better standing posture for Hanna as she grew.

5.4.3. A new construction of the frame

The frame was redesigned based on a low centre of gravity with sufficient width and length for the stability needed to support Hanna's height and weight without overturning. Another change was from front wheel drive to back wheel drive. The benefit of having back wheel drive was the extended locomotive ability. If you stand on the rotating wheels, your ability to move sideways is clearly improved. If you stand on the driving wheels, with the turning wheels behind you, you lose all the action of the turning wheels. You risk crashing into things not observed behind you when you turn right or left since the back of the walking aid hangs out like a tail. Hanna wanted the locomotive action of standing on the turning wheels, having them in the front, and the driving wheels in back. The direct power transmission with gears made the power transmission more efficient increasing speed and strength. The increased speed was due to Hanna's strong wish to move faster.

A seat was constructed that could be put on the lower frame after removing the standing device so Hanna could sit down without the loss of the independent locomotion (see Fig. 4). This was done because she disliked wheelchairs: manual ones were hard for her to manoeuvre and electric ones too big and clumsy to be

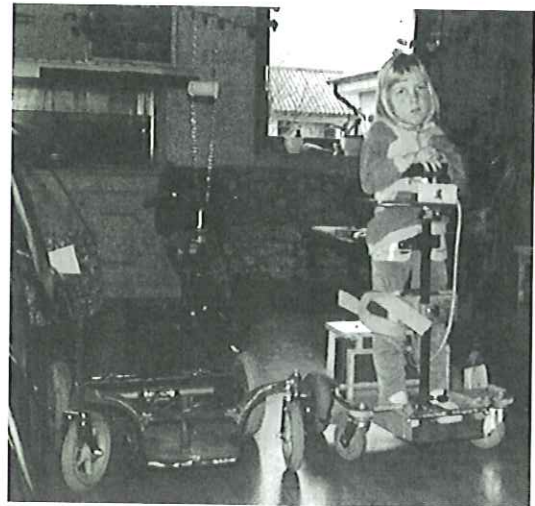


Fig. 5.

used indoors. The same conditions as for the standing posture applied to her sitting position. She needed to be a little sway-backed to maintain her balance, but she did not have the strength to do it on her own; her pelvis had to be tilted forward. It was decided to keep the standing and sitting postures technically separated; they only shared the frame. This way technical issues of the two postures could be solved separately; a better standing posture was achieved for Hanna and a sitting one to her liking without having to develop mechanical parts to fit both functions. Hanna was happy and content when the new walking aid finally was ready for action.

5.5. The third prototype – the choice

5.5.1. March 1989, Hanna is 6 years, 4 months

The third prototype was built in 1989 (see Fig. 5). Hanna's standing aid needed to be improved. She had grown tall and heavy and she wanted to move faster. Other important and necessary changes included bigger front wheels and a protective foot shield. She had agreed to this because she wanted to be able to move faster, but this time the change was not easy. Hanna was reluctant to build a new walking aid and it was hard to get her to take part in the design process this time, but a new walking aid simply had to be built necessary as it was for her safety. At this time in life Hanna had many different kinds of assistive technology, among them, toilet seats, chairs, powered and manual wheelchairs, carriers and special bikes. The motorized walking aid, however, was the only one that evoked a strong personal reaction when threatened. It had become Hanna's most

dominant AT and the one she chose when presenting herself to the world. The motorized walking aid had become the foundation of Hanna's existence.

So in the beginning, as the new frame took shape, Hanna only quite reluctantly took part in the design process. It was crucial to make her feel at ease with what was happening and in control so every effort was made to make her feel at ease with the project. For once, Hanna wanted to keep the standing device, the part of the walking aid that kept her body in an upright position and this was accomplished by building the new frame so that it was compatible with the old standing device. She chose the colour; and was satisfied with the fact that the new motors were stronger making the walking aid faster. Slowly she became more positive. Adaptations were made for her to sit and move independently in her new frame as she had done in her old one (see Fig. 4) giving her the same options in the new frame. Finally the frame was ready to use together with the standing device and the seat. All that remained were the fixation points for Hanna's seat. At the evening of this building phase Hanna suddenly declared she didn't want to sit down any more when moving around, she only wanted to "walk" and the 3rd prototype was built without the sitting option.

5.5.2. *Prototype 3 continued – August 1989, Hanna is 6 years, 9 months*

At this point in her life Hanna chose between the two options available for independent locomotion: the seated posture of a powered wheelchair and the upright posture in her powered walking aid. She chose the autonomous upright mobility. Her choice was contrary to Wright-Ott [40] who considered the standing posture in the GoBot to be a transitional one, not a replacement for a powered wheelchair. To Hanna the walking aid was a replacement for the powered wheelchair. The reason was she liked the joy and satisfaction of standing upright and being more like others, the easy access to things in the environment, the considerably more comfortable posture when standing and the small size and adaptable design of the walking aid. To help her get better standing comfort an arm support was positioned under her arms in which the joystick was mounted in the centre to make it easier for Hanna to get hold of it. As Hanna had been considerably taller she also was given a corset to help her stabilize the torso while standing, as she had a small range of motion and her body needed to be as well balanced as possible if she was going to be able to control her balance and stand comfortably.

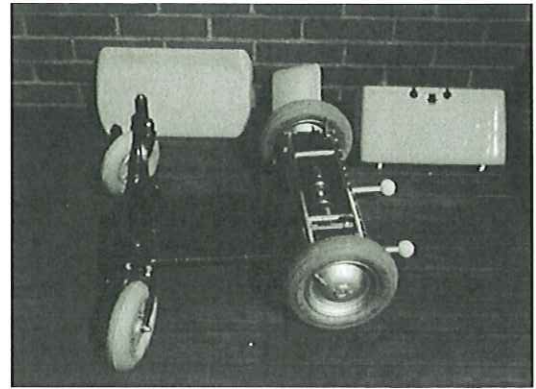


Fig. 6.

5.6. *The importance of head control*

5.6.1. *The neck support October – 1990, Hanna is 7 years, 11 months*

It is important to be able to control one's head in order to feel independent and free; for Hanna, this became more difficult as she grew older. This is to be expected in a child with SMA II, due to the double bodily stress when growing [38]. Hanna started to have trouble holding her head upright, at the approximate age of 7 1/2 years, especially when motion and gravity affected her body. This of course also affected her independent locomotion in the walking aid. It became more and more difficult for her to hold her head up straight while running, turning, starting and stopping. A neck-supporting device was developed and added to the walking aid (see Fig. 7). Her accuracy in moving improved almost instantly, and she used her new neck stability to expand her mobility. What was important to Hanna, as always, was that the neck-supporting device was as small and undetectable as possible.

5.7. *Additional design aspects*

When Hanna was almost 13 years old, she was once again faced with the difficulty of deciding on a new frame. This time it was not for safety reasons but because of Hanna's desire to have a wider range of options, better ability to move on all surfaces, such as lawns, and greater speed. A manufactured frame from a powered wheelchair company already in production was tested. It was initially used as an under frame for a powered wheelchair and had better motor capacity, better electronics, which offered the option of not having to build everything. A spare parts supplier was available for the first time. The seat was removed and a



Fig. 7. Padded neck support for greater comfort and stability.

fixation point for Hanna's standing device was adapted. The company was interested in someone to test their products and this was Hanna's part of the deal.

5.7.1. Testing the manufactured frame October – 1995, Hanna is 12 years, 11 months

When arranging the meeting with the manufacturer, Hanna was asked what colour she wanted for the frame. She deliberately chose black in an attempt to make the machine look smaller. She stood firm with her choice to the manufacturer's surprise. She decided not to have any stripes or other applications on the frame and she turned down the horn and the flashing indicators. Different features are commonly looked upon as positive assets when it comes to AT and bright colours, stripes and other car-like devices are often considered appealing but Hanna wanted the frame to be as invisible as possible and painting it in a bright colour would have interfered with her design idea of the walking aid. She explained this standpoint: "I don't want to look like a car; I want to look like a human being."

Hanna hereby declared she wanted a walking aid that was small, discreet, easy to manoeuvre, and designed to be an almost transparent extension of her in order to be able to look like a girl and not a machine. In Hanna's case, the body needs supporting technology to be able to accomplish pedestrian independent locomotion; this is what the walking aid adds to Hanna's bodily competence. As Hanna's weight is low due to loss of mus-

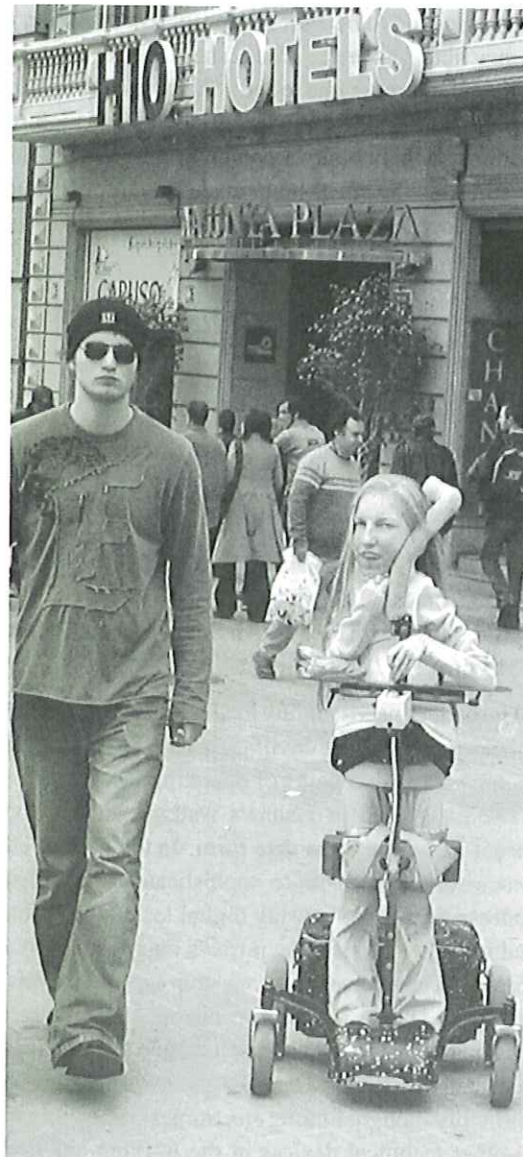


Fig. 8.

cular mass, it was unnecessary to build a bigger and heavier walking aid than necessary to assure her safety. In the ongoing design process, the frame, of course, had to be built to secure stability and safety for her or someone in her weight/length class, but in addition to the safety aspects, she wanted the walking aid to be as small as possible. Many wheelchairs are designed to accommodate a wide range of people of different ages and diagnoses. Manufacturers are required to make them bigger and heavier than necessary for a girl like Hanna in order for the AT to be safe for a wider range of clientele. Hanna wanted, in the best-case scenario,

the walking aid to be entirely transparent to let her, not the machine, be seen. Thus, she decided not to use the manufactured frame tested. She wanted to continue with the homemade one, despite its lack of high-tech solutions such as built-in computer programs. Today she still uses the small homemade frame for her independent locomotion and she is now 24 years old (see Fig. 8).

5.8. Technical description

Below is a description of the technical devices:

Motor effect: 2 x Pittman DC motors type 14206
24v / 70 W

Gearbox: 2 x Pittman 18:1

Electronics: BEC 40

Batteries: 2 x 12V / 15 Ah Sonnenschein Batteries
dryfit A212 /15G

The battery needs nightly loading for about 4–5 hours with normal use in the daytime; normal in Hanna's case meaning about 4–5 hours of operating.

The parts used in Hanna's walking aid are today present in a more up to date form. In the field of electronics for instance more sophisticated and efficient products are available using digital technique. Motors used in wheelchairs today possess bigger strength and more efficient power transmission capacity. This is something Hanna has been a bit interested in as the electronics used today is quite loud and she has always been keen on increased speed capacity. There has been a difficulty though, finding electronics compatible with the other technical devices in the walking aid, and if changing the motors as well with the mere construction of the frame. As the design of the frame is made to fit the used motors and other components, such as gears, it is somewhat difficult to change some of the technical components without changing the frame. As Hanna is using the walking aid every day there has been no possibility to remodel the present under frame. At one point in time there was a discussion about building a bigger frame with a new set of motors, gears, electronics etc. for safety reasons; Hanna grew and the risk she'd turn over increased. This was something Hanna was quite reluctant to and today she is fully grown and the third prototype still is totally safe for her. The third prototype has become a permanent AT.

6. Conclusion

This study demonstrates that it is fully possible for a young child to participate in the development of AT. In this case it was AT providing independent locomotion and the participation was accomplished by a situated, iterative process [16,31], where Hanna's wishes and desires were taken into account and used to guide the design process. By being sensitive to Hanna's expressions it was possible to support her strive for normal development and use it as a means to decide how to construct the AT she needed and thrived from. Later when she got older and was able to express herself by using words, she many times surprised the people around her by choosing in a way that wasn't expected. Hanna's ability to talk about what she wanted and how she wanted it made the process easier. Hanna's wishes and desires strongly affected the way the AT was built as she had a strong opinion on how she wanted her AT to be constructed; she wanted to be seen as a girl and not a machine making the AT for independent locomotion as small and transparent as possible. To this day this wish lies behind her strong belief that she wants something that gives her a human appearance and not looks like a car. This study would strongly suggest that the needs and desires of a handicapped person should and **must** be the guideline for the designer of Assistive Technology.

The study also demonstrates that independent locomotion was important to Hanna, as a means to explore and conquer the world around her in many ways as earlier studies have stated [3,11,12,22] and that the upright posture was important to Hanna from both a physical and psychological point of view even though she was unable to accomplish it on her own. Psychologically it gave her a better overview of the environment thus changing her way to perceive the world, and furthermore the way others interacted with her as well. Physically it gave the bodily benefits highlighted in many other studies [5,8–10,13,19,23–25,28,35,36]. The combination of these two competences, giving Hanna access to independent locomotion in an upright position, made her able to prolong the time in the upright position, making the bodily benefits of the upright position more prominent at the same time as it provided her with independence in the form of upright access to the world and the things in it, including other human beings.

The construction of the powered walking aid made it comfortable enough for her to stand up for long periods of time despite her lack of muscular strength, so that she was able to internalize the upright position in

her existence. By this intervention, she has also experienced life in a different way than she would have sitting. The results of this case study strongly support previous research [1,18,27], which has concluded that independent locomotion at an early age is of great importance for the well-being and development for children with motor impairments, but it would also like to add that the bodily position in independent locomotion is of great importance too. The upright position with access to independent locomotion became the way Hanna chose to present herself to the world and has affected Hanna's existential conditions and added to her quality of life. Every child with SMA II may not prefer the upright position for independent locomotion as did Hanna but it is suggested that these children should be given the opportunity to access independent locomotion in an upright, comfortable position, test it and decide for themselves. Finally this study would like to suggest that the upright position combined with independent locomotion could have advantages for physical and mental development and is highly underestimated as a way of living for a person with SMA II. Future research would add knowledge on this matter as well. In Hanna's case the third prototype, built some twenty years ago is still today the walking aid Hanna is using and this means the technical components used in it are rather old fashioned. Yet, this low-tech solution have been, and still is, capable to provide her with the things she craves to feel comfortable as a human being, independent locomotion in an upright position.

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This licentiate thesis is a monography complemented with one published article: "Interactive Design – the desire for autonomous upright mobility: A longitudinal case study, Technology and Disability 19 (2007) 213-224". My hope is that the combination of the monographic part (with its phenomenological tone, personified and situated), and the more unbarked "Technology and Disability" article (with its orientation towards the general rather than the personal aspects) will contribute to dialogues on different scientific approaches.

The overall purpose of this thesis is to develop new knowledge on child development under the conditions of SMA II. As I use a life-world phenomenological approach my first quest is to highlight and make explicit what appeared in Hanna's life-world and how these experiences have contributed to her overall development.

I also want to put forward how Hanna's motility and mobility were supported, guided by what she expressed and strived for, in order to promote a healthy physical, psychological and social development. A special focus is on independent locomotion and how this was accomplished for Hanna. By using technology in a new way it was possible to enhance Hanna's access to the world through the medium of her lived body, thus changing her life-world by widening her life-world horizon. The second quest of this licentiate thesis is to make this journey explicit.

This thesis can also be found on the Internet:
www.certec.lth.se/doc/tomoveahead



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LICENTIATE THESIS CERTEC, LUND UNIVERSITY 1:2008
ISBN 978-91-976894-3-4

MAY 2008

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