

# SOCIETAL SERVICES AFTER TRAUMATIC SPINAL CORD INJURY IN SWEDEN

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

From the <sup>1</sup>Neurotec Department, <sup>2</sup>Spinalis SCI Research Unit, and <sup>3</sup>Frösunda Center Research Unit, Karolinska Institutet, Stockholm, Sweden

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

Design: Survey of an incidence population.

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

Methods: Structured interviews using a standardized questionnaire

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

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

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

J Rehabil Med 2003; 35: 121-126

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

Submitted May 23, 2002; accepted November 19, 2002

## INTRODUCTION

A spinal cord injury (SCI) may have devastating consequences for the person affected and commonly leads to significant, permanent disability. The need for societal services is thus obvious and an extensive and life-long reliance upon such services will typically be established. In order to restore social integration, re-establish autonomy, compensate for functional losses and facilitate activities of daily living (ADL), society

provides various supportive services. Legislation regulates service availability by prioritizing those most in need. Services are administrated by several separate authorities, each with different organizations, objectives and cultures.

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

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

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

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

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

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

The purpose of this study was to identify the spectrum of

Table I. Societal services and criteria for allocation

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

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

# **METHODS**

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

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

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

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

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

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

## **RESULTS**

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

Table II. Neurological classification

Neurological level of lesion	Total n	%	Complete <sup>a</sup>	Incomplete <sup>b</sup>
Cervical	18	53	2	16
Thoracic	3	9	0	3
Lumbar	7	21	0	7
No level <sup>c</sup>	6	17	0	0
Total	34	100	2	26

<sup>&</sup>lt;sup>a</sup> American Spinal Injury Association (ASIA) A; <sup>b</sup> ASIA B-D; <sup>c</sup> No residual sensorimotor deficit that makes it possible to identify the original lesion, ASIA E.

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

	Level of lesion					
Number of applications	Cervical $n = 18$	Thoracic $n = 3$	Lumbar $n = 7$	No level $n = 6$		
0	2	0	0	0		
1	1	0	0	2		
2	1	0	0	0		
3	3	1	1	0		
4	1	0	0	4		
5	2	0	0	0		
6	0	1	2	0		
7	3	0	0	0		
8	0	1	2	0		
9	1	0	0	0		
10	4	0	1	0		
11	0	0	1	0		

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

## Category of service

Table IV shows the distribution of applications for the different

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

# Handling and outcome

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

### Information about the service

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

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

Service by category	Yes n	Handling <sup>a</sup> Best ever and Very good n	Outcome <sup>b</sup> Completely and To a large extent n	Already receiving 1998	Did not need 1998	Did not know about the service <i>n</i>
Income support						
Disability pension	3	2	2	4	25	2
Temporary disability pension	6	5	4	1	26	1
Sickness allowance	16	7	14	0	17	1
Disability allowance	13	6	7	0	11	10
Work		Ü	•	v		10
Training allowance	1	1	1	0	29	4
Rehabilitation allowance	7	4	6	0	27	0
Wage supplement	Ó	0	0	Ŏ	34	Ô
Assistant (while at work)	Ö	0	0	Ŏ	34	0
Technical aids	7	6	7	0	27	0
Work adaptation	1	1	1	Ŏ	33	Ô
Accommodation	•	•	•			•
Priority to an apartment	8	8	8	0	25	1
Housing allowance	8	6	6	0	24	2
Home adaptation	17	7	12	1	16	0
Transportation	1,	,	12	•	10	· ·
Car allowance	11	1	9	0	20	3
Car adaptation	9	1	5	ŏ	23	2
Parking card	14	13	13	0	18	$\frac{1}{2}$
Transportation service	31	29	30	1	2	0
National transportation service	5	5	4	0	22	7
Attendance	2	5	•	•		•
Attendance allowance	6	3	5	0	27	1
Home help (service)	9	6	7	Ŏ	24	1
Home nursing service	2	2	2	Ŏ	32	0
Escort service	1	1	1	0	33	0

<sup>&</sup>lt;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 intraindividual complexity of the administrative handling process, narratives of 3 plausible cases are presented.

#### Case 1

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

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

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

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

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

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

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

#### Case 2

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

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

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

#### Case 3

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

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

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

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

# **DISCUSSION**

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

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

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

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

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

Living with an SCI poses several obstacles in daily life. Overcoming these is time consuming. For the affected individual with the intention of living fully integrated in society with work, family and leisure activities, time thus becomes a problem, i.e. the impairment leads to less time being available. For most individuals with new SCI, contacts with and knowledge of the social welfare system are new experiences. There is a complicated system of rules, which is often dependent on the budgeted resources. The necessity of acquiring knowledge of this system demands effort and time. In most cases the social worker assists the individual, resulting in a more effective handling. As most services have a time limit and must be applied for iteratively, the disabled individual typically has to re-apply

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

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

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

In conclusion, the social security system in Sweden has allocated significant resources for allowing independence and financial compensation for SCI-related impairments. The number of services available reflects this notion. However, this study shows that the present state of affairs often creates frustration and disappointment on the part of the disabled person. The complexity of the system is often reported as a

shortcoming within the entire disability movement and not only within the SCI sphere. The problem is the same for all affected, but it might have greater impact for those persons acquiring a complex, life-long injury/sickness. In spite of the social worker's role as a co-ordinator between the authority and the person in need, insufficient information and co-ordination are reported as examples of weaknesses. In order to achieve a fully satisfactory system of societal services either the number of processes and authorities must be reduced, or an official co-ordinator must be appointed, with the explicit task of acting as a proxy for the person in need. The task must be determined without delay so that the person with SCI is given the opportunity to be properly supported throughout life.

# **ACKNOWLEDGEMENTS**

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

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