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

Nordgren, Camilla

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

Camilla Nordgren
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Certec
Department of Design Sciences
Lund University
Sweden

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“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.

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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 Deamer. 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!

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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 Paper*, 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

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

Summary .................................................................................. 1
Acknowledgement ...................................................................... 3
List of papers and my contributions ........................................... 5
Contents .................................................................................. 7
Introduction .............................................................................. 9
Background ............................................................................. 11
  A traumatic spinal cord injury ............................................... 12
  Societal resources .................................................................. 12
  An abrupt transition ............................................................. 14
  A complex system .................................................................. 14
Resources in a resourceful yet resource-limited society ............. 15
  Previous research .................................................................. 16
Aims ....................................................................................... 18
Material ................................................................................... 19
  Prevalence and incidence group ............................................. 19
  The National Patient Register .............................................. 19
  Narratives ............................................................................. 20
Methods .................................................................................. 21
  Posing questions – semi-structured interviews ...................... 21
  Posing questions – The National Patient Register ................. 25
  Narratives ............................................................................. 25
Results .................................................................................... 26
  Results from the studies ....................................................... 26
  Some cross perspectives ....................................................... 27
Discussion

- The need for a time frame 30
- Disability definitions 31
- Being in need of 31
- Defining utilization 32
- On the individual’s initiative 33
- The authorities’ versus the lived perspectives 34
- A burden? 36
- Epistemic risks 36

Further studies 38
Conclusions 39
Svensk sammanfattning 41
Definitions and vocabulary 49
Reference List 51

Summary of papers 55

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.spinalistics.se/lang-sea, http://www.nhr.se, http://www.dnr.se, http://www.rtf.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 Certecc (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 Certecc 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 Certecc 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 support 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 exemplar 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 (Trafikfördöranden), 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 (Riksırskningsverket) 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.

![Diagram of societal contact network for people with complex needs.](image)

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 fulfill 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/rewriting 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% (5). 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/cpc/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 Hylén, 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). Jonsson 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 examples can be derived is obvious. I agree with Flyvberg (24) when he states that a discipline without examples 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, nor 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?”

<table>
<thead>
<tr>
<th>Support</th>
<th>Human assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Disability pension?</td>
<td>19. Personal assistant?</td>
</tr>
<tr>
<td>2. Temporary disability pension?</td>
<td>20. Home help services?</td>
</tr>
<tr>
<td>4. Disability allowance?</td>
<td>22. Other personal (companion)?</td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td></td>
</tr>
<tr>
<td>5. Education subsidy?</td>
<td>23. Technical aids?</td>
</tr>
<tr>
<td>6. Rehabilitation allowance?</td>
<td></td>
</tr>
<tr>
<td>7. Wage subsidy?</td>
<td></td>
</tr>
<tr>
<td>8. Workassistant?</td>
<td></td>
</tr>
<tr>
<td>9. Assistive work devices?</td>
<td></td>
</tr>
<tr>
<td>10. Workplace adaptation?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Housing</td>
<td></td>
</tr>
<tr>
<td>11. Priority?</td>
<td>24. Were you in need of other</td>
</tr>
<tr>
<td>12. Housing allowance?</td>
<td>resources in 1998 that were not</td>
</tr>
<tr>
<td>13. Home adaptation?</td>
<td>available for you to apply for? If</td>
</tr>
<tr>
<td></td>
<td>so, which ones?</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
</tr>
<tr>
<td>14. Car allowance?</td>
<td></td>
</tr>
<tr>
<td>15. Car adaptation?</td>
<td></td>
</tr>
<tr>
<td>16. Parking permit?</td>
<td></td>
</tr>
<tr>
<td>17. Transportation service?</td>
<td></td>
</tr>
<tr>
<td>18. National transportation service?</td>
<td></td>
</tr>
</tbody>
</table>
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 your understanding of your 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**

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 your 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 or 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. Examples 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 Götvik 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. Sometimes, 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 receive 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.
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. Hertzler (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). Davidson’s book is addressed to students and administrative investigators on how to handle support and applications for services. Davidson 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). Hertzler’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 socially-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 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.
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


För en person med en omfattande och livlång skada kommer således kontakten med olika instanser och myndigheter att pågå under resten av livet. Figur 1 illustrerar rångfalden av resurslag, komplexiteten i samhällsresursernas organisation och det nätverk av kontakter som kommer att etableras.
Figur 1. Möjligt samhällskontaktnät för personer med komplexa behov

Flerta 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 härdnad ur designkontexter.
- Att designa och genomföra en kontroll av innehållet i ett existerande slutvårdsregister.
- 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 rehabiliteringsenhet 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 rämma sig detta område är starkt influerat av min förstudie. Jag har levit 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 sammanklägningsavhandling 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, inkluderaende en självskattning av tillfredsställelsegrader 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 kuratern. Förr 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. Otollicklig information och koordinering rapporteras som svagheter. Individens försök att förstå hur systemet av stöd fungerar tar tid i anspråk tid, som isäkta skulle kunna användas i rehabiliteringen.

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

Syfte och metod: Att analysera hur generella etiska riklinjer 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 överväganden med hänrysning av erfarenheterna från personerna i deras relation till design. Det är den sammanhållna kedjan av design och teknik liksom den sammanhållna kedjans 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
Accepted for publication in Spinal Cord, 2008
Published online:
http://www.nature.com/sci/journal/vaop/ncurrent/pdf/sc200842a.pdf

Syfte: Att designa och genomföra en process för att kontrollera slutenvårdssdata i Patientregistret, Socialstyrelsen.
Design: Registersstudie.
Resultat: Den första slutenvårdsregistreringen korrelerade med skeddatum för 62% (n=413). För resterande 38%, rapporterades vårdepisoden starta mellan 2 till 8651 dagar efter skeddatum. 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 underskatning av slutenvårdsanvändningen. Studien visar att systematiska fel kan upptäckas genom omfattande kunskap om diagnostikgruppen.

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


Resultat: Genomgående kan konstateras att individens erfarenhet av världssituationer 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. Förändring till detta söks i termerna 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 longitudinalt individuellt perspektiv.** Att undersöka användning av resurser i ett longitudinalt 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 longitudinalt perspektiv tillämpades.
Tidskonsumtion. Designen av stödsystemen och de olika resurslagen är inte anpassade till det faktum att individerna vill leva sitt liv som alla andra och inte spendera tid och kraft på kontakter med myndigheter och resursköreträdare.

Likadan design för livslänga som följe tillfälliga samhällsrutiner. Det livslänga behovets stämmer inte överens med tidsbegränsade stöd och resurser. Det är när varaktigheten i behovet möts av ett system som kännetecknas av förändringar och kortslutning som systemet framstår som inadekvat för individ. 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, intervjuar 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 slutnivå och data konsistens individ för individ. Att göra longitudinella studier också vad gäller livs situationen för individer med funktionsnedsättning är ovanligt, på grund av obefintligt (1). I stället tar man nästan uteslutande sin utgångspunkt i metoder och modeller lämpade för att fatta aktuella tvärsnitt och sedan jämföra utfallen med varandra. Att så många häller sig till blixtnässerier och jämställer 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


Definition av funktionsnedsättning

Föreliggande studier har fördele 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


På individens initiativ

Omfattande resurser finns ansvariga för dem som har behov. Inga resurser tillhandahålls automatiskt utan samtliga resurser känner en egenansvär, dvs 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 förägad inställe. Samtidigt som systemet är komplett är individen oftast osäker i att fylla i ansökningar och förstå de byråkratiska språket. Systemet av komplicerade och oklara regler förändras dessutom ofta (33), och tilldelning förändras eller fördjöjs i tid pga otillräcklig resursallokering. Tanken på individen som en aktiv stödsökande aktör lyftes upp i ”1994 års handikappreform”. Denna individisering har fått konsekvenser. Flera av personerna i studie I anger att de var omedvetna om vissa stöd vilket dikterar att informationsöverföring om stöd och service är särbar. Ett antal ansökningar avslags helt eller delvis. Att kontakta en myndighet och förklara behovet av stöd innebär att individen måste veta var det ska vända sig och förklara sitt behov. Studier har visat att denna individisering kan ha begränsat antalet individer som erhåller resurser (1;12).

Myndighetsperspektiv kontra upplevt perspektiv

Mycket av det som beskrivs om upplevda perspektivåterges oftast inte av de berörda utan återfinns i auktoritets (forskarar eller handläggares) rapporter. I utredningar som undersöker samhällsresurser från myndighets- eller lagstiftningsperspektiv förekommer också beskrivningar och analyser av individens med funktionsnedsättningar upplevelser i samhället i termer av benämning, 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 bekvämlighet på att individen inte är
självsändig (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 tillförliklig statistik.
4. Samhällssöd kan vara underutnyttjade.
5. Informationsexkommunikation 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 hämfas till individen. Istället behöver de utvecklas med hänsyn tagen till tidsperspektiv vad gäller tidsanda och vilka de normstödande strukturerna är.
## Definitions and vocabulary

<table>
<thead>
<tr>
<th>Swedish Term</th>
<th>English Term</th>
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<tr>
<td>Aktivitetsersättning</td>
<td>Activity compensation</td>
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<td>Aktivitetsstöd</td>
<td>Activity support</td>
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<tr>
<td>Arbetsbiträde</td>
<td>Work assistant</td>
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<tr>
<td>Arbetshjälpmedel</td>
<td>Assistive work devices</td>
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<td>Assistansersättning</td>
<td>Assistance allowance</td>
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<td>Bilstöd</td>
<td>Car allowance</td>
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<tr>
<td>Bostadsanpassning</td>
<td>Home adaption</td>
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<tr>
<td>Färdtjänst</td>
<td>Transportation service</td>
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<tr>
<td>Handikappersättning</td>
<td>Disability allowance</td>
</tr>
<tr>
<td>Hjälpmedel</td>
<td>Technical aids</td>
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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%.

<table>
<thead>
<tr>
<th>Swedish Term</th>
<th>English Term</th>
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<tr>
<td>Kommunalt bostadsbidrag</td>
<td>Housing allowance</td>
</tr>
<tr>
<td>(Kommunalt bostadsstöd för handikappade)</td>
<td></td>
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<tr>
<td>Lagen om stöd och service (LSS)</td>
<td>Act Concerning Support and Service for Persons with Certain Functional Impairments</td>
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<tr>
<td>Lönebidrag</td>
<td>Wage subsidy</td>
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<tr>
<td>Parkeringstillstånd för rörelsehindrade (Handikapparkeringsstillstånd)</td>
<td>Parking permit</td>
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<tr>
<td>Patientregistret</td>
<td>The National Patient Register (NPR)</td>
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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.
<table>
<thead>
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<th>Swedish Term</th>
<th>English Translation</th>
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<tr>
<td>Rehabiliteringsersättning</td>
<td>Rehabilitation allowance</td>
</tr>
<tr>
<td>Samhällsstöd</td>
<td>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</td>
</tr>
<tr>
<td>Sjukersättning</td>
<td>Sickness compensation</td>
</tr>
<tr>
<td>Sjukpenning</td>
<td>Sickness benefit</td>
</tr>
<tr>
<td>Sjukvårdsregistret</td>
<td>The Hospital Discharge Register (HDR)</td>
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<tr>
<td>Traumatisk ryggmärgskada</td>
<td>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</td>
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<tr>
<td>Vilande sjuk- och aktivitetsersättning</td>
<td>Dormant sickness and activity compensation</td>
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Reference List


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 Sverstok
Design Philosophy Paper, 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/scj/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 5 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, Rejsefl., 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 discusses 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.
SOCIETAL SERVICES AFTER TRAUMATIC SPINAL CORD INJURY IN SWEDEN

Camilla Nordgren,1,2 Richard Levi,1,2,3 Gunnar Ljunggren1 and Åke Seiger1,2,3

From the 1Neurotec Department, 2Spinalis SCI Research Unit, and 3Fro¨sunda 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

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 1). 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
potentially relevant societal services early after SCI and analyse
user satisfaction with the application process and resource allo-
cation.

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
died, 3 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 administrat-
ing 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 adminis-
tration 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>
<thead>
<tr>
<th>Service</th>
<th>Criteria for allocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability pension</td>
<td>Chronic illness or disability and therefore inability to work</td>
</tr>
<tr>
<td>Temporary disability pension</td>
<td>Reduced working capacity for a limited period</td>
</tr>
<tr>
<td>Sickness allowance</td>
<td>Illness and therefore inability to work</td>
</tr>
<tr>
<td>Disability allowance</td>
<td>Need for time-consuming help from somebody in order to manage daily living, job or studies or substantial additional costs</td>
</tr>
<tr>
<td>Training allowance</td>
<td>Taking part in a labour market programme</td>
</tr>
<tr>
<td>Rehabilitation allowance</td>
<td>Undergoing rehabilitative treatment with a view to restoring employability</td>
</tr>
<tr>
<td>Wage supplement</td>
<td>Employing a person with reduced work capacity (a subsidy for the wage disbursed to the employer)</td>
</tr>
<tr>
<td>Assistant (while at work)</td>
<td>Letting an employed person at the working place help a disabled person with simple duties (a subsidy for the wage disbursed to the employer)</td>
</tr>
<tr>
<td>Technical aids</td>
<td>Need of technical aid due to the disability at the working place</td>
</tr>
<tr>
<td>Work adaptation</td>
<td>Need of adaptation due to the disability at the working place</td>
</tr>
<tr>
<td>Priority to an apartment</td>
<td>Social or medical reason for prioritizing in a housing queue</td>
</tr>
<tr>
<td>Housing allowance</td>
<td>Additional costs for the rent due to the disability</td>
</tr>
<tr>
<td>Home adaptation</td>
<td>Need of adaptation in the home due to the disability</td>
</tr>
<tr>
<td>Car allowance</td>
<td>Difficulties in transporting oneself or using public transportation</td>
</tr>
<tr>
<td>Car adaptation</td>
<td>Difficulties in walking (permit parking on special places)</td>
</tr>
<tr>
<td>Parking card</td>
<td>Difficulties using public transportation within the community</td>
</tr>
<tr>
<td>Transportation service</td>
<td>Difficulties using public transportation within the nation</td>
</tr>
<tr>
<td>National transportation service</td>
<td>Difficulties in walking (permit parking on special places)</td>
</tr>
<tr>
<td>Attendance allowance</td>
<td>Severe disability and necessity of personal assistance with basic needs, i.e. personal hygiene, dressing/undressing, eating, communicating with others, in daily living situations</td>
</tr>
<tr>
<td>Home help (service)</td>
<td>Need of help with, e.g. cleaning, laundry, providing meals</td>
</tr>
<tr>
<td>Home nursing service</td>
<td>Need of help with, e.g. changing bandage, medication</td>
</tr>
<tr>
<td>Escort service</td>
<td>Need of assistance while performing recreational activities</td>
</tr>
</tbody>
</table>

Table II. Neurological classification

<table>
<thead>
<tr>
<th>Neurological level of lesion</th>
<th>Total</th>
<th>Complete*</th>
<th>Incomplete*</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>%</td>
<td>n</td>
<td>n</td>
</tr>
<tr>
<td>Cervical</td>
<td>18</td>
<td>53</td>
<td>2</td>
</tr>
<tr>
<td>Thoracic</td>
<td>3</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>Lumbar</td>
<td>7</td>
<td>21</td>
<td>0</td>
</tr>
<tr>
<td>No level</td>
<td>6</td>
<td>17</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>100</td>
<td>2</td>
</tr>
</tbody>
</table>

* American Spinal Injury Association (ASIA) A, B, C, D, E
* No residual sensorimotor deficit that makes it possible to identify the original lesion, ASIA E.
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

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

<table>
<thead>
<tr>
<th>Level of lesion</th>
<th>Number of applications</th>
<th>Cervical (n = 18)</th>
<th>Thoracic (n = 3)</th>
<th>Lumbar (n = 7)</th>
<th>No level (n = 6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>7</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>9</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
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</tr>
<tr>
<td>10</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>11</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Service by category</th>
<th>Handling&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Outcome&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Accommodation</th>
<th>Attendance</th>
<th>Transportation</th>
<th>Income support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (n)</td>
<td>Best ever and</td>
<td>Completely</td>
<td>To a large extent</td>
<td>Already receiving 1998</td>
<td>Did not need 1998</td>
</tr>
<tr>
<td>Disability pension</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>25</td>
<td>2</td>
</tr>
<tr>
<td>Temporary disability pension</td>
<td>6</td>
<td>5</td>
<td>4</td>
<td>1</td>
<td>26</td>
<td>1</td>
</tr>
<tr>
<td>Sickness allowance</td>
<td>16</td>
<td>7</td>
<td>14</td>
<td>0</td>
<td>17</td>
<td>1</td>
</tr>
<tr>
<td>Disability allowance</td>
<td>13</td>
<td>6</td>
<td>7</td>
<td>0</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>Training allowance</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>29</td>
<td>4</td>
</tr>
<tr>
<td>Rehabilitation allowance</td>
<td>7</td>
<td>4</td>
<td>6</td>
<td>0</td>
<td>27</td>
<td>0</td>
</tr>
<tr>
<td>Wage supplement</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>34</td>
<td>0</td>
</tr>
<tr>
<td>Assistant (while at work)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>34</td>
<td>0</td>
</tr>
<tr>
<td>Technical aids</td>
<td>7</td>
<td>6</td>
<td>7</td>
<td>0</td>
<td>27</td>
<td>1</td>
</tr>
<tr>
<td>Work adaptation</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>33</td>
<td>0</td>
</tr>
<tr>
<td>Priority to an apartment</td>
<td>8</td>
<td>8</td>
<td>8</td>
<td>0</td>
<td>25</td>
<td>1</td>
</tr>
<tr>
<td>Housing allowance</td>
<td>8</td>
<td>6</td>
<td>6</td>
<td>0</td>
<td>24</td>
<td>2</td>
</tr>
<tr>
<td>Home adaptation</td>
<td>17</td>
<td>7</td>
<td>12</td>
<td>1</td>
<td>16</td>
<td>0</td>
</tr>
<tr>
<td>Car allowance</td>
<td>11</td>
<td>1</td>
<td>9</td>
<td>0</td>
<td>20</td>
<td>3</td>
</tr>
<tr>
<td>Car adaptation</td>
<td>9</td>
<td>1</td>
<td>5</td>
<td>0</td>
<td>23</td>
<td>2</td>
</tr>
<tr>
<td>Parking card</td>
<td>14</td>
<td>13</td>
<td>13</td>
<td>0</td>
<td>18</td>
<td>2</td>
</tr>
<tr>
<td>Transportation service</td>
<td>31</td>
<td>29</td>
<td>30</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>National transportation service</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>0</td>
<td>22</td>
<td>7</td>
</tr>
<tr>
<td>Attendance allowance</td>
<td>6</td>
<td>3</td>
<td>5</td>
<td>0</td>
<td>27</td>
<td>1</td>
</tr>
<tr>
<td>Home help (service)</td>
<td>9</td>
<td>6</td>
<td>7</td>
<td>0</td>
<td>24</td>
<td>1</td>
</tr>
<tr>
<td>Home nursing service</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>32</td>
<td>0</td>
</tr>
<tr>
<td>Escort service</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>33</td>
<td>0</td>
</tr>
</tbody>
</table>

<sup>a</sup> Ratings possible: Best ever, Very good, Good, Pretty good, Bad, Very bad, Worst ever; <sup>b</sup> 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 about “sickness allowance”. Bill found the administrator at the social insurance office unable to understand the importance of an accessible car. Bill saw a car dealer and the social worker stressed the importance of an accessible car. The social worker at the rehabilitation clinic informed him about the “disability allowance”. Karl found a company dealing with car adaptations. Bill rated the handling as 1 and the outcome 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 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 care, the administrative handling of 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 3

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

<table>
<thead>
<tr>
<th>Applications</th>
<th>No. rejected</th>
<th>% of all</th>
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<td>Car allowance</td>
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<td>78</td>
</tr>
<tr>
<td>Car adaptation</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Parking card</td>
<td>2</td>
<td>33</td>
</tr>
<tr>
<td>Attendance allowance</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td>Home help (service)</td>
<td>2</td>
<td>22</td>
</tr>
</tbody>
</table>

J Rehabil Med 15
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 services and the level of lesion, but the result is still worth noting.

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. The necessity of compensating 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.

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 fulfills 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 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 contained 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

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II
ethics in the making

Bodil Jönsson, Peter Anderberg, Eva Flodin, Lone Malmberg, 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.

- **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], [8] 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. 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 that 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.
Anderberg introduces what might be the beginning of a relevant model, analysis, not towards practical everyday solutions for experienced functioning. In 'Making both ends meet', Peter adjusts and means.

Of course, there are many models in disability sciences, but none that is satisfactory for design. Design versus the medical or social model

The aim, as Glaser explains, is to discover the theory implicit in the data. The 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 designer in a rehabilitation context has quite a different task than a researcher in a grounded theory context, these offerings in the first place that we perceive when we are confronted with phenomena.

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.

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 general medium for having a world.

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. 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.

In rehabilitation engineering and design, the researcher is supposed to lean forward rather than lean backward, to be a practitioner but a reflective one. 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.

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’. 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. 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.

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. One of the advantages with the FACE model is that it necessitates the consideration of ethical aspects.
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. 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.


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

III
ORIGINAL ARTICLE

On the need of validating inpatient registers

C Nordgren 1,2,3

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

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 6 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
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 a description 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/TheSwedishHospitalDischargeRegister.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

<table>
<thead>
<tr>
<th>Number of days between injury date and first registered inpatient stay</th>
<th>Number of persons (N = 413)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>With exact day and month of injury (N = 191)</td>
</tr>
<tr>
<td>-1, 0 or 1</td>
<td>257</td>
</tr>
<tr>
<td>2–10</td>
<td>43</td>
</tr>
<tr>
<td>11–100</td>
<td>38</td>
</tr>
<tr>
<td>101–1000</td>
<td>19</td>
</tr>
<tr>
<td>1001–10,000</td>
<td>34</td>
</tr>
</tbody>
</table>

Table 2 Number of individuals distributed according to neurological classification

<table>
<thead>
<tr>
<th>Neurological level of lesion</th>
<th>ASIA A (complete) N</th>
<th>ASIA B-D (incomplete) N</th>
<th>ASIA E N</th>
<th>ASIA no information N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cervical</td>
<td>29</td>
<td>86</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thoracic</td>
<td>36</td>
<td>33</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Lumbar</td>
<td>3</td>
<td>40</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Sacral</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>No level</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No information</td>
<td></td>
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</tbody>
</table>

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

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.

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 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. Others calculate the LOS from the day of injury, include individuals admitted for their initial episode or use date of the index hospitalization as the date of the SCI. All these studies lack further analysis regarding possible divergence between the onset of traumatic SCI and admission date. Putzke et al. and Fine et al. 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. 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. 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. as patients whose LOS exceed the mean by more than two standard deviations, while Cifu et al. 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. Several studies spring from persons discharged from the Model System with an enrolment 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

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

Keywords:
handikappolitisk målsättning, rättslig reglering, normperspektiv, narrativ, personer med funktionsnedsättning, konkurrerande norm
1. INLEDNING


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 jämlighet 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 jämlighet i vardagssituationer.
3. HANDIKAPPOLITISK BAKGRUND


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).


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


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

6. TEORETISKT UTGÅNGSPUNKT – NORMER


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 kommuniserad socialt eller t ex via en gestaltning och 3. att utgöra individens uppfattning avseende omgivningens förväntningar på det egna beteendet. Normer vidmakthållas via tre olika mekanismer: genom koordinering av ageranden, genom hot om konsekvenser om du bryter mot normen och slutligen genom att de är internaliserade och överensstämmende 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 upprätthåelseformer, sociala samband och sociala effekter. Interpersonell


7. METOD

Gerd Peterson et al (Peterson, Ekensteen och Rydén 2006, s. 109) konstaterar utifrån en datainsamling från människor med omfattande funktionsnedsättning att tillgången till den offentliga miljön DWW,SUDNWLNHQnWHUVWnUPnQJDKLQGHUVRPLOOXVWUHUDVDYYnUDLQIRUPDQWHUVHUIDUH


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-Christinnydén 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 s yttrar just till att förmedla en praktik som innefattar ett antal personers individuella situation med känslor och detaljer i förhållande till livsvärlden.


8. EMPIRI


Ansökan om assistans

Ett exempel av goda grannar


Årendebalansen mäste hållas


**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 ganger 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 o tillgängliga 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**

Boende


Sjukskrivning efter kejsarsnitt


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, jämlighet 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
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.

<table>
<thead>
<tr>
<th>Narrativ</th>
<th>Rådande norm</th>
<th>Individuell förväntan baserat på rådande norm</th>
<th>Utfall av situationen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ansökan om assistans</td>
<td>Är man assistansberättigad bör man få assistans vid behov handlagt på ett professionellt sätt</td>
<td>Jag kommer att få den assistans jag behöver handlagt på ett professionellt sätt</td>
<td>Jag får inte den assistans den jag be-höver handlagt på ett professionellt sätt</td>
</tr>
<tr>
<td>Beroende av goda grannar</td>
<td>Är man god grannen bör man få hjälp av goda grannar</td>
<td>Jag kommer att kunna få hjälp av goda grannar</td>
<td>Jag kommer inte att få hjälp av goda grannar</td>
</tr>
<tr>
<td>Arendebalansen måste hållas</td>
<td>Är man sjuk bör man bli sjukskriven i den omfattningen man behöver</td>
<td>Jag kommer att kunna vara sjukskriven i den omfattningen jag behöver</td>
<td>Jag kommer inte att kunna vara sjukskriven i den omfattningen jag behöver</td>
</tr>
<tr>
<td>Mamma i rullstol</td>
<td>Är man mamma med barn bör man ut och gå med barnvagn</td>
<td>Jag kommer att få hjälp med att gå ut och gå med mitt barn i barnvagn</td>
<td>Jag får inte hjälp med att gå ut och gå med mitt barn i barnvagn</td>
</tr>
<tr>
<td>Student i Lund</td>
<td>Är man student i Lund bör man bo på nation/studenthem</td>
<td>Jag kommer att kunna bo på vald/valt nation/studenthem</td>
<td>Jag kan inte bo på vald/valt nation/studenthem</td>
</tr>
<tr>
<td>På bio</td>
<td>Är man biobesökare bör man själv ta sig ut från bion i en nödsituation</td>
<td>Jag kommer att kunna ta mig ut själv från bion ifall nödsituation uppstår</td>
<td>Jag kan inte själv ta mig ut från bion i en nödsituation</td>
</tr>
<tr>
<td>På bio</td>
<td>År man biobesökare bör man, om det finns plats, köpa biljett</td>
<td>Jag kommer att kunna köpa biljetter oavsett antal rullstolsburna besökare</td>
<td>Jag får inte köpa biljett till bion</td>
</tr>
<tr>
<td>--------</td>
<td>---------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>Boende</td>
<td>År man husspekulant bör man köpa ett hus som motsvarar ens behov</td>
<td>Jag kommer att kunna köpa ett hus på nybostadsmarkanden som motsvarar mina behov</td>
<td>Jag kan inte köpa ett hus på nybostadsmarknaden som motsvarar mina behov</td>
</tr>
<tr>
<td>Sjukskrivning efter kejsarsnitt</td>
<td>Ar man nyförlöst mamma bör man bli sjukskriven då hänsyn tages till den individuella hälsosituationen efter ett kejsarsnitt</td>
<td>Jag kommer att kunna bli sjukskriven efter som hänsyn tages till min individuella hälsosituation</td>
<td>Jag kan inte räkna med att bli sjukskriven med hänsyn tagen till min individuella hälsosituation</td>
</tr>
</tbody>
</table>

**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 (Norm1) som råder. Istället träder en annan norm in (Norm2) som skiljer sig från den förväntade normen.

![Figur 1: Empirin tydliggör konkurrens mellan förväntad norm och annan norm](Vardags-Situation.png)
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)](image)

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 fakta 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 Norm1 till Norm2). Dessa två normer står i konflikt och av empirin framgår att det konsekvent är Norm2 som är starkare och som därför blir den norm som utgör grunden för den handling som sker.

10. DISKUSION 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 sjuksskrivning eller personer med krav på snabba assistansbeslut. Handlingsmönstret som har framkommit i samtliga berättelser pekar i riktning mot effekter i form av särskiljning och exklundering. 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 sammansättats och uttrycker att "vi har ett stort antal forskningsresultat som tyder på att det finns en diskrepanse mellan funktionshindrade personers rättmätiga förväntningar, som bl a har sin grund i viss sags 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 beroende med människor som ska göra ord ord till verklighet. Variabeln 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 samt­dig" (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 mångsidig 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 samhällsnivå och genomsysra denna. Om rättslig reglering inte kan hjälpa individen, kan konkurrierande normer ge förklaringsgrund. Genom att skaffa kunskap om normer som avvisar 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 domineras då ofta "den andra normen"?


I Norge utgavs 1966 boken ”Rettferd för de handikappade” (Skouen 1966). Författaren Arne Skouen hävdade att välfärdsamhället 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 av den aktuell Förändringen, ett nytt klimat. Men välfärdsstaten är tvärt emot på rask väg bort från det klimat vi eftersträvar. Välfärdsstaten, säger Skouen, är ständig uttappning med att skilja ut dugliga och odugliga, så att den teknisk-kommersiella utvecklingen inte skall riskera att satsa på fel häst. Denna kännanlade demon- nazism för oss in i samhället där det starkast rätt härskar. I ett sådant samfund är alla med handikapp automatiskt hänvisade till en auktoriserad jumboplats. Samma tankengångar har Harald Oftstad beskrivit i boken ”Vårt förakt för svaghet” (Oftstad 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 avsnittet ”Och många av dem [internationella mastersstudenter, min anm.] anser att vi har på tok för höga krav på boendet standard, 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 särst skall ekonomiskt skulle vilja ha lägre standard om de fick lägre hyra, säger han. […] och alla toaletter kanske inte behöver handikappan- passas, föreslår Rolf Svensson vidare. – Byggs hundra nya bostäder behöver kanske inte alla hundra handikappan- passas 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.)
lighetssuppfattningar 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”.


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 normstödande 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.


Men det är dags nu - som jag ser det.
Referenser


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

18


Författarpresentation: