Swiss Paraplegic Research

Swiss Paraplegic Centre

ICF Case Studies

Translating Interventions into Real-life Gains – a Rehab-Cycle Approach

Rights of Persons with SCI

Case Study 20

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Content

Rights of Persons with SCI

Preface

Functioning is a central dimension in persons experiencing or likely to experience disability. Accordingly, concepts, classifications and measurements of functioning and health are key to clinical practice, research and teaching. Within this context, the approval of the **International Classification of Functioning, Disability and Health (ICF)** by the World Health Assembly in May 2001 is considered a landmark event.

To illustrate the use of the ICF in rehabilitation practice **Swiss Paraplegic Research (SPF)** together with **Swiss Paraplegic Centre (SPZ)**, one of Europe's leading (acute and rehabilitation) centres for paraplegia and spinal cord injury (SCI), performed a series of case studies. Conducting ICF-based case studies was one approach to address SPF's aim to contribute to optimal functioning, social integration, health and quality of life for persons with SCI through clinical and community-oriented research. The ICF-based case studies project began in October 2006.

In this project, persons of different age groups and gender and who are living with SCI of varying etiology and levels of severity, were accompanied during their rehabilitation at SPZ. The rehabilitation process is then described using the Rehab-Cycle® and the corresponding ICF-based documentation tools. Since persons with SCI are faced with a number of physical, psychological and social challenges, the case studies aimed to cover a broad spectrum of these challenges. With this in mind, each case study highlighted a specific theme of SCI rehabilitation.

A booklet is published for each case study conducted. To better understand the case studies described in these booklets, find below some basic information about SCI, the ICF, ICF Core Sets, the Rehab-Cycle® and the ICF-based documentation tools.

Spinal Cord Injury (SCI)

Spinal cord injury (SCI) is an injury of the spinal cord that results in a temporary or permanent change in motor, sensory, or autonomic functions of the injured person's body. The spinal cord is divided into four sections which can be further subdivided into individual segments:

– 8 cervical segments (C1 to C8)
– 12 thoracic segments (T1 to T12)
– 5 lumbar segments (L1 to L5)
– 5 sacral segments (S1 to S5)

The damage of the spinal cord is called lesion. Important functions such as mobility (motor functions) or sensation (sensory functions) fail below the lesion. To help determine future rehabilitation and recovery needs, the extent of a SCI in terms of sensory and motor functions is described using the American Spinal Injury Association (ASIA) impairment scale.

International Classification of Functioning, Disability and Health (ICF)

The ICF is a classification of the **World Health Organization (WHO)** based on the integrative bio-psycho-social model of functioning, disability and health. Functioning and disability reflect the human experience related to the body functions, body structures, and activities and participation. It is viewed in terms of its dynamic interaction with a health condition, personal and environmental factors.

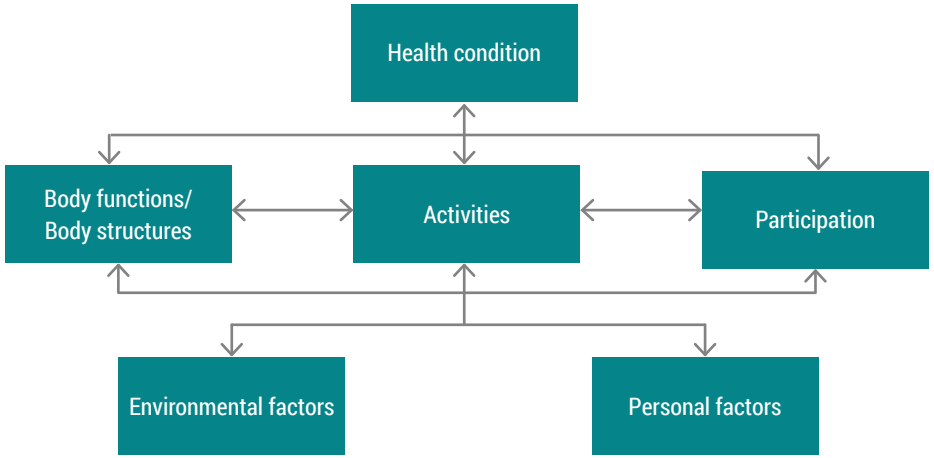

Figure 1: *Bio-psycho-social model of functioning, disability and health*

The ICF classification corresponds to the components of the model. Within each component, there is an exhaustive list of categories that serve as the units of the classification. ICF categories are denoted by unique alphanumeric codes and are hierarchically organised in chapter, second, third and fourth levels. When going from the chapter level to the fourth level, the category's definition becomes more detailed.

The classification also comprises so-called ICF qualifiers, which quantify the extent of a problem experienced by a person in a specific ICF category. Since environmental factors can also be facilitators, the ICF qualifier for facilitators are indicated with a plus sign.

Generic Scale of ICF Qualifiers	
0	NO problem (none, absent, negligible,...) 0-4%
1	MILD problem (slight, low,...) 5-24%
2	MODERATE problem (medium, fair,...) 25-49%
3	SEVERE problem (high, extreme,...) 50-95%
4	COMPLETE problem (total,...) 96-100%
8	not specified (used when there is insufficient information to quantify the extent of the problem)
9	not applicable (used to indicate when a category does not apply to a particular person)

ICF Core Sets

To facilitate the use of the ICF in clinical practice, it is essential to have ICF-based tools that could be integrated into the existing processes. The first step toward providing ICF-based tools for clinical practice was the development of ICF Core Sets. ICF Core Sets are shortlists of ICF categories that are considered to be most relevant for describing persons with a specific health condition or in a particular setting. In a rehabilitation setting an ICF Core Set can help guide the rehabilitation management process. ICF Core Sets have been developed for several health conditions e.g. for spinal cord injury, health condition groups e.g. for neurological conditions and for various settings. ICF Core Sets can serve as a basis when using the **ICF-based documentation tools** that follow the **Rehab-Cycle®**.

Rehab-Cycle® and Corresponding ICF-based Documentation Tools

The Rehab-Cycle® is one approach that reflects the structured processes inherent in multidisciplinary rehabilitation management. The Rehab-Cycle® consists of an assessment phase, assignment phase, intervention phase and evaluation phase. An ICF-based documentation tool has been developed to guide each of the Rehab-Cycle® phases: the ICF Assessment Sheet, the ICF Categorical Profile, ICF Intervention Table and ICF Evaluation Display. These tools can help a multidisciplinary rehabilitation team to better understand the role of functioning within the rehabilitation process and to more comprehensively describe a person's functioning - hence support ICF-based rehabilitation management.

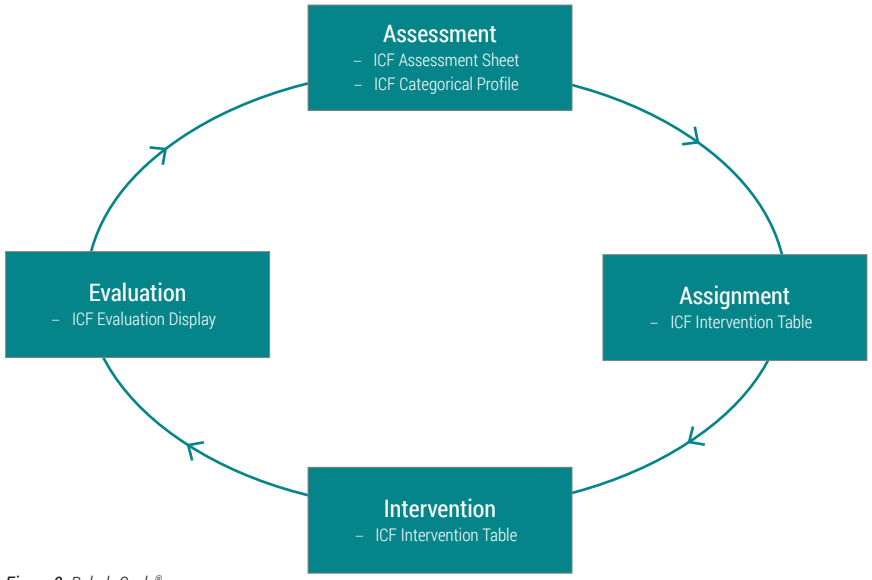

Figure 2: *Rehab-Cycle®*

You can find more detailed information about SCI, the ICF, ICF Core Sets, the Rehab-Cycle® and the ICF-based documentation tools on the website www.icf-casestudies.org.

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General Introduction

After experiencing a spinal cord Injury (SCI) the person not only has to deal with regaining body functions and learn strategies to adapt to activity limitations, the person is often confronted with physical and social accessibility issues as well as loss of income or questions of cost coverage for medical/rehabilitative interventions. As a person with disability, being aware of his or her rights and how to navigate through the legal and social security systems could help optimise the person's community reintegration after SCI.

Rights of Persons with Disability

Globally, the entitlement of social security is incorporated in the *Universal Declaration of Human Rights* of 1948[1] as well as in the *International Covenant on Economic, Social and Cultural Rights* of 1966.[2] These declarations do not explicitly mention persons with disabilities, since they apply to all human beings irrespective of the presence of disability. To address the specific situation of persons with disability, the *United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD)* was adopted by the UN General Assembly in 2006.[3] **The CRPD lays out the basic rights of persons with disability around the world, emphasising autonomy and self-determination. Accessibility is also a central theme throughout the CRPD.** An optional protocol to the CRPD was also adopted in 2008 that recognises the role of the Committee on the Rights of Persons with Disabilities to hear individual complaints.

One of 173 countries (as of May 2017), Switzerland ratified the CRPD in April 2014. This obliges Switzerland to enact specific legislation that grant persons with disability the rights outlined in the CPRD.[3]

Role of Legislation

Laws play an important role in addressing some issues faced by persons with disability, including persons living with SCI. It is also a tool that can be used to implement social and disability policy. Disability policy, as a part of social policy, is implemented through laws that define the current understanding of disability and outline the rights granted to persons with disability. These laws can be differentiated between social security legislation and anti-discrimination legislation. **While social security legislation generally focuses on outlining the provisions for financial benefits, anti-discrimination legislation aims to ensure fair opportunities and equality (including addressing accessibility barriers that deny equality).** In Switzerland these two types of legislation also dictate two different definitions of disability; *see box 1*.

Box 1 | Disability Definitions in Switzerland

"Disability" or "invalidity" is defined in Swiss social security legislation ***General Part of the Federal Social Insurance Law (ATSG) Article 8*** as "a probable permanent or long-term complete or partial incapacity to work" (unofficial translation from German)[4]. In Swiss anti-discrimination legislation, the person with disability is defined in the *Disability Discrimination Act (BehiG) Article 2* as "a person, for whom a probable long-term physical, mental or psychological impairment makes it difficult or impossible to perform daily activities, to maintain social contacts, to move about, to engage in education and training or gainful employment" (unofficial translation from German)[5].

In addition to defining disability, legislation can also specify the rights persons with disability have. In Switzerland, for example, the *Swiss Constitution* provides the legal basis to ensure social justice, social equality and social security for all persons in Switzerland – with or without disability.[6] There is also **specific legislation for various aspects of social security and for persons with disability.** For example, the *Federal Law on Disability Insurance (IVG)* outlines, among other things, the provisions for facilitating return-to-work/work participation of persons with disability, e.g. vocational re-training or assistive devices[7,8], and the BehiG ensures accessible public buildings and transportation.[5]

"… most laypeople are unaware of [laws pertaining to persons with disability] until they need to apply them – that is, when they themselves become disabled."

Although these laws are publically available on the website of the Swiss Confederation, most laypeople are unaware of them until they need to apply them – that is, when they themselves become disabled. For persons with SCI, becoming disabled is often sudden and unexpected. They are suddenly faced with impairments of functioning, possible loss of income and mounting financial burden of disability, and uncertainty about living independently in the community. To help address these issues, it is essential that persons with SCI gain knowledge about their rights as persons with disability, what services and interventions they are entitled to, and in general how to navigate around the social and legal systems. As stated in the Preamble of the CRPD: "Recognizing the importance of accessibility to…information and communication, [enables] persons with disabilities to fully enjoy all human rights and fundamental freedoms".[3] Accordingly, the International Perspectives on Spinal Cord Injury (IPSCI) recommends empowering persons with SCI and their families with necessary information so that "they can take responsibility for their own healthcare after discharge".[9]

"…IPSCI recommends empowering persons with SCI and their families with necessary information so that 'they can take responsibility for their own healthcare after discharge'."

This case study of Ben provides insight into the challenges related to legal and social security issues that a person with SCI experiences during rehabilitation. It also illustrates that gaining knowledge about one's own rights could be demanding as much as empowering, and how the implementation of disability policy contributes to optimising participation of persons with SCI.

Ben's Story

As an enthusiastic freestyle snowboarder 18-year-old Ben regularly participated in international competitions. It was during an European championship that he incurred a spinal cord injury (SCI) as a result of a snowboard accident.

At the time of the accident **Ben had been living with his parents and his younger brother in a house near the Swiss capitol city of Berne and was in the second year of his apprenticeship as a carpenter. He had a girlfriend and a huge circle of friends. Ben loves outdoor activities, especially sports activities.**

Ben received his first treatment for the injury, including spinal surgery, in one of the biggest non-university hospitals in Switzerland. One day later he was transferred to a rehabilitation centre specialising in SCI.

Ben's SCI was graded with an **American Spinal Injury Association (ASIA) Impairment Scale grade A with a lesion in the spinal cord segment below the twelfth thoracic vertebrae (T12), meaning that he had no sensory or motor functioning below the waist.** Furthermore, he suffered from post-traumatic stress disorder, urinary tract infections and neuropathic pain – all of which were able to be treated successfully.

In addition to the interventions that addressed Ben's impairments and limitations in completing activities of daily living, a number of issues related to participation and community reintegration had to be addressed during rehabilitation. One issue was related to Ben's work reintegration. As a result of his accident **he had to quit his apprenticeship as a carpenter and find another occupation. Independent mobility, specifically using public transport and driving a car, was another crucial issue that Ben and his rehabilitation team had to tackle. Moreover, being able to move around in his home was essential to successful community reintegration and independent living.**

Critical to addressing these issues was not only acquiring the insurance coverage for the provision of services at the rehabilitation centre, but also the clarification of cost coverage for possible education and training as part of Ben's vocational re-orientation, for interventions toward getting a special driver's license and an adapted car, for mobility-related assistive devices, and for required modifications to his home. Furthermore, clarification about a public transport pass for persons with disability was necessary. Since the legal framework applicable to Ben's case and the social security system in Switzerland played a fundamental role in these clarifications as well as for his future as a person living with SCI in the community, **it was important that Ben became aware of the relevant laws and regulations and his rights as a person with disability.**

At beginning of rehabilitation, Ben's knowledge about his rights and eligibility for various services and financial support was very limited.

> *"One learns the theory behind the Swiss social security system at school, but the real need to understand how the system works only becomes important when you have to rely on it. As a layperson it is almost impossible to have a clear overview about all existing laws and regulations and related policies."*
>
> *Ben, five months following his SCI*

After five months of initial rehabilitation during which Ben showed major functioning improvement, he and his rehabilitation began to plan his discharge from the rehabilitation centre, and a new Rehab-Cycle® started. To help address some unresolved issues related to his integration into the community and to empower Ben to gain knowledge and exercise his rights, members of the rehabilitation team, especially the social worker, the occupational therapist and the vocational counsellor, supported Ben with practical advice about managing insurance and social security mechanisms.

Assessment

Focused on discharge planning and community reintegration Ben's new Rehab-Cycle® started off with a comprehensive assessment of his functioning that included a battery of discipline-specific testing and evaluations and a face-to-face interview with Ben.

In addition to capturing the health professional's perspective, as reflected by the battery of tests and evaluations, the comprehensive assessment also captured the patient's perspective through the interview with Ben. Using the **ICF Assessment Sheet, the assessment results were summarised according to the International Classification of Functioning, Disability and Health (ICF)** components of body functions, body structures, activities and participation, environmental factors and personal factors.[10] **The ICF Core Set for spinal cord injury (SCI) in the post-acute context.[11] was used as a basis for the documentation of the assessment results.** *See "Table 1: ICF Assessment Sheet" on page 28 at the end of this booklet.*

The comprehensive assessment revealed three major areas in which issues had to be addressed during this Rehab-Cycle® – vocational re-orientation, mobility, and housing.

Vocational Re-orientation

Vocational counselling had already commenced shortly after admission to the rehabilitation centre and before the Rehab-Cycle® began. **It was clear from the beginning that Ben had to find an alternative to his pre-injury apprenticeship in carpentry.** In the first phase of vocational counselling, his interests and wishes were explored. **Thanks to intensive vocational counselling, Ben found a new apprenticeship as an administrative clerk.** The apprenticeship was scheduled to start several months after discharge from the rehabilitation centre. In the period of transition before the start of the apprenticeship, **Ben had planned to take a language course in the United States as well as participate in a short internship** at the same company where he would become an apprentice – in order to gain work experience and get oriented to his new career path.

In planning for discharge and community reintegration, some follow-up questions arose during the comprehensive assessment. These questions had to be answered and issues resolved during the course of the Rehab-Cycle®:

- Who will pay for the language course in the United States?
- Is everything related to the internship with the new employer organised?
- Will Ben receive some income support during the transition period before the start of the new apprenticeship?

Mobility

Besides the questions related to work reintegration, there were also some open questions related to mobility. The comprehensive assessment revealed that **Ben had no difficulty in transferring himself, in fine hand use, nor in moving around using equipment.** However, he had moderate difficulty in using transportation.

> *"…since I am currently not able to drive a car, I have to travel by train."*
>
> *Ben at the beginning of the Rehab-Cycle®*

After the assessment, the rehabilitation team concluded that **being able to drive would be useful for Ben's work reintegration.** This meant that Ben and the rehabilitation team had to explore the possibility of obtaining a special driver's license for wheelchair-users and acquiring an adapted car. Again questions came up, this time related to mobility, that had to be resolved during the Rehab-Cycle®:

- What is Ben required to do to take the exam for the driver's license?
- What car modifications are needed?
- Has cost coverage for obtaining the driver's license and acquiring an adapted car been clarified?

Housing Situation

An assessment of Ben's home conducted before the start of the Rehab-Cycle® resulted in a list of recommended modifications. This was considered in the overall assessment at the beginning of the Rehab-Cycle®. A few questions remained:

- To what extent will the modifications to Ben's home be realised before discharge?
- Who will pay for all the modifications to his home?
- Is living independently in his own apartment an option?

To help answer these questions relevant laws and regulations and Ben's rights as a person with disability were considered as part of goal-setting and for intervention planning during this Rehab-Cycle®. The legal framework relevant to Ben's case is presented in box 2.

Case Study 20 | Rights of Persons with SCI | Assessment

Box 2 | Legal Framework in Ben's Case

Vocational Re-orientation

Work participation after SCI is generally considered important for economic self-sufficiency and overall adjustment to disability, and shown to be associated with better outcomes.[12,13] To enable persons living with SCI to work, employers may need to make necessary and reasonable modifications to the workplace, e.g. wheelchair accessible bathroom facilities, or accommodations to fit the person's needs, e.g. adjusted work schedule. Providing personal aids (assistive devices) may also be crucial for the person to perform job tasks. If a person cannot return to his or her previous job, a vocational retraining might be necessary.[12,13]

Article 27, Paragraph 1d of the *United Nations Convention on the Rights of Persons with Disabilities (CRPD)*[3] calls for legislation to safeguard and promote the right of a person with disability to work by enabling him or her to effectively access, among other things, vocational training. Furthermore, Article 27, Paragraph 1k calls for legislation that promotes return-to-work programmes.

In Switzerland, the *Federal Law on Disability Insurance (IVG)*[7] addresses the right to work and outlines work-promoting interventions, which a person with disability is entitled to. The following IVG Articles are relevant to Ben's case:

- **Article 15**: Vocational counselling
- **Article 16**: First vocational training
- **Article 17**: Vocational re-training
- **Article 18**: Job placement and internship, including provisions for a daily allowance during the internship, when the internship evolves into a permanent job
- **Article 21**: Access to assistive devices and technology
- **Article 22-25:** Daily allowance provisions and requirements

There are also federal regulations that detail the provisions outlined in laws. For example, the *Federal Disability Insurance Regulations (IVV)*[14] provides regulations that underpin the IVG and the *General Part of the Federal Social Insurance Law (ATSG)*[4].

In Ben's case, Article 4, sub-paragraph 5.2 of the IVV specifies that he was entitled to an intervention that would enable him to maintain a daily structure and engage in activities until he started vocational re-training. This is referring to Ben's internship during the period of transition before he started his apprenticeship. Furthermore, under Article 18 of IVV, Ben was entitled to a daily allowance during this transition period.[14] Other federal regulations that were relevant for Ben's case include the *Federal Regulations on the Distribution of Assistive Devices through the Disability Insurance (HVI)*. Specifically, Paragraph 13 in the list of assistive devices enclosed in the HVI specifies Ben's eligibility for assistive devices and physical adaptations to the workplace as well as environments that prevented him from getting to work.[15]

Mobility

To facilitate successful work reintegration and to ensure participation of persons with SCI in education and social activities, it is essential that independent mobility, especially accessibility of transportation, is achieved.[9,12,13] Moreover, being able to drive has shown to be positively associated with return-to-work after SCI.[13,16] Inaccessible transportation has been identified as one of the most frequent self-reported barriers for work reintegration, especially in rural areas.[9,17,18]

Article 9 of the CRPD[3] as well as Articles 3b, 7, and 15 of the *Federal Disability Anti-Discrimination Act (BehiG)*[5] clearly outline provisions for the accessibility of public transportation systems, including the train and bus stations, airports, the corresponding communication system, the ticket machines, and the transportation vehicles themselves.

Since Ben was leaning more toward the possibility of driving an adapted car, other legislation and regulations applied. For example, Paragraph 10 in the HVI list of assistive devices defines the annual coverage of car adaptation costs. According to Article 8 of HVI, coverage of high-cost assistive devices, such as for an adapted car, would be paid on an amortisation/instalment basis. Article 7 of HIV is also relevant for driving. Article 7, Paragraph 1 stipulates that if special training is a pre-requisite for using the assistive device – in this case the cost of learning to drive an adapted car, the Disability Insurance would cover the training costs.[15]

Housing Situation

In addition to accessibility at the workplace or of public transportation, a wheelchair-accessible home is crucial for successful community reintegration after discharge from the rehabilitation centre.[9,17,19,20,21] According to a study of 123 older persons with SCI published in March 2017, accessible housing was perceived as the most important physical environmental factor that supported community participation.[21] The most common housing modifications are ramps, wide doors, and adapted bathrooms. Since these modifications can be very expensive, financial resources are required.[19]

As with vocational re-orientation and mobility, the CRPD, specifically Article 9 Accessibility, also addresses accessible housing issues. In Ben's case, Swiss legislation that applies to his housing needs include:

- Article 21 of IVG and Article 2 of the HVI, addressing access to assistive devices and technology in general
- Paragraph 14 in the list of assistive devices enclosed in the HVI, detailing the cost coverage for diverse architectural modifications to the home as well as assistive devices, such as a wheelchair lift
- Article 14, Paragraph 1b of IVV, stipulating cost coverage for disability-related modifications of buildings

Goal-setting/Determination of Intervention Targets

In setting rehabilitation goals and identifying specific targets to address with interventions, Ben and his rehabilitation team considered the comprehensive assessment results as well as the questions that came up during the assessment regarding discharge planning and community reintegration.

Setting Goals Oriented Toward Community Reintegration

Since the focus of Ben's new Rehab-Cycle® was discharge and community reintegration planning, the short and long-term rehabilitation goals set reflected this focus as well. Accordingly, 'community reintegration' was defined as the long-term **global goal**. As an important step toward achieving this global goal, Ben and his rehabilitation team agreed to strive for 'independence in daily living' as the **service program goal**. The service program goal is the goal that is expected to be achieved at the end of this particular Rehab-Cycle®. As "stepping stones" toward meeting the service program goal, three short-term **cycle goals** – 'clarification of vocational re-orientation', 'improvement in mobility', and 'accessible housing' – were set. These cycle goals directly corresponded to the main problems that were identified during the comprehensive assessment as potential barriers to Ben's community reintegration.

These rehabilitation goals were documented using the ICF Categorical Profile. The **ICF Categorical Profile** created for Ben not only showed his goals, but also a visual depiction of the comprehensive assessment results as categories of the International Classification of Functioning, Disability and Health (ICF) and a bar chart that reflected Ben's status in these categories at the time of the assessment using ICF qualifiers. *See "Table 2: ICF Categorical Profile" on page 30 at the end of this booklet.*

Determining Targets to Address with Interventions

The ICF categories that corresponded to one or more of the goals and were intended to be addressed with specific interventions during the Rehab-Cycle® were considered **intervention targets.**

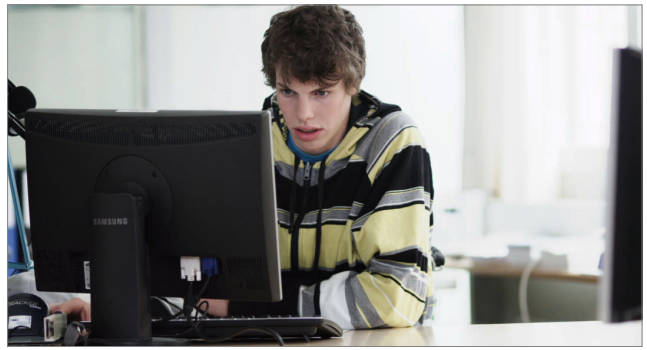
Intervention targets were identified for each of the cycle goals. For cycle goal 1 'clarification of vocational re-orientation', d840 Apprenticeship and d870 Economic self-sufficiency were defined as intervention targets. For cycle goal 2 'improvement in mobility', many intervention targets were identified. *See "Table 2: ICF Categorical Profile" on page 30 at the end of this booklet.* Lastly, for cycle goal 3 'accessible housing', e155 Design, construction and building products and technology of buildings for private use was defined as an intervention target.

…d920 Recreation and leisure was identified as an important target for intervention to foster Ben's love of outdoor activities and sports and to facilitate community reintegration, Ben's global goal.

Ben's rehabilitation team also defined d5300 Regulating urination as an intervention target, this time for the service program goal 'independence in daily living', since bladder management is essential for independence in daily living. Otherwise, Ben would have had to depend on personal care assistants or his family for this everyday activity. Moreover, d920 Recreation and leisure was identified as an important target for intervention to foster Ben's love of outdoor activities and sports and to facilitate community reintegration, Ben's global goal.

Normally, goal values, i.e. ICF qualifier ratings intended to be reached after an intervention, are set for each intervention target. This is meant for evaluating whether the goal for each intervention target was achieved at the end of the Rehab-Cycle®. However, in the case study of Ben, the ICF Categorical Profile contained no goal values, since the case study focused on the role played by Swiss laws and regulations in Ben's rehabilitation rather than the outcome of the rehabilitation itself.

Assignment and Intervention



After the short and long-term goals were set and the intervention targets were defined, individual members of the rehabilitation team were assigned to each of the intervention targets. At this point, the intervention phase of Ben's new Rehab-Cycle® began.

The members of Ben's rehabilitation team included a physician, nurses, a physical therapist, a sports therapist, an occupational therapist, and a vocational counsellor. Given the crucial role laws and regulations played in Ben's rehabilitation, especially in answering some of the open questions that remained after the comprehensive assessment, a social worker was also part of his rehabilitation team.

"Given the crucial role laws and regulations played in Ben's rehabilitation,…a social worker was also part of his rehabilitation team."

The intervention targets, the team member(s) assigned to address individual targets, and the corresponding interventions were documented on the **ICF Intervention Table** . The ICF Intervention Table provides an overview of the responsibilities and interventions at-a-glance, and can help avoid redundancies and gaps in providing interventions.

The ICF Intervention Table prepared for Ben's case also indicated the relevant legislation that applied to address specific intervention targets.

See "Table 3: ICF Intervention Table" on page 34 at the end of this booklet.

Interventions To Address Vocational Re-orientation

"The vocational counsellor…had already provided support to Ben even before the Rehab-Cycle® began."

The vocational counsellor on Ben's rehabilitation team had already provided support to Ben even before the Rehab-Cycle® began. He was instrumental in securing Ben's new apprenticeship as an administrative clerk as well as the internship with the new employer. He also arranged Ben's participation in English and French language courses and a computer course that had started in the initial rehabilitation period.

During the Rehab-Cycle® the vocational counsellor helped Ben to clarify the duration and the working hours of the internship. Furthermore, with the help of the vocational counsellor, **Ben applied for financial support through the Swiss Paraplegic Foundation (www.paraplegie.ch) for the language course in the United States** that he wanted to attend during the transition period before starting his new apprenticeship. The vocational counsellor (together with the social worker) also **intervened after the statutory Disability Insurance rejected Ben's initial application for income support** for the duration of the language course. He also assisted Ben **in finding a suitable, wheelchair-accessible language school, and supported Ben in initiating the process to get released from mandatory military duty due to his SCI.**

Interventions To Address Mobility

To address Ben's cycle goal 2 'improvement in mobility', the social worker assisted Ben in **getting funding for his wheelchair** through the Disability Insurance, while the occupational therapist (OT) **counselled him on the most suitable wheelchair** to order and oversaw the wheelchair adjustments that fit Ben's specific needs.

The OT and the social worker also worked together to help Ben **in getting a special license to drive an adapted car** as well as to acquire a car adapted to Ben's needs.

Unfortunately, there were long delays in getting approval to take the driver's license examination. Ben felt quite frustrated with these delays.

> *"It even takes a long time to get permission to take the theoretical part of the driver's license examination..."*
>
> *Ben on the challenges to receiving a driver's license*

The OT organised an appointment with **orthopaedic technicians, who conducted a pre-driving assessment to clarify Ben's driving capacity, and informed Ben about possible and necessary car adaptations as well as the standard procedure for getting the adaptations financed through the Disability Insurance.** This information was also important for Ben's community reintegration as he was responsible for taking care of these issues on his own after discharge from the rehabilitation centre.

Given that Ben still did not have a driver's license, Ben had to use the public transport system to get around. To optimise his use of public transport and in getting around in an urban environment, the OT provided **outdoor wheelchair training and city training, as well as assistance in applying for a Disabled Passenger's ID Card to use the Swiss Federal Railways (SBB).** With this card any person who accompanies Ben during his travels within the SBB system was able to ride for free (with the assumption that Ben's mobility restrictions required him to travel with a companion).

Interventions To Address Accessible Housing

With regard to Ben's third cycle goal 'accessible housing", **the social worker, OT and an architectural modifications expert worked together to help Ben get the necessary modifications to his home.**

While both the social worker and the OT coordinated to get insurance coverage for the modifications, the OT and the architectural modifications expert collaborated in arranging the essential modifications. However, the OT alone provided counselling and coordination to ensure that the modifications to Ben's home, such as building in a lift and a wheelchair-accessible balcony door, were completed. The OT also provided assistance in acquiring necessary assistive devices, such as a special bathtub seat and mat.

Unfortunately, not all of the modifications identified as essential were funded.

> *"Due to the fact that I am living with my parents and my brother, the Disability Insurance would not pay for modifications to the kitchen."*
>
> *Ben on the cost coverage for modifications to his home*

Interventions To Address Other Functioning Areas

"…the social worker together with Ben and Ben's parents initiated the application to get income support for him."

There were other areas of Ben's functioning that were addressed through interventions. For example, to address the intervention target of d870 Economic self-sufficiency, the social worker together with Ben and Ben's parents initiated the application to get income support for him.

Another example relates to bladder management. Although the comprehensive assessment revealed that Ben had major problems in both defecation functions and urinary incontinence, he only had problems in regulating urination in daily life. Thus, it was only necessary to tackle Ben's bladder management problems with interventions. The interventions provided by the physician and nurses included instruction on catheter use and medication.

For other interventions provided during Ben's Rehab-Cycle® *see "Table 3: ICF Intervention Table" on page 34 at the end of this booklet.*

Evaluation

Approximately one month after Ben's Rehab-Cycle® started and shortly before his discharge, a final evaluation of his functioning was undertaken.

During this final evaluation, each member of the rehabilitation team provided feedback regarding Ben's status in the intervention targets. **The purpose of this evaluation was to assess whether there was improvement in the intervention targets identified during the assessment phase and whether the goals set were achieved.**

Normally, the results of the final evaluation would have been documented using the **ICF Evaluation Display**, a "before and after" visualisation (bar chart) of Ben's functioning in terms of ICF qualifier ratings given at the beginning and at the end of the Rehab-Cycle®. The ICF Evaluation Display is intended to help with determining whether the goal set for each intervention target, the global, service-program, and cycle goals were achieved at the end of the Rehab-Cycle®. However, in the case study of Ben, only a verbal confirmation of the successes and open issues was provided.

"As a whole, the rehabilitation team concluded that the interventions performed before and during Ben's Rehab-Cycle® had been successful in preparing him for community reintegration."

As a whole, the rehabilitation team concluded that the interventions performed before and during Ben's Rehab-Cycle® had been successful in preparing him for community reintegration.

Regarding Ben's goal of vocational reintegration, a new apprenticeship in a new vocational field was arranged and an agreement for the 3-month-internship was in place.

> *"Thanks to the initiative of the vocational counsellor at the clinic, I quickly found a new apprenticeship."*
>
> *Ben at the end of Rehab-Cycle®*

With regard to the goal of improving mobility, the wheelchair that the OT had ordered was delivered and adjusted to Ben's specifications. Ben was also able to take the written exam to get the special driver's license. However, the practical exam was still pending at the time of the final evaluation. Also pending was the final decision about the choice of car Ben would buy. Consequently, it was not possible to undertake the necessary adaptations to the car.

Regarding the goal of ensuring accessible housing, the architectural modifications to Ben's home were almost finished. This meant that Ben's goal of being discharged to an accessible home was achieved.

Despite these successes, some issues of cost coverage and financial support remained unresolved at the end of Ben's Rehab-Cycle®. Specifically, the final approval of the applications for cost coverage for various products delivered and interventions that had already been initiated or completed was still pending. This included applications for assistive devices, home modifications, car adaptations, the language course in the United States, and income support.

Nevertheless, Ben was seen as ready for community reintegration. This included having knowledge about his rights as a person with disability and the processes for claiming benefits and cost coverage through the Disability Insurance and other funding sources. This knowledge is very important to have as a person with disability in the community. Although the rehabilitation team, especially the OT and the social worker, actively involved Ben in the process of clarifying and applying for cost coverage and income support, Ben stated that he acquired much of his knowledge about his rights and navigating the insurance and social security systems from his peers at the rehabilitation centre:

> *"I learned most of what I know about my legal rights and how I can apply them from other people with SCI."*
>
> *Ben shortly before discharge*

To further support Ben in manoeuvring around the insurance and social security systems after discharge, the social worker prepared an information sheet with details of all relevant insurances and government authorities, including addresses and contact persons.

Case Study 20 | Rights of Persons with SCI | Evaluation

Discussion

This case of Ben shows the importance of being aware of the legal (and insurance/social services) framework and corresponding regulations that could influence rehabilitation planning and interventions, and planning of community reintegration.

This knowledge is important to help ensure that persons with spinal cord injury (SCI) who are engaged in rehabilitation, like Ben, receive the benefits he or she is entitled to and that are essential for successful rehabilitation and community reintegration. It is also valuable for empowering these persons to take the responsibility for applying these rights in life situations, such as in accessing healthcare services.[9]

"...being able to access healthcare services is not just about the availability of services, it is also about the utilisation of the available services."

Empowerment Through Knowledge and Advocacy

The right to access healthcare is one of the many fundamental rights a person with disability has according to the *United Nations Convention on the Rights of Persons with Disabilities (CRPD)*.[3] Accessibility is a central theme throughout the CRPD along with its emphasis on autonomy and self-determination. With regard to healthcare, however, being able to access healthcare services is not just about the availability of services, it is also about the utilisation of the available services.[22] **One way to promote the utilisation of available services, according to the International Perspectives on Spinal Cord Injury (IPSCI) report, is to empower persons with SCI (and their family members) by providing them with information and education so that they are able to look after their own healthcare to the greatest extent possible.[9] This could include information and education about relevant social security and anti-discrimination legislation, regulations and corresponding administrative procedures.**

In addition to empowering persons with SCI with knowledge and information, **there is also a need to provide advocacy and assistance with regard to the legal system and insurance benefits.** In a study of 81 newly injured persons with traumatic SCI receiving independent living services in the community, 37% of the participants indicated that assistance with legal rights was an unmet need. Furthermore, 29% indicated that the need for assistance in obtaining governmental benefits was not met.[23]

In Ben's case, the social worker and occupational therapist (OT) were pro-active in involving Ben in the process of clarifying his eligibility and applying for cost coverage for health (e.g. bladder management training) and health-related products, technology, and services (e.g. home modifications). Furthermore, Ben gained knowledge about his rights as a person with disability and received helpful tips for dealing with the complexities of the insurance and social security systems from his peers at the rehabilitation centre.

The Value of Peer Support

As seen in Ben's case, peers (other persons with SCI) can be a valuable source of knowledge and support. The advice and support, such as pointing out specific services, agencies and sources of funding, received from someone who has had similar experiences and faced similar challenges can have a powerful empowering effect. The personal experience of living with SCI lends credibility to the advice given by a peer. **It has also shown to have the potential of improving rehabilitation outcomes. For these reasons, peer mentoring is increasingly becoming an integral part of rehabilitation programmes.[9,17,24]**

Peer support can be provided on an informal basis or within a formal peer mentoring programme. Based on their 2-year study on the reintegration and quality of life of adults with SCI living in the community, Boschen and colleagues advocate for offering both informal and formal opportunities for exchanging peer advice and providing peer support, since some may be more willing to utilise informal peer support than formalized peer mentoring programmes.[17]

Irrespective of the type of peer support – informal or formal, peer support can strengthen the rehabilitation of persons with SCI.[9,17,24]

"The advice and support...received from someone who has had similar experiences and faced similar challenges can have a powerful empowering effect."

As illustrated by this case study of Ben, gaining insight into legal and social security challenges that a person with SCI can face and acquiring knowledge about disability rights and strategies for navigating the complex legal and social security systems, can provide the necessary tools to be successful in living independently in the community.

Annex

– *Table 1: ICF Assessment Sheet*
– *Table 2: ICF Categorical Profile*
– *Table 3: ICF Intervention Table*
– *Literature*
– *Questions*

Table 1: ICF Assessment Sheet

ICF Assessment Sheet

		Body Functions & Structures	Activities & Participation
Patient Perspective		– My bladder and bowels don't function anymore – I have pressure sores at my heel – Some areas of the skin are hypersensitive, for example my bottom – I have pain in my upper legs – I have pain in my wrist due to a fracture several years ago – I have no sleep problems – My sense of balance that was really good before the accident came back very quickly – I have bladder spasms mainly in the evenings and that is my main issue at the moment	– I can catheterise independently – I am not able to finish my apprenticeship as a carpenter – I am independent in daily living and in my routines – In the morning hours I am as fast as I was before the accident because I now follow a routine – I have no problems with mobility, but since I am currently not able to drive a car; I have to travel by train – If I travel by train, I have to call the SBB (Swiss Railways) to request that someone is onsite to help me get onto and off the train I cannot snowboard anymore – I am currently planning a holiday with my family – I go out in the evening like before the accident
Health Professional Perspective		– No impairment in sleep functions – Complete impairment in proprioceptive functions – Complete impairment in touch functions – No impairment in blood pressure functions – Mild neuropathic pain in lower limb (upper leg) – Mild pain in wrist due to a previous injury – Complete impairment in defecation functions – Moderate impairment in weight maintenance functions – Severe impairment in urinary continence – Complete impairment in sexual functions – Mild impairment in mobility of joint functions, as well as in power of muscles of lower half of the body – Mild impairment in protective functions of the skin – Complete impairment of the thoracic spinal cord – Moderate impairment of the structure of the urinary system	– Mild difficulty in carrying out daily routine – Mild difficulty in handling stress and other psychological demands – No difficulty in transferring himself – No difficulty in fine hand use – Complete problems in walking and moving around – Will have no difficulty in moving around within the home once modifications are completed. Otherwise, moderate difficulty. – Moderate difficulty in moving around within buildings other than his home, as well as in moving around outside the home and other buildings – No difficulty in moving around using equipment – Moderate difficulty in using transportation – Complete difficulty driving a car, not because he is not capable to but rather because he still does not have a special driver's license to drive an adapted car – No difficulty in washing himself nor dressing – Severe difficulty in regulating urination – No difficulty in regulating defecation – Mild difficulty in looking after his health – Severe difficulty in intimate relationships – He cannot return to his apprenticeship as a carpenter; will start a new apprenticeship as an administrative clerk – Severe difficulty in engaging in recreation and leisure

Environmental Factors	Personal Factors
– Electro-TENS is extremely helpful – Medication to treat bladder spasms in the evening is also extremely helpful – Stairs and sloping pavements are moderate barriers – Bank ATMs and kiosks are also moderate barriers – Architectural modifications to make home accessible, especially bathroom, are necessary – Huge circle of friends are supportive – There is a wheelchair club close to home – The experience of other wheelchair users plays an extremely important role – Support of health professionals, including the social worker, is very helpful – The topic of sexuality seems to be taboo, even in the rehab hospital, thus the role of the urologist is very important – Understanding the complexities of the insurance system is extremely difficult	– 18 years old, male – Living with parents and younger brother – Being sporty facilitated rehabilitation – Having previous mental training is an advantage – Always did well in school – Is ambitious and pro-active – Has no psychological issues – Accepts disease well – Positive attitude

Table 2: ICF Categorical Profile

ICF Categorical Profile											
Assessment											
Global Goal: Community reintegration											
Service-Program Independence in daily living											
Cycle Goal 1: Clarification of vocational re-orientation											
Cycle Goal 2: Improvement in mobility											
Cycle Goal 3: Accessible housing											
ICF categories		**ICF Qualifier**									**Goal Relation**
						problem					
						0	1	2	3	4	
b130	Energy and drive functions										
b134	Sleep function										
b152	Emotional function										
b260	Proprioceptive functions										
b265	Touch functions										
b28015	Pain in lower limb										2
b28016	Pain in joints										2
b420	Blood pressure functions										
b440	Respiration functions										
b445	Respiratory muscle functions										
b455	Exercise tolerance functions										2
b525	Defecation functions										
b530	Weight maintenance functions										
b550	Thermoregulation functions										
b6202	Urinary continence										
b640	Sexual functions										
b710	Mobility of joint functions										2
b7305	Power of muscles of the trunk										2
b7303	Power of muscles on lower half of the body										
b7353	Tone of muscles of lower half of the body										2
b740	Muscle endurance functions										2
b750	Motor reflex functions										
b755	Involuntary movement reaction functions										
b760	Control of voluntary movements										
b7603	Supportive functions of arms										2
b765	Involuntary movement functions										
b780	Sensations related to muscles and movement functions										
b810	Protective functions of the skin										
b820	Repair functions of the skin										
s12001	Thoracic spinal cord										
s610	Structure of the urinary system										
s730	Structure of upper extremity										
s810	Structure of areas of skin										
d230	Carrying out daily routine										
d240	Handling stress and other psychological demands										
d410	Changing basic body positions										
d4153	Maintaining a sitting position										
d420	Transferring oneself										
d430	Lifting and carrying objects										
d440	Fine hand use										
d445	Hand and arm use										
d450	Walking										
d455	Moving around										

Table 2: ICF Categorical Profile continued

ICF categories		ICF Qualifier									Goal Relation
						problem					
						0	1	2	3	4	
d4600	Moving around within the home					■	■	■			2
d4601	Moving around within buildings other than home					■	■	■			2
d4602	Moving around outside the home and other buildings					■	■	■			2
d465	Moving around using equipment					■					2
d470	Using transportation					■	■	■			2
d475	Driving					■	■	■	■	■	2
d510	Washing oneself					■					
d520	Caring for body parts					■					
d5300	Regulating urination					■	■	■	■		SP
d5301	Regulating defecation					■					
d540	Dressing					■					
d550	Eating					■					
d560	Drinking					■					
d570	Looking after one's health					■	■				
d620	Acquisition of goods and services					■					
d760	Family relationship					■					
d770	Intimate relationship					■	■	■	■		
d840	Apprenticeship					■	■	■	■	■	1
d870	Economic self-sufficiency					Needs clarification					1
d920	Recreation and leisure					■	■	■	■		G

ICF categories		ICF Qualifier									Goal Relation
		facilitator					barrier				
		4+	3+	2+	1+	0	1	2	3	4	
e110	Products or substances for personal consumption		■	■	■	■					
e115	Products and technology for personal use in daily living		■	■	■	■					
e120	Products and technology….for personal…mobility …		■	■	■	■					2
e140	Products and technology for culture, recreation and sport					■					
e150	Design, construction…of buildings for public use					■	■	■			
e155	Design, construction…of buildings for private use			■	■	■					3
e310	Immediate family	■	■	■	■	■					
e320	Friends	■	■	■	■	■					
e325	Acquaintances, peers, colleagues, neighbours…	■	■	■	■	■					
e355	Health professionals		■	■	■	■					
e360	Other professionals				■	■					
e410	Individual attitudes of immediate family members	■	■	■	■	■					
e420	Individual attitudes of friends	■	■	■	■	■					
e450	Individual attitude of health professionals			■	■	■					
e515	Architecture and construction services, systems…			■	■	■					
e540	Transportation services, systems and policies			■	■	■					
e555	Associations and organizational services, systems…		■	■	■	■					
e570	Social security services, systems and policies		■	■	■	■					
e580	Health services, systems and policies		■	■	■	■					
pf	Sporty person			■	■	■					
pf	Optimistic person			■	■	■					
pf	Coping strategies			■	■	■					
pf	Acceptance of disease			■	■	■					

Table 2: ICF Categorical Profile; ICF Qualifier: rate the extent of problems (0 = no problem to 4 = complete problem) in the components of body functions (b), body structures (s), activities and participation (d) and the extent of positive (+) or negative impact of environmental (e) and personal factors (pf); Goal Relation: 1, 2, and 3 refer to Cycle Goals 1, 2, and 3; SP refers to the Service-Program Goal; G refers to the Global Goal.

Table 3: ICF Intervention Table

ICF Intervention Table

	Intervention target		Intervention	Applicable legislation and regulations[4,5,7,14,15]	Doc	Nurse	PT	Spo	OT	VC	SW	Other
Body functions/structures	b28015	Pain in lower limb	Electrotherapy				x					
			Medication		x	x						
	b28016	Pain in joints (wrist)	Clarification of pain		x							
	b130	Energy and drive functions	Arm ergometry					x				
	b710	Mobility of joint functions	Passive movements				x					
			Swimming				x					
	b7305	Power of the muscles of the trunk	Training with equipment					x				
	b7353	Tone of muscles of lower half of body	Electric muscle stimulation				x					
			Water therapy				x					
	b740	Muscle endurance functions	Training with equipment					x				
	b7603	Supportive functions of arm or leg	Instruction on alternative support techniques; Prop-up training				x					
	d4600	Moving around within the home	Counselling on possible architectural modifications to home	Access to assistive devices and technology in general: Article 21 of IVG and Article 2 of the HVI; Cost coverage for diverse architectural modifications to the home and assistive devices, e.g. wheelchair lift: Paragraph 14 in the list of assistive devices enclosed in the HVI; Cost coverage for disability-related modifications of buildings: Article 14, Paragraph 1b of IVV								x
			Clarification of cost coverage for modifications and assistive devices for making home accessible						x			
	d4601	Moving around within buildings other than home	Wheelchair training	Accessibility of buildings and public transportation systems: Articles 3, 7, and 15 of BehiG					x			
	d4602	Moving around outside the home and other buildings	Outdoor wheelchair training; City training	Accessibility of buildings and public transportation systems: Articles 3, 7, and 15 of BehiG					x			
Activities / Participation	d465	Moving around using equipment	Wheelchair purchase; Wheelchair training	Access to assistive devices and technology in general: Article 21 of IVG and Article 2 of the HVI; Acquisition and cost coverage for assistive devices: Article 14 of IVV and Paragraph 9 (wheelchair) in the list of assistive devices enclosed in the HVI					x			
	d470	Using transportation	Assistance with acquiring the Disabled Passenger's ID Card for the Swiss Federal Railways SBB	Accessibility of buildings and public transportation systems: Articles 3, 7, and 15 of BehiG					x		x	
	d475	Driving	Instruction on driving an adapted car; Counselling on possible car adaptations; Ordering of an adapted car	Cost coverage of car adaptation: Article 8 in HVI and Paragraph 10 in the HVI list of assistive devices; Cost coverage for driving instruction: Article 7, Paragraph 1 of HVI					x			x
			Clarification of cost-coverage for an adapted car								x	
	d5300	Regulating urination	Instruction on catheter use; Medication		x	x						
	d840	Apprenticeship	Vocational counselling including arrangements for transition phase activities (internship, English course in USA); Participation in computer (Excel) and language (English and French) courses	Vocational counselling: Article 15 of IVG; First vocational training: Article 16 of IVG; Vocational re-training: Article 17 of IVG; Daily allowance provisions for first vocational training and re-training: Article 22 of the IVV; Job placement and internship including provisions for a daily allowance: Article 18 of IVG and IVV, and Article 4, sub-paragraph 5.2 of the IVV; Access to assistive devices and technology: Article 21 of IVG; Assistive devices and physical adaptations to the workplace: Paragraph 13 in the list of assistive devices enclosed in the HVI						x		
			Clarification of cost coverage for language course in the United States; Assistance with applying for financial assistance from Swiss Paraplegic Foundation							x	x	

Activities / Participation	d870	Economic self-sufficiency	Clarification of income support as part of insurance benefits, including during transition period before apprenticeship starts	Daily allowance in general: Article 22-25 of the IVG; Daily allowance provisions for first vocational training and re-training: Article 22 of the IVV Provisions for a daily allowance: Article 18 of IVG and IVV						x	x	
	d920	Recreation and leisure	Sport therapy					x				
Environmental factors	e1201	Assistive products and technology for personal indoor and outdoor mobility and transportation	Counselling regarding a suitable wheelchair and possible car adaptations; Ordering of the wheelchair and helping to make arrangements for acquiring an adapted car	Cost coverage for wheelchair: Paragraph 9 in the HVI list of assistive devices; Cost coverage of car adaptation: Article 8 of HVI and Paragraph 10 in the HVI list of assistive devices; Cost coverage of the training to drive an adapted car: Article 7, Paragraph 1 of HIV					x			x
			Clarification of cost coverage for ordering the wheelchair and acquiring an adapted car								x	
	e155	Design, construction and building products and technology of buildings for private use	See d4600 Moving around within the home									

Table 3: ICF Intervention Table; Doc = Physician; PT = Physical Therapist; Spo = Sports Therapist; OT = Occupational Therapist; Psych = Psychologist; VC = Vocational Counsellor; SW = Social Worker. IVG = Federal Law on Disability Insurance; HVI = Federal Regulations on the Distribution of Assistive Devices through the Disability Insurance; IVV = Federal Disability Insurance Regulations; BehiG = Federal Disability Anti-Discrimination Act; ATSG = General Part of the Federal Social Insurance Law. No personal factors were identified as intervention targets.

Case Study 20 | Rights of Persons with SCI | Annex

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Questions

Q1. **Name the two types of legislation in Switzerland that define the definition of disability.** *(Refer to page 9 for the answer.)*

Q2. **Which Articles of the *United Nations Convention on the Rights of Persons with Disabilities* address the right to work and call for return-to-work progammes?** *(Refer to page 15 for the answer.)*

Q3. **Which Swiss laws address the accessibility of public transport?** *(Refer to page 15 for the answer.)*

Q4. **Name Ben's 3rd cycle goal and the corresponding intervention targets.** *(Refer to page 30 for the answer.)*

Q5. **Explain the value of peer support in awareness-building about the legal (insurance/social services) framework and corresponding regulations.** *(Refer to page 25 for the answer.)*

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