

Successful (re-)Integration of People Living with Spinal Cord Injury

Introduction

All ESCIF projects aim to provide member organisations with information, shared experience and recommendations that will help them in their efforts to improve the quality of life of people living with SCI in their countries.

The issue of social inclusion is a central tenet of the United Nations Convention on the Rights of Persons with Disabilities. The opportunity to take part in society and the community on an equal footing with all other population groups is no longer simply 'desirable' – it is a must! It is however perfectly clear that many people with disabilities are still on the margins of social and community life – and these include those with Spinal Cord Injury (SCI).

In order to improve social inclusion for people living with SCI - all the involved parties need to contribute and cooperate, with initiatives that emanate from all SCI consumer advocacy organisations.

In the light of these assertions - the European Spinal Cord Injury Federation (ESCIF), together with pan-European national SCI consumer advocacy organisations, set up a multi-national project to draw upon their combined knowledge and experience to answer the following question:

“What can your organisation do to facilitate the successful (re-)integration of people with spinal cord injury in the community?”

Based on discussions with the ESCIF member organisations the project had five focus areas:

- Quality of Life
- Social and Leisure Activities
- Family Roles
- Education and Paid Work
- Mobility Aids and Assistive Devices

This report is intended to be a tool and an inspiration to national SCI consumer advocacy organisations - to their setting up programs and activities focused on improving SCI persons' social inclusion.

We thank each and every one of the working group participants for their time and effort invested in this important project. And we especially thank Coloplast for their financial support, which enabled each volunteer to participate without drawing on the funding of their national organisation.

Even though the chapter *General Conclusions* contain a summary of conclusions and recommendations - the *Appendices* reproduce the original reports from the working group involved. Any organisation feeling the need to develop their own service towards a particular focus area is encouraged to read the group's report pertaining to that, as there may be further specifics of interest contained within it.

Thank you and good reading
The Executive of ESCIF

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Project Description

1. Project Description

In July 2014, an invitation was sent to all the ESCIF member organisations inviting them to participate in a new ESCIF project entitled 'Successful Integration of People Living With Spinal Cord Injury'.

Based on discussions with ESCIF members - the Federation's Executive agreed upon five different focus areas key to social inclusion. Interested participants were asked to choose a first and second priority from the five. The preference was to pull together working groups of members from different countries. As it happens - individuals from sixteen organisations across 13 countries participated. Most were able to be placed within the group of their first choice.

The project, was configured to run over 18 months (see figure 1) kicking off with a 2-day-seminar in Nottwil, Switzerland in November 2014. The Executive drew up a program and gave an introductory presentation at the seminar. Although the participants would divide into five working groups with different focus areas, it was considered important they saw themselves part of the overall project.

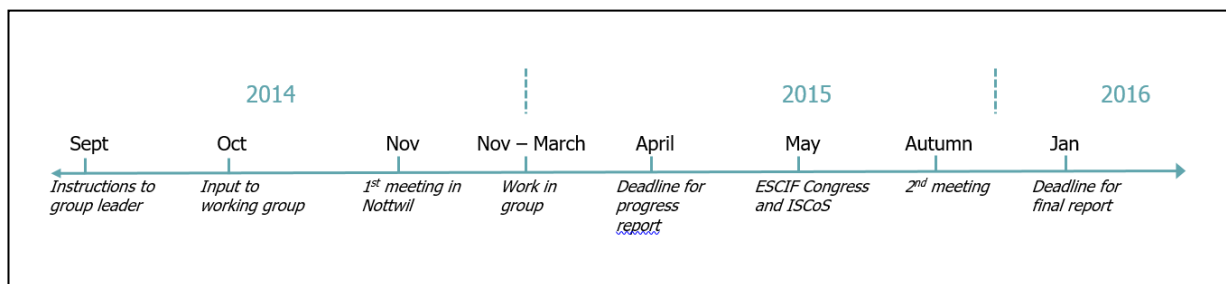


Figure 1. **Proposed Timeline for this project**

The seminar in Nottwil gave the work groups an opportunity to define their topic area and formulate a process. It enabled each group to hear & consider the ideas of the others - so as to correlate and yet limit the inevitably overlap between each topic areas. The groups each selected a leader to pilot their work according to the proposed timetable.

Over subsequent months, most groups communicated through regular Skype meetings and/or e-mail correspondence. They selected methods of data collection; literature reviews, questionnaires, telephone interviews, compilation of case studies, and studies of their organisation's own material.

In April 2015, they were asked to deliver a progress / interim report. These reports were later used for oral presentations at the ISCoS congress in Vancouver 2015, and at the ESCIF congress in Vienna the same year.

A second meeting was in Nottwil, September 2015, where the groups were asked to share working experiences and their practices, and how they overcame obstacles. The participants were also given the opportunity to discuss the content of the final report, how it might be used by ESCIF member organisations, and how it should be disseminated. The groups were reminded of the timeline in which to finish and conclude their reports.

In January 2016, the working groups delivered their final reports. The theme of the ESCIF Congress in Vienna, May 2016 *Successful integration after SCI* focused on the results, where each group made a presentation of their study as part of the congress program.

Originally, the project consisted of five areas of focus. However, due to ill health, one group's work on the importance of 'Family Roles' in a person's successful integration after SCI has been delayed. In January 2017, it was decided not to delay disseminating this report any further, and so the results of that specific focus are not included in this edition. We hope to present it in the near future.

Background to Spinal Cord Injuries

2. Background to Spinal Cord Injuries

In non-medical jargon; a spinal cord injury (SCI) is a break or severe damage of the spinal cord. The damage can occur as a result of biological / health issues, or through accident injury, or from an intrusive wound, or subsequent complications. Although often different in cause - any of these can occur at any stage in a person's life.

The central nerve system 'carries impulses to and from the brain, for initiating and coordinating many reflex acts' (..Merriam-Webster dictionary) which in layman's terms means; little or no useful feelings &/or motor drive signals to muscles are transferred between above and below the break / damage / injury.

Consequently, a break near the base of the spine renders the injured person unable to feel &/or use his or her legs but is still usually able to feel and use his or her upper body, arms, shoulders and neck. This person would be classified a paraplegic. Whereas, a break near the top of the spine renders everything below that as null feeling &/or those muscles are unable to be used even for support. That person would be classified a tetraplegic. In the spine are a lot of vertebrae and the break can happen at any point. The vertebrae points are classified by region in the spine.

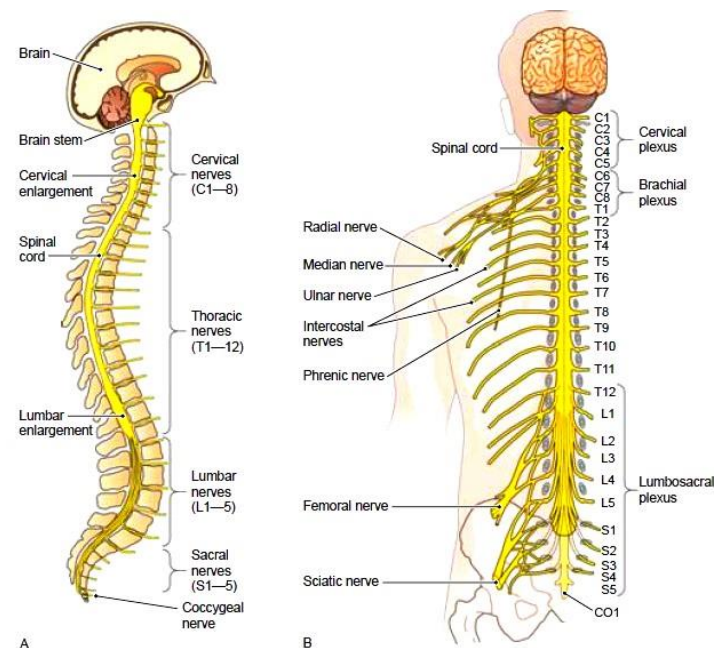


Figure 2.

Image courtesy:

<<https://aliciareagan.files.wordpress.com/2013/07/spinal-cord-and-spinal-nerves.jpg>>

Further classification is regarding the degree of damage, and whether any feeling or motor impulses are getting passed the break / damage. For example:

Spinal cord injuries are classified¹ as complete and incomplete by the American Spinal Injury Association (ASIA) classification. The ASIA scale grades patients based on their functional impairment as a result of the injury, grading a patient from A to D (see table 1 for criteria). This has considerable consequences for surgical planning and therapy.

A: Complete	No motor or sensory function is preserved in the sacral segments S4 - S5.
B: Incomplete	Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4 - S5.
C: Incomplete	Motor function is preserved below the neurological level, and more than half of key muscles below the neurological level have a muscle grade less than 3.
D: Incomplete	Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade of 3 or more.
E: Normal	Motor and sensory function are normal.

Table 1. **ASIA impairment scale**

Part of the problem in collating accurate data is that there are many different classifications, which change / developed over an age, and were / are different according to medical or other professional needs, and again by bureaucratic authority and nation. Whatever.. It is persons we are talking about here, and this damage may have catastrophic life changing consequences. Yet further classifications may try to quantify an injured persons' capabilities. Here is just one example:

Instrumental activities of daily living (IADLs)² are not necessary for fundamental functioning, but they let an individual live independently in a community.

- ❖ Cleaning and maintaining the house
- ❖ Managing money
- ❖ Moving within the community
- ❖ Preparing meals
- ❖ Shopping for groceries and necessities
- ❖ Taking prescribed medications
- ❖ Using the telephone or other form of communication

A useful mnemonic is SHAFT: shopping, housekeeping, accounting, food preparation/meds, telephone / transportation.

The consequences of an SCI person not being able to do any of the above can be devastating, and yet the list reflects relative 'able' abilities. Many SCI persons have great difficulty or need help with the fundamental things in life, like getting up, moving from wheelchair to bathroom or other furniture. And a tetraplegic cannot turn unassisted in a bed and will need support to remain seated upright in a chair. ...yet they survive and given the support and assistive aids can lead productive, useful and good quality lives.

One of the most famous of these is of course Stephen Hawking (Theoretical Physicist, Cosmologist, etc.) Stephen was diagnosed with ALS, a form of Motor Neurone Disease, shortly after his 21st birthday, but continues to combine family life (he has 3 children & 3 grandchildren) and his research together with an extensive programme of travel and public lectures.

Other famous and celebrity tetraplegia include artists, sportsman, inventors, journalists, and more..

Further to these are tens of thousands of tetraplegic and paraplegic persons ..who haven't made the top 25 'most famous', but have gone on to have fulfilling and productive lives. Who have raised families and made a useful contribution to society ..and their employer !

The point being that each and every one of the above, who went on to accomplish - needed the encouragement, support and the opportunity before they could do those great things. Aiding and abetting their 'Successful Integration' was worthwhile. And every other spinal cord injured baby, son, daughter, parent, and grandparent - deserves a chance ..not just to survive, but to live a fulfilling life and to give something back.

How Many SCI persons are there?

There are some organisations like the World Health Organisation who might possibly estimate the numbers of SCI with vague accuracy, but the fact is that nobody really knows exactly. This is because the figure is constantly changing, because classifications vary according to bureaucratic needs, and because some nations are simply not keen on saying. There have been many studies, the following is an extract from just one (2014), and this reports from previous (and therefore older) studies..

RESULTS³

" The initial search yielded 5,874 articles, 48 of which met the inclusion criteria. Forty-four studies *estimated* the incidence of SCI and nine reported the prevalence, with five discussing both. Of the incidence studies, 14 provided figures at a regional, 10 at a state or provincial level and 21 at a national level.

The prevalence of SCI was highest in the United States of America (906 per million) and lowest in the Rhone-Alpes region, France (250 per million) and Helsinki, Finland (280 per million).

With respect to states and provinces in North America, the crude annual incidence of SCI was highest in Alaska (83 per million) and Mississippi (77 per million) and lowest in Alabama (29.4 per million), despite a large percentage of violence injuries (21.2%).

Annual incidences were above 50 per million in the Hualien County in Taiwan (56.1 per million), the central Portugal region (58 per million), and Olmsted County in Minnesota (54.8 per million) and were lower than 20 per million in Taipei, Taiwan (14.6 per million), the Rhone-Alpes region in France (12.7 per million), Aragon, Spain (12.1 per million), Southeast Turkey (16.9 per million), and Stockholm, Sweden (19.5 per million).

The highest national incidence was 49.1 per million in New Zealand, and the lowest incidences were in Fiji (10.0 per million) and Spain (8.0 per million).

The majority of studies showed a high male-to-female ratio and an age of peak incidence of younger than 30 years old. Traffic accidents were typically the most common cause of SCI, followed by falls in the elderly population.

One of the working groups of this very report asked the question in one of their questionnaires. Addressed to ESCIF member organisations / European National SCI organisations they received 15 sets of answers. This is what they were told ..

Just How Many SCI persons are there?

..an extract of answers from the topic 'Mobility Aids and Assistive Devices'.

The bottom line figure is.. well - undefined. But other studies estimate that just 0.1% of the European population is SCI. That may seem a lot, or very few, depending on one's perspective, so to put a figure on it - we are talking in the region of 350,000 individuals in Europe.

What may be particularly noteworthy to a national organisation, to professionals working in social services or healthcare, and to the individuals concerned - is to see from the table above just how many are not members / part of their country's national organisation. One has to wonder then - if they have any advocate for their special needs and human rights? and how many of these are not Successfully Integrating ..and why?

Reports from the working groups

3. Reports from the working groups

These sections of the report present the objective, the process, the finding, and the conclusion with recommendations of the four working groups. Each subject / section of this written report is the work of those teams. The final version of these studies were submitted c. January 2016, and then presented at the ESCIF Congress in May 2016, Vienna.

But please note: Further to the final submissions of the four individual studies, each has now been reformatted into this one report with common titles, layout and font. Each have been corrected to UK common English, which often necessitated using different words, rewriting some sentences & phrases, and restructuring the order of the text. Some changes were necessary to enable a person with dyslexia to read it. In addition, many points have been elaborated upon, for written clarity &/or context. Others have been augmented to, from the first hand experiences of a small-business owner / professional manager in the UK.

We acknowledge and truly thank each member of each working group for their time, effort, and valuable contribution. And we trust the editing / changes meet with the approval of each.

Working group “Quality of Life”

Tomas Moravik (Czech Republic), Kenneth Ørbæk (Denmark), Veronika Hublová (Czech Republic), Gunilla Åhrén (Sweden)

Working group “Social and Leisure Activities”

Ulla Carlsson (Sweden), Mirjam Kanalec (Slovenia), Gabriele Kirchmair (Austria), Joanna Martin (Scotland), Esther Peris (Spain), Winnifred de Moes (The Netherlands)

Working group “Education & Paid Work”

Aurelian Anghelescu (Romania), Niels Balle (Denmark), Veronika Hublová (Czech Republic), Lauri Louhivirta (Finland), Tetyana Panasyuk (Ukraine)

Working group “Mobility Aids and Assistive Devices”

Stefan Opresnik Jorlev (Denmark), Carrie Moss (Ukraine), Gelu Onose (Romania), Nuutti Hiltunen (Finland), Higinio Serrano Pérez (Spain), Jani Trdina (Slovenia)

Quality of Life

4. Quality of Life

Working group: **Tomas Moravik (Czech Republic), Kenneth Ørbæk (Denmark), Veronika Hublová (Czech Republic), Gunilla Åhrén (Sweden)**

Introduction / background

The concept of Quality of Life (QoL) is multi-dimensional and spreads across many areas of human activity. Usually the distinction is made between objective QoL that addresses issues of living conditions (economical, political, environmental), health, and 'subjective'.^{1,2} The subjective factor represents a substantial element in QoL and may be thought of as individual well-being, which encompasses cognitive and emotional evaluation of one's life.^{3,4}

After an SCI, enabling environmental factors are undeniably essential to good QoL⁵, however as the appraisal and actually dealing with psycho-social consequences of SCI are primarily in the hands of the individual with SCI - this study focused on answering this question:

How might SCI consumer organisations help motivate people after SCI to achieve their desired QoL?

Project work

To try and answer this question, we set several project goals:

1. To survey previous research on QoL after SCI (literature & website published reports).
2. To learn from ESCIF member organisations of their ideas, experience, & services concerning QoL. (Appendix 3.)
3. To ask SCI persons in different nations what quality of life means to them.
4. To evaluate our findings and consider how QoL issues can be addressed by SCI consumer organisations, particularly in terms of successful integration.
5. To draw conclusions and offer recommendations how SCI consumer organisations can promote quality of life of their members.

A questionnaire was drawn up (Appendix 3.) and sent to 30 ESCIF member organisations, to which 15 answers were received from across Europe: Austria, Belgium, Croatia, Czech Republic, Denmark, Ireland, Italy, Netherlands, Scotland, Slovenia, Spain, Sweden, and Switzerland.

In brief, the four questions asked of these organisations were:

- Can you define what QoL for people living with SCI means to your organisation?
- Does your organisation have any past, present, or proposed future projects &/or services pertaining to QoL?
If yes, please describe the background and idea with the project &/or service & what actions or elements that are part of the project &/or service?

- Have you any past, present, or planned future projects &/or service regarding; self motivation, self-determination, empowerment, coaching &/or peer-support in this area?
If yes, please describe the background and idea with the project &/or service & what actions or elements that are part of the project &/or service?
- If unlimited in manpower or finances - what would be a perfect project in your country regarding QoL for people living with SCI?

Review & Discussion

1. Prior research on 'Quality of life after SCI' (from literature & website published reports)^{1,3 4 5}

After injury, a SCI person's QoL often diminishes because of the real and perceived limited possibilities in participation and activity.

There are significant differences in environmental & social barriers / facilitators across European countries, and of course those who suffer SCI also differ in degree of physical and cognitive damage. Subjective QoL, in the context of the SCI, therefore means successfully facing and adjusting to the physical, psychological, and social & environment consequences as much as possible - with the objective of regaining a level of QoL comparable to that experienced prior to injury.

Particularly important to success in an SCI achieving this are the psychological support resources available because they play such a crucial role in the progression of adjustment after such a catastrophic injury. Consistent determinants have been identified to be the perceived:

- purpose in life
- hope (contrary to; feeling oneself to be hopeless / useless, or 'the situation is hopeless').
- degree of perceived comprehensibility
- manageability and meaning of one's life (ie. sense of coherence).
- degree of personal control over the outcome of events in their lives (in personality psychology it is referred to as 'locus of control', in difference to external forces beyond their control).
- self-worth e.g. self-efficacy (the ability to produce a desired or intended result) and self-esteem.

In the process of adjustment to SCI; 'purpose in life' and 'active engagement' were especially influential towards higher life satisfaction and functional independence, and as such they may be a focus for suitable intervention to support persons with SCI.

2. Response to the questionnaire

The responses of the fifteen national organisations who participated in this study's questionnaire, led us to summarise the following.

1) Definition of Quality of Life for people living with a SCI?

In addition to exogenous influences, the study recognised three fundamental prerequisites pertaining to QoL;

i) Independence and Participation

To live independently and participate as an equal and respected member in society was a common factor to all the organisations and appeared to be the most important issue overall.

“to live a more independent and full life and participate as any other citizen”

For this to be realised - accessibility is the most important facilitator and is therefore a primary objective.

ii) QoL according to one's own wishes

Stressing the importance for persons living with SCI - to live their lives according to their own wishes, adding that it is up to the individual to define his or her life.

“to develop your own life project based on your needs and objectives”

iii) Personal capacities

Even though most of the factors focused on issues in society - the personal capacities of the individual were also recognised. It was a general opinion that it is up to the individual to achieve QoL and that the personal capacities could be either a facilitator or a barrier for this.

“take charge of your own life instead of having others doing it ”

2) Organisations' projects &/or services to help improve their members' Quality of Life?

Each organisation answered that they do have projects &/or services pertaining to QoL. Their actions depended on their particular health care and welfare systems (more on that below), but the following were particularly prominent:

- ✓ Sports and leisure time activities
- ✓ Information
- ✓ Legislation and policy lobbying
- ✓ Advocacy
- ✓ Individual counselling
- ✓ Advice and information on health issues
- ✓ Peer support
- ✓ Accessible accommodations and transportation
- ✓ Vocational training
- ✓ Skills for independent living
- ✓ Courses
- ✓ Camps
- ✓ Seminars
- ✓ Support service to set and achieve person centred goals

Exogenous Factors: Most organisations alluded to the numerous barriers &/or facilitators in their society, with direct consequence on QoL after SCI. And then also the definition of common needs such as 'independence', varied between cultures. This was reflected in their country's welfare system.

For example: Accessible housing is provided by the welfare system in some countries, but not in all, or to the same extent. Accordingly, this was reflected in the work and services of the SCI national organisation. See Figure 1.

Facilitators or barriers	Response: organisation / interpersonal:	
Acceptance from the public	Consumer organisations to enforce the rights and interests of people living with SCI	Peers to exchange experiences
Accessibility	Consumer organisations to help people get back to life	Professional and leisure time opportunities
Access to information	Technical aids - advice and help with the choice, finances, maintenance...	Knowledge about SCI to avoid complications
Adequate medical care & rehabilitation	Legal support	

Table 2. Barriers & Facilitators to QoL after a SCI

NB. these factors are mutual to the reports of other working groups.

- 3) Projects &/or services aimed at stimulating: self-motivation, self-determination, empowerment, coaching and/or peer-support?

Universally, responses to this focused on different kinds of peer support, but further included:

- ✓ Social and vocational rehabilitation
- ✓ Personal assistance
- ✓ Person centred goal setting
- ✓ Self-help groups and self-advocacy courses.

- 4) The perfect project regarding improving the Quality of life of people living with SCI?

Once again, the answers reflected the different health care and welfare systems. Some mentioned the possibilities of providing;

- ✓ better rehabilitation
- ✓ lifelong care and follow-up systems
- ✓ creating jobs
- ✓ personal assistants free of charge
- ✓ technical aids and accessible infra structures

It was implied that these services would follow the “Nothing about us without us” principle. However, the most common factor suggested was the possibility to create some kind of personal coaching and mentor services, in order to help their SCI persons move forward in life.

3. Results from the interviews with people living with a SCI

Thirty individuals, comprising of ten persons from each of the three countries represented by this working group team, were interviewed. Aware that the small number of respondents & countries represented would make it impossible to draw any general conclusions, the objective was to simply represent different personal opinions of QoL after a SCI.

The outcome of these individual interviews reinforced the findings of this study's questionnaire to the organisations and its review of literature, with each clearly stressing the importance of 'Independence and Participation', and thus the importance of their organisations addressing issues of barriers and facilitators.

When asking about the motivation to achieve QoL? The importance of peer-support and helping set personal goals were most frequently mentioned.

“everybody needs some kind of a facilitator to get back on track. Being empathic and supportive, not to impose thoughts, treating as equal, helping to find personal strengths”

4. Evaluation our findings and consider

To evaluate our findings and consider how QoL issues might be better addressed by SCI consumer organisations, particularly in terms of improving integration.

In our survey we concentrated on the content and the meaning of quality of life after SCI, as ESCIF national organisations perceive it. We were particularly interested in ideas, suggestions &/or projects they might have to motivate and facilitate their clients to achieve a better QoL.

Our results showed that there are numerous functioning services that do this, but then also enhance the scope of possibilities for persons after SCI ..to get back on track. With the objective of making independent life possible for SCI these included; consumer advocacy and legal support, raising public awareness, free access to information about issues of SCI, promoting accessibility, and helping to create both professional and leisure time opportunities.

Furthermore, from both the questionnaires and interviews, it was apparent that there was a need for more information and sharing of experiences from peers. Additionally, for some kind of guidance focused on the individual's psychological resources and goals, specifically targeting life satisfaction (not only health, adaptation &/or vocational) which according to recent studies is equally important.¹

Clearer information and interpersonal guidance would also help prevent 'mistakes'. SCI's often report that rehabilitation did not adequately prepare them for the transition to living in the community, and there being gaps between the skills taught in rehabilitation settings and those required in the 'real world'.⁵ Functioning peer-support, mentoring, or similar service seem to be especially important.

Peer-counselling and Peer support services

(From the ESCIF Policy Statement, which was unanimously approved and accepted by the ESCIF Assembly of Delegates on 26 April 2008 in Umag, Croatia.)

In a study carried out by ESCIF there was general consensus that newly-injured persons with SCI, undergoing rehabilitation, can learn a great deal from meeting people already living with a spinal cord injury. This included everything from 'tips' that can be used in everyday activities, through the more sensitive issues of sexuality and identity, to the overall problem of 'coming to terms' with what has happened and how to move on.¹³

It is, however, not enough to rely on chance meetings or ad-hoc voluntary activities. In order to gain maximum benefits from this invaluable resource of information & experience, a comprehensive peer-counselling / peer support service must be established at the spinal cord / rehabilitation centres.

ESCIF and its member organisations' experience is that peer-counselling makes a significant and positive contribution to the rehabilitation of people with spinal cord injuries. To achieve best results it is essential that these services receive regular and sufficient funding from the relevant authorities.

The role of the peer-counsellor is multi-faceted:

- To provide a role model who demonstrates the possibilities for life with SCI, and not just the limitations.
- To offer advice based on experience - particularly useful in sensitive areas like relationships and sexuality.
- To suggest solutions and coping strategies that are not anchored in the routines and regime of a hospital-like environment.
- To use the organisation's network to help make further contacts with others with SCI, who may provide further support and inspiration.
- To collaborate with personnel to arrange activities and events for the patient and their family.
- To introduce the activities and facilities available after the rehabilitation; sports activities, wheelchair clubs, seminars and courses (educational / interests), etc.

5. Conclusions and offer recommendations

To draw conclusions and offer recommendations, on how SCI consumer organisations might further promote better quality of life for their members.

It is important to note that QoL is not the same as joy in life. A person can have every facility, opportunity and comfort, and indeed might be very wealthy and have the love and support of family and friends, but still feel hollow inside. Adverse states of mind such as acute melancholy and depression are very real barriers. Subjectively a good quality of life must include joy, and most often that may be found through achievements and satisfaction beyond / are outside of the person themselves.

Based on this study's findings - we propose ESCIF member organisations might offer a service for people living with SCI - to help them set and pursue their own goals.

Such service should take place after post-acute medical care and rehabilitation, with significant others (family and friends) and personal assistants sometimes being involved and helping. Family and friends were repeatedly cited in both the questionnaires & interviews as a crucial source of support. However, such a service or programme is to focus almost exclusively on the individual with SCI - to guide him or her to be more self-directed, to encourage him/her to take control of their life and to achieve his/her own goals.

We suggest 'life coaching' may be an appropriate expression of the service being proposed. Coaching is quite different from either peer-support or mentoring, or from psychotherapy and counselling, and so we include in this discussion a précis on the subject.

Coaching: According to International Coach Federation (ICF) coaching is “partnering with client(s) in a thought-provoking and creative process that inspires them to maximize their personal and professional potential.”⁷

Coaching, as a relatively new service, is still expanding, and there are many approaches. Life coaching for an SCI would deal with topics like discovering and achieving personal goals that they face after rehabilitation.^{8,9}

If for example they following the GROW model⁶ (please see figure. 2) during meetings with client, the coach uses specific means and style of communication to establish, embellish upon, and motivate. He or she is not there to advise but is to help the person establish his or her own objective, potential pathways, and then to empower them. Stepping stone goals are a means to realising progress, which ultimately become self-motivating:

The GROW model
G – goal settings
R – finding out what the reality is
O – options: different strategies to reach the goal
W – who has the will to do what and when?

Table 3 **The GROW model**

Service	Aim of the service	The Aim in Coaching
Psychotherapy	The focus is often on resolving difficulties arising from the past that negatively influence an individual's emotional functioning in the present or improving overall psychological functioning.	While positive feelings/emotions may be a natural outcome of coaching, the primary focus is on client-created feasible strategies for achieving specific goals in personal life &/or work.
Counselling	Consultant diagnoses problems and prescribe and sometimes implement solutions.	The assumption is that individuals (or team) are capable of generating their own solutions, with the coach supplying supportive, discovery-based approaches and frameworks.
Mentoring	A mentor is an expert who provides wisdom and guidance based on his or her own experience. Mentoring may include advising, counselling and coaching.	The coaching process does not include advising or counselling and focuses instead on individuals or groups setting and reaching their own objectives.

Table 4 What **are the significant differences between coaching and other services?** ²

Note. Life coaching is sometimes viewed as similar to psychotherapy ..without restrictions or an over-seeing authority, regulation, and so without established ethical policies.^{10, 11} Currently there are no licensing requirement and so the vast majority of life &/or wellness coaches lack formal training or certification.¹² It is crucial therefore for any ESCIF consumer organisation to use only trained and experienced coaches with ICF certification, or else with overriding professional expertise &/or trusted experience.

Summary

The concept of Quality of Life is spread across many areas of human activity. The distinction is often made between the objective QoL issues of living conditions and health, and the subjective. This subjective component, may be thought of as individual well-being, as it encompasses cognitive and emotional evaluation of one's life and situation. It is of equal significance in overall QoL.

An enabling environment and programmes to actively engage SCI persons are undeniably essential to the SCI person achieving a good QoL. However, dealing with psycho-social consequences of such an injury is very much down to the individual.

This study's survey of 15 national SCI organisations from across Europe, in addition to inter-viewing some thirty individuals who live with SCI, together with a survey of published research, led the team to isolate the 'subjective' component. At the core of these, the study recognised three fundamental prerequisites (aside from exogenous and health influences) pertaining to QoL:

- ❖ *Independence and Participation*
"To live independently and participate as an equal and respected member in society."
- ❖ *Life according to one's own wishes*
"To develop and pursue one's own life - based on own needs and objectives."

❖ *Personal capacities*

“Take charge of your own life instead of having others doing it.”

Consistent determinants were perceived to be:

- *Having a purpose in life and hope (contrary to feeling 'the situation is hopeless').*
- *degree of perceived comprehensibility*
- *manageability and meaning of one's life (ie. sense of coherence).*
- *self-worth / self-esteem and the ability to produce a desired or intended result.*

All of which lead to;

- *personal control over the outcome of events in their lives.*

Adverse states of mind such as acute melancholy and depression are very real barriers. Subjectively a good quality of life must include joy, and most often that may be found through achievements and satisfaction outside / beyond the person themselves. Having a purpose in life and active engagement were especially significant to higher life satisfaction and functional independence, and as such they may be a focus for suitable intervention to support persons with SCI.

How might SCI consumer organisations help people after SCI to achieve a desirable QoL?

Accessibility and opportunities are most important facilitators - and therefore primary objectives. Without these self-sufficiency and active engagement is impossible, and then the other determinants just crumble away. Thereafter, it's a matter of helping the SCI person find purpose, to encourage, motivate and guide him or her to take control of their life, and to achieve their own goals.

Rehabilitation often inadequately prepares them for the transition to living in the community. There are gaps between the skills taught in rehabilitation settings and those required in the real world. Motivational support of family and friends is essential, but there is a cry for more peer support, which would help the newly SCI person avoid mistakes and generally how to cope. Peer support also shows them first hand that there is life after injury and helps them achieve this for themselves.

In addition to calling for further peer supporters, this study urges National Organisations to seriously consider implementing a service along the lines of professional 'life coaching' (but to be aware of un-regulated practitioners in that vocation).

Life coaching uses specific interpersonal means to establish, embellish upon, and motivate. The life coach should be impartial and is not there to advise - but is to help the person establish his or her own objective(s), potential pathways, and to empower them. Stepping stone goals are a means to realising progress, which ultimately become self-motivating. The study further emphasises that this practice is quite different from either psychotherapy or counselling, or indeed from a mentor, and should be in addition to those. Clearly the craft skills of an accomplished life-coach would bring invaluable expertise to any SCI consumer organisation.

“everybody needs some kind of a facilitator to get them back on track. Being empathic and supportive. Not to impose thoughts, but treating as equal, helping to find personal strengths”

Social and Leisure Activities

5. Social and Leisure Activities

Working group: **Ulla Carlsson (Sweden), Mirjam Kanalec (Slovenia), Gabriele Kirchmair (Austria), Joanna Martin (Scotland), Esther Peris (Spain), Winnifred de Moes (The Netherlands)**

Introduction / background

Full 'Social Inclusion' means that no matter who you are or what you believe ..no matter what passport you have or language you speak ..no matter what colour your skin is, which sex you belong to, or your sexuality, and no matter if you're disabled or not - You are part of, and you have the right to participate in that society.

After an injury, it can be a long journey before a spinal cord injured person becomes fully reintegrated into society. And there are many factors which effect how successful an individual might be including: age, injury & health, economics, family, social skills, rehabilitation support, and of course - the personality of individual.

From being a 'victim', the SCI has to take control over his or her life and the situation, which is in a new package. Before reintegration, they first have to become comfortable with themself and their new life. Spending time with people who have experience of living with an SCI, and who have a good attitude - will inspire the newly injured and help them gain the confidence to try new things.

Social & leisure activities can then play a large part in helping the person through the process of reintegration - as most of these activities involve getting out of the house and meeting up with others in the community. And then a person can progress to more active participation and ultimately to vocation - which is the only route to full social inclusion.

Although ESCIF's member organisations are working on different projects, all of them are focused on the same target: Successful (re)Integration. We strongly feel our national and regional associations ought to be a springboard for new SCI persons, as these organisations have the tools, the knowledge and the infrastructures to not only work directly with the SCI persons in recovery of their ability to participate successfully in the society, but also to intercede with private companies, administrations and governments - to fight for the SCI rights as citizens.

They have an important role in support and guidance, and can give a person with a spinal cord injury the social resources he or she needs to regain self-confidence and to find joy in life again. Each person is different though, and so each have to find a route that best works for them. Accordingly, the organisation should provide opportunities where SCI persons can try different activities. For example, it should be recognised that many persons were not interested in sport or certain leisure activities prior to sustaining an SCI ..and therefore will be less likely to want to participate in them thereafter.

But social and leisure activities are important playgrounds - where the SCI can be lost in the moment, to distract from the consequences of SCI, the worries and pain. They are also important for getting together with family and in making new friends, when otherwise the tendency may be to become with-drawn and recluse. Many kinds of activity also provide the opportunity to get rid of frustration and find satisfaction.

With revitalised confidence and new friends, the path to reintegration is much easier.

Project work

This study group conducted a survey among ESCIF member organisations and exchanged information about national organisations' activities in different countries. It further studied internet-accessible reports from other European countries, from sources in North America, Middle East, and Asia. These mostly focused on SCI organisations and what they are doing to help SCI individuals with successful integration ..their activities, programs, etc.

A questionnaire was compiled (Appendix 2.) and sent to 39 National SCI Organisations, mostly ESCIF members, and received answers from seventeen, which provided a broad diversification of demographics and culture:

Austria, Belgium, Croatia, Czech, Finland, Denmark, Italy, Netherlands, Poland, Portugal, Romania, Spain, Slovenia, Serbia, Scotland, Turkey, and the Ukraine

Discussion

The World Health Organisation, Institute of Medicine, 'Model of the Enabling-Disabling Process' (IOM - 1997) suggests the degree to which a person with disability is an active productive member of society, and well integrated into family and community life, is a complex phenomenon influenced by many factors.

These include:

- ❖ Characteristics and consequences of the injury or pathology, including impairment at the organ level and activity restrictions at the person level.
- ❖ Individual characteristics, including demographics, lifestyle, and behaviour nature.
- ❖ The environment, including physical, social attitudes and cultural issues.

From this basis, and its inference of exogenous barriers and endogenous factors versus facilitators, we observed how the function of SCI organisations vary in different parts of the world. We concluded this was largely a consequence of differing levels of disabled access in their country, different legislation and human rights (in health, accessibility, employment, social right, etc.), together with the geographic &/or economic situation of a country or area.

As a generalisation; countries in the southern and eastern parts of Europe tend to have poorer levels of disabled accessibility and equalities legislation - so the work of the SCI organisation is focused mostly on these matters. They are very active in field of human rights and cooperating with their governments to amend legislation specific to persons with SCI disabilities, so as to provide a base infrastructure of inclusion.

In addition, most (but not all) organise SCI sporting events and activities. Some also organise social events, provide personal assistance, accessible transportation, and other interest or educational activities. Others are able to go further in raising awareness, and also providing; peer-counselling, organising holidays and social gatherings, providing more broad ranging classes such as in poetry, painting, training in computers and languages, etc., and different workshops. All organisations have websites and issue news-letters or publications.

Countries to the north of Europe, already have legislation in place for SCI re. accessibility, adaptive devices, health care, personal assistance and independent living, etc. And so, the role of the SCI organisation is very different. An interesting and significant difference is that there are also associations (of different need groups) where the SCI organisation is one of the members.

The economical and geographical differences of these countries also influence how SCI organisations are structured, often having both national and local SCI associations with the economy &/or geographies tending to inspire the way they are shaped.

Furthermore, there is a big difference if a person with SCI lives in an urban or rural area.

Developed countries, with accessible towns & cities can ensure that almost every event or activity (sport and leisure) is disability friendly, thereby helping with integration. For example, the SCI person can practice table-tennis in a 'normal' local club with able-bodied friends. The SCI person can go out with friends to cultural and leisure events, and enjoy other activities using accessible public transport to get there. Those communities are more used to meeting disabled persons, and so SCI person can be comfortable in the environment. The role of SCI organisation is not as influencing as the infrastructure is, insomuch as it better accommodates people with disabilities.

Conversely, in lesser-developed countries and remote or rural communities with no, or an under developed disabled-access environment, and possibly a society and their services with little experience of working with and supporting SCI disabled - there are completely different challenges for an SCI person when integrating. The role of the SCI organisation can be huge, from pushing for accessible public buildings, transportation and housing, to themselves organising SCI accessible sports facilities, interest activities and courses, excursions, information, etc.

Integration then can very much depend on where the SCI happens to live (town, province, or country), its transportation and physical accessibility, social services support, etc., as well as the SCI's age, companionship & physical ability,

Perhaps the single most important factor for successful integration lies with having accessible transportation. Adapted public transport aside - there is, in some countries, financial support (via government agencies) to help buy or adapt a vehicle if the SCI person is able to drive.

But if a person cannot drive, because of their disability, age, or other health issues or impediments, then they are dependent on their family, friends, public transportation, &/or transportation provided by an organisation. Some SCI organisations can help individuals with transportation to some events, whereas others simply cannot (due to lack of resources, distances involved, etc).

Clearly the way SCI organisations function differs depending on social economic development of the country or region and the demographic spread of SCI persons. Nevertheless, we found much excellent work going on within SCI organisations regarding social and leisure activities:

- ✓ Peer support & counselling
- ✓ Promoting the importance of the SCI in volunteering
- ✓ Organised sport events and social activities (..unfortunately most are not integrated)
- ✓ Organised social gatherings, excursions, cultural events, summer and winter camps
- ✓ Organised workshops and courses, including; art and music, poetry, paintings, computer, etc. These may also be open to personal assistants.
- ✓ Assistance with and SCI consumer guides for tourism & travel (not only checking accessibility of hotels, country houses, monuments, museums, beaches, restaurants, etc., but also publishing the results as customer guides & apps. They may also promote and work with establishments to achieve good accessibility for disabled people.
- ✓ Informational news & other bulletins for members and the general public. Each organisation has its own website and use print and electronic media for information dissemination and more.
- ✓ Focused activities for different groups. ie., for women, tetraplegic, for recently injured persons, and for the long-term injured.
- ✓ Most organisations maintain good relations with SCI rehabilitation units and have contact with the SCI patients during their rehabilitation.

All are actively trying to help new injured SCI successfully (re)integrate into society.

Further to our questionnaire (Appendix 2.)

From research and opinions of members we gained an indication as to what successful integration via Social & Leisure Activities looked like. We were impressed that practicing sport and volunteering were both important tools to ease successful integration. We sought confirmation, or denial, of this through a questionnaire. In brief, this consisted of four questions. We had answers from 17 national organisations of very diverse countries:

1. **What does successful integration regarding social and leisure activities mean?**
We offered 10 suggestions + 'other' and asked they be numbered in order of importance.
2. **Does your organisation promote sport and leisure activities that lead to integration into society?**
If yes which is the one best activity for integration into society?
Two countries answered NO.
15 replied that they promoted different kinds of sports activities.
3. **Does your organisation use SCI volunteers?**
We suggested; Sport activities / Awareness / Peer counselling / Board members / Website or Newspaper / Administrative and Office / Leading courses / Other
One country answered No.
16 confirmed that they did ..with the majority checking all of the (above) suggested activities.

4. **Do you think your organisation should have a programme to encourage SCI individuals to volunteer for other organisations / groups?** (We offered 6 suggestions + 'other')
70% confirmed that such programmes would be a good thing.

Further analysis / review of the specific answers from the national organisations that participated generally confirmed our supposition that both active participation in sports and volunteering are most beneficial to a SCI person's successful social integration.

It is interesting though that the confirmation from the organisations was not unanimous. There is an impression that this may have been because of already overstretched resources and limited finances. For example, to ask if an organisation has any additional programmes may receive a negative response - not because they disagree, but simply because they cannot meet the more pressing demands of their members.

One has to remember that these organisations are charities, often manned by volunteers, possibly having administrative issues, and usually desperate for funds. In any case they are working in very difficult circumstance and against deeply routed bureaucracy in still-developing national economics. In such societies the integration of a marginalized group of SCI persons is important, but of lesser a priority than the welfare of their millions.

Overall though, our study confirmed that persons with SCI who participate in activities such as sport, exercise, and/or art ..as well as volunteering - have a better quality of life, added life satisfaction, and live healthier. Some of the benefits of Social and Leisure Activities are:

- ✓ Social inclusion
- ✓ Maintenance of health
- ✓ Gaining fitness and strength
- ✓ Possibility of speeding up rehabilitation
- ✓ Gaining self-confidence and motivation
- ✓ Psychological benefits.

The barriers to be overcome ..are mostly regarding limited or absent levels of disabled access.

Recommendations

In broader community terms; SCI organisations must (continue) work with other organisations, their government as well as regional / local authorities on a legislative level - to provide accessible public transport & buildings, as well as accessible social and work environments.

Equally important is raising public awareness (through local media, in schools, in commerce and other awareness campaigns) regarding different disabilities and the humanity matters of SCI inclusion, accessibility, human rights, and laws regarding equal opportunities. Such awareness initiatives should reach and educate the public of all ages, professionals, commercial, and government officials ..so that the SCI person can integrate with ease back into the community after injury, without constantly facing barriers, ignorance & prejudices, anxiety or discomfort.

On an interpersonal level, the role of SCI organisations is to inform, encourage and support SCI persons; in how to use public facilities (such as accessible transportation), in providing information regarding their rights to financial benefits, care and assistance, and to SCI / disabled equipment and aids, through which they may help adapt a SCI's home, workplace, and/or car.

But for most SCI's - social integration, having friends ..and loving is absolutely fundamental to quality of life. Without that, the finest care and equipment in the world, may be likened to a hollow gong. Remember, the newly wheelchair bound individual may not be able to look outside their very limited perception of the immediate situation - They may need a helping hand. Meeting someone who has gone through SCI and come out the other side - to live a decent life and who has a positive outlook can really help the person in hospital or rehabilitation. This is something that neither able-bodied nor generous resources can do better than another SCI !

Here are a few suggestions which are both useful and a social icebreaker to a SCI community they probably know nothing about.

- ✓ Peer Support: Have spinal injured volunteers, or people working with SCI associations, visit persons (of similar age / demographics) with recent spinal injuries - while they are still in hospital. Information about living in the community can be given at this time including accessible places and accessible transport.
- ✓ Excursions (early on): Ensuring new spinal injured persons, while still resident of the spinal rehabilitation unit, are taken out / into the community ..maybe to the local park, shopping or to the movies. If time and help is available ..encourage this as often as possible.

For the newly injured it is essential their focus be on achieving what can be done rather than what cannot. This is best conveyed in action, rather than repeated word, from the very earliest aware-ness and continually thereafter. It takes empathy from those around them and facilitating, rather than sympathy and doing everything for them.

The crucial objective is to empower the injured person, despite their disabilities, rather than to let them become absorbed in dismal thought, where their hope slips away. Ie. it is necessary to try and avoid the depth of depression rather than trying to deal with it later on.

- ✓ Mentorship Scheme: When the patient is being discharged into the community - pair that person with a mentor with a similar injury. Set goals for the patient, to achieve during the first 12 weeks, and follow these up weekly preferably face-to-face, but otherwise personal contact by telephone, or Skype (depending on accessibility & resources).
- ✓ Friends & Family: Invite the friends and family to SCI social, cultural and sporting events to integrate them into that community and to show them that injured persons can live a good life. Their first invites / visits might be before the injured person even leaves the SCI unit / rehab facility so that even they are more positive about the potential for quality of life, and also more comfortable when visiting activities with their injured friend / family member.
- ✓ Ensure that they also know what is available in the local area, both within the SCI calendar and where integration of SCI with able bodied has been successful - so they can encourage the injured to attend clubs/events.

Close friends need to go out of their way to integrate with SCI. It is too much for the newly injured party to roll into one of their old social circles and not feel the weight of what has happened in their life. Such re-integration may come later, when the SCI is more able to cope with their new environment.

- ✓ Sport & Exercise: Highlight the benefits of the different sporting activities available, but be aware that sport and exercise is not for everyone. Never-the-less it is sometimes necessary to encourage exercise and dexterity, and even if that is a fun race around the park - to stretch the limits of what they might be able to do. "When it's fun, it's not exercise"

NB. Swimming is considered by many to be a leisure pursuit rather than a 'sport' ..and yet for the SCI it can be particularly liberating ..and, as an aside, good exercise. Be aware though that many individuals cannot swim or enjoy it because they fear drowning. And because the injured person cannot 'feel the bottom' those fears cannot just be dismissed.

Often individuals feel awkward and so resist participation, but may go along with friends when invited & gently encouraged - "we are all going to go _____ , ..we'd love for you to come along"

- ✓ Other Activities: Although a lot of different adaptive sports may be on offer, it is important to also offer alternative leisure pursuits and activities such as art, photography, music, book clubs, writing, crafts, or even just coffee mornings. The age and abilities of SCI participants will help determine which interests might be most attractive but beware of marginalizing those who do not share the same interests as the majority.

One project, from Sweden, called the 'Third Language' explored ways to express oneself through different creative activities, and the subliminal benefits of leisure activities. It is worth reading - *please see Appendix 2.*

- ✓ Collaboration with other organisations: All SCI organisations, support groups, and rehabilitation centres are encouraged to work with other organisations to put on &/or participate in events - to enable individuals from either organisation to attend the other's events.

These are particularly important to those who don't comfortably fit in with the activities normally organised, perhaps because they have a specific condition (like damaged sight) or are a different age group, or (sub)cultural background.

- ✓ Apps: Mobile phone 'apps' (applications) are a useful tool which convey mainly up-to-date information on what events are happening, and what facilities are available - including whether a building is wheelchair friendly.
- ✓ Holidays: Ensure individuals and their care giver know where / how to find adapted properties & hotel rooms.
- ✓ Volunteering: as soon as the SCI is able (physically, cognitively and emotionally) - encourage their volunteering with a local spinal organisation, or perhaps for one which caters for an interest.

Volunteers are essential. Only an SCI can truly relate to a newly injured SCI person. Only they can show by example that there is life, and hopefully a good one, to be had after the event. Volunteers not only help the newly injured though - it immeasurably helps those who are doing the volunteering.

This report's work-group study on 'Education and Work' conveys how volunteering can provide work satisfaction and an important sense of achievement. And along with boosting self-esteem, it helps re-train motor and cognitive skills, and is an invaluable stepping stone to social reintegration & paid vocational work. Vocational work can be the path to rediscovering self-worth.

Some areas and topics for all SCI organisations to focus on:

- Reaching out to persons in rehabilitation centres before they go home. This includes introducing the benefits of diverse leisure pursuits on an SCI's motor functions and cognitive skills. ie. to focus on what a injured person can do - with an fun / absorbing objective (the leisure task) rather than in abstract (exercises).
- How do we find / identify and understand SCI persons tucked away in your society - who are not integrating?
- What activities / schemes / initiatives are currently working - to successfully draw persons in and encouraging integration.?
- Are there new activities that are fun / positive / healthy / interesting - and which may integrate others / more persons?
- Is there a need &/or opportunities to make your society / community more aware of SCI needs?
- Role models?
- Friends and family are really important. Can the organisation's Social & Leisure Activities better include them? After all, a SCI person's sibling being there is an opportunity for another SCI to integrate with an able bodied person.
- Different activities for elderly &/or other infirm SCI minorities (like those with limited manual dexterity or the partially sighted).
- Communication, particularly for those so impaired as a secondary consequence of their injury.
- Would an insight into your SCI activities and their successes be useful to other national organisations? (ie., to disseminate information on projects and initiatives)

For example: One project from Sweden called the 'Third Language' explored ways to express oneself through different creative activities. The project also took a closer look at creative activities and their rehabilitative effects - testing and evaluating the different leisure activities and reported on how they had positive effects on the patient's motor functions and cognitive skills. See Appendix 2.

Conclusions / Summary

Social integration, having friends ..and loving is absolutely fundamental to quality of life. Without that - the finest care and equipment in the world may be likened to a hollow gong.

There are many factors which might effect how successful an individual SCI will be in each of these, not least; the intellect and personality of individual, their social skills, the extent of injury and secondary health issues, economic limitations and transportation, as well as rehabilitation, family and friends' support. From being a 'victim', the person has to regain control over their life and their debilitating 'new package'.

And as every person is individual - they each have to find a way that works for them. Social and Leisure Activities are an essential part of helping people reintegrate, to grow in self confidence and rebuild value and worth in their life. Additionally, every one of these 'leisure' activities help re-train motor functions and cognitive skill sets.

The very broad diversity of social & leisure pastimes, from; sporting activities through to arts and crafts, collecting and other hobbies, music and entertainment, cultural and other intellectual pursuits - offer the best hope for any person to find something of interest to grasp onto ..And from that to look up from the situation they find themselves in to again see 'worthwhile' activities in life. These lie on the path to achievement, boosted self esteem, and social and perhaps even vocational reintegration.

This study, which looked across the globe and working directly from feedback from seventeen very eco-politically diverse European nations, confirmed that SCI persons participating in social-leisure activities enjoyed a better quality of life and live healthier. They social integrated.

Each SCI organisation has an crucial role to play in influencing their society's disabled accessibility and facilitating resources, as well as providing information and the means, the guidance and support, and the opportunities, a person with a spinal cord injury needs to re-gain self-confidence and to find joy in life again.

The ease and success of SCI persons social and vocational reintegration is a bit of a lottery, insomuch as it can depend on where they happen to live. Northern European nations, with stronger economies and a developed legislative framework for human rights & equalities, have as a result better disabled / wheelchair accessible environments and transportation, as well as better resources and more diverse leisure activities. But even in these nations SCI's living in urban communities are often noticeably better served than their counterpart who happens to come from a rural backwater.

Nations, predominantly in southern and eastern Europe, with still-developing economies & legislative regimes, can be very hard on the SCI. Those national SCI organisations are struggling against all odds to influence their bureaucracy, and even when they do their nation's economy cannot bring about accessibility and opportunities in any short time. Outlying rural communities fare worse because of both the lesser density of SCI persons and the distances involved, and their very limited resources.

This study proposes numerous recommendations, some of which are low budget such as - guiding / encouraging longer term SCI's to volunteer as peer supporters for newly injured persons, and again - for the organisation to integrate / co-operate with other non-SCI organisations in their social and leisure activities, workshops and courses.

It also recognises the possibility of marginalizing SCI persons within their own organisations. Those whose interest don't lie with sports, and/or are not interested in many of the other activities because their age &/or infirmities (for example those who have lost manual dexterity, or are partially sighted), or are of a different education / intellect or sub-cultural background. We further emphasis the need to identify and understand SCI persons tucked away who are not integrating. Unless everyone who chooses to do so is successfully socially integrating then a National organisation should refrain from being complacent.

We strongly urge SCI organisations, rehabilitation centres and care support professionals, family and friends - to move their focus, and to start activities towards social reintegration much sooner in their care / rehabilitation program ..by using various 'leisure' activities as a conveyor. The arguments for the benefit of these activities, in re-training an SCI's finer motor functions and cognitive skills, is very convincing. And leisure pursuits focus on what a injured person can do - with an objective (the interesting task) ..rather than in abstract (many medical-type exercises).

Even for those able to return to work - a social life is as important to them as it is to any other person of any nation. 'All work and no play' is not healthy. Humans beings are (on the whole) sociable creatures, and as is evident across every species of mammal where we see examples of relaxation, leisure and play, and social integration - It is fundamental to quality of life.

Education and Paid Work

6. Education & Paid Work

Working group: Aurelian Anghelescu (Romania), Niels Balle (Denmark), Veronika Hublová (Czech Republic), Lauri Louhivirta (Finland), Tetyana Panasyuk (Ukraine)

Introduction / background

To almost all able-bodied European men - the concept of learning a trade or career skills, getting a job and earning a livelihood to provide a home and to support a family is a given. Likewise, women, aside from maternal and homemaking roles, are very often expected to contribute to their household's income. Our family and society anticipate it, and so we were schooled and socialised from an early age to do it.

Equally as important is - it is what we were brought up to expect to do - to qualify us as 'worthwhile' and to be regarded 'a good, hardworking and honest person'. Consequently a first pay cheque is to most a proud moment in life, and a milestone which says: 'no longer a dependent' ..and that in turn gives us rights.

Even a shallow deliberation of the above recognises the threefold probable significance to SCI persons. The first is of course the financial burden when unable to do that. And of equal gravity is the person's perception of no longer being able to fulfil those deeply routed expectations, with consequently psychological impact on self worth. Thirdly is the subliminal discern of society towards the disabled.

The somewhat crude social observations regarding gender roles also have a bearing on the subject of work & employment, because statistically close to two-thirds of all Spinal Cord Injury (SCI) are male. The far greater majority of those are of employment age, and so were likely to be a primary earner for the family.

Whether a SCI person's work is/was actually that important or not (..to the future of mankind, blah, blah, blah) is not an issue. What is important is; if they cannot support or contribute to providing for their family, and/or they cannot have the family they dreamed of and believed they had a right to, nor might they enjoy the lifestyle of leisure pursuits (like playing football or dancing with a loved one) ..that their childhood had set them up for, then - what is there to live and to strive for? And how could they go out and happily socially integrate, if they carry the feeling of being a burden to their family, their friends, and society? ..who in turn see the wheelchair as a symbol of dependency?

It is unreasonable to expect them to simply dismiss those inherited responsibilities without it unbalancing their mindset and self-esteem. And it really doesn't matter too much whether just 0.06% of the European population (presently who are unemployed SCI) are making 'a significant economic contribution' or not. What matters are the 200,000 fathers, mothers, sons and daughters being pushed to the side margins of European society and left to feel like beggars on charity and handouts.

In lieu of otherwise redirecting those obligations & expectations towards something else worthwhile and rewarding, then - returning to productive work, whether full or part time, paid or voluntary in a trade or profession or in the arts & culture - ought to be a primary objective in SCI rehabilitation, rather just than a 'possibility'.

In short: Participation is fundamental to every individual's quality of life.

Project work

Observations are one thing. The objectives of this study were to:

1. Gather statistical evidence as to how European societies are performing in vocational reintegration of SCI persons.
The study group carried out a systematic study of socio-medical websites to try and identify a process of (re)employment for the SCI person. It used articles from EBSCO (e.g., PubMed / Medline, Web of Science), Science Direct, and Google Scholar.
Approximately 438 reports, published between 1953 and 2015, were found based on an advanced search of 'Return to work following a spinal cord injury'. These were mainly statistical / analytic rather than experiences or projects. And most were from, or published through agencies in, North America, Canada, or Australia, with far fewer from Europe.
2. Gather an overview of SCI employment issues in different eco-political societies.
The group compiled two questionnaires. The first was sent to persons living with SCI, to learn of their personal experiences and situation. The second was to learn of ESCIF member organisations' own projects, interventions and experiences.
3. Make recommendations - focusing on the practical issues and activities - aimed at promoting reintegration via employment.

Discussion

1. The number of SCI

Spinal Cord Injury is a major life-disrupting condition, which can deprive a man or woman of their livelihood. Different epidemiological studies present a very broad statistical variation on the incidence rate of SCI. The figures are corrupted by variation in SCI classification used in different countries &/or a lack of reliable data, but suggest that there may be up to 246 new cases per million inhabitants per year in some countries, with anything between 3.3 and 130.6 per million across broader Europe.

In recent times, survival-after-injury rates and life expectations after a catastrophic injury are each increasing - thanks largely to improvements in ambulance services, medical care in sequential multi-disciplinary teams, life-long medical supervision and social support. In short, ever more severely injured SCI are surviving and most might expect to enjoy longer lives. This has a significant impact on potential employment years, on the working age of SCI employees and in long-term secondary health issues.

- 1.1 Extent of damage: Approximately one-third of SCI patients are reported to be tetraplegic, and 50% of all SCI patients have a complete lesion (AIS/A classification). Only 10% of tetraplegic and 4% of paraplegic would become incomplete lesion one month after the SCI.

Recovery & natural healing is generally greatest during the first year, continuing at a slower rate (in varying degree) for some time after the event. Patients are usually re-admitted a couple of times to a rehabilitation centre, where they are reassessed and their program extended, then including varying degrees of vocational counselling and work-oriented occupational therapy.

- 1.2 Limitation: Aside from the constraints of being wheelchair bound, paraplegic also, but in particular quadriplegic persons may have dexterity problems in performing basic and instrumental daily activities (ADL & IADL) &/or require frequent assistance as a result of severe limitations in motor functions.

Aside from limited motor functions, paraplegic or tetraplegic persons may also have suffered neuro-sensory impairment. And then they are likely to have other chronic / worsening health issues associated with; infection, tissue trophicity (mainly pressure sores), kidney, metabolic &/or cardio-vascular problems.

In a job interview "how long can you do your job before you ought to lay down" is not a question asked of an able-bodied person. But a responsible SCI person needs to consider this carefully ..in respect to the number of hours each day they may reliably ..and without further compromising ones health, be able to work.

- 1.3 (Re)Employment: For a person living with (medically stabilised) SCI - returning to gainful employment has been described as being 'the final piece of the puzzle to fit in'. Statistically, this level of fitness / ability might occur anywhere between 3 to 108 months after the event. The median being close to 12 months.

Thereafter, figures present successful employment reintegration varies from just 15% of disabled persons (not only SCI) in Romania and Czech Republic. Re-employment of persons in the EU is broad ranging and varies between 21 to 67%. The higher percentage is generally linked to higher educational demographics. (NB. 'successful' is not quantified further than 'in paid work').

Experience & Education: Of those SCI who managed to return to or gain work (again unqualified in type of, or degree of part time or full time):

- 21 - 67% had prior-experience (pre-injury employment).
- 59% have low levels of education.
- 69% have a secondary educational level.
- 100% of those with a higher education, where choosing to, were able to secure (re)employment (of some kind).

However, we might bring all this down to; the average percentage of SCI persons in employment across the EU is around about 44%. This leaves 56% of the estimated 350,000 SCI population as unable to work, not wanting to, or unable to find work.

And so the scope of the issue being discussed is almost 200,000 individuals (with the number growing each year) and their families - within Europe. And conceivably half of those who found employment are working for 'whatever hours' might be available / they be able to ..in 'whatever work they might possibly get'. Available figures do not differentiate between those in paid or unpaid employment.

NB: any figures presented in this study should be considered a guideline only. Accurate statistics are corrupted by differing classifications of 'SCI ' and of 'employment ' (re. hrs / week, paid or voluntary, etc) as used in study reports from different nations. They are further compromised by limited access to accurate data sources when the statistics were gathered &/or the breadth of study and demographics.

2. To gather an overview of SCI employment issues in different eco-political societies.

This study sought to more specifically identify exogenous barriers vs facilitators, and endogenous factors (personal cognitive and physical capabilities) which so greatly effect employment of SCI persons.

From the interaction with different nation's SCI organisations, the questionnaire sent to persons living with SCI to record personal experiences & situation, and the perspective of an experienced employer, we learn of real and impeding obstructions to SCI employment:

2.1 Personal SCI factors

Health status: The nature & intensity of physical available work, &/or the intellectual demands of the task, may be a great hindrance to a SCI intent on returning to work. Determining factors include; injury severity, post-injury complications, and secondary health issues.

It may be that an SCI very much wishes to work ..but is unable to sustain 35, 40 or more hours per week that the job description / the employer specifies. And in most European cultures 'a decent part time job' is difficult to find. To find one with some flexibility, that may better suit the needs of a SCI person with secondary health issues, is very rare indeed.

In many case; the SCI person is qualified and wanting to work, but their health condition is unstable. Some days they have energy and enthusiasm, but on others they are physically or cognitively unable (unassisted) even to get dressed in the morning and have breakfast. They are unfit for a day's work. If they work on those 'good days' then the benefits office says "you have proved yourself fit for work - so we are taking you off disability benefits altogether. Reapply, after two weeks, if you stop work. You will then be reassessed for a new application".

NB: The above wording is fabricated, but the underlying scenario is real.

Personal / Family finances: Especially in urban societies, with a higher cost of living & individual financial commitments, it may be unaffordable for the SCI person / family to return to paid work, because of the loss of social care / medical / other disabled persons benefits.

Part time work, particularly those where the employee does not have the benefit of a higher education &/or proven experience, tend to be of a lesser pay grade. Often the SCI person is able to only work part-time (..between 12 and 30 hrs / week). Sometimes, those are the only hours available to a SCI person (..an employer barely serving his legal quota). Then of course, a limited number of hrs / week x Low hourly rate = Poorly paid

If a person is wanting and able to work, let's say 20 hours per week, but after 10 hours of paid employment they lose all or a substantial part of their disability benefit ..and the work is lowly paid - then that person cannot financially survive on what they might earn.

In addition, in most nations a part time employee is not legally entitled to the same worker-benefits as a full-time employee. Among numerous factors, these may include; no or reduced National Insurance contributions, pensions, holiday entitlement, and even redundancy pay.

It may be that if a SCI / disable person works for a few hours a week even - then his or her spouse / relative is no longer admissible to benefits as a home help / care giver. He/she is able and willing to provide the necessary personal care, they work hard and are needed both day & night but cannot afford to do this without some sort of financial support.

Volunteering: Even those who part time volunteer, helping out 'whenever they feel able', must declare the total hours they 'work' each week, as this may affect their benefit status.

Historical debt and financial commitments: Many able-bodied/normal family households experience everyday financial struggles. Prior to SCI injury, he or she worked as any 'normal' person in his or her occupation / profession. Accordingly, he/she and the family already had binding long-term financial like a mortgage or rent (ie., their home), had unpaid bills & credit cards balances, car repayments, etc, etc. These ongoing commitments and debts did not go away when the person was injured, in fact in coping with the emergency they were added to. And they have to be paid / repaid from whatever income or benefits the person might now get.

These and other individual financial factors, many of which are unavoidable - leave the disable person little or no choice but, for the sake of his or her family - to be humble and accept welfare and charity ..or else lose everything. They simply cannot survive on the income from part-time work.

Personal aptitudes, Psychological / attitude / self-motivation: The world of a person suddenly falls away from under their feet, leaving them looking up from the low elevation of a SCI wheelchair as if a child ..but without a hope of ever growing up. Then the chronic aches, repeated medical examinations & intrusive care. The frustration of their limitations (not being able to reach into that damned cupboard.!) And the financial worries with seemingly little hope of ever bounding back. Is it any wonder that many SCI suffer from some degree of psychological / attitude / self-motivation issues.?

They were brought up to live a life that revolved around going to work, coming home and enjoying a social life, buying a car and saving for a home, having a family, enjoying life to the full and possibly making a £-million before they were 40 years old. Together with his or her

pride - it's (seemingly) all gone. Their self-esteem is shattered and they don't know their place in this world. Even their faith is being tested in the extreme. And they face a world of every conceivable environmental obstacle, of sideways glances and uneasy silences, and every other sort of 'cannot do that now' barrier. Even their boy / girlfriend / partner appears to be having second thoughts.

They worked hard at school and were good at what they previously did. But the job interview is not for anything they ever thought of, or wanted to do, it's for menial work, part time, and lowly paid.

Pre-existent capabilities.. education, talent, skills, abilities, specific training and specialty skills (of pre-injury work).

Most jobs will be given to those whose specific educational standards &/or long / applicable experience best suits. Either education, training or experience may represent an unobtainable objective to an SCI person, unable to return to the same type of work as he or she previously used to do. In effect - after injury an SCI may face starting out a working life / career from scratch, with few relevant skills, experience or training.

Conversely, if highly qualified; the SCI may find that they are over-qualified to get work locally and of a part-time nature.

2.2 Environmental / community barriers

It takes considerable self motivation to get out and about when you are at home and alone, and to find something positive to do with whatever little you have going for you. Where does a sense of achievement and self-respect or worth come from? The usual answer would be; if not from the job then at least from being able to provide for or contribute to the well-being and future of the family.

But for the community; a person who is not part of their working team, who cannot afford to socially integrate, or to be a consumer, and who is not paying taxes because they do not work, is.. well is not.! The fact of the matter is that everyone else is too busy with the schedules, demands and responsibilities of their own life and family, and work, that any person who is not part of those ..is outside their focus. Old people, the infirm, and disabled alike are most often politely marginalized.

Additionally, SCI persons all too often confront different kinds of external barriers within their own community, such as:

- Architectural: limited accessibility within public or commercial institutions and transport.
- Negative attitudes in the community, with discriminative or unhelpful attitudes from colleagues and employers.
- limited access to further or adaptive training.
- limited or inappropriate health care provision.
- Fire regulations, Insurance limitations, Health and Safety etc., may prohibit wheelchair users. (*for example:* when a business uses stairs for the fire exit). Other regulations may prohibit the SCI person's operation of potentially dangerous machinery and equipment.
- Legislative and Information (..or misinformation) issues re. employment of SCI persons in different European nations).

There appears to be a lack of clear guidelines or actual facts among potential employers, or the staff of small and medium sized businesses. Assumptions are made ..and there is no clear-cut data on how to, and what are the obligations. What is involved, what is the likely cost versus potential benefits of employing SCI persons, &/or if there are any, and how to tap into 'incentives'.

Negative attitudes in the business community: The average small-business employer is likely to suspect that any and all disabled persons will be unreliable and always be off work 'on medical grounds'. And once employed the person would be protected by equal opportunity legislation and will be impossible to dismiss, even if they foul up the job. There is an underlying prevalence of 'employing a disabled person is wrought with hassles and bureaucracy ..it will cost thousands in special equipment & accessibility handrails, ramps & elevators, and then when that money is spent 'they' just disappear to live off state benefits - it is just not worth the trouble !'

Mostly these concerns are based on hearsay, but to be fair to employers, there was a significant (and only later) publicised 'benefits-fraud' problem, for decades in the UK and other stronger economies.

Those unscrupulous persons included some with disabilities (although not necessarily SCI) but most were able-bodied crooks posing as a person with a disability or exaggerating their health problems.

Those persons didn't want to work (or were already working - black market). And so, when pushed by the employment office into taking a job - they feigned physical or cognitive ailments & limitations - until dismissed as being unfit for the task. Having not been fired, they could resume claiming benefit.

All the employer saw was a 'disabled person', often being late and unreliable for work, taking time off for 'medical appointments', and otherwise doing bad work and costing the company money. In the UK, in recent years (since 2008/9 the recession) the checks to prevent benefit fraud have been tightened considerably. But the legacy is that 'anyone with medical issues is trouble' remains.

Significantly, very few successful entrepreneurs step forward as an advocate for employing disabled persons.

There is also a conservative attitude among most businesses regarding not allowing flexible working hours, or an alternative place of work. Ostensibly employers don't trust employee's time keeping (..although officially it is to avoid discrimination & otherwise sets a wrong precedent to other employees).

Notable too in many countries is the lack of enforcement in equal-opportunities & discrimination legislation. Even when business organisations, like Chambers of Commerce and government agencies, disseminate regulations or guidelines, it is apparent that most small & medium sized businesses completely ignore them. Only if and when directly confronted with such a 'problem' are legal matters and obligations looked up.

Conversely, there is often a lack of readily accessible information to SCI persons about their EU / national legal right to work, &/or vocational counselling services. And equally what regulations might prevent them from doing a job.

2.3 Commercial needs

Employment opportunities can very much depend on the type and nature of the work (..agrarian, trade, industrial, transport, administrative, commercial, servicing, education, scientific, or technical domains). The nature and intensity of available work (..the physical, cognitive &/or the intellectual demands of the task) may be a genuine hindrance or obstacle to a SCI intent on returning to work.

Charities and other organisations may have a different agenda ..but any commercial business has a primary objective to make a profit and to successfully compete. A fact of life in a capitalist world is that without trade, the society and community as we know it - will cease to function.

Performance: Both cognitive and physical abilities are, in the eyes of most employers, subject to speed and overall task-accuracy performance. A business needs high performance from all of its staff to be competitive, and very few can afford to 'carry someone' unable to keep up with the pace or workload. It doesn't matter very much if the employing entity is a remote farm or an International business group, in almost all organisations (whether commercial, government, public service, or charity) the competitive survival of the entity overrides the needs an individual, because any business no longer able to compete will eventual cease trading ..with much farther reaching hardships.

Along with performance goes reliability ..being there when a job has to be done. And again someone with SCI (or any other disability) will most likely need more time off than a fit & able bodied person. Small businesses in particular almost always work pushed hard against a deadline / a job finish date. And because they are still trying to find their feet financially, are usually undermanned. It is difficult to frequently or with little notice to loose an employee to doctor's appointment and sick leave at such times, as they simply don't have the manpower to cover the position.

Cost of Employment: It should be noted that the cost of employing any person is not only in wages or incentives. There are many other expenses including; National insurance & pension contributions, healthcare, health & safety, employer insurance, holidays (both national and an annual holiday entitlement), time off for doctor and dental appointments, sick leave, maternity leave, compassionate leave, a pension scheme, on-the-job training, rework due to mistakes, and even the person's workspace, rest-room facilities, car-parking, etc., are overheads.

If an individual (an SCI) needs better accessibility, possibly a place to rest up once in a while, &/or special adapted equipment, and more time off for medical reasons - then those costs come into the equation as well. Likewise, if a person needs (re)training, adaptive training, or an assistant. And then, where a company is expected under EU law to provide healthcare and insurance for their employees - the business may look at a prospective SCI employee and (perhaps without even looking into the facts) assume that to employ such a person might be costly.

So, the question any employer must ask is - who (able bodied or disabled) would give a better return, re. those costs.?

Equal Opportunities Legislation: Even when a business or organisation is subject to equal opportunities legislation, to employ the disabled ..and not all countries across Europe have this. Nor are 'small businesses' required to meet the criteria. Nor are those laws strictly adhered to / enforced ..then the nature (..agrarian, trade, administrative, ..whatever) and intensity of work, and a minimum performance criteria, may rule out the employment of an SCI applicant.

To comply / satisfy the regulation - many companies fill 'their disabled quota' in the most lowly paid and menial jobs. These tasks may be soul-destroying for any thinking and educated SCI individual.

Minimum Qualification requirement: For SCI persons living in economically developing countries &/or the remote rural areas - educational standards of the community at large may be very low (basic literacy), and so the employment opportunities for a previously 'good & reliable' manual worker - now SCI, are very limited indeed. Further disadvantage may be in a lack of vocational counselling &/or re-training opportunities / infrastructure, and possibly in community discrimination and priority

Moreover, opportunities can be very limited, particularly in communities where unemployment is high. And travelling for many hours to where work is available, or staying in a rented room during the working week, is unlikely to be a long term viable option for the SCI. In rural communities there may no adapted transport whatsoever.

In almost every circumstance, an SCI person must also compete for work with lesser-disabled applicants, as well as with able bodied persons, for any job.

2.4 Facilitators

Personal motivations for an SCI trying to find or (re)gain some sort of work, either full or part time, are often much the same as for an able-bodied person, but perhaps closer aligned to someone who had been made redundant and suffered life changes as a direct or indirect consequence. Their motive to get back to work might be or include:

- Financial pressure / concerns
 - Family pressure of 'responsibility'
 - Peer pressure of »come on - you can.."
 - Personality traits of self-respect / stubbornness / the challenge / determination
 - To rebuild a life / a brighter future, to do fun things again, for the sense of achievement, for a romantic cause, or for a million other reasons.
 - Concerns (for the family, for the children's future)
 - Wants.. an objective or goal. To socially integrate takes money ..as does buying things and paying to do things, irrespective of whether that is to go out for a beer, to enjoy good music, to buy a slicker wheelchair, or an adapted car to regain independence, or to travel the world.
 - They enjoyed their previous job / the type of work &/or the social aspect of integrating with other employees. They may have useful career skills, work experience, or expertise that is 'worth' doing &/or sharing.
- or simply because..
- They would go crazy sitting at home!

3. Recommendations

Recognising the great difficulty facing the SCI when looking for gainful employment, and yet that returning to work represents a momentous milestone for a person in wheelchair, a questionnaire was sent to ESCIF member organisations focused on practical interventions, own projects & activities aimed at promoting reintegration via employment.

In addition to that feedback; the study team from five very different national organisations brain-stormed, which with additional input from a management professional are presented below. There are three main goals: **to Find, Secure, and to Maintain employment:**

3.1 To improve opportunities of Finding employment

- In many countries vocational rehabilitation program is too short or even absent. For best results in SCI persons' reintegration, a focus on vocational reintegration is needed sooner, and should start before the patient is discharged from the rehabilitation centre.^{13, 14}
- Discuss the demands of working as a SCI with the injured person. Talk about how they may be limited in what they can do (by physical & health issues, and by limited accessibility). Examine together how adaptations may be made to the tasking of their work ..and how (reasonable) changes might be made to their work place. They need to be contributing to and have invested in the solution.
- An SCI organisation or rehabilitation centre may call upon and draw from experts working outside the sphere of SCI and disabilities, on how to motivate people to return to work. Inviting professional speakers, sports coaches, mentors, etc. will help motivate and share helpful hints & tips to facilitate securing work. It may also sparking ideas for in-house programmes, and who knows - perhaps those speakers may be encouraged to become involved.
One such programme is suggested in this report's 'Social and Leisure Activities' regarding recruiting the services of professional experienced Life Coach.
- Information & a positive message on employing the disabled together with legislative obligation should be broadly and repeatedly disseminated ..by SCI organisations to businesses and organisations, on both a national and local community level. This may be done through the press and media interviews, through chambers of commerce and other professional associations, and even through presentations to the local employment offices.
Such dissemination and pressure are most commonly aimed at the business employer. But the civil services and other bureaucratic / public service offices should not be forgotten. The following are each very big employers, who tend to quietly shy away from making an effort themselves: the legal system, educational institutes (at all levels), health industry, emergency services, highways agency and other amenity offices, the media and entertainment industries, agriculture and farming, etc.
The objective should be to have every employer actively looking to employ the disabled, including SCI, rather than having the individual SCI person scratching around for whatever he or she might find. Collaboration with other disabled charities would be worth developing, as together you will have a louder voice. If changes to the law, or the enforcement of those laws are needed - then lobbying is called for.

- National SCI organisations urgently need to extensively survey their members with their employers to build up a reliable and accurate database of how many SCI are employed and how that employment is working out ..for either party. And for those who are not employed then the facts ought to be established as to exactly why?
 ESCIF is an umbrella of 37 national SCI organisations. And if every one of those were to use the same format (SCI and employment classifications) then that 'league table' would be a very powerful tool when it came to lobbying for improvements. No Minister of Employment (especially at times of election) wants to be seen placed lower down on the league table than a predecessor or neighbouring country.
 The same sort of survey might be done, and results achieved, at the local community / county or town level. The election of a Town Mayor is big local news in some countries. And such news draws questions regarding who they have promised to help and how well they have performed.
 Information is Power ..and law together with the media are the engine. Only when SCI national organisations really work together to get that will they power up the momentous change needed.
- SCI organisations should work in very much closer league with other disability organisations, rather than feeling as if in competition. Draw in from every quarter and ally with them, including those with a higher media profile such as those for ex-servicemen. Common objectives ought to be established with programmes working together to achieve those.
 High unemployment, poor opportunities, low wages, lack of benefits that full time employees enjoy, are just the sort of situation where collaboration and pooling resources would help all working-aged disabled. The numbers of disabled persons (of all types) together with their careers, families and friends, are big enough to bring pressure for real changes in opportunities in employment, for a better quality of life and social reintegration.

3.2 To improve opportunities of Securing (re)employment;

Where there was a job before injury ..and there is any (even remote) possibly to go back to it (subject to extent of injury, the job's prerequisites, and agreement from each party), then that is almost always the best way forward. In the longer term if that is not such an amicable solution - then change. Even for able bodied workers it is often said "to find a new job is much easier when one is already employed".

With the SCI person:

- Focus on work-orientated skills as soon as possible after injury, together with rehab specialists and peers.
 - As a substitute for 'work experience', the SCI person should be given tasks and responsibility as soon as possible after injury, within the rehabilitation centre. This should be expected of them. There are no free rides in the real world when confronted with bills to pay. These tasks will help take the person out of themselves, to look up and see to their own responsibilities. And the tasks should stretch the limits of what they think they now cannot do.
 - Wheelchair agility including negotiating (simulated) curb-stones and door thresholds, reaching into awkward cupboards, handling heavier and awkward items of loose files or equipment, moving at a pace which suggests 'motivated' rather than 'victim', and a hundred other abilities - are each a necessary preparation for workplace reintegration.

With the employer: Counselling interventions with the employer can play a decisive role.

- The employer is unlikely to know what the person's SCI needs may be (each being individual), nor of what they might now be able to do. A conversation is needed with the employer to give him/her the information they need to accommodate the injured employee, possibly to re-allocate some of the duties to other staff, to at least give the person time to get back up to speed.
- Almost certainly there will have to be workplace / environment adaptations, even if only to make a little more space around a desk. But most likely there will be costly issues of accessibility and accommodating the SCI person's needs, and possibly issues of fire exits & insurance. Employers need to be informed of any incentives or grants that might be available.

Where there is no possibility of re-employment in the same job ..but there is a good history of employment - then a route forward is to go back to that employer and work with him/her to find something that the SCI person might do ..perhaps after retraining.

For the employer: A good employee is worth going out of the way to help. It offers many benefits, not least in their knowing and trusting the person. Their personality is known to fit in with other employees, and the SCI person already knows his/her way around the business (= less settling-in time) as well as other employees and what they do.

And because the SCI already knows much about the work, that industry - his/her hands-on experience and knowledge (perhaps of a previously manual worker moved across to administration) can be a great asset to the office.

For the SCI person; it will be very much easier to reintegrate where faces are familiar and sympathies are working in favour of giving a helping hand, and perhaps even offering a lift (transport) to & from the place of work. Furthermore, the familiarity of the industry, the glossary of terms used, etc. will be less stressful than any new job in a different industry.

Counselling Interventions:

- Counselling with effective interventions can play a decisive role - to link the patient, the employer, the rehabilitation team, and vocational professionals who may become involved in reintegration and re-training programmes.
- Workplace training and ongoing counselling to help with adapting to working from a wheelchair

Vocational Retraining:

Where the SCI persons former occupation was of a manual nature and that is no longer possible, then consideration must be given to facilitating re-education / re-training of the SCI, appropriate to the needs of the employer and whatever type of work there is available.

Proactively explore the possibilities of this being done in collaboration with an employer, after all it is commonplace in every community for young people with no prior work experience to train 'on the job', and for the person to day-release for further education / training at a college.

Although inevitably this will be lowly paid, many governments and demographic regions have schemes of financial support designed to help their unemployed while training for a new vocation.

These schemes often have incentives for the employer too (not unlike not apprentice training), but all too often the employer has no knowledge of these, and no time to explore the possibilities. Again, this needs to be presented to the business. The more manageable the incentive, the more likely there is for the SCI person to be employed.

For the SCI, retraining on the job and day release has the additional benefits of promoting social reintegration, as well as giving the SCI a focus / goals to achieve.

When re-employment with a former business employer is just not possible (..and every avenue with former employers have been explored, with humanity issues and legal obligations brought to bear), then the SCI person is faced with whatever the wider job 'market' may offer.

Many urban community employment offices offer facilities and even 'job clubs' to help their unemployed find a job. These not only list job vacancies but often provide computers / printers, along with guidance on how to write a better resume, and then stationery to send job applications. In an urban community these are now mostly wheelchair friendly. But, if the employment office does not have these then perhaps the SCI organisation can set up their own.

In communities where unemployment is already high, and the work is usually manual, then again consideration must be given to facilitating re-education / re-training of the SCI, appropriate to the needs of whatever type of work there is available for the SCI's abilities.

Seriously consider volunteering, as a stepping stone to paid employment

As previously discussed - business and therefore the workplace is a competitive environment. And experience, and a résumé of proven abilities, are usually necessary to secure a good job. But when a person is changing vocation and perhaps for the first time hoping to work in an office environment - then they are faced with a dilemma that might only be filled by 'work experience' in the voluntary sector. The SCI organisation, in collaboration with other charities, need to make such workplace opportunities a priority.

Furthermore, the SCI might consider working for an employer for free. Don't be shocked, the author of these pages did exactly that when he started a new career. And it is commonplace in some professions (like in architecture and design) to do a lot of unpaid preparatory work - to tender for a contract. For the would-be employer, this demonstrates first-hand the commitment and the abilities of a person. One month working for nothing (but the unemployment / disability benefit) may very well lead to a long-term well-paid job.

- o Volunteering for unpaid work may be necessary to build up a new base skills (perhaps for office work) as well as a new 'employment history'.
- o Whether 'new to wheelchair' or 'new to workplaces' the SCI person must get used to navigating his or her way around the workplace environment. They need to get used to getting to work (navigating the outside world) by wheelchair ..preferably independently. And they need to stretch to the limits of what they didn't think they were capable of.
- o Even though unpaid - voluntary work can be very rewarding. Something is achieved &/or the SCI person is able to help someone else.

- Focusing on the task in hand / the work &/or the cause (unpaid work is usually for a charity or church) will open up the SCI person's outlook, from themselves to other things. This too is an essential part of reintegration.
- Even though unpaid, expenses might be offered

Remembering "to find a new job is much easier when you are already in work".

- Useful contacts and opportunities will be more apparent from almost any place of work ..than from sitting at home.
- Organisations where one might volunteer may have benefits, even if that is only some help with an envelope. But they will also have persons to talk to, to discuss how and where to find gainful employment. "Two minds are (often) better than one".

Stepping stones, however small in the right direction, and achievements are a great boost to self-motivation and self-esteem. A path with milestones can be envisaged towards the goal. While never forgetting that the journey ought to be enjoyed as much as the destination.

Self employment:

Many professional and experienced persons, who find themselves unemployed, turn to self-employment or to becoming a consultant (ie. they start their own business) because of the limited or otherwise unattractive options of being an employee again.

In many places there are employment agency / government training incentives to teach business fundamentals like bookkeeping. Some may even offer low-rent 'starter premises' with communal office facilities. Chambers of Commerce and similar business or trade organisations also have initiatives for their new business members. They often have guest speakers who share business acumen &/or how to deal with specific issues. Importantly they are a network of contacts which may be customers or suppliers, or even a mentor for the new business.

What can an SCI do? Well in the first instance it is worth looking back at page 6 and 7 of this report to review the list of famous and celebrity tetraplegia. It is then worth considering how the Executive of ESCIF and many SCI National organisations are themselves SCI. And then perhaps the question would be What can an SCI person not do?

Nevertheless, here are just a few suggestions (community colleges offer classes in computer and many other subjects):

- Be a consultant in the field he/she previously worked in.
- run an internet business
- Web site creation, and/or graphic design.
- write an interesting or fun blog and 'earn from the number of hits'
- Artist / photographer / musician / author / journalist / philosopher / model maker or light engineering / make clothes perhaps to your own fashion / hand made craft produce / grow pot plants / keep chickens !

And if non of these work, why not reverse family rolls and let your partner go out to work and the SCI become a house husband / dad. Counsellors should however be aware of the vulnerability of the SCI to introspection / self esteem issues.

3.2 To improve the likelihood of maintaining employment

Over the longer term, it is very easy for any of us to become complacent in a job, to slide into a comfort zone (lazy-mode), or else to become disgruntled. If the SCI person has been fortunate enough to find him/herself re-employed with the same business as before injury - they will not appreciate how very difficult it might otherwise have been for them to find (any) work. They may not be aware even of (or sometimes forget when faced with day-to-day issues of life) the goodwill extended to him/her by that employer.

Furthermore, they will not be so closely attuned to how their own personality has, and will continue to change post-injury ..as a result of the frustrations related to their physical / cognitive limitations, secondary health issues, the loss of hopes and dreams, and of course struggling with the finances. These (often subdued) emotions are prevalent for many years after the initial recovery.

There'll be days when, like any other (able-body) employee, they will want to throw in the towel and tell the boss where to stuff his job. That would be a particularly rash move - the opportunities for SCI employment are more scarce than he/she might possibly imagine.

To avoid / lessen the chance of this happening:

- Systematic / ongoing long-term counselling intervention is needed with the SCI, his/her spouse or family, and his/her work supervisor ..to avoid an issue coming to a head. The employer is unlikely to fully appreciate what it is like for the SCI, and often an understanding intermediary can smooth the waters. To do this, they need to be in close contact.
- Perhaps a 'buddy scheme' or mentor, for the SCI to call when things are not going well.
- Ongoing / long-term vocational counselling (..long after the initial phase of helping an SCI adapt to working from a wheelchair). This might anticipate what else can be done to a) make life easier for the SCI, and b) to ensure the person increasingly becomes a more useful / productive member of staff. Often the two sides are not opposites but need massaging together.
- Possibly reassign. If the person / employer is genuinely unhappy with the work, or the SCI is unable to perform to the task's prerequisites then perhaps they can be assigned to another job within the same business. Mediating on behalf of the SCI, and then re-training and adaptation to a different environment and task may be called for.

Engaging work has many advantages for the person living with SCI as it offers social inclusion and connectedness, a sense of self-worth, and it helps enhance and sustain a person's mental capacity.¹⁶⁻¹⁸

Who provides the counselling, the mediating, and/or vocational training?

It is a valid question to ask, and the answer very much depends on the resources of any particular nation's or region's disabled care and post injury support services. It may be that those resources need extra manpower or expertise for vocational services (for all disabled persons), and so the SCI national organisation, collaborating with other disability groups, need to lobby for those services.

It may be that such post-injury professionals do not exist in the community's existing system. Again, is this something that lobbying the ministers of health, welfare, and employment might respond to. After all, if the SCI person is not working, then they are not paying taxes. Indeed,

they are drawing on welfare to completely support them and their family. As that is very costly. To employ counselling and vocational professionals is likely to be very much less expensive.

If still not, or until those resources come through, then the task falls on the already over-stretched SCI organisations themselves to help, on a regional level,. Coincidentally most SCI organisation have plenty of individuals looking for gainful employment! and many have 'been through it all before' and might make themselves available to support & mentor a fellow SCI. Perhaps a 'buddy' scheme can be organised, or with training those persons might become officials of the organisation or self-employed professionals.

Conclusions

*Contrary to convention, in this conclusion I'll not even try to summarise this study. Although lengthy the pages of **discussion** and **recommendations** are each only a précis. There are really just too many points to be made, and the subject too multifaceted for a single page of text. Instead I ask the reader to consider ..*

How important is having paid work? Most anyone reading this report might ask the same question of the breadwinner of the home. Often we/they might want to stay at home to enjoy extended leisure time, but the reality of paying for weekly groceries, monthly rent, and then utility & insurance bills ..as well as buying things we need or otherwise might like, including clothes, a vehicle, and perhaps even a holiday, reminds us that we must work and get paid. When a person struggles-by on benefits, they can rarely afford to go out or to buy nice things, or to do very much more than simply 'get by '.

Take away the opportunity for a person to work and not only do they/their family struggle financially, but the person is faced with too little physical activity and too much time to think ..to dwell on what they cannot do, cannot have, and their self-worth. Gainful employment, even when unpaid voluntary work is to most cognitively aware working age adults more than a means to improve quality of life ..for many it is essential. Without contributing, without being useful or needed - significant psychological issues arise, and then that person is (often) unable to help themselves. They are trapped.

With 200,000 unemployed SCI in Europe alone, and possibly a large number again in an unsatisfactory work position - there is unquestionably a lot to be done. The recommendation of this study makes numerous practical suggestions, many of which come down to understanding the issues from both the SCI and the employer's point of view, and then in proactive vocational counselling for the SCI. The potential employer needs to be aware of the benefits of helping a former employee and provided with ready information regarding what the SCI needs and also of any incentives.

Successfully employed SCI role models and exceptional achievers should be a focus of promoting disabled employment across all media. And an extensive & coordinated study is needed to provide a league table of all disabled employment. This would be a powerful tool to influence positive change

*Every SCI organisation, every person involved in SCI person's rehabilitation, every family member, and every responsible and humane employer, government official or civil servant need to **look again** ..and keep looking at what they are doing to motivate and enable employment of SCI and other disabled persons. We are all on the same journey, and we face the same obstacles - let's pull together.*

"most people with SCI can work and can be productive members of society - if there are appropriate work accommodations."'¹⁵

Mobility Aids and Assistive Devices

7. Mobility Aids and Assistive Devices

Working group

**Stefan Opresnik Jorlev (Denmark),
Carrie Moss (Ukraine), Gelu Onose
(Romania), Nuutti Hiltunen (Finland),
Higinio Serrano Pérez (Spain), Jani
Trdina (Slovenia)**

Introduction / Background

The 'International Perspectives on Spinal Cord Injury' report¹ published by the World Health Organisation (WHO) defines 'assistive technology' as 'any piece of equipment, or product, whether it is acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities.'

The report goes on to say that wheelchairs are one of the most widely used & most important types of assistive technology for people with SCI. And it cites research indicating that assistive technology increases independence and autonomy, increases mobility in and control of environments, increases potential for participation in community, social and civil life.

Furthermore, assistive technology helps promote learning and development in children with SCI, contributes to successful employment, helps ensure reintegration of people with SCI and improve their quality of life.

Accordingly, SCI persons without the benefit of such equipment risk developing functional limitations, with increased dependency on others, including increased physical burden for care givers and adverse economic consequences.

“Access to a broad range of assistive technology can enable people with SCI to perform everyday activities that they would otherwise be unable to perform.”

As generally acknowledged spinal cord injuries (SCI) with their marked disabling potential, are among of the most severe conditions within human pathology, for which there is yet no cure.

Pharmacological &/or biological methods which might significantly improve the overall poor results in repairing spinal cord lesions, thus lessening the consequence of disabilities, still seem far off. On the other hand, work with advanced technologies and devices, such as robotic and bionic assisted exoskeletons, are now beginning to show promise.

But, even though each of these approaches are advancing; through close contact with some 37 nations' SCI organisations (ESCIF) - we are well aware that many with SCI who desperately need assistive devices, do not have access even to the technology already available.

Barriers such as; inadequate national & regional human rights & equality laws, lack of bureaucratic understanding in their supply, and their unattainable cost, often hinder the appropriate provision of assistive technology, which is necessary to overcome environmental barriers and allow successful society integration of all SCI persons throughout Europe.

The object of this study was to identify the real situation in getting mobility aids and assistive devices for persons with SCI, and the differences between countries.

Project work

Stage 1. We sought to identify both the user needs and everyday obstacles among active people living with SCI, and so began the study with individual interviews in the six countries embodied by this study's working group; Denmark, Finland, Romania, Slovenia, Spain and the Ukraine.

An interview template was prepared (Appendix 1.) with open questions, in which an active SCI persons' entire day was mapped out. It further enquired how the person gets information regarding new assistive technology, mobility aids, financial aid and/or legal rights.

Stage 2. From the feedback of the initial interviews - the second phase of this study was extended to other European countries. With the kindly cooperation and support of ESCIF member organisations, we sent a questionnaire (Appendix 1.) out to 37 national SCI organisations. We received answers from seventeen of those.

The object of this study was to identify, for persons with SCI, the situation with getting mobility aids and assistive devices in different European countries. To facilitate this, the study focused on the usual process of obtaining a standard wheelchair, which for most poorly ambulatory persons with SCI is singularly the most needed / intensively used mobility aid.

It may reasonably be assumed that the findings from this singular example will in general practice carry across to the process of obtaining other of the more essential mobility aids & assistive devices.

The questionnaire asked the participants to describe the common process (in their country) of:

1. obtaining the first wheelchair after SCI. Who pays for it, and who is involved in the decision making / choice?
 2. obtaining a replacement wheelchair.
- And we enquired;
3. what is the time period involved?

Unfortunately, the limited scope of this study did not allow us to survey the extent of fully adapting the SCI person's home or (for example) a car, etc.

Findings and Discussion

Initial Interviews

From the initial interviews, we established the level of importance for individual assistive devices is almost the same in different countries, with a primary need for:

- independent mobility (the wheelchair) and accessibility to & around the home: to bed & clothes, the bathroom & toilet, for cooking and other kitchen tasks, for dining, and for relaxing.
- as well as mobility outside the home / across distances: to a place of work, to the shops, for medical appointments, &/or for social interaction. (either by car or via convenient and cost effective enabled public transport, etc.)
- Equally there was a need for social interface: communication & information access (via phone & computer technology)

Access to quality and appropriate mobility, aids and devices is very diverse in their availability and they being well-suited for purpose. Even across the EU, who might like to think they are leading the modern world, there are large differences.

Having appropriate mobility and assistive devices is most important to the SCI individual's self esteem and have a positive psycho-social impact.

But needs change during the life cycle of a SCI person, according to changes in vocation, health status, dwelling, etc.

2nd phase questionnaire - regarding the process, who pays for it, and time involved in getting a wheelchair, in different countries:

A copy of this questionnaire together with the completed answers is present in full as Appendix 1. This has been included because it details the specifics for each nation. Below is a brief summary.

"Our view is that a wheelchair is the most used and needed mobility aid among poorly ambulatory persons with SCI. We use the process of obtaining it as an example of the process of obtaining mobility aids and assistive devices in general."

What is the usual process of obtaining the first wheelchair after SCI. Who pays for it and who is involved in the choice / decision making?

In almost all countries persons with a new SCI get their first wheelchair in the hospital or rehabilitation centre. These institutes help with all procedures and propose the most appropriate wheelchair.

Only in Ukraine is neither the person with SCI nor an SCI specialist involved in this procedure.

There are differences among the countries regarding who pays:

Payment is sourced at the national level for; Czech Republic, Lithuania, Portugal, Romania, Scotland and Slovenia.

And at a regional / local level in; Belgium, Denmark, Finland, The Netherlands, Spain and Sweden.

Or else a combination of both national and local authorities in; Austria, Serbia, Slovakia and Ukraine.

What is the common process of obtaining a replacement wheelchair.

In most countries the procedure for obtaining a renewal wheelchair is basically the same as for the first wheelchair, but the person with SCI and the local community SCI professionals are more involved with the decision making.

What is the usual time period / anticipated lifespan of a wheelchair before renewal?

The answers were almost the same from each nation, ranging from 3 to 5 years. In some countries (Denmark, Finland, Scotland, and Sweden) a replacement can be obtained whenever the old one wears out, or when the person has needs that can only be solved with a new wheelchair or a new model.

Barr accidental damage or an exceptional harsh environment, we agree that with proper maintenance a wheelchair should last for at least 5 years. Naturally growth of the young, changes in physical needs &/or environment, are each unavoidable factors.

With the full price of the wheelchair being approximately € 3500 - cost is a determining factor in whether the SCI person has a new wheelchair. in assessing overall satisfaction in the process, we categorised our results according to country:

Good: The entire price is covered and the person with SCI is an equal partner to select the wheelchair that suits them.

☺ Austria, Denmark, Finland, The Netherlands, Scotland and Sweden

Satisfactory / adequate: Most of the cost for a standard active wheelchair is covered

☹ Belgium, Slovenia and Romania

Poor: Less than half the cost of a standard active wheelchair is covered.

☹ Czech Republic, Lithuania, Portugal, Serbia, Spain, Slovakia, Turkey and Ukraine

In the majority of countries, the cost of anything more sporting, lightweight, stylish, folding or otherwise convenient, wheelchair and/or their optional extras - have to be met by the individual. And in still-developing countries, there are a significant number of people who require mobility aids and assistive devices but who are not well supported by their national, regional, or local authorities. The study heard of many bureaucratic &/or economic barriers. It can be very difficult for any person relying on State benefits to do much more than survive.

Selection and Fit: From the questionnaire answers it is apparent that some SCI are assigned mobility aids by unqualified persons:

"The person who gives out the wheelchairs is not a physician or rehabilitation specialist. ...who provide a wheelchair they deem appropriate to the person with SCI. Again, the person with a SCI will not be present, so it is up to the family to figure out and make any needed adjustments to achieve a correct fit."

Clearly this is as inappropriate as fitted wrong size shoes to an able child's feet, or a wrong prescription of spectacles to any person, or even the wrong size of artificial limb to an amputee. Aside from the sheer discomfort and inconvenience of a wheelchair being wrongly sized &/or fitted - there are well-documented secondary health consequences of a poor posture, unsuitable support (either too much or too little) and of pressure points. Likewise of damage when a SCI's null feeling foot falls off its wheelchair rest while being pushed along, and again of clothing and finger's getting trapped in moving parts.

The efficient mobility of a wheelchair is difficult enough for any new user, but even for long-term wheelchair users there are twist, stresses & strains which ultimately painfully damage the user's shoulders, elbows and wrists. Only if a wheelchair is appropriate for its environment and use, and is correctly sized and fitted can this damage be minimised.

Advanced Technologies

Advanced technologies and devices, such as robotic and bionic assisted exoskeletons appear to be getting close to being feasible for effective use. There is still much work to do in this area but newer types such as Indego are particularly promising.

It is likely that this technology will (initially) only be available / useable for specific classification of SCI, rather than to all criteria (age, levels strength & fitness, etc) and extent of damage including tetraplegic. Furthermore, they do not help with cognitive damage.

Unfortunately, even when marketed, the cost of any 'new' technology will again be beyond the reach of most SCI persons &/or their medical services. It might be many decades before these sorts of solution becomes readily available for every SCI man, woman and child across wider Europe.

But for the SCI with lower spinal damage there is real and foreseeable promise. The good news is that new technology, from the world of prototype and low-volume production, has already made 3-dimensional laser printing an affordable reality. This can be used with advanced (lightweight but very strong) composites. Together they mean exoskeletons will become both lighter-weight and more cost effectively made for different physiques. And again, new technology, this time in the field of power storage / ever-lighter & more powerful battery packs, will advance the development of robotic exoskeletons. And this is great news for the situation of the more severely disabled.

There are very important benefits to the use of exoskeletons, aside from the upright posture and the ease of many (home and work) tasks that might permit, and those include face to face social integration, physical and motor control exercise, and lessening of the consequences of being sedentary.

The global market for assistive devices and advanced technology for the disabled (not only SCI) is huge, particularly as some / many of these might be 'convenient' for non-disabled consumers (a somewhat ironic example of this is electric powered golf carts for 'sportsmen'). Most likely very soon other devices will be recognised as mass-marketable by industry, who will then want to capitalise on their ideas. As with any other potentially big-dollar earning consumer product, those products will be aggressively marketed, and in the intermediate term their technology & the manufacturing processes will develop ..and prices will drop. Great!

Contrary to the health benefits of exoskeletons mentioned above, there can be **a downside to affordable advanced technology**. It can be seen afflicting the wealthier able-bodied population like a virus, and that is the lack of fitness, with deteriorating health / chronic conditions, directly related to a lack of exercise. Certainly, this doesn't apply to all mobility and assistive devices but it does to electric wheelchairs. Many SCI individuals really need these, but there is the likelihood that as prices drop and these machines become lighter and every more compact - then SCI in manual wheelchairs will be tempted to opt for 'a little easier' life.

For an SCI facing secondary health issues (now or in foreseeable years) the almost inevitable reduction in everyday physical activity will accelerate & amplify those complications. Weight gain is difficult enough for the SCI (or their care giver) when he/she moves from the wheelchair in a bathroom, or to other furniture, or to a vehicle, but a lack of fitness and increased weight / strain on joints is going to become an increasing issue within the SCI & wheelchair bound community.

Recommendations

National SCI organisations should lobby for a more enabling and understanding system of special needs equipment provision. Here are some objectives:

- a competent SCI rehabilitation specialist, with the authority of the SCI's qualified physician (who signs & stamps the prescription), should determine which wheelchair / assistive device is most suitable for the individual SCI.
- Aside from the particular needs the SCI person, the specification of that wheelchair should take into account the activity of the SCI. And although it sounds obvious; the wheelchair and assistive devices should enable the user rather than be an unnecessary burden of being the wrong size, too heavy &/or cumbersome for their lifestyle.
The environment should be a factor in the specification. *For example* an SCI living in a poorer community might prefer a more robust all-terrain type wheelchair.

- In light of the extreme financial difficulty facing anyone living on benefits, and the lack of well paid employment opportunities - the cost of such essential equipment should be provided in full from public / National Insurance funds.
Those agencies may subsequently seek reimbursement from insurance companies (such as car accident insurance) where appropriate, but the SCI patient should be relieved of the delays, the stress re. cost, and the bureaucracy, particularly at a time when they are unable to cope.
- The fitting of mobility aids and assistive devices should be done under the expert guidance of a SCI professional.
- Both the consumer and his/her care givers (whether family, close friends, or paid help) should receive basic training in avoiding health damage due to accidental impact or entanglement.
- Options such as high-quality cushions to help prevent pressure sores should be standard.
- Subject to reasonable care by its user, a wheelchair should be replaced or repaired 'as required', and not after a specific period of time.
Again, this cost should automatically be met from National Insurance funds, because regional & community funding is all too often subject to the wealth of a local region, and yet the harshness of a poorer region's environment would often have detrimental consequences on the lifespan of mobility equipment.
For example, the wheelchair of a person working in an office environment, who lives in an urban community / enabled environment will have less wear than a wheelchair being used by a person living on a remote farm, where the ground is uneven and the distances may be greater.
- In Sweden it is deemed reasonable for an individual to have two wheelchairs:
" Everyone is entitled to a single wheelchair, but you can get others if you can justify the need. Many have two wheelchairs - for outdoor and indoor use."
This may be too much for other less understanding societies to stomach, but perhaps two sets of wheels ought to be freely available; one set for outdoor & another for around the home or office.

Regarding the probability of users substituting their manual wheelchair for an electric one, each consumer organisations need to immediately initiate an awareness campaign of the risks and the benefits of exercise to chronic health issues.

Conclusions

Although this study was limited to wheelchairs, it recognises that there are many other devices / aids which make life with SCI easier (both for he/she and for the care giver). Proper aids improve quality of life, which is reflected in the competency, adaptability and self-esteem of persons with SCI. And so there are also direct results in education, employment, family life and health.

Consequently other costs such as health care, daily care, and pensions will be lower. However it is apparent that not all European SCI's are the recipient of suitable equipment and aids, and that even when wheelchairs (in this example) are given, they may not be appropriated by SCI professionals, nor are they suitably fitted and correctly adjusted.

Furthermore for the SCI and his/her family having to rebuild their life & live on benefits the bureaucracy involved & cost of obtaining a suitable wheelchair (and so we may presume also - other assistive devices) is crippling. Likewise the process and cost of a replacement wheelchair, or their parts like lesser pressure sore cushions and wheels (which might be easily damaged). Few countries offer a second chair for indoor / outdoor use, even though the criteria for each is so very different.

Recent advances in technology, in particular with exoskeletons, are showing great promise and in particular for the stronger, less damaged SCI seem to be nearing a practical reality. Advances in low volume production techniques and light-weight composites and where applicable small but powerful battery packs have and will continue to accelerate this development. Furthermore, the benefit of upstanding posture and exercise bode well in improved long-term health of their users.

However, the designs are still new and there is still development to be done, and then training of the user. Unfortunately, the cost of any new technology is usually prohibitive to persons of low income and to medical establishments pushed to work within ever tightening budgets. In time this technology will become more cost effective and even more flexible in the extremes of SCI damage it can bypass. In the meantime, the world of medicine and surgery are constantly trying to find the means of successful biological repair.

As electric powered mobility aids become more affordable, and also more compact, there is an increased probability of SCI users of manual wheelchairs switching to their convenience. SCI consumer organisations, particularly in economically more developed nations, are urged to initiate an awareness campaign as to the long-term risks in the inevitable lack of exercise & weight gain.

General Conclusions

8. General Conclusions

A few issues reoccur in all the working groups' reports regardless the focus area. It is therefore essential that the national SCI consumer advocacy organisations address these issues in order to contribute to social inclusion for people living with SCI in their countries.

These issues are:

- **Accessibility**
- **Discrimination of people with disability incl. attitudes and awareness from the public**
- **Information about SCI, legislation, support from society...**
- **Psychological support to the individual and their family**
- **Access to assistive devices**

How these issues can best be addressed depends vastly on the culture, legal system and infrastructure of the country. It is very clear though that one of the actions is to raise awareness regarding these issues in the society.

Conclusions from Quality of Life

- Need for information and experiences from peers for some kind of guidance that could focus on individual psychological resources and individual goals to experience more life satisfaction.
- Offer a service for people living with SCI to help them set and pursue their own goals. Such service should take place after post-acute medical care and rehabilitation.
- “Life-coaching” may be a good example of service mentioned above. These coaches are using specific means and style of communication that follow the GROW model.

Conclusions from Social and leisure activities

- Information about possibilities and alternative ways to be active needs to be available.
- Arrange excursions and activities on different difficulty levels to ease to process of expanding ones' boundaries.
- Promote volunteering as a tool to try out different activities.

Conclusions from Education and paid work

- Vocational reintegration should start before discharge from the rehabilitation centre.
- Counselling and effective interventions are essential to link the patient, the employer, the rehabilitation team and other professionals involved in the reintegration process.
- There are both external and endogenous factor (barriers & facilitators) that affect the possibility to work and therefore needs to be addressed.
- The person living with SCI need to take on a journey from patient to consumer and finally to producer in their vocational reintegration process.

Other aspects of this project, such as 'Social & Leisure Activities' present a wealth of ideas & activities to help motivate the SCI into social integration ..but many of these would be very limited on such a tiny budget and when physically impaired. And how many of us can focus on any leisure pursuit for a whole year ..let alone a lifetime - particularly if you are not blessed with the talents of an artist, craftsman, musician, philosopher or author? Where is the job satisfaction, where is the achievement, and so - where comes from a sense of self respect or worth?

Conclusions from Mobility aids and assistive devices

- Wheelchairs are one of the most widely used and most important types of assistive technology for people with SCI.
- The level of importance for individual assistive devices is almost the same in different countries (wheelchair, access to home, computer technology, car...).
- Mobility aids and assistive device needs change during the life cycle of a person with SCI (education, employment, change of health status...).
- Appropriate mobility aids and assistive devices maximize individual self-esteem and have a positive psychosocial impact.

Mobility Aids & Assistive Devices

1.1 Questionnaire 2

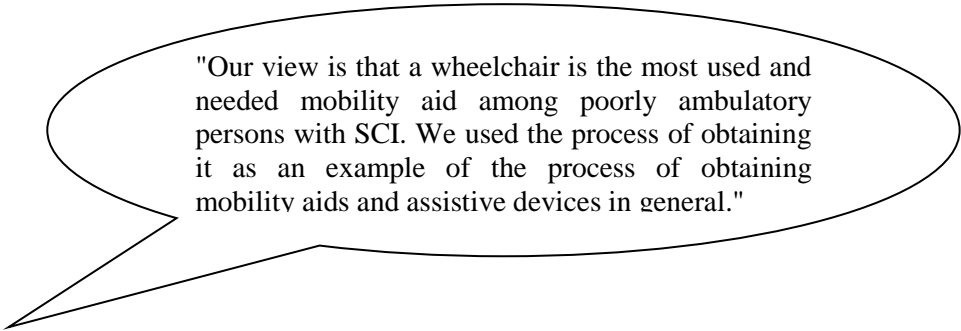
1.2 Questionnaire 1

1.3 Additional reading


1.1 Questionnaire 2



How do you get a new wheelchair in your country?



For context - we collected answers based on this question:







Question 1: Please describe the common process of obtaining a wheelchair in your country. Please include the professionals involved, steps required, timeline, and if it is a manual or electric wheelchair.

Country	First wheelchair	Renewal wheelchair
 Austria	The usual way: Doctor's prescription - medical supply store (Bandagist) - Adjustment - cost estimate - order - transfer 2 – 3 months	Same

 <p>Belgium</p>	<p>A medical doctor fills in a medical prescription form for the kind of wheelchair the patient needs, along with a diagnosis of the current medical situation and a prognosis concerning the mobility (presently and in the future).</p> <p>All kinds of activities are evaluated: ability to move around in the house, outside the house, ability to get up, use of hand and arm in the wheelchair, ability to do transfers, seating function in the wheelchair, cognitive functions.</p> <p>This form is then sent to the person's health insurance for approval. When their answer is positive, the patient can order his wheelchair by an acknowledged provider. Once the wheelchair is delivered, he/she sends the invoice to his/her health insurance company. Or he/she can agree that the acknowledged provider sends the invoice directly to his health insurance company (the so-called third party arrangement). In both cases, the eventual supplement is to be paid directly to the provider.</p>	<p>Almost the same as for the first demand.</p> <p>One difference: the patient has not to wait for the approval of his health insurance company since he/she already has a dossier.</p>
 <p>Czech Republic</p>	<p>Person with SCI usually choose his/her first wheelchair during the first stay in rehabilitation center. Team of professionals – occupational therapist (OT), physiotherapist (PT), and doctor of neurology/rehabilitation/orthopaedics helps to choose right wheelchair. The user can try it in rehabilitation center.</p> <p>With electric wheelchairs; the user has to obtain medical report of visual and psychological examination (to drive an electric wheelchair). Medical prescription of wheelchair has to be authorized by an inspection doctor of health insurance company.</p> <p>After his/her agreement is prescription send to manufacturer/dealer company of wheelchairs. After client guarantees covering the whole cost, the firm will arrange producing the wheelchair. Timeline from prescription to obtaining wheelchair is usually two months.</p>	<p>If you need renewal wheelchair you have to get a prescription from your doctor of neurology / rehabilitation / orthopedics in region where you live. If person with SCI wants to personally choose a wheelchair or other aids, he/she can contact professional consultants, usually in non-government organisations for SCI users (Czech Paraplegics Association – CZEPA; ParaCENTRUM Fenix).</p> <p>From prescription to obtaining wheelchair is no different from first wheelchair.</p>

 <p>Denmark</p>	<p>First wheelchair will be arranged by the clinic together with your local community. You will get the wheelchair within 3 - 4 months after accident / occasion. Until then you will use a wheelchair from the clinic.</p>	<p>Depend on which local community you live in this can take up to a year to get a wheelchair renewed. It also depends on which kind of wheelchair / brand etc...</p> <p>Normally both your SCI clinic and the local community is involved in this process and even sometime your SCI organisation.</p>
 <p>Finland</p>	<p>In Finland, assistive equipment is usually arranged by healthcare and insurance companies. Within healthcare, the services and the responsibility of distributing assistive equipment are divided between the basic healthcare and specialized healthcare so that the specialist healthcare is in charge of the more technical, electric assistive devices</p> <p>The need assessment for a first wheelchair and the selection of its model are usually done in the specialized healthcare unit in charge of the acute treatment of a person with a spinal cord injury. The customer must have a written statement for the need for the assistive equipment, written by the treating doctor.</p> <p>In practice, the unit's physiotherapist is usually in charge of selecting the wheelchair. This support is more intense for the recently injured people. Even though the specialized healthcare services select the manual wheelchair, it is paid by the basic healthcare and the customer's home municipality.</p> <p>The insurance companies pay for the assistive equipment of their customers after similar preliminary work.</p>	<p>The initiative for updating the wheelchair and for selecting a new model can come through the specialised healthcare unit in charge of the rehabilitation and follow up care of a customer with a spinal cord injury, but also the basic healthcare services can make the initiative.</p> <p>If the customer is an experienced user, the basic healthcare services trust the customer's own views, but as the payer they naturally have the last word in the matter. In some of the municipalities, manual wheelchairs have already gone through a competitive bidding process.</p> <p>If the customer wishes to have a wheelchair that is not included in the tendered model selection, the reason for this must be argued for carefully.</p> <p>In practice, it is possible to get a new wheelchair whenever there is a sound reason for choosing a new wheelchair.</p>

 <p>Lithuania</p>	<p>During rehabilitation (usually ~2-3 months after SCI) PMR doctor writes prescription, then local wheelchair seller comes to the rehab hospital to take measurements and to propose particular model. Usually wheelchair arrives in 2-3 weeks.</p>	<p>Every 5 years the disabled can get new wheelchair. First, they need prescription from PMR doctor. With this, they go to the 'Center of Technical Aid for Disabled People under Ministry of Social Security and Labour' to get letter of indemnity. With this they go to the seller and order a wheelchair.</p>
 <p>The Netherlands</p>	<p>When a SCI is still in a primary rehabilitation center, the rehab doctor must officially prescribe the patient needs a wheelchair. Then an occupational therapist (OT) and sometimes also a physiotherapist (PT) get involved. The patient and his OT try different wheelchairs, find the right cushion, etc. etc. to choose the right wheelchair for her/him.</p> <p>Sometimes the solution is a 'standard' wheelchair, but sometimes he/she needs a custom-made wheelchair. The rehab doctor and the patient together then send a request to the municipality where the patient lives to ask for permission for this wheelchair – because by Dutch WMO law the municipality pays for the wheelchair.</p> <p>When the municipality gives the permission, the wheelchair can be bought. But some of the bigger municipalities have their own WMO staff / 'experts' regarding (for example) wheelchairs and ask (a lot of) questions before the permission is granted. Sometimes the permission is not given or they say "this (cheaper) wheelchair is also a good solution". Then negotiation (by the OT, rehab doctor, &/or patient) with the municipality starts. In the end a solution is found, possibly not entirely to the liking of those involved.</p> <p>This procedure is more or less the same regarding a manual or an electric wheelchair.</p> <p>This process starts in the rehab center as soon as one knows, more or less, what kind of wheelchair might be required. Sometimes the procedure with the municipality takes weeks, sometimes months. Sometimes you have to appeal, sometimes even with the help of a lawyer.</p>	<p>This depends on your relationship with the WMO staff of the municipality where you live. If your SCI situation is the same for many years and you need, more or less, the same kind of wheelchair again - you get in contact with the preferred supplier of the municipality, and with their company expert you make the request for a new wheelchair. If the municipality approves the request, the wheelchair is provided. This is the easy way.</p> <p>Otherwise you have to go back to your rehab doctor and follow the procedure as described in obtaining a first wheelchair.</p>

 <p>Portugal</p>	<p>In Portugal, wheelchairs (manual or electric) are considered supporting products (produtos de apoio). There are products, appliances, equipment or technical systems of specialised production to; prevent, compensate, mitigate, or neutralize limitations in activity, or participation restrictions of persons with disabilities.</p> <p>They can be financed by the Social Security Institute, Institute of Employment and Training, Central Administration of Health Systems and the General Directorate of Education.</p> <p>Each year, state funds are available to financing to support assistive devices. The most common procedure for the allocation of assistive devices is through the social security system.</p> <p>Application is required for the person with disability:</p> <ul style="list-style-type: none"> a) Have a prescription from wheelchair prescribed by a physiotherapist. b) Provide the certificate of incapacity. c) Provide proof of no debts to finances and social security.?? I think this means that there is no arrear of taxes or National Insurance?? d) three different suppliers' quotes. <p>Unfortunately, the process can be long.</p> <p>If persons with disabilities opted to present applications for other assistive entities, the process is the same.</p>	<p>Identical to the allocation of the first wheelchair process.</p>
 <p>Romania</p>	<p>During the early post-acute stage after the traumatic event or surgery for SCI, the patient is admitted in the neuro-rehabilitation department, where the doctor who treats the patient recommends the wheelchair. This made on a standardized form, from the Romanian National Health Insurance House (NHIH). Wheelchairs are available from different companies appointed by the Ministry of Health. It is freely given by the NHIH</p>	<p>According to national regulations, applicable throughout Romania, renewal of a wheelchair for an adult person once in 5 years.</p>



Scotland

Your first wheelchair, manual or powered will be measured up for you while in the Spinal Injuries Unit. The level of injury, ability, and personal preference, will determine whether you get a rigid or folding manual chair.

Senior physiotherapists in the Injuries Unit will assess your abilities and whether you will be an active user or not. It is also dependent on whether the injury is a complete or incomplete. You are likely to be two thirds of your way through the injuries unit before being assessed & measured for a chair. The timescale for delivery will be approximately 8-weeks for a manual chair.

Presently, the majority of manual wheelchairs being issued as a first chair will be a Quickie Life R (rigid) or a Quickie Life F (folding).

We have a number of centers around Scotland that will supply the wheelchair, if one is not provided in the time you are in the spinal unit. The spinal unit do their best to have your chair ordered and delivered while you are in the unit but this is not always the case and if this is so, you will be loaned a chair until such times as your own chair is ready for collection. This is rare but it does happen.

If you require a powered chair, the same process applies although the timescale for delivery could be longer depending on needs, such as postural requirements. The assessment will decide whether you are likely to get an indoor or an outdoor chair, depending on needs and ability of the individual.

The disrepair state of your wheelchair will depend on when you get a replacement. If / when you require a new chair, you contact the local center, who will have an



assessor carry out a needs assessment and discuss the options available.

The different centers around Scotland are funded by the government, but some may be limited in what chairs / device are available.

An active wheelchair user will have to demonstrate certain wheelchair skills. Whether you drive can have a bearing on the decision as well.

An active user will have a wider choice of chairs, such as a Quickie Argon or Helium, and if you require a folding chair you could possibly get a Quickie Xenon. Some centers also offer Kuschall wheelchairs but I am unsure which models.

The same applies for powered chairs, but I don't know what choices are available, if any.

 <p>Serbia</p>	<p>The Doctor prescribes and fills a form document for wheelchair,</p> <p>This is passed on the medical commission, which assesses whether the patient is expected to change in health status.</p> <p>Within 90 days of being prescribed, the SCI should receive the wheelchair from the supplier (orthopedic companies).</p>	<p>Identical to the allocation of the first wheelchair process.</p> <p>For an SCI; re-evaluation by the medical commission is not required.</p>
 <p>Slovakia</p>	<p>First wheelchair is from the Health Insurance company, prescribed by Neurologist and Rehabilitation doctor</p> <p>Second wheelchair you can get from Central office of Labour, Social affairs and Family.</p>	<p>The wheelchair renewal period is 5 years in case of first wheelchair.</p> <p>Second wheelchair from Central office of Labour, Social affairs and Family may be acquired after 7 years.</p>





Slovenia

Our rehabilitation center (The University Rehabilitation Institute, Republic of Slovenia) helps the individual get a wheelchair. It is paid for by National Insurance.

The process of obtaining equipment is:

- Visit your personal doctor, who refers you to a specialist doctor at the University Rehabilitation Institute (URI).
- The specialist at URI (terciar) determines what kind technical device is most suitable. The doctor has the medical records of the insured person, with medical background, eligibility and history, type and code of injury, and the prescribed technical device.
- You test devices at the URI and select the manufacturer and type.
- The doctor from URI prescribes the right wheelchair
- You to go to a supplier (dealer), who issues a pro forma invoice. This is sent with the URI documents to the National Insurance (NI)
- NI will approve (or not) if they will pay for the device. On the basis of the estimate and the documents sent in, they will approve a sum to be paid, with respect to the functionality of the wheelchair for the user. The sum granted is very different from the actual total value of the wheel-chair.
- When approved, the dealer orders the device, and you wait for approx. 8-weeks to get it.

 <p>Spain</p>	<p>There are two main methods to obtain a wheelchair:</p> <p>1. Public Healthcare System: The first wheelchair (manual or electric) will be provided by the Servicio Madrileño de Salud (SERMAS) [since each autonomous region of Spain has its own Healthcare System]. It is obtained by prescription of the doctor according to a standardized scale of criteria in which the size, features, and structure will be decided by them from a closed catalogue.</p> <p>There is an orthopaedics catalogue for each autonomous region with the minimum requirements and services, as well as renovation periods.</p> <p>2. Private: There is the option of buying a wheelchair by yourself without subsidy of the Government, but it will not be insured by them, and only be covered by its guarantee.</p>	<p>1. Public HC System: There are set periods to opt for renewal. The wheelchair will be insured and can be renewed upon prescription. It must be prescribed by an specialist Physician, Neurologist or Traumatologist. The doctor issues a prescription for the SERMAS.</p> <p>The patient can opt to advance the money for the prescribed wheelchair and get it from the shop straightaway, or the SERMAS will reimburse the money afterwards (in 12 - 18 months).</p> <p>The patient can also apply for endorsement, therefore the SERMAS will pay for the wheelchair direct (18 - 24 months). Occasionally, an inspection will take place to confirm the repair or substitution.</p> <p>2. Private: No limitations.</p>
 <p>Sweden</p>	<p>A spinal injury obtains the first wheelchair when he or she is in rehabilitation after the injury. The wheelchair is tested while there.</p> <p>In some cases, you do not just keep the wheelchair, but you get a similar wheelchair from the regional hospital a person belongs to.</p> <p>Wheelchairs in Sweden are free.</p> <p>You do not own your own wheelchair in Sweden, but you get the prescribed as an aid, but it still belongs to the healthcare.</p>	<p>You get a new chair when the old one is worn out or if you have a new need, for example, because of changes in disability, age, or any other cause.</p> <p>Everyone is entitled to a single wheelchair, but you can get others if you can justify the need. Many have two wheelchairs - for outdoor and indoor use.</p> <p>Accessibility equipment in Sweden is not the same across the country, each region is responsible for their own prescription and range. An occupational therapist / patient may select from a different region. This is how it is in the region I live (Dalarna). There are no major procedural differences between the regions in the country, but there are some.</p> <p>Regarding wearing parts of the wheelchair; they will be changed at the hospital as required, ie. when it is broken or worn out. The tires, tubes, and treads to the front wheels, are paid by yourself.</p>



Turkey

The disability person has benefits of social rights, medical supply, disability identity card, education, employment, etc. They will have a full health report from a state hospital if they apply. This health report includes a diagnosis of the injury and the degree of disability.


The doctors apply for a wheelchair from a medical firm, after approval from the health commission. Sağlık Uygulama Tebliği (Health Practice Notification), who determine the price and special details of the wheelchair (active wheelchair, special electric wheelchair, bath toilet chair, standard electric wheelchair).

The person first pays the total price of the wheelchair and needs to claim it back from the state. You pay that difference if there is a difference between the budget of the state and the wheelchair bought.


Electric wheelchairs are allocated to persons only if they satisfy certain conditions. For example a person who can use his hands cannot get a prescribed electric wheelchair.




You have to know your rights, as this process is only for those who apply for it. This process takes 15 days.





If you want a wheelchair renewal you have to do the process all over again.





 <p>Ukraine</p>	<p>Obtain physician's documentation which states the disability category of the person with a spinal cord injury.</p> <p>Undergo examination by a city medical board which will classify the disability as working or non-working.</p> <p>Take this documentation, along with a completed application form for a wheelchair to the Department of Labour and Social Security office. The person with a disability does not have to be present for this as no one will further examine or measure them.</p> <p>If the person with a disability has educated himself/herself, he/she can fill in some details about the wheelchair size and type on the application, but it is not guaranteed he/she will receive it. The person who gives out the wheelchairs is not a physician or rehabilitation specialist.</p> <p>Within 45 days, the Social Services department will provide a wheelchair they deem appropriate to the person with a spinal cord injury. Again, the person with a SCI will not be present, so it is up to the family to figure out and make any needed adjustments to achieve a correct fit.</p>	<p>The paperwork required is slightly different but the process is the same as for the first wheelchair.</p>
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Question 2: Who pays for it?



Country	National, Regional or Combined?	Time period to renewal?	How much do they cover?	Is there a manufacturer of wheelchairs in your country?
 <p>Austria</p>	<p>National - Social insurance Pension insurance General Accident Insurance</p> <p>Regional - Health Insurance</p>	<p>5 years</p>	<p>Whole</p>	<p>-</p>

 <p>Belgium</p>	<p>Regional - Health insurance company</p>	<p>4 years. For people older than 65 years: 6 years.</p>	<p>Whole or partial: depends on the type of wheelchair chosen.</p> <p>The maximum coverage is € 2.511,42 for a manual wheelchair, € 6.333,24 for an electronic wheelchair.</p> <p>A person buying a cheaper model, is refunded only what he actually paid for it.</p> <p>Important: the wheelchair has to be approved by a commission and must figure in the list of approved wheelchairs. If not, no refunding.</p>	<p>Vermeiren NV</p>
 <p>Czech Republic</p>	<p>National - Health Insurance Company pays the wheelchair. However, part of the price has to be paid by the SCI with his/her own money, sponsors or foundations.</p>	<p>5 years for mechanic wheelchair 7 years for electric wheelchair</p>	<p>Partial - There is difference between prices of wheelchair from the manufacturer or dealers. A manual wheelchair for an active SCI user in Czech Republic costs about 3.000 Euro. National health insurance company pays from 1/3 (in case of dealer) to 1/2 of the price (in case of manufacturer).</p>	<p>KURY MOVE Technologies</p>
 <p>Denmark</p>	<p>Regional -</p>	<p>Depend on which local community you live in. It can take up to a year to get a replacement wheelchair. It also depends on which kind of wheelchair / brand, etc.</p>	<p>Whole</p>	<p>Wolturnus</p>

 Finland	<p>Regional - The municipality will pay for all the costs incurred by the purchase and use of the wheelchair, including maintenance costs.</p>	<p>There are no nationally agreed time limits for the matter. The standards regulating the assistive equipment service - highlighting need-based, case-by-case consideration in all decisions. It is justifiable for a full-time wheelchair user to have at least two chairs. Often the previous, older wheelchair is kept to be used as a back-up.</p>	<p>Whole</p>	<p>Talart</p>
 Lithuania	<p>National</p>	<p>5 years</p>	<p>Partial. up to 1216 EUR</p>	<p>Punktukas</p>
 The Netherlands	<p>Local - the municipality where you live</p>	<p>Most municipalities allowed you to have a new wheelchair after 6 years if the wheelchair is worn.</p>	<p>Normally they cover the whole wheelchair, but sometimes the municipality claims 'this solution is adequate'. They then pay for 'their solution' and you pay the difference to buy a wheelchair you want.</p>	<p>O⁴ Wheelchairs There are also a few small workshops building custom-made chairs, especially sports types.</p>
 Portugal	<p>National - Social Security Institute, Institute of Employment and Training, Central Administration of Health Systems and the General Directorate of Education</p>	<p>5 years</p>	<p>Partial. It depends on the economic situation of people with disability.</p>	<p>Invacare</p>

 Romania	National - NHIH	5 years	Whole for standard Partial for electric &/or a wheelchair with specific extra facilities	-
 Scotland	National Health Service which is government funded	Dependent on the condition of your current wheelchair. I think after approx 5-years you can apply for a new chair, but this is dependent on the chair you are currently using. The Quickie Life chairs are supplied new to those in the spinal unit - so they should last for at least 4 or 5 years. But they may not carry spares to repair the older styles of wheelchair. They will suggest you get a new chair, as it is uneconomical to repair the old one.	Whole	Draft Wheel-chairs. RGK Wheel-chairs. Davinci Mobility. Vross Wheel-chairs Ltd Chunc Wheel-chairs (Kids) Carbonblack
 Serbia	Combined	It depends. I can get a new classic wheelchair every five year. However, you can also get an active-easy wheelchair every seven year.	Partial. I paid one half of the price, and my regional Center for Social Work paid the rest.	-
 Slovakia	National - Health insurance company Regional - Central Office of Labour, Social affairs and Family	The renewal wheelchair period is 5 years in case of first wheelchair. Second wheelchair from Central office of Labour, Social affairs and Family may be acquired after 7 years.	Health insurance company: mechanical 1632 €, electrical 1632 € Central Office of Labour, Social affairs and Family: mechanical 1 660 €, electrical 4 979 €	-

 Slovenia	<p>National - ZZZS – Health Insurance Institute of Slovenia</p>	<p>3 years, if you are employed 5 years, if you are retired</p>	<p>Partial. 950 € (usually) or 1800 € in case some other medicine problems (for paraplegics).</p>	<p>-</p>
 Spain	<p>Regional - Sermas</p>	<p>18 months for manual wheelchairs, 36 months for electric wheelchairs.</p> <p>The period of renewal for the batteries of electric wheelchairs is of 12 months, but SERMAS will pay 214 euros.</p>	<p>Partial in the Public Healthcare System: Manual 330 euros. Electric 3.500 euros.</p> <p>Private. 100% by the patient. There are private initiatives from companies to help their workers in this aspect, but this is not widely extended yet.</p>	<p>DROMOS</p>
 Sweden	<p>Regional -</p>	<p>In Sweden, you get a new wheelchair when the old one is worn out, or when the person has needs that can only be solved with a new wheelchair or a new model.</p> <p>Hospitals have a facilities shop that handles repairs on the wheelchair. They can also tell whether the wheelchair is worn out and must be replaced.</p>	<p>Whole</p>	<p>Panthera ETAC TiArrow Permobil</p>

 Turkey	National - SGK (Social Security Insurance)	5 years	Partial. manual wheelchair 1200 TL, Persons who are working -20% of that price. ie., if he works 960 TL Persons who are retired -10% of that price	Yes
 Ukraine	Regional: Government	4 years	<p>If the person is willing to take whatever standard wheelchair they are given - the cost is fully covered.</p> <p>Often this wheelchair does not meet the actually needs of the person with a disability, but first-time wheelchair users are unaware and typically have to take what they are given.</p> <p>If someone knows of another wheelchair they want, that costs more than the standard wheelchair determined for them, then Social Services say they will help obtain it and the person with a disability must cover the cost difference. But the process is difficult and so most people simply find and pay for a wheelchair on their own.</p>	ICKPA (or ISKRA in English)

1.2 Questionnaire 1: Need for Mobility aid and Assistive Devices

This interview is part of the project 'Successful integration of people living with spinal cord injury' which includes the topic 'Mobility aids & assistive devices'. Your participation in this study is voluntary and your answers will form part of the project and will not identify you as an individual.

Please answer these background questions, and then complete the main section. If you have a query while answering the survey - please ask. Thank you very much for your time!



ESCIF c/o Swiss Paraplegic
Association
Kantonsstrasse 40
CH-6207 Nottwil
Tel +41 (0)41 939 54 03
Fax +41 (0)41 939 54 39
Mail secretary@escif.org
www.escif.org

Background:

What is your gender?

- ☐ Male
- ☐ Female

What is your age?

years old

What was your age at time of spinal cord injury?

years old

How would you describe your current spinal cord injury condition?

- ☐ Partial Paraplegic – Partial loss of muscle strength or paralysis to the lower half of the body
- ☐ Full Paraplegic – Complete loss of muscle strength or paralysis to the lower half of the body
- ☐ Partial Tetraplegic – Partial loss of muscle strength or paralysis to all extremities
- ☐ Full Tetraplegic – Complete loss of muscle strength or paralysis to all extremities

Which best describes the place in which you currently reside?

- ☐ My own home or apartment
- ☐ Someone else's home or apartment
- ☐ Nursing home
- ☐ Hospital
- ☐ Other Institution
- ☐ Other

Country: _____

Employment status

- Employed: ☐ Full-time ☐ Part-time ☐ Other:
☐ Seeking Employment
☐ Not employed: _____

Are you familiar with legal rights and procedures to get your mobility aids or assistive technology equipment?

- ☐ Yes ☐ No

Where do you get the information regarding new:

Assistive technology :

Mobility aids :

Legal rights :

Please describe your usual day and special equipment needs during a weekday. The day is of usual tasks, from the morning to the evening.

Approx. (from - to)	Tasks - Usually	Special equipment (mobility aids &/or assistive technology that you are using)	Special equipment (mobility aids &/or assistive technology that would improve your life)

1. Waking up to leaving the house (please describe if you need help or not. Describe also if there is something special, not regular task.

- 1.1. Getting up
- 1.2. Going to the toilet/bathroom
- 1.3. To put on clothes
- 1.4. Breakfast (alone, with family, friends...)
- 1.5. Preparing for daily tasks (catheters, mobility aids, computer any other assistive technology)
- 1.6. Leaving the house
- 1.7. Any other task(s)?

2. To routine destination (please describe if you need help or not; if you are staying at home, please describe the day on the next page)

- 2.1. During the transport
- 2.2. Usual destination (office, sport hall, studio...)
- 2.3. Getting to the destination
- 2.4. Working process
- 2.5. Does your working task include travelling?
- 2.6. Going to lunch (lunch in the building, going out, cooking yourself...)
- 2.7. Any other task(s)? (Coffee...)

3. Afternoon work or hobby activities (please describe if you need help or not)

- 3.1. Transport to another destination (where) and getting there, or staying at the same destination as a.m.
- 3.2. What kind of activities do you usually do (sport, art, hobby, family...)
- 3.3. Working process (if you stay at the same destination as a.m., when is the end of the working day?)
- 3.4. Any other task(s)?

4. Afternoon work or hobby activities (please describe if you need help or not)

- 4.1. Transport to another destination (where) and getting there
- 4.2. What kind of activities do you usually do (sport, art, hobby, family, friends, restaurant, culture...)
- 4.3. Transport to home
- 4.4. Any other task(s)?

5. Getting home – going to bed (please describe if you need help or not)

- 5.1. Getting home
- 5.2. What kind of activities do you usually do at home
- 5.3. Dinner
- 5.4. Evening activities (TV, reading book, computer, kids, partner...)
- 5.5. Going to the toilet/bathroom
- 5.6. Going to bed (also reading, watching TV...)
- 5.7. Any other task(s)?

Please describe unusual day (Sunday, holiday...)

1.3 Additional reading

The Past, Present and the Future

The PAST

'Mobility aids and assistive devices' is relatively new phrase. Regardless, the history of the wheelchair (the most common mobility aid) Some scholars suspect begins in China sometime between the 6th and 4th centuries BC. The first record dates back to the 2nd century BC as a wheeled seat being used for transporting the person with a disability.

Wheeled chairs entered Europe in the 12th century. Another important milestone was in the 20th century, when Herbert A. Everest, an engineer with SCI, invented a folding cross-frame wheelchair from tubular steel. With this type of wheelchair, persons with disabilities could leave their homes. This wheelchair became standard design in 1933. Since that time, the development of mobility aids moved slowly almost until the end of the 20th century.



¹ Brian Woods & Nick Watson - The Editors of Encyclopædia Britannica
< <http://www.britannica.com/topic/history-1971423> > *photo*: Christies Sale 5188 - Furniture & Decorative Objects - 17 July 2007, London, South Kensington
< http://www.christies.com/lotfinder/lot_details2.aspx?intObjectID=4944799 >

The PRESENT



Currently, new technologies based on computer and communication technologies bring a new perspective in the area of mobility aids and assistive devices. They are also a powerful tool to obtain information regarding assistive technologies for disabled people.

At the beginning of this study, we noted how important this area is for persons with disabilities.

“As a good example we can take Mr. Stephen Hawking, Ph.D. This brilliant mathematician and theoretical physicist discovered that it is not true that black holes were completely black. Without use of various types of

mobility aids and assistive devices Professor Hawking the world would have been deprived of his scientific genius."

Currently, mobility aids and assistive devices have become an integrated part of persons with disabilities. Special attention is given to industrial and graphic design and some are already talking about graphic design as a tattoo. Mobility aids have started to become part of the body.

The FUTURE

What is the future of 'mobility aids and assistive devices'?

In the future, technology will certainly continue to grow in areas such as information technology, materials, manufacturing, design, etc.

Research and development of new products will most likely also begin to adopt new methods for interfacing various assistive technologies.

An example of this may be to use the latest smart phones with assistive technology, such as having a speaking voice provide walking directions for a person with a visual disability.

The market for assistive devices for the disabled (not only SCI) is huge and will soon be recognised as such. Industry will want those orders, particularly as some of these will be 'convenient' for non-disabled consumers.



Photo: courtesy of New Mobility Magazine., featuring the 'Whill' electric wheelchair. An article written by and illustrated by Ian Ruder and Tim Gilmer, with Bob Vogel
<<http://www.newmobility.com/2015/08/whill/>>

Social and Leisure Activities

2.1 Questionnaire

2.2 Additional reading

2.1 Questionnaire

1. From our research so far, we have found that successful integration regarding social and leisure activities means the following:

- ☐ Focus on how you want to live and not on your injury.
- ☐ Live normally not dependent on going out only with other spinal injured people.
- ☐ Take part in all activities you want to.
- ☐ Face barriers and don't see them as a handicap.
- ☐ Go out with family and friends.
- ☐ When others don't see you as a wheelchair user.
- ☐ Sometimes family and friends can be overprotective – associations may be able to help with this.
- ☐ Depends on injury how successfully you are able to integrate.
- ☐ Environment makes a difference to successful integration.
- ☐ Easier to integrate if you have transport.
- ☐ Other

Please put the number of importance (from 1 to 10).

2. Does your organisation promote sport and leisure activities that lead to integration into society?

YES/NO

If yes which is the one best activity for integration into society?

3. Does your organisation utilize SCI volunteers?

YES/NO

If YES note in which field:

- ☐ Sport activities
- ☐ Awareness
- ☐ Peer counselling
- ☐ Board member
- ☐ Website, newspaper
- ☐ Administrative, office
- ☐ Leading courses
- ☐ Other

4. Do you think your organisation should have a program to encourage SCI individuals to volunteer for other organisations/groups?

YES/NO

If YES note in which field:

- ☐ Sport activities
- ☐ Awareness
- ☐ Board member
- ☐ Website, newspaper
- ☐ Administrative, office
- ☐ Leading courses
- ☐ Other

2.2 Additional reading

Third Language - Communicating with all senses

An injury can result in losing parts of ones 'body language' and self-confidence, which adversely effects an individual's social life and leisure activities.

In the project 'Third Language - communicating with all the senses', we tested and created other forms & methods of expressing oneself. In light of our own membership - we included persons with cognitive problems.

The project took a closer look at creative activities and their rehabilitative effects - testing and evaluating the following; Garden / mindfulness, listen to music, acrylic and water colour painting, creative writing, theatre, music and singing.

Models for theatre, painting, music, writing, etc. were developed in the project and collected in a methods book. It is designed for local RTP branches and other local actors. As a guidebook for instructors - it proposes; an outline structure for courses, content, and prospects of its rehabilitative effects.

The hope is that local SCI branches would organise courses for their members utilising this work-book.

And for individuals trying out a course, organized by their consumer organisation - in which the course is customised to what they can and dare - it provides the opportunity to 'push the limits' at a safe yet encouraging pace. Finding and developing new /workable forms of self expression boosts confidence and with it self-esteem. And so, the prospect of social (re)integration increases.

Analytical example:

Third Language - Communicating with all senses in *Watercolour* painting

Memory is trained in cognitive awareness and the use of motor functions. This applies both to the working memory which maintains and manages the information necessary to perform tasks here and now, as well as in long-term memory where one stores the impression, and from where it is retrieved.

Likewise, artistic & creative perception is trained - using visual and tactile interpreters to identify materials, themes, tones and composition.

The following is a functional analysis of how abilities may be (re)trained:

- ✓ When selecting colours and designs, and in combining colours - the artist needs to be able to pick out what they want to emphasise ..and then manage to retain that emphasis.
- ✓ Painting calls upon ones ability to have an idea and to take an initiative - to create ones own ideas, to make choices.

- ✓ To paint and hold a brush - trains fine motor skills and the interaction between different muscle groups.
- ✓ In the planning of the painting and while painting - organisation and planning is trained.
- ✓ To assemble parts into an entirety - to develop a methodology for how to do it.
- ✓ In the arrangement of the painting - the spatial perception and orientation are put to test.
- ✓ Cognitive flexibility is called upon to shift ideas and actions as the painting evolves.

As may be ascertained from the above example, a seemingly elementary expression through art can and does involve a complex interaction of cognitive & motor functions that may have been damaged as a result of a SCI &/or post trauma and psychological struggles. Noteworthy is that 'expressions in art' may be 'beyond reproach' - There should be no such thing as 'not good enough'.

Offering a diversity of subjects; Garden / mindfulness, listen to music, acrylic and water colour painting, creative writing, theatre, music and singing - there ought to be something of interest ..and fun, in the 'Third Language - Communicating with all senses' course guidelines. It, or a derivative of it (..perhaps adapted to ones own local arts, crafts & culture) may be a valuable aid to SCI's recuperation, and to free their expressiveness ..ultimately working towards further social integration.

The World Health Organisation's (WHO)

The World Health Organisation's Institute of Medicine (IoM)'s ' Model of the Enabling-Disabling Process ' suggests the degree to which a person with disability is an active productive member of society, and well-integrated into family and community life, is a complex phenomenon influenced by many factors. These include;

- characteristics and consequences of the injury or pathology, including impairment at the organ level and activity restrictions at the person level.
 - individual characteristics, including demographics, lifestyle, and behaviour nature.
- and
- the environment, including physical, social attitudes and cultural issues.

The Reintegration to Normal Living Index (RNLI)

Wood-Dauphinee and Williams - McGill University and Montreal General Hospital (1987).

The 'Reintegration to Normal Living Index' was developed to qualitatively assess the ability of individuals with traumatic or incapacitating illnesses and their reintegration into normal life.

The RNL questionnaire comprises of 11 questions which assess; mobility, self-care, daily activity, recreational activity, and family roles. Reintegration to normal living was defined by the authors as the "reorganisation of physical, psychological, and social characteristics of an individual into a harmonious whole so that one can resume well-adjusted living after incapacitating illness or trauma"

The questionnaire's Scoring Procedure:

Each domain contains a visual analogue scale (VAS). On one end (score 1): “does not describe my situation” to (score 10) “fully describes my situation”. Individual scores are summed to provide a total. The higher the score, the better the patients 'perceived' integration.

Questions in RNLI:

- 1 I move around my living quarters as I feel necessary.
- 2 I move around my community as I feel necessary.
- 3 I am able to take trips out of town as I feel are necessary.
- 4 I am comfortable with how my self-care needs (dressing feeding toileting bathing) are met.
- 5 I spend most of my days occupied in work activity that is necessary or important to me.
- 6 I am able to participate in recreational activities (hobbies crafts sports reading television games computers etc.) as I want to.
- 7 I participate in social activities with family friends and/or business acquaintances as is necessary or desirable to me.
- 8 I assume a role in my family which meets my needs and those of other family members.
- 9 In general I am comfortable with my personal relationships.
- 10 In general I am comfortable with myself when I am in the company of others.
- 11 I feel that I can deal with life events as they happen.

Summary of strengths and weaknesses:

Courtesy: College of Health - University of Utah, USA

Weakness:

- Not recommended for individuals with cognitive or visual impairments
- It is not recommended that healthcare professionals answer as a proxy for their patients
- Significant others are allowed to answer, but research shows poor reliability between patient and significant other scores. Patients usually rate themselves higher (having good community reintegration) than their significant others who typically rate them lower (poorer community reintegration outcomes): Tooth, Smith, & O’rourke (2003)
- No generally accepted standards for interpretation
- Multiple variations of the assessment, limited information on when to use which assessment

Strengths:

- The assessment is free, short and simple to administer
- No training required
- The results are not impacted by age or gender

< <http://health.utah.edu/occupational-recreational-therapies/docs/evaluations-reviews/rnl.pdf> >

The Community Integration Questionnaire (CIQ)

Barry Willer Ph.D. < <https://www.tbims.org/ciq/> >

The Community Integration Questionnaire consists of 15 items relevant to living, loving, and working, or more formally; home integration, social integration, and productive activities ..to provide a measure of community integration after traumatic brain injury.

It is scored to provide subtotals for each of these, as well as for community integration overall. The basis for scoring is primarily in the frequency of performing activities or roles, with secondary weight given to whether or not activities are done jointly with others, and the nature of these other persons (for example, with/without TBI (traumatic brain injury) helper or professional.

In its current format, the CIQ can be completed, by an in-person interview, in about 15 minutes. Telephone interviewing is quite common and TBI model systems also utilize self-administered CIQs. No formal training and credentialing process for the administration of the CIQ exists; it is recommended that prospective users contact Dr. Willer or another experienced user for guidance in administration, mock interviews, etc.

Barry Willer Ph.D., who was the principal investigator in developing the CIQ, holds the copyright. Permission for use of the CIQ is freely given but should be requested by contacting him at the Centre for Research on Community Integration at the Ontario Brain Injury Association, 3550 Schmon Parkway, Thorold, Ont L2V 4Y6, Canada. *email:* bswiller@buffalo.edu

Quality of Life

3.1 Questionnaire

3.2 Interview

3.1 Questionnaires compiled by each of the work groups

Questionnaire to the ESCIF member organisations

1. QoL means different things to everyone. Can you define what QoL for people living with SCI means to your organisation?
2. Does your organisation have any past, present or future projects and/or services regarding to QoL?
☐ Yes ☐ No
If yes, can you describe in your own words the background and idea with the project and/or service?

If yes, can you describe what actions or elements that are part of the project and/or service?
3. Have you any past, present or future projects and/or service regarding self-motivation, self-determination, empowerment, coaching and/or peer-support in this area?
☐ Yes ☐ No
If yes, can you describe in your own words the background and idea with the project and/or service?

If yes, can you describe what actions or elements that are part of the project and/or service?
4. If you had no limitations regarding manpower or finances what would, in your own words, be a perfect project to do in your country regarding QoL for people living with SCI?

If there are any questions that we would like to ask you about the experiences/knowledge you have shared with us, can we contact you again by mail or telephone?

If yes, please write the contact information:

Name:	E-mail:
Phone number:	When is a good time to phone you up?

Thank you for your participation!

3.2 Interview questions for people living with SCI

Dear responders

European spinal cord injury federation - ESCIF is performing the "*Successful integration of people living with spinal cord injury*" project at the moment. The purpose of the project is help member organisations to manage *the successful (re-)integration of people with spinal cord injury to the community*. ESCIF has identified five focus areas that are important for successful integration and formed five different working groups working with these focus areas. You can read more about the project on www.escif.org.

One of these focus areas is *Quality of Life* (QoL). The QoL working group would like to know more about your personal experiences in this area. This experience is very important for us, so we can do our best to finish the project successfully. The questions that we would like to discuss with you in an interview are:

1. What does Quality of life means to you?
2. What is important to you to have quality of life?
3. What have you done to get quality of life?
4. How can we motivate ourselves to get quality of life?
5. What did motivate you to get quality of life?
6. What kind of support do you think is important for a newly injured person to get to help that person to move forward with his/her life?
7. Can you tell us of any kind of support that you got that helped you to move forward with your life?
8. What do you think is the most important support a consumer organisation can give their members to help them to move forward in life and have o good QoL?
9. Is there anything else that you want to tell us that we haven't asked about?

**References,
Bibliographies and
Website addresses**

References, Bibliographies, and website addresses

Please note: Each subject / section of this written report were the work of working group teams. Each team presented the then current edition of their report at the ESCIF Congress: 20 - 22 May 2015 Brno, Czech Republic.

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RESULTS:

The initial search yielded 5,874 articles, 48 of which met the inclusion criteria. Forty-four studies estimated the incidence of SCI and nine reported the prevalence, with five discussing both. Of the incidence studies, 14

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Methods

A systematic review for 2000 – 2006 was carried out in PubMed/Medline (**USA**), AMED (**Allied / UK**), (ISI) Web of Science (**UK**), EMBASE (database for often used by drug companies referencing Medline (**USA**) & unspecified others), CINAHL (EBSCO, **USA** - a library database of nursing journals dating back to 1937), PsycInfo and Sociological abstracts database (PsycINFO, **USA** - database in behavioral and social sciences).

The keywords 'spinal cord injuries', 'spinal cord disorder', 'spinal cord lesion' or 'spinal cord disease' were cross-indexed with 'employment', 'return to work', 'occupation' or 'vocational'.

Results. Out of approximately 270 hits, 110 references were used, plus 13 more found elsewhere. Among individuals with SCI working at the time of injury 21 – 67% returned to work after injury.

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Design: Descriptive analysis of data from a questionnaire.

Setting: Rehabilitation centre with special department for patients with SCIs, Groningen, The Netherlands.

Subjects: A total of 57 patients with traumatic SCI living in the community, who were admitted to the rehabilitation centre two to 12 years before the current assessment.

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2. http://who.int/disabilities/policies/actionplan/disability_action_plan_en.docx
3. For further information, please contact the specialists below – team leaders and senior member:
 - Prof. GELU ONOSE, MD, PhD, MSc Senior Physician in Physical and Rehabilitation Medicine (PRM) and Gerontology & Geriatrics (GG)PhD, geluonose@gmail.com
 - Eng. VALERIU AVRAMESCU, Scientific Researcher II, valeriuavramescu@yahoo.com
 - Eng. VLADIMIR CARDEI, Scientific Researcher I, vladimircardei@yahoo.com

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