LUND UNIVERSITY

# The Art of Living with a Traumatic Spinal Cord Injury in its relation to Resources and Norms in Swedish Society

Nordgren, Camilla

2008

*Citation for published version (APA):*
Nordgren, C. (2008). *The Art of Living with a Traumatic Spinal Cord Injury in its relation to Resources and Norms in Swedish Society*. [Doctoral Thesis (compilation), Certec - Rehabilitation Engineering and Design]. Division of Rehabilitation Engineering Research.

*Total number of authors:*
1

LUND UNIVERSITY

PO Box 117
221 00 Lund
+46 46-222 00 00

# The Art of Living with a Traumatic Spinal Cord Injury in its Relation to Resources and Norms in Swedish Society

Camilla Nordgren

Doctoral thesis
Department of Design Sciences
Certec
Lund University

1666

The Art of Living with a Traumatic Spinal Cord Injury in its Relation to Resources and Norms in Swedish Society

Certec
Department of Design Sciences
Lund University
Sweden

ISBN 978-91-976894-4-1

Printed in Sweden by Media-Tryck, Lund

"Would you tell me, please, which way I ought to go from here?"
"That depends a good deal on where you want to get to," said the Cat.
"I don't much care where……" said Alice.
"Then it doesn't matter which way you go," said the Cat.
"……so long as I get somewhere," Alice added as an explanation.
"Oh, you're sure to do that," said the Cat, "if you only walk long enough."

Alice's Adventures in Wonderland, Lewis Carroll

# Summary

The overall aim of this thesis is to elaborate on the art of living with a traumatic spinal cord injury (SCI) in its relation to resources and norms in Swedish society. The thesis originates in part from a prevalence group of SCI individuals and is based on four studies. One is longitudinal and register based, and one is interview based. A paper on "ethics in the making" elaborates how general versus situated ethics might influence design. A norm perspective is applied in another study highlighting the double sets of social norms via narratives in the context of a severe disability. Through these approaches, I hope to open up an area in which little or no research has previously been carried out.

A traumatic spinal cord injury is today not curable and commonly leads to a significant, permanent disability with a risk for severe complications. Living with a traumatic spinal cord injury poses, beside all the medical implications, a wide range of obstacles and circumstances in daily life that must be dealt with. The need for accessible environments and societal resources is thus obvious; an extensive and lifelong reliance upon such services will typically be established. The complexity of the injury and its effects on physical functions mean that the needs are great. Society provides various supportive services in order to restore social integration, re-establish autonomy, compensate for financial and functional losses and facilitate activities of daily living. Acute care, rehabilitation and readmissions both as inpatient and outpatient services are, of course, of great importance and are cost-consuming. Other services, though, will also be comprehensive due to their repetitive use in a life-perspective.

The comprehensive aim of the thesis is formulated in the following sub-purposes:

- Identify the spectrum of potentially relevant societal resources after traumatic SCI.
- Investigate an incidence population's use of societal resources including self-rated levels of satisfaction with the application process and resource allocation.
- Discuss how general ethical guidelines are challenged by situated ethics in a design context.
- Validate an existing inpatient register.
- Analyze and discuss how a norm perspective can be utilized to understand why legislation is not sufficient to achieve Swedish disability policy goals.

Results show that about 25 separate services are available and that each service has to be applied for separately by the individual. Information about the services was provided by a social worker but still individuals reported ignorance about the existence of various services. Applications were partially or totally rejected. The National Patient Register proved to be lacking information and was thereby validated by raising three questions: Is an inpatient stay registered in association with the injury date? Is the reported first length of stay plausible given the level and extent of injury? Are all the anticipated care and/or rehabilitation providers represented in the register? For 62%, the first registered hospitalization date correlated with the injury date, leaving 38% with a hospitalization that started later. Considering the level and extent of injury, individuals were reported to have unrealistically short initial hospital stays. The prevalence group visited 42 different hospitals

and 47 clinics. Five rehabilitation clinics, though, were not reported. The study on double sets of social norms found that the individual's experience in everyday situations runs contrary to the prevailing, expected norms. This results in the individual not being able to identify with everyone else or to rely on the current set of norms. The discussion elaborates on the time frame needed to perform and interpret longitudinal studies, as well as the impact different disability definitions have on the results. The use of the term "being in need of" in this area and how utilization can be estimated are also considered. The consequences of access to services being dependent on the individual's initiative are examined. This section also highlights that the perspective of the authorities versus that of the individual (i.e. the lived perspective) are not only separate but different, and that the individual may be seen as a burden.

# Acknowledgement

My research path during this longitudinal study has been long and winding. Colleagues, research partners and friends have paved the way. My research process, culminating in this thesis, led me to Certec. Here Professor Bodil Jönsson, my primary supervisor, has given me space and support to explore the research field. Her interest and stimulation in turning life experiences and questions into scientific scholarship have taught me much. For that I am very grateful. The process that led to Certec started at Spinalis where I was recruited through the efforts of Dr. Claes Hultling, M.D. My encounters with Professor Åke Seiger have involved an introduction to the scientific sphere as well as guidance and inclusion in it. Associate Professor Richard Levi and Dr. Gunnar Ljunggren, M.D., have also advised me. Without their commitment and supervision I would not have been able to realize my ideas.

Colleagues at Certec and the Department of Design Sciences have at different times and to different extents been involved in this winding path. In particular, I mention Arne Svensk for always being there to listen and to offer constructive criticism. He has enabled me to think in another way and that is the most revolutionary I can imagine. I envy him and his knowledge. Without "morning prayers" with Gunilla Knall, I would not be here today. Thank you for always sharing and listening. And to Henrik Enquist for inviting me to collaborate. After a long time of struggling on my own, this co-operation was particularly invigorating and time-effective. I have enjoyed this process. Thank You.

This thesis would not have been so fluently expressed in English if it were not for Eileen Deaner. My gratitude for all her work. And to Robert Olsson for preventing an outbreak of *Reference Manager* hysteria, or any other computer related frenzy. I have learnt a great deal, but what an exhausting process. Elin Olander has helped design the cover and involved me in planning what will come after the thesis. Thanks Elin! Now I will have more time to realize our ideas!

Associate Professor Per Wickenberg has contributed a great deal to my understanding of norms and their elaboration. I thank him for encouragement in exploring this area and for sharing his knowledge.

Region Skåne, The Foundation for Support to Physical Impaired People in Skåne (Stiftelsen för bistånd åt rörelsehindrade i Skåne) and the Norrbacka Eugenia Foundation) (Norrbacka-Eugeniastiftelsen) are acknowledged for their financial support.

To all my friends for sharing parts of our lives and for all our activities – from skiing, playing games, to handling the cash register. I like and enjoy!

My Mum and Dad, for always being there, fixing everything for me and us, large and small. You are my wonderful support. Love and Vera, our children, for bringing me back to the here and now. I love you. And Fredrik, of course, you have been on this journey with me from the very beginning, and I know that you are as happy as I am that it is now time for the "full stop".

Lund 5th of October, 2008

Camilla Nordgren

# List of papers and my contributions

The thesis is based on the following papers:

I. Societal services after traumatic spinal cord injury in Sweden
Camilla Nordgren, Richard Levi, Gunnar Ljunggren and Åke Seiger
*Journal of Rehabilitation Medicine*, 2003; 35: 121-126
I was responsible for data collection, data analysis and for writing the article.

II. Ethics in the making
Bodil Jönsson, Peter Anderberg, Eva Flodin, Lone Malmborg, Camilla Nordgren and Arne Svensk
*Design Philosophy Papers*, No. 4, 2005
I contributed to this paper mainly by supplying examples and in the overall discussion. If it had been published today, I would have included this entire thesis as an example of situated ethics in a design research context.

III. On the need of validating inpatient registers
Camilla Nordgren
Accepted for publication in *Spinal Cord*, 2008
Published online:
http://www.nature.com/sc/journal/vaop/ncurrent/pdf/sc200842a.pdf

IV. Dubbla sociala normer – Existenser och effekter i vardagen för personer med funktionsnedsättning (Double sets of social norms – Their existence and effects on the everyday lives of people with disabilities)
Camilla Nordgren
Forthcoming 2009, *Retfærd, Nordisk juridisk tidsskrift* (Nordic Legal Journal)

Other paper of relevance

Intuition in Design and Emotion? – Transforming raw data into conclusions, a meta-analysis of the 2006 Design & Emotion conference papers
Henrik Enquist and Camilla Nordgren
*6th Design & Emotion Conference Proceedings, Dare to Desire*, Hong Kong: The Hong Kong Polytechnic University School of Design, 2008.
I contributed to this paper mainly in the collection and analysis of the empirical data.

# Contents

I Societal Services After Traumatic Spinal Cord Injury in Sweden

II Ethics in the making

III On the need of validating inpatient registers

IV Dubbla sociala normer

# Introduction

Throughout this thesis the focus is consistently on the individual. This is true not only for the individual examples, interviews and narratives, but also for the published articles in which the source material has been retrieved from medical registers. In these I have followed a large number of individuals longitudinally through the medical system by both examining the registration of inpatient care and the consistency of the data registered, individual by individual. Other longitudinal studies in this area for comparison purposes lacking (1). Instead, researchers almost exclusively take their point of departure from methods and models suited for capturing current cross sections and then comparing the results with one another. That so many restrict themselves to taking "flash photographs" has meant that the type of inconsistencies I found in my research along with the descriptions of the consequences presented here have not previously come to light.

A consistently individual focus over time reveals how individuals live in a world of continually changing best-practice. When it comes to traumatic spinal cord injuries (SCI), the many changes that have occurred in the last 50 years have been considerable, to say the least. Survival has increased to the level that the average life expectancy for people with traumatic SCI is now close to that of the normal population (2). A 50 to 60-year-old Swede who incurred a traumatic SCI earlier in life has lived through an era not only of changes in medical practices, but also one in which the medical approach has been fundamentally altered. Inpatient care was much more extensive before than it is today, both initially and afterwards. The knowledge and view of what conditions should be treated in a hospital setting have changed, just as has the view of the individual. If a person with an SCI had pneumonia 50 years ago, he or she was chiefly considered to be a person with a traumatic spinal cord injury who had pneumonia. Today, they are treated as persons with pneumonia who in addition have a traumatic spinal cord injury. When a pregnant woman with an SCI has a caesarean section and requests to be on sick leave a bit longer due to the extra difficulties that arise, her request can be rejected with the terse declaration that childbirth is not considered an illness; the effects of the spinal cord injury are somehow not at all taken into consideration.

Notions of what makes up best-practice have not only changed in the medical realm, but in the rest of culture and society as well. The middle-aged person mentioned above initially lived in a world that was disposed to the idea that having a traumatic spinal cord injury would result in early retirement – if the person concerned had even managed to enter the job market. Previously, children with SCIs could receive schooling in the neighbourhood only if their parents really pushed for it. Otherwise it meant attending school at an institution further removed. As time went by the walls of exclusion and separation started to crumble, but for a long time society still maintained the view of the affected individual as a passive creature. Based on this view, legislation made it possible for people with traumatic SCI to receive assistance from the state. They were not expected to be active in the process themselves, though. Instead, they were to take on the role of care recipients for whom problems would be solved and for whom the rest of us could feel sorry.

In the early 1990s this all changed as the result of specific civil rights legislation for people with severe disabilities: *The Act Concerning Support and Service for Persons with Certain Functional Impairments* and *The Assistance Allowance Act* (1). A person with a disability was now expected to be quite active in the process. Society would make the resources available, but it was up to the individual to search for and gather information about the right ones, apply for and utilize them. In spite of a severe disability, it was assumed that the person not only had a greater capacity but more time and energy than others to learn all about the available resources. The consequences have been that the person with a disability now has to accept that society demands more, not less involvement from her than from others in order to understand and keep track of these constantly changing rules and regulations for all the different kinds of permits and allowances.

A traumatic SCI is clearly a medical diagnosis, but it is not only the direct medical problems that affect everyday life; instead, it is the consequences of the injury for the lived life that are decisive. These in relation to resources and norms are the focus of this thesis. At the same time, I would like to clarify that if your initial assumption is based on the *entirety of the individual* and the *longitudinal* in the lived life, you will view norms (be they abstract or implemented) and resource distributions in another light, than if you start out from the on-the-spot accounts of medical statistical data or comprehensive resource utilization statistics based on a societal point of departure. I have chosen to limit the research presented to Swedish conditions, as the resources available to people with disabilities vary widely from country to country.

This thesis presents an initial, overall picture of the art of living with a traumatic spinal cord injury in its relation to resources and norms in Swedish society. This is quite ambitious, particularly as it is a pioneering attempt, and so I have chosen not to elaborate the following issues:

- The significance of personal characteristics such as gender or age at the time of injury.
- The significance of geographic domicile in Sweden (I utilize material from Stockholm without problematizing this issue).
- The legal right to support (e.g. if the right to a given service is withdrawn because a person has reached retirement age or a certain income level).
- Types of health care consumption that are not directly related to the SCI or its deterioration, but would be there in any case.

This list is not complete; nor is it presented in any particular order of precedence. Each of these perspectives is fully possible to penetrate based on the methods and material I have had access to. All are important. But not so important that I will allow them to obscure the comprehensive view that I want to present: that the utilization of resources can be considerably improved if it focuses on the individually experienced entireties, not on all the scattered partial perspectives.

# Background

For men and women who have sustained or are already living with a traumatic spinal cord injury, obstacles in daily life due to an inaccessible society and inaccessible resources – or more correctly, lack of or insufficient resources – have a dominant influence on their daily lives. Over the years I have read many publications, web pages, and information material from a variety of disability organizations (e.g. http://www.spinalistips.se/?lang=en, http://www.nhr.se/, http://www.dhr.se, http://www.rtp.se ). They mainly focus on learning to cope with society and systems, and provide advice on assistive devices, adaptations and individually designed solutions. Frequently reported comments and complaints involve the infrastructure and how buildings are constructed, restrictions on societal resources, how to formulate your requests, recommendations on how to report inaccessibility, government proposals circulated for consideration, descriptions of new laws and their consequences, and statistics about living conditions and work situations. It is striking how dominant these issues are and how little space is left for discussions of medical problems.

I myself sustained a traumatic SCI when I was three years old. This has influenced what I have been able to discern here on both a large and small scale, and in both the long and short-term. The distinguished patterns have, in turn, directly and indirectly affected how I searched for and gathered my material, what research questions I asked of it, what follow-up questions I chose and what analyses I was able to carry out. Benefitting from one's own life experiences in research has also been used by others (3).

The settings in which I have lived and worked over the last 15 years have also exerted their influence. First I was employed by Spinalis, the Spinalis Cord Injury Centre at Karolinska University Hospital in Stockholm. There I observed and reflected over patients who had the same diagnosis as I had. Even though Spinalis was a medical unit, common topics of conversation between the patients did not centre much on health issues but were more often based on irritation that they hadn't received a particular allowance or permit, or inquisitiveness as to "What do you do if you want to find out more about. . .?" It was actually these overheard conversations at Spinalis that led to the first research questions of this thesis. In 2001 I came to Certec (Division of Rehabilitation Engineering Research), and there I have worked surrounded primarily by natural scientists, engineers and designers with their sights aimed at the meeting between human dreams, wishes and needs, on the one hand, and technological possibilities on the other. I have been influenced by design methods and approaches (4) to consider how the supply of resources can be better designed to respond to the needs, wishes and dreams as experienced by the people who receive them.

At Spinalis I was an outsider in relation to the medical culture, and at Certec it has been the same in relation to the technological and design emphasis. Nevertheless, the scientific foundations of both settings have been essential for the entirety I have been able to realize. In addition, I was in need of mental structures and concepts that take into account how continually changing *norms* affect the life a person can live, for example, with a traumatic SCI. An altered norm at Spinalis expressed itself as an altered medical praxis; at Certec as a technological implementation. My desire was to capture how changing norms express themselves as changes in praxis in societal resources or in others as elementary as the order of priority in a housing queue. In this endeavour, I have received significant supported from the Sociology of Law unit at Lund University.

## A traumatic spinal cord injury

Sustaining an SCI is a devastating trauma and the effects on physical functions are extensive. A traumatic SCI means that the spinal cord has been injured by significant physical impact. This implies that individuals were generally healthy and without physical limitations before the occasion of injury. A traumatic SCI often entails a considerable loss of motor activity and sensory input and many become dependent on wheelchairs (5). The most common causes of injuries are traffic accidents and falls (6). A traumatic SCI commonly leads to a significant, permanent disability with a risk for severe complications. The survival rate of people who incur a traumatic SCI has increased dramatically since the Second World War. Surveys of prevalence (total number) of people with traumatic SCI are few. A Swedish study concluded that prevalence in the Stockholm region amounted to 233/1,000,000 at the beginning of the 1990s (7). Dahlberg et al. reported a prevalence of 280/1,000,000 for the Helsinki region (8). Investigations about the incidence (number of new injuries per year) are more frequent with figures ranging from 10.4 to 83/1,000,000 (9). The total number of individuals living with such an injury may be considered to make up a small group. However, the great majority will live a long time with the injury since most are young when they sustained it and because there is no cure. The average life expectancy of people with SCI is approaching that of the normal population (2).

The condition was diagnosed and documented as early as 2500 B.C. It was considered then and right up to the first part of the 20th century as "an ailment not to be treated" (10). In step with several discoveries such as antibiotics, X-ray and computer tomography, the ability to keep SCI patients alive in and after the acute phase increased. It required, however, that pioneers in the field in the USA, Australia and Great Britain realized the need for professional interest in the patient's total needs as well, not only in the medical ones. In spite of this awareness, it would not be until the beginning of the 1970s that the professional community began to treat the patient's psychology as well as physical needs (11). In recent years, famous people such as the American actor Christopher Reeve and the Swedish skier Thomas Fogdö have meant a lot for the discussion climate on the effects such an injury can have and the resulting needs. For all that, it has been the mass media if anything rather than the research community that has succeeded in seizing upon these changes.

## Societal resources

There is a wide variety of resources available to a person with SCI, some more familiar and obvious to the general public than others. One such resource is a parking permit. The acquisition or loss of it has such widespread consequences for the SCI individual in his/her daily living that it deserves to be elaborated on as an examplar in the societal resource context.

This is the well-known sign of a parking space intended for individuals with such a permit. These spaces are located all around in the community. For a person with limited mobility, being able to park close to one's house, place of work, shops, friends' homes, the cinema, etc., is a matter of vital importance. This might even be the factor that determines whether one is actually able to carry out his or her plans. Regulations about these parking spaces and who is entitled to a parking permit can be found in The Swedish Road Traffic Regulations (Trafikförordningen), in The National Board of Housing, Building and Planning Regulations (Boverkets Byggregler), at The Swedish National Road Administration (Vägverket) and in local municipal plans (Kommunala planer). Those who have applied for and been granted a parking permit are allowed to park in these spaces. The municipality processes the application in which the applicant has enclosed a physicians' certificate and a photo. The permit is only valid for a given period and must be applied for repeatedly. It is not valid on private or state-owned land and thus one needs to check with the owner/responsible contractor first.

The organization of resources, such as parking permits is distributed in the community. Different authorities are responsible for different services. Some are centralized within the organization whereas others are decentralized. Within the responsible organization, every service is also processed differently and has different turnaround times. The organization of the services has been altered over the years. Each service is regulated by a variety of legal documents. What is typical for a great many is that the applicant is subjected to an evaluation to determine if he or she qualifies. The outcome can vary considerably, based apparently upon regulations but also including unofficial documents, presumptions and other agreements by officials.

Medical and rehabilitation resources are certainly of great importance. Without these, individuals would not survive the acute phase directly connected to the injury, nor the rest of their lives when medical complications arise. Many medical disciplines are involved due to the complex medical status of an individual living with traumatic SCI. The organization of such services traditionally comes under different specialists. However, in recent decades the organization has grown more centralized, especially when it concerns acute care and initial rehabilitation. The establishment of referral procedures, which ensure the patient continuity and resources that are already well-defined, is an organizational matter as well as a qualitative one. When it comes to secondary rehabilitation and outpatient care, though, only a few clinics are specialized in traumatic spinal cord injuries. This means that a wide number of hospitals and rehabilitation clinics are to be involved, many of which have no experience in caring for this population.

Contrary to what is valid for resources, it is more obvious how one should act when in need of medical help. At the time of the accident the initial need is attended to by ambulance and acute care personnel. Further transfers to other care units are managed most often without the SCI individual needing to or even being able to apply for these services.

## An abrupt transition

Individuals who sustain a traumatic spinal cord injury have almost exclusively lived their lives as healthy individuals before the injury. Many of them have never been in contact with the societal system of services and resources. This means that they most likely have not been exposed to the gradual learning process of how the system works and the norms that are valid. For the SCI individual, everything changes in the instance that he/she sustains the injury. Beside all the medical implications, living with a traumatic spinal cord injury poses a wide range of new obstacles and circumstances in daily life that must be dealt with. The need for adaptations, accessible environments and resources is obvious, and an extensive and lifelong reliance upon such services will typically be established. The injury per se and its effects on function indicate that the need for resources will be great. Society provides various supportive services in order to restore the person's social integration, re-establish autonomy, compensate for financial and functional losses and facilitate activities of daily living. Medical care such as acute care, rehabilitation and readmissions both on an in- and outpatient basis are essential and cost consuming. Expenditures for other services, though, will also be comprehensive due to their repetitive use in a life-time perspective.

## A complex system

Today, an injured person's service consumption is borne by different authorities: the county, the municipality, and the state, private insurance companies and foundations. As an individual with a traumatic SCI, you will have lifelong and at times frequent relations with theses authorities. Support and services are distributed after a person has applied for them. No services are automatically supplied after an SCI and each can be granted after being subjected to a needs test based on an application with certificates from doctors, social workers, occupational therapists and/or physiotherapists. The case is processed and decided upon at the regional office and the applicant is notified of the decision.

In a report from the National Insurance Department (Riksförsäkringsverket) it was presumed that only a few individuals can have a total overview of the consequences of having several authorities and administrative officials as representatives for resources. And from the perspective of the experts and authorities, little is known of the total effects of all the resources (12).

For a person with an extensive and lifelong injury, contacts with different authorities/agencies will continue for the rest of his or her life. Figure 1 illustrates the complexity of the organization of societal resources and the network of contacts that will be established entirely or in part. Several public authorities are included, three of which dominate: county/region, social insurance office and municipality. The large number of different types of support and service are also illustrated. The structure can vary from region to region in Sweden, but each unit is typically organized as teams for particular types of errands that different administrators deal with. For an individual, this means that many different administrators are and will be involved in all the application processes.

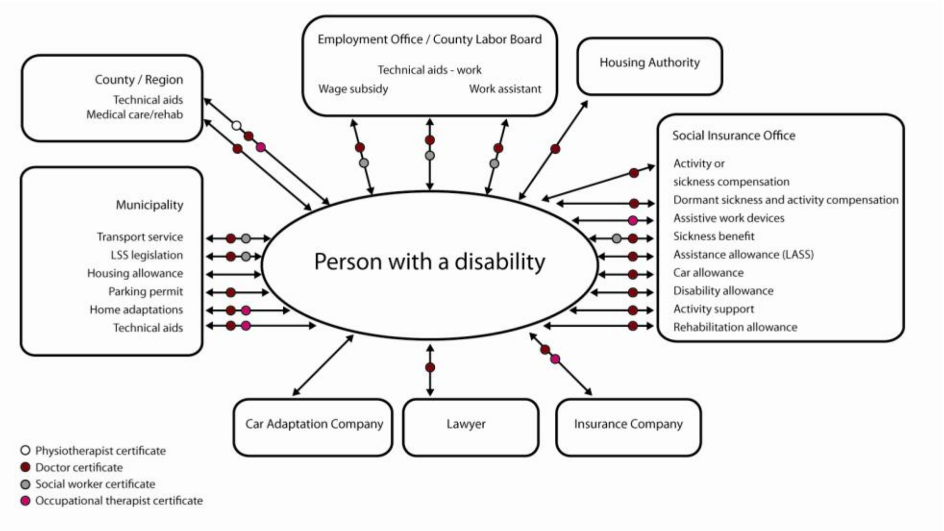


Figure 1. Possible societal contact network for people with complex needs.

## Resources in a resourceful yet resource-limited society

It is well known that resources are finite and thus limited whereas needs appear to be constantly on the rise. This imbalance means that the resources have to be distributed as equitably and efficiently as possible. For those who have lived for several decades with their injury and have been subjected to varying decisions by the authorities according to the prevailing ideology, it is obvious that the resources are not only scarce but also dependent on new knowledge and political fluctuations. New laws and regulations resulting in deteriorations or severely restrictive decisions for applications are frequent. In 2007, for example, the frequency with which you could receive a car allowance was reduced from every seven years to every nine. However, other resources have also been allocated, as when the *Act Concerning Support and Service for Persons with Certain Functional Impairments*, LSS (1993:387) was passed. This Act states the individual's right to utilize resources according to his or her needs and choice of life style (*Assistance Allowance Act*, LASS, 1993:389 as well). In August, 2008 a committee appointed by the Swedish Parliament filed its final report on reform of this legislation. In addition to a number of organizational changes, several suggestions for cutting costs were included (13).

Modern day Swedish disability policy has its origins in the movement of the 1960s to achieve equality for all. Brusén and Hydén describe it as an integrated part of social-political developments that have resulted in the successive emergence of different policy measures. In recent decades this has meant decentralization, deinstitutionalization and self-determination. Resources for people with disabilities are regulated in a number of laws. Their formulation and content reflect the prevailing view of the times and are seen as being among several important tools for improving living conditions (14). The goals of current disability policy are built on full participation in society, equality in living conditions, self-determination, increased independence, the opportunity to establish a life with dignity, as well as the promotion of international cooperation (15). They are derived from the UN's *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* which were adopted in 1993. A government report from 2003 evaluated Swedish disability policies. The living conditions of people with disabilities were compared with those of a selection of the general Swedish population. The disparity was obvious and the report concluded that, "Much remains to be done for the aims of disability policy to be fully achieved" (16). Individuals with disabilities feel they are outsiders who lack support and services and an accessible environment. "It is a matter of a direct and structural discrimination of people with disabilities" (17).

It can be concluded that in spite of extensive legislation, ordinances and regulations aimed at giving individuals all that is required to fulfil the aims of the Swedish disability policy, serious obstacles remain in meeting the goals according to official investigations as well as reports from people with disabilities.

A norm perspective from studies in the sociology of law can be used as the intermediary link between the regulations and society. Hydén explains the perspective as ". . . the norm as an explanatory factor for the understanding of people's actions" (18) and Svensson emphasizes that, "Norms arise as the result of people collecting information about their surroundings and interpreting/reworking and communicating that information so that it becomes the foundation for decision making. To the extent that the information consists of socially reproduced instructions on how to act, it is a question of norms. To the extent that it deals with interpreting material circumstances, the norms arise when these interpretations are socially disseminated in the form of instructions on how to act" (19).

## Previous research

It is difficult to introduce one "state of the art" that covers the whole spectrum of the art of living with a traumatic spinal cord injury in its relation to resources and norms. Only on a very general level is it possible to relate to other researchers, as for instance Jonsson et al. who state that the amount of support from different actors/authorities/organizations makes it difficult for individuals to influence the kind of support and service that can be applied for and received (20). But more specific research about the relation between individuals and the resource system and norms as a whole, and the resulting multifaceted interaction, is scarce. Focusing on the whole spectrum of services that could be adequate for the individual (instead of on only one given service) and which depends on the establishments of norms is rather unique in research situations. This limits the ability to compare with other research findings. Confining the empirical data to only include individuals with a given injury and diagnosis, i.e. traumatic SCI, delimits even more. Including the research question that stems from the individuals' point of view instead of investigating resources from the perspective of authorities or legislation also contributes to the delimiting sphere. This reflection is corroborated in a report from the National Insurance Department (Riksförsäkringsverket). It states that analyses of the whole system of resources is a deprived area. It concludes that knowledge about individuals with disabilities is improving. Still, studies are lacking that focus on the effects of the services on individuals with disabilities.

The necessity for widespread evaluations is obvious and more knowledge about the effects of services is needed, without limiting the analyses due to responsible authority. The report concludes that analyses, to the extent that they occur, have been carried out within the framework of the responsibility for evaluation that is incumbent on the authorities (12). However, research or investigations based on other inclusion criteria could also be of interest and valid in the current discussion. Some of these will be referred to in the discussion section where I elaborate my findings as compared to those of others.

# Aims

The overall aim of this thesis is to elaborate the art of living with a traumatic spinal cord injury (SCI) in its relation to resources and norms in Swedish society. The relation is studied in terms of identifying available resources and then examining the utilization/non-utilization of these services by individuals with traumatic SCI. The relation is also researched by exploring why legislation is not sufficient to achieve the goals of Swedish disability policy. The aim and approach though, are also suited for other lifelong illness or injuries that result in a disability and that are characterized by a similar complexity. The comprehensive aims are formulated in the following objectives:

- Identify the spectrum of potentially relevant societal resources after traumatic SCI.
- Investigate an incidence population's use of societal resources including self-rated levels of satisfaction with the application process and resource allocation.
- Discuss how general ethical guidelines are challenged by situated ethics in a design context.
- Design and implement a validation process to check the completeness of an existing inpatient register.
- Analyze and discuss how a norm perspective can be utilized to understand why legislation is not sufficient to achieve Swedish disability policy goals.

# Material

The research is based on a number of individuals who have incurred a traumatic spinal cord injury. Several sources have been used:

- Stockholm SCI database at Spinalis, Stockholm County, Sweden
- Interviews with an incidence group
- Information material from the social insurance office, municipalities, employment office, county labour board, insurance companies and foundations
- Wording of legislation
- Swedish National Population Register
- The National Patient Register (formerly The Hospital Discharge Register, HDR) from the Swedish National Board of Health and Welfare
- Narratives

## Prevalence and incidence group

The target group was recruited from Spinalis, a comprehensive regional SCI outpatient clinic in the greater Stockholm area and the island of Gotland, comprising about 1.9 million inhabitants. The SCI database was established in the beginning of the 1990s from a survey of regional registers and after individual patient contacts by the Spinalis rehab team. The dropout rate was 6.9% (6). This procedure assured the accuracy of the database as an SCI health care database. Spinalis is a part of the established referral procedure, which insures further incidence inclusion in the database. Whilst diagnosis detection is a problem for many researchers, these studies have the advantage of having access to a population-based cohort of individuals with traumatic SCI. Since the study group actually is a prevalence group, defined as a whole and population based, the difficulty with the representativeness is not of immediate importance. I submitted a retrieval request to the database with the inclusion criteria of living patients with traumatic spinal cord injury. 495 persons met these requirements. Data about date of birth, gender, injury date, level and extent of injury (ASIA) and cause of injury were collected for each individual.

## The National Patient Register

The inpatient care utilization of the prevalence group over time was studied using data from the National Board of Health and Welfare's National Patient Register (formerly The Hospital Discharge Register, HDR). Statistics of diseases and surgical treatments of patients have a long history in Sweden. In the 1960s, the National Board of Health and Welfare started to collect data on individual patients who had been treated as inpatients at public hospitals (www.socialstyrelsen.se/en/about/epc/Centre_for_Epidemiology.htm). Since 1972 the county of Stockholm has reported all inpatient care to the National Patient Register. There are different types of information in the inpatient register: data on the patient and hospital, administrative data such as date of admission and discharge, and medical data. For all records reported to The National Patient Register, data and quality controls are carried out.

The unique personal identity number assigned to each Swedish resident retrieved through Spinals was used to obtain data from the HDR. Information about each person's registration regarding hospital/institution, clinic, unit, date of admission and discharge were collected. Data analysis was carried out from 1972 through 2002.

## Narratives

In order to be able to live one's everyday life and understand what is happening as well as to solve problems and examine alternative courses of action, we convert practical experiences into language in the form of a narrative (21). The narrative constitutes, as it were, a means of understanding an individual's attempts to manage his or her life situation. Interest in narratives as a research tool has increased as has their significance in social sciences studies of medicine and illness, among others. According to Hydén, what characterizes narratives about illness "... is that they formulate and express a central aspect of being ill in modern society, namely the difficulty of giving voice both to suffering and to the lifeworld context of illness" (22).

The purpose of the narratives in Papers I and IV is to convey an experience that embraces a number of people's individual situations with feelings and details in relation to the lifeworld. Searching for empirical knowledge among people with their own experience of living with a comprehensive disability is thus essential. With examples from situations where dissatisfaction arises in the operationalization of the disability policy goals or in the meeting with society, two different empirical collection methods have been chosen. One is based on written, published narratives of different people; the other on my own narratives (i.e. autobiographical narratives).

# Methods

The approach is grounded in a sincere respect for the differences between the experienced and lived disability on the one hand side, and the medically diagnosed or societally judged disability, on the other. The thesis per se is proof of the existence of such differences: my results differ significantly from the results of research in which subjects are neither individualized nor followed longitudinally.

The research presented is based on quantitative as well as qualitative methods. For the register study in Paper III, and in the semi-structured interviews in Paper I, a quantitative approach was used. In Paper II a number of design cases are in focus. Papers I and IV elaborate on narratives out of qualitative methods. The methods are described in each paper. Here I would only like to contribute some additional perspectives.

The approach to this field is strongly influenced by my pre-understanding, some of which probably cannot be explicitly formulated since it is so deeply rooted in me. I have lived with my traumatic SCI as a child, teenager, adult, university student, employee, researcher, partner, mother, daughter, friend, etc. In other words, I have been "involved through situated action" (23). Jönsson et al. discuss further in the book *Situated Research and Design for Everyday Life* how the researcher's opportunity and ability to be involved (compared to the possibilities for a researcher who is a freshman in the field) can influence methodological applications and result analysis. Narratives and episodic stories from persons and organizations are integrated with my own experiences and form an integrated background from which to examine and evaluate the data and emerging patterns. I consider myself as an important case and thus as an eye-opener when exploring the field and the data. There is a lack of case studies to refer to in this field; the need for well-elaborated case studies from which guiding examplars can be derived is obvious. I agree with Flyvberg (24) when he states that a discipline without examplars is an ineffective one. The exclusive use of register studies is not sufficient, nor are data from interviews and narratives. This thesis presents an effort to combine the two in order to capture the actual use of resources for this group (i.e. not attitudes, not reflections, not physiological or psychological effects but actions represented by resource usage).

In my publication list at the beginning of this thesis I have chosen to include the study entitled *Intuition in Design & Emotion?* from a related scientific area. There are two reasons for this inclusion. The first is to show my involvement in design contexts. The second is to present the quantitative methodology also elaborated on design research.

## Posing questions – semi-structured interviews

A two-part questionnaire was constructed for the interviews in Paper I. The first (Table 1) surveyed what services the persons had or had not applied for in a one-year period. The second (Table 2) focused on the application process as such and the extent to which the resulting service allocation agreed with what was applied for. It also asked the respondents to rate their level of satisfaction with the administrative handling. I did not ask the interviewees to enumerate all the services they had applied for so as not to put pressure on them to remember or feel they had to check their papers. I knew this would have been a virtually impossible task and that the results would be unreliable. Instead, all services were listed (with the option to add others): the respondent only had to answer “Yes, applied for” or “No, not applied for”. This procedure was chosen in order to avoid the interviewees’ neglecting a service. Questions about why a person had not applied for a service (if this was the case) were formulated with the intention of finding disparity in usage. Three alternatives were thus identified: the person was already receiving the service; the person did not claim to need the service in the actual year; or the person did not know about the service. By interviewing an entire incidence group and not just the individuals who received a given service, it was possible to examine the reasons why a service was not utilized.

## Table 1. Questionnaire Part 1. The kind of resources

The informant was asked about the following resources and where he/she had applied for them (local social insurance office, employment office/employability institute, assistive technology centre, municipality, housing authority, other). Each question was first answered "Yes" or "No" with the follow ups: "Did not know about the resource? Would you have needed to know about it? Had you already received it? Other?)

**Support**

1. Disability pension?
2. Temporary disability pension?
3. Sickness benefit?
4. Disability allowance?

**Work**

5. Education subsidy?
6. Rehabilitation allowance?
7. Wage subsidy?
8. Work assistant?
9. Assistive work devices?
10. Workplace adaptation?

**Housing**

11. Priority?
12. Housing allowance?
13. Home adaptation?

**Transportation**

14. Car allowance?
15. Car adaptation?
16. Parking permit?
17. Transportation service?
18. National transportation service?

**Human assistance**

19. Personal assistant?
20. Home help services?
21. Home health care?
22. Other personal (companion)?

**Technical Aids**

23. Technical aids?

**Other**

24. Were you in need of other resources in 1998 that were not available for you to apply for? If so, which ones?

## Table 2. Questionnaire part 2. Application procedure

### General

1. Are you a first time applicant?
2. How did you get the information?
3. Was the information clear about your rights, possibilities, responsibilities? (4-grade scale. Encouraged to explain and give examples.)
4. How did you apply for the allowance? (Filled in a form? Telephone contact with case worker? Other? More alternatives possible).
5. Were the forms/instructions easy to understand? (4-grade scale. Encouraged to explain and give examples.)
6. Did you have to supply supporting documentation? (Yes/No, Certificate from doctor? Social worker? Occupational therapist? Physiotherapist? Other?)
7. How did you obtain this documentation?
8. How long did it take after the initial contact for you to receive them?
9. Was the content of the documents in agreement with you understanding of you resource needs? (Yes/No, How did it deviate? Was the process delayed because the application was incomplete? What did the delay consist of?

### Case worker contact

10. How did the contact take place? (Telephone? Letter? In person? Other? More alternatives possible.)
11. How were you treated by the case worker?
12. Was the case worker quite familiar with your situation? (4-grade scale. Encouraged to explain and give examples.)
13. What were you expectations of the content of the decision? (4 alternatives: received all that was applied for, part of it, rejection, other.)
14. Were you informed of the possibility/right to be present when the decision was taken?
15. Were you present when the decision was taken?
16. How long did it take (from submitting your application until you received notification of the decision?)

### Decision

17. Was the decision in accordance with your application?
18. Were you satisfied with the content of the decision? (4-grade scale. Encouraged to explain and give examples.)
19. Were you provided with information about you right to appeal?
20. Did you appeal?
21. What did that result in?
22. What has the decision meant for you, positive and negative?
23. How long did it take before the decision went into effect?
24. State your level of satisfaction with the entire application procedure. (7-grade scale)
25. Give 3 important suggestions for improvements in the application process.
26. How has the entire process affected your rehabilitation?

## Posing questions – The National Patient Register

The prevalence group's inpatient utilization over time was examined using data from The National Patient Register of the National Board of Health and Welfare. The register in the region examined is complete from 1972 on those who were injured earlier (n=58) were excluded from this study. In processing the data from the inpatient utilization study, unexpected information was observed at different points in the analysis. This information was detected more or less by chance. The first detection led to further investigations which resulted in the formulation of three questions related to appropriate expectations of the content of an inpatient register for traumatic SCI individuals. One would assume that sustaining an injury would lead to immediate care. Thus the first question was: Is an inpatient stay registered in association with the injury date? It was also assumed that having a severe injury would involve a great amount of inpatient care. The second question was thus: Is the reported first hospitalization episode plausible given the level and extent of injury? Since a range of care providers are involved in the rehabilitation of an individual, the third question was formulated as: Are all the anticipated care and/or rehabilitation providers represented in the register? These three fundamental questions were used to assess the validity of the material.

Based on the three questions, I was able to determine that the group's total inpatient utilization could not be established on the basis of data extracted from The National Patient Register. It was apparent that the register first had to be validated, at least on the three essential criteria stated above, in order to be of use for further studies.

## Narratives

Interviews, published narratives and additional narratives related by others and my own complemented the outcomes of the register studies. The published narratives were located by searching the web pages and publications of different interest organizations and by using Libris, a national search motor for titles at Swedish universities and research libraries. The lived disability is not as easily or exactly assessed as is the traditionally diagnosed and treated disability. But the narratives and other examples could not be excluded just because they do not satisfy the objectivity criteria of disability professionals. For the experiencing person, the story she narrates represents a truth, and many such narratives taken together can be an important source of information. The narratives are used as a medium and as a tool to illustrate inter-individual variations as well as the intra-individual complexity of how the administrative process is handled (Papers I and IV) in order to examine the double sets of norms, i.e. the norm confusion between the experienced world and the expected.

# Results

The results of the studies presented in the papers are presented on two levels. The first level is a reproduction of the results as they are described in each paper. The second consists of an interpretation of the results and some cross perspectives.

## Results from the studies

In Paper I, about 25 separate services were identified as being available for persons with traumatic spinal cord injury. Each service has to be applied for separately by the applicants. The average number of applications per person was 5 (range 0-11). The most common service was "transport service" followed by "home adaptations" (See Fig. 1, page 14).

There were 13 available services for which at least 1 subject claimed ignorance about the given service's existence. Ten persons (out of 34) answered that they did not know about the "disability allowance" service. 17% of the applications were partially of totally rejected. Most subjects received information about available services from a social worker. Generally, the individuals were more satisfied with outcomes of their applications than with the handling process as such.

Paper II. Applied ethics in research is no longer regarded as a concern only for the medical field. Examplars in ethics from other fields such as design are, however, meagre, as are relevant practical and design applied guidelines. The more ethically grounded a given area of research is, the greater the chance it can contribute to long-term meaningful breakthroughs in knowledge. An improved ethics in design can enable a critical questioning that in turn leads to entirely new research questions.

This was the background for Paper II where we elaborated the differences between situated ethics and efforts to follow more general ethical rules such as the Nuremberg Code, the Helsinki Declaration and The European Convention (with its explanatory report). None of these has been formulated based on experiences from design of civil products for everyday life. Nonetheless, ethical aspects are definitely present in test usages as well as in the influence of the resulting technology in later, everyday use.

The study presented in Paper III validated a national inpatient register and concluded that about 62% of the group (n=257) had an inpatient stay reported in direct connection with the injury date, leaving 38% with their first hospital stay registered 2 days or more after the injury date. Seventeen persons did not have any inpatient care at all reported after the injury date. Length of stay ranged from 2 to 653 days during the reported first hospitalization period. Some individuals with a severe injury were registered as having utilized only a couple of days in inpatient care. This result seems highly unrealistic and requires further investigations. Even though the group had utilized care at 42 different hospitals/institutions and 47 different clinics in the investigated area from time of injury through 2002, at least 5 institutions/rehabilitation units were not represented at all in the register.

The results presented in Paper IV show that the individual's everyday experience runs contrary to the prevailing, expected norm. The individual cannot identify with everyone else or rely on the current, expected norm to prevail. Instead, other norms come into play that cancel out the expected one. Consequently, the individual lives under a double set of social norms. This results in the individual being excluded instead of being equal and able to participate.

## Some cross perspectives

Reality is made up of single components, perceived as more or less coherent structures. In Paper IV on norms, I illustrate through examples how different cross perspectives appear in everyday concrete situations:

- Application for assistance (the power play involved in resource application and decision)
- Dependency on neighbours (reliance on good neighbours in a dependency situation)
- The balance of errands (when the individual becomes "an errand")
- Mother in a wheelchair (when the needs fall outside of the existing regulations)
- Student in Lund (opportunity to study includes only some aspects, decided by others)
- At the cinema having to face other risks (to be left without my wheelchair and so being extremely dependent on others in the case of an emergency) and other exclusion criteria different from those of the general public (only a limited number of tickets allocated for individuals with certain kinds of disabilities.)
- Housing (when forces in society outside of your control determine where you can live)
- Sick leave after a caesarean section (when the individual's entire health situation is not taken into consideration)

In addition to the results described above and in the papers, there are also results on more generalized levels that can be described as follows:

- The individual longitudinal approach
- Time consumption
- The same design for lifelong as for temporary societal resources

### The individual longitudinal approach

Information about the utilization of societal resources on the individual patient level is not collected in any one database or register in Sweden. Thus, it has to be collected from primary sources (the individuals) or from existing isolated records. It is necessary when doing so to have considerable familiarity with the types of services that are currently available and appropriate in order to obtain a complete collection. In Paper I the method of listing possible services was used instead of letting the interviewees' relate which services they had utilized. This was because the respondents had some difficulties knowing exactly what allowances they had actually received (i.e. were paid out). This happened when the respondent received several services from the same authority and payment was disbursed in a lump sum. When collecting data from isolated records the quality and relevance of the data supplied should always be checked. Paper III describes the risk of using a database without first validating the contents. Drawing conclusions based on the assumption that a diagnostic group's utilization of inpatient care is the same as the contents of the database results in a considerable underestimation of the group's actual total utilization. Investigating resource utilization from the individual longitudinal perspective produces results that differ from an "on-the-spot" approach. The discovery of systematic errors presented in Paper III was due to investigations that were made on an individual level and in the long-time view. If only data taken over a short period had been examined and on a group level, the likelihood of detecting the information that was lacking would have been much lower.

Consequently, this approach yielded results that differed from studies based on statistical overviews without a consistent individual focus that stretched over time. The advantage with the snapshot studies is that they can present data in one time frame and in one context. But to a person living with a traumatic spinal cord injury, it is the usage of resources over time that is the reality, not the snapshots.

The longitudinal aspects can be valuable for health care utilization predictions. Mine is the only study reported that follows patients so long and therefore is able to provide a better longitudinal basis for planning. For the 257 persons whose hospital stays I analyzed from 1972 through 2002, it was shown that they returned to the hospital in all 1600 times during that period. The individual variation was great (0-73 times, average 6, median 3). The duration of the episodes was from 1 to 1198 days (average 17, median 4) and the person with the most hospital days was an inpatient for a total of 2710 days.

### Time consumption

No services are at the individual's disposal automatically. Information about available services is most often given by the social worker during the individual's initial rehabilitation. However, contacts with the social worker diminish as life goes on and the need for services requiring new applications or re-applications will be on one's own initiative. For those who have lived with an injury for a long time, they know from experience that the resource system alters. Transparency is low and changes in regulations, resources structuring and labelling are frequent. This means that the individual must learn about the system over and over again, every time he or she needs a service.

### The same design for temporary as for lifelong societal resources

When you have a traumatic SCI your contacts with the authorities in terms of resources will be frequent, extensive and comprehensive for the rest of your life. This dependency on the system is a source of frustration for the individual, and the norm conflicts presented in Paper IV become obvious. The SCI individual's everyday experience runs contrary to the prevailing, expected norm. This does not just happen occasionally but is repeated and reproduced over and over again.

The permanent nature of an SCI is a great disadvantage in a resource distribution system where the procedures for SCI applicants are identical to those for people with shorter-term resource needs. Other routines need to be introduced into the system – ones that enable the person with an SCI to live with it over time. Aaron Antonovsky (25) has made it clear that *the sense of coherence* and the ability to cope require not only participation but also comprehensibility and manageability. The existing system is neither comprehensible nor manageable.

# Discussion

No comprehensive study has previously been carried out on this diagnostic group and the services utilized in Sweden. Individual types of services have been examined by Levi et al. (26;27), for example, which describe the utilization of prescription medicine, disability pensions and temporary disability pensions by 326 persons in Stockholm by using data gathered from the annual *Level of Living Survey* (*Undersökning av Levnadsförhållanden*) distributed by Statistics Sweden.

## The need for a time frame

Knowledge of the resource utilization that results from illness or injury is important as a basis for planning and prioritizing research, prevention, health care and rehabilitation (28). The utilization consequences of chronic conditions are difficult to study since the services are utilized over a long period, involving a number of different actors who neither economically nor operationally come from organizations that share a common vision or are any way coordinated. Consequently, remarkably little is known of the total effects of all the collective supports together (20). Since a traumatic SCI is a physical and generally non-progressive state, one would expect the utilization of resources to be fairly consistent over time. When determining the level of support and aid, it is the individual's needs and shortcomings that are in focus and that are evaluated. However, when looking retrospectively, the utilization has changed over time, also independently of the SCI conditions for an individual. The utilization is, of course, related to the services that are available, and the services offered, in turn, are a product of the time period studied. Changes occur not only due to medical developments but also to the society and its changing norms. Studying and surveying utilization of services require the analysis to be carried out and presented in a time frame. A longitudinal investigation of the use of societal resources turns up results that must be interpreted, not only in terms of quantity but also in a context.

Legislation in the disability area has progressed from institutionalization to integration into the community, and resources have been made available over several decades. When the *Act Concerning Support and Service for Persons with Certain Functional Impairments*, LSS, (1993:387) was passed, the individual's right to utilize resources according to his or her needs and choice of life style was emphasized (29) (the *Assistance Allowance Act*, LASS, 1993:389 as well). The individual's functional ability is only one of the factors that govern service needs and utilization. Another is treatment – the way the person is received – which is thoroughly analyzed in a government report by Bengt Lindqvist (29). These are influenced by the administrator's work situation, the system of complicated and unclear rules and regulations that are often modified, limited resources and changes in values. Other examples of influencing developments and altered approaches are hospital care and self-care and their effectiveness, technology, policy, allocated resources and public attitude towards people with disabilities. An example of a political measure is the disability pension, which was intended for individuals who for medical reasons had a reduced work capacity, but that from 1972 until 1990 was also granted for purely labour market reasons (30). An example of insufficient funding is the annual car allowance budget. In recent years, all the funds have been spent before the end of the fiscal year and late applicants have had to wait until the next fiscal year.

## Disability definitions

Whilst diagnosis detection or other definition criteria are a problem for many researchers, my studies have the advantage of having access to a population-based cohort of individuals with a traumatic SCI. The Spinalis database was established in the beginning of the 1990s from a survey of regional registers and after individual patient contacts, review of medical records, interviews and physical examinations of subjects. The dropout rate was 6.9% (6). This means that the differentiation by Grönvik into different disability categories in relation to what is studied – the functional, environmental, administrative, subjective definitions and the social model of disability (31) – which may be useful in other contexts is of no relevance in my studies. The administrative definition is often used in a range of official reports and research when the effect of a certain societal resource should be investigated. A problem with this definition is that only individuals who actually draw a resource will be included, leaving those without the resource outside. The group studied will thereby appear smaller than the actual group "suffering" from difficulties (1). "Defining some people as disabled and some as not allows authorities to distribute support to some people, but at the same time provides arguments for not giving support to others. Although some people long for a society in which everyone who thinks s/he needs support gets support, the realistic picture is quite the opposite. Most countries, in the EU as well as outside, are fighting the rising costs of social security. This will likely strengthen the need for definitions that clearly indicate who should receive and who should not. Thus, two important agents of the administrative definition are politicians and welfare authorities." (31). The selection of inclusion criteria will influence the result and the interpretation of these. Investigations based on a prevalence group are rare.

## Being in need of

The term "being in need of" is consistently used when it comes to requesting resources. The prominent position of the need concept in the social policy field or in social work, however, is not matched by any well-developed ideas about or clear definitions of what the needs really are. The lack of agreed definitions means that the reasoning behind the decisions is often unclear and that the scope for questioning their legitimacy increases (32). The list of possible services and resources could be interpreted as an expression of the kind of need that will be financed by society. The need that the individual expresses or that is interpreted by the social insurance officer is at risk of not being given the status of a "legitimate need" until there is an established corresponding resource that one can receive. Sometime, somewhere, someone has determined which needs are to be met. There are regulations that cover reimbursement for housing adaptations for one's permanent residence, but they do not stipulate the number of times reimbursement can be granted. Adaptations for one's summer cottage and aids to be used in spare-time activities are examples of support that one cannot received compensation for. Paper I describes actual utilization in the traumatic SCI population. It is not possible to tell from the data whether this corresponds to the individual's needs for care, support and services. Paper I indicates that utilization would perhaps have been higher if the group that did not know about a given service had actually applied for and received it.

The support system's requirement for rational solutions can result in problems for the individual. According to a report from the National Insurance Department (Riksförsäkringsverket), several of the people interviewed related situations where their everyday lives and living conditions were not in agreement with the system's general construction (12). A spent resource is the result of an expressed or interpreted need that is granted, whilst an unspent resource could be the result of not being in need or an expressed or interpreted need that has not been fulfilled. This division is important whilst if it is not fully understood, studies and reports that analyze utilization could result in an underestimation of the resources needed.

## Defining utilization

Measuring and surveying utilized services is complicated for a comprehensive, lifelong and complex condition. As previously described, a number of different authorities are involved and the types of support are many. Since the condition is lifelong, many are young when the injury is incurred, and since their life expectancy is normal, the individual will be applying for and receiving different kinds of support and service for a long time. The support will vary depending on need and life situation. It is, as a rule, time limited and has to be applied for iteratively. Other types of support can be applied for when there is an existing need but sometimes it is unclear how many times you will be able to receive it (e.g. home adaptation).

Despite the unique National Patient Register, even inpatient care utilization proved to be complicated to assess. Figure 2 illustrates the many sources that have to be considered in order to establish the total inpatient care utilization in a prevalence group. The number of people who utilize health care and the extent to which they do cannot be determined from the available material in the studies presented here.

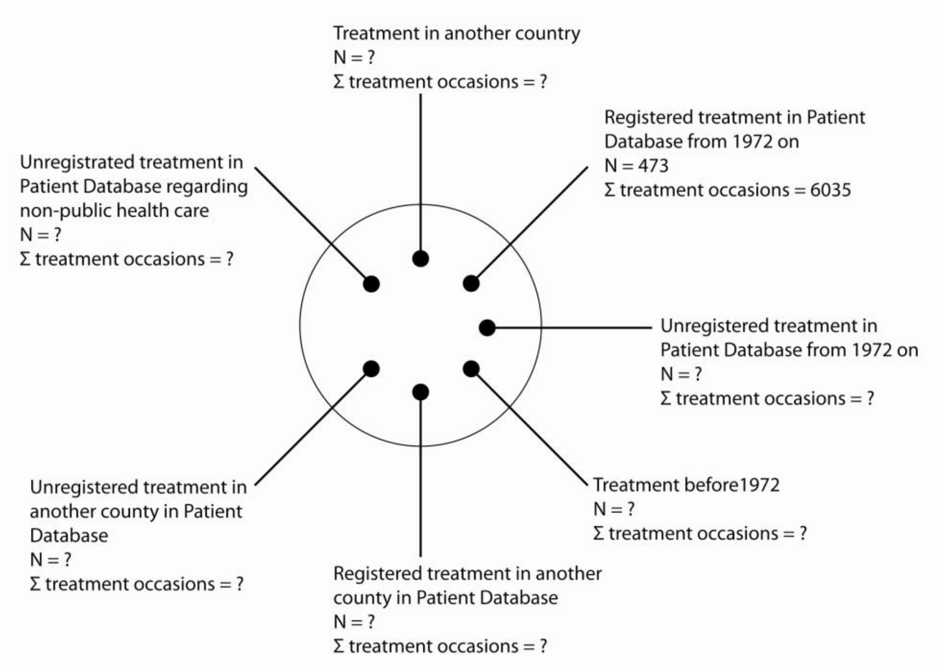


Figure 2. Sources for establishing the total inpatient care utilization for a prevalence group (n=489) up to and including 2002.

## On the individual's initiative

A great amount of support, service and care is allotted to people who are in need. Paper I reveals, however, that the number of services and their organization are difficult to grasp and cause considerable anxiety for the individuals affected. There is no existing structured and formalized information on all the support; one gathers this information by making inquiries instead. At the same time since the support is complex, the individuals are often inexperienced in filling out forms and understanding the language of bureaucracy. The system of complicated and unclear rules and regulations is often modified (33), and spending is changed or just suspended due to insufficient funding. The social worker at the hospital or rehabilitation centre plays a central role in providing information about the types of support, and assists the individual in the application process. This source of information is also corroborated by other studies, e.g. Hetzler (34). Results showed that no service or allowance is automatically at one's disposal. All of them have to be applied for. In the qualitative investigation carried out by the National Insurance Department (Riksförsäkringsverket) (12) and based on interviews describing the experiences of societal resources for individuals with a disability, it was argued that this approach of the individual as an active subject was highlighted in the 1994 *Disability Reform Act*. The effect has been that services have to be applied for actively by the individual. The political motivation for this was twofold: First, that the general system of services should include possibilities for individual variation. The needs and conditions of the individual should serve as guidance when supplying the services. This individualization has long been manifested in Swedish disability policy. The second emphasizes the initiative on behalf of the individual when he or she identifies a need for a service or support. The policy focused on the individual's right to integrity and self-determination and a way to achieve this was letting the individual receive services when and only when the he or she so wanted (12). This individualization has, however, had some negative consequences. Several of the people interviewed in the Paper I study reported that they were unaware of certain available services, which indicates that the transfer of information about support and services is vulnerable. A number of applications were rejected, entirely or in part. This involved primarily disability benefits and car adaptations. In an investigation on living conditions in 2005 of about 1000 individuals with inter alia mobility problems, it was concluded that most did not draw a disability allowance. An explanation given for this is lack of knowledge about the resource or rejection of the application. Many in the investigated population said that the allowance did not cover their expenses (17). In the Hetzler study more than 3000 applications and decisions were investigated in 1986 and 1987 and the rejection rate was about 30%. Hetzler explains that how and when the applications are granted is dependent on the pressure on the social insurance office in terms of amount of errands and the previous allowance history, and on processes within the organization. Hetzler certifies that the need for resources varies depending on type of disability which is also reflected in the decisions from the social insurance office. However, it is pinpointed that all applications represent a need experienced from the individual's point of view (34).

A National Insurance Department (Riksförsäkringsverket) report stated that, "The increased emphasis in the disability reform legislation on the individual taking the initiative in applying for services has meant that people who are unable to do so risk missing out on them. The report supplies examples of people who were not aware of the services that were available" (12). Contacting authorities and explaining service needs requires that the individual knows where to turn and how to explain their request for resources. Studies suggest that this form of individualized efforts may have limited the number of people who receive the support and services they are entitled to (1;12).

## The authorities' versus the lived perspectives

Much of what is described of the lived perspective is expressed not by the person experiencing it, but is to be found in reports published by the authorities. This is also corroborated in an official report that surveyed knowledge about attitudes towards persons with disabilities. It concluded that research from the individual's point of view is a rare occurrence (35). Much more common are reports that investigate resources from the authorities' perspective or from that of legislation. There is a wide range of official reports. Here descriptions and analyses of the situation for individuals with disabilities in terms of such factors as treatment, integration and disability policy are elaborated upon. These reports are extensive and include at times, in addition to empirical data, theoretical frames and literature reviews of the subject at hand. More uncommon are narratives written by individuals with a disability relating how they live their daily lives. Even though they contain descriptions of the relation to the resources and norms in society, they are often short and only describe a few areas in life.

A thesis by Jarkman deals with everyday life in families who have a child born with an impairment. It explores inter alia the relations to health care and authorities. Lack of information regarding the resources and insufficient experience from the authorities are reported. The results are discussed in terms of similarity and dissimilarity and show how the families live in a world which is similar to the world everyone else lives in, but at the same time dissimilar due to the disability (36). This corresponds to the study presented in Paper IV, which discusses how the individual is unable to identify with everyone else and thus actually lives under a double set of social norms.

In another thesis by Jacobson, life conditions experienced by persons who require extensive assistance is investigated (37). Jacobson discusses how a person's identity is affected by the fact that decisions concerning the need for assistance are made in society's name. These decisions seldom correspond to the ideology of solidarity that characterizes the public debate in Sweden. In an official report, *Checked Up On and Questioned* (*Kontrollerad och ifrågasatt*), thirteen people with disabilities were interviewed about how they were treated. All had similar experiences expressed in such statements as, "You have to argue to get what you need", "Man, nothing to do but appeal", and "It takes so much energy to cope with all these battles" (38).

Peterson, Ekensteen and Rydén in their research on how people with disabilities perceive and handle their situations and themselves, criticize the medicalization that describes and shapes the existence of people with disabilities. The main theme elaborates on an activity focus, i.e. how people handle their contacts with the health care bureaucracy and the public as well as how one's self-image is impacted by the disability (39). This focus differs from mine, which highlights the degree of utilization of resources and what actually is possible to achieve.

The conclusion reached in Paper I, is that individuals were less satisfied with the application process than with its outcome. This result is in line with Hetzler's study on disability allowances and individuals with disability (34). She establishes that, "The studies on the Swedish social insurance legislation and its application that have been carried out up to now have demonstrated considerable problems precisely in the application route. The application is not uniform, the law's intentions are not realized in the application process, and the individual's ability to benefit from the rights that the laws regulate is limited by a series of obstacles."

It can be discussed whether the individual should put any effort into trying to learn about the societal system and regulations or instead let the street level bureaucrats act as advocates after the initial contact. In an investigation of resources to individuals with disabilities, the relation between the applicant and the street level bureaucrat is described to include the aspect of power. The bureaucrat has great influence over a decision that could set limits on the individual's ability to impact his or her life. Several individuals state that it requires a great deal of time, effort and personal resources to be able to assert their claims before the authorities (12). Davidsson's book is addressed to students and administrative investigators on how to handle support and applications for services. Davidsson states that, ". . . individuals are uncertain if they dare to also describe what they are actually able to manage. The aim of the evaluation is actually to determine the individual's inability to manage different situations. . . . Individuals have described that they are worried about missing out on a given type of assistance because they can manage certain activities and situations. The case worker needs then to try and convey assurance by explaining that the purpose of the evaluation is to determine the need of and right to services, not possible reasons to deny the application." (40). The population studied in Paper I reported partial or total rejections for a range of resources. For more than 50% of them this was for the services “Disability allowance” and “Car adaptation”.

In a government inquiry about treatment of individuals with disabilities from inter alia social insurance offices, more than one quarter thought that individuals would actually be met with negative attitudes in contact with social policy and social insurance office personnel: “Complaints that reach the personnel are primarily about processing times that are entirely too long, insufficient support, support that was not received, and not being evaluated on the basis of their own needs.” Explanations given were the social insurance system’s rules and regulations that are entirely too complicated, lack of resources, coordination (1). Hetzler’s experiences from investigating the foundation on which and how the disability allowance will be granted or rejected were that the authorities and politicians were somewhat indifferent; a legal right was perceived as an easily achieved goal in itself, and evaluations of the justice and development were not considered to be social-politically motivated (34). It can be concluded that the relation between the authority and the individual is complex and difficult.

## A burden?

Despite their eligibility for services, several experienced themselves as a burden on society. The services granted are seen by some as a confirmation that they are not self-sufficient (12). It was noted in people’s narratives that they are defined in terms of negation and weakness. Definitions emphasize what the inability of a disability means. This in turn leads to the disability overshadowing everything else, and being disabled becomes synonymous with something negative and tragic (35). This view of people with disabilities is also confirmed in Paper IV. Medical progress and the view of individuals with disabilities are two of the factors that influence the situation. In general, people with disabilities are much like the rest of us. They share similar dreams of professional identity, family, housing, social activities, etc. The design of the societal service system does not, however, correspond to the fact that these individuals want to live like everyone else. The time they must invest in contacts with authorities detracts from the time they may wish to be spend living just like anybody else.

A quotation from the description of the book written of Peter Brusén after he sustained a traumatic SCI will serve to conclude this discussion: “Based on his own experiences, he discusses if society in practice is a partner or an opponent in the struggle of a person with a disability for increased accessibility and participation in the social life of the community.”(41).

## Epistemic risks

The risk of not knowing or not knowing enough is very difficult to handle methodologically. Lack of robust knowledge may lead to incorrect results and actions. Sahlin (42) states that research is a dynamic process which sometimes will result in actual results. But if we examine the results without inclusion of the research process it means that we neglect the epistemic risk. An extension of the aim of this thesis would be to make prognostic judgments of what individuals with SCI will use in the future. Thus, the epistemic risks ought to be elucidated and elaborated upon. The following risks have been recognized:

### Usage versus need

The inpatient care is surveyed via The Hospital Discharge Register (HDR). The usage per se does not as discussed, however, say everything about the need. From a superficial point of view, there is no restriction stating that care will not be given if there is a need in Sweden. In the investigated region, Stockholm, no person has a long geographical distance to a hospital or care-unit. Distance could otherwise result in less usage in spite of need. Care is not, in a broad perspective, limited in terms of accessibility or due to high fees. The epistemic risks here, rather, deal with how individuals behave. Do different individuals define their needs differently and thus allow this to lead to different levels of usage?

### Registers as a representation of reality

Different methods could be used when surveying inpatient care in a longitudinal and retrospective perspective. One alternative is to ask the individual, but this might not result in the most reliable data retrieval due to the time spectra and absent-mindedness on the part of human beings. The statement from an individual would not necessarily represent the actual reality. Another way would be to examine medical records. Taking into account the great number of hospitals that have been involved in inpatient care over the years, this would be an unreasonable task, the results of which would also risk not being complete. The HDR is accessible and also recognized as an accepted form of reality. The Swedish National Board of Health and Welfare carries out quality controls with good results and many researchers do use this register. Despite this, it was shown in the Paper III study that inpatient services that have been utilized are not registered in the HDR.

### Inpatient – Outpatient – Self-patient

The medical sphere is developing and altering. New techniques, new knowledge, new analysis methods and different approaches lead to different treatment and care. Conditions that a decade ago resulted in inpatient care can be treated today on an outpatient basis or even as self-care. The view of the patient and her own responsibility, commitment and motive has changed. What will change and when is difficult to predict. Thus, an epistemic risk is that the retrospective survey of inpatient care does not say so much about future usage.

### Usage yesterday – Usage tomorrow

The aim of surveying retrospectively on an individual level is that this information could say something about the future. But what do we know today about usage tomorrow? Perhaps a breakthrough in SCI research will lead to a cure. Or perhaps our national economy will collapse, which would lead to quite different prerequisites. The assumed relation between usage yesterday and usage tomorrow, on an individual level or a cohort level, might be too simple.

# Further studies

My hope is that this thesis with its pioneering character will inspire others to dive into the field of "The art of living with…." out of different and more specific perspectives than mine. I am not the one to be able to foresee which among all the different approaches could be most fruitful to start with – that will have to emanate from the scientific contexts and the areas of interest of the researchers. Without such a bouquet of approaches, however, the research community will find itself far behind the important issues of the contemporary empowered individual, so apparent in culture and society.

My own interest is to proceed into the area of housing and living. Here, the individual is still being excluded instead of being equal and able to participate. The current political, economic and other trends in society are to no longer build one-storied houses but only one-and-a-half, two- or three-storied houses to maximize the use of land area.

# Conclusions

The multifaceted norms and societal system in combination with the complex effects of the injury result in considerable difficulties not only for the individual with traumatic SCI but also for a researcher wanting to describe and analyze the utilization of societal resources from a lifelong perspective. The seven most important research difficulties are:

1. The lack of comprehensive studies stemming from individuals' narratives of their relation to resources and norms.
2. The need for reliable statistics.
3. The need for more narratives from individuals to contribute missing perspectives.
4. The possible underutilization of societal resources for a variety of reasons.
5. The special analysis required in the field of information transfer and its accessibility.
6. Elaborations on ethical and existential perspectives – "Who knows what I need?"
7. Since failings due to an impairment are not only due to the individual at the very moment of the failing, these should be elaborated out of an extended time frame, considering norm supportive structures.

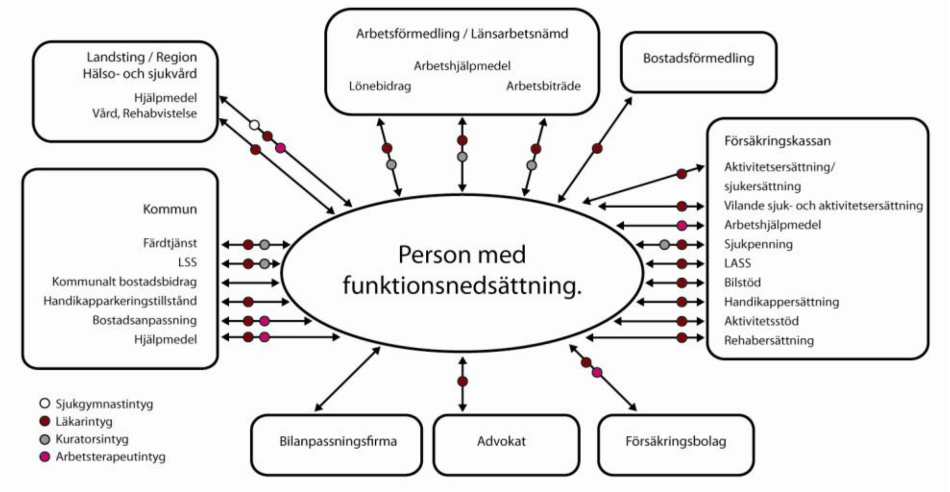
# Svensk sammanfattning

Att drabbas av en ryggmärgsskada innebär ett stort trauma. En traumatisk skada innebär att ryggmärgen har skadats av fysiskt våld och effekterna på de fysiska funktionerna är omfattande med risk för allvarliga komplikationer, många blir livslånga rullstolsanvändare (5). De vanligaste skadeorsakerna är trafik- och fallolyckor (6). Det totala antalet människor som lever med en skada kan anses vara en liten grupp. Emellertid kommer majoriteten att leva länge med sin skada, eftersom de flesta är unga vid tiden för skadan, det inte finns något botemedel och den förväntade livslängden närmar sig genomsnittsbefolkningens (2).

Individer som drabbats av en traumatisk ryggmärgsskada har nästan uteslutande levt sina liv som friska individer utan några skador före skadan. De flesta har aldrig haft kontakt med olika samhällsstöd och det svenska stödsystemet. Detta innebär att det för individen aldrig har funnits någon läroprocess kring hur systemet fungerar och vilka normer som föreligger i dessa möten. För individen förändras allting i det ögonblick som han/hon skadas. Att leva med en skada innebär förutom alla medicinska konsekvenser en rad olika hinder och omständigheter i det dagliga livet som måste hanteras. Behovet av anpassning och tillgängliga miljöer och samhällsstöd är uppenbart och ett omfattande och livslångt beroende av sådana åtgärder uppstår. Skadan i sig och dess inverkan på kroppsliga funktioner innebär att behoven av resurser är stora. I syfte att återupprätta den sociala integrationen, återställa autonomin, kompensera för ekonomiska och funktionella förluster och underlätta vardagslivet ger samhället olika stöd.

Medicinska resurser är traditionellt organiserade efter olika specialiteter. På grund av den komplexa medicinska statusen för en individ med traumatisk ryggmärgsskada kommer många olika discipliner att vara inblandade. Organisationen av andra stödresurser är spridd i vårt samhälle. Olika myndigheter ansvarar för olika resurser. Vissa stöd är centraliserade inom organisationen medan andra är decentraliserade. Olika resurser handläggs också på olika sätt inom respektive organisation och har också olika handläggningstid. Organisationen av stöd förändras också genom åren. Varje stöd/service regleras i ett antal olika juridiska dokument såsom lagar/förordningar. Typiskt för det stora flertalet av resurserna är att de är föremål för en bedömning av handläggaren.

För en person med en omfattande och livslång skada kommer således kontakten med olika instanser och myndigheter att pågå under resten av livet. Figur 1 illustrerar mångfalden av resursslag, komplexiteten i samhällsresursernas organisation och det nätverk av kontakter som kommer att etableras.



Figur 1. Möjligt samhällskontaktnät för personer med komplexa behov

Flera myndigheter är inblandade och det är tre som dominerar: Landsting/region, Försäkringskassan och kommunen. Strukturen kan se olika ut för olika delar av landet. För en individ innebär denna organisation att många olika handläggare kommer att vara inblandade i alla olika resursansökningsprocesser.

Avhandlingens syfte

- Att identifiera potentiellt relevanta samhällsresurser efter en traumatisk ryggmärgsskada.
- Att undersöka en incidensgrupps (antal nyskadade individer) användning av samhällsresurser och att mäta tillfredsställelsegraden av ansökningsprocessen och resursallokeringen.
- Att diskutera hur generella etiska riktlinjer kan utmanas av situerad etik hämtad ur designkontexter.
- Att designa och genomföra en kontroll av innehållet i ett existerande slutenvårdsregister.
- Att utifrån berättelser av personer med omfattande funktionsnedsättning analysera och diskutera hur ett normperspektiv kan användas för att förstå varför rättslig reglering inte är tillräcklig för att uppnå den handikappolitiska målsättningen.

# Material och Metod

Flera källor har använts:

- Spinalis ryggmärgsskaderegister. Spinalis är en öppenvårds- och rehabiliteringssenhet för personer med bl a en traumatisk ryggmärgsskada i Stockholms läns landsting samt Gotland. I början av 1990-talet byggde enheten upp en databas omfattande alla personer med en traumatisk SCI i området. (Bortfallet uppgick till 6.9% (6)).
- Intervjuer med en incidensgrupp
- Informationsmaterial från försäkringskassan, kommun, arbetsförmedling, försäkringsbolag och stiftelser
- Lagtexter
- Folkbokföringsregistret
- Patientregistret, Socialstyrelsen
- Berättelser

Sättet att närma sig detta område är starkt influerat av min förförståelse. Jag har levt med min egen traumatiska ryggmärgsskada som barn, tonåring, vuxen, universitetsstudent, anställd, forskare, partner, mamma, dotter, vän etc. Med andra ord, jag har varit situerad i den kontext som denna avhandling beskriver.

Avhandlingen baseras på såväl kvantitativa som kvalitativa metoder. Den är en sammanläggningsavhandling och baserar sig på följande 4 studier:

I. Societal services after traumatic spinal cord injury in Sweden
Camilla Nordgren, Richard Levi, Gunnar Ljunggren and Åke Seiger
Journal of Rehabilitation Medicine 2003; 35: 121-126

Syfte: Undersökning av samhällsstöd efter en traumatisk ryggmärgsskada, inkluderande en självskattning av tillfredsställelsegraden med ansökningsprocessen och resursallokeringen.
Design: Undersökning av en incidensgrupp.
Metod: 34 personer av en total incidensgrupp om 48 personer med en traumatisk ryggmärgsskada intervjuades enligt ett semistrukturerat formulär.
Resultat: 25 olika stöd identifierades som möjliga att söka för personer som drabbats av en traumatisk ryggmärgsskada. I genomsnitt hade varje person ansökt om 5 stöd under ett år i nära anslutning till skadan. Det vanligaste stödet var färdtjänst. 17% av alla ansökningarna rapporterades helt eller delvis avslagna. De flesta individer fick information om stöden av kuratorn. För 13 möjliga stöd hävdade åtminstone 1 person att de inte kände till stödet.
Slutsats: Omfattande resurser finns avsatta i syfte att uppnå oberoende och

ekonomisk kompensation för individen. Emellertid resulterar detta stödsystem i frustration och besvikelse. Otillräcklig information och koordinering rapporteras som svagheter. Individens försök att förstå hur systemet av stöd fungerar tar tid i anspråk tid, som istället skulle kunna användas i rehabiliteringen.

II. Ethics in the making
Bodil Jönsson, Peter Anderberg, Eva Flodin, Lone Malmborg, Camilla Nordgren and Arne Svensk
Design Philosophy Papers no 4, 2005

Syfte och metod: Att analysera hur generella etiska riktlinjer utmanas av situerad etik i en designkontext. Detta arbete illustrerar hur värderingar existerar inte bara i vad som görs utan också i hur det görs. Vare sig "den medicinska modellen" med dess fokus på individuella funktionsnedsättningar eller den "sociala modellen" med sitt fokus på sociala och ideologiska analyser kan ensamma tillhandahålla en fast grund för etiska övervägande med hänsyn tagen till erfarenheterna från personerna i deras relation till design. Det är den sammanhållna kedjan av design och teknik liksom den sammanhållna kedjan av samhällsresurser som är relevanta för det etiska utfallet: från den ursprungliga idén och designval genom designprocessen och över till slutanvändning där individens vardag påverkas av den design som finns. Etiska forskningsperspektiv diskuteras i termer av internationella koder, kontrakt och deklarationer om mänskliga rättigheter såväl som i relation till situerad etik.

III. On the need of validating inpatient registers
Camilla Nordgren
Accepterad för publicering i Spinal Cord, 2008
Publicerad online:
http://www.nature.com/sc/journal/vaop/ncurrent/pdf/sc200842a.pdf

Syfte: Att designa och genomföra en process för att kontrollera slutenvårdsdata i Patientregistret, Socialstyrelsen.
Design: Registerstudie.
Metoder: En prevalensgrupp om 495 personer med en traumatisk ryggmärgsskada identifierades hos Spinalis, Karolinska Sjukhuset. I syfte att kontrollera validiteten i Patientregistret ställdes 3 frågor till registret: Är ett slutenvårdstillfälle registrerat i samband med skadedatum? Är den rapporterade första slutenvårdsperioden rimlig med hänsyn tagen till skadans omfattning och nivå? Är alla förväntade vård- och/eller rehabiliteringsaktörer representerade i materialet?
Resultat: Den första slutenvårdsregistreringen korrelerade med skadedatum för 62% (n=413). För resterande 38%, rapporterades vårdepisoden starta mellan 2 till 8651 dagar efter skadedatum. Med hänsyn tagen till nivå och

omfattning av skadan rapporterades individer ha orealistiskt kort initial slutenvårdsperiod. Prevalensgruppen hade vårdats på 42 olika sjukhus och 47 kliniker, 5 rehabiliteringskliniker fanns dock ej med bland dessa.
Slutsats: Patientregistret är en värdefull källa vid epidemiologisk och slutenvårdsforskning. Studien visar emellertid att användning av registret utan validering kan såsom för föreliggande prevalensgrupp resultera i en underskattning av slutenvårdsanvändningen. Studien visar att systematiska fel kan upptäckas genom omfattande kunskap om diagnosgruppen.

IV. Dubbla sociala normer
Existenser och effekter i vardagen för personer med funktionsnedsättning
Camilla Nordgren
Kommer i Retfaerd, Nordisk Juridisk Tidsskrift, 2009

Syfte och metod: Den svenska handikappolitiken har full delaktighet, jämlikhet och alla människors lika värde som målsättning. Trots omfattande rättslig reglering rapporteras både på offentlig utredningsnivå och från personer med funktionsnedsättning att allvarliga hinder finns kvar. Artikeln syftar till att utifrån narrativ av personer med omfattande funktionsnedsättning analysera och diskutera hur ett normperspektiv kan användas för att förstå varför rättslig reglering inte är tillräcklig för att uppnå den handikappolitiska målsättningen.
Resultat: Genomgående kan konstateras att individens erfarenhet av vardagssituationer inte stämmer med den rådande och förväntade normen. Individen tycks inte kunna identifiera sig med alla andra och lita på att det är den gängse, förväntade normen som råder. Istället träder andra normer in som konkurrerar ut den förväntade.
Slutsats: Individen lever under dubbla sociala normer. Effekten är att individen inte blir delaktig och jämlik utan exkluderas. Förklaring till detta söks i termer av kategorisering eller värdering av individer.

Förutom framkomna och beskrivna resultat i respektive artikel, analyserades också resultat på en övergripande nivå beskrivna enligt följande:

**Ett longitudinellt individuellt perspektiv**. Att undersöka användning av resurser i ett longitudinellt perspektiv medför andra resultat än om ett korttidsperspektiv används. T ex kunde förekomsten av systematiska fel i registergranskningen i delarbete III fastställas genom att ett individ- och longitudinellt perspektiv tillämpades.

**Tidskonsumtion.** Designen av stödsystemen och de olika resursslagen är inte anpassade till det faktum att individen vill leva sitt liv som alla andra och inte spendera tid och kraft på kontakter med myndigheter och resursföreträdare.

**Likadan design för livslånga som för tillfälliga samhällsresurser.** Det livslånga behovet stämmer inte överens med tidsbegränsade stöd och resurser. Det är när varaktigheten i behovet möts av ett system som kännetecknas av förändringar och kortsiktighet som systemet framstår som inadekvat för individen. Individen tvingas att lära sig om och om igen om nya aspekter i systemet.

# Diskussion

Denna avhandling har genomgående ett individfokus. Det gäller inte bara för enskilda exempel, intervjuer och narrativ utan också för de artiklar där källmaterialet är hämtat från medicinska register. I dem har jag följt ett stort antal individer longitudinellt och både granskat registrering av slutenvård och datas konsistens individ för individ. Att göra longitudinella studier också vad gäller livssituationen för individer med funktionsnedsättning är ovanligt, på gränsen till obefintligt (1). I stället tar man nästan uteslutande sin utgångspunkt i metoder och modeller lämpade för att fånga aktuella tvärsnitt och sedan jämföra utfallen med varandra. Att så många håller sig till blixtfotografier och jämförelser mellan dem gör att sådana beskrivningar av inkonsistenser och deras effekter som jag gjort i denna avhandling inte tidigare kommit fram.

## Behov av en kontext

Eftersom en traumatisk ryggmärgsskada är en fysisk och icke progredierande skada borde användningen av resurser se ungefär likadan ut över tid. I stöd- och biståndsbedömningar är det just individens behov och tillkortakommande som fokuseras och utreds. Emellertid framkommer det i retrospektiva analyser att användning över tid är olika. Hur ska ett sådant resultat från en longitudinell studie tolkas? Användningen är givetvis en konsekvens av vilka stöd som funnits tillgängliga. Utbudet beror i sin tur på vilken tidsperiod som studeras. Resurstillgång och användning beror alltså på mycket mer än ryggmärgsskadan. Ett skäl till detta är den pågående medicinska utvecklingen, en annan förändringar i tidsandan (exempelvis förändringar vad gäller vem som skall förtidspensioneras och vem skall förväntas vara yrkesverksam) . Med detta för ögonen finns anledning att uppmärksamma vad som kan tänkas orsaka en förändrad användning av samhällsstöd. Studiet av användningen av samhällsresurser kräver att analysen genomförs och presenteras inte bara i termer av kvantiteter utan också i en kontext.

## Definition av funktionsnedsättning

Föreliggande studier har fördelen av att ha tillgång till en populationsbaserad kohort av individer med en traumatisk ryggmärgsskada. För många forskare går det inte att (som för mig) få tillgång till en hel population ett problem, och därför blir val av inklusionskriterier avgörande för resultat och tolkning av dessa. För egen del har jag inte behövt fördjupa mig i några inklusionskriterier genom att jag haft en hel prevalensgrupp.

## Vara i behov av

Uttrycket att "vara i behov av" används konsekvent när det gäller ansökningar av samhällsresurser. Behovsbegreppets position inom det socialpolitiska fältet eller i det sociala arbetet inom social omsorg är emellertid inte utrett eller har några klara definitioner. Att arbeta mot behov och att ge hög prioritet till dem med omfattande behov uppfattas vanligen som en självklarhet (32). Det är inte möjligt att utifrån studiernas resultat dra slutsatser om huruvida användning av resurser korrelerar med individens behov av vård eller stöd. Studie I ger en indikation om att användning av resurser skulle ha varit mera omfattande om gruppen som angav att de inte hade kännedom om ett stöd faktiskt hade sökt och erhållit stöd. Det är således av stor vikt att skilja mellan använda och icke använda resurser vid diskussion om resurser. En använd resurs är resultatet av ett uttryckt och tolkat behov som är beviljat av en handläggare, emedan en icke använd resurs kan vara resultatet av att inte ha ett behov eller ett uttryckt och tolkat behov som inte har beviljats. Denna distinktion borde vara central i studier och rapporter som analyserar användning av resurser.

## På individens inititativ

Omfattande resurser finns anslagna för dem som har behov. Inga resurser tillhandahålles automatiskt utan samtliga resurser kräver en egenansökan, d v s en aktiv insats av individen. I studie I framkommer emellertid att antalet stöd och dess organisation är svår att sätta sig in i och orsakar missnöje. Det finns ingen strukturerad och formaliserad information om samtliga stöd, information ges efter förfrågan istället. Samtidigt som systemet är komplext är individen oftast oerfaren i att fylla i ansökningar och förstå det byråkratiska språket. Systemet av komplicerade och oklara regler förändras dessutom ofta (33), och tilldelning förändras eller fördröjs i tid p g a otillräcklig resursallokering. Tanken på individen som en aktiv stödsökande aktör lyftes upp i "1994 års handikappreform". Denna individualisering har fått konsekvenser. Flera av personerna i studie I anger att de var omedvetna om vissa stöd vilket indikerar att informationsöverföringen om stöd och service är sårbar. Ett antal ansökningar avslogs helt eller delvis. Att kontakta en myndighet och förklara behovet av stöd innebär att individen måste veta vart den ska vända sig och förklara sitt behov. Studier har visat att denna individualisering kan ha begränsat antalet individer som erhåller resurser (1;12).

## Myndighetsperspektiv kontra upplevt perspektiv

Mycket av det som beskrivs om upplevda perspektiv återges oftast inte av de berörda utan återfinns i auktoriteters (forskares eller handläggares) rapporter. I utredningar som undersöker samhällsresurser från myndighets- eller lagstiftningsperspektiv förekommer också beskrivningar och analyser av individers med funktionsnedsättningar upplevelser i samhället i termer av bemötande, integration och handikappolitik.

## En börda?

Trots omfattningen av resurser upplever individer att de är en börda för samhället och att de beviljade och tilldelade resurserna betraktas som en bekräftelse på att individen inte är självständig (12). Av berättelserna i studierna framkommer att individerna definieras utifrån sina tillkortakommanden och svagheter.

## Slutsats

1. Det saknas omfattande studier som härrör från individer och som beskriver deras relation till resurser och normer.
2. Det finns ett behov av tillförlitlig statistik.
3. Berättelser från berörda individer behövs för att belysa saknade perspektiv.
4. Samhällsstöd kan vara underutnyttjade.
5. Informationsöverföring och tillgänglig information kräver en egen och speciell analys.
6. Etiska och existentiella perspektiv såsom “Vem vet vad jag behöver?” behöver genombearbetas och analyseras.
7. Behov på grund av en funktionsnedsättning kan inte bara hänföras till individen. Istället behöver de utvecklas med hänsyn tagen till tidsperspektiv vad gäller tidsanda och vilka de normstödjande strukturerna är.

# Definitions and vocabulary

| | |
|---|---|
| Aktivitetsersättning | Activity compensation |
| Aktivitetsstöd | Activity support |
| Arbetsbiträde | Work assistant |
| Arbetshjälpmedel | Assistive work devices |
| Assistansersättning | Assistance allowance |
| Bilstöd | Car allowance |
| Bostadsanpassning | Home adaption |
| Färdtjänst | Transportation service |
| Handikappersättning | Disability allowance |
| Hjälpmedel | Technical aids |
| Incidens | Incidence is a measure of the risk of developing some new condition within a specified period of time. It is often expressed as the number of new cases within a specified time period divided by the size of the population initially at risk. For example, if a population initially contains 1,000 non-diseased persons and 28 develop a condition over two years of observation, the incidence proportion is 28 cases per 1,000 persons, i.e. 2.8%. |
| Kommunalt bostadsbidrag<br>(Kommunalt bostadstillägg för handikappade) | Housing allowance |
| Lagen om stöd och service (LSS) | Act Concerning Support and Service for Persons with Certain Functional Impairments |
| Lönebidrag | Wage subsidy |
| Parkeringstillstånd för rörelsehindrade<br>(Handikapparkeringstillstånd) | Parking permit |
| Patientregistret | The National Patient Register (NPR) |
| Prevalens | In epidemiology, the prevalence of a disease in a statistical population is defined as the total number of cases of the disease in the population at a given time, or the total number of cases in the population, divided by the number of individuals in the population. |

| | |
|---|---|
| Rehabiliteringsersättning | Rehabilitation allowance |
| Samhällsstöd | Inpatient care, outpatient care, services that are administrated by the social insurance office and the municipality but also services administrated by the employer and/or the Employability Assessment Institute |
| Sjukersättning | Sickness compensation |
| Sjukpenning | Sickness benefit |
| Sjukvårdsregistret | The Hospital Discharge Register (HDR) |
| Traumatisk ryggmärgsskada | A spinal cord injury (SCI) is an insult to the spinal cord resulting in a change, either temporary or permanent, in its normal motor, sensory, or autonomic function |
| Vilande sjuk- och aktivitetsersättning | Dormant sickness and activity compensation |

# Reference List

(1) SOU 2000:38. Välfärd, vård och omsorg; 2000.

(2) McColl MA, Walker J, Stirling P, Wilkins R, Corey P. Expectations of life and health among spinal cord injured adults. Spinal Cord 1997 Dec;35(12):818-28.

(3) Anderberg P. FACE - Disabled People, Technology and Internet (doctoral thesis). Lund, Sweden: Dept. of Design Sciences, Lund University; 2006.

(4) Jönsson B. (ed.) Design Side by Side. Lund, Sweden: Studentlitteratur; 2006.

(5) Biering-Sorensen F, Hansen RB, Biering-Sorensen J. Mobility aids and transport possibilities 10-45 years after spinal cord injury. Spinal Cord 2004 Dec;42(12):699-706.

(6) Levi R, Hultling C, Nash MS, Seiger Å. The Stockholm spinal cord injury study: 1. Medical problems in a regional SCI population. Paraplegia 1995 Jun;33(6):308-15.

(7) Levi R. The Stockholm spinal cord injury study - Medical, economical and psychosocial outcomes in a prevalence population (doctoral thesis). Stockholm: Karolinska Institutet; 1996.

(8) Dahlberg A, Kotila M, Leppanen P, Kautiainen H, Alaranta H. Prevalence of spinal cord injury in Helsinki. Spinal Cord 2005 Jan;43(1):47-50.

(9) Wyndaele M, Wyndaele JJ. Incidence, prevalence and epidemiology of spinal cord injury: what learns a worldwide literature survey? Spinal Cord 2006 Sep;44(9):523-9.

(10) Hughes JT. The Edwin Smith Surgical Papyrus: an analysis of the first case reports of spinal cord injuries. Paraplegia 1988 Apr;26(2):71-82.

(11) Donovan WH. Donald Munro Lecture. Spinal cord injury--past, present, and future. J Spinal Cord Med 2007;30(2):85-100.

(12) Riksförsäkringsverket 2002:1. Frihet och beroende - Personer med funktionshinder beskriver samhällets stödsystem; 2002.

(13) SOU 2008:77. Möjlighet att leva som andra. Ny lag om stöd och service till vissa personer med funktionsnedsättning; 2008.

(14) Brusén P, Hydén L-C. Inledning. In: Brusén P, Hydén L-C, editors. Ett liv som andra. Livsvillkor för personer med funktionshinder. Lund, Sweden: Studentlitteratur; 2000. p. 11-27.

(15) Regeringen1996/97:120. Skrivelse om handikappolitik; 1997.

(16) Riksförsäkringsverket 2003:15. Ojämlikhet i levnadsvillkor - en jämförelse mellan personer med funktionshinder och övriga befolkningen; 2003.

(17) Utredningsinstitutet HANDU AB. Levnadsnivåundersökning 2005 - En rapport om levnadsnivån för rörelsehindrade, hörselskadade, döva och synskadade personer. Stockholm, Sweden; 2005.

(18) Hydén H. Normvetenskap. Lund, Sweden: Dept. of Sociology, Lund University; 2002.

(19) Svensson M. Sociala normer och regelefterlevnad. Trafiksäkerhetsfrågor ur ett rättssociologiskt perspektiv (doctoral thesis). Lund, Sweden: Lund Studies in Sociology of Law 28, Lund University; 2008.

(20) Jonsson D, Hass U, Persson J. The cost of the Swedish handicap service system - Implications for technology assessment. Int J Technol Assess Health Care 1995;11(2):269-75.

(21) Skott C. Introduktion: Berättelsens betydelse. In: Skott C. (ed.). Berättelsens praktik och teori - narrativ forskning i ett hermeneutiskt perspektiv.Lund, Sweden: Studentlitteratur; 2004. p. 9-11.

(22) Hydén L-C. Illness and narrative. Sociology of Health & Illness 1997 Jan;19(1):48-69.

(23) Jönsson B, Svensk A, Malmborg L, Anderberg P, Brattberg G, Breidegard B, et al. Situated Research and Design for Everyday Life. Lund, Sweden: Certec, Dept. of Design Sciences, Lund University; 2007.

(24) Flyvbjerg B. Five misunderstandings about case-study research
1. Qualitative Inquiry 2006 Apr;12(2):219-45.

(25) Antonovsky A. Unraveling the Mystery of Health: How people manage stress and stay well. 1st ed. San Francisco, CA, USA: Jossey-Bass:1987.

(26) Levi R, Hultling C, Seiger Å. The Stockholm Spinal Cord Injury Study. 3. Health-related issues of the Swedish annual level-of-living survey in SCI subjects and controls. Paraplegia 1995 Dec;33(12):726-30.

(27) Levi R, Hultling C, Seiger Å. The Stockholm spinal cord injury study: 4. Psychosocial and financial issues of the Swedish annual level-of-living survey in SCI subjects and controls. Paraplegia 1996 Mar;34(3):152-7.

(28) Shiell A, Gerard K, Donaldson C. Cost of illness studies - An aid to decision-making? Health Policy 1987;8(3):317-23.

(29) Peterson G. Specifik och generell lagstiftning. In: Tideman M. (ed.). Perspektiv på funktionshinder & handikapp. Lund, Sweden: Studentlitteratur; 2000.

(30) Marklund S. Utträdet från arbetsmarknaden - utvecklingen av sjukfrånvaro, förtidspension och arbetslöshet i Sverige. In: Marklund S. (ed.) Rehabilitering i ett samhällsperspektiv. Andra upplagan. Lund, Sweden: Studentlitteratur; 1995.

(31) Grönvik L. Definitions of Disability in Social Sciences (doctoral thesis). Uppsala, Sweden: Dept. of Sociology, Uppsala University; 2007.

(32) Bergmark Å. Nyckelbegrepp i socialt arbete. 1:8 ed. Lund, Sweden: Studentlitteratur; 1998.

(33) SOU 1999:21. Slutbetänkande av Utredningen om bemötande av personer med funktionshinder. Lindqvists nia - nio vägar att utveckla bemötandet av personer med funktionshinder. Statens offentliga utredningar, Socialdepartementet; 2006.

(34) Hetzler A. Socialpolitik i verkligheten. De handikappade och försäkringskassan. Lund, Sweden: Bokbox Förlag; 1994.

(35) SOU 1998:16. När åsikter blir handling - En kunskapsöversikt om bemötande av personer med funktionshinder; 1998.

(36) Jarkman K. Ett liv att leva - Om familjer, funktionshinder och vardagens villkor (doctoral thesis). Stockholm, Sweden: Linköping Studies in Art and Science; 1996.

(37) Jacobson A. Röster från en okänd värld - Hur människor med fysiska funktionshinder och omfattande hjälpbehov upplever sina existensvillkor (doctoral thesis). Stockholm, Sweden: Pedagogiska Institutionen, Stockholms University; 1996.

(38) SOU 1998:48. Kontrollerad och ifrågasatt - intervjuer med personer med funktionshinder; 1998.

(39) Peterson G, Ekensteen W, Rydén O. Funktionshinder och strategival - Om att hantera sig själv och sin omvärld. Lund, Sweden: Studentlitteratur; 2006.

(40) Davidsson B. Handläggning av stöd och service till människor med funktionshinder - enligt LSS och SoL. Lund, Sweden: Studentlitteratur; 2007.

(41) Brusén P. Livet en gång till. En ryggmärgsskadad möter svensk handikappolitik. Malmö, Sweden: Égalité; 2005.

(42) Sahlin N-E, Persson J. Epistemic Risk: The Significance of Knowing What One Does Not Know. In Bremer, B. and Sahlin, N-E. Future Risks and Risk Management, Kluwer; 1994.

# Summary of papers

This thesis is based on the following papers:

I. Societal services after traumatic spinal cord injury in Sweden
Camilla Nordgren, Richard Levi, Gunnar Ljunggren and Åke Seiger
*Journal of Rehabilitation Medicine* 2003; 35: 121-126

Objective: Societal services after traumatic spinal cord injury in Sweden were investigated, including self-rated levels of satisfaction with the application process and resource allocation.
Design: Survey of an incidence population.
Subjects: Thirty-four persons of a total regional incidence population (n=48) with traumatic spinal cord injury.
Methods: Structured interviews using a standardized questionnaire.
Results: About 25 separate services were identified being available for persons with traumatic spinal cord injury. The average number of applications per person was 5 (range 0-11). The most common service was "transportation service". Of the applications, 17% were partially or totally rejected. Most subjects received information about available services from a social worker. For 13 available services at least 1 subject claimed ignorance about its existence.
Conclusions: In Sweden, significant resources are allocated for allowing independence and financial compensation for individuals with traumatic spinal cord injury. However, this support system sometimes also results in frustration and disappointment. Insufficient information and co-ordination are reported as weaknesses. The persons' efforts to acquire knowledge of how the system works take time which could be better used for rehabilitation and full integration into the community.

II. Ethics in the making
Bodil Jönsson, Peter Anderberg, Eva Flodin, Lone Malmborg, Camilla Nordgren and Arne Svensk
*Design Philosophy Papers*, No. 4, 2005

Objective: To analyze how general ethical guidelines are challenged by situated ethics in a design context. This paper illustrates how values are present not only in what is done, but also in how it is done. Neither "the medical model" with its focus on individual impairments and interventions, nor "the social model" with its focus on social and ideological analysis can alone provide firm ground for ethical considerations with respect to the experiences of the people affected by the design. It is the whole chain of design and technology as well as the whole chain of societal resources that

are relevant for how ethics are experienced: from the initial inspiration and design decision through the design process to actual usage where human everyday life is influenced by the design results. Ethical research perspectives are discussed in the context of international codes, charters and declarations of human rights as well as in the context of situated ethics and particular desiderata, with an emphasis on the latter.
Method: Comparative study.

III. On the need of validating inpatient registers
Camilla Nordgren
Accepted for publication in *Spinal Cord*, 2008
Published online
http://www.nature.com/sc/journal/vaop/ncurrent/pdf/sc200842a.pdf

Objective: To design and implement a validation process to check the completeness of The Hospital Discharge Register (HDR) held by the Swedish National Board of Health and Welfare.
Design: Register study.
Methods: An accurate traumatic spinal cord injury prevalence group (n=495) was acquired from the Swedish Spinalis Clinic. A register control was performed on the group by raising 3 questions to check the validity of The HDR: Is an inpatient stay registered in association with the injury date? Is the reported first length of stay plausible given the level and extent of injury? Are all the anticipated care and/or rehabilitation providers represented in the material?
Results: For 62% (of 413 cases) the first registered hospitalization date correlated with the injury date. For the other 38%, hospitalization was reported to start between 2 and 8651 days after injury. Considering the level and extent of injury, individuals were reported to have unrealistically short initial hospitalization. The prevalence group visited 42 different hospitals and 47 clinics. Five rehabilitation clinics, though, were not reported.
Conclusion: The HDR is a valuable source when conducting epidemiological and health services research. However, using the register without any validation process could, as detected in the investigated diagnosis group, lead to a severe underestimation of the inpatient usage. The study showed that systematic errors could be detected by means of extensive knowledge of the diagnosis group.

IV. Double Sets of Social Norms
Camilla Nordgren
Forthcoming 2009, *Retfærd, Nordisk juridisk tidsskrift* (Nordic Legal Journal)

Objective and Method: The goal of Swedish disability policy is the full participation, equality and equal worth of all people. In spite of extensive legislation, ordinances and regulations, serious obstacles remain according to official investigations and reports from people with disabilities. Based on the narratives of people with severe disabilities, this paper analyzes and discuses how a norm perspective can be utilized to understand why legislation is not sufficient to achieve policy goals.
Results: Results consistently show that the individual's situated everyday experience runs contrary to the prevailing, expected norm. The individual cannot identify with everyone else or rely on the current, expected norm to prevail. Instead, other norms come into play that cancel out the expected one.
Conclusion: Consequently, the individual lives under a double set of social norms. This results in the individual being excluded instead of being equal and able to participate. An explanation is sought in the categorization or evaluation of individuals.

# I

J Rehabil Med 2003; 35: 121–126

# SOCIETAL SERVICES AFTER TRAUMATIC SPINAL CORD INJURY IN SWEDEN

Camilla Nordgren,[1,2] Richard Levi,[1,2,3] Gunnar Ljunggren[1] and Åke Seiger[1,2,3]

*From the [1]Neurotec Department, [2]Spinalis SCI Research Unit, and [3]Frösunda Center Research Unit, Karolinska Institutet, Stockholm, Sweden*

***Objective:*** **Societal services after traumatic spinal cord injury in Sweden were investigated, including self-rated levels of satisfaction with the application process and resource allocation.**

***Design:*** **Survey of an incidence population.**

***Subjects:*** **Thirty-four persons of a total regional incidence population ($n = 48$) with traumatic spinal cord injury.**

***Methods:*** **Structured interviews using a standardized questionnaire.**

***Results:*** **About 25 separate services were identified being available for persons with traumatic spinal cord injury. The average number of applications per person was 5 (range 0–11). The most common service was "transportation service". Of the applications, 17% were partially or totally rejected. Most subjects received information about available services from a social worker. For 13 available services at least 1 subject claimed ignorance about its existence.**

***Conclusions:*** **In Sweden, significant resources are allocated for allowing independence and financial compensation for individuals with traumatic spinal cord injury. However, this support system sometimes also results in frustration and disappointment. Insufficient information and co-ordination are reported as weaknesses. The persons' efforts to acquire knowledge of how the system works take time which could be better used for rehabilitation and full integration into the community.**

*Key words:* traumatic spinal cord injury, societal services, consumer satisfaction, application process, resource allocation.

J Rehabil Med 2003; 35: 121–126

*Correspondence address: Camilla Nordgren, BSc, Certec, Box 118, SE-221 00 Lund, Sweden. E-mail: camilla.nordgren@certec.lth.se.*

Submitted May 23, 2002; accepted November 19, 2002

## INTRODUCTION

A spinal cord injury (SCI) may have devastating consequences for the person affected and commonly leads to significant, permanent disability. The need for societal services is thus obvious and an extensive and life-long reliance upon such services will typically be established. In order to restore social integration, re-establish autonomy, compensate for functional losses and facilitate activities of daily living (ADL), society provides various supportive services. Legislation regulates service availability by prioritizing those most in need. Services are administrated by several separate authorities, each with different organizations, objectives and cultures.

In Sweden, in addition to resources of a medical and rehabilitative nature, there are approximately 25 separate societal services potentially available for persons with SCI (Table I). Some of these services are mutually exclusive, but most are not and have to be applied for separately. In most cases, services are administrated by at least 2 different authorities, e.g. the regional social insurance office and the municipality. The employer and/or the Employability Assessment Institute may also be involved.

The population with SCI, however, often expresses dissatisfaction with this quite complicated system for service allocation (1, 2). Knowledge of the nature of this dissatisfaction is essential and its causes must be determined, described, analysed and fully understood in order to counteract it.

The relevance of factors such as demographics, injury characteristics and social support for community reintegration has been focused in earlier studies, e.g. by Whiteneck et al. (3). The issue of societal services, however, has not been closely investigated.

An SCI involves costs that are carried to varying degrees by the person involved, his/her social network and society, respectively. The most evident and easily identifiable cost is that of initial hospitalization. Several authors (4–7) have estimated initial and subsequent life-long direct and indirect costs. Berkowitz et al. (4) and Walsh (6) found, *inter alia*, that the costs of initial hospitalization constitute only a minor part of the total SCI cost. Since the services provided by society in most cases are iterative and life-long, they will represent a large part of the total costs.

A first step towards service allocation is an application. Each service has to be applied for separately by the applicants themselves. In most cases certificates from a doctor, social worker and/or occupational therapist are required in order to corroborate the person's conditions and/or application. The case is then processed and decided upon at the regional office and the applicant is notified of the decision. The decision can be appealed against.

Little is known about how the applicant experiences this process. The widespread use of patient satisfaction measures has not yet, to our knowledge, been applied in this field. Both the application process and its outcome are of relevance in this context.

The purpose of this study was to identify the spectrum of

*ISSN 1650–1977*

Table I. *Societal services and criteria for allocation*

| Service | Criteria for allocation |
|---|---|
| Disability pension | Chronic illness or disablement and therefore inability to work |
| Temporary disability pension | Reduced working capacity for a limited period |
| Sickness allowance | Illness and therefore inability to work |
| Disability allowance | Need for time-consuming help from somebody in order to manage daily living, job or studies or substantial additional costs |
| Training allowance | Taking part in a labour market programme |
| Rehabilitation allowance | Undergoing rehabilitative treatment with a view to restoring employability |
| Wage supplement | Employing a person with reduced work capacity (a subsidy for the wage disbursed to the employer) |
| Assistant (while at work) | Letting an employed person at the working place help a disabled person with simple duties (a subsidy for the wage disbursed to the employer) |
| Technical aids | Need of technical aid due to the disablement at the working place |
| Work adaptation | Need of adaptation due to the disablement at the working place |
| Priority to an apartment | Social or medical reason for prioritizing in a housing queue |
| Housing allowance | Additional costs for the rent due to the disablement |
| Home adaptation | Need of adaptation in the home due to the disablement |
| Car allowance | Difficulties in transporting oneself or using public transportation |
| Car adaptation | Need of adaptation due to the disablement |
| Parking card | Difficulties in walking (permit parking on special places) |
| Transportation service | Difficulties using public transportation within the community |
| National transportation service | Difficulties using public transportation within the nation |
| Attendance allowance | Severe disability and necessity of personal assistance with basic needs, i.e. personal hygiene, dressing/undressing, eating, communicating with others, in daily living situations |
| Home help (service) | Need of help with, e.g. cleaning, laundry, providing meals |
| Home nursing service | Need of help with, e.g. changing bandage, medication |
| Escort service | Need of assistance while performing recreational activities |

potentially relevant societal services early after SCI and analyse user satisfaction with the application process and resource allocation.

## METHODS

In the years 1997 and 1998, 48 persons in the Greater Stockholm area and on the island of Gotland, Sweden sustained a traumatic SCI. The study group comprised 34 (71%) of these individuals. Fourteen persons were unable to participate in the study, out of which 2 had died, 2 declined, 3 suffered from cognitive limitations and 7 could not be reached. With regard to gender, age at injury and level of lesion, no differences were found between the study group and the excluded group.

Demographic data were obtained from the Stockholm SCI database (8). This database is a medical record system, which was adapted and implemented in the early 1990s as an instrument for structuring investigations, data storage and processing of patients with SCI. Descriptive data for the study group as regards level and completeness of lesion, according to the American Spinal Injury Association (ASIA) (9), are depicted in Table II. The group comprised 11 women and 23 men. Mean age at injury was 47 years (range 15–76, SD 17, median 48 years).

The criteria for being eligible for resource allocation, such as income, expenses, age or extent of disability were not investigated. It is therefore not possible to exclude any individual. The purpose of this study was to investigate an incidence group in order to illustrate the actual situation.

A questionnaire was constructed for the interviews, which were performed by one of the authors (CN) who had no connection with any of the authorities nor any professional contact with the social workers. The interviews took place between November 1999 and February 2000 and lasted between 20 minutes and 2 hours. The time was dependent on the number of services that were applied for and the complexity of the processing. The questionnaire comprised 2 parts. The first surveyed which services the persons had or had not applied for during 1998. The second focused on the application process as such and to what extent the resulting service allocation was in accordance with what was applied for and on the level of satisfaction with regard to administrative handling.

Whenever a person had not applied for a service, 3 possible reasons were identified: (i) the person was already receiving the service; (ii) the person did not claim to need the service in 1998; or (iii) the person did not know about the service.

Questions about the application process included information about available services, request for certificates, contact with the administrating authority, level of resource allocation, degree of satisfaction, information about the possibility of appealing and time from decision to delivery. The degree of satisfaction with resource allocation was assessed on a 4-point self-rating scale (1, not at all; 2, to a limited extent; 3, to a large extent; and 4, completely). A 7-point self-rating scale was used in order to measure the degree of satisfaction with the administration of the application (1, worst ever; 2, very bad; 3, bad; 4, pretty good; 5, good; 6, very good; and 7, best ever).

## RESULTS

The study group applied for 175 services during 1998, with a range of 0–11 and an approximate average of 5 applications per person. No significant difference in the average number of

Table II. *Neurological classification*

| Neurological level of lesion | Total *n* | % | Complete[a] *n* | Incomplete[b] *n* |
|---|---|---|---|---|
| Cervical | 18 | 53 | 2 | 16 |
| Thoracic | 3 | 9 | 0 | 3 |
| Lumbar | 7 | 21 | 0 | 7 |
| No level[c] | 6 | 17 | 0 | 0 |
| Total | 34 | 100 | 2 | 26 |

[a] American Spinal Injury Association (ASIA) A; [b] ASIA B-D; [c] No residual sensorimotor deficit that makes it possible to identify the original lesion, ASIA E.

Table III. *Number of applications during 1998 vs level of lesion*

| Number of applications | Level of lesion<br>Cervical *n* = 18 | Thoracic *n* = 3 | Lumbar *n* = 7 | No level *n* = 6 |
|---|---|---|---|---|
| 0 | 2 | 0 | 0 | 0 |
| 1 | 1 | 0 | 0 | 2 |
| 2 | 1 | 0 | 0 | 0 |
| 3 | 3 | 1 | 1 | 0 |
| 4 | 1 | 0 | 0 | 4 |
| 5 | 2 | 0 | 0 | 0 |
| 6 | 0 | 1 | 2 | 0 |
| 7 | 3 | 0 | 0 | 0 |
| 8 | 0 | 1 | 2 | 0 |
| 9 | 1 | 0 | 0 | 0 |
| 10 | 4 | 0 | 1 | 0 |
| 11 | 0 | 0 | 1 | 0 |

applications could be found between women and men. The number of applications in relation to level of lesion is illustrated in Table III. Persons with lumbar injuries showed the highest number of applications per person and persons with no level, the lowest.

### *Category of service*

Table IV shows the distribution of applications for the different services. The most common service applied for was "transportation service" ($n = 31$) followed by "home adaptation" ($n = 17$) and "sickness allowance" ($n = 16$). Ten persons answered that they did not know about the "disability allowance" service and 7 did not know about the "national transportation service". None had applied for "wage supplement" or "assistant (while at work)".

### *Handling and outcome*

The subjects were asked to rate their degree of satisfaction with the administrative routines, including the attitudes and behaviour of the authority representatives, the time interval from submission of the application to decision, the quality and extent of pertinent information and the resource allocation. Table IV depicts the results of the maximal ratings of these questions. For the services "car allowance" and "car adaptation" only 1 person out of 11, and 1 out of 9, respectively rated the handling as "Best ever" or "Very good". Generally, subjects were more satisfied with outcomes than with the handling process as such.

### *Information about the service*

One piece of information extracted from the questionnaire was that the vast majority of the study group was informed about available services by a social worker at the hospital or rehabilitation clinic. The social worker typically handled the

Table IV. *Distribution of service applications 1998 and ratings of handling and outcome by category* (n = 34)

| Service by category | Yes *n* | Handling[a] Best ever and Very good *n* | Outcome[b] Completely and To a large extent *n* | Already receiving 1998 *n* | Did not need 1998 *n* | Did not know about the service *n* |
|---|---|---|---|---|---|---|
| Income support | | | | | | |
| Disability pension | 3 | 2 | 2 | 4 | 25 | 2 |
| Temporary disability pension | 6 | 5 | 4 | 1 | 26 | 1 |
| Sickness allowance | 16 | 7 | 14 | 0 | 17 | 1 |
| Disability allowance | 13 | 6 | 7 | 0 | 11 | 10 |
| Work | | | | | | |
| Training allowance | 1 | 1 | 1 | 0 | 29 | 4 |
| Rehabilitation allowance | 7 | 4 | 6 | 0 | 27 | 0 |
| Wage supplement | 0 | 0 | 0 | 0 | 34 | 0 |
| Assistant (while at work) | 0 | 0 | 0 | 0 | 34 | 0 |
| Technical aids | 7 | 6 | 7 | 0 | 27 | 0 |
| Work adaptation | 1 | 1 | 1 | 0 | 33 | 0 |
| Accommodation | | | | | | |
| Priority to an apartment | 8 | 8 | 8 | 0 | 25 | 1 |
| Housing allowance | 8 | 6 | 6 | 0 | 24 | 2 |
| Home adaptation | 17 | 7 | 12 | 1 | 16 | 0 |
| Transportation | | | | | | |
| Car allowance | 11 | 1 | 9 | 0 | 20 | 3 |
| Car adaptation | 9 | 1 | 5 | 0 | 23 | 2 |
| Parking card | 14 | 13 | 13 | 0 | 18 | 2 |
| Transportation service | 31 | 29 | 30 | 1 | 2 | 0 |
| National transportation service | 5 | 5 | 4 | 0 | 22 | 7 |
| Attendance | | | | | | |
| Attendance allowance | 6 | 3 | 5 | 0 | 27 | 1 |
| Home help (service) | 9 | 6 | 7 | 0 | 24 | 1 |
| Home nursing service | 2 | 2 | 2 | 0 | 32 | 0 |
| Escort service | 1 | 1 | 1 | 0 | 33 | 0 |

[a] Ratings possible: Best ever, Very good, Good, Pretty good, Bad, Very bad, Worst ever; [b] Ratings possible: Completely, To a large extent, To a limited extent, Not at all.

application and requested doctors' certificates as well. For some services, such as "parking card" and "transportation service", the social worker was typically in charge of the whole application process and the outcome for the person with SCI was a letter containing the "parking card" or licence for "transportation service". For other services, the social worker assisted initially in the application process, whereas subsequent phases of the process involved direct contact between the representative of the relevant authority and the person in need.

### *Resource allocation*

An application being made is no guarantee of a service being granted. The outcome of an application for services is either provision of the service or partial or total rejection. A "car adaptation" application can, for example, be partially rejected when all adaptations applied for are not granted. The authority representative has then made a judgement that the applicant does not fulfil the criteria for the allocation. Table V gives an overview of partially or totally rejected applications in the study group. Seven persons (out of 13) received a partial or total rejection of an application for "disability allowance". The corresponding figure for "car adaptation" was 7 (out of 9).

### *Three narratives*

In order to illustrate inter-individual variations as well as intra-individual complexity of the administrative handling process, narratives of 3 plausible cases are presented.

### *Case 1*

Bill sustained his C5, ASIA B injury in a motorcycle accident at the age of 30 years. He was a gym trainer at the time of injury, he lived with his wife in a single-storey house. She contacted the social insurance office soon after the accident to arrange for "sickness allowance". Bill felt too sick to participate at that time. His wife reported that the administrator seemed to lack insight into Bill's predicament and was unhelpful. Bill felt the administrator to be ignorant about his situation. However, the allowance was provided immediately and Bill rated his satisfaction with the handling as 5 and the outcome as the maximum 4.

Table V. *Partially or totally rejected applications. Number and percent of total number of applications for each respective service*

| Service | Applications<br>No. rejected | % of all |
|---|---|---|
| Disability allowance | 7 | 54 |
| Priority to an apartment | 1 | 12 |
| Housing allowance | 2 | 25 |
| Home adaptation | 4 | 24 |
| Car allowance | 3 | 27 |
| Car adaptation | 7 | 78 |
| Parking card | 1 | 7 |
| Attendance allowance | 2 | 33 |
| Home help (service) | 2 | 22 |

The hospital social worker informed Bill about "disability allowance", to be handled by another administrator than the one handling "sickness allowance". Bill provided much the same information again and this duplication in reporting was further emphasized by the involvement of 2 or 3 additional administrators. The handling of the application, however, did not take long and Bill rated it as 5 and the outcome as 4.

The hospital social worker also informed them about "home adaptation". Bill's wife helped him to contact the municipal department. Its administrator failed to grasp what needed to be done and why in spite of drawings being provided. When 2 weeks remained of his 5-month in-patient stay at the hospital no adaptation had yet been carried out. When Bill called attention to the cost of additional in-patient care, things started to happen. Bill rated the handling as 1 and the outcome as 4.

Bill also became aware through the social worker of the possibility of applying for a "car allowance" and "car adaptation". Bill found the administrator at the social insurance office unable to understand the importance of an accessible car. Bill and a car dealer therefore had problems filling out the forms properly. Then funds were temporarily low and the allowance was transferred with a delay. Bill rated the handling as 1, the outcome of the "car allowance" as 3 and the "car adaptation" as 1 since he did not get all the required adaptations. The social worker also helped Bill apply for a "parking card", which he received immediately. The handling and the outcome were both rated maximally.

Bill applied for "personal assistance" after information from the social worker at the rehabilitation clinic. The administrator showed little sympathy for the requested amount of assistance. However, Bill was content with the outcome and rated it as 4. The handling was also rated as 4.

### *Case 2*

Karl sustained his L3, ASIA B SCI when he fell from a tree, while picking cherries at the age of 50 years. Being a teacher Karl contacted the social insurance office about the "sickness allowance", which was administrated immediately and he rated the outcome as 4 and the handling as 7. The administrator of the "sickness allowance" informed him of the "disability allowance" and the administrator who dealt with this. Karl found a need to exaggerate his functional disability rather than showing rehabilitation results. The allowance was less than applied for and did not cover his extra costs, so he rated the outcome as 1. The handling was rated as 3.

The social worker and the occupational therapist at the hospital informed him about "home adaptation". Karl applied to the municipal administrator but was not granted all the adaptations he considered necessary. He rated the outcome as 2 and the handling as 6. Karl decided to obtain all the adaptations anyway and thus paid for some of them himself.

The social worker at the rehabilitation clinic informed him about "car allowance" and "car adaptation". Additional information was provided by a company dealing with car adaptations. Karl was completely satisfied with the outcome of the "car allowance", but rated the outcome of the "car adaptation" as 2 since his application was partly rejected. Karl rated the handling for the allowance and the adaptation as 4. Karl also applied for a "parking card". He was informed by the social worker and the card arrived within 2 weeks. The outcome and handling were both rated maximally.

### *Case 3*

Anna sustained a C5, ASIA C injury at the age of 45 years when her bicycle collided with a car. She was married and the mother of 3 children. Anna's husband and the hospital social worker helped her to make contact with the social insurance office to apply for "sickness allowance". Later Anna also applied for a "rehabilitation allowance". She rated the outcome as 4, while the handling was affected by insufficient information and rated as 4.

The hospital social worker helped Anna to apply for a "disability allowance" through the social insurance office. The application was approved and the payment arrived immediately. Anna rated the outcome as 4 and the handling as 6. The social worker also handled the "home adaptation" application. The adaptations were performed without delay and Anna rated the outcome as 4 and the handling as 7.

The rehabilitation clinic informed her about "car allowance". The outcome was satisfactory and was rated as 4. However, the information was delayed and the handling was therefore rated as 5. Anna was also told at the clinic about "car adaptations" and experienced the lack of comprehensive information assembled in one place. The formal application was made by telephone and the outcome was rated as 3. The handling was also rated as 3. On Anna's behalf the social worker applied for a "parking card", which Anna received by post. The outcome was rated as a maximum 4 and the handling as 6.

The hospital social worker dealt with the application for "personal assistance". The outcome was rated as 4. However, the implementation was late and the handling was therefore rated as 4.

## DISCUSSION

The present study reflects that several societal resources are available to individuals with SCI in Sweden soon after the injury. Only a few of these resources are utilized by the majority of the SCI study group.

There is no formal, structured information provided by society about services available to individuals who have sustained a disability. The authorities provide information on request. None of the above-mentioned services are placed at the SCI person's disposal automatically; every service requires some kind of application. Social workers at the hospitals or rehabilitation clinics typically arrange help for persons with SCI. The fact that a number of the study group individuals did not know about particular services indicates that this routine is vulnerable. This suggests that services that the persons are entitled to may not be granted, due to poor information, or because the social worker judges that the applicant does not fulfil the criteria for the service to be granted. This result shows the importance of examining a total prevalence group in order to determine the experiences not only of persons who are "in the system".

Many subjects indicated that they did not need the service in 1998. One interpretation is that they did not consider the service necessary in compensating for the disability. Another is that they did not require the service in 1998 (but maybe did later on). A third interpretation is that the individual with SCI was already receiving another service, mutually exclusive to the one required. Still another interpretation is that the family was providing the service. The fact that the degree of service depends mainly on income, expenses, age or extent of disability, may explain why some persons do not apply for the service. They are aware of this regulation and know that they are not eligible. Such individuals also answered that they did not need the service in 1998. It should be emphasized that it is not possible to determine the total need of services for the study group by considering only the granted services, since regulations and/or insufficient information exclude some persons with needs.

Persons with lumbar injuries made the highest number of applications. Comparisons between level of lesion on one hand and quality of life and medical problems on the other have been reported earlier, see, for example, Westgren & Levi (10) and Levi et al. (11). Since many services are provided in order to compensate for the disability, one might assume that those with higher injuries, and thus more extensive impairments, would also have had more need of services and consequently applied for more. It is not possible in this study to establish a statistically significant correlation between the number of applications for services and the level of lesion, but the result is still worth noting.

The study population more frequently reported partial or total rejection of their applications for the services "disability allowance" and "car adaptation". One explanation for this may be a significant component of subjective judgement on the part of administrative staff based on indistinct legislation. The reported number of rejections was only for formal applications. Since many intended written applications start with a telephone contact with an administrator, this may result in verbal discouragement. Such inhibiting effects are difficult to estimate, both in number and impact on the life of the person affected.

Living with an SCI poses several obstacles in daily life. Overcoming these is time consuming. For the affected individual with the intention of living fully integrated in society with work, family and leisure activities, time thus becomes a problem, i.e. the impairment leads to less time being available. For most individuals with new SCI, contacts with and knowledge of the social welfare system are new experiences. There is a complicated system of rules, which is often dependent on the budgeted resources. The necessity of acquiring knowledge of this system demands effort and time. In most cases the social worker assists the individual, resulting in a more effective handling. As most services have a time limit and must be applied for iteratively, the disabled individual typically has to re-apply without continued support from the social worker. Post et al. (12) showed in a study from the Netherlands that a majority of respondents rated satisfaction with service delivery procedures as low, especially factors such as attitude, number of organizations and officials involved and the amount of time required for these procedures.

If the person with SCI unequivocally fulfils certain criteria for receiving the service an application may be considered as a "reservation". This is valid for such services as "parking cards" and "sickness allowances". From the SCI person's perspective, verification comes in the delivery of the card or payment in response to the application. For other services such as "home adaptation" and "disability allowance", the application is but a first step towards a further assessment of the needs. Such a procedure may require considerable time and patience. The difference between these 2 ways of handling an application may be confusing and misleading to the person in need. Keith (13) showed that research in healthcare generally demonstrates high levels of satisfaction and that dissatisfied patients tend to seek other providers. For a person in need of societal services, however, there are few if any alternatives. This creates a double "lock-in", firstly because of the rules and judgements and secondly because there may be no other provider.

The questionnaire included an inquiry about handling time. Post et al. (12) found that discharges for one-third of the respondents from the rehabilitation centre in the Netherlands were delayed because residential adaptation was not completed, while the corresponding figure in Forrest & Gombas' study (14) was 10%. In our study one person reported a similar situation. A certain degree of adaptation of the home is often necessary before discharge. However, it is likely that further modifications will need to be carried out when the person with SCI has settled in.

An holistic approach to rehabilitation needs to include the entire process of returning to independent living. Today, different organizations are responsible for different parts of the rehabilitation and reintegration for SCI individuals. An initial period of hospitalization with the objective of minimizing the impact of the injury and optimizing the conditions for long-term survival with good quality of life must, however, be enhanced by the authorities responsible for services meeting the objective of rehabilitation for full community reintegration. If this enhancement does not succeed, many of the resources invested in the initial phase will not be as useful and effective as expected.

In conclusion, the social security system in Sweden has allocated significant resources for allowing independence and financial compensation for SCI-related impairments. The number of services available reflects this notion. However, this study shows that the present state of affairs often creates frustration and disappointment on the part of the disabled person. The complexity of the system is often reported as a shortcoming within the entire disability movement and not only within the SCI sphere. The problem is the same for all affected, but it might have greater impact for those persons acquiring a complex, life-long injury/sickness. In spite of the social worker's role as a co-ordinator between the authority and the person in need, insufficient information and co-ordination are reported as examples of weaknesses. In order to achieve a fully satisfactory system of societal services either the number of processes and authorities must be reduced, or an official co-ordinator must be appointed, with the explicit task of acting as a proxy for the person in need. The task must be determined without delay so that the person with SCI is given the opportunity to be properly supported throughout life.

## ACKNOWLEDGEMENTS

This study was supported by grants from The Swedish Association of Neurologically Disabled and The Spinalis Foundation. Ms Nordgren was partly supported by The National Board of Health and Welfare and Stockholms Sjukhem Foundation. The authors thank Mr Petter Gustavsson, PhD, for statistical advice.

## REFERENCES

1. Lindqvists nia—nio vägar att utveckla bemötandet av personer med funktionshinder (Nine ways to develop the treatment of persons with disability.) [summary in english]. Statens offentliga utredningar, Socialdepartementet. SOU 1999: 21.
2. Jarkman K. A life to live. Families, disabilities and everyday conditions. Dissertation. Linköping: Linköping University, 1996.
3. Whiteneck G, Tate D, Charlifue S. Predicting community reintegration after spinal cord injury from demographic and injury characteristics. Arch Phys Med Rehabil 1999; 80: 1485–1491.
4. Berkowitz M, O'Leary PK, Kruse DL, Harvey C. Spinal cord injury: An analysis of medical and social costs. New York: Demos Medical Publishing, Inc., 1998.
5. DeVivo MJ. Causes and costs of spinal cord injury in the United States. Spinal Cord 1997; 35: 809–813.
6. Walsh J. Costs of spinal cord injury in Australia. Paraplegia 1988; 26: 380–388.
7. Johnson RL, Brooks C, Whiteneck GG. Cost of traumatic spinal cord injury in a population-based registry. Spinal Cord 1996; 34: 470–480.
8. Levi R, Hultling C, Westgren N. A computer assisted follow-up system for spinal cord injury patients. Paraplegia 1994; 32: 736–742.
9. Ditunno J, Young W, Donovan W, Creasey G. The international standards booklet of neurological and functional classification of spinal cord injury. Paraplegia 1994; 32: 70–80.
10. Westgren N, Levi R. Quality of life and traumatic spinal cord injury. Arch Phys Med Rehabil 1998; 79: 1433–1439.
11. Levi R, Hultling C, Seiger Å. The Stockholm spinal cord injury study: 2. Associations between clinical patient characteristics and post-acute medical problems. Paraplegia 1995; 33: 585–594.
12. Post M, van Asbeck F, van Dijk A, Schrijvers A. Services for spinal cord injured: Availability and satisfaction. Spinal Cord 1997; 35: 109–115.
13. Keith RA. Patient satisfaction and rehabilitation services. Arch Phys Med Rehabil 1998; 79: 1122–1128.
14. Forrest G, Gombas G. Wheelchair-accessible housing: Its role in cost containment in spinal cord injury. Arch Phys Med Rehabil 1995; 76: 450–452.

# II

From *Design Philosophy Papers* no 4, 2005 www.desphilosophy.com

# ethics in the making

**Bodil Jönsson, Peter Anderberg, Eva Flodin, Lone Malmborg, Camilla Nordgren & Arne Svensk**

Applied ethics in research is no longer regarded as a concern exclusive to the medical field. Exemplars in ethics from other fields such as design are, however, meagre, as are relevant practical and design applied guidelines. The more ethically grounded a given area of research is, the greater the chance it can contribute to long-term, meaningful breakthroughs in knowledge. An improved *ethics in design* can enable a critical questioning that in turn leads to entirely new research questions.

The mere involvement of human subjects and the application of safety provisions in design research do not guarantee it will meet ethical considerations, best practices or standards. The entire complex interaction with users offers intriguing possibilities and risks, or can result in mediocrity in areas such as: preparation and implementation that is worth the research person's time; respect for users' contributions; dignified treatment; feedback in an iterative and interactive process with mutual information and inspiration; and products and processes that are truly influenced by the users. This reasoning applies to all, but with special distinction to people who are disabled and elderly. Starting with specific needs as opposed to more general ones (the latter of which result in the necessity for more abstract specifications for the multitudes) can, above and beyond the ethical dimension, also result in increased innovation and effectiveness for society on the whole. Proceeding from the particular to the general is of considerable value, for ethical reasons as well as for sheer effectiveness.

Involving persons with a variety of disabilities in product development helps to ensure innovative and useworthy products.[1] One of many prerequisites for ethically sound user involvement is that all participants are aware of the interference taking place in an iterative design process.

An elaboration of ethical aspects in design can be valuable for different stakeholders (user organisations, NGOs and the design community) and, of course, for the relevance of resulting products and processes. A more considerate ethical approach could have substantial economical value due to the higher relevance of the results. There has been a considerable increase in the ethical expectations placed on businesses and professions in recent years. Scores of organisations have reacted by developing ethical codes of conduct and professional guidelines to explicitly state their values and principles.[2] Moreover, the drafting of a code of ethics can be seen as an indication of professionalism in an emerging profession.[3]

## Ethical guidelines versus situated ethics

Traditionally, medical research and clinically practicing professionals have been in the vanguard of creating ethical guidelines, with other research fields involving human subjects and human well-being close behind. Today, the medical disciplines are also front runners in combining their work on general ethical principles (autonomy, justice, and beneficence, for instance) with research on situated ethics, which is less mechanistic and closer to the context of real people in actual situations and work practices.

Situatedness urges different approaches for different disciplines. The engineering and design sciences, having safety, accessibility and 'universal design' of artefacts and the built environment on their agenda, cannot lean towards medical exemplars. They need to develop their own. An initial difficulty is that the existing key ethical principles, however 'universal' they appear to be, originate from medicine. The spirit of the *Nuremberg Code*, the *Helsinki Declaration* and *The European Convention* (with its explanatory report) is not particularly vitalised in design, to say the least.[4], [5], [6] The reason is obvious: none of them have been formulated based on experiences from design of civil products for everyday life. Nonetheless, ethical aspects are definitely present in test usages as well as in the influence of the resulting technology in later, everyday use.3 Ethical design perspectives can also be deduced from *The Charter of Fundamental Rights of the EU* ('the right to freedom of expression and information'), [7] the *Convention on the Rights of the Child*, [8] and from *Citizens Rights and New Technologies: A European Challenge* in which the European Group on Ethics in Science and Technologies (EGE) stresses the two basic concepts of *dignity* and *freedom.*[9] Accessibility and 'design for all' are such fundamental perspectives that they should not be treated separately. They have societal implications for education, information and participation in social and political processes. *The Principles of Universal Design*, with the approach that environments, services and products should be designed for use by as many people as possible regardless of situation or ability, is an example of this perspective.[10]

Creating common guidelines for rehabilitation design is a challenge, as is the possibility of working the other way round: to open up for a mainly *situated ethics,* based on the spirit of existing codes and declarations rather than being deduced from them. The core of situated design ethics is made up of means and methods that (using the main declarations as guidance) reveal the most important ethical aspects in a given situation, elaborate these, document the thoughts, their implementations and outcomes and make them openly available with the goal of yielding exemplars and inspiring a vital and on-going discussion.

### Exemplar 1: You have to have options to make a choice

Hanna was born with a nerve-muscle disease that severely restricts her mobility. At 1½ years of age, she received her first standing support device in order to exercise her muscles and put pressure on her skeleton. In the process of standing, however, she discovered that there was a lot to see from this upright vantage point. Objects in other parts of the room caught her attention. Without the support of her mother's arms she was suddenly on her own in the world. She wanted to come closer to the objects that she could see at the edge of her upright horizon. Her mother had to move the stationary supporter to the thing that attracted Hanna's attention. 'There! There!' she said and pointed. She quickly focused on something else and wanted to move on to it and then the next object and the next. Her mother soon realised that this was not so much about Hanna's wish to interact with different objects: what she actually was after was the enjoyable feeling of moving around in an upright position. This resulted in the construction of a motorised standing support device that offered Hanna the opportunity to move around in an upright position on her own.

One such device after the other has seen the light of day and enabled Hanna, now a young adult, to gain the identity of a standing – not a sitting – person, including all the existential, physical and practical effects and side effects involved. One such side effect (that was foreseen) is that Hanna will never master the ability to sit – she will remain a standing or a lying person for the rest of her life. The critical moment is to be found in her early childhood when the people in her surroundings were open-minded enough to start questioning whether a future position as a seated person would be right for Hanna with her 'stand-up' ambitions.[11], [12]

This exemplar might serve as a revelation: what are the ethics (if any) behind the dominating 'wheel-chair-for-all' attitude that in no way questions the underlying assumption that somebody who cannot stand up and walk on her own has to live her life primarily as a seated person? In design terms: what are the ethical issues involved in not offering motorised standing supports as an option for mobility injured people? It is easy to understand that an aid in the best of cases does not only fulfil the function it is meant to (to stand up in the example of Hanna); it can also reshape the person's existence and existential terms (Hanna achieved an autonomous, upright mobility). This aspect should be involved in future body technology.[13]

In design, the focus might be on 'that-which-ought-to-be' (*desiderata*) versus 'that-which-is' (description and explanation).[14] The concept of *desiderata* is an inclusive whole of aesthetics, ethics and reason. *Desiderata* is about what we intend the world to be, which is more or less the voice of design. The greater the difference between the designer's and the user's worlds of concepts, the greater is the need for a user-adjoining and situated design process. You need to immerse yourself in concrete experiences – not only base your understanding on abstract ones. You need to accept and acknowledge the existence of different communities of practice.[15] You need to accept desire as an initiator of change. You need to allow disturbances and not only inform and be informed, but also inspire and be inspired. Designers may be informed and inspired by the users, at the same time as the users are informed and inspired by the designers. Utilising this two-way information and inspiration in both groups to its full extent has profound ethical implications, while at the same time making the process more efficient and situated. Cf. the framework by Kensing and Munk-Madsen.[16]

### *Cultural probes*

Among situated design methods, cultural probes have a special position and they have developed in two primary directions: the inspirational and informational. The pioneer version of cultural probes belongs to the first direction. It was developed at the Royal College of Art, Computer Related Design by Bill Gaver and focuses on novel forms of self-reporting by participants on details of their everyday lives. These are then taken up to inspire the design process. The group of academic and artistic members were working on redesigning three community sites in Norway, Holland and Italy. The idea behind these probes was to provoke inspirational responses from elderly people living at the sites.[17], [18], [19]

The informational direction of cultural probes developed out of the design research community oriented towards use of ethnographical methods in the design process. Pioneers in this usage of cultural probes have been members of the Cooperative Systems Engineering Group, Computing Department, Lancaster University in the UK, which has extensive experience in the use of ethnography in design.[20]

We believe that the "friction" contained in the probe's design also works as a way of inspiring users to create new use situations and to look at their environment in a new way – with new glasses.

In interactive design processes involving people with extensive language limitations, questionnaires and interviews are extremely blunt instruments for capturing people's dreams, needs or aversions. Cultural probes are many times preferable in this context because they do not require specific prerequisite knowledge or language abilities. We introduced a number of probes in a day activity centre for people with cognitive and communicative limitations. The reactions to these cultural probes have both inspired and surprised us.[21]

### Example: Cultural probes as a source of inspiration

One probe was a web camera for communication. During the initial connection, the sound disappeared so the researcher and day activity centre participant could only see one another on their respective computer screens moving their lips. The researcher quickly telephoned the person at the day activity centre (the phones were next to the computers) and on the screen the two of them could see each other sitting there holding the telephone receivers to their ears and talking. From the facial expression of the person at the centre, it was obvious that this was a true "Aha!" experience. It took a while before the researcher realised that the surprise was because this was the first time the person in question had actually seen what it was like for the person at the other end of the line. Since then, the two take turns phoning one another even though the sound works on the computer because the feedback the user receives from using the telephone and from seeing the person he is talking to doing the same, provides him with more clues to the mystery of telephoning.

## Design ethics and the human sector

> To smash the little atom,
> All mankind was intent.
> Now every day,
> The atom may
> Return the compliment.
>
> Max Born, Physicist, Nobel Prize Winner, 1882-1970

State-of-the-art in design ethics has been well elaborated in another issue of *Design Philosophy Papers*, particularly in the articles by Donahue and Fry.[22], [23] Addressing ethics makes it possible to discuss what design does, what it contributes and what designers may affect in their work. As Tonkinwise puts it, ethics has always been associated with human-to-human relations.[24] But, according to Latour, artefacts are society and culture made sustainable.[25] Products, artefacts, built environments and communication are also 'actants' themselves and therefore enter the ethical domain not only as neutral means used by humans in their relations to other humans. Using an analogy from physics, Bruno Latour finds in designed activities what he labels 'the missing masses', which is to say that if we only take into account what we currently understand by 'sociality', our cultures should have long since collapsed into irretrievable immorality. The 'missing masses' names an ethical force hidden beyond what we now call 'the social', and the force is in the things per se. Things are acculturating or ethos-generating and a vital part of any ethos with a future.

In the *human sector* people work with and for other people. In addition to healthcare, schools and social services, this sector comprises people-to-people operations in business, the rest of society and the large, informal sector/economy in which people help people because they are relatives or friends. Awareness of the role of artefacts and design of new artefacts requires design processes that proceed from the *logic of the human sector*, not the technical one as is the case in the electronic, manufacturing and forest industries. With another approach to humans in design, the opportunities for real participation of people with disabilities increase, as do their opportunities to make decisions on their own.

The design of a new technology can have a strong impact on the human sector and help improve it.

### Exemplar 2: Being there

The following excerpts from Peter Anderberg's study elaborate how people who have significant mobility/physical impairments *and* who are accustomed to using computers experience the internet:

For the individual, the bodiless presence on the internet has many advantages. Why waste energy trying to convince your banking establishment to rebuild its entrance, when internet banking is so much easier? Why risk the danger of being dragged up the stairs to the local pub when it is so much easier to go to an online forum for company, where you do not have to worry about physical safety, accessible restrooms or deal with the attitudes of others? This ease and convenience, however, can easily lead to self-imposed restrictions, where what is experienced as choice becomes a restraint instead. The choice is very understandable on the individual level, but for the political endeavours of disabled people as a group, the picture becomes somewhat more complicated. The invisibility of the body can undermine the understanding of how disability is created in society, and be used against the community of disabled people. Why should a university adapt its buildings when most classes are available as online and distance studies?

> There was a sense that the world was moving in their direction, with increasingly more societal functions being moved to the internet. An online identity is becoming a more ‘normal’ one for all. If everybody else finds their information or does their banking over the internet, *being there* is the most important. [[26]]

This exemplar not only illustrates the influence of design and technology on human individuals and groups/mankind as a whole but also pinpoints some reflections with special significance for the human sector. If a successful innovation system is to be achieved in the human sector, it should be based on how people live and act rather than how machines function. A methodology can be initiated that deals not so much with ‘running faster’ but with ‘running differently’ and with a clear sense of purpose.[14]

### Design science in relation to other sciences

Our intention here is not to elaborate this relationship generally but restrict ourselves to perspectives from the field of disabilities and the natural sciences. By doing so we hope to add new dimensions to the ethical discourse.

Human needs, wishes and dreams are the starting points for design research in rehabilitation engineering. The design of technical solutions represents in itself an interpretation of problems in a language of its own, different from the word-based analyses of observations, interviews, questionnaires and the like.

A design process in a disability context has to start with the person, end with the person and interact with her throughout the process if the results are to have any success. The situated is a necessary but not sufficient condition. It is a matter of understanding the action in its context and having previous scientific knowledge and considerable, solid experience in order to see the structures and possibilities and from that, propose solutions. The solutions that grow out of the situated processes represent in themselves an interpretation of the actual problem and illuminate them in an implemented form and in their own ‘languages’, based less on words and interpretation and more on that we humans, in action, can show one another what we mean. This was already pinpointed and analysed by Vygotsky in the 1930s.[27] Paul Dourish discerns similar perspectives from a phenomenological interactive design perspective.[28]

### Exemplar 3: Pictures as a language

Sometimes virtual reality can be experienced as more real than actual reality. This can only be revealed through artefacts. For some people with autism, communication with other people isn’t sufficient, not even that which includes pointing at the real object. It may require a detour by means of artefacts so that the concrete can be made real for the person involved. During an outing in the woods, a special education teacher placed her hand on a stone at the same time as she asked a pupil with autism to sit on it. The pupil did not seem to understand at all what she meant. She then took a photo of the stone with a digital camera and showed the display screen to the pupil while at the same time asking him to sit down on the stone. He did so immediately.[29]

#### *Case studies compared to statistically based studies*

Case studies should not be considered merely pathfinders for later statistically based studies.[30] They have significant advantages that cannot be found in statistical studies and vice versa. The field of rehabilitation engineering and design is based largely on case studies. This is not only because of the difficulties in finding enough subjects in the same ‘category’; it is also (mainly) connected to the situated: it is the human being in her environment together with those around her that is the focal point. To pretend that one’s own everyday environment can be replaced by a laboratory environment without considerably influencing usability tests is not only naïve but unethical in its approach.

### Exemplar 4:

When designing a friendly restroom for elderly or disabled persons, interactions with the future users play an important role. To replace authentic users with young people loaded with weights and knee-joint movement restrictors reveals a misunderstanding of the situation as well as an absence of respect. Our experience tells us that research persons from the actual groups are happy to commit their time, share experiences and take part in testing. But it is pointless not to take into account outside influencing factors such as how much sleep the person got the night before, time of the day, season, increased or decreased weight, temperature, etc. Average percentages in usability tests that disregard the influences of these factors are misleading and of much less importance than relevant situated descriptions of individual cases and processes out of which later important patterns of needs and wishes can be detected.

Most often, the design of doors, locks, alarms, toilet seats, lighting, etc. are carried out separately. For the target groups, the margins are so small that a failure in one can result in a failure of all that follows – it is the entire chain of artefacts and the complete process that ought to be tested. The key question is whether the research person is satisfied with the situation and can carry out the desired activity without too great an effort even if one of the tasks negatively affects what follows.

### *Design and action research versus phenomenology and grounded theory*

In rehabilitation engineering and design, the researcher is supposed to lean forward rather than lean backward, to be a practitioner but a reflective one.[31] Although seldom mentioned or brought up to a conscious level, technology and design involve action research. Action research is sometimes considered questionable in social sciences. There is a fear that the researcher might be involved to such a degree that he or she is no longer 'objective', and that the situation is so biased that it can no longer be scientifically studied. However, *not* being an action researcher in rehabilitation engineering and design, *not* aiming to improve situations, solve problems, strengthen capabilities, enable functioning – at least in the long run – is unethical in the context discussed here.

The quality criteria of design in a disability context are linked to interaction with the user, through cultural probes, sketches, mock-ups, prototypes, material or immaterial artefacts; and observing and intervening in actual usage. It is possible to use emerging technology early in the design phase to reveal new knowledge about the user. Of course, a process of this kind influences the persons involved, but that is not to be considered a drawback. On the contrary, it is a built-in part of the process and a cornerstone of the research. It is part of the aim of the iterative design process. Including the user with the designer and researcher in the design process is 'a goal, not a foul.'

Let's take a look at two of the fundamental concepts in phenomenology: *phenomenon* and *lifeworld*. Phenomenon in this context does not stand for the occurrence in and of itself, but for the occurrence experienced by someone. The word 'phenomenon' means 'that which shows itself' and it is implicit in the definition that there is someone to whom it is shown. Our focus on the experienced person – the individual with the disability – thus becomes obvious from a phenomenological perspective. It is the phenomenon as it appears to her that we want to call attention to; how she experiences her world and the special conditions that we, if we understand them, can help to improve and enhance with an assistive aid. 'We want to go back to the things themselves,' says Edmund Husserl, phenomenology's founder, in his 1901 publication *Logische Untersuchungen*.[32]

The *lifeworld*, the lived world, is the other indispensable concept and is strongly associated with that of phenomenon. The lifeworld is the world we already find ourselves in, are familiar with and take for granted. It is pre-reflexive and pre-scientific and it both influences us and is influenced by us. We exist in this world with our bodies, which, in the philosophy of the French phenomenologist Maurice Merleau-Ponty, is an integrated whole that he calls 'the lived body'. 'The body is the vehicle of being in the world'. 'The body is the general medium for having a world'.[33]

Phenomenology's desire to allow phenomena, the things that appear, to be the controlling factors, in our opinion is close to Norman's affordance, a concept that surfaced 80 years later.[34] A significant difference is that phenomenology does not just indicate the phenomena, the individual things and how they emerge, but also the lifeworld as the point of departure. Affordance is a concept that originally was used in psychology to describe how objects, people, situations and so forth, offer or afford opportunities for possible interactions to an observer. It is these offerings in the first place that we perceive when we are confronted with phenomena.

The designer in a rehabilitation context has quite a different task than a researcher in a grounded theory context, where the task is mainly to understand what is happening and how the players manage their roles. The researcher gains understanding through observations, conversations and interviews. Data collection, note taking, coding and sorting are all part of the work before writing; categories and theories are supposed to emerge during the process. Grounded theory is distinguished in that it is explicitly emergent and does not test hypotheses. The aim, as Glaser explains, is to discover the theory implicit in the data.[35]

### *Design versus the medical or social model*

Of course, there are many models in disability sciences, but none that is satisfactory for design. *The medical model* oversimplifies disability as an individual characteristic and directs awareness towards individual adjustments and means. *The social model*, on the other hand, directs awareness towards ideological and political analysis, not towards practical everyday solutions for experienced functioning. In 'Making both ends meet', Peter Anderberg introduces what might be the beginning of a relevant model, *FACE,* in which Function is analysed from three different factors: Attitude, Control and Enabling.[36] One of the advantages with the FACE model is that it necessitates the consideration of ethical aspects.

*Design science and natural sciences*

Regardless of theoretical or methodological standpoint, the only research result worthy of the name is new knowledge. Accordingly, in a research project it is seldom the entire process or the project results as such that are the actual research results; the new knowledge generated in the project often constitutes a rather minor portion. But it is essential to identify and define this knowledge and relate it to what already exists. This is quite a delicate task. It helps considerably if the methods involved are standard for the related scientific fields. However, this is not always possible. The phenomenology of Husserl's time as well as grounded theory and to some extent abduction mean that the phenomenon that is the object of investigation can and should be the controlling one.32 The disadvantages with inventing your own methods are manifest – much is required for the results to be considered credible. At the same time, the advantages are also manifest: it is through them that you achieve proximity to the reality being investigated. The researcher is forced to take more responsibility for the knowledge building than if he or she follows established methods.

Large areas of rehabilitation engineering and design can be dealt with within the framework of epistemology and can thus pride itself on:

- its ability to systematise and accumulate
- its ability to articulate new questions
- its openness and transparency even in its handling of methods and data
- its capacity to generalise on the basis of experience gained
- its openness to other perspectives which may make the results look different

In all these instances, epistemology strives for universality, context-independence and non-relativism. This is advantageous – *provided that it is possible and relevant*. If not, the priority of the particular must apply.[37]

## To sum up

In rehabilitation engineering and design, there is a need for concrete experiences, acknowledgement of different communities of practice, acceptance of desire as an initiator of change, and an openness for the value of two-way inspiration and information. This all implies an ethics that is dual: operationally situated but with its exemplars continuously questioned and examined in the spirit of international ethical codes, charters and declarations. Induction, deduction, and abduction in between the generalised ethical level and the situated one would vitalise ethics in the design research community. The processes can be strongly facilitated if the confusion and overlaps of design concepts could be replaced by more standardised and agreed-upon core concepts.

Bodil Jönsson is Professor of Rehabilitation Engineering in the Department of Design Sciences at Lund University, Sweden. A physicist and educator, she focuses on the benefits of new technological and educational concepts for people with disabilities. Peter Anderberg, Eva Flodin, Camilla Nordgren and Arne Svensk are doctoral candidates at the same Department with the following research areas respectively: IT, learning and disabilities; spinal muscle atrophy; economic consequences of traumatic spinal injury; design of cognitive assistance. Lone Malmborg is Associate Professor in Arts & Communication at Malmö University, Sweden and the Royal College of Art, London. Her interests include embodied interaction, augmented spaces and artefacts, interaction design and virtual reality environments as well as computer supported collaborative learning and working.

---

[1] Håkan Eftring 'The Useworthiness of Robots for People with Physical Disabilities' Doctoral thesis, Lund, Sweden: Certec, LTH, Lund University, 1999. Available at: http://www.english.certec.lth.se/doc/useworthiness/useworthiness.pdf

[2] Online Ethics Center for Engineering and Science, Ohio, USA: Case Western Reserve University, 2004. Available at: http://onlineethics.org/

[3] Marjo Rauhala and Päivi Topo 'Independent living, technology and ethics' *Technology and Disability* no 15, 2003, pp. 205-214.

[4] *Nuremberg Code* Washington, D.C., USA, 1949-1953. Available at: www.ushmm.org/research/doctors/Nuremberg_Code.htm

[5] *Helsinki Declaration* Helsinki, Finland: 18th World Medical Assembly, June 1964, amended 1975, 1983, 1989. Available at: http://onlineethics.org/reseth/helsinki.html

[6] *The European Convention 2003*. Available at: http://european-convention.eu.int/

[7] *The Charter of Fundamental Rights of the European Union* Nice, France, Dec. 2000. Available at: http://www.europarl.eu.int/charter/default_en.htm

[8] *Convention on the Rights of the Child* UNICEF, 2002. Available at: www.unicef.org/crc/crc.htm

[9] *Citizens Rights and New Technologies: A European Challenge* Brussels, May, 2000. Available at: http://europa.eu.int/comm/european_group_ethics/docs/prodi_en.pdf

[10] Bettye R. Connell, Mike Jones, Ron Mace, Jim Mueller, Abir Mullick, Elaine Ostroff, Jon Sanford, Ed Steinfeld, Molly Story, and Gregg Vanderheiden *The Principles of Universal Design* NC, USA: NC State University, The Center for Universal Design, Version 2.0, 1997. Available at: http://www.design.ncsu.edu/cud/univ_design/principles/udprinciples.htm

[11] Eva Flodin 'Assistenter i min livsvärld (Assistents in my lifeworld)' Praktiskt-Pedagogiska Problem (Practical-Pedagogical Problems) Halmstad, Sweden: Halmstad University, no 12, 2000.

[12] Eva Flodin 'Jakten på Instinktivspelaren' (Hunt for the Instinctive Player) Master thesis, Halmstad, Sweden: Halmstad University, 2000.

[13] Edward Tenner *Our Own Devices – The Past and the Future of Body Technology* New York: Random House, 2003.

[14] Håkan Edeholt Design Innovation och andra Paradoxer – förändring satt i system (Design, Innovation and other Paradoxes) Doctoral thesis, Göteborg, Sweden: Chalmers University of Technology, 2004. Available at: http://webzone.k3.mah.se/k3haed/

[15] Jean Lave and Etienne Wenger *Situated Learning: Legitimate Peripheral Participation* New York, USA: Cambridge University Press, 1991.

[16] Finn Kensing and Andreas Munk-Madsen 'PD: structure in the Toolbox' Communication of the ACM vol 36, issue 6, New York, USA: ACM Press, 1993, pp. 78-85. Available at: http://doi.acm.org/10.1145/15371.163278

[17] William Gaver, Anthony Dunne, and Elena Pacenti 'Design: Cultural Probes' *Interactions* vol 6, no 1, 1999, pp.21-29.

[18] William Gaver, Anthony Dunne, and Elena Pacenti 'Projected Realities: Conceptual Design for Cultural Effect' Proc. of CHI '99 ACM Press, 1999, pp. 600-608.

[19] Hilary Hutchinson, Wendy Mackay, Bosse Westerlund, Benjamin Bederson, Allison Druin, Catherine Plaisant, Michel Beaudouin-Lafon, Stéphane Conversy, Helen Evans, Heiko Hansen, Nicolas Roussel, Björn Eiderbäck, Sinna Lindquist, and Yngve Sundblad 'Technology Probes: Inspiring Design for and with Families' in Proc. of CHI '03 ACM Press, 2003, pp. 17-24. Available at: http://insitu.lri.fr/~roussel/publications/CHI03.pdf

[20] Cooperative Systems Engineering Group, Computing Dept., Lancaster University,UK. Available at: http://www.comp.lancs.ac.uk/computing/research/cseg/index.html

[21] Bodil Jönsson, Arne Svensk, David Cuartielles, Lone Malmborg and Pierre Schlaucher *Mobility and learning environments: engaging people in design of their everyday environments* Lund, Sweden: Certec, LTH, Lund University and Malmö University, Creative Environments, 2002. Available online: http://www.certec.lth.se/doc/mobility1/MobilityLearningReport021215.pdf

[22] Sean Donahue 'Discipline Specific Ethics' Design Philosophy Papers no 2, 2004.

[23] Tony Fry 'Design Ethics as Futuring' *Design Philosophy Papers* no 2, 2004.

[24] Cameron Tonkinwise 'Ethics by Design, or the Ethos of Things' *Design Philosophy Papers*, no 2, 2004.

[25] Bruno Latour 'Technology is Society Made Durable' in J. Law (ed) *A Sociology of Monsters. Essays on Power, Technology and Domination* (Sociological Review Monograph) New York and London: Routledge, 1991, pp.103-131.

[26] Peter Anderberg 'Being there' *Disability and Society* vol 20, no 7, 2005, pp. 721-735.

[27] Lev S. Vygotsky *Mind in Society* Cambridge, MA, USA: Harvard University Press, 1930.

[28] Paul Dourish *Where the Action Is. The Foundations of Embodied Interaction* Cambridge, MA, USA: MIT Press, 2001.

[29] Bodil Jönsson 'Enabling communication: pictures as language' in Malcolm MacLachlan and Pamela Gallagher (eds) *Enabling Technologies. Body Image and Body Function* Edinburgh, UK: Churchill Livingstone, 2004, pp. 33-57.

[30] Vilayanur S. Ramachandran and Sandra Blakeslee *Phantoms in the Brain. Probing the Mysteries of the Human Mind* New York: William Morrow & Company, 1998.

[31] Donald Schön *The Reflective Practitioner. How Professionals Think in Action* New York: Basic Books, 1983.

[32] Edmund Husserl *Logische Untersuchungen (Logical Investigations) vol II*, 1901, p.7. Available online in German at: http://www.princeton.edu/~batke/phph/husserl/lu/

[33] Maurice Merleau-Ponty *Phenomenology of Perception* New York and London: Routledge, 1962, pp. 82 and 146.

[34] Donald Norman *The Psychology of Everyday Things* New York: Basic Books, 1988.

[35] Barney G. Glaser ‘Naturalist Inquiry and Grounded Theory’ *Forum: Qualitative Social Research* Jan., 2004. On-line Journal, vol 5, no 1, art 7. Available at: http://www.qualitative-research.net/fqs-texte/1-04/1-04glaser-e.htm

[36] Peter Anderberg ‘Making both ends meet’ *Disability Studies Quarterly* vol 25, no 3, 2005.

[37] Martha Nussbaum *Love’s Knowledge. Essays on Philosophy and Literature* Oxford, UK: Oxford University Press, 1990.

# III

**Spinal Cord (2008),** 1–5

www.nature.com/sc

## ORIGINAL ARTICLE

# On the need of validating inpatient registers

C Nordgren[1,2,3]

[1]*Certec, Department of Design Sciences, Lund University, Lund, Sweden;* [2]*Neurotec Department, Karolinska Institutet, Stockholm, Sweden and* [3]*Spinalis SCI Research Unit, Karolinska Institutet, Stockholm, Sweden*

**Study design:** Register study.
**Objectives:** To design and implement a validation process to check the completeness of the Hospital Discharge Register (HDR) held by the Swedish National Board of Health and Welfare.
**Setting:** Sweden.
**Methods:** An accurate traumatic spinal cord injury prevalence group ($n = 495$) was acquired from the Swedish Spinalis Clinic. A register control was performed on the group by raising three questions to check the validity of the HDR: Is an inpatient stay registered in association with the injury date? Is the reported first length of stay plausible, given the level and extent of injury? Are all the anticipated care and/or rehabilitation providers represented in the HDR?
**Results:** For 62% (of 413 cases) the first registered hospitalization date correlated with the injury date. For the other 38%, hospitalization was reported to start between 2 and 8651 days after injury. Considering the level and extent of injury, individuals were reported to have unrealistically short initial hospitalization. The prevalence group visited 42 different hospitals and 47 clinics. Five rehabilitation clinics, though, were not reported.
**Conclusions:** The HDR is a valuable source when conducting epidemiological and health services research. However, using the register without any validation process could, as detected in the investigated diagnosis group, lead to a severe underestimation of the inpatient usage. The study showed that systematic errors could be detected by means of extensive knowledge of the diagnosis group.
*Spinal Cord* advance online publication, 13 May 2008; doi:10.1038/sc.2008.42

**Keywords:** administrative database; inpatient care utilization; inpatient register; LOS; traumatic spinal cord injury; validation process

## Introduction

Understanding the nature and extent of health service utilization is essential for prognosticating future care utilization and for conducting economic evaluations, epidemiological studies and clinical trials. Principally, there are three different ways to collect utilization data: patient supplied, medical records or administrative databases. Several studies have been conducted evaluating the accuracy of the patient reported method, for example.[1] Both over- and under-reporting of hospitalization episodes have been detected. Horwitz *et al*.[2] assessed the reliability of epidemiological data, in terms of different health conditions, from medical records and proposed strategies for improving the basic quality. Utilizing administrative databases or secondary data involves analysis after collection without a specific research purpose and without interference by the researcher.[3]

In recent years, data retrieval has been facilitated by the vast amount of health care information collected and stored in databases and registers. The advantages of using these secondary sources are substantial time and cost savings, the size of the sample, the representativeness and the reduced likelihood of bias due to for example, recall, nonresponse and effect on the diagnostic process of attention caused by the research question.[3] Despite these advantages, this method has possible shortcomings that must be dealt with. Those mentioned stem from the system *per se* and include structural weaknesses and biases due to incomplete and inconsistent reporting and coding. Furthermore, completeness, accuracy, validity and reliability are critical issues.[4]

A common problem for many administrative database researchers is whether the diagnosis code in question detects all true cases in these databases, for example.[5] Blomqvist[4] discusses three methodological approaches for assessing the completeness of registration of cases. The first is to compare the data source with several other independent data sources, the second is review of medical records and the third builds on a comparison between total number of cases in different

---

Correspondence: C Nordgren, Licentiate of Philosophy, Department of Design Sciences, Certec, Box 118, Lund S-221 00, Sweden.
E-mail: camilla.nordgren@certec.lth.se
Received 5 April 2007; revised 27 February 2008; accepted 2 March 2008

sources. De Vet *et al.*[6] provide a theoretical background for performing and reading systematic reviews of diagnostic studies by discussing methodological quality in terms of internal and external validity. Rosen[7] argues that validation has been studied and reported. However, determining true cases is not enough. In analyses examining health care utilization, the data must also be validated. Nevertheless, studies seem to lack descriptions of the validation process and its application to the data included.

Statistics of diseases and surgical treatments of patients have a long history in Sweden. In the 1960s, the National Board of Health and Welfare started to collect data on individual patients who had been treated as inpatients at public hospitals. The county of Stockholm has since 1972 reported all inpatient care to the Hospital Discharge Register (HDR) (www.socialstyrelsen.se/en/Statistics/statsbysubject/The+Swedish+Hospital+Discharge+Register.htm). The register contains different types of information: data on the patient and hospital, administrative data such as date of admission and discharge, and medical data with diagnosis and surgical procedures. For all records reported, data and quality controls are carried out. In an international evaluation of Swedish public health research, it was concluded that Sweden is one of the world leaders in public health research including epidemiology and register-based research.[8] The use of the HDR has resulted in numerous research articles in different fields.

This paper examines the inpatient care utilization registered in the HDR in an accurate diagnosis group: traumatic spinal cord injury (SCI). While diagnosis detection is a problem for many researchers, this study has the advantage of having access to a population-based cohort of individuals with traumatic SCI through Spinalis, a comprehensive regional SCI outpatient clinic in the greater Stockholm area and the island of Gotland, comprising about 1.9 million inhabitants. The SCI database (Swedish Spinalis Clinic Database, SSCD) was established in the beginning of the 1990s from a survey of regional registers and after individual patient contacts by the Spinalis rehab team and a review of medical records, interviews and physical examinations of subjects. The dropout rate was 6.9%.[9] This procedure assured the accuracy of the database as an SCI health care database. Spinalis is a part of the established referral procedure, which insures further incidence inclusion in the database.

## Methods

This study was a register control, first of the data for the Spinalis group, one by one, to decide whether they were to be included in the prevalence group or not, then of how each of the group members appears in the HDR.

### *The subject group*

In June 1999, the author submitted a retrieval request to the SSCD with the inclusion criteria of living patients with traumatic SCI. The present study is based on the 495 persons who met these requirements. Data about date of birth, gender, injury date, level and extent of injury (ASIA) were collected for each individual. Since the HDR is complete in the investigated region from 1972 all cases with an earlier injury date were excluded ($n=58$). For the remaining 437 persons, the Swedish national registration office was checked to detect those who had died before 1999 ($n=1$). This case was excluded, as were seven others due to incorrect data (erroneous personal identity number and uncertainty regarding the diagnosis) while one was added. Thus the final total prevalence group consisted of 430 traumatic SCI cases. This study was approved by the Ethics Committee of Karolinska Institutet in Stockholm, Sweden.

### *The elaborated Hospital Discharge Register*

The unique personal identity number assigned to each Swedish resident was used to obtain data from the HDR. Information was collected about each person's registration regarding hospital/institution, clinic, unit, date of admission and discharge. Data was examined from 1972 through 2002.

As the HDR consists of numerous individual pieces of information validating such an extensive register requires investigation on an individual level. Understanding each person's incentive and condition for utilizing inpatient care requires knowledge about individual characteristics. Three fundamental questions were formulated to penetrate the validity of the material:

(1) Is an inpatient stay registered in association with the injury date?
(2) Is the reported first hospitalization episode (length of stay, LOS) plausible, given the level and extent of injury?
(3) Are all the anticipated care and/or rehabilitation providers represented in the material?

## Results

### *Is an inpatient stay associated with the injury date?*

For 22 individuals, the exact day and/or month of injury was not specified in their medical records. For those individuals ($n=12$) for whom the month was specified, the first of the month was calculated as the injury day. For those lacking both an injury month and day ($n=10$), the first of January of that year was specified as the injury day and month.

Table 1 shows the number of days between injury date and the first registered inpatient stay. Seventeen persons did not have any inpatient care at all reported after the injury date. Sixteen individuals actually had an inpatient stay already registered the day before the actual injury. About 62% of the group had an inpatient stay reported in direct connection with the injury date (−1, 0, 1 days), that is, 38% had their first hospital stay registered 2 days or more after the injury date.

### *Is the reported first hospitalization episode plausible, given the level and extent of injury?*

The number of inpatient days was checked for the individuals with a first hospitalization stay in direct conjunction with the injury date. Included were those with a reported inpatient stay of −1, 0 and 1 day in relation to the injury date ($n=257$). Table 2 shows the distribution according to

**Table 1** Number of days between injury date and first registered inpatient stay

| *Number of days between injury date and first registered inpatient stay* | *Number of persons (N = 413)* | |
|---|---|---|
| | *With exact day and month of injury (N = 391)* | *Without exact day and month of injury (N = 22)* |
| −1, 0 or 1 | 257 | 0 |
| 2–10 | 43 | 3 |
| 11–100 | 38 | 6 |
| 101–1000 | 19 | 3 |
| 1001–10 000 | 34 | 10 |

**Table 2** Number of individuals distributed according to neurological classification

| *Neurological level of lesion* | *ASIA A (complete)* N | *ASIA B-D (incomplete)* N | *ASIA E* N | *ASIA no information* N |
|---|---|---|---|---|
| Cervical | 29 | 86 | | |
| Thoracic | 36 | 33 | | 1 |
| Lumbar | 3 | 40 | | 1 |
| Sacral | 2 | 2 | | |
| No level | | | 23 | |
| No information | | | | 1 |

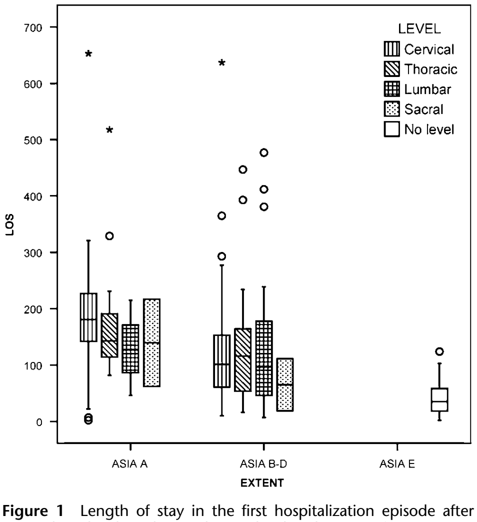


**Figure 1** Length of stay in the first hospitalization episode after injury date distributed according to level and extent of injury.

level and extent of injury and Figure 1 provides information of LOS for the initial hospitalization. Length of stay ranges from 2–653 days, with a mean of 126 and a median of 108 days.

Initial LOS for some individuals seemed to be interrupted by a holiday such as Christmas or New Year. For 20 individuals this was indeed the case. These inpatient stays had an interruption that lasted between 3–31 days, and by including these individuals' inpatient care after the interruption, the total stay was thus prolonged by 2–171 days.

### *Are all the anticipated care and/or rehabilitation providers represented in the material?*

The inpatient stay prevalence group had utilized care at 42 different hospitals/institutions in the Stockholm area, and 47 different clinics from injury date through 2002.

## Discussion

This paper examines the validity of the content in the HDR. The use of a verified population-based SCI health care database including additional controls is supposed to insure the validity of the diagnosis group investigated and the validity process can thus focus on the inpatient data. Considerable knowledge of the diagnosis and its effects in terms of health care utilization proved to be a prerequisite when putting questions to the HDR. Interpreting data and estimating the validity was absolutely necessary to determine under-reporting and lack of reporting.

Extensive investigations were made regarding the patients included in the health care database, for example, if and when a person had died and verification of his/her residential registration. Atypical inpatient entries, such as being admitted to inpatient stay and sustaining a traumatic SCI during that time, were also examined.

To investigate inpatient care in an administrative database presupposes that the disease or condition of the individual has been reported and recorded in the system. Blomqvist[4] points out three factors that influence this: the care-seeking behavior of the person, the supply of health care and the physician's propensity to admit patients. The nature of an SCI does not leave a person in doubt whether to seek care or not. Nor can the health care organization in Sweden be seen as a hindrance to inclusion in the information system.

### *Is an inpatient stay associated with the injury date?*

A traumatic SCI is an acute and serious condition where immediate care is necessary. The alternative of not seeking care or waiting a couple of days occurs, if ever, in exceptional cases. Some studies that analyze LOS separate acute care hospitalization from rehabilitation hospitalization and stipulate a time limit from the injury date as an inclusion criterion.[10–13] Others calculate the LOS from the day of injury,[14] include individuals admitted for their initial episode[15] or use date of the index hospitalization as the date of the SCI.[16] All these studies lack further analysis regarding possible divergence between the onset of traumatic SCI and admission date. Putzke *et al.*[17] and Fine *et al.*,[18] on the other hand, include individuals admitted on the first day of injury. In the present study, more than one-third of the prevalence group did not have an initial inpatient registration (−1, 0, +1 day) in conjunction with the injury date. The time lapse between injury date and first inpatient stay should be interpreted as possible days spent in inpatient care.

The prevalence population examined includes persons who moved to the investigated region with a traumatic SCI sustained earlier. This group includes immigrants and residents moving from other parts of the country. The health care system in Sweden allows people to seek health care anywhere in the country. It is most common, however, to utilize the health care system in one's own county. As the patient data originated from one region, utilization of care in other parts of the country was not included. In 2002, controls carried out at the Swedish National Registration Office resulted in finding 31 persons who were registered in a region other than Stockholm. Not being a resident of Stockholm in 2002 does not, however, say anything about place of registration at the time of injury. If a person had moved out of the area and then moved back before April 2002, these movements could not be traced. One explanation for the high figure of divergence besides immigrants could be individuals injured during a temporary stay abroad or in another region in the country. These individuals are typically moved to their residential hospitals after the first trauma period and so, their initial hospitalization would not have been recorded in the investigated register.

*Is the reported first hospitalization episode plausible given the level and extent of injury?*

Comparing results from other investigations is a way of determining whether the reported inpatient figures are plausible. Other studies on traumatic SCI and initial LOS show a great variation in the number of days spent in hospital/rehabilitation with figures ranging from 1 up to 4742 days.[19] These studies all have different inclusion criteria, terms of description and grouping when it comes to etiology, age, injury year, level and extent of injury and type of care.[10–13,15–17,20] This impedes comparison. No discussion has been found in any of the published studies about how realistic it is to have very few or many inpatient days registered. SCI patients at high risk of extended LOS, referred to as outliers, are defined in a study of Burnett *et al*.[21] as patients whose LOS exceed the mean by more than two standard deviations, while Cifu *et al*.[10] use four standard deviations. These studies discuss the outliers in terms of long LOS, but it should also be of considerable interest to focus on outliers in the other direction, in terms of short LOS.

The present findings do not differentiate type of care: acute vs rehabilitation. The data represent days of inpatient stay irrespective of type, in a public hospital. Some researchers do not examine the acute LOS, for example.[15,16] Several studies[11–13,20] spring from persons discharged from the Model System with an enrol system of patients being admitted within 60 days of injury. In some studies, 86–93% of all patients were admitted to the investigated clinics within 21 days of injury. It is thereby uncertain how much inpatient time the patients have consumed before the rehabilitation LOS. It can therefore be interpreted that the LOS could in some cases actually be prolonged by as much as 60 days. A lack of differentiation between the acute and rehabilitation organization could perhaps explain some of the differences and the great range of LOS.

Having a complete (ASIA A) cervical injury and utilizing only 2, 7 or 22 inpatient days seems unrealistic (Figure 1). Further investigation through other sources of data would be required to reveal the likelihood of having an extremely short or long initial inpatient stay. Knowledge about medical care organizations in your country, rehabilitation regime and, of course, the investigated diagnosis are of value when determining which cases need more examination.

*Are all the anticipated care and/or rehabilitation providers represented in the material?*

The HDR contains inpatient data from public hospitals. At least five institutions/rehabilitation units were not represented at all in the register. This was surprising even though these institutions are typically foundations or privately owned, because the county council regularly purchases care and rehabilitation services from these providers, making these rehabilitation beds regarded as public. One of these is also included in the established referral procedure of rehabilitation and a great majority of all incidence patients stay at this rehabilitation unit for a while.

## Conclusions

Systematic errors are not easy to discover and the chance of discerning them does not correlate with the size of the sample. When found, it is possible to compensate for them. What this study reveals is that extensive knowledge of the investigated diagnosis group can be a necessity when examining and evaluating the data. Researchers using administrative databases like this one need to validate their data to attain reliable results.

## Acknowledgements

This study was made possible by the kind assistance of the Spinalis unit. The author thanks Lars Werhagen, MD, PhD and Peter Kitzing, MD, PhD for valuable help. The financial support for this research, provided by Stiftelsen för bistånd åt rörelsehindrade i Skåne, is greatly appreciated.

## References

1 Kennedy ADM, Leigh-Brown AP, Torgerson DJ, Campbell J, Grant A. Resource use data by patient report or hospital records: do they agree? *BMC Health Serv Res* 2002; **2**: 2.
2 Horwitz RI, Yu EC. Assessing the reliability of epidemiologic data obtained from medical records. *J Chron Dis* 1984; **37**: 825–831.
3 Sorensen HT, Sabroe S, Olsen J. A framework for evaluation of secondary data sources for epidemiological research. *Int J Epidemiol* 1996; **25**: 435–442.
4 Blomqvist P. *On the Use of Administrative Databases in Health Care Analyses [Dissertation]*. Karolinska Institutet: Stockholm, Sweden, 1998.
5 Augutis M, Malker H, Levi R. Pediatric spinal cord injury in Sweden; how to identify a cohort of rare events. *Spinal Cord* 2003; **41**: 337–346.
6 De Vet HCW, van der Weijden T, Muris JWM, Heyrman J, Buntinx F, Knottnerus JA. Systematic reviews of diagnostic research. Considerations about assessment and incorporation of methodological quality. *Eur J Epidemiol* 2001; **17**: 301–306.

7 Rosen M. National health data registers: a Nordic heritage to public health. *Scand J Public Health* 2002; **30**: 81–85.

8 Kamper-Jorgensen F, Arber S, Berkman L, Mackenbach J, Rosenstock L, Teperi J. Part 3: international evaluation of Swedish public health research. *Scand J Public Health* 2005; **33**: 46–84.

9 Levi R, Hultling C, Nash MS, Seiger A. The Stockholm spinal cord injury study: 1. Medical problems in a regional SCI population. *Paraplegia* 1995; **33**: 308–315.

10 Cifu DX, Seel RT, Kreutzer JS, McKinley WO. A multicenter investigation of age-related differences in lengths of stay, hospitalization charges, and outcomes for a matched tetraplegia sample. *Arch Phys Med Rehabil* 1999; **80**: 733–740.

11 Eastwood EA, Hagglund KJ, Ragnarsson KT, Gordon WA, Marino RJ. Medical rehabilitation length of stay and outcomes for persons with traumatic spinal cord injury—1990–1997. *Arch Phys Med Rehabil* 1999; **80**: 1457–1463.

12 McKinley WO, Seel RT, Gadi RK, Tewksbury MA. Nontraumatic vs traumatic spinal cord injury: a rehabilitation outcome comparison. *Am J Phys Med Rehabil* 2001; **80**: 693–699.

13 Seel RT, Huang ME, Cifu DX, Kolakowsky-Hayner SA, McKinley WO. Age-related differences in length of stays, hospitalization costs, and outcomes for an injury-matched sample of adults with paraplegia. *J Spinal Cord Med* 2001; **24**: 241–250.

14 Webb SB, Berzins E, Wingardner TS, Lorenzi ME. Spinal cord injury: epidemiologic implications, costs and patterns of care in 85 patients. *Arch Phys Med Rehabil* 1979; **60**: 335–340.

15 Tooth L, McKenna K, Geraghty T. Rehabilitation outcomes in traumatic spinal cord injury in Australia: functional status, length of stay and discharge setting. *Spinal Cord* 2003; **41**: 220–230.

16 Dryden DM, Saunders LD, Rowe BH, May LA, Yiannakoulias N, Svenson LW *et al*. Utilization of health services following spinal cord injury: a 6-year follow-up study. *Spinal Cord* 2004; **42**: 513–525.

17 Putzke JD, Richards JS, Devivo MJ. Gunshot versus nongunshot spinal cord injury—acute care and rehabilitation outcomes. *Am J Phys Med Rehabil* 2001; **80**: 366–370.

18 Fine PR, Stover SL, Devivo MJ. A methodology for predicting lengths of stay for spinal cord injury patients. *Inquiry* 1987; **24**: 147–156.

19 Samsa GP, Landsman PB, Hamilton B. Inpatient hospital utilization among veterans with traumatic spinal cord injury. *Arch Phys Med Rehabil* 1996; **77**: 1037–1043.

20 Greenwald BD, Seel RT, Cifu DX, Shah AN. Gender-related differences in acute rehabilitation lengths of stay, charges, and functional outcomes for a matched sample with spinal cord injury: a multicenter investigation. *Arch Phys Med Rehabil* 2001; **82**: 1181–1187.

21 Burnett DM, Kolakowsky-Hayner SA, Gourley EV, Cifu DX. Spinal cord injury ‘outliers’: an analysis of etiology, outcomes, and length of stay. *J Neurotrauma* 2000; **17**: 765–772.

# IV

Forthcoming 2009, *Retfærd, Nordisk juridisk tidsskrift* (Nordic Legal Journal)

# Dubbla sociala normer

Existenser och effekter i vardagen för personer med funktionsnedsättning

Camilla Nordgren, fil lic
Institutionen för Designvetenskaper, Certec
Lunds universitet
Box 118
S-221 00 Lund
Telefon: + 46 46 222 05 17
E-post: camilla.nordgren@certec.lth.se

## Abstract

Den svenska handikappolitiken har full delaktighet, jämlikhet och alla människors lika värde som målsättning. Trots omfattande rättslig reglering rapporteras både på offentlig utredningsnivå och från personer med funktionsnedsättning att allvarliga hinder finns kvar. Artikeln syftar till att utifrån narrativ av personer med omfattande funktionsnedsättning analysera och diskutera *hur* ett normperspektiv kan användas för att förstå *varför* rättslig reglering inte är tillräcklig för att uppnå den handikappolitiska målsättningen. Genomgående kan konstateras att individens erfarenhet av vardagssituationer är motsatt från den rådande och förväntade normen. Individen tycks inte kunna identifiera sig med alla andra och lita på att det är den gängse, förväntade normen som råder. Istället träder andra normer in som konkurrerar ut den förväntade normen. Individen lever således under dubbla sociala normer. Effekten blir att individen inte blir delaktig och jämlik utan exkluderas. Förklaring till detta söks i kategorisering eller värdering av individer.

Keywords:

handikappolitisk målsättning, rättslig reglering, normperspektiv, narrativ, personer med funktionsnedsättning, konkurrerande norm

## 1. INLEDNING

Den svenska handikappolitiken har full delaktighet, jämlikhet och alla människors lika värde som målsättning (Regeringens proposition 1999/2000:79). Ett sätt att möjliggöra för individer med funktionsnedsättning att kunna delta fullt ut i samhället som medborgare är att anpassa och tillgängliggöra samhället. Ett annat sätt, eller i kombination, är att inrätta och tillhandahålla olika vård-, stöd och serviceresurser i samhället. Dessa syftar till att lindra eller bota den medicinska komplikationen, kompensera ekonomiskt, möjliggöra samhällelig integration, skapa oberoende, kompensera funktionsnedsättning och underlätta den dagliga livsföringen. Lagar om dessa stöd har inrättats under ett flertal årtionden och reglerar skilda områden såsom t ex anpassning av bil och bostad, assistans och färdtjänst. Personer med omfattande och/eller kroniska funktionsnedsättningar kommer under sin livstid att ha ett stort behov av och en stor förbrukning av vård-, stöd- och serviceresurser i samhället. Vårdanvändning i både sluten och öppen form utgör en stor andel men också andra resursbehov kan bli omfattande genom att i ett livsperspektiv vara repetitiva. Att leva med en omfattande funktionsnedsättning innebär stora ansträngningar samt kräver förändringar och anpassningar i den levda miljön för alla berörda medborgare. Handlingsalternativen begränsas, marginalerna blir mindre och konsekvenserna av oförutsedda skeenden blir större. I den av riksdagen år 2000 antagna propositionen ”Från patient till medborgare” (Regeringens proposition 1999/2000:79) konstateras att ”bilden av dagens handikappolitiska läge är motsägelsefull” och att allvarliga hinder finns kvar på vägen mot ett samhälle för alla. Detta bekräftas också återkommande av personer inom och utom intresseföreningar för personer med funktionsnedsättningar och i olika publikationer alltifrån avhandlingar till kiosklitteratur. Inte sällan berättas och skrivs det om personers erfarenheter av att möta samhällssystem som ska operationalisera handikappolitiska målsättningar men där utfallet inte blir tillfredsställande.

## 2. SYFTE OCH FORSKNINGSFRÅGOR

Föreliggande artikel syftar till att beskriva, analysera, problematisera och diskutera *hur* ett normperspektiv kan användas för att förstå *varför* lagar, förordningar, policydokument och handlingsplaner inte är tillräckliga för att individen med funktionsnedsättning ska uppnå full delaktighet och jämlikhet i vardagssituationer. Genom att utgå från berörda personers konkreta berättelser, narrativ, om vardagliga handlingar med egna och andras reaktioner kopplade till värden i aktuella, nationella lagar och handlingsplaner för att sedan analysera dessa handlingar utifrån ett normperspektiv, syftar artikeln också till att skapa en fördjupad förståelse av frekventa och reproducerade sociala handlingsmönster med skilda förväntningar och reaktioner hos olika aktörer. Syftet är då också, utifrån denna fördjupade förståelse av sociala normer och dessas effekter, att diskutera hur rätten i grunden kan byggas upp för att individer med funktionsnedsättning ska kunna, som riksdagen har beslutat, uppnå full delaktighet och jämlikhet i vardagssituationer.

## 3. HANDIKAPPOLITISK BAKGRUND

Inställning till personer med fysisk och/eller psykisk funktionsnedsättning har under årens lopp skiftat från negligering och utstötthet, via anstaltsvård och isolering, till mer öppna vårdformer och social integration. Under stora delar av de här samhällsprocesserna har människor med funktionsnedsättning själva oftast setts som föremål för insatser enligt rådande ideologi, snarare än beslutsfattare i sina egna liv (Tidningen Handikapphistoria 2004). Den moderna handikappolitiken har sitt ursprung i 1960-talets jämlikhetssträvanden. Peter Brusén & Lars-Christer Hydén beskriver den svenska handikappolitiken som en integrerad del av den socialpolitiska utvecklingen vilket medför att olika åtgärder successivt har vuxit fram. De senaste decennierna har utvecklingen inneburit decentralisering, avinstitutionalisering och självbestämmande. Stöd för personer med funktionsnedsättning regleras i en rad lagar vilkas utformning och innehåll speglar tidens rådande synsätt och ses som ett av flera viktiga verktyg för att förbättra levnadsvillkoren (Brusén och Hydén 2000, s. 11-14). ”Genom olika stödformer har man försökt att ge den enskilde funktionshindrade makt att forma sitt eget liv” (Tidningen Handikapphistoria 2004). Målen för dagens handikappolitik bygger på full delaktighet i samhällslivet, jämlikhet i levnadsvillkor, självbestämmande och ökad självständighet, möjlighet till att skapa sig ett värdigt liv samt främjande av internationellt samarbete (Regeringens skrivelse 1996/97:120) och utgår från FN:s standardregler om funktionshindrade som antogs 1993. Magnus Tideman konstaterar att förståelsen av handikapp inom den samhällsvetenskapliga forskningen genomgått en tämligen radikal förändring under de senaste årtiondena. Synen har förändrats från att se handikapp som ett tragiskt individuellt fenomen, ett medicinskt problem, till att se handikapp som ett tillstånd av kollektiv diskriminering och som ett uttryck för socialt förtryck vilket inte åtgärdas med medicinska insatser utan med politisk handling (Tideman 2000, s. 9). Den sociala modellen till skillnad från den medicinska modellen tar således avstamp i strukturer och processer där dessa människor utesluts och det är samhället som verkar handikappande. Handikapp utgör så att säga en form av socialt förtryck (Barnes och Mercer 2000, s. 79).

Handikappombudsmannen inrättades som statlig myndighet 1994 (Lag om Handikappombudsmannen 1994:749) och har till uppgift att bevaka frågor som rör funktionshindrade personers rättigheter och intressen. Utgångspunkten för arbetet är FN:s standardregler om delaktighet och jämlikhet för människor med funktionshinder. Målet för verksamheten skall vara full delaktighet i samhällslivet och jämlikhet i levnadsvillkor för personer med funktionshinder. I början av 2000-talet inrättades myndigheten Handisam med uppgift till övergripande samordning av handikappolitiken. Regeringen ville på ett effektivare sätt driva igenom den nationella handlingsplanen för handikappolitiken.

Sammanfattningsvis kan konstateras att aktiv opinionsbildning och lagstiftning pågått i över 40 år. I den nationella handlingsplanen för handikappolitiken konstateras att utvecklingen har gått framåt. Vad beträffar individuella stöd finns däremot fortfarande allvarliga hinder kvar på vägen mot ett samhälle för alla. I planen skrivs att ”De grundläggande värderingarna som skall styra handikappolitiken tycks heller inte i tillräcklig hög omfattning nå fram till de forum där beslut som rör personer med funktionshinder fattas.” (Regeringens proposition 1999/2000:79).

## 4. RÄTTSLIG REGLERING OCH SAMHÄLLELIGA AKTÖRER

En rad olika aktörer; landsting, kommun, stat/försäkringskassa, försäkringsbolag och stiftelser, ansvarar för olika stöd och service och för operationaliseringen av den rättsliga regleringen. För en person med en omfattande och livslång sjukdom eller skada kommer kontakterna med olika myndigheter och instanser att fortgå hela livet. Strukturen kan se olika ut för olika regioner i landet, typiskt är att varje enhet är organiserad efter ärendeslag där olika handläggare hanterar dem. För den enskilde personen innebär detta att många olika handläggare är och kommer att bli involverade i alla olika ansökningsprocesser (Nordgren 2006, s. 8).

Olika lagar och rättsliga regleringar styr de resurser som finns t ex Hälso- och sjukvårdslagen (1982:763), Socialtjänstlagen (2001:453), Lagen 1993:389 om assistansersättning (LASS), Lagen 1993:387 om stöd och service till vissa funktionshindrade (LSS), Lag 1992:1574 om bostadsanpassningsbidrag m m och Förordning 1988:890 om bilstöd till personer med funktionsnedsättning. På anställnings- och arbetsmiljöområdet reglerar bl a Lagen 1974:12 om anställningsskydd som ger anställda med nedsatt arbetsförmåga särskilt skydd vid uppsägningar, Lagen 1974:13 om anställningsfrämjande åtgärder och Arbetsmiljölagen 1977:1160. Plan- och bygglagen styr bl a byggnation (1987:10). Några lagar behandlar diskriminering, Lagen 1999:132 om förbud mot diskriminering i arbetslivet på grund av funktionshinder, Lagen 2001:1286 om likabehandling av studenter i högskolan, Lagen 2003:307 om förbud mot diskriminering, Lagen 1994:749 om Handikappombudsmannen. En proposition med förslag till ny diskrimineringslag gällande fr o m år 2009 föreslås ha till ändamål att motverka diskriminering och på andra sätt främja lika rättigheter och möjligheter oavsett kön, könsöverskridande identitet, etnisk tillhörighet, religion, funktionshinder, sexuell läggning eller ålder (Regeringens proposition 2007/08:95).

Den rättsliga regleringen är således omfattande och det stora antalet av samhälleliga aktörer som operationaliserar regleringarna utgörs från medborgarens perspektiv av komplexa och svårtillgängliga organisationer.

## 5. TIDIGARE SVENSK FORSKNING

Trots att forskning inom handikappvetenskap är ett växande område tycks forskning om mötet (tolkat som bemötandet) mellan en person med fysisk funktionsnedsättning och olika samhällsföreträdare vara sparsam. Med tillägg att forskningen ska utgå från personer med funktionsnedsättnings eget perspektiv och/eller ta sin utgångspunkt i medborgarrätten så är forskningsläget ännu sämre (SOU 1998:16). Däremot finns sådana möten beskrivna i sammanfattande termer i olika slags offentliga utredningar. Samtliga dokumentationer pekar dock åt samma håll. Bengt Lindqvist tydliggör ”Att så många beskriver sina känslor runt mötet med samhället så lika har att göra med allmänmänskliga reaktioner på beroende och utsatthet.” (SOU 1999:21). Maktförhållanden, utsatthet och beroende framkommer således genomgående. Annika Jacobson har i en avhandling åskådliggjort, gett kunskap om och skapat förståelse för livssituationen hos människor som har fysisk funktionsnedsättning och som är i behov av personlig hjälp. Det framkommer att ”Informanterna i denna undersökning upplever på många sätt stor maktlöshet. Hjälpen de får synes ofta utgöra ett hot mot deras integritet och identitet.” (Jacobson 1996, s. 217). Munir Dag har i sin avhandling undersökt hur unga personers arbets- sociala och ekonomiska situation påverkats av deras fysiska funktionsnedsättning. Han konstaterar bl a att dåligt anpassade arbetsplatser och arbetsgivares negativa attityder utgör hinder för individerna (Dag 2006). Camilla Nordgren et al har i en studie undersökt individer med fysisk funktionsnedsättning och deras tillfredsställelsegrad av ansökningsprocesserna till en samhällelig resurs. Informationsbrister och komplexa organisationer framhålls som svagheter (Nordgren, Levi, Ljunggren och Seiger 2003). I en offentlig utredning *Kontrollerad och ifrågasatt* har tretton personer intervjuats om sina upplevelser av bemötande. Alla har liknande upplevelser av bemötandet som uttrycks bl a som ”Man måste argumentera för att få det man behöver”, ”Man får inget utan att överklaga” och ”Det tar så mycket energi att klara av alla dessa duster” (SOU 1998:48).

Man kan således konstatera att det handikappolitiska målet i termer av lagstiftade insatser inte alltid förmår att tillfredsställa individen. Förklaring till detta faktum söks vidare i teorier om normer och regler.

## 6. TEORETISK UTGÅNGSPUNKT – NORMER

Rättssociologi hanterar förhållandet och samspelet mellan rättsliga regler och samhället. Regleringar som syftar till att styra individers handlingar vidmakthålles genom övervakning och sanktioner och/eller samhällelig acceptans. Måns Svensson pekar på att det både politiskt och ekonomiskt är problematiskt att driva fram förändrade handlingar enbart med hjälp av övervakning och sanktioner. Politiker som driver igenom regleringar utan eller med bristande samhällelig acceptans får i längden svårt att attrahera väljare och kostnaderna för att bedriva tillräcklig övervakning blir orimligt stora. Att förändra utbredda handlingar är således beroende av förmågan att skapa acceptans. Repressiva interventioner måste därför ske parallellt med sociala normbildningsprocesser (Svensson 2008, s. 34). Det vetenskapliga synsättet normvetenskap förklaras av Håkan Hydén med ”normen som förklaringsfaktor för förståelsen av människors handlande” (Hydén 2002, s. 14). Thomas Mathiesen förklarar normmodellen som de gemensamt bestämda förväntningarna på varandras beteende vilka i det att de påverkar människors beteende utgör styrande krafter i samhället (Mathiesen 1973, s. 9-14). Ett tydligt exempel på en norm är när två obekanta personer hälsar på varandra i en trappa. Det finns här en förväntan på varandra om att man ska hälsa. Samma gäller för hur man beter sig i en busskö, här finns en förväntan om att man ställer sig sist. Måns Svensson poängterar att ”Normer uppstår som ett resultat av att människor samlar information om sin omgivning och tolkar/bearbetar och kommunicerar den informationen så att den kan ligga till grund för ett beslutsunderlag. I den mån informationen består av socialt reproducerade handlingsanvisningar är det frågan om normer. I den mån det handlar om att tolka materiella omständigheter uppstår normerna när dessa tolkningar ges social spridning i form av handlingsanvisningar.” (Svensson 2008, s. 52).

En norm är ett automatiskt handlande och har således tre essenser eller kännetecken; 1. att vara *handlingsanvisande*, d v s att vara imperativ, 2. att ingå i en kommunikativ verklighet och därmed vara *socialt reproducerade*, d v s upprepad och använd och kommunicerad socialt eller t ex via en gestaltning och 3. att utgöra individens uppfattning avseende *omgivningens förväntningar på det egna beteendet*. Normer vidmakthålles via tre olika mekanismer: genom koordination av ageranden, genom hot om konsekvenser om du bryter mot normen och slutligen genom att de är internaliserade och överensstämmande med individens egna tumregler (Svensson och Hydén 2008). Normer existerar i en social kontext och uppfattas och upplevs på liknande sätt av människor som exponeras för dem. Först när en åsikt om hur man ska förhålla sig till ett varande är spritt kan man benämna det som en norm. Per Wickenberg lyfter fram ”normer som uppträder i en social kontext, som kommuniceras i en social gemenskap, och som har sociala uppträdelseformer, sociala samband och sociala effekter. Interpersonell norm – om jag *kommunicerar den med andra* och dessa omfattar denna norm – blir det som kallas ”norm”.” (Wickenberg 1999, s. 262). En norm existerar således inte som ett fysiskt objekt i sig utan uttrycks och tolkas genom lingvistik och semiotik och kan endast uppfattas genom dess effekter. Dessutom kan reproduktionen ”avläsas empiriskt i form av iakttagandet av kommunikation eller artefakter” (Svensson 2008, s. 46). En trappa t ex är skapad av människan i en viss avsikt och med ett socialt syfte: att ta sig upp och ned i omgivningen. Den uttrycker därmed också tydligt en handlingsanvisning som är förankrad, kommunicerad och förstådd i en social kontext. Trappan är alltså en norm som blir en social norm. Om man som rullstolsanvändare närmar sig trappan tydliggörs omedelbart normens innehåll och handlingsanvisning. Det kan ses som en konflikt mellan två normer, den ena – Här bör man kliva uppåt med fotsteg-normen och den andra – Här bör man rulla framåt med hjul-normen. Denna konflikt är inte omedelbart lösbar utan insatser.

Att utgå från empiri medför ett analysarbete dels kring vilka normer som föreligger generellt och dels kring de av empirin framkallade normerna. Normer som handlingsanvisningar kan upptäckas genom studiet av individens relation till sin närhet. Eftersom det är individer som handlar och denna handling uppmärksammas kan vidare undersökning ske av individers skäl till just denna handling. ”Om vi kan följa en norm från dess ursprung, över en tillämpning och till dess effekt, kan vi också på ett bättre sätt förstå förändringsprocesser.” (Baier 2007, s. 16). Med ökad insikt finns också möjlighet till att förstå hur normer konkurrerar med rättslig reglering och andra normer och hur handling kan förändras.

## 7. METOD

Gerd Peterson et al (Peterson, Ekensteen och Rydén 2006, s. 109) konstaterar utifrån en datainsamling från människor med omfattande funktionsnedsättning om tillgången till den offentliga miljön att ”I praktiken återstår många hinder som illustreras av våra informanters erfarenheter.”. Vad är det då för praktik och erfarenhet som avses och hur ska detta kunna återges? Att söka empiri från personer med egen erfarenhet är essentiellt. Handikapporganisationerna har som motto ”Nothing About Us Without Us” vilket betonar principen om delaktighet. För ett mera exakt tydliggörande och exemplifiering av situationer där missnöje kan uppstå i operationaliseringen av de handikappolitiska målen eller i mötet med samhället har två olika insamlingsmetoder av empiri valts. Den ena utgår från skrivna, publicerade berättelser av olika personer, den andra från berättelser av författaren till denna artikel, d v s ett självbiografiskt berättande.

Carola Skott redogör i boken ”Berättelsens praktik och teori”, om berättelsens betydelse i den s k narrativa forskningen. Hon beskriver att vi upplever på skilda sätt förändringar av livsvillkor. För att kunna leva det dagliga livet och förstå vad som händer och lösa problem och undersöka handlingsalternativ förvandlar vi praktiska erfarenheter till språk som tar form som ett berättande (Skott 2004, s. 9). Berättelsen utgör så att säga ett medel för att förstå individens försök att hantera sin livssituation. Berättelser har väckt ett ökat intresse och ökat i betydelse inom bl a samhällsvetenskapliga studier av medicin och sjukdom. Lars-Christer Hydén uttrycker att karaktäristiskt för en sjukdomsberättelse ”is that they formulate and express a central aspect of being ill in modern society, namely the difficulty of giving voice both to suffering and to the lifeworld context of illness.” (Hydén 1997, s. 64). Berättelser i denna artikel syftar just till att förmedla en praktik som innefattar ett antal personers individuella situation med känslor och detaljer i förhållande till livsvärlden.

Kriterier för urval av berättelser har varit deras relevans utifrån forskningsfrågan, beskrivning av svenska förhållanden vad gäller vardagssituationer för personer med funktionsnedsättning, publicerade i svensk litteratur, belysning av olika områden inom livet. Antalet har inte på förhand varit bestämt utan bestäms av möjligheten att hitta dem. Metoden har varit en systematisk litteratursökning i Libris (via klassifikationssystemet för svenska bibliotek, SAB-klassningen), där olika sökkategorier har kombinerats för att finna den typ av individuella livsberättelser som anger i forskningsfrågan. Tidsmässigt gjordes en begränsning till år 2000 och framåt. Sökkombinationen har varit Lz (biografi med genealogi, särskilda personer) *och* Ohfhf-c (social omsorg, handikappade, rörelsehindrade, Sverige). Vid en sådan preciserad sökning fås fyra (4) träffar. Endast en av böckerna i sökresultatet har en sådan konkretionsnivå att den kan användas här som empiri med konkreta vardagsbeskrivningar av sociala händelser. Den andra använda referensen blir istället Lindquist (2004) som anmärkningsvärt nog inte har klassificerats enligt detta mönster (Lz & Ohfhf-c) utan som istället klassificerats som Lz & Vef (där Vef står för: allmän medicin, nervsystem). Ulla-Carin Lindquist är en välkänd TV-personlighet i Sverige och hennes bok fick stor genomslagskraft i media. Boken har nu redan kommit i en ny upplaga och blivit översatt till 12 språk samt i storstil och video. Av det skälet var denna bok med livsberättelser/narrativ redan väl känd och självklar att använda för föreliggande studie.

Det går inte att bortse från författarens erfarenhet av att i 40 år ha levt med en funktionsnedsättning och ett flertal av författarens berättelser ingår i empirin. Vilka som är författarens respektive andras berättelser redovisas. En berättelse är subjektiv till sin natur och huruvida berättelserna i en slags objektiv mening är sanna är inte möjligt att ta ställning till. För den person som har berättat dem är de sanna. Berättelserna används som ett medel, som ett redskap för att undersöka vilka normer som kan utkristalliseras från dem och huruvida dessa normer särskiljer sig från de rådande och förväntade normerna. Endast berättelser som beskriver vardagssituationer där individens förväntningar om ett utfall inte stämmer överens med andras reaktioner har inkluderats i syfte att skapa fördjupad förstående av reproducerade sociala handlingsmönster. Situationer som ej orsakar någon sådan konflikt är således ej av intresse i denna studie.

## 8. EMPIRI

Generellt delar personer med funktionsnedsättningar sina livsmål med alla andra människor. Drömmar om yrkesidentitet, familjebildning, boende, sociala aktiviteter m m ser likartade ut. Att leva med en omfattande fysisk funktionsnedsättning är dock (förutom alla medicinska, fysiska och psykiska aspekter) också opraktiskt. För att vardagssituationer ska fungera krävs att omgivningen är tillgängliggjord och/eller att riktat stöd kan erhållas. I berättelserna nedan illustreras en rad vardagliga situationer baserade på artikelförfattarens och andra personers erfarenheter.

### *Ansökan om assistans*

I Ulla-Carin Lindqvists (Lindquist 2004, s. 79-82) bok om sin dödliga sjukdom ALS, beskriver hon handläggningsproceduren kring sin ansökan om assistans. ”Ett par veckor senare kommer en grupp människor med beslutsrätt hem till mig för att på ort och ställe diskutera de hjälpinsatser som behövs. De sitter i vardagsrummet. En utredare från försäkringskassan och en från kommunen. Kuratorn från sjukhuset och Mimmi. – Vi måste veta exakt hur lång tid det tar för dig att utföra olika sysslor. – Hur menar du? – Hur lång tid tar det när du klär dig? – Men jag kan ju inte klä mig. – Ungefär hur lång tid? – Jag kan ju inte. Läste du inte brevet

jag skrev? Hon från kommunen har missat det. Hon från försäkringskassan har med en extra kopia. – Det räcker inte. Vi måste ha en tid. – Du skojar. – Nej. – Men jag kan inte. Hemtjänsten klär mig. Jag kan inte få på mig ett par byxor utan att ramla.
Så där håller det på ett tag. Jag klassificeras, vägs in, värderas. Varken Kommunen eller Kassan har insett Mimmis kaliber. Hon ilsknar till: – Vill ni veta hur lång tid det tar för henne att byta tampong? Generade. Men det visar sig att Kommunen och Kassan vill visa sin makt. – Vi har våra regler. – Vad väntar ni på? Här finns ju läkarutlåtande som intygar. Arbetsterapeutens utredning. Ser ni inte? Hon kan ju inte ens pilla sig på näsan! – Vem beslutar på kommunen, frågar jag. – Det gör jag. – Bara du? – Ja. – Besluta dig nu! – Så går det inte till. – Besluta dig i morgon. – Så går det inte till. Jag kan fatta beslut nästa vecka. Då byter Kassan, en erfaren dam, planhalva: – Jag för min del kommer att tillstyrka att Ulla-Carin behöver de hjälpinsatser hon ansöker om. Tidigt nästa morgon, när jag ligger i sängen och väntar på hemtjänsten, ringer telefonen: – Hej, det är från kommunen. Jag har beslutat mig nu. Du beviljas den assistanshjälp du begärt. Återigen får jag bekräftat att en stor käft är nödvändig. Att ha mål i mun och skinn på näsan. Hur skulle Aden från Somalia klara sig?”

*Beroende av goda grannar*
Ett exempel av Peter Brusén (Brusén 2005, s. 134) ”Trots min fyrhjulsdrivna Subaru blev jag mer och mer nervös över vad som skulle hända om det blev kallt och mycket snö. Tänk om jag inte kom upp för den branta backen? Jag måste hålla ena handen på gas/bromshandtagen och har alltså bara en hand för ratten. Det är inte så lätt att styra om det är is och snö i backen. Jag behövde planera för nödläget om jag inte kom upp eller om jag blev sjuk och behövde ambulanstransport. Att dra rullstolen uppför backen är en omöjlighet – ja, t o m nerför. Men jag blev lugnad när jag kom på att det fanns en bra lösning – att ta bakvägen genom dörren i mitt plank mot bostadsrättsföreningen Rönninge Källa. Där fanns nämligen en asfalterad gång nästan ända fram. Men jag kanske för ordningens skull behövde ett OK från föreningen att ta rullstolen den vägen i en nödfallssituation. Efter två månader (!) ringde ordföranden och meddelade att det nog inte gick för sig. Han hade frågat några enstaka personer i ett grannhus och de ville inte ge sin tillåtelse. Ett argument var till exempel ”vem hade ansvaret om jag trillade ur rullstolen och skadade mig?” Jag blev fullkomligt förstummad och fruktansvärt kränkt. Så fina allmänna åsikter och en så bedrövlig handling. Det var mitt första möte med den djupa intoleransen och den oförsonliga diskrimineringen. Jag har mött så mycket tillmötesgående från andra människor och var fullkomligt oförberedd på detta.”

*Ärendebalansen måste hållas*
Ett andra exempel av Peter Brusén (Brusén 2005, s. 150-151) ”Jag satt på jobbet och funderade på om jag skulle fara hem tidigare för att slippa bilköerna. Det var i augusti och fortfarande varmt. Jag bestämde mig för att ge mig iväg. Just när jag började klä på mig ringde telefonen uppfodrande. Ett tag funderade jag på att inte svara, men Socialstyrelsen skall ju vara en tillgänglig myndighet så plikten tog överhanden. Personen presenterade sig kort som min handläggare på Försäkringskassan. Jag hade aldrig tidigare pratat med henne. Hon frågade hur jag mådde och gick sedan snabbt över till sitt egentliga ärende. Hon hade läst igenom min akt och tyckte att jag varit sjukskriven ganska länge – cirka ett år efter olyckan. Hon undrade om jag funderat över att förtidspensionera mig eller gå över till sjukbidrag på den halvtid som jag fortfarande var sjukskriven på. Hon hade sett i läkarintyget att min skada bedömdes som permanent. Det var visserligen ett år sedan olyckan, svarade jag, och framhöll att sjukskrivningen varit lång men att det bara var ett drygt halvår efter att jag kommit hem efter fem månader på sjukhus och rehabilitering. Dessutom hade jag arbetat deltid i ett halvt år. Jag berättade vidare att jag fortfarande tränade och att jag senare under hösten skulle gå upp till 75 procent och planerade till våren 2002 att gå på heltid. Jag var lite konfunderad över det hon sagt om själva

skadan, så jag försökte förklara att det faktum att min skada var permanent inte betydde att min arbetsförmåga också behövde vara permanent dålig. Det är ju hela poängen med rehabilitering, anpassning och hjälpmedel att förbättra min funktionsförmåga trots min bestående skada. Hon envisades, trots detta, med att en förtidspensionering nog var något jag skulle tänka på och att hon skulle skicka över blanketter. Hon tryckte avslutningsvis åter på att min sjukskrivning varit i längsta laget och rundade till sist av med ett litet hot om att det var tveksamt hur länge Försäkringskassan kunde fortsätta att bevilja den. Jag var inte bara förbluffad utan kände mig ganska tillplattad. Tillvägagångssättet att ringa mig på min arbetsplats för att diskutera förtidspensionering gjorde mig minst sagt förvånad. Ingen fråga om mitt arbete, min arbetsgivares inställning eller om det fanns en rehabiliteringsplan. Ingen fråga om den medicinska rehabiliteringen och hur mina kontakter med Spinalis såg ut. Ingen diskussion kring min egen motivering och planering. När jag senare fick hennes broschyr och blanketter gick dessa raka vägen ner i papperskorgen. Men händelsen startade ett tänkande hos mig om hur samhället ser på personer med funktionshinder och deras rehabilitering.”

*Mamma i rullstol*

När jag blev mamma för första gången erfor jag att det som alla andra barnlediga mammor gör - promenerar med barnet i barnvagnen – är omöjligt när man som jag sitter i rullstol. Att köra rullstol och barnvagn samtidigt är oförenligt. När jag väntade mitt andra barn tog jag därför i god tid kontakt med kommunen för att efterhöra om jag kunde få hjälp med att köra barnvagnen ett par gånger i veckan när vi skulle ut på promenad. Via en kommunikation per telefon fick jag reda på att eftersom jag med min funktionsnedsättning inte själv behöver hjälp och barnet inte hade särskilda behov föll mitt barns och mitt gemensamma behov utanför lagstiftningen. (CN)

*Student i Lund*

När jag började mina studier på Universitetet i Lund i början av 1980-talet valde jag utbildning efter i vilka lokaler utbildningen bedrevs. Undervisning i många ämnen skedde då i hus som var helt otillgängliga med rullstol. Idag ser det annorlunda ut. Nya hus har byggts och anpassningar har gjorts i gamla. Dock har inte samma förändringar skett i de nog så viktiga husen och lokalerna för studenterna, nämligen nationerna och studentboendena. (CN)

*På bio*

De moderna biografsalongerna är brant uppbyggda. Förr i tiden bestod sidogångarna i salongerna av sluttande golv, nu har de ersatts med trapp- och avsatsformationer. Oftast finns en eller två rullstolsplatser och där vill biografpersonalen oftast att man ska sitta. Vid höga protester eller inkännande personal kan jag faktiskt själv få välja vilken rad jag ska sitta på men det kräver då att jag får hjälp att ta mig dit (p g a trapporna). Om jag hoppar över från rullstolen till ett biosäte händer det att personalen vill ta ut min rullstol från gången/salongen. Detta med motiveringen att gångarna måste vara fria vid en evakuering. Jag fråntas alltså alla möjligheter att kunna ta mig ut för egen maskin. Jag har till och med blivit stoppad från att köpa biljetter med motiveringen att det redan fanns två rullstolsburna personer som köpt biljetter till samma föreställning. Motiveringen löd då att brandkåren inte tillät mer än ett visst antal rullstolsburna personer i salongen. Andra funktionsnedsättningar såsom panikångest eller hjärtproblem som kan utlösas vid stress har tydligen brandkåren inga sådana regler för. I ett examensarbete med titeln ”Funktionshindrades riskbild i publika lokaler – med avseende på utrymning” konstateras att personer med funktionsnedsättning har en högre risknivå, ibland oacceptabelt hög när det gäller utrymning från publika lokaler p g a byggnadstekniska hinder (Möller och Nygren 2004). (CN)

*Boende*
I princip finns ingen bostad som passar mig fullt ut. Förändringar och anpassningar måste alltid göras. För att kunna få bostadsanpassningsbidrag är jag tvungen att välja en bostad som är lämplig med tanke på min funktionsnedsättning. Sådan val innefattar för mig först och främst ett enplansboende och plan mark i direktomgivningen. Om man som jag ådragit sig skadan vid unga år är det ganska naturligt att boendet kommit att ändras ett antal gånger. Jag har bott och levt som barn med mina föräldrar. Jag har bott och levt som student vid Universitetet. Jag har bott singel i lägenhet och senare som sambo i andra lägenheter. Jag har fått barn och bott med familj i radhus och jag har skaffat ett fritidshus. När en förändring av boende har varit aktuellt har jag precis som alla andra fått söka mig till bostadsmarknaden. Att då hitta boende som passar i läge, standard, pris, utseende, planlösning och som dessutom är i ett plan är inte lätt. En möjlighet är att bygga nytt hus som redan från början skulle kunna skräddarsys för mina behov. Att hitta tomtmark i attraktiva områden är svårt. Många kommuner har tomtmark som säljs till byggbolag och till privatpersoner i tomtkö. Byggbolagen föredrar generellt i dagens läge att bygga 1 ½, 2 eller 2 ½ -plans hus. Hur fördelningen mellan försäljning till byggbolag respektive privatpersoner ser ut är olika. Emellertid kan konstateras att ju färre tomter som går till privatpersoner eller där detaljplanen sätter hinder för enplanshus, desto svårare blir det för personer med behov att hitta ett lämpligt boende. Hela strukturen kring bostadsfrågor betonar ett antal frågor; Hur förväntas man hitta ett boende som är lämpligt när begagnatmarknaden är överhettad och man som privatperson förutom lämpligheten i boendet också har andra hänsyn att göra såsom familjens önskemål, avstånd till arbetsplats, pris m m? Hur medverkar kommunernas detaljplaner och sätt att fördela tomtmark till att öka förutsättningarna för att personer ska kunna ordna ett lämpligt boende? Hur många gånger kan man begära bostadsanpassning när ens bostadsbehov förändras? (CN)

*Sjukskrivning efter kejsarsnitt*
Det finns många personer med traumatisk ryggmärgsskada som är förtidspensionerade. Inte för att deras arbetsförmåga skiljer sig från dem som arbetar utan för att de skadade sig i en tid då förtidspensionering istället för arbete var den lösningen man hade. När jag födde mitt andra barn med kejsarsnitt ville jag bli sjukskriven c:a tre veckor för återhämtning. Mitt rörelsemönster, balans och förflyttning är helt annorlunda utan än med en baby i magen. Detta blir tydligt då magen från en dag till en annan ”försvinner” när barnet är förlöst. Vid denna önskan bemöttes jag med skepsis av en läkare som sa att kejsarsnitt inte automatiskt leder till sjukskrivning och att det var tveksamt om försäkringskassan skulle godkänna en sådan. Med vetskap om hur många det är som är förtidspensionerade kändes det onyanserat att ifrågasätta min önskan om en kort sjukskrivning. (CN)

I samtliga berättelser framkommer det att individen med funktionsnedsättning har förväntningar baserat på det generella men där erfarenheten blir att man upplever hinder mot att uppnå full delaktighet, jämlikhet och lika värde. Detta konstaterande analyseras och diskuteras nedan.

## 9. RESULTAT OCH ANALYS

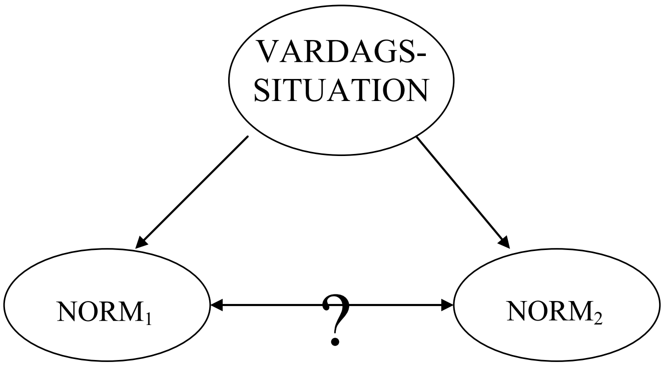
I respektive berättelse ovan finns ett underliggande budskap som kan tydliggöras i syfte att belysa de normer som råder. Samtliga berättelser speglar att hos den berörda personen finns en slags förväntan eller en kunskap om vad som allmänt och vanligtvis brukar gälla för personer i de situationer som uppkommer, t ex vid biljettköp till en bioföreställning, sjukskrivning vid sjukdom, boende i universitetsstaden Lund. Denna norm är generell, alltså på en nivå som man kan uttrycka med ”Man bör”. Som individ utgår man från de vanliga sociala normerna som råder och som man känner till. Tanken är att individen genom att initialt försätta sig i situationen har förväntningar om att uppnå ett visst resultat – det allmänt kända. Om man från början vetat om att någon annan norm än den man känner till gäller, är det troligt att man hade handlat annorlunda i situationen, alternativt aldrig hade exponerat sig eller utsatt sig för situationen. Det första steget i processen är att definiera vilka normer som råder och om de skiljer sig åt i den allmänna situationen versus den aktuella situationen. Nästa steg blir att utifrån den rådande normen tydliggöra vilka föreställningar individen har om vad han/hon kan förvänta sig i den aktuella situationen. Vi rör oss här i riktning från en social nivå till en individnivå. Efter att situationen har uppstått har nu individen erfarenhet om utfallet, vilket utgör det tredje steget i analysprocessen. Se Tabell 1. Förutsättningar såsom det specifika i situationen, t ex slag av funktionsnedsättning, personkaraktäristika, när i tid m m har utelämnats i uttolkningen för att normerna i möjligaste grad ska vara allmänna, d v s inte bundna vid en specifik situation.

| **Narrativ** | **Rådande norm** | **Individuell förväntan baserat på rådande norm** | **Utfall av situationen** |
|---|---|---|---|
| Ansökan om assistans | Är man assistansberättigad bör man få assistans vid behov handlagt på ett professionellt sätt | Jag kommer att få den assistans jag behöver handlagt på ett professionellt sätt | Jag får inte den assistans den jag be-höver handlagt på ett professionellt sätt |
| Beroende av goda grannar | Är man god granne bör man få hjälp av goda grannar | Jag kommer att kunna få hjälp av goda grannar | Jag kommer inte att få hjälp av goda grannar |
| Ärendebalansen måste hållas | Är man sjuk bör man bli sjukskriven i den omfattningen man behöver | Jag kommer att kunna vara sjukskriven i den omfattning jag behöver | Jag kommer inte att kunna vara sjukskriven i den omfattningen jag behöver |
| Mamma i rullstol | Är man mamma med barn bör man ut och gå med barnvagn | Jag kommer att få hjälp med att gå ut och gå med mitt barn i barnvagn | Jag får inte hjälp med att gå ut och gå med mitt barn i barnvagn |
| Student i Lund | Är man student i Lund bör man bo på nation/studenthem | Jag kommer att kunna bo på vald/valt nation/ studenthem | Jag kan inte bo på vald/valt nation/ studenthem |
| På bio | Är man biobesökare bör man själv ta sig ut från bion i en nödsituation | Jag kommer att kunna ta mig ut själv från bion ifall nödsituation uppstår | Jag kan inte själv ta mig ut från bion i en nödsituation |

| | | | |
|---|---|---|---|
| På bio | Är man biobesökare bör man, om det finns plats, köpa biljett | Jag kommer att kunna köpa biljetter oavsett antal rullstolsburna besökare | Jag får inte köpa biljett till bion |
| Boende | Är man husspekulant bör man köpa ett hus som motsvarar ens behov | Jag kommer att kunna köpa ett hus på nybostadsmarkanden som motsvarar mina behov | Jag kan inte köpa ett hus på nybostadsmarknaden som motsvarar mina behov |
| Sjukskrivning efter kejsarsnitt | Är man nyförlöst mamma bör man bli sjukskriven då hänsyn tages till den individuella hälsosituationen efter ett kejsarsnitt | Jag kommer att kunna bli sjukskriven eftersom hänsyn tages till min individuella hälsosituation | Jag kan inte räkna med att bli sjukskriven med hänsyn tagen till min individuella hälsosituation |

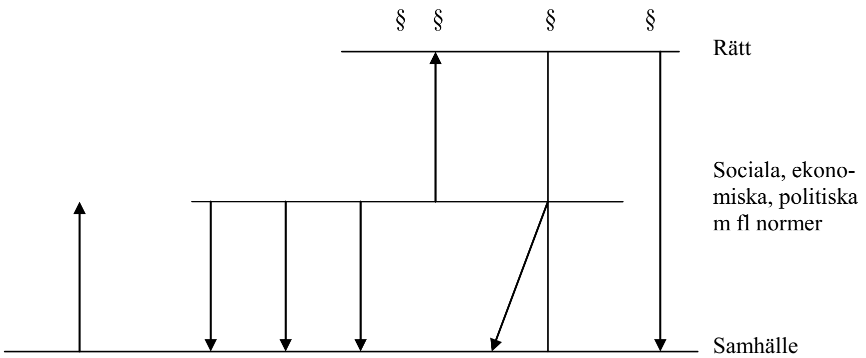
*Tabell 1: Analys av empiri utifrån ett normperspektiv*

Genomgående kan konstateras att individens erfarenhet av utfallet går i motsatt riktning från den rådande normen, se Figur 1 nedan. Individen tycks inte kunna identifiera sig med alla andra och lita på att det är den gängse, förväntade normen ($Norm_1$) som råder. Istället träder en annan norm in ($Norm_2$) som skiljer sig från den förväntade normen.



*Figur 1: Empirin tydliggör konkurrens mellan förväntad norm och annan norm*

Dessa två olika normperspektiv baseras på två olika nivåer; det lokala samhälleliga normperspektivet och det normperspektiv som baseras på centrala, nationella normer och rättsregler, se Figur 2.



*Figur 2: Normer mellan rätt och samhälle (Hydén 2002, s. 272)*

Vad är det då som händer i den faktiska situationen som gör att den förväntade och rådande normen inte kan gälla? Myndighetspersonen, företrädaren eller bärarna av det socialpolitiska systemet förefaller att agera utifrån ett faktum som individen har med sig in i mötet, t ex en funktionsnedsättning, vilket leder till att andra normer gör sig gällande. Det specifika hos individen tycks utlösa en annan handling baserat på en annan norm (från Norm$_1$ till Norm$_2$). Dessa två normer står i konflikt och av empirin framgår att det konsekvent är Norm$_2$ som är starkare och som därför blir den norm som utgör grunden för den handling som sker.

Då den rådande, förväntade normen är baserad på social reproducerbarhet och individens uppfattning avseende omgivningens förväntning på det egna handlandet uppkommer frågan vad den nya normen (Norm$_2$) har för grund. Kan man hävda att den nya, lokala normen bygger på riktlinjer, lagar, förordningar? Den svenska handikappolitiken har som tidigare beskrivits *full delaktighet, jämlikhet och alla människors lika värde* som målsättning. Det kan således konstateras att det lokalt inte finns uttalat stöd eller kraft för den rättsliga normen. Det måste alltså vara en annan lokal norm som styr handlandet och gör att den nationella rättsliga regleringen inte kan dominera eller ha tillräcklig kraft. Det kan då, som vi noterat i exemplen ovan, vara normer som är baserade på en lokal ekonomisk, politisk eller social rationalitet.

## 10. DISKUSSION OCH SLUTSATSER

Det skulle vara enkelt att avfärda berättelserna ovan som enstaka händelser eller som ett unikt möte mellan några personer. Det finns emellertid ingenting i merparten av berättelserna som pekar på att historien inte upprepar sig eller att resultatet av situationen har med personen som individ att göra, d v s att utfallet i situationen enbart är en relation enskild individ versus situation. Snarare pekar det i riktning mot att det handlar om upprepade händelser för en grupp personer med otydliga karaktäristika, t ex personer i rullstol, personer med lång sjukskrivning eller personer med krav på snabba assistansbeslut. Handlingsmönstret som har framkommit i samtliga berättelser pekar i riktning mot effekter i form av särskiljning och exkludering. I en kunskapsöversikt om bemötandet av personer med funktionshinder inom områden som är av stor betydelse för funktionshindrades livskvalitet har forskningsresultat från de senaste 20-25 åren sammanställts och uttrycker att ”vi har ett stort antal forskningsresultat som tyder på att det finns en diskrepans mellan funktionshindrade personers rättmätiga förväntningar, som bl a har sin grund i vad som sägs i lagar och regler, och den verklighet de möter när de kommer i kontakt med myndigheter, sjukvård, skola, barnomsorg etc.” (SOU 1998:16). Den lokala särskiljning som berättelserna visar möjliggör en urholkning av, och till och med, brott mot lagstiftningens intentioner. Peter Brusén och Anders Printz skriver i boken ”Handikappolitiken i praktiken” att ”Politiken fungerar inte i ett vakuum utan i ett beroendefält med människor som ska göra ord till verklighet. Det som bestäms av riksdag och regering filtreras genom alla de människor som ska tillämpa tankarna och lagarna. Resultatet blir därför helt avgörande för hur pass mycket som tjänstemän, lokala politiker och personal på olika nivåer uppfattar det som tänkts på samma sätt. Handikappolitiken måste därför tillämpas på flera nivåer samtidigt” (Brusén och Printz 2006, s. 10).

Artikeln har tagit sin utgångspunkt i hur ett normperspektiv och föreställningen om normbyggande processer kan tillämpas på en rad berättelser för att förstå vilka normer som råder och varför rättslig reglering i sig inte räcker till för att individen ska uppnå full delaktighet och jämlikhet. Trots mångårig och omfattande lagstiftning visar berättelserna att dessa ofta inte hjälper individen att uppnå den handikappolitiska målsättningen. Instiftade lagar förmår uppenbarligen inte ensamma att operationaliseras på lokal samhällsnivån och genomsyra denna. Om rättslig reglering inte kan hjälpa individen, kan konkurrerande normer ge förklaringsgrund. Genom att skaffa kunskap om normer som anvisar handlande kan vi också påverka i riktning mot förändring (Baier 2007, s. 15). Berättelserna illustrerar vardagens sociala normer (konkurrensnormer eller normer i konflikt) som är den sociala grogrund som de rättsliga normerna kommer att möta i vardagen. Dessa lokala sociala vardagsnormer är starkare i situationen än de avlägsna, långt ifrån kommande rättsnormerna vilket leder till att de rättsliga normerna ofta inte kommer att tillämpas eller fungera. Individen med funktionsnedsättning lever i vardagen således *under dubbla sociala normer*.

### *Varför dominerar då ofta ”den andra normen”?*

I ett möte som bygger på mänsklig relation och respekt uppstår en jämbördighet som relateras mellan två eller flera subjekt, en s k en-till-en- relation. När en starkare och övertagande norm träder in reduceras individen till ett objekt och relationen som uppstår kan beskrivas i termer en-till-noll. I berättelsen om biobesöken har en annan norm övertagit den generella – den som gäller för människor i allmänhet. Denna andra norm handlar om andras aspekter på säkerhet och utrymning vilken de facto reducerar biobesökaren till ett objekt vars eventuella utrymning ska lösas och tryggas av andra. I exemplet med studentboende har individen förvandlats från en fritt bostadssökande student till ett objekt som endast kan bo där andra har bestämt att det är lämpligt. Andra lokala ekonomiska normer manifesteras i en tvärpolitisk debatt nyligen om studentbostäder. Med ekonomiska förtecken framförs att sänkta boendekostnader kan erhållas genom bl a slopande av krav på handikappanpassning på studentboendena (Mikkelsen 2008, s. C8).[1]

Brusén och Printz problematiserar kring att strukturella förändringar inte räcker till i samhället om vi inte samtidigt kan förändra de mänskliga. ”Det är människor som inte har ett funktionshinder som, medvetet eller omedvetet, orsakar att de förutsättningar som finns ändå inte kan utnyttjas av personer som har ett funktionshinder. Det handlar om de föreställningar som finns hos både den funktionshindrade personen och personer som inte har funktionshinder. Ofta är det föreställningen om oförmåga som blockerar tanken. Det kan vara hos såväl allmänheten, yrkesmänniskor eller beslutsfattare som hos enskilda med eget funktionshinder. Föreställningen riskerar starta en självuppfyllande profetia. Eftersom negativa förväntningar sällan är synliga, orsakar de en diskrimineringsprocess som är svår att få grepp på och förstå eftersom orsaken är dold.” (Brusén och Printz 2006, s.10).

Varför personer med funktionsnedsättningar upplever negativa attityder och dåligt bemötande har förklarats med en rad olika modeller; socio-kulturella-, psykodynamiska-, historiska-, demografiska och personlighetsrelaterade. Vidare anges otydligt regelverk, människors ångest och rädsla för det som är annorlunda, människors tendens att kategorisera och gruppera andra människor, språkets betydelse och mediernas betydelse som opinionsbildare (Allport 1965; Goffman 1963; Grönvik 2007, s. 27-31; Holme 2000, s. 75; SOU 1998:16). Samtliga handlar om att någon gör en slags kategorisering eller värdering av individer. Effekterna i berättelserna ovan visar att individen är en förlorare i situationen och inte uppnår det man från början trodde var möjligt. Myndighetspersonen/företrädaren, som i dessa fall har en maktposition, tycks agera i situationerna genom att hemfalla åt en restriktiv eller direkt avvisande handling baserat på andra konkurrerande normer. En del hanterar situationen – om det föreligger bristande erfarenhet, kunskap och värdegrund - med ett avståndstagande. Denna exkludering i samhället skapar en åtskillnad i vi och dem och ett förakt för svagheter som givet vissa sociala omständigheter kan utlösas i vardagens sociala situationer. Grunden finns i ett utanförskap som är en grogrund för diverse handlingsmönster: olikheter, mobbing, dåligt bemötande – och i allra sista hand våld.

I Norge utgavs 1966 boken ”Rettferd for de handikappade” (Skouen 1966). Författaren Arne Skouen hävdade att välfärdssamhället är de starkares samhälle och att kampen för de handikappades rättigheter måste föras i ett samhälle där tiden och utvecklingen arbetar mot dem. Djupast sett är kampens lyckliga utfall avhängigt en attitydförändring, ett nytt klimat. Men välfärdsstaten är tvärtemot på rask väg bort från det klimat vi eftersträvar. Välfärdsstaten, säger Skouen, är ständigt upptagen med att skilja ut dugliga och odugliga, så att den teknisk-kommersiella utvecklingen inte skall riskera att satsa på fel häst. Denna kamouflerade demonazism för oss in i det samhälle där den starkastes rätt härskar. I ett sådant samfund är alla med handikapp automatiskt hänvisade till en auktoriserad jumboplats. Samma tankegångar har Harald Ofstad beskrivit i boken ”Vårt förakt för svaghet” (Ofstad 1979). Boken diskuterar att nazismens brutalitet inte var en produkt bara av en bestämd situation i landets historia, utan också av en bestämd världsåskådning, en viss uppsättning normer, värderingar och verk-

---

[1] Utdrag ur artikeln ”Och många av dem [internationella mastersstudenter, min anm.] anser att vi har på tok för höga krav på boendestandard, enligt Rolf Svensson som vill se över möjligheten att sänka kraven på standarden när nya studentbostäder ska byggas. – Jag vet att många av dem som har det sämst ställt ekonomiskt skulle vilja ha lägre standard om de fick lägre hyra, säger han. [….] Och alla toaletter kanske inte behöver handikappanpassas, föreslår Rolf Svensson vidare. – Byggs hundra nya bostäder behöver kanske inte alla hundra handikappanpassas när det är så kort tid man ska bo där. Hisskravet är en annan sak man kan se över. (Rolf Svensson är vd på AF Bostäder, min anm.)

lighetsuppfattningar vilka vi praktiserar än idag. Det väsentligaste draget i nazismen är att den starke skall härska över den svage och i grunden föraktar den ”svage”.

I en brevväxling mellan två författare till boken ”Funktionshinder och strategival” skriver Vilhelm Ekensteen angående omvärldens värderingar: ”Självklart uppfattar jag inte allmänhet, regering och riksdag som en bromskloss. De kan dock från tid till tid vara det, opinionerna svänger på alla nivåer. Något allmänt framåtskridande tror jag inte på, jag hävdar inte heller att du gör det. Deklarationen om mänskliga rättigheter är för allmän (en funktionshinderkonvention är under utarbetande) för att nämnvärt ha påverkat funktionshindrades livsbetingelser i Sverige. ……., men generellt har det aldrig funnits någon given rörelse i etablissemanget, någon systematisk plan, som syftat till inkludering av dem vi skriver om.” (Peterson, Ekensteen, and Rydén 2006, s. 35).

Finns det då inte utrymme i den generella normen att ta hänsyn till ett specifikt faktum? Då vardagens sociala normer är de som kan dominera blir den nationella intressekampen i vardagen viktig och en stark kraft för förändring av värden och normer. Den naturliga frågan efter ett sådant konstaterande blir hur man då kan bygga upp normstödjande strukturer på olika samhälleliga nivåer? Detta beror i sin tur på hur tydliga och starka de rättsliga normerna är och vem som hävdar dessa nationellt *och* lokalt.

Ett sätt att angripa problematiken är att livligare samtala offentligt om vilka värderingar som styr i samhället. Om inte lagen och samhällets målsättningar är kongruenta med våra sociala normer så kan inte lagen genomföras och tillämpas. Nya normer måste skapas på olika sätt och användas för att samhällsmålen ska kunna nås. Avskiljandet eller segregationen av olika grupper av medborgare leder till mentala avstånd och bristande kunskaper, förståelse och empati. I vardagsmötet mellan människor skapas och växer våra sociala normer och förhållningssätt. Fler vardagsmöten kan skapa bättre förutsättningar för att nya och andra sociala normer gör sig gällande. Stöd för förändring måste ske på olika nivåer. Kraftfullare lagstiftning kan leda till kollektiva insikter. Individer måste våga gå sin egen väg och ta ett personligt individuellt moraliskt ansvar för sina vardagshandlingar genom att bryta grupptryck d v s bryta mot de verkande gruppnormerna och gemensamt bygga in normstödjande strukturer i samhället i syfte att stärka människors moraliska autonomi.

Som slutord används ett utdrag ur en intervju med Bengt Lindqvist (tidigare svensk socialminister) efter 8 år som FNs generalrapportör om handikappades situation: ”Handikapprörelsens företrädare har väldigt svårt att hävda sig i mediebruset i dag. De försöker så gott det går. Men det gäller också att väcka journalisterna, de som har läsarnas uppdrag att granska överheten, så att de inte fortsätter att gäspa över handikappades berättelser. Jag kanske är konspiratorisk, men jag känner det på något sätt som att eliten värjer sig. Det här är lite obehagligt. Att gå riktigt på djupet i den här frågan, det vill man inte riktigt.” (Webbtidning - Mot diskriminering - för öppnare arbetsliv ).

Men det är dags nu - som jag ser det.

# Referenser

Allport, Gordon W. *The nature of prejudice.* MA: Addison-Wesley: Reading, 1965.

Baier, Matthias. *Om normer, vers 2.* Lund: Kompendium, Rättssociologiska enheten, Lunds universitet, 2007.

Barnes, Colin och Mercer, Geof. "Granskning av den sociala handikappmodellen", s. 79-105, Magnus Tideman (red), *Handikapp synsätt, principer, perspektiv.* Lund: Studentlitteratur, 2000.

Brusén, Peter. *Livet en gång till. En ryggmärgsskadad möter svensk handikappolitik.* Malmö: Égalité, 2005.

Brusén, Peter och Hydén, Lars-Christer. "Inledning", s. 11-27, Peter Brusén och Lars-Christer Hydén (red), *Ett liv som andra. Livsvillkor för personer med funktionshinder.* Lund: Studentlitteratur, 2000.

Brusén, Peter och Printz, Anders. "Framtiden i dag", s. 9-18, *Handikappolitiken i praktiken. Om den nationella handlingsplanen.* Växjö: Förlagshuset Gothia, 2006.

Dag, Munir. *Unga människor med rörelsehinder - förankring, marginalisering och social exkludering*. Örebro: Örebro Studies in Social Work 6, Örebro universitet, 2006.

Goffman, Erving. *Stigma: Notes on the management of spoiled identity.* Englewood Cliffs, N.J.: Prentice-Hall, 1963.

Grönvik, Lars. *Definitions of Disability in Social Sciences*. Uppsala: Sociologiska Institutionen, Uppsala universitet, 2007.

Holme, Lotta. "Begrepp om handikapp - En essä om det miljörelativa handikappbegreppet", s. 67-78, Magnus Tideman (red), *Handikapp synsätt, principer, perspektiv.* Lund: Studentlitteratur, 2000.

Hydén, Håkan. *Normvetenskap.* Lund: Sociologiska Institutionen, Lunds universitet, 2002.

Hydén, Lars-Christer. "Illness and narrative", (1):48-69, *Sociology of Health & Illness* 19, 1997.

Jacobson, Annika. *Röster från en okänd värld - Hur människor med fysiska funktionshinder och omfattande hjälpbehov upplever sina existensvillkor*. Stockholm: Pedagogiska Institutionen, Stockholms universitet, 1996.

Lindquist, Ulla-Carin. *Ro utan åror. En bok om livet och döden.* Stockholm: Norstedts Förlag, 2004.

Mathiesen, Thomas. "Inledning", s. 9-14, Stig Edling och Göran Elwin (red), *Rättssociologi - om lag, konflikt och behov.* Stockholm: Wahlström & Widstrand, 1973.

Mikkelsen, Jens, 2008. "Studenter kan få lägre bostandard - AF Bostäders vd:s recept för sänkt hyra", *Sydsvenskan*, 28 Feb., s. C8.

Möller, Martin och Nygren, Göran. *Funktionshindrades riskbild i publika lokaler - med avseende på utrymning*. Lund: Avdelningen för Brandteknik, Lunds universitet, 2004.

Nordgren, Camilla. *Komplexet traumatisk ryggmärgsskada - samhällsresurser*. Lund: Institutionen för designvetenskaper, Lunds universitet, 2006.

Nordgren, Camilla, Levi, Richard, Ljunggren, Gunnar och Seiger, Åke. "Societal services after traumatic spinal cord injury in Sweden", (3):121-126, *Journal of Rehabilitation Medicine* 35, 2003.

Ofstad, Harald. *Vårt förakt för svaghet. Nazismens normer och värderingar - och våra egna.* Stockholm: Bokförlaget Prisma, 1979.

Peterson, Gerd, Ekensteen, Wilhelm och Rydén, Olof. *Funktionshinder och strategival - Om att hantera sig själv och sin omvärld.* Lund: Studentlitteratur, 2006.

Regeringens skrivelse 1996/97:120 *Skrivelse om handikappolitik.*

Regeringens proposition 1999/2000:79 *Från patient till medborgare - en nationell handlingsplan för handikappolitiken.*

Regeringens proposition 2007/08:95 *Ett starkare skydd mot diskriminering.*

Skott, Carola. "Introduktion: Berättelsens betydelse", s. 9-11, Carola Skott (red), *Berättelsens praktik och teori - narrativ forskning i ett hermeneutiskt perspektiv.* Lund: Studentlitteratur, 2004.

Skouen, Arne. *Rettferd for de handicappede.* Oslo: H Aschehoug & Co. (W. Nygaard), 1966.

SOU 1998:48 *Kontrollerad och ifrågasatt - intervjuer med personer med funktionshinder.*

SOU 1998:16 *När åsikter blir handling - En kunskapsöversikt om bemötande av personer med funktionshinder.*

SOU 1999:21 *Slutbetänkande av Utredningen om bemötande av personer med funktionshinder. Lindqvists nia - nio vägar att utveckla bemötandet av personer med funktionshinder.*

Svensson, Måns. *Sociala normer och regelefterlevnad. Trafiksäkerhetsfrågor ur ett rättssociologiskt perspektiv*. Lund: Lund Studies in Sociology of Law 28, Lunds universitet, 2008.

Svensson, Måns och Hydén, Håkan. "The Concept of Norms in Sociology of Law", *Scandinavian Studies in Law* 53, 2008.

Tideman, Magnus. "Inledning", s. 9-12, Magnus Tideman (red), *Handikapp synsätt, principer, perspektiv*. Lund: Studentlitteratur, 2000.

*Tidningen Handikapphistoria.* Handikapphistoriska Föreningen, 2004. Hämtad 2008-05-30, http://handikapphistoria.hhf.se/hh/hh.nsf/0/22A78BA726858E75C1256F08003FCE76/$File/Handikapphistoria_1-04.pdf.

*Webbtidning - Mot diskriminering - för öppnare arbetsliv.* Utsatta grupper förlorar mest när statens inflytande minskar. Hämtad 2008-06-03, www.paraplyprojektet.se/upload/Bengt%20L.rtf .

Wickenberg, Per. *Normstödjande strukturer. Miljötematiken börjar slå rot i skolan*. Lund: Lund studies in sociology of law, Lunds universitet, 1999.

**Författarpresentation:**
Camilla Nordgren, själv traumatiskt ryggmärgsskadad sedan många år, bedriver doktorandstudier inom området samhällsresurser och personer med en traumatisk ryggmärgsskada vid Certec, Lunds universitet. Lade 2006 fram sin licentiatuppsats ”Komplexet traumatisk ryggmärgsskada – samhällsresurser”. Föreliggande artikel är en del av avhandlingen.