Different Voices – Different Stories

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Communication, identity and meaning among people with acquired brain damage

Eleonor Antelius



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To Fredrik & Linnéa ~ my heart belongs to you ~

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PART II

PAPERS I - IV

The following papers are presented in Part II:

Paper I

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Paper II

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Paper III

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Paper IV

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PART I

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Trosa, April, 2009.

Prologue

According to the Swedish Disability Act (abbreviated in Swedish as LSS), people with disabilities are entitled to special support and certain rights which should be provided for them by the municipality. However, in order to know who is entitled to what rights, people with disabilities are assessed in regard to their disability and labelled as a 1, or a 2 or a 3. People who fall under Category 1 (people with autism or mental retardation) and those who fall under Category 2 (people with developmental disabilities or people who have acquired brain damage in adulthood) are assessed from a medical perspective; it is their diagnoses that are central. In Category 3 on the other hand (people who have severe and permanent physical or mental disabilities that result in profound difficulties in daily life and a need for substantial support), the diagnosis or the cause of the disability is irrelevant. The individual's difficulties in everyday life and the need for support and service are instead central to being labelled as a 3.

When I first entered the field, the superintendent of the day centre wanted to explain the idea behind it to me. She told me that this was a day centre for people with severe disabilities who indeed needed a great deal of support and service in their everyday lives. However, the people in this day centre had not been labelled as 3s; most of them were "only" 2s and hence not entitled by law to this service. With pride she told me that this day centre was unique in providing these services for people for whom they had no obligation to do so. She told me that the participants would most likely all fall under Category 3 anyway if they had only gone through with the municipality's assessment in regard to the LSS law. However, now they did not have to go through such an "additional assessment" (their medical diagnosis was enough) and she said she knew this was very important to most of the participants because they had told her that they did not want to be labelled as "not normal".

CHAPTER 1

Disability & Sense of Self

The self, as that which can be an object to itself, is essentially a social structure, and it arises in social experience. (Holstein & Gubrium 2000:15; Mead 1972)

In recent years we have seen quite a surge in literature (academic as well as popular) that dwells upon the issue of a changed life: when being diagnosed with an (incurable) illness/disease or becoming disabled it seems that life is divided into a before and an after. Life after trauma can no longer be pursued as before: one has this new perspective that changes not only how one perceives one's future but also how one tells about the past. In much of this literature we also seem to find a focus upon how illness and disabilities (even if they are permanent) are thought of as an interruption of "normal life". However, defining illness as an interruption also means looking for a recovery (Charmaz 1997:13). In other words, there is usually an intention to return to the normal state of things, to return to life as one lived it before. Not only can we detect the individual's wish/intention to return to this "normal state" but it also seems as though health care and care professionals demand this:

[t]he aim of returning the individual to normality is the central foundation stone upon which the whole rehabilitation machine is constructed. If, as happened to me following my spinal cord injury, the disability cannot be cured, normative assumptions are not abandoned [...] they are re-formulated so that they not only dominate the treatment [...] but also totally colour the helper's perception [...]. The rehabilitation aim now becomes to assist the individual to be as "normal as possible". (Oliver 1990:54)

Very little, however, has been written about people like Oliver: people who have had their lives changed so profoundly that there exists no possible chance of recovery or "return to normal life". Even less have been written about those who suffer from such severe disabilities that society no longer even deems it possible to try to rehabilitate them. Rather, what seems most important is to at least make

sure they do not deteriorate from their present function and skills. This dissertation is about some of these people.

Disability – a Relational Category

In virtually all societies we find a separation between the "able" and the "disabled" body even though this separation differs greatly from one society to the next. Nonetheless we do find that in almost all societies and groups, the "disabled" label leads to some sort of prejudice that is often connected to social disadvantages (Helman 2001). In order to try to offer a unified and standard language and framework for issues related to disabilities, WHO has produced an international classification of functioning, disabilities and health, the ICF. Here WHO states that:

[d]isabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives. (WHO 2009b)

There is a distinction between concepts that should be made here, of vital importance – that of *disability* or *impairment*. Impairment is used to describe a body lacking a limb, or part of a limb, or having a defective limb while disability is used to describe the many disadvantages (social, economical etc.) that often are imposed upon people with impairments (Helman 2001). Impairment can thus be seen as the actual physical state of the body while disability should be viewed in relation to the society in which such impairment occurs. It is crucial to have this distinction in mind because it leads to rejection of a purely medical model of disability that focuses on the individual and

¹ For instance Groce (1999) has shown, in her splendid book, *Everyone here spoke sign language*, how deafness ceased to be defined as a disability in a society where everyone was able to speak by signs.

² The ICF is a revision of the ICIDH (the International Classification of Impairments, Disabilities, and Handicaps) that was first published by WHO in 1980. After several years of systematic field trials and international consultations, several of the formerly used terms (in the ICIDH) have been replaced by new terms in the ICF. For instance the earlier used terms "impairment", "disability" and "handicap" (as used in the ICIDH) are replaced with the new lists of body functions and structures, as well as a list of activity and participation in order to also account for positive experiences (*ICF* 2001:3; WHO 2009a).

physical state of the body and instead emphasizes how disability is a socially constructed phenomenon (Oliver 1990). In other words, disability is not a disability per se. As such, disability needs to be understood as a *category* that changes depending on what social setting and what context the impaired person lives in. Disability then is not an individual problem (by problem I mean difficulties that are apprehended to be connected to the ability to act according to situated expectations and norms (Hydén, Karlsson & Nilholm 2003) but a societal one. It is in relation to its context that a disorder or a disability becomes exactly that (Hacking 1986; Kleinman 1988; Kovarsky & Crago 1990-1991). The social model of disability thus stipulates that disability is not an attribute of an individual but rather a complex collection of conditions, many of which are created by the social environment (ICF 2001:28). Hence, I will from now on speak of people with disabilities rather than people with impairments since this dissertation focuses upon identity- and personhood-creating practices, practices that are social and co-created in context with others rather than located within the individual.³ Hence, just as Hughes & Paterson (1997) and Paterson & Hughes (1999) criticise the models that build on the idea that the body is "ruled" by the laws of biology, I argue that we need to look at disabilities from an interactionistic perspective, where disability is perceived as contextually tied and situated.

Taking an interactionistic approach towards disability means that I place myself in a growing tradition of both researchers and disability activists, who argue that disability is best viewed from a societal rather than medical point of view (e.g. Barton 1993, 1996; Crew & Zola 1983; Goodwin 2003; Karlsson & Nilholm 2006; Linton 1998; Olney 2001; Papadimitriou 2001). It means that:

[p]eople may have physical, mental or emotional differences from some norm, but the degree to which a person is *disabled* by those differences depends on the interaction of that person with the world in which he or she lives. (Ramsberger & Menn 2003:283, emphasis in original)

[d]isability cannot be abstracted from the social world which produces it; it does not exist outside the social structures in which it is located and independent of the meanings given to it. In other words, disability is socially produced. (Oliver 1992:101)

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³ I wish to point out that this view of disability as a social construction should not be seen as a belittlement of those who actually live with their disability. To them, and their significant others, the disability is real in a very physical way and we should not minimise this fact nor diminish the challenges it could inflict on everyday life (Kontos 2004). It simply means that the disabling nature for two people might differ quite a lot even if their physical symptoms are similar.

Hence, I write in a tradition that started with Mead in the early 20th century where focus is not so much on the individual but rather upon how we together, by using language as our most important social system, create and establish meaning in our socially shared world (Goode 1994; Hydén 2001; Mead 1972). It also means that I write in a tradition where selfhood is seen as "the human being in relation to others" (Kitwood & Bredin 1992:275) as one of the key ideas of social interactionistic theory is that the origin of the self is social in that it is guaranteed through social interaction (Garfinkel 1984; Goffman 1959). It is by engaging in interaction with others that we become who we are; the self is not something internal or individual. Rather, the self is a social construction, that we reproduce in everyday life (Holstein & Gubrium 2000:ix). Identity thus becomes something that is fluent and relational and which gets negotiated and created within an interactional process (Adelswärd & Nilholm 2000; Harré & Secord 1976).

As such, self construction is never one-dimensional, there are often innumerable different sources that together make up a persons sense of self, one's identity (Holstein & Gubrium 2000:105f.). However, in regards to disability it has often been noticed that to be perceived as disabled is to have all other aspects of oneself "cancelled out". Suddenly one is *disabled* and nothing else (Mitchell & Snyder 2003; Murphy 1990). As Ingrid, a Swedish woman suffering from aphasia, puts it:

I felt [...] that I now belonged to a particular category of people. I was no longer myself. I was a disabled. Disabled in the brain. I reacted strongly against the fact that just like that, I was identified with a group of people who have nothing more in common than a disease. (Tropp Erblad 1982:55, my translation)

Of course there are other aspects to people with disabilities as well and it is not only through comparison with other groups that they could, or should, be defined (Rommetveit 1974). In order to understand the life-worlds of those labelled as severely disabled we must not forget to listen to their experiences from their own perspective (Hydén & Mishler 1999). Just like gender, ethnicity, class or any other categorization of people, we must not forget that disability is as miscellaneous as any other category. Hence it is important to remember that disability:

[m]ay affect the form or the function of the body, or both; it may be invisible or manifest; it may be static, intermittent, or progressive in its manifestation; it may be acquired at birth or later in life; it may affect physical, sensory, or cognitive function; and it may be moderate or severe in degree. Any of these differences may have powerful implications for the way a disability is represented in narrative. As much as one needs to insist on the reality of the

category of disability and its power to construct our lives, there is a danger in thinking of disability as a single condition. (Couser 2002:112, my emphasis)

This dissertation emanates from this thought, that just like any other category, disability is diverse and each person living with his/her disability may represent that disability differently. However, it also emanates from the fact that, as stated above, disability seems to take over every other possible way of being identified. Even if we live in a society where people with disabilities should have the same rights to inclusion as able-bodied people,⁴ when it comes to terms of identity it seems as if being disabled is suddenly all that one is. Hence, this dissertation wishes to bring forward issues regarding identity and personhood in relation to disability. And, as identity and personhood are such central concepts within this dissertation, let me define them before moving on.

Identity and personhood are two concepts used side by side throughout this dissertation, but it needs to be stated that they do not mean exactly the same thing. In this dissertation identity is used to mean personal identity, i.e. a sense of self, of who we are. However, in the post-modern world the sense of personal identity is not a given; we need to *construct* our identities and decide how to categorize ourselves *and* also account for how others try to categorize us (Loseke 2005:130). Identity (as used in this dissertation) thus comes to mean social/relational/attributed identity rather than individual identity. In other words, identity is part of a social process, formed by interplay between the individual and the other (Berger & Luckmann 1991:194). And, as I will return to later on, a central part of this social process is storytelling and hence we could also talk about narrative identity.

Personhood could be thought of in terms of a similar process but also needs to be recognized as related to the fact that there are "rights associated with full personhood" (Hylland-Eriksen 1995:45). Hence, with personhood comes the moral obligation to treat a person right.

Consequently, in this dissertation I wish to illuminate different ways of constructing identity and personhood in relation to disability. Since disability is a relational category I will try to do so by observing and interviewing both people with disabilities and their carers (as it is in the interaction and communication between people that meaning-making practices such as identity and personhood creation can occur).

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⁴ In light of historic views on people with disabilities this is a quite recent view in terms of policy. Rather than thinking that it is the person suffering from disabilities that should be "removed from society" and reformed into a "normal" person (by living most of their lives within large institutions) as one did during the 1960-70s, we nowadays think that it is the living conditions of people with disabilities that need to be reformed, not the person him/herself (Goffman 1961, 1963; Karlsson & Nilholm 2006; Olney 2001).

Although I write from a perspective emanating from the idea that disability is best viewed from a societal perspective it is important not to forget that a person with disabilities lives with an impaired body and hence the actual physical body cannot be left out of the analysis. It is especially important to remember this, as many researchers tend to focus *only* on the physical body and thus risk separate body from mind, body from world and body from person (Toombs 1993; Young 1997). I do not wish to repeat such separations which makes it important to realize that even if we take on an interactionistic approach to disability the physical body should not (in fact cannot) be left out of the analysis because a person's lived experience of an impaired body matters greatly in how meaning-making can occur (van Manen 1997:35ff.; Merleau-Ponty 1962; Toombs 1995, 2001a, 2001b).

In order to set the agenda for the rest of the dissertation and to be able to illuminate the discourse on disability I would like to employ three different authors who have all been of great importance in helping me grasp the multilayered life-world of what it might mean to be labelled as severely disabled and what that could do to meaning-making practices such as identity and personhood creation. I will use Albert Robillard's theorems to show how severe disability needs to be understood in relation to issues of communication. Kay Toombs thinking will be used to point out how the physical body cannot be left out of analysis even if one is primarily interested in a social rather than a medical point of view. Finally I will use Robert Murphy's concepts to show how the label of disability is connected to issues of liminality. These three authors are chosen not only because they are excellent scholars in the field of disability studies, but also because they themselves are persons who live with disabilities. All three of them therefore have contributed greatly to the field of disability studies with a unique combination of great scholarship and a 'view from within' (and hence to our understanding of what it could be like to live with a disability and what that means in relation to meaning-making practices such as identity and personhood creation).

Disability and communication: the case of Robillard

Albert Robillard's (Professor of Sociology at the University of Hawaii at Manoa) "normal" life suddenly changed when he began to suffer from symptoms of motor-neuron disease. In his book *Meaning of a disability. The lived experience of paralysis* (1999) he explains what it is like to have life dramatically changed as he became paralyzed and lost a great deal of his speech. Robillard, being a trained ethnomethodologist, started to observe his own life and the new challenges that were thrust upon him. He writes about being forced

to confront the limits of a disabled person's social world when life suddenly is not as it once was. Robillard teaches us, from a firsthand view, what it could be like to have to struggle every single day in the meaningful interaction with other people and how this struggle challenges the sustaining of one's identity.

Often, those who communicate with me become impatient. I have to speak through a lip-reading translator, spelling out words letter by letter, frequently having to repeat forgotten or mistakenly heard letters. Some people complain that they cannot find their own sense of interactional competence in my elongated replies, and they break off further interaction after voicing their grievance. [...] My expertise in anger does not lie in disagreement sequences of normal conversational interaction. Of course I have these kinds of disagreements, as does every conversationalist. The situations I am writing about here are far more radical and disruptive to one's feelings of competence. (Robillard 1999:64-65)

Robillard goes on to list a number of settings in which he is treated as an *incompetent interactor*, such as suddenly and without notice being moved by a carer; when meeting someone who indicates that he/she wishes to talk, the person pushing the wheelchair will not stop to do so. He also mentions being disrobed by carers in full public view, being jerked into another position than the one he is currently in even though he is already sitting comfortably and so on. He then goes on to write that:

[w]hen I find myself being addressed by interactional practices that exclude me from a realm of interactional competence, and portend further exclusion, I usually protest vigorously, often with visible signs of anger, because interaction is sequential, and the relevance of any practice of body or voice can be transformed by a subsequent move in the sequence, I can never be sure that any one utterance, positioning, or posture that appears exclusionary will imply further exclusionary behaviour. (ibid:66)

What Robillard so expressively points out is that he is not only physically and verbally impaired but that he becomes disabled due to the fact that he is not allowed to be a competent interactor. Other people decide for him whether or not he should be moved or jerked out of his current position or even who he is allowed to talk to by not stopping to let him engage in conversations. He is not asked for his opinion and this makes him angry because, as he states, interaction is sequential and if he is excluded once he cannot be sure that that exclusion will not imply that he will keep on being excluded. As he so vividly portrays throughout his book; if he is treated as an incompetent interactor, his whole identity is threatened because identity is something that gets negotiated in

interaction with others. To be labelled as disabled (and hence also as an incompetent interactor) is thus to have one's identity seriously threatened.

We also get to understand that this is why Robillard has chosen to present himself as someone who suffers from motor-neuron disease rather than someone who suffers from ALS or Lou Gehrig's disease (two more commonly known names for the same disease) as these names are much more known to the rest of society and hence bear a much stronger stigma. After once being introduced as the one who suffers from Lou Gehrig's disease, Robillard writes: "I felt as if the aura of *spoiled identity* had descended on me" (ibid:113, my emphasis). Hence, in order to try to retain a sense of identity, for Robillard himself it seems best to "hide" the illness because the label of the disease comes with prejudices and stigmas that seem to indicate that he is not a competent interactor.

Disability and embodiment: the case of Toombs

Kay Toombs, a doctor of philosophy at Baylor University, Texas, has approached her own disability, living with MS, from a slightly different angle. She too writes about the importance of communication, but where Robillard speaks mostly of the need to be seen as a competent interactor (and communicator) in spite of being severely disabled, Toombs focuses mostly upon the communication between doctor and patient. In doing so, she shows the importance of understanding the nature of the body and its relationship with world and self, and the body's connection to understanding the meaning of health and illness (Toombs 2001a, 2001b). As she writes about her own illness MS, that:

a mechanistic description (based as it is on a biomedical model of disease) captures little, if anything, of my actual experience of bodily disorder. I do not experience the lesion(s) in my brain. Indeed, I do not even experience my disorder as a matter of abnormal reflexes. Rather, my illness is the impossibility of taking a walk around the block, of climbing the stairs to reach the second floor in my house, or of carrying a cup of coffee from the kitchen to the den. [...] I do not experience my body primarily as an object among other objects of the world. Rather than being an object for me-as-subject, my body as I live it represents my particular view on the world. [...] [T]he lived body is the locus of my intentions. I actively engage the world through the medium of my body. (Toombs 2001b:247-248)

What Toombs so vividly explains is that people who have become disabled always come to view the world through the limits and possibilities of their bodies (ibid:250). When one's bodily functions have changed, one's interaction with the surrounding world also changes. This affects how one is perceived and

how one perceives oneself in the world – who one is, is now someone else than one was before. And we can never understand the life-world of someone who is labelled as disabled if we do not understand that their (new) life-world gets expressed *through* the (impaired) body. Toombs (writing in the tradition of phenomenology and Mearleau-Ponty) thus argues that *all* people live their lives as embodied human beings – it is just that able-bodied persons normally do not consciously go around and think about this. But, when one has become disabled the body becomes impossible to ignore because:

I am my body for I cannot escape my impaired embodiment. [...] [T]he objectification of body in illness results from a forced attention to physical function and the awareness of some impairment or other physical change. In chronic illness [and in disability] this forced attention to body is a daily occurrence. [...] On a daily basis, whether I like it or not, I am aware of my dysfunctional body. (Toombs 1993:75)

Hence, we are all our bodies and we all live embodied lives, but when one has become chronically ill or disabled, one is "forced" to think about this on a daily basis. The (impaired) body becomes *the* most prominent feature of who one is (Leder 1990). Just the simple fact that one cannot longer stand upright changes dramatically who one is perceived to be. Toombs writes that:

[i]n my wheelchair I am approximately three and a half feet tall and the conversation takes place above my head. When speaking to a standing person, I must look up at them and they look down on me. This gives me the ridiculous feeling of being a child again [...] [And] loss of upright posture does not only concretely diminishes one's own autonomy [...] but it causes others – those who are still upright – to treat one as dependent. (Toombs 2001b:255)

I argue that just as we cannot understand how identity constructions are threatened if one is not considered a competent communicator (as in Robillards case) we cannot understand what it might mean to be perceived as disabled if we do not understand that the body becomes prominent particularly at times of error and limitation (Leder 1990). We thus cannot understand identity in relation to severe disability if we do not also try to understand how the impaired body suddenly becomes all that one is, through which everything is experienced and expressed (or as Leder states: "I forget my feet until the moment I stumble", ibid:85).

Disability and liminality: the case of Murphy

And finally, we cannot understand identity creation in relation to disability if we do not also try to understand the feelings of liminality that could come with such a label, something that I believe both Robillard and Toombs have hinted at in the quotes above, but perhaps is best understood through the words of the late Robert Murphy, a trained anthropologist who suffered from quadriplegia due to a tumour that grew on his spinal cord.

From the time my tumor was first diagnosed through my entry into wheelchair life, I had an increasing apprehension that I had lost much more than the full use of my legs. I had also lost a part of myself. It was not just that people acted differently toward me, which they did, but rather that I felt differently toward myself. I had changed in my own mind, in my self-image, and in the basic conditions of my existence. It left me feeling alone and isolated, despite strong support from family and friends [...] With the onset of my own impairment, I became almost morbidly sensitive to the social position and treatment of the disabled [...] One of my earliest observations was that social relations between the disabled and the able-bodied are tense, awkward and problematic. This is something that every handicapped person knows. (Murphy 1990:85-86)

As such, Murphy vividly shows us how being perceived as disabled becomes something that threatens your identity because it assaults your social standing and ties with others. And it is threatening not only because others perceive you as different, but also because you start to perceive yourself as different. Drawing on the anthropological concept of liminality (cf. Turner 1967), Murphy explains this feeling of living with such an ambiguous position in society:

[t]he long-term physically impaired are neither sick nor well, neither dead nor fully alive, neither out of society nor wholly in it. They are human beings but their bodies are warped or malfunctioning, leaving their full humanity in doubt [...] The sick person lives in a state of social suspension until he or she gets better. The disabled spend a lifetime in a similar suspended state. They are [...] undefined, ambiguous people. (Murphy 1990:131)

Living with the feeling of being an ambiguous person most likely comes to affect issues of identity and personhood and I believe it to be important to have this in mind when we discuss meaning-making practices in relation to those labelled as severely disabled.

I would like to bring these three great scholars and their views on disability together by quoting yet another scholar with disabilities, sociologist

Rod Michalko. Michalko, having become blind, has written about his own disability that:

I belong here, but not naturally anymore. Now that I am blind, *belonging is a struggle* [...] *there is the struggle of creating a social identity* "out of blindness" as one who is valuable and worthwhile. (2002:38-39, my emphasis)

Hence, to be disabled affects how one "fits in" with the rest of "normal" society. Belonging becomes a struggle because when one is not considered a competent communicator (Robillard), or when one is constantly reminded that one lives in (rather than with) an impaired body (Toombs), or when one lives with the constant feeling of being a liminal person (Murphy), one has to fight in order to be able to create a sense of self, a (social) identity.

Disability and Trauma

There is a distinction that should be pointed out when we talk about disability in relation to identity- and personhood-creating practices and that is whether the disability is due to congenital or acquired causes. It is important to make this distinction since disability as a consequence of trauma is usually considered to be a major disruptive life event and often implies a changed interaction with the surrounding world (Toombs 2001b). Life is not as it always was and persons with disabilities often talk about their lives as before and after the trauma. It is thus important to make this distinction because even though those who live with disability due to congenital causes probably suffer from being excluded in interaction as well, it may not affect their personhood in the same way as it would affect someone who becomes disabled later in life. If one has congenital causes for the disability one has probably always lived with a "disability identity", with all the exclusion that could come with that. In other words, one's personhood has always been understood and negotiated in relation to this.

Becoming disabled later in life, on the other hand, brings identity and personhood into the light in new and often complex ways. Acquired disabilities could then be percieved as "a crisis that presents a fundamental threat to one's experience of self and identity" (Medved & Brockmeier 2008:469) because one must then articulate a new sense of self and find a way to incorporate the "new" disabled body into one's own life story (Mattingly 1994, 1998). It is thus necessary to acknowledge the difference between congenital and acquired causes of disability because:

[t]he necessity for continually finding new ways to solve the challenges posed by objects differentiates the experience of someone who has had abilities and then lost them from the experience of a person who has never had those abilities. Indeed, some of the uncertainty experienced [...] relates to the fact that one has to *learn and relearn how to negotiate the surrounding world on an ongoing basis*. (Toombs 2001b:251, my emphasis)

This dissertation dwells a great deal upon this matter (all four individual papers in Part II regard this issue). Because, the creation of a new sense of self is extremely fragile since the origin of the self is social and negotiated in the interactional process. If one is not perceived as a competent interactor, due to one's (new) label as disabled, one's sense of identity and personhood is indeed threatened.

Earlier studies about how to create meaning in interaction in regard to disability have been conducted in several different ways. There is of course (medical) research that focuses upon the actual brain damage and its consequences. For instance Leduc et. al. (1999) have shown how damage to the frontal lobe is linked to decreased self-awareness and Vanderhaeghen (1986) discusses how the ability to understand self-concepts differs depending on whether the brain injury has occurred in the right or left hemisphere. However important it is to study the medical aspects of brain pathology it is also necessary to understand that people suffering from acquired brain damage are not just passive recipients of their symptoms – they are the people who actively live with these symptoms and try to give them meaning (Nochi 1998). Hence (and here I fall into line with researchers Medved & Brockmeier 2008) I would argue that to "reduce" self-awareness to being located within an individuals brain, is also to "wipe out" severely disabled people's own agency, whereby their own understanding of their senses of self get downgraded. Instead, I argue for the necessity to try to understand the interactive processes that also severely brain damaged engage in and thus also try to understand how their senses of self get created within such processes.

A great deal of research has already been conducted in order to challenge the perceived images of disability; the 'view from within' (i.e. stories told about disability by disabled people themselves) is not new to disability research (see for example Atkinson 2004; Barton 2007; Couser 2002; Engel & Munger 2007; Smith & Sparkes 2005, 2008, who have all conducted research involving people with disabilities, or Michalko 2002; Murphy 1990; Robillard 1999; Toombs 1993, who have all written autobiographically about their disabilities). There has also been quite a lot of research conducted regarding how to create meaning in interaction through facilitated communication and in augmentative communication.

What seems to be missing though in research regarding people with severe disabilities is then perhaps not the 'view from within' but rather how that view has been accessed. Who is it that has been able to put their stories forward, and how have those stories been analyzed? Have "all" disabled been able to come forward?

Communicative Disability

This dissertation is about people with disabilities due to acquired brain damage. They are people who are regarded as *severely disabled*. As written above, disability should be understood as the individual in relation to his/her social settings. Hence, the term severely disabled has different connotations depending on context (Olney 2001:87). In this dissertation it refers to people who are participants at a day centre for people with acquired brain damage. The term severely disabled refers to both physical and verbal disabilities due to acquired brain damage that has had a profound impact on various parts of the participants' lives. They cannot live or work independently, they cannot interact in "typical" or expected ways, they cannot communicate as they once did and all of them require around-the-clock assistance or live in group homes for people with disabilities.

There is earlier research that has focused upon people with acquired brain damage (e.g. Carlsson et. al 2007; Goodwin 1995, 2003, 2004; Medved & Brockmeier 2008; Smith & Sparkes 2005, 2008; Sparkes & Smith 2003), but much of that research has been based upon spoken narratives of the people with disabilities. Thus it is the people who are still able to speak well enough to produce a (coherent) story that we have seen most of in this literature. It is people with severe disabilities, but these disabilities have (mostly) been of a physical nature rather than verbal. What is missing in this field of research is a greater acknowledgment of what consequences *communicative disabilities* might have in relation to identity- and personhood-creating practices, especially if we take an interactionistic approach where said practices are a *co-constructed* activity. How are narratives constructed in relation to people with severe communicative disabilities? Is there only one grand narrative, the "disabled narrative" or are there other stories told? And if there are, who is telling them and how are they told?

The ethnography of communicative disability

In addition to basing my study on the idea that meaning-making practices like identity and personhood creation are socially constructed in interaction, I also fall back on a tradition that started with Dell Hymes in the 1960s, that of communicative ethnography.

Hymes (1964, 1972, 1974) argued that language is not "neutral" or something that can be taken for granted. Instead we must understand that also language is an interactional resource and hence communication must be studied in its wider context in order to try to understand the relationship between language and social life. If one intends to study meaning-making practices such as identity and personhood creation one indeed needs to be an "ethnographer of speaking" because language is an interactional resource and as such, language is a key (cultural) idea about personhood. Thus language is one of our most important social system (Mead 1972) and should be understood as a constitutive feature of social life (Duranti & Goodwin 1992; Hymes 1972; Woolard & Schieffelin 1994) (Hymes argued that to be able to study these communicative events, we need to employ ethnographic methods, thus evolved the field of communicative ethnography).

In the early 1990s, Kovarsky & Crago (1990-1991) took this field of research one step further and argued for the ethnography of *communication disorders*. They argued that not only do we need to study what people say in interaction in order to understand what constitutes our social life and how our ideas about how identity and personhood are created; it is just as important to study what *cannot* be said in various contexts. How does *not* being able to talk affect meaning-making practices such as the creation and/or upholding of identity and personhood?

Aims and Purposes

The primary aim of this dissertation is to understand problems that could emerge when people – in the midst of their lives – suffer acquired brain damage that results in severe (communicative) disabilities. By conducting an ethnographic field study at a day centre for people with acquired brain damage I try to describe how people with these types of disabilities try to sustain an identity, a sense of self, with limited communicative resources. More specifically I pose four research questions (which are addressed in the separate papers in Part II):

• Is speaking crucial when creating a sense of identity and personhood? Previous research shows that spoken language seems to be one of the most

important ways to sustain an identity in interaction with other persons as being able to speak is to be able to remain yourself. Then, having limited abilities to use spoken language, an important question is how persons with communicative disabilities try to maintain their own senses of identity and personhood. (Paper I)

- (How) can narratives help in trying to sustain a sense of self? If persons with communicative disabilities have problems "speaking" stories as a way to promote self-definition and self-determination it becomes of interest to study various other ways that they might use storytelling in order to do so. It thus also becomes of interest to study if there could be differences in narratives that are told in different ways? (Paper II)
- How does the idea of incurability come to influence narratives about severe disability? The participants were diagnosed as incurable and that seemed to become a major part of whom they were perceived to be. Their identity and personhood was seen as firmly connected to the fact that they would never improve from their current impaired status, i.e. there was no hope of a recovery or cure. This risks leaving carers with a dilemma, specifically how to be able to unite a medical understanding of someone as incurable with the fact that it is a requirement of the job to keep the participants motivated for their training, something that could come to influence how severe disability is perceived. (Paper III)
- (How) can we learn to detect untold stories? Not being able to tell stories due to communicative disabilities makes it hard to engage in social interaction with others, as telling and listening to stories is an important tool for establishing a commonly shared world and a sense of identity. The traditional idea of narrative (with a structured set of organized events and with a distinct beginning, middle and end, told verbally by one storyteller) risks excluding people with severe communication disabilities as not being able to tell stories at all. Perhaps then, we need to redefine what is meant by narrative? (Paper IV)

These questions, and hence the papers, deal with issues of *stories* – of how we narrate and tell a story of disablement. However, even if I also look at the actual stories and what is told, it is not always the actual story in itself that is the most important but rather the ability to look at *how* the stories come about (something achieved through adopting ethnographic methods). In other words, I use narratives rather as tools in order to understand meaning-making practices in relation to severe (communicative) disability.

In conclusion then, this study follows a path of social interaction rather than medical diagnoses. The study of disability is related to a social discourse and the interaction between people, rather than being located within individuals, even if the individual impaired body cannot be left out of the analysis. In particular it follows a path of studying communicative disability through the joint acts of narration. Meaning-making practices such as how to create and/or sustain one's identity and personhood when not being able to talk are in focus, and the need to adopt a new way of studying narratives is identified.

CHAPTER 2

Voices & Stories

¹In the beginning God created the heaven and the earth. ²And the earth was without form, and void; and darkness was upon the face of the deep. And the Spirit of God moved upon the face of the waters. ³And God said, Let there be light: and there was light. (Holy Bible, King James' Version; Genesis 1:1-3)

Something that has always fascinated me with the Christian creation myth is that God creates the world by *speaking* (in comparison to, for example how Winnebago Indians' Earthmaker created the world, by thinking and whishing for it, or how the Uitoto of Colombia believe that creation comes from mere appearance, Eliade 1967). When God speaks his words out loud, the world comes into being. To me, there is a sense of fascination here, a fascination with the spoken word that seems to bear a crucial connection to the idea of creation. This idea has been of great significance for me in trying to grasp what it might mean then to *not* be able to talk. Staying with Christianity for one more brief moment, one could indeed ask as James Woodward (1982) did in trying to depathologize deafness, "How you gonna get to heaven if you can't talk with Jesus?".

The spoken word and our ability to use a symbolic language has long been said to be one of primary distinctions between humans and other animals (Goode 1994; Kuper 1994). Our ability to speak and communicate with each other, using a symbolic language (Mead 1972) that can refer to the past, the present and the future is said to make us unique as a species. Language, it seems, is:

[t]he factor that enables us to express the unique order of existence that is the human realm, because it serves as the medium through which we express the world as meaningful. (Polkinghorne 1988:23)

As I have stated above, I base my study on social interactionistic theories where identity and personhood are relational concepts which are created in context with others, most commonly through spoken interaction. What happens, then, if one loses the ability to speak and use language? If we tend to think on a

somewhat lower plane then when God (supposedly) created the world, and instead focus on the creation of our identities, is the spoken word still of uttermost importance?

Narrative Research

Perhaps we could expand the above question slightly, and ask not only whether the spoken word is important but whether the ability to narrate, to put the words into stories, is crucial in the creation of identities. Ever since the "narrative turn" (Riessman 2008:14-17) we have seen a vast increased interest in narratives, especially in how narratives could be used as one of the most promising ways to understand meaning-making practices such as identity and personhood creations. In fact, narratives have been suggested not only to be a great tool in *understanding* these practices, several researchers argue that in order to even be able to become who we are, we have to tell about it – we have to narrate our identities in order to have any. I will return to this very shortly. First though, a definition of narrative is needed. It could be put simply, as Barbara Herrnstein Smith did, when she defined narrative as:

[v]erbal acts consisting of someone telling someone else that something has happened. (Smith 1981:228)

To elaborate slightly we could add that:

[t]he most inclusive meaning of "narrative" refers to any spoken or written conversation. [However] I will confine my use to the more specific meaning of the term, that is, the organizational scheme expressed in story form. (Polkinghorne 1988:13)

And further, a narrative is characterized through the organization of events:

[w]hatever the content, stories demand the consequential linking of events or ideas. Narrative shaping entails imposing *a meaningful pattern on what would otherwise be random*. (Salmon & Riessman 2008:78, my emphasis)

It is this organization that turns the narrative into exactly that, a narrative, rather than a report or description:

[w]ithout an event or an action, you may have a "description", an "exposition", an "argument", a "lyric", some combination of these or something else altogether, but you don't have a narrative. (Abbot 2002:12)

Hence, the bare sum of what constitutes a narrative seems to be that something has to happen and these "happenings" (events/actions/ideas) need to be told with some sort of meaningful (organizational) pattern.

However, narrative is broadly used and to try to define what narrative *research* means is not an easy task. Narrative research has become quite diverse and multi-layered and one could for instance discuss *where* to look for stories (is it in everyday speech, in newspapers, in diaries, in the pattern of a cloth?). We could also discuss the division between studying "small" (Bamberg 2006; Georgakopoulou 2006, 2007) or "big" stories (Freeman 2006) and how this division seems to connect to whether we should study past *events* that happened to the narrator or if we should indulge in *experience*-centred work. And, to make things even more complicated we could of course also question what a story is (even if at least the bare sum seems to be somewhat recognisable). Riessman duly notes in her famous "little blue book" that "there is considerable disagreement about the precise definition of narrative" (1993:17).⁵ Yet, even if there is "considerable disagreement" about the definition of narrative, I of course mean something by the way I use it, in this dissertation.

The three quotes above do say something about how I perceive the concept of narrative, namely as an organization of events or "happenings" into some sort of (culturally and socially) meaningful pattern. However my view on narrative must also be understood in relation to both the vast amount of narrative research that has already been conducted where narratives have mostly been studied as spoken discursive entities or as textual units (cf. the discussion in Ochs & Capps 2001) and in relation to the fact that I study people who cannot talk, at least not unimpededly. I agree on the fact that narratives are one of the most promising tools⁶ to understand meaning-making practices such as identity

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⁵ The discussion about what constitutes a narrative, and what narrative research is, and is not, could be dwelled upon for some lenght... However, we do not have room for that here. For further study I highly recommend "the little blue book" (*Narrative Analysis*, 1993) and *Narrative Methods for the Human Science*, 2008, both by C. Riessman and *Doing Narrative Research* by (Eds.) Andrews, Squire & Tamboukou 2008.

⁶ I find it important to stress though, that we should be aware of what has been called "narrative seduction"; i.e. that a story is so compelling that nothing but a single interpretation is possible. Riessman (1993:4f.) cautions us to keep in mind that not everything is narrative even though it might seem so in our contemporary society where everyone seems to have a story to tell. In order to reveal anything about human experience, narratives need to be interpreted (for a further elaboration on the need for interpretation see heading *Turning data into result*, below). Hence I would also like to stress that I have not chosen to use narrative research because narratives are seductive and today are both "chic and fashionable" (Atkinson & Delamont 2006; Smith 2007). Instead I use narrative research because I believe it to be of great value in order to be able to understand both the individual stories that are told and enacted by the people with disabilities themselves and how those stories could be understood and related to a larger social and cultural whole.

and personhood creation because, as I concive of narratives, as primarily told between people; they are interactive accomplishments and as such they could reveal a great deal about they way we together create a sense of self. Therefore, I believe narratives to be of especially great value when conducting research concerning people with severe communicative disabilities, something that might sound odd, to think that the telling of stories has extra value when studying people who cannot talk unimpededly. But, as I see it, narratives are at least partly independent of media, i.e. they are not necessarily linked to a verbal telling of stories; they could just as easily be embodied and/or enacted/performed. As these three concepts are central to this dissertation (as also identity and personhood are) let me define also these.

The terms *embodied*, *enacted* and *performed* narratives are used side by side throughout the dissertation but do not mean or refer to the same thing. In this dissertation embodiment is used to mean that when we experience something (for instance severe physical disability) and express these experiences through storytelling, the stories are not *about* the (impaired) body. Rather, they are *from* the (impaired) body (Csordas 1994:xi). As such embodiment comes to mean that body and mind, subject and object, cannot be separated (Csordas 1990). As stated in the case of Toombs above, it thus means that nothing is experienced and/or expressed outside the body. As nothing is expressed outside the body, the body could be thought of as a communicative tool and therefore the moving of the body could be interpreted as a narrative (something I will return to later on).

Enactment and performance are used synonymously⁷, and are used to mean that we are always composing impressions of our selves. We always try to project a definition of who we are, and we do so by staging performances of desirable selves (Goffman 1959; Riessman 2008). Thus, in performing ourselves we again see that the self, one's identity, is relational because a performance is always intended for someone, an audience. In storytelling this means that the narrator takes his/hers experience and makes it the experience of those listening to the story, this pointing to the constitutive nature of narrative – it forms our reality and our identities (Langellier 2001). As such it also becomes important to point to the fact that narrative performance means that there is no "fixed" or "stable" self but that we always have to struggle over our social identity. As our identities are exactly that, social, they also become extremely fragile because the desirable self we wish to project may not be acknowledged by those listening. One can use bodily ways of communication when staging these performances, but spoken language is perhaps the most common tool to use when trying to do

⁷ As both Riessman (2008, eg. page 108) and Langellier (2001, eg. page 150) do.

so (Riessman 2008:106). In relation to this study we must then realize that the idea that "identity is a performative struggle" (Langellier 2001:151) is perhaps foremost a *bodily struggle* as the people in this study cannot speak unimpededly.

The way that narrative research has mostly been conducted so far (as in studying spoken discursive entities or as textual units) therefore becomes troublesome because narratives are thus thought to be characterized by structure and coherence (topical as well as temporal). Stories that do not live up to such norms are often considered to be "failed" stories. Consequently, people who lack the ability to tell stories in this expected (or even normative) way are often perceived as less competent than they actually are (cf. Hydén & Örulv 2009). In relation to the fact that I study people who cannot talk unimpededly, the idea of what constitutes a narrative must perhaps then be broadened in order to show that also people with communicative disabilities are able to present themselves as competent storytellers. One way to approach this situation is to argue that persons with some form of communicative disability can, and often in fact use, other means to tell stories. As stated above, they can for instance embody and /or enact/perform stories rather than tell them. (I will return to this discussion in Chapter 5.)

Finally, narratives have also been shown to be of great importance because even if they are often told from a personal perspective, they are, as just stated, interactive accomplishments. As such, narratives are both personal as well as they are social and cultural (Riessman 1993; Smith 2007). In relation to this study narrative analysis thus gives us the opportunity to learn not only about the people who live with their disabilities but also about society at large. As pointed out by Smith and Sparkes (2008) – studying individual narratives told by persons with disabilities not only increases the understanding of the world of disability from within, it also reveals aspects about the larger socio-cultural life, especially about its norms and conventions.

Narrative Identity

Bruner (2001) argues that the idea of one's self is closely entwined with autobiographical narrative – meaning that we cannot understand the notion of "a self" if we do not also understand that identities are constructed through ongoing narratives (i.e. that they are discursive localizations of the self in time, Medved & Brockmeier 2008:470). Hence, we become who we are by telling about it (and through how others tell about us) and thus the study of narrative is not just another "sub-discipline" among others that is somewhat more helpful in our efforts to study human identity. Rather:

[t]here is a deeper, philosophical point about the relation between narrative and identity [...] that the very idea of human identity – perhaps we can even say, the very possibility of human identity – is tied to the very notion of narrative and narrativity. (Brockmeier and Carbaugh 2001:15)

Smith (2007) duly notes that not all researchers would agree on the claim that humans are essentially storytelling animals (MacIntyre 1981) and hence he would probably also note that not all researchers would agree on the idea that human identity is so crucially connected to our ability to tell stories. However, if we agree on the idea that our social world is a co-created construct it at least seems possible that telling stories to one another is one way to construct such a social world. And based upon what my own research has shown me, I would say that I am more inclined to agree with those researchers who argue that narratives are important because:

[i]llness [disability] has meaning, and narrative is the language of meaning. (Medved & Brockmeier 2008:469)

And that

[n]arrative is a fundamental human way of giving meaning to experience. (Garro & Mattingly 2000:1)

Hence, we need to study narratives because to be able to tell (and to listen to stories) seems to be one of the most powerful tools we have to enable us to share experiences with each other. In fact Somers (1994) has even gone so far as to say that narratives are an ontological condition of life in that we, as social beings, live storied lives (Smith & Sparkes 2008). Researchers Medved and Brockmeier (2008) argue along the same line, stating that autobiographical narratives are the way to actively try to give meaning to the world. Hence, narratives become one of the most powerful tools we have to negotiate and establish a commonly shared social world. That means that it is also one of the greatest tools we possess when trying to create and/or uphold a sense of identity and personhood in relation to others (Freeman 2006). By telling autobiographical stories we become who we are because it helps us connect with others and reflect upon ourselves (Medved & Brockmeier 2008). Hence, we understand ourselves through the stories we tell and through the stories we feel part of (Smith 2007). Autobiographical narrative is then at least one of the ways, if not the way, by which we can create a sense of identity and personhood (Bruner 2001).

However, if one suffers from acquired brain damage, this "meaning-making tool" could suddenly be out of reach since trauma to the brain almost always affects the cognitive and communicative abilities one needs to be able to

narrate. Narratives may then become 'broken' (Hydén & Brockmeier 2008) because:

[a]n individual suffering from neurotrauma [is not only] confronted with the existential crisis of illness and disability, but also with the crisis of narrative dysfunction. And [...] it is likely that such radical alteration of narrative competence would have profound consequences for a person's experience of his or her self, in fact, for the entire process of identity construction. (Medved & Brockmeier 2008:470)

As a consequence we need to try to see what other ways there might be to experience one's self and to be able to construct a sense of identity if one cannot do so through spoken language. Since identity and personhood, a sense of self, are created in how people try to represent themselves in stories, I find it obvious that also people who live their lives without words try to tell us about such lives. They just do not depend solely on verbal speech to do so.

Voices

As has been argued above, one of the key ideas of interactional theory is that the origin of the self is social and guaranteed through social interaction. Identity and personhood are relational concepts that are created in context with others. In relation to narratives it is thus crucial to remember that it is not only one person who tells a story; there is always (at least) one more person involved in creating a narrative, the one who listens to the story, who asks questions, who nods and says "hmm", who helps push the story forward. Thus "all narratives are, in a fundamental sense, co-constructed" (Salmon & Riessman 2008:80). A focus on stories and storytelling should perhaps then not rely so much upon the individual but rather upon how we together create and establish our socially shared world (Hydén 2001). It also appears that in our everyday communication this joint creation mostly occurs through verbal communication (Adelswärd & Nilholm 2000; Goffman 1959).

Most traditional narrative research has primarily focused upon autobiographical stories and thus upon the verbal voices of those who tell the stories. Spoken words and the actual, physical voice have been in focus when studying the life-worlds of various groups, as compared to the possibility to study different perspectives in stories, i.e. to apply a sense of a metaphorical voice (Bakhtin 1986). Perhaps this is not that strange if we also look at the fact that most narrative research uses interviewing as the most prominent method to bring forward such stories. In addition, as interviewing is an interpersonal situation where (at least) two partners engage in a conversation about a theme of

mutual interest where knowledge is constructed through dialogue (Kvale 1996; Owens 2007), it seems as if to be able to construct such shared knowledge, both researcher and informant must be able to "provide full and sensitive descriptions of the experience under description" (Polkinghorne 1988:47). If we then add to that the fact that most researchers have norms about what constitutes autobiographical life stories (that they are thought to be discursive entities about events experienced by the teller, preferably with a beginning, middle and end, and that they are coherent) it seems inevitable that narratives are mostly produced by people with a high level of articulacy. This is true, especially if we also realize that in narrative research it is often assumed that it is always the informants who are the experts on their own lives and thus unsurpassed in telling their story (Czarniawska 2004).

This idea about what constitutes a narrative is no different when we turn to the many (narrative) studies about people with severe disabilities. As stated above, the disabled "view from within" has been brought out in much narrative research by interviewing people with disabilities. There exists an ambition to be inclusive and to let people with disabilities come to the fore. That has mainly been done by asking people to tell their story, to speak it out loud. Thus, by interviewing, researchers have tried to help people with disabilities to tell their stories and to publish these stories in both scientific and public realms (Atkinson 2004). With regard to people with physical disabilities there is no or little "problem" with this; their means of telling a story has (in most cases) not been affected by their disablement. Their voices can still be heard. However, people who suffer from disabilities or diseases that affect cognitive and communicative abilities (such as brain damage, learning disabilities, Alzheimer's disease etc.) might have their voices "lost". In order to try to be inclusive, researchers have adopted several different techniques so that people who might have difficulties voicing their story can do so anyway. In many studies involving people with communicative disorders there has thus been a great emphasis on methodological issues (see Carlsson et al. 2007 for a thorough review) where the question has been how to "liberate the voices and stories of people who would ordinarily remain silent" (Owens 2007:299). In these studies however, the focus has been on just that, "to liberate voices" and thus it seems, to liberate physical voices. This has been accomplished by helping people with communicative disabilities to do so foremost within an interview situation; here the focus has still been on the act of speaking, of listening to voices that can verbally tell a story. And, even if we can detect that more researchers now tend to highlight how narratives are *performed*, it still seems as though is the spoken words *about* such performance that have been studied (Langellier 2001; Peterson & Langellier 2006).

The excluded voice thesis

If we can conclude then that many narrative researchers have focused upon *spoken* autobiographical stories, and even if they have tried to be inclusive, we find a troublesome fact that many people have been left out of such research – those who cannot speak unimpededly. Booth and Booth (1996) have tried to take measure against this fact and have suggested that (narrative) researchers need to put more emphasis on overcoming the idea that inarticulate people have more limitations as informants than able-speaking people have. Booth and Booth draw on what has been called "the excluded voice thesis", a thesis that:

postulates that narrative methods provide access to the perspectives and experience of oppressed groups who lack the power to make their voices heard through traditional modes of academic research. (Booth & Booth 1996:55)

I agree that we as narrative researchers need to do much more in trying to include those who have been left out of academic research because they have been deemed to have too many limitations to function as "good informants" (in narrative research that would seem to mean those whot cannot tell coherent life stories).

I am not sure, however, that the changes that Booth & Booth (1996) and Owens (2007) suggest (that the interview should be adopted to the specific situation, that the researcher needs to be "empathically aware" and offer a lot of conversational support, only ask closed questions, or "loan" words to the informants) are all that helpful. They could probably help us as researchers to be able to understand and also put forward some more stories that otherwise could not have been heard. However, even if we realize that "silence may be as telling as talk [and we] learn to read the spaces between the words" (Booth & Booth 1996:57) it is still in order to try to "liberate the voices and stories of people who would ordinarily remain silent" (Owens 2007:299). The main focus, therefore, is to help people who are inarticulate to *overcome* their inarticulatness, so that we are able to listen to their (verbally told) stories. I believe not only that that would still exclude some people from narrative research because not all people can overcome their inarticulatness and tell verbal stories even if we lend them words, simply because they cannot talk. However, more importantly, it also seems to reduce the agency of people with disabilities. Even if all stories are coconstructed it seems troublesome to state that people with disabilities need our help to even be able to create a story, or that we, able-speaking researchers, should tell the stories for them. Do they not tell stories on their own, from a firsthand perspective? I will return to this discussion in Chapter 5 (Disabled or *Dislabelled*) below. For now though, we might ask if there is no other way to approach this problem of being able to listen to "untold" stories.

Stories

What Booth & Booth (1996) and Owens (2007) seem to imply is that the physical voice is the only (worthy) way of telling stories. Perhaps the voice *could* be perceived as especially important when telling stories because there is always:

a living person, throat, chest, feelings, who sends into the air [a] voice, different from all other voices [...] A voice includes the throat, saliva. When the human voice vibrates, there is someone in flesh and bone who emits it. (Cavarero 2004:4)

Thus, there is an embodied uniqueness to every voice: the voice comes from within the body of one singular person, different from all other persons. It is perhaps not that strange then that the physical voice is seen as *the* tool to use when someone whishes to tell one's own story.

However, Cavarero (2004) also suggest that the physical voice is not the only way to express oneself (and thus one's sense of self). We do not distinguish a person from his/her voice only, we also recognize people's uniquness by their apperances. If a person has lost the ability to speak (due to for example acquired brain damage as the informants of this study) perhaps then, they could tell stories anyway because even if we cannot hear them, we can see them. If we start to look at these different ways to express oneself we could argue that people have other means of telling stories than to use their "throat and saliva". We could perhaps talk about *multiple types* of voices – i.e. instead of focusing only on the physical voice we could also try to implement the thought of voices as metaphorical – that one could still voice one's opinion and perspective on things even if one does not have the physical voice to do so (Bakhtin 1986).

Story-making

Starting as early as the 1960s with Merleau-Ponty's (1962) idea about embodiement as a crucial feature of perception, we have in recent years seen a vastly increased interest in *embodied* and *enacted/performed* stories, stories that are told by using neither throat nor saliva but rather by using the body as a field of expression (e.g. Thornquist 2006; Toombs 1993, 2001a, 2001b).

David Goode (1994) is one researcher who has taken on this interest in embodiment and devoted his research to children born with congenital deafblindness and mental retardation (due to Rubella Syndrome). Goode studied the interaction between these severely disabled children and their surroundings and focused especially on how these children (who are deaf, blind and without any "formal" language) communicated with the people around them. In explaining his own communication with one of these severely disabled children Goode states that:

[t]o treat verbal communication as the basic vehicle for human understanding is to fall victim to what Merleau-Ponty (1962) called "the ruse of language". The lack of a shared normative symbol system [...] between Christina and me, did not transform our communication work together into an entirely different enterprise. We were two people trying to understand one another with the resources we had available. Many of these resources are undoubtedly used in "normal" communication, but because of the "ruse of language", they go unnoticed and unappreciated. (Goode 1994:88-89)

What Goode has so vividly portrayed in his research and which I have accepted as a "scientific truth" regarding people with severe communicative disabilities is that even though these children suffered severe disabilities and lived in a world without words, they certainly did not live in a world without communication. There were many ways in which these severely disabled children could communicate with those close to them, and they used many different "voices" to do so, for example mimicking, jumping and rocking their bodies. But, as he states, it can be hard for us to detect that because we usually fall victim to "the ruse of language".

Also Cheryl Mattingly has contributed greatly to research involving people with severe disabilities (communicative as well as physical). In her research we find convincing claims that even if you lack a physical voice, you are still able to (metaphorically) voice stories because, she argues, stories are not always verbal, rather they can be told through social doings (Mattingly 1994, 1998). Mattingly, who studied occupational therapists and their in-clinic practice with their patients, shows us how the therapists helped the patients to construct stories by engaging them in emplotment; that is, telling stories not by using words but rather by using their bodies and telling the story through social action. By performing clinical action, stories are told without words being uttered. Thus she argues that in this effort at *story-making*, story-like structures are created through interaction: i.e. there is narrative structure in action and experience.

For instance, getting a patient, Steven, (who has just awakened from a coma) to comb his hair is not just an act by the therapist, Donna, to be able to establish the patient's physical strength and possibilities but also an act that brings the patient into a story. By combing his hair, the patient is soon emplotted in a story where physical appearance is important (and it is important because

the patient is supposed to improve from his current disabled status and re-enter a social life where appearance is deemed important). However, Mattingly also states that not just *any* sort of action will do. They must be actions that matter deeply to the patient and which calls to the body: i.e. that by moving one's body, by acting with one's body, one also moves one's very self (Mattingly 2008:94). Thus, her concept of emplotted time (1994, 1998) means that there exists a narrative construction of lived time, i.e. narratives could be created before they are told and that these narratives are crucial in how one perceives and expresses oneself if one cannot do so by speaking.

We also come to understand communication as an interactive process when studying the research of Charles Goodwin. In one of his articles (1995) we are presented with a case analysis of Rob, an aphasic man who communicates with only three words - ves, no and and. What we learn through Goodwin's article is the fact that Rob undeniably communicates with those close to him even though he uses only three words. However, as in any other communication, Robs' does not make sense if his ves, no, and and are not placed in context, where his three words can be connected to what other people say and how they respond to his utterances. Goodwin elaborates further on Rob's (in)ability to communicate and his possibility to narrate about himself in a later article (2004) where Goodwin shows that even if the three words that he is able to utter are crucial to Rob's ability to narrate, his non-verbal communicative resources are just as important. In order for Rob to be able to narrate and tell stories about himself and his life, he needs his communicative partners to be attentive to how he uses his gaze, how he nods, and so on. His non-verbal communicative resources are equally as important, if not more important in Rob's ability to create narratives about himself than his (broken) voice is.

Thus, even if narrative research among people with severe communicative disorders is sparse and the research that has been conducted has mostly focused upon spoken narratives, these three researchers show us that even if one has lost one's voice, or one's voice has become "broken", one does still tell stories, stories that are co-created with the people close to you. And, as I have tried to show in this chapter, that is also how I see narratives; as stories that are told between people. They are however, at least somewhat independent of media. Many stories are most certainly verbal, but not all – they could just as well be embodied and performed – and as such, also people who lack the physical voice to tell a story can do so. Hence, also people with severe communicative disabilities can use stories as a tool for meaning-making.

CHAPTER 3

An Ethnographic Approach

The way that people construct the social activities of their everyday lives is not in satisfaction of scientific versions or theories of phenomena [...] Everyday phenomena are constructed in an orderly way by those who live them, with or without the existence or conduct of professional research [...] everyday human existence is the raw stuff upon which social scientists depend for dissection and measurement. (Goode 1994:49)

As I set out to observe and explore the life-worlds of people with severe brain damage I kept to ethnographic methods as these have been proven to be the best methods to use when studying everyday phenomena. The reason for this is the idea that one should always start from the observations of the everyday lives and activities of the people that one studies. A great fear of mine would namely be to conduct what Goode (ibid:140) has called 'the discovered irony'; that is, to try to say something about everyday life without actually observing it, hence ethnographic methods seem to fit this study best.

The Field

The day centre that I observed is run by the municipality (commissioned by the public health board) and is one out of four centres that fall into the same sector. Depending on the assessment of how severe the brain damage is, and how severe its consequences, the person will be placed accordingly (which should not be mistaken for the fact that participation is voluntary).⁸

I was given the opportunity to participate in the activities at all four of these day centres and spent time at three of them.⁹ I tried to enter the field as "blank" as possible (but not completely void of theoretical assumption as I do

⁸ See prologue about the conditions of the Swedish Disability Act.

⁹ The fourth was a vocational training centre for those who had been rehabilitated enough to be able to go back into the labour market, hence they spent most of their days at different worksites rather than at the centre.

not believe that possible: see *Turning data into results*, below). Thus I spent time observing and gathering field notes from all three of these centres. After my initial period of fieldwork I started to get a better picture of what to study in relation to people with acquired brain damage and meaning-making practices. My focus turned towards issues of communication and interaction where said issues could not function in "typical" ways, and towards how this seemed to have a great impact on meaning-making practices such as identity and personhood creation. I thus decided to focus upon the day centre where the participants had the most problems interacting in "typical" ways, namely The Boost, ¹⁰ which was the centre for those labelled as most severely disabled. Therefore, this dissertation primarily deals with data from this one day centre.

The Boost is a day centre that offers individually adapted activities for the participants. During my time there approximately 20 participants attended, with the time of each one apportioned according to what had been deemed suitable in relation to their disabilities. Attendence thus ranged from between half a day a week to four days a week. The Boost is what is called a "daily activity" and is not considered to be a rehabilitation centre since all who attended have been considered medically incurable. The participants were diagnosed as being beyond hope of improvement from their current medical status. Hence, the focus of the day centre was to offer the participants daily activities (adjusted to their personal needs) in order to maintain and preserve their present functions and skills, rather than improving them.

Seven assistant nurses, one physiotherapist and one occupational therapist worked at The Boost. The assistant nurses worked with the participants on a daily basis, often on a close one-on-one basis (there was a principle, or at least an ideal, that each participant should have his/her "own" nurse for the day). As the participants had many joint activities as well as individual training, the personnel divided the participants into two bigger groups (later on in the fieldwork, there were three groups) where they conducted these joint activities (such as playing games, going out on excursions, eating lunch, having coffee). It was deemed necessary for the participants to be divided into smaller groups (rather than doing everything together as one big group) since several of them had trouble concentrating if surrounded by too much noise/activities. Hence, the personnel worked with the participants on a one-on-one basis but also worked closer together with some of the other staff members and hence also with some of the other participants. As the personnel also shifted participants from week to week on a rotating schedule, seen over a long period of time, all personnel worked with all participants.

¹⁰ All names, of people and places, are fictional.

The two therapists' work schedule looked a bit different; they came in more seldom since they also worked at the other day centres and some additional sheltered houses. Thus, they did not have this close one-on-one contact with the participants. Finally, once a week a man who called himself a "music-communicator" came in and played instruments and sang with some of the participants, both as an exercise and also just for fun.

The participants

The participants ranged from age 28-64 and were of both Swedish and foreign descent. Both men and women attended the day centre. The participants have all been labelled as having severe disabilities due to acquired brain damage. The time-span that they had lived with these damages differed from three to over 20 years. The causes of their damage, and the stories behind them, are as numerous as the participants attending. There are the two young men who both crashed their family's cars (one when he was just a teenager, the other one who drove under the influence of both alcohol and drugs), the middle-aged woman who was in two car crashes (she recovered from the first one), the newlywed man who, on vacation, dove into a rock, the man who was assaulted after a night out and suffered a severe blow to the head, the man who drank too much, the man who used too many drugs and the man who was working on a roof and fell off. Then there are the participants who suffered their brain damage medically, including the doctor who suffered a massive stroke while at work (if she had not been in the hospital when the stroke hit, she would not have survived), another middle-aged woman and one man, who both suffered strokes, the woman who had had a diabetic coma, a man with MS, a woman with MS, a young woman with the hereditary disease Huntington Chorea and finally the anorexic man who starved himself to much, causing a brain seizure.

Thus, the participants had various kinds of brain damage and they all ranged in terms of disabilities. Some were in wheelchairs (self-manoeuvred or manoeuvred by others). Some walked on their own, some with the aid of others and some with the aid of a walking frame on wheels. Some had partial paralysis of the upper and/or lower body, some were quadraplegic, and others were paraplegic. One had severe difficulty controlling her body movements. Verbal disabilities ranged as well, between having no speech at all to speaking almost fluently. Some suffered from explicit aphasia and others had slow or guttural speech patterns (and phonologies).

In spite of the fact that the participants were quite a heterogenic group of people, they were often considered as exactly that, "a group of people" who had one major thing in common – they were all severely disabled due to their

acquired brain damage. However, what *kind* of brain damage they had suffered was never discussed (if the damage had occurred in the right or left cerebral hemisphere, if it was in the cerebellum, the cerebrum or the frontal lobe) probably because the personnel did not have that information. Or, in the rare cases that they did have such information they did not know what to do with it since none of them were educated in the different functions of the brains areas. Hence, the participants were often treated as having the same problems and difficulties, despite the medical diagnosis behind their disabilities. This is also why this dissertation does not consider the medical diagnoses and the underlying causes of the participant's disabilities. I was interested in what happened in the social interaction and how the participants created meaning within that interaction with the personnel and with each other. The medical diagnoses were simply a very small part of that.

I tried to study the participants and the personnel as "broadly" as I could but some (especially among the participants) came to be key informants. How these were chosen I will discuss under the *Interviews* and *Videoethnography* headings below. And, most importantly, what implications these selections might have on the results will be discussed under the *Turning data into results* heading.

Ethical considerations

During this study I have followed the Swedish Research Counsil's ethical principles for research in the humanities and social sciences and the criterion that the individual must not be harmed – a criterion including several rules requiring information, consent, confidentiality and how research data may be used (VR 2002, 2006:83). All persons included in this study have given their informed consent to participate, in all parts of the study (observations, video recordings and interviews).

Initially I started out by going to a staff meeting where I introduced myself and the research I intended to conduct. I would say that some were more enthusiastic than others when they heard that I would "follow them around, quite as a little mouse" (as one assistant nurse expressed it) but they all agreed to participate, and most of them saw it as a great opportunity to learn more about themselves. After the personnel had consented I attended the day centre for a couple of days, introducing myself to the participants to see if they would approve of the study. I explained what I intended to do and what my role would be (that I was not another assistant nurse but a researcher there to observe them in their daily life). All of the participants gave me their consent as well.

However, in some cases it was uncertain if that consent was truly "informed", i.e. that they understood what I intended to do, that they could say no and that they could withdraw from the study at any given point if they wished to. Some of the participants suffered from cognitive disabilities due to the brain damage and some suffered an impaired short-term memory, resulting in the fact that I had to tell them many times over throughout the entire field study who I was and why I was there. Then there was the fact that I did not understand some of the participants' ways of communicating this early on in the study; I could have misinterpreted their wishes. As such, I also asked each participant's legal guardian (in Swedish *God Man*) for consent, and all agreed to the study.

Trying to be ever so clear about the study did not stop incidents from happening. Once I was filming the group doing physiotherapy together and the camera was put out of the way in one corner of the room. One of the participants suddenlty came up to me, and angrily asked why I, a journalist from the Swedish newspaper *Expressen*, was there filming them. He certainly did not what to be filmed by a journalist he did not know, whose precence he had not approved. I tried to explain who I was but it did not work. He grew more and more angry and also a bit afraid. In the end the personnel succeeded in explaining to him who I was and why I was there and he calmed down. I put away the camera for the rest of that day and talked more to him the next day, again explaining who I was and why I was there, something he now had no trouble understanding and he had no problem with me wanting to use the camera. (This episode could easily be compared with that of researchers Paterson & Scott-Findlay, 2002, who had an informant consent to doing interviews but later on forgot that and thought that the interviewer was from the government.)

This episode made me very dubious about whether I could continue filming or not since the last thing I wanted to do was to upset the participants. Even though they all had consented initially I could not be sure from day to day that they actually understood who I was and what they had consented to. However, I decided to continue to use the camera for two reasons. (1) It had proved invaluable in being able to conduct my research. If I wanted to study the narrations of people with severe communication disorders I had gained the insight that I needed to study embodied and enacted/performed narratives rather than only focusing on what was spoken and observations alone would not work, I needed to be able to go back to the data over and over again in order to do that. (2) I also decided to keep the camera to help the participants remember who I was (even if that might sound strange in relation to the episode above). However, the camera did make my role as a researcher more clear (see under the Videoethnography heading, below) and this I deemed especially important in order to avoid the participants becoming emotionally dependent on me (Örulv 2008).

As an ethnographer, one's roles are often very shifting (again, see Videoethnography, below) and in one case, one of my key informants actually fell in love with me. After that I wanted to make it even clearer why I was there, as a researcher. I deemed that the camera would help me do that. (Even though in this case that did not help; he suffered no cognitive disabilities and knew exactly why I was there, he was enamoured anyway.) I tried to set up more "boundaries" (as Malinowski, 2000, would have pleaded for in order to keep "a scientific ideal") but at the same time I do not believe that one should try to stand too far apart from one's informants. Even more so in research involving people with communicative disabilities; being social and personal could in fact help to do justice to a person with communicative disabilities (Öruly 2008:47). The longer I stayed at the day centre and the more I got to know my informants, the more we were able to communicate with each other, as increased familiarity allowed me to learn their different ways of communicating. Being personal helped me communicate with my informants in ways that would have been impossible otherwise. However, choosing informants and building personal relationships with them requires a great deal of consideration from both moral and political aspects (for a great read on this subject, see Sanjek 1993). Throughout the fieldwork this was something that I continuously dwelled upon and in every decision I made (as in keeping the camera) I always tried to consider the interests of my informants first.

Gathering of Data

In 2004 I set out to gather my data. I thought it would take me approximately six months to gather it. In the end I ended up working at it for one year because it proved necessary to adopt several different methods of data gathering.

Participant observations

As stated above, I place myself in the field of studying communication disorders and I enter that field from the same angle as Hymes (1964) and Kovarsky & Crago (1990-1991), i.e. that language (or the loss of language) must be studied in relation to the group or society who uses it and that it cannot be separated from the people who speak, or do not speak. The study must therefore take place *in context*, by using ethnographic methods. Thus I entered this study as a communicative ethnographer.

By employing participant observations I got to know the field, and let the field get to know me not only as a "professional stranger" (Agar 1996) who just

"was around" but rather as someone who participated in their activities in order to understand them better. In doing so, I was accepted into the group, and that allowed me to detect patterns and structures within the day centre that I could later on study in detail. To be a *participant* observer would prove to be most necessary – if I had not taken the time to participate in the daily activities, the game-playing, the excursions and the coffees I would not have gained their trust, and without their trust I would not have been able to follow them more closely and detect the stories that they told, in their own ways. And, as the assistant nurses worked on a close one-on-one basis with the participants, I would have been quite out of place if I had tried to position myself as a bystander.

I started out by conducting participant observations and writing field notes for about six months. After that, I also decided to try to conduct in-depth informal interviews and to record my observations with a video camera (while at the same time continuing on with the participant observations and writing of field notes). In all, I spent one year gathering my data at this day centre for people with acquired brain damage.

Interviews

Even though I study people with severe communication disorders I also chose to try to conduct informal in-depth interviews. The reason for this is that during the first six months of my fieldwork, I had gotten to know some of the participants quite well. My observations had provided glimpses of phenomena that I wished to both study further (by engaging in more observations) and also wished to talk to the participants directly about. I wanted to get *their* views and perspectives on these phenomena. For example, I wanted to know their views on being dependent upon other people and their views on having difficulties talking to other people. That, however, does not mean that the interview is some sort of technique where one can coax thoughts and ideas from the interviewees as long as one asks the right questions. We must keep in mind that:

[r]espondents are not so much repositories of knowledge – treasuries of information awaiting excavation – as they are constructors of knowledge in association with interviewers. Interviews are collaborative accomplishments. (Holstein & Gubrium 2004:141)

Hence, there is no "pipeline" that can transport knowledge between interviewee and interviewer as all interviews are interactional and co-constructed (collaborative) events (Mishler 1986; Riessman 2008; Salmon & Riessman 2008:80). And as such, information cannot just be given from one individual to another; there is always an interpretation going on in the space between us.

Interviews were then conducted in order to get a deeper understanding of the individuals own perception of the perceived life-world. I conducted these in the last two months of the fieldwork mainly for two reasons; (a) everyone was accustomed to having me around and we had gotten to know each other quite well and (b) it was the findings that had occurred to me during my now quite long observation that I wished to elaborate on.

All staff members were asked to participate in the interviews, although two felt uncomfortable with the exposure of their being singled out in an interview situation (even if they of course were guaranteed anonymity) and did not want to participate. This resulted in my interviewing seven members of the staff. Regarding the participants another form of selection was needed. Six persons were asked to participate, based simply upon the fact that they had speech abilities that I as a researcher had learnt to understand. One said no, based on the same argument as the two assistant nurses, he did not want to be singled out (being observed and filmed within the joint activities was, however, no problem for either the participant or the assistant nurses). Out of the five participants that were interviewed, three communicated verbally (more or less) and the other two communicated both verbally and through a Lightwriter (a communicative augmentation aid). Other participants were considered but decided against based primarily on two facts: (1) as a researcher I had not learned their speech patterns and phonologies well enough and hence did not understand them when they spoke (nor could they communicate by writing), and (2) some simply did not speak at all, making it very hard to conduct an interview with them (since they could not communicate by writing either).

The interviews were based on open-ended questions and in several cases took on the format of an informal conversation rather than an interview (Briggs 1986). In interviewing the personnel I used a tape recorder while in interviewing the participants I used a video camera to document the interview (since much of the communication and interaction between us would be dependent upon bodily actions rather than just words).

Videoethnography

I also decided to collect data with video recordings for three reasons: (1) a great deal of what I set out to observe and explore (i.e. meaning-making practices in relation to people with severe communicative disabilities) takes place in nonverbal communication. So much happens at once in communicative events (whether they are verbal or not). There is body language, mimicking, facial gestures, the flick of a hand, the blink of an eye – and any of these can easily be missed. All of these expressive dimensions of a gesticulating body are

fundamental to human interaction and hence to communication (Kontos 2004:840). It could be hard to capture all this richness of expression by relying on observation alone. Hence, there is a sense of security in being able to return, and refer, to recorded data.

(2), video data was also a great advantage while preparing for my interviews with the participants. As Goode (1994) writes, by having the possibility to look at the same sequences over and over again, one can learn to detect logical communication patterns that at first sight (or first "hearing") are hard to detect. Hence, I greatly benefited from the possibility to return to my recorded data, learning to detect patterns and structures in speech patterns (and phonologies) that to me often seemed very different and hard to grasp.

That, however, did not mean that the interviews ran smoothly, quite the opposite. Often we would create the meaning together through quite a hard struggle, with me taking a large part of the communicative act. But, and this is an important but, when I was able to return to the videotaped interviews I hardly had any trouble understanding the participants. The so obvious struggle of understanding, and the very long process of joint creation of meaning in the conversation that I saw before me, seemed so unnecessary. It is important to stress this fact, that this struggle that I saw before me (which was extremely frustrating now that I so clearly understood what they were saying) clearly affected what data I was able to gather. My role, as a speaking researcher who did not understand these unfamiliar speech patterns and phonologies created a very specific context. The analysis of my gathered data cannot be understood outside the frames of this context.

And finally and most importantly (3), when studying the life-worlds of people with communicative disorders and trying to listen to their narratives it could be blatantly wrong not to listen to their embodied and enacted/performed stories. To use only methods like interviewing could then exclude not only important aspects of a person with communicative disorder actual communicative abilities (such as body movements, gestures, facial expressions), but also entire narratives that they do tell.

All in all, I collected about 70 hours of video data, covering all aspects of the day centre (except toilet visits). Filming was not random; focus was on one participant at a time (I followed five participants more closely). However, all participants were filmed since they had many joint activities. The five that were followed more closely somewhat overlapped the participants that I interviewed but not entirely; three of those that I filmed more closely were also interviewed. The other two were filmed because I wanted to increase the filmed sample in order to study the non-verbal ways of interacting and communicating and these two participants seemed to enjoy being singled out. Others were asked but did not want to be filmed if it was not part of a joint activity.

I have analysed the videodata that has been used and presented in the individual papers by focusing on certain salient aspects. First, the interplay between verbal and non-verbal communication in terms of both non-verbal communication supporting verbal communication, but also how non-verbal communication can take the place of verbal resources. And second, the use of gestures and body movements was emphasized in order to see how the participants acted within a social (and material) context that they could envoke in order to make their (methaphorical) voice heard (Goodwin 2004).

As I was the one who operated the camera, and hence also observed the action that was filmed, I wrote notes on what every tape contained as I was filming it. These notes were then used as a guide, which made the tapes more analytically useful and available, as I knew where to look for certain actions/happenings (Goode 1994:150ff.). By looking at certain episodes and scrutinizing every movement that was made on tape (and by comparing it with field notes) I was able to detect structures/patterns in bodily action – patterns that could be interpreted as parts of narrative structure (Mattingly 1994). Hence, what otherwise could be thought of as random could be shown to have a meaningful pattern (Salmon & Riessman 2008). Consequently, the recorded video data became the basis for display of what was judged important everyday happenings in relation to the study of meaning-making practices among people with severe communicative disorders, as the videotapes allowed me to capture "perspicuous happenings" related to the research object (Goode 1994:153).

While I have benefited from these video recordings one should not forget that there are also disadvantages in using a camera (or tape recorder). Sometimes it created a distance between me and the people at the day centre, 11 positioning me as a bystander, someone who was not really a part of the everyday life (which up until I introduced the camera I had become quite successfully). However, sometimes my role at the day centre was quite ambiguous (being positioned as "the young woman", "a quiet little mouse who sneaks around and looks at us", "a staff member" and so on) and using the video camera helped me dissociate myself from the personnel (who quite often "used" me as a helping hand when being short-staffed), making my role as a researcher more clear. I do not believe that that was all negative.

¹¹ Something that has become even more apparent to me after finishing my own study but having a colleague who observes a completely different setting, one in which a friend of mine is one of the observed. One day my friend told me: "You know, your colleague, when he places the microphone in front of us, we all stop talking..."

Lost in translation?

There are two primary aspects that need to be addressed regarding translation and these aspects differ greatly. First there is the need to consider what I just wrote above, that there is always a translation going on between the syntactic and the semantic elements of things; the researcher always interprets the data before generating an analysis. This, however, I will deal with under the next heading, *Turning data into results*. Now I wish to discuss what one must be very subtle with when data gathered in a Swedish setting, in the Swedish language, are presented in English.

I collected my data in a Swedish setting, where all participants who were able to speak spoke in Swedish (except one who used to speak Swedish but lost that ability after his brain damage and had gone back to speaking his native language. He now had a personal assistant with him at all times who also "doubled" as his translator). However, I have wished to publish my findings in English, to reach a wider audience. In Papers I, II and III, I use a great deal of my audiovisual data, both the video-recorded and the tape-recorded, in order to illustrate my findings (a small sample is also used in Paper IV). Close analyses of excerpts are used to present and bring the arguments forward and due to lack of space only the English translations have been presented. I have, however, tried to stay as close as possible to the original transcripts when presenting the data and have tried to preserve the flow of language by replacing Swedish idiomatic expressions with similar expressions in English. As much as possible, I have tried to maintain the meaning of the Swedish emphasis (Öruly 2008:41). However, language is an important part of conceptualisation and carries different cultural and social meanings that cannot be ignored so easily. What is being expressed in Swedish and in this particular social reality may not have a conceptual equivalence in English, which I have chosen to translate it into (Bassnet 1994; Temple & Edwards 2002). The same words can mean different things. Hence, the words we choose matter (Temple & Edwards 2002).

We should be aware of the difficulties that are presented to us when we translate our data. However, we should perhaps not be overly concerned about it, at least not to such a degree that we stop translating our findings. In fact, there is also the possibility that when we translate we learn something from the translation itself – about what can and cannot be said. What seems crucial is rather that one does not try to hide the fact that the data has been translated. And perhaps most importantly, that when working with translated data the analysis should always be made in the original language. Hence, in order to be as "true" to the data as possible I have conducted all analyses using the original data and the Swedish transcripts; translation into English came last.

Turning Data into Results

As explained above I lean towards a conceptual base of social interactionism, meaning that I find it crucial to point out that both my informants and I, the researcher, created the meaning together. Fact is that data cannot, and should not, be treated independently from the ethnographer who collected them:

if substance ('data', 'findings', 'facts') are products of the method used, substance cannot be considered independently of method: what the ethnographer finds out is inherently connected with how she finds it out. As a result, these methods should not be ignored. Rather, they should comprise an important part of written field notes. It thus becomes critical for the ethnographer to document her own activities, circumstances, and emotional responses as these factors shape the process of observing and recording others' lives. (Emerson, Fretz & Shaw 1998:11)

To separate what we as researchers do, say and feel from what those we study do, may result in the fact that we treat the data as "objective information". We might then see our data as having a fixed meaning independent of how these data were gathered and I do not believe that is the case. After all I, the researcher *interpret* the data that I gather. The goal then is not to gather objective, social truths which exist external to the self (since nothing as such exists). Rather, the quest is to interpret human behaviour and experience from the "actor's" point of view (Kovarsky & Crago 1990-1991), and to be able to describe these experiences as "thick" as possible.

According to Geertz (1973), "thick description" means that descriptions of a field should be rich in details and in contexts. Here I may falter a little since my descriptions are mostly of microsituations and not of the entire field. What is more important, though, in Geertz's idea about thick description is that not only should the ethnography be rich in details and contexts but also in *meaning* and *interpretation*. Just reporting back what was observed is not enough. Thus, getting stuck in the empiric data would do no good. As researchers we need to go beyond what we see and what we hear and try to *conceptualize* it. Thus, also the descriptions of microsituations could be thick as long as the ethnography is rich in meaning and interpretation. As Geertz states (when discussing how to interpret the rapid contractions of eyelids – now if that is not a microsituation, then what is?):

the point is that between [...] "thin description" of what the rehearser is doing ("rapidly contracting his right eyelids") and the "thick description" of what he is doing ("practicing a burlesque of a friend faking a wink to deceive an innocent into thinking a conspiracy is in motion") lies the object of ethnography: a stratified hierarchy of meaningful structures in terms of which

twitches, winks, fake-winks, parodies, rehearsals of parodies are produced, perceived, and interpreted, and without which they would not [...] in fact exist, no matter what anyone did or didn't do with his eyelids. (Geertz 1973:7, my emphasis)

In other words, an ethnographic approach could be framed as a study of the microscopic, as long as it is rich in meaning and interpretation, interpretations that include *a stratified hierarchy of meaningful structures*, i.e. that the microscopic is something *more* than just that, microscopic. The study of the microscopic does not mean that we cannot make larger generalizations. Again, as Geertz states:

[t]his is not to say that there are no large-scale anthropological interpretations [...] It is merely to say that the anthropologist characteristically approaches such broader interpretations and more abstract analyses from the direction of exceedingly extended quantities with extremely small matter. (ibid:21)

Thus, also the analyses of microsituations (the "small matters") could tell us something about society at large (further discussed in Chaper 5, under the *Normality and grand narratives* heading) by connecting them to broader interpretations and abstract analysis.

Further, a focus on the researcher's interpretation of the data also means that the results one is able to put forward are clearly dependent on one's own role as a researcher. Since I, the researcher, am part of the social interaction where the meaning is created I cannot be left out of the equation. That, however, does not mean that I should be the centre of my own research. As a great inspiration of mine, Cathy Riessman, said at a seminar we both attended: "We should write personally without being confessional". The focus should always be upon the persons we study. It does, however, require an attentiveness to issues such as for instance the fact that I, the researcher, am a healthy, ablespeaking, highly educated, married, working young woman in the midst of life, researching people who suffer from incurable impairments and:

[i]n this respect, the [research]context is not a neutral locus [...] beliefs are ideological in that they are sustained within a wider social discourse that shapes just not how individuals think, but how they feel they *ought* to think. The sick are encouraged by the healthy to redefine their misfortune in positive ways, thus avoiding embarrassment (for the healthy), while resulting in the sick being accorded attributes such as 'strength of character' [...] [Hence] the tacit grounds of exchange [between ill and healthy] become the basis of the speaker's concern to justify his or her position or to articulate a role that is congruent with that believed to be held by so-called normal or healthy others. (Radley & Billing 1996:226-228, my emphasis)

This means that the stories I was told during the interviews as well as what people disclosed to me during the entire fieldwork (or the stories that the persons with disabilities told with the personnel) most possibly are affected by the fact that some of us were (physically) healthy and able-speaking while others were not. If the participants were to tell their stories to someone else, the stories would probably be told differently. (However, since that is always the case in interviews and storytelling, as these are *joint* activities created in context, this should perhaps not be that surprising, just as the fact that the embodied stories that were told would perhaps be different if told in another setting.) It is, however, important to have the non-neutrality in mind as this is at least one (recognizable) factor that probably will affect what stories are told.

The analysis of this dissertation is empirically driven, i.e. I take as my starting point the observations of the people I study. However, I am not a grounded theorist as I focus more upon analyzing qualitative data than developing such. I did not enter the field "blank" and without theoretical assumptions (I do not believe that that is even possible...). As mentioned above I lean towards a conceptual base of social interactionism and the idea that narratives are one important way to create meaning in social interactions. I entered the field with that in mind. I did try to have an open mind, though, and always let the daily life of the day centre be in focus. I did not try to seek out specific contexts, situations or stories – I analyzed those that were "just there". However, I have not analyzed them all. The papers that are based primarily upon my ethnographic data (Papers I, II and III) are based on narratives and/or situations that I found especially interesting. Other situations and other stories have been left out and some participants/personnel came to be more prominent (i.e. to be key informants). How did I choose which situations/narratives to analyze? And what implications could be derived from the fact that some persons stand out more than others?

Well, first and foremost I have tried to bring forward the voices and stories (be they verbal or embodied/enacted) of my informants. That means that I have excluded data where little or no storytelling is going on. I have for instance numerous episodes on tape where the participant sits alone in front of a computer, silently playing video games, or sits at a handloom, working under silence. But still, there are many situations and stories left to study that were not analyzed; how did I choose which ones to indulge in?

As I write in Paper I for instance, I did not set out to study a preference for speaking but the longer I conducted my field study the more I realized that this preference played a major part in the social interactions at the day centre. I then became more and more attentive to this particular phenomenon and started categorizing the data, looking for patterns and structures within *all* my data (the field notes, the video recordings, and the interviews). By analyzing a few

excerpts I hoped to illustrate this phenomenon on a micro-level but then also try to connect such a micro-approach to grander social theories. Even though I present only a few (micro-)situations and analyze them, there are others that could have been chosen. The situations that I have chosen to present do not differ much from the rest of my data. On the contrary, I have chosen them because they display the everyday situation at the day centre very vividly. Perhaps they are more expressive than other situations but nonetheless, they depict the "ordinary" everyday life at the day centre.

As to what situations/phenomena I deemed interesting enough to go into this deeper analysis I can only say that with such a long time in the field, some phenomena came to stand out. Paper II, for example, was almost impossible *not* to write since that particular struggle (to be able to go out for a smoke) occurred every single day that Peter (the participant around whom the article revolves) attended the day centre. In fact, there was a similar struggle between another participant, Charles, and the personnel – Charles had to negotiate with the personnel every time he wanted to go to the toilet. However, in order to portray the phenomenon that Paper II revolves around (joint verbal storytelling, as well as the embodied telling of counter-narratives) I deemed it necessary to go into a very detailed description of one long excerpt. Thus Peter's struggle to be able to smoke was "singled out" and therefore also gets to represent Charles' wishes to go to the toilet when he wants to, not when the personnel deems appropriate.

Papers I, II and III are all based upon this way of generating analysis. Paper IV, however, is a bit different. Paper IV could be seen as more of a reflection made afterwards. After spending one year in the field, after trying to make sense of very different ways of telling stories, after using several different methods in order to try to *get* to those stories in the first place and after reading shelf after shelf about disability, narrative theory, narrative method and so on, Paper IV came about as a reaction towards my own experiences. When dealing with communicative disability studies and narratives, some important problems have been neglected in earlier research and this neglect has had serious implications in understanding the life-worlds of those labelled as having severe communicative disabilities.

Secondly, my wish to put forward the voices and stories of the informants has resulted in some persons being pushed more to the fore than others (as to why some were chosen and not others, see *Interviews* and *Videoethnography* headings, above). It thus becomes important to realize that the people we see and hear in this dissertation all have different backgrounds for the stories they tell. When studying narratives (and life stories) it also becomes important to realize that these persons are in different stages of their lives. Some were very young when they were injured, some were in mid-life and had already started their own families, some still lived with their families, some had divorced and

now lived in sheltered housing, some lived in their own apartments, some had lived with the brain damage for over 20 years and some for as little as three or four years. Where in life one is now, and where in life one was when the brain damage occurred probably affects what stories one tells and how these stories are connected to issues of identity and personhood. Because, it seems that:

[m]ost of us [...] operate with a definite 'social clock' which guides our expectations of events within the biographical context. [...] [Hence] *timing* and *context, norms* and *expectations*, alongside our *commitment* to events, anticipated or otherwise, are crucial to the experience of our lives, healthy or sick, and the meaning with which we endow it. (Williams 2000:51-51, emphasis in original)

That is, where and when in life a biographical disruption (cf. Bury 1982) such as acquired brain damage occurs (damage that results in incurable impairments and lifelong disability) will most probably affect what (life) stories are told. It is crucial to keep this in mind but that is not to say that these stories that I have heard (and seen) cannot be thought of as "more" than individual stories. They are most definitely coloured by the individual telling them, from their own, unique perspective but they are also told as joint stories, in context with others (able as well as disabled). As such we can try to understand and research those stories in order to comprehend how they come to affect meaning-making practices such as identity and personhood creation in relation to severe disability.

CHAPTER 4

Summary of Articles

It has been said: The whole is more than the sum of its parts. It is more correct to say that the whole is something else than the sum of its parts, because summing up is a meaningless procedure, whereas the whole-part relationship is meaningful. (Koffka 1963:176)

In a summary like this, one is only supposed to present the separate papers (from Part II) one by one. No attempt of pulling them together is to be conducted here. Instead, it is in the next chapter, *Disabled or Perhaps Dislabelled?*, I will attempt to pull all the parts together, the separate papers as well as the synthesis and try to create a whole that is perhaps not more than its parts, but at least something different than the sum of its parts.

Paper I: "Would you like to use one of these or would you rather be able to talk"? – facilitated and/or augmentative communication and the preference for speaking.

In this article, the concepts of identity and personhood in relation to people with severe communicative disabilities are discussed in relation to the usage of spoken language. Based on several forms of data (interviews, written field notes and video excerpts) I presented the idea that there are (at least) three main strategies in the communication between able-speaking and impaired-speaking. These include (1) perfunctory strategies, (2) jigsaw puzzle strategies, and (3) conjectural strategies. All three strategies being based on the act of speaking with one's physical voice. Strategy (1), perfunctory strategies, indicates that what the impaired-speaking person *actually* says is not always deemed as important to understand. Instead, their speech often worked as a signal into cut-and-dried responses. In other words, the able-speaking persons had learned what the impaired-speaking person *usually* said in a situation like this, and replied and acted according to that. Strategy (2), jigsaw puzzle strategies, refers to the situations where able-speaking and impaired-speaking together create a conversation that is meaningful, by hooking into one another's speech. This

strategy requires time, a lot of time, and patience in order to work and hinges a great deal upon the ability of the able-speaking to understand the impaired-speaking person's speech pattern and phonologies (a great deal of this is done by guessing). Strategy (3) conjectural strategies, is similar to the second strategy in that this strategy is also based on guessing. But where the guessing in strategy 2 is always connected to what was said, in this strategy guessing is "wild" and not connected to the impaired-speaking person at all. Instead the able-speaking person tries to tell the story *for* the impaired-speaking person.

By analyzing the data and finding these three strategies, I also found what seems to be a strong preference for speaking with one's own physical voice. The article discusses the issue that there seems to exist an ideology of spoken language and that such an ideology has very practical implications in everyday life because it shows that to be able to speak is to be able to remain yourself. By discussing (Western) ideologies of language I relate this detected preference for speaking to issues of identity and personhood creation. This preference for speaking with one's own, physical voice becomes very intelligible when we understand that to speak with one's own voice is to be able to maintain a sense of self; your voice is your personhood. If you cannot remain yourself without speaking, that is what you will try to do, even though your speech pattern might be severely impaired. Thus, impaired-speaking persons will probably do almost anything in order to (try to) speak with their own vocal voices because this seems to imply that they can maintain their sense of personhood.

This preference for speaking (which seems to hinge upon Western notions of voice as crucial to personhood) results in practical implications on at least three different levels. First, the ideology of spoken language seems to result in the fact that impaired-speaking persons do not wish to use facilitated and/or augmentative communication. When people who are impaired-speaking wish to rely (solely) on spoken language in order to keep their sense of personhood, this might in the end mean that they lose the ability to affect the perception of who they are because the communicative able-speaking partner does not understand them and no or little meaning-making can occur with the framework of the situation. In other words it often leads to "broken" meaning making and as such, their identity appear to crumble since this is something created in interaction with others.

Secondly, there are practical implications for the health-care personnel. In order for impaired-speaking persons to be able to be self-determined, it is crucial that the personnel acts as competent communication partners, who understand, respect and support the impaired-speaking persons. In other words, they need to be very competent and attentive to the communicative attempts of the impaired-speaking person.

Finally, this discovery of an ideology of spoken language has practical implications for narrative research. It makes it crucial to attend to embodied and enacted/performed narratives since that might be the only way for an impaired-speaking person to (metaphorically) voice a (counter-)narrative of what it might mean to be severely disabled.

Paper II: Whose body is it anyway? Verbalization, embodiment, and the creation of narratives.

This article discusses the issue of co-created narratives between people with severe disabilities and the people working with them. By proceeding from the fact that people with severe disabilities are active decision makers rather than recipients of care I argue (as in Paper I) that the personnel working with people with severe disabilities need to be communicative partners who respect and support the individual autonomy and competence of the person with disabilities. However, as the personnel working with these severely disabled people are often referred to as carers, there seems to exist a complexity between the personnel and the persons with disabilities – a complexity about who has the power to decide what the disabled body can or cannot do.

By starting with a brief excerpt from an interview with Peter, a young man who is labelled as severely disabled (mostly physically but also verbally), the article takes a stand from Peter's expressed frustration of being dependent on other people. This frustration promted me to look for other ways that Peter expressed himself in than "just" being dependent. By analyzing a videorecorded situation (a lunch episode that spans 68 minutes) I show how the complexity of who has the power to decide what a disabled body can or cannot do, is expressed in the communicative practices at the day centre and in the creation of narratives. By focusing on the fact that narratives are co-constructed it is shown how a "disability identity" is created between the personnel and the persons with disabilities; it is an identity that relies upon the people with disabilities as dependent upon others (this narrative is called *the story of dependence*).

However, a major concern of the article is to show that the usual focus upon verbal narratives could be troublesome in relation to people with communicative disabilities in that it might lead to the fact that we miss other stories, stories that are not primarily verbal but rather embodied and enacted/performed. By also studying these embodied narratives I show how there is another narrative (a counter-narrative) told by the person with disabilities – *the story of autonomy*. By analyzing the video excerpt in great detail I am able to show how the verbal narrative of dependence is rejected and challenged. This only becomes clear, however, when we recognize three central

claims: (1) there is a connection between where the physical body of the person with disabilities is positioned in space and what he/she is allowed to do; (2) since the body is a communicative tool, the moving of the body could be interpreted as a narrative; and (3) the embodied story can challenge existing social structures. In focusing on *how* narratives could be told (embodied and enacted/performed just as well as being verbal) I show that the all-embracing "disability-identity" (as being dependent and hence also not being viewed as competent interactor) could be questioned and a counter-narrative could be told by the person with the disabilities – a counter-narrative opposing the social structure that leaves the power of control in the hands of the personnel.

Paper III: The meaning of the present: Hope and foreclosure in narrations about people with severe brain damage.

This article addresses the issue of hope in relation to people with severe disabilities. The participants that I followed were diagnosed as incurable and that seemed to become a major part of whom they were perceived to be. Their identity was seen as closely connected to the fact that they would never improve from their current impaired status. By analyzing and presenting excerpts from all the interviews conducted with the nursing staff, as well as some interviews conducted with the participants, the paper raises the issue of who the participant is and who he/she *will* be, in the eyes of the carers.

By focusing on the fact that disability as a consequence of trauma is considered to be a major disruptive life event and that such trauma needs to be addressed in a person's narrative about whom one is (something that Papers I and II also concentrate upon), it could be concluded that new narratives must be told, narratives that comprehend the experience of being disabled. One must reclaim the new, impaired body and tell about it in one's new life story. By relating this idea to the fact that it is considered the nursing staff's job to help the participants achieve such reclamation, it also seems to become the nursing staff's job to help the participant create a new sense of self. It has also been shown that in the creation of such new identities, nursing staff, in order to provide "good" care, needs to instil hope in the narratives.

By turning to an analysis of the phenomenon of hope, the article reveals that when it comes to people with severe disabilities, people who are perceived as incurable, hope needs to be redefined, because the notion of hope, in relation to illness, is strongly connected to the idea of being cured. There seems to exist a distinct correlation between time and hope, i.e. it is through hope that we are able to perceive different possibilities and hence look forward. The future holds the unknown and hence a possible recovery or cure. And, as hope is generally directed towards the future it refers to both temporality and *action* – what

happens in the present creates a sense of meaning because action taken in the present can bring about change in the future. Thus, hope could be seen as an opening of time; the future is like a distant horizon with impressionable possibilities. And one of the most powerful ways to create such a future is to tell narratives about it.

By showing that there is a cultural mandate for the nursing staff to instil hope in the participants the paper reveals a dilemma, a dilemma that the nursing staff face in their daily work. How do you incorporate a perception of the person with disabilities as incurable (i.e. there is no hope of *any* recovery) with the fact that they need to be motivated to keep on training in order to prevent deterioration? In other words, how could a sense of narrative foreclosure be related to issues of hope? Because, even though time is "fixed" and the narratives seem foreclosed, there is still the sense that hope is crucial. But also that such hope is to be given *to* the participants because they are perceived as "immobile" in the sense that they would never have the strength to take their own action and commit to this lifelong training that is necessary in order not to deteriorate from their present status.

By turning to the term "therapeutic emplotment" I am able to show that even though the narratives told about people with severe disabilities are foreclosed, they do not lack hope. There is no larger "unfolding" life story but there is a story where the plot implements the present. Thus it is still with the possibility of action that hope can be created because action taken in the present can allow for no negative change in the future. Even if the participants can never improve from their current status, they can at least avoid deterioration. By invoking hope into the present, the nursing staff is able to help the participants create a new sense of self. It is not a sense of self that will improve, but at least a sense of self that will not deteriorate. This is crucial because it seems that even if the narratives about the persons with disabilities are fixed and foreclosed there is still an urgent matter of getting the participants to understand the value of action. Even if they can never improve and thus "return to normalcy" it is not acceptable to give up on such an idea. Helping the participants to create narratives that imply the need to take action in the present thus becomes a meaning-making practice as it allows for the participants to at least strive towards "normalcy", something apparently deemed necessary.

Paper IV: Communicative disability and narrative.

This article shows that not being able to tell stories (due to communicative disorders) makes it hard to engage in social interaction with others since telling and listening to stories is an important tool for enabling establishment of a commonly shared world and a sense of identity. To be able to tell stories is thus

to be able to create a sense of meaning. If one then looks at the traditional idea of narrative (with a structured set of organized events, with a distinct beginning, middle and end that is told, verbally, by one storyteller) it seems as if people with severe communicative disabilities should have extreme difficulties telling stories or in fact not be able to tell stories at all. That is, however, not the case and I argue therefore that it is necessary to redefine what is meant by narrative. Most importantly it becomes crucial to learn how to identify stories that may not fit in with conventional expectations of what a narrative is, or how it is told.

Stories are deemed important not only because they are one of our greatest tools to create a sense of self and meaning in our everyday lives (something that all the papers concentrate on) but also because they are perceived to give the "view from within". By listening to stories we as researchers can understand and describe experiences and hence also contextualize them politically and culturally. In recent years many researchers in disability studies have turned to narrative forms of inquiry in order to achieve this. There is, however, one major problem that has often been neglected in this context and that is that "disabled" has been treated somewhat as an umbrella term. Regardless of what kind of disability is involved, narrative inquiry has been deemed one of the greatest ways to achieve this 'view from within'. In this paper I discuss that in relation to people who have severe *communicative* disabilities we must perhaps reconsider how we think about, and analyze stories.

By analyzing both some of my own data as well as some other empirical cases, I show that the relationship between story and storytelling event as well as the relationship between the primary and the vicarious storyteller are crucial to understand when we discuss storytelling in relation to people with severe communicative disabilities. This is because people with severe communicative disabilities seem to be quite inventive in being able to present themselves in stories even though they may not be able to do so through a verbal, coherent story. Hence, in my analysis of these empirical examples I am able to show that persons with communicative disabilities can be involved in storytelling that does not necessarily conform to the traditional idea about narratives (i.e. that they are structured and organized events, told primarily by one teller).

I argue that this implies at least three things: (1) that storytellers suffering from severe disabilities actively make use of the interactive resources within the situation where they are telling their story. (2) This active use of interactive resources implies that we need to redefine what a narrative is (i.e. that it could be embodied/enacted/performed just as well as it could be told) and finally (3) this implies that we need to draw attention to/set a discussion going about methodologies used in narrative inquiries in the field of disability studies. This is because, even if it could be thought of as a general problem in narrative research to leave out performative aspects of narratives, it becomes something

that has serious implications when we aim to study and bring forward the stories of those labelled as severely communicatively disabled. To leave out performative aspects could then be not only a way to portray these people as less communicatively capable than they actually are – it could result in the fact that we miss their stories altogether.

A possible conclusion is then that the use of interviews in collecting and studying narratives among persons with severe communicative disabilities may not be the optimal method. Instead I suggest that in a field such as (communicative) disability studies, narrative methods are perhaps best used if combined with ethnographic methods where the performative aspects of narratives could be studied more easily.

CHAPTER 5

Disabled or perhaps Dislabelled?

Three years ago I knew nothing of the situation of the deaf, and never imagined that it could cast light on so many realms, above all, on the realm of language. I was astonished to learn about the history of the deaf people, and the extraordinary (linguistic) challenges they face, astonished too to learn of a completely visual language, Sign, a language different from my own language, Speech. It is all too easy to take language, one's own language, for granted – one may need to encounter another language, or rather another mode of language, in order to be astonished, to be pushed into wonder, again. (Sacks 2000:xi)

The words above by Oliver Sacks could almost be my own. Five years ago, I knew nothing about people living with severe (communicative) disabilities, and could not imagine that it would shed so much light on the realm of language, and thus also shed so much light upon meaning-making practices such as identity and personhood creation. I was fortunate to be allowed to follow some remarkable people, both people living with severe disabilities and their carers for a whole year and this has left me with a great sense of gratitude. However, I would not say, like Sacks, that I am astonished or "pushed into wonder", probably because I did not start out with an idea that these were people without language. However, as in Sacks case, the participants that I followed also faced extraordinary challenges – challenges related to their ability to create and/or sustain a sense of identity and personhood. And, just as Sacks points out, these challenges seem to be related to the fact that it is all too easy to take one's own language for granted, or as stated earlier in this dissertation that we seem to get caught up in "the ruse of language".

This dissertation is aimed at studying meaning-making practices among people with severe (communicative) disabilities. It proceeds from theories about social interaction and the idea that it is through the telling and sharing of stories that we are able to create/sustain a sense of self, that we are who we are in relation to others and through our ability to tell stories about ourselves with our significant others. If then, in the middle of life, one suffers an acquired brain

damage resulting in severe disabilities that mean than one can no longer interact and communicate in expected and typical ways, this ability to tell and share stories, this "toolbox" for meaning-making could suddenly be out of reach. How then does one create a sense of self? By analyzing and theoretically contextualizing my empirical data I have reached the following four (major) conclusions.

Narrative norms as inabling

As sketched out in the second chapter of the synthesis, the use of narratives, especially autobiographical narratives, has been presented as a most useful tool in relation to disability research. By using narrative forms of inquiry we as researchers are thought to be able to collect and analyze stories from people with disabilities, and by understanding and describing those experiences that are expressed in the stories we should be able to contextualize these experiences politically and culturally. However, in suggesting this use of narrative forms of inquiry in relation to disability research, a fundamental problem seems to have been neglected – how to think about and analyze stories when the storyteller suffers from communicative disabilities that affect his/her ability to interact and communicate in "typical" ways. This is of great importance as it comes to affect how one tells stories with other people. It becomes vital to put this neglected problem in full view and I have tried to do so by researching the question: "(How) can we learn to detect untold stories?".

Even if I start backwards by posing this question first (as it is the last of my research questions and related to Paper IV) I find it crucial to raise this question now, at the outset of my final conclusions because it is of vital importance for the rest of the discussion. By asking in what ways impairedspeaking people tell stories, Paper IV shows the importance of studying not just verbal stories but also embodied and enacted stories. Hence, the way a narrative could be performed is shown to be of vital importance in relation to communicative disability studies. It is of vital importance because if we do not study the performative aspects of narratives we most likely reduce the storytelling capacity of people with severe communicative disabilities. To ignore performative aspects is then to make these people appear as less competent than they actually are (cf. Hydén & Örulv 2009). If we keep to the norms of what "should" constitute a narrative (i.e. that it should be a coherent and wellorganized story, told verbally by an author who is also the owner of the story) then we necessarily exclude people with severe communicative disabilities from narrative research as they often cannot conform to such an ideal and norm. Thus, such narrative norms are inabling people.

Instead, I argue, we need to realize that also people who cannot tell a story in the expected way do tell stories. Sometimes these stories are in fact verbal (as discussed in Paper I) but as the persons in this study are people who cannot talk unimpededly, the stories are more likely to be told through other means of language use. By analyzing the relationship between story and storytelling event as well as analyzing what has been called the primary and vicarious storyteller (as discussed in Paper IV) I have been able to show that people with communicative disabilities are often quite inventive in their efforts to present themselves in stories when they cannot do so verbally. One way to achive such presentation of selves could for instance be by telling stories through the embodiment of space (as discussed foremost in Paper II). I argue that this means that we need to acknowledge the fact that people with severe disabilities are also creators of their own lives despite their diagnoses.

As stated in Chapter 2, narrative researchers in the field of disability studies have suggested that in order to be inclusive, we should put more emphasis on overcoming the idea that inarticulate people have more limitations as informants than able-speaking people have and help liberate the voices and stories of people who would ordinarily remain silent. This is suggested to be achieved mainly through narrative interviews:

when an informant lacks the necessary articulation to answer [...] then the skills of the interviewer become increasingly important. The interviewer needs to be adaptable and posse a high degree of flexibility and experience to be able to use different tactics to secure meaningful narratives wherever possible. Multiple voices may emerge as a result, but the main voice would, in the case of people lacking verbal articulacy, be that of the author. The alternative would be to deny the existence of people lacking verbal articulacy and suppress their stories. (Owens 2007:304)

Thus the main focus is still to help people who are inarticulate to tell *spoken* stories. It is even suggested that not to help them do so (even if that means that it is really the researcher's story that is being presented) is to suppress their stories, and as such also to "deny their existence". Based upon my own empirical data this is an argument with which I cannot concur. Instead I argue that people with severe communicative disabilities are most capable of telling their own stories because they are quite inventive in finding other ways to present themselves as competent storytellers than through verbally spoken narratives elicited in an interview. I agree on the fact that there is multiple voices to listen to, but that perhaps we are better served by listening to the multiple voices that the informant is able to use (see discussion about Cavarero and Bakhtin, above, p. 26. This means that I as a researcher do *not* wish to try to give a voice to those

who might lack such, instead I argue that we need to try harder to listen to the "untold" stories that are already there, but that we might not have heard/seen.¹²

This is primarily discussed in Paper II, where I try to answer the research question of "(How) can narratives help in trying to sustain a sense of self?". By showing how there are (at least) two different stories about what it means to be severely disabled, to be dependent or to be autonomous, I present the idea that we need to regard people with severe communicative disorders as competent communicators because the body is said to be a communicative tool. Hence, by moving their impaired bodies in space in specific ways, the participants are able to tell stories because the moving of the body could be interpreted as a narrative.

Also, in showing that narratives can be both verbal as well as embodied and enacted/performed I was able to show that the all-embracing "disability-identity" (as discussed in Chapter 1) could be questioned and counter-narratives could be told. By showing *how* the narratives were created I was also able to show *who* narrates what. And it seemed as if even though the story of dependence was a joint co-constructed story told by both the personnel and the participants, the counter-narrative (i.e. the story of autonomy) which was enacted/performed when the disabled participant embodied the space of the room, seems to suggest that disability as dependence is not the only story a person suffering from acquired brain damage tells. Yet it seems to be the most prominent story that the personnel tells.

I must, however, point out that it is of uttermost importance to acknowledge the fact that even though I argue that it is not my place to give voice to their stories, but that people with severe communicative disabilities are most capable of doing so themselves if we just learn to listen in new ways, my findings also reveals a complex dilemma: Papers II and IV suggest that people with severe communicative disorders are most capable of telling stories that are not primarily coherent or verbal (rather they could be embodied and enacted/performed) while at the same time Paper I suggests a hierarchy among different modes of language use where spoken language is supreme. This I believe is a crucial finding, and I will return to it shortly, as it needs further elaboration.

¹² We might however also benefit from trying to disentangle the argument somewhat and acknowledge that there is of course a difference between researching how much free scope a person with disabilities has to be able to put their stories forward and researching how we as researchers are able to discover and retell such stories. The first question focuses on whether people with disabilities are *able/allowed* to tell their stories and the second question concerns how we can *discover* such stories.

Disability as dependence

The findings drawn above lead me to the second conclusion, that to be labelled as disabled means to be perceived as dependent rather than autonomous or self-determined. This brings me to the third paper, which is centred on the research question of "How does the idea of incurability come to influence narratives about severe disability?". The decision to focus mainly on narratives about people with severe disabilities (as told by the personnel) was made in order to comprehend how the label of disability could come to be determined by people not living with such disabilities themselves but rather those who work with disabled people on a close, daily basis. By focusing on the nursing staff's narratives about the participants we could understand how their perception of what it means to be severely disabled comes to influence the participants' own narratives as they are created in context with the staff.

By analyzing the interviews I conducted with the nursing staff I was able to detect how a dilemma they had to face in their everyday work at the day centre (the dilemma of having to motivate the participants to lifelong training despite the fact of there being no hope of a cure or improvement of their physical status) came to influence who the staff perceived the participants to be, and foremost who the participants will be in the future. This third paper shows an even greater connection between the idea that to be disabled is equated to being dependent. In this paper, we see that when the staff narrates about the participants they state that the participants need to be motivated (or coaxed/pushed/pepped up) otherwise they would never have the strength to commit to the lifelong training that faces them. Most importantly, this motivation must be given to them by the personnel. Hence, the physical immobility of the participants seems to have "stretched out", implying that the participants are immobile not just in the physical sense but also in the sense of them being unable to be active decision makers who are able to take own actions. 13 The fact that the personnel are perceived (and perceive themselves) as carers means that the participants must be viewed as care recipients - a perception that seems to imply that the participants are not active agents.

The paper discusses the fact that the personnel perceive the participants as incurable and hence having a narrative future that is foreclosed. However, for the personnel it becomes necessary to implement hope in their daily work because the participants *need* to be motivated (I will return to why this need is so important in the next conclusion *Normalcy and grand narratives*). As there is no hope of a cure or improvement the nursing staff must implement a will to

¹³ A phenomenon also Papadimitriou (2001) writes about: that a disabled person's need for assistance usually becomes generalized, meaning that if one requires assistance in some spheres of life, one automaticly comes to need it in all spheres of life.

exercise based upon other prerequisites. Hope in this clinical setting is not about a cure, and thus it cannot be about the future either. Consequently, to implement the physical act of training in the present becomes a meaning-making practice used by the personnel because it enables them to narrate about the participants and thus to help the participants create a sense of self that hinges upon their need to re-embody themselves and tell new narratives that includes the experience of being disabled (something that Mattingly (1994, 1998) has argued is part of the nursing staff's tasks).

It thus seems as if to be labelled as disabled means that one comes to live with an identity that hinges upon being dependent upon other people. This is perhaps not that strange. As argued above, disability is always contextually tied and situated, and as long as the surrounding context is not adjusted to meet the particular needs of people living with impairments they will be disabled and thus dependent upon other people to help them do everyday tasks. In Paper II for instance, we saw how Peter talked about himself as dependent because he was in a wheelchair and thus could not get a pint of milk for himself since the refrigerator was placed too high up for him to reach the cartoon of milk (see also quotes by Toombs, above, pp.8 -9).

What is more important, though, is that I have been able to conclude that this physical dependence upon other people seems to "stretch out" and also imply that to be disabled means to be unable to take own action. This means that when one becomes disabled, one is also perceived as inactive, resulting in what we saw in Paper III, that the participants are regarded as incompetent interactors, and hence not competent communicators. And, if they are not perceived as competent communicators it becomes hard to detect how they narrate about themselves in the interaction. I find it of utmost importance to bring forward this conclusion since narratives have proven to be so vital in order to be able to create/sustain a sense of identity. If one then is not perceived as a competent communicator/interactor one's sense of identity is seriously threatened because identity is something that gets negotiated in interaction with others. Thus, as Robillard showed us, to be labelled as disabled (and hence also dependent as well as an incompetent interactor) is to have one's identity seriously threatened.

Now, let us take a step back and recall the words of the superintendent of the day centre (see prologue). According to her, the day centre was unique and much appreciated by the participants as they did not need an "extra" LSS-assessment in order to be able to attend the day centre. As such, the participants did not need to be labelled as "not normal". In other words, what the superindentemt explained to me was that there existed a will among the participants to be identified as "normal" (a will that I as well came across during my participant observations). However, this will, this *desirable identity*, can be hard to come by if one is not able/allowed to be a competent communicator,

because then one has to rely on others to narrate about oneself in this desirable way. But then, what does it mean to be "normal"?

"Normal" in relation to living with severe disability seems to mean to be perceived as independent. If we look at the superintendent's words in the prologue one more time, we could detect this in that having a medical diagnosis of one's brain damage does not seem to be a threat to a "normal identity", however, a LSS-assessment is, because it would label you as one who has "a need for substantial support". We see a glimpse of this also in Paper III, when Andrew states that not being able to walk is very hard because "I was so *free* before, then I could get up and do exactly what I wanted" (Paper III, p. 329). What was unfortunately cut from the article (due to lack of space and a need to focus on the primary aim of the article) is that shortly after, Andrew elaborates and states:

"I want to be able to be a *normal* guy when I get back on my feet and then patience and endurance is everything because *you need to make it on your own*". (my emphasis)

What Andrew suggests is that to be "normal" is to be independent; in order to be "normal" you need to make it on your own. Therefore, the found narrative of disability equals dependency is also a narrative that seems to state that disability equals "not normal".

Hence, in order for people who are severely disabled to try to create/sustain a sense of self that is "normal" it seems as if other narratives need to be told, stories that do not necessarily portray the participants as dependent, at least not dependent in the sense of not being able to take own action and be an active decision maker. Still, we have seen that the story of dependence is told both by the personnel and the participants themselves – the story of dependency is thus formed in dialogue in the conversations between personnel and participants. On the other hand, it does seem that it is primarily based upon how non-disabled perceive the people living with their disabilities. Both Papers II and III suggest this. But it also seems as if such an identity, to be dependent, gets picked up by the participants themselves, as they tell their narratives in cocreation with the personnel. We saw that primarily in Paper II, where participant Peter told the story of dependence together with the personnel. However, in the same paper we also saw that he rejected that story and told yet another story, one where he is *not* dependent but rather autonomous, meaning that he does not just tell the jointly constructed story of disability being equated to dependence.

Normality and grand narratives

This brings me to my third conclusion because even though a story of autonomy was told, the wish to be perceived as "normal" seems hard to fulfil because the individual's narrative needs to be understood in relation to grand narratives.

This dissertation states that there has been a historical change in terms of policy in relation to disability and thus also in relation to the "normal" (see page five and note four, above). Rather than thinking that it is a person with disabilities that should be reformed into a "normal" person, it is the living situations of people with disabilities that need to be reformed. This change in perception has had profound effects on disability politics where issues of empowerment and the ability to be self-determined have been pushed to the fore. At least, this is in theory; people living with severe disabilities *should* be allowed to be self-determined. I cannot say that my empirical data concurs with this. In fact, I would say that they imply quite the opposite. The participants in this study *were not able to be (allowed to be) self-determined* because they were not considered competent interactors/communicators — this being mainly connected to the fact that their non-verbal narratives were not recognized as valid narratives.

I am not suggesting that this neglecting is explicit or done on purpose, quite the opposite. The personnel seemed to do almost everything in their power to try to make the day centre as pleasant as possible for the participants and to put the needs of the participants first (including discussing reducing their own salaries in order to be able to bring in more personnel, something they believed the participants would benefit from). However, an identified ideology of spoken language (Paper I) seems to imply a hierarchy between different modes of language use, where both personnel and participants come to focus mainly upon spoken narratives. This has vital consequences when it comes to identifying narratives among those labelled as communicatively disabled. As we saw at the outset of this dissertation (in the prologue) the participants do not want to be perceived as *not normal*. One way for them to contest such a perception could thus be to tell counter-narratives about what it means to be severely disabled (as we saw Peter do in Paper II). However, as Mattingly has stated:

[w]hen there is no chance of return to the person one once was, or when there is no hope of being "normal", a person's very sense of self is lived in a special way through the body. Personal identity becomes intimately tied to the pain, uncertainty, and stigma that come with an afflicted body. (Mattingly 2008:73)

Thus, it seems that when one has become severely disabled, one lives through the body because the impaired body becomes impossible to ignore (as discussed in the section on Toombs above, pp. 8-9). In other words, the impaired body

becomes *the* most prominent feature of who one is (Leder 1990). If the body then is not recognized as a valid tool for storytelling one cannot really question the label of disability meaning to be dependent and an incompetent interactor, because one of the ways one could tell such a story (through the body) is not heard (or seen). It thus seems quite hard to tell a story that does not label persons who are severely disabled as "not normal" because:

[t]he aim of returning the individual to normality is the central foundation stone upon which the whole rehabilitation machine is constructed. If, as happened to me following my spinal cord injury, the disability cannot be cured, normative assumptions are not abandoned [...] they are re-formulated so that they not only dominate the treatment [...] but also totally colour the helper's perception [...]. The rehabilitation aim now becomes to assist the individual to be as "normal as possible". (Oliver 1990:54, see also page 1, above)

In light of such aims, it seems as if the principle of normalisation dominates practical care work (and politics) related to people with disabilities (Moser 2000:201).¹⁴ As Oliver states in the quote above, these normative assumptions come to "colour the helper's perception" and therefore I argue that they will also come to influence the meaning-making practices of creating identities and personhood that occur in the telling of narratives.

As argued in both the synthesis and all the individual papers, this can be understood in relation to how (individual) narratives are given meaning in being related to a cultural whole, a grand narrative. Particularly, in Paper III, I was able to identify the fact that in order for the narrative of hope to be meaningful it needed to be related to a grand narrative that implied that it is OK to be "deviant" just as long as one does everything in one's power to return to "normal productive life", a return to "normality" thought to be facilitated through the capacity of a person to take action in the present in order to change one's future into a healthier, "normal" one. As the narratives in Paper III showed, however, the participants' future is perceived as foreclosed, and no such "return to normalcy" is possible. Yet, just as Oliver states, such normative assumptions are not abandoned. Instead it becomes the ability to *strive towards* such normality that seems to be most important. The striving towards, rather than the achievement of, normality becomes ubiquitous.

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¹⁴ Moser (2000, 2003) also argues that such a principle of normalization will always result in disabled people being constituted as Other as they will always falter in being measured against this norm. Hence, she argues against normalisation as an inclusive principle. Even though I speak of, or rather the participants in this study speak of, normalisation as being able to be perceived as independent, and Moser taks about normalisation mostly in relation to societal consequences, we take the same point of departure, namely that the issue of normalization is related to the issue of being able to take own action.

By studying how individual stories about disability are connected to a cultural whole (i.e. by relating to the idea that the stories are personal as well as social and cultural, Riessman 1993; Smith 2007) I have thus been able to show that it seems almost impossible for people living with severe disabilities to be perceived as normal. Paper III suggested this in regard to Parson's theories about social action that stipulate that what we achieve is more important than what is ascribed to us. Thus, the striving towards normality is possible, or even mandatory, but to actually achieve normality is perceived as almost impossible. This connection between individual and cultural (grand) narratives was established also in Paper I, which brings me to my fourth conclusion.

Hierarchy among modes of language use

In the first paper I was able to identify a strong preference for speaking with one's own (physical) voice and found an *ideology of spoken language*: a cultural, grand, narrative that makes it almost impossible to narrate one's identity if not doing so by speaking. In researching the question "Is speaking crucial when creating a sense of identity and personhood?", I was able to show that to be able to talk with your own physical voice is indeed deemed as important because to do so is to be able to remain yourself. Not giving up one's speech is the same as not giving up one's own sense of self.

Thus, there seems to be a hierarchy among various modes of language use where verbal/spoken language is supreme which result in the fact that spoken narratives take priority over embodied and enacted/performed narratives. A crucial conclusion that I am able to draw here is that this implies a power imbalance where the able-speaking are usually the ones in control over the communicative situations and therefore the ones that can set the agenda for these communicative events. Therefore, they are also the ones who have the most power of deciding what a label such as severely disabled means, as they are the ones who "control" what is and what is not narrated. As a consequence, the nonverbal aspects of narratives seem downplayed, a phenomenon identified in all four papers.

This can also be traced back to the synthesis, where I tried to sketch out what it might mean to be labelled as severely disabled primarily by using three different cases (Robillard, Toombs and Murphy). I tried to show how being identified as disabled turns one into a liminal person – an all-embracing identity that seems to be given to severely disabled people where they are not perceived as competent enough to make their own decisions. My empirical data, as shown in the papers and as analyzed in the conclusions above, seem to confirm this. It thus seems crucial to acknowledge the power relation that occurs within

narration (something discussed primarily in Paper II) as this is related to who has the power to control the disabled body and hence also determine what it can and cannot do. Through the act of narration we see that power relations, as well as the conception of identities are (re)created as well as contested.

As such, as both the third and this fourth conclusion shows, individual narratives need to be identified as related to the grand narrative (or the ideology) of spoken language because in doing so we are able to realize that such an ideology comes to shape our social practices. To express it in words used in Paper IV – by turning to individual narratives we are able to contextualize the expressed experiences politically and culturally. Thus, the study of individual narratives about living with severe disabilities has not only helped in understanding the world of disability, it has also revealed aspects about our larger socio-cultural life, especially about its norms and conventions. These norms and conventions seem to suggest that it is hard to fulfil the expressed wish of the participants to be labelled as normal. As already stated, to be labelled as disabled seems to mean to be labelled as dependent and to be labelled as dependent seems to mean to be labelled as "not normal". When we then also realize that identity and personhood creation on an individual level is connected to an ideology of spoken language that stipulates verbal narratives we must conclude that non-verbal communication and storytelling gets downplayed, and spoken communication becomes the supreme among different modes of language use. This means that those who are able-speaking will most likely be the ones who "determine" what it means to be severely disabled rather than the persons living with such disabilities. To me this suggests that we might have to ask ourselves if the story of dependence is a necessary theme within care institutions; if one wishes to be part of these activities, is one required to embrace the story of dependence?

Implications for Clinical Practice

I would like to use a quote that a colleague of mine used in her dissertation regarding people living with dementia, "How we think of people with dementia will be crucially important in determining how we care for them" (Hughes, Louw & Sabat 2006:35, Örulv 2008:67). Substitute "people with severe brain damage" for "dementia" and such a statement would be no less true. How we think of people, or perhaps, in keeping with my earlier used vocabulary, how we *categorize* people, is vital in how we treat and care for one another, because:

[o]ur reactions to people are influenced by how we categorize them [...] identities are associated with practical experience. (Loseke 2005:132)

And, as this categorization is often created through narrations it becomes important to realize that:

[n]arratives offer a powerful way to *shape conduct* because they have something to say about what gives life meaning. (Garro & Mattingly 2000:11, my emphasis)

Thus, how people are able to present themselves and who they are, as well as how others categorize people, through the joint acts of narration matters because it will influence how one is treated.

My empirical data seem to fall in line with Mattingly's (1994, 1998) theories suggesting that people with severe (communicative) disabilities due to acquired brain damage need to tell new stories about themselves. Their disability, as a consequence of trauma, has forever altered their lives and a need to address the issues of identity and personhood is identified. This re-addressing is, however, often complex and co-created in relation to others (in this dissertation in relation to the health care personnel caring for them).

As shown above (see *Narrative Identity*) this re-addressing usually takes the form of identity and personhood creation in the telling of stories about one's sense of self. As these stories are co-created with the personnel it becomes crucial for the personnel to understand that that is in fact what they are doing, or at least perhaps should be doing – helping people with disabilities to reaffirm a sense of self. This means that:

[k]nowledge about the experience of persons living with illness or disability is essential for the provision of good nursing care. (Carlson et. al 2007:1369)

And as such, that:

[c]linical professionals need a better understanding of how people make sense of themselves, especially under extreme circumstances [such as having a damaged brain]. (Medved & Brockmeier 2008:471)

I therefore suggest that the findings in this dissertation lead to *practical implications for the health care personnel* working with people with severe (communicative) disabilities due to acquired brain damage. The personnel need to consider the complex issue that in order for them to be "competent communicative partners" to the persons with disabilities, they need to learn to listen in new ways, at least if we aspire to the idea that people with disabilities should be in control of their own lives. To *truly* be a supportive communicative partner and acknowledge the people with disabilities' rights to be self-determined, the health care personnel needs to try to listen to, and co-create/reaffirm, the narratives that the disabled participants tell. It seems also

that even though these narratives can be told verbally, they are perhaps primarily told through the impaired body.

As the social model of disability stipulates that disability is mainly a socially created problem it also establishes that:

[m]anagement of the problem requires social action, and it is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life. The issue is therefore an attitudinal or ideological one requiring social change. (*ICF* 2001:28)

I wish to argue that my findings in this dissertation point to the fact that it is not only environmental modifications that is needed. It is equally important to realize that to listen to and reaffirm embodied and enacted/performed stories of people living with severe communicative disabilities could be a way to help these people to portray themselves as being independent and therefore also as "normal", something that seems to be of vital importance. Hence, in realizing that for severely disabled people to be able to reaffirm themselves we need to take a joint responsibility for the communicative and narrative practises they take part in. This is then perhaps not only a question for the health care personnel working with them but for society at large. It is indeed an attitudinal/ideological issue that requires social change. As I was able to show in Paper II, one way for people living with severe (communicative) disabilities to challenge the social structures that labelled them as dependent is to be able to tell embodied and enacted/performed counter-narratives, narratives that tell of autonomy rather than dependence. Therefore, I argue, we need to learn to hear (or rather see) these stories as valid narratives.

Implications for Narrative Research

As stated above (see *Voices*), Peterson & Langellier (2006) conclude that there has been a performance turn in narrative research but that even this turn to performance hinges upon spoken narratives. Hence they also state that narrative is always constrained by situational conditions; not everyone can function as a storyteller at all times and at all places, and not all stories are developed or heard (Peterson & Langellier 2006:176). I would like to elaborate on that statement and suggest that there are *many* stories that are not developed or heard because we have listened in the wrong way, at least when it comes to narrative identity in relation to communicative disability. The focus on spoken (autobiographical) narratives is troublesome because that also means that there has been a focus on narratives elicited mainly through interviews and thus downplayed the focus on

non-verbal communication. That means, at least according to my findings, that we have probably missed many other stories that could help us explain our social world. As suggested in Paper IV, further narrative studies in relation to communicative disabilities are perhaps best served if joined with ethnographic methods, such as participant observations and videoethnography. To keep on using "only" interviews when studying people with severe communicative disabilities would be to keep excluding some people from narrative research because not all people tell verbal stories even though we lend them words as suggested by Owens (2007). It would be interesting to see further studies in relation to severe (communicative) disabilities that combine narrative research with ethnographic methods.

For instance it would be extremely interesting (at least to me) to use these combined methods of research in order to study people who have congenital causes for their communicative disabilities. As has been stated (see *Disability and trauma*, above) living with severe disability due to congenital causes probably does not affect one's identity and personhood in the same way as when one becomes disabled later on in life because then one has probably not perceived any "normality" to return to; one's identity has always been understood in relation to being disabled (and thus dependent). To me this suggests different ways of constructing one's identity and personhood. A comparative study would be interesting!

It would also be of great interest to use these combined methods to study whether there are more enabling narratives out there, narratives that do not necessarily label the disabled as dependent and incompetent communicators. It would be interesting to see if such enabling narratives could also be applied to people who are thought of as incurable. One could imagine that such narratives could be created between people with disabilities and their significant others (such as spouses, relatives and friends). Perhaps then would it be possible to detect narratives that could label the participants as "normal" – since that seems to be what they prefer.

Final conclusion and critical reflections

This leads me to a final conclusion, or, rather, a final thought. In the first conclusion drawn above (i.e. that narrative norms are inabling) I ended by stating that my findings draw us towards a complex dilemma, namely that people suffering from severe communicative disorders are most capable of telling their own stories if we just learn to listen for them in new ways (i.e. to see them rather than hear them), at the same time as a preference for speaking has been identified. Thus a tension exists here between what the persons in this

study wish to do (i.e. to be able to speak in order to (re)create/sustain a sense of self that is autonomous and hence "normal") and how I state that they are most likely to be able to actually tell such a story – by performing it.

Some years ago, I attended the same conference as Cheryl Mattingly. And she spoke about her research findings that stories could be lived before they are told, i.e. that they could be told through social doings rather than through words. She then told us that she had gone back to the clinic and presented her findings to the occupational therapists and that they had protested vigorously. They said that they had no intention of creating stories with the patients; they were just doing their jobs, trying to get the patients to exercise and use their bodies.

By retelling this short episode I do not mean to suggest that Mattingly was wrong in her findings (nor did she herself think she was wrong). On the contrary, by retelling it I wish to suggest that as researchers we might be able to detect meaningful (organizational) structures/patterns within social settings that the participants in such settings has not thought about themselves (perhaps one could then say that we as researchers try to see the implicit/untold stories?). As I stated above (see Turning data into results), this is in fact what we as researchers should do; we should take our empiric data and try to conceptualize them. Thus, my own findings that people living with severe communicative disorders most likely can contest the identity of being dependent (by embodying space and perform narratives rather then speaking them) are perhaps not recognized by either the participants themselves or the personnel. Hence, I hope that through my presentation of these findings, I have opened our eyes to the fact that people living with severe (communicative) disabilities are often labelled as dependent, non-determined and non-active because their ways of telling stories are not identified as valid, and that this results in the fact that people with severe disabilities are perceived as incompetent interactors, something that strikes a very discordant note in our strivings towards all peoples inclusion in society.

One could then perhaps question my own way of researching this. After all, most of my studies (the individual papers presented in Part II) are based upon studying verbal aspects of storytelling. I am of course aware of this paradox but I can honestly say that if I had *not* focused upon the verbal mode of language use I would not have been able to detect its supremacy and what that means in relation to people living with severe communicative disabilities. Namely, that to be labelled as disabled is to be labelled as dependent and "not normal" because the supremacy of spoken language downplays other ways of telling stories and the spoken narrative of disability stipulates that disability is equated to dependence. The body has become absent and my study shows a *necessity* to bring the body into the study of (disability) stories: to study only spoken stories in relation to persons with severe disabilities is to downplay their

own agency and ability to create themselves in narration. The initial focus on spoken stories thus led me to be able to identify the ideology of spoken language which in turn led me to identify the need to use another way of gathering data: videoethnography. It was then that I was able to identify the opposite – that if we learn to appreciate embodied and enacted/performed storytelling (or rather, *story-making*), we will find other stories. These stories could then make us ask ourselves if people suffering from severe acquired brain damage are in fact disabled, or if perhaps they could instead be dislabelled?

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