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ICF Case Studies

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

# Time-Related Aspects

Case Study 16



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## 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.

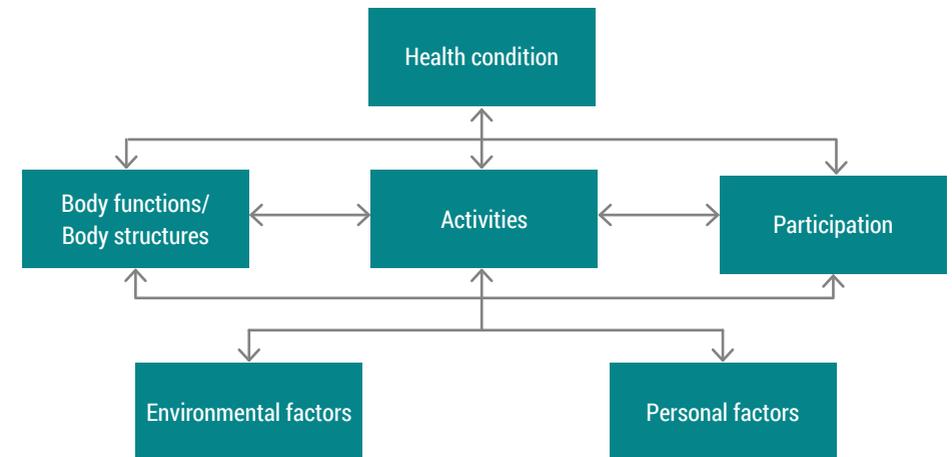


Figure 1: Bio-psycho-social model of functioning, disability and health

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.

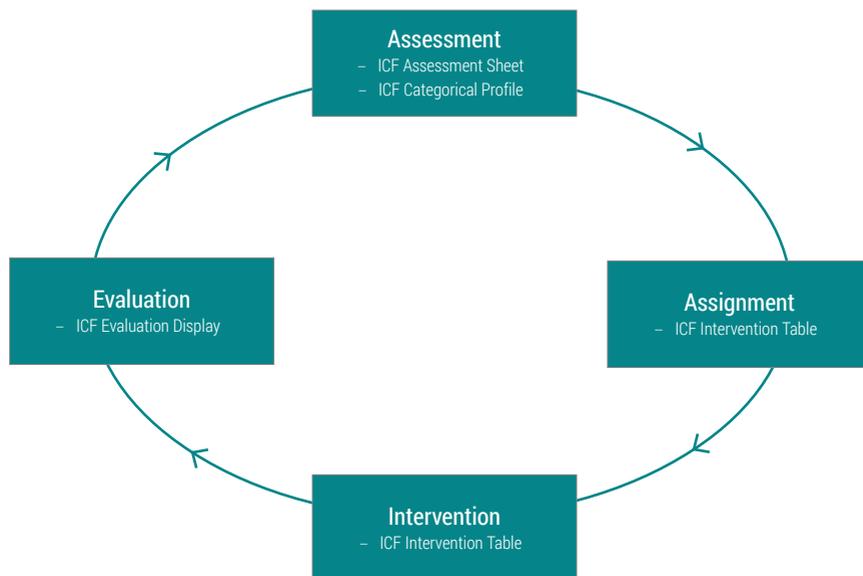


Figure 2: Rehab-Cycle®

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](http://www.icf-casestudies.org).

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## General Introduction



The aspect of time can have an impact on the lived experience of persons with spinal cord injury/disorder (SCI/SCD) – on a person's independence in daily activities and participation in economic, social, and community life.

*"Everything around me moves so fast...people with disabilities are not taken into consideration."*

*Stefan, an adolescent with spina bifida reflecting on the aspect of time*

The International Classification of Functioning, Disability and Health (ICF) describes "disability" as the dynamic interaction between impairments in body functions and body structures, limitations in activities, restrictions in participation, and both environmental and personal factors.<sup>1</sup> Although not specifically addressed in this description, disability can lead to a level of dependency in daily living.

Dependency pertaining to disability is often characterised by the reliance on a person (e.g. personal assistant) or technical equipment (e.g. assistive

device) in order to perform tasks autonomously and/or participate in life situations. The role of environmental factors, such as physical barriers, has also been mentioned in the context of dependency.<sup>2,3</sup> **The degree of dependency, or from a positive standpoint – independence – in a given activity not only relates to the extent a person can perform activities without personal or technical assistance, but also the time available and necessary to perform them.** Temporal (time) aspects of functioning are implicitly and explicitly addressed across a number of categories in the ICF.

### Box 1 | Aspect of Time As Reflected in the ICF

The following are examples of ICF categories (in verbatim)<sup>1</sup> in which the aspect of time is reflected:

- **b1642 Time management:** Mental functions of ordering events in chronological sequence, allocating amounts of time to events and activities.
- **d210 Undertaking a single task:** Carrying out simple or complex and coordinated actions related to the mental and physical components of a single task, such as initiating a task, organising time, space and materials for a task, pacing task performance, and carrying out, completing, and sustaining a task.
- **d220 Undertaking multiple tasks:** Carrying out simple or complex and coordinated actions as components of multiple, integrated and complex tasks in sequence or simultaneously.
- **d230 Carrying out daily routine:** Carrying out simple or complex and coordinated actions in order to plan, manage and complete the requirements of day-to-day procedures or duties, such as budgeting time and making plans for separate activities throughout the day.
- **d850 Remunerative employment:** Engaging in all aspects of work, as an occupation, trade, profession or other form of employment, for payment, as an employee, full or part-time, or self-employed, such as seeking employment and getting a job, doing the required tasks of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups.

### Assessing Independence of Persons with SCI/SCD

A number of instruments are available to assess independence (dependency) of persons with disability in various areas of functioning.

**The Functional Independence Measure (FIM)<sup>®</sup> is one example of an instrument that was designed to measure independence in a person living with any disability (not specifically for persons with SCI or SCD).**<sup>4,5</sup> In FIM, independence is assessed using 18 items in the areas of self-care, sphincter control of bladder and bowel, transfers,

locomotion, communication, and social cognition. The 18 items are graded according to a seven-point scale with a score of 7 indicating complete independence to a score of 1 indicating total assistance (or complete dependency). Although only the score of 7 refers to the timeliness of completing an activity, **FIM scoring is considered a reflection of "burden of care" i.e. the amount of time and ene.g. provided by another person or the amount of time the person needs when using assistive devices to do an activity.**<sup>4</sup>

*“Despite the fact that FIM is widely accepted and employed in rehabilitation, there are some limitations to using it in the SCI/SCD population.”*

Despite the fact that FIM is widely accepted and employed in rehabilitation, there are some limitations to using it in the spinal cord injury/spinal cord disorder (SCI/SCD) population.<sup>4,6,7</sup>

An instrument that has been developed to assess the independence of persons with SCI or SCD is the Spinal Cord Independence Measure (SCIM).<sup>6,7</sup>

### Box 2 | Spinal Cord Independence Measure (SCIM)

The current version of SCIM<sup>8</sup> contains 19 items that cover the sub-scales of Self-care, Respiration and Sphincter Management, and Mobility:

- **Self-care; 6 items:** Feeding, Bathing the upper and lower body, Dressing the upper and lower body, and Grooming
- **Respiration and Sphincter Management; 4 items:** Respiration, Sphincter management bladder, Sphincter management bowel, and Use of toilet
- **Mobility (room and toilet); 3 items:** Mobility in bed and action to prevent pressure sores, Transfers bed-wheelchair, and Transfers wheelchair-toilet-tub
- **Mobility (indoors and outdoors, on even surface); 6 items:** Mobility indoors, Mobility for moderate distances (10-100 metres), Mobility outdoors (more than 100 metres), Stair management, Transfers wheelchair-car, and Transfers ground-wheelchair

A SCIM score (0-100) is reached by adding up the sub-scale scores (0-10 in Self-care, 0-40 in Respiration and Sphincter Management, 0-40 in Mobility). The scoring of each

item is different. For example, the scoring for Bathing the upper body goes from "0; Requires total assistance" to "3; Washes independently, does not require adaptive devices or specific setting...", while Mobility indoors goes from "0; Requires total assistance" to "8; Walks without walking aids", with scores 1-7 indicating a specific type of mobility aid.<sup>8</sup>

A self-report version of SCIM (SCIM-III-SR) is also available.<sup>9</sup>

Unlike FIM, SCIM-III and SCIM-III-SR do not contain any references to the amount of time a person needs to complete an activity. The aspect of time only refers to the frequency assistance is required.<sup>6,8,9</sup> Thus, **a person can score high on a particular item in SCIM even though that person needs a lot of time to complete the targeted activity independently.**

### Assessing Independence of Children/Youth with SCI/SCD

*“...for optimal use in children and youth, the items and response options [of SCIM-III-SR]...had to be reworded to adapt to the language children and youth are able to read and understand.”*

Despite the lack of scientific literature on the specific use of SCIM-III in children and youth, SCIM-III is seen as highly relevant for this age group as well.<sup>10</sup> However, for optimal use in children and youth, the items and response options required modifications. Based on formal cognitive testing and a Delphi study using SCIM-III-SR, Mulcahey et al. found that the items and the response options had to be reworded to adapt to the language children and youth are able to read and understand. Some items also required a bit more explanation. For example, the item "Bladder management. Please think about the

way you empty your bladder" was reworded to say "Do you need help with urination, or how you pee?". Instead of "Use of indwelling catheter" one response option was reworded as "I have a tube (foley) inside of me all the time that lets me urinate (pee)". Consequently, Mulcahey et al. developed a paediatric version of SCIM-III-SR (SCIM-III-SR-Y).<sup>10</sup>

Again, **like the other versions of SCIM, SCIM-III-SR-Y does not contain any references to the amount of time a person needs to complete an activity.**<sup>6,8,9,10</sup>

### Time Issues and SCI/SCD

While few studies have addressed issues of time in relation to the functioning of persons with disability, the available research indicates that persons with disability require more time to complete daily activities as compared to those without disability. Persons with disability spend

more time on household duties, sleeping, personal care, medical treatment, etc. In a study conducted by Strazdins et al. persons with disability were more likely to report feeling rushed and having insufficient time for completing activities.<sup>11,12</sup>

*“...the inability to meet time demands of a job is seen as a possible hindrance for persons with disability to participate in the workforce... providing assistance that optimises the time spent on everyday activities... (can) ultimately increase the labour market participation of persons with disability.”*

Furthermore, the inability to meet time demands of a job is seen as a possible hindrance for persons with disability to participate in the

workforce. However, it has been suggested that providing assistance that optimises the time spent on everyday activities such as household

duties, can increase the time available for work and ultimately increase the labour market participation of persons with disability.<sup>11,12</sup>

These findings are consistent with results of scarce research investigating time issues related specifically to persons with SCI/SCD.

In one study that was found, Pentland et al. reported that the 312 men with SCI living in the community who they included in the study spent considerably more time (on average 78 minutes/day versus 40 minutes/day in the non-SCI group) on personal care activities e.g. washing, dressing, medical care, than men without SCI, and 20% more time on leisure activities, predominately with communication or media-related activities, than those without SCI.<sup>13</sup> In another study conducted by Burns et al., participants with SCI reported being frustrated that the increased time

requirements for bowel management (compared with before the injury) took time from other activities and placed restrictions on their daily schedule.<sup>14</sup> This is supported by the findings of Gribble et al. who investigated the predictors of toileting time of children with spina bifida.<sup>15</sup>

With regard to time-related issues and work participation, Pentland et al. found that study participants with SCI spent on average 2.7 less hours or 53% less time in paid work than those without SCI.<sup>13</sup> In another study Schönherr et al. revealed that 47% of the employed study participants reported working under time pressure, and 21% wanted more job modifications, specifically more freedom with personal time management.<sup>16</sup>

Extensive time requirements to complete daily activities can also impact on social participation.

*"It looks awkward when you're using the bathroom for 45 minutes in someone's house."*

*Participant of Burns et al. study on reluctance to leave home for socialising<sup>14</sup>*

In the case of children/youth, extensive time requirements for example for bowel or bladder management<sup>15</sup> could mean that the child/young person experiences restrictions in socialising at the playground or learning in a classroom with other pupils.

### Time Issues and Independence – A Case Study

Although an association is not always clearly shown (see information above on SCIM-III and SCIM-III-SR-Y), independence and time issues are ever-present themes in the lives of persons with SCI/SCD. This is evident in the case of Stefan, a young man living with spina bifida.

**In short, persons with disability, including those with SCI/SCD, require more time to complete everyday activities. This, in turn, can result in restricting participation in various life situations.**

This case study of Stefan illustrates how time issues confounded the challenges he faced in his effort to increase his independence in daily activities.

## Stefan's Story



This is the story of Stefan, an adolescent born with spina bifida, a congenital condition affecting the central nervous system, who also incurred a traumatic cervical spinal cord injury (SCI). Stefan's case highlights how the aspect of time impacts his independence in daily activities and lived experience in general.

**Stefan, 17 years old at the time of the case study, was born with myelomeningocele spina bifida, the most common and severe form of spina bifida<sup>17</sup>.** When Stefan was 2 years old he developed hydrocephalus, an abnormal build-up of cerebrospinal fluid in the brain causing increased pressure within the skull,<sup>17</sup> and later scoliosis,<sup>18</sup> that led to stiffening of his spine as a result of surgeries to correct the scoliosis.

Stefan spent much of his young life undergoing medical procedures and rehabilitative interventions to treat a number of secondary conditions e.g. dislocation of the bone from the hip joint and pressure ulcers related to his spina bifida. The extensive medical procedures began with surgeries at the age of nine, and rehabilitation

interventions followed after **a traumatic SCI that he experienced as a result of a skibob accident when he was 15 years old.**

Stefan's incomplete SCI at the 6th cervical vertebrae was graded with an American Spinal Injury Association (ASIA) Impairment Scale grade C. This meant that **he had motor functioning below the elbow region, albeit with decreased muscle power. Stefan experienced paralysis from the hip region and below, with total paralysis from the knee and below. Furthermore, he was unable to control his bladder and bowel once they were full.**

At the time of the case study Stefan was living with his family. He enjoyed solitude, maintaining

only a few close friendships, and reported being a passionate reader, a gifted panpipe player, and skilled in working with computers.

Stefan was soon to graduate from a regular school, and after graduating he had intended to take part in a one-year vocational preparatory course.

In preparation for this new phase of life, Stefan's health insurance agreed to pay for a three-week in-patient rehabilitation programme specifically designed to increase the independence of adolescents with congenital SCD or traumatic SCI. **Stefan hoped to gain more independence**

**not only through the interventions within the rehabilitation programme, but also through the experience of travelling by train between the rehabilitation centre and home every weekend.**

In the structured rehabilitation programme the rehabilitation team conducted a comprehensive assessment of Stefan's functioning, and together with Stefan set individualised rehabilitation goals based on the assessment results. The rehabilitation team performed interventions to meet those goals and re-evaluated Stefan's functioning at the end of the rehabilitation programme in order to make recommendations for further measures.

## Assessment

At the beginning of the rehabilitation programme a comprehensive assessment was conducted to identify Stefan's and the rehabilitation team's perspective of his functioning status.

The results of the comprehensive assessment of Stefan's functioning, that included an interview with Stefan as well as diverse tests and examinations performed by individual rehabilitation team members, was summarised on the **ICF Assessment Sheet** and presented according to the components of the **International Classification of Functioning, Disability and Health (ICF)**.<sup>1</sup> While some of Stefan's statements during the interview were listed under "Patient Perspective" in the ICF Assessment Sheet, the rehabilitation team assessment results were presented under "Health Professional Perspective" in ICF terms without

codes. See "Table 1: ICF Assessment Sheet" on page 30 at the end of this booklet.

For example, under the ICF component of body structures and functions Stefan's sensory problems were expressed in Stefan's statements "the sensitivity in my body decreases more and more, the lower the body location" and "I can't sense any pressure when sitting". This was supported by the rehabilitation team, who documented moderate to severe impairment in proprioceptive functions, touch functions and sensations related to muscles and movement functions.

### Independence in Mobility and Self-care

Under the ICF component of activities and participation, Stefan's mobility problems were expressed in several statements:

*"I can't transfer in and out of the car...When I fall out of the wheelchair I am unable to get back by myself."*

*Stefan during the initial interview*

**The rehabilitation team supported Stefan's statements about his mobility problems**, and added that in addition to having severe difficulty in transferring himself, Stefan also had severe difficulty using public transportation.

One factor that contributed to Stefan's mobility limitations was his stiffened spine resulting from the surgeries to treat scoliosis. Another

contributing factor was spasticity (increased muscle tone); this led to reduced mobility of Stefan's right elbow joint, that in turn, impacted on transferring and other mobility problems.

**In addition to mobility problems, Stefan faced problems in self-care.** He was unable to dress nor wash himself independently, requiring assistance (most often provided by his mother) for eating, toileting and looking after his health e.g. controlling for bed sores or other skin conditions.

**Stefan's low or lack of independence in some aspects of mobility and self-care is consistent with research** that indicate that body function impairments in persons with spina bifida, especially in the lower extremities, are determinants of independence in mobility and self-care.

Schoenmakers et al. found that mental status, contractures and muscle strength in the lower extremities of children with spina bifida were strong determinants of independence in mobility and self-care. Specifically, mental ability, good muscle strength, and no contractures were associated with independence in mobility and self-care.

Muscle strength in the knee was also found to be significantly associated with independent transferring, stair-climbing, and moving around indoors and outdoors. Furthermore, independence in mobility seemed to contribute more to quality of life than independence in self-care.<sup>19</sup> These study results were supported by other study findings.<sup>20</sup>

### Aspect of Time and Independence in Mobility and Self-care

The aspect of time played a major role in Stefan's independence in mobility and self-care, or lack thereof. He himself stated that he was slow in performing tasks, such as shaving, moving around, and using public transportation, and that time management was a problem for him. The rehabilitation team concurred, adding that Stefan had moderate difficulty in handling stress and severe difficulty carrying out a daily routine.

*"I am dependent on others for transferring from bed to wheelchair – with more time I am able to transfer more independently."*

*Stefan during the initial interview*

A possible contributing factor may have also been Stefan learning difficulties (based on his own statements). This is consistent with the aforementioned research that identified mental status as a determinant of independence in mobility and self-care.

*"Stefan's limited independence in mobility and time management problems had an impact on his performance of various daily activities as well as on his participation in major life situations."*

Stefan's limited independence in mobility and time management problems had an impact on his performance of various daily activities as well as on his participation in major life situations. At the time of the case study, Stefan had planned to attend a one-year vocational preparatory course

after finishing school. Since the course was offered in another city, his participation in the course was contingent upon Stefan's ability to independently use public transportation in a time-efficient manner.

### Influence of Contextual Factors on Independence

Contextual factors, both environmental and personal factors, also influenced Stefan's independence in daily life.

Stefan owned two manual wheelchairs and a Swiss-Trac™ (a motorised device for pulling the wheelchair). **Despite living in a wheelchair-adapted house, he frequently experienced the physical environment as a barrier.**

*"My mother does everything for me...she says: 'You should do this on your own,' but still goes ahead and helps me anyway."*

*Stefan*

In terms of personal factors, the fact that Stefan attended regular school rather than a special school for persons with disability, his thirst for knowledge (particularly history), and his plan to participate in a one-year vocational preparatory course were all facilitators of his functioning. In contrast, poor self-esteem (Stefan described himself as a "loner" and "lazy") and a fear of

For the majority of his activities of daily living, **Stefan received support from his family (primarily his mother).** While this support was welcomed, it also had an unintended consequence – Stefan gradually "unlearned" some of the skills necessary to perform activities such as transferring and self-care.

falling, in combination with an aversion to speed, were counterproductive to Stefan's efforts toward gaining independence.

The ICF Assessment Sheet provided an overview of Stefan's functioning that helped him and the rehabilitation team to identify his needs and to plan appropriate interventions.

## Goal-setting/Determination of Intervention Targets



Based on the results of the assessment conducted by the rehabilitation team as well as Stefan's own statements about his functioning, intervention targets and concrete goals to achieve during Stefan's participation in the three-week rehabilitation programme were identified.

In consideration of the assessment results and Stefan's expressed view about his functioning and independence in daily life, Stefan and the rehabilitation team identified three goals. They identified 'increased independence in daily routine' as a **service-program goal**, the goal to achieve at the

end of the rehabilitation programme. As small steps toward achieving the service-program goal, they identified 'improved mobility' and 'increased independence in self-care' as two **cycle goals**. Implicit in these goals is the efficient use of available time in performing daily activities.

*"Implicit in these goals is the efficient use of available time in performing daily activities."*

These three goals were documented on Stefan's **ICF Categorical Profile**, a visual depiction (bar graph) of his functioning status at the time of assessment. The bar graph reflects the ICF qualifier<sup>1</sup> rating given for each of the ICF categories and personal factors identified during the assessment. To compare Stefan's functioning at the

initial assessment with his functioning at the end of the rehabilitation programme, ICF qualifiers were also used to indicate the goal value i.e. the rating that was intended to be reached at the end of the rehabilitation programme. See "Table 2: ICF Categorical Profile" on page 32 at the end of this booklet.

The ICF categories (and personal factors) that correspond to any of the goals set and were associated with a goal value were considered **intervention targets**. The intervention targets were those categories intended to be addressed with specific interventions. For example, for his service-program goal 'increased independence in daily routine', Stefan and the rehabilitation team defined d230 Carrying out daily routine as an intervention target with a goal value of '2'. By setting this goal value, Stefan and the rehabilitation team expected an improvement in carrying out daily routine from severe to moderate difficulty after providing one or more interventions.

As intervention targets to address cycle goal 1 'improved mobility', Stefan and the rehabilitation team included body functions, for example b710 Mobility of joint functions and b730 Muscle power functions, as well as a range of activities and participation categories such as d410 Changing basic body positions and d470 Using transportation. Another example of an intervention target for cycle goal 1 'improved mobility'

is d420 Transferring oneself. Transferring is one aspect of functioning that Stefan highlighted during the initial assessment as especially problematic, requiring regular assistance from a helper (predominately from his mother). For this intervention target Stefan and the rehabilitation team set a goal value of '2' (moderate difficulty) from a starting point of '3' (severe difficulty).

Like with cycle goal 1, the intervention targets defined for cycle goal 2 'increased independence in self-care' encompassed body functions e.g. b620 Urination functions, as well as activities and participation categories e.g. d520 Caring for body parts, such as shaving. To optimally use the time available to Stefan for performing his morning self-care routine, the adaptation of assistive devices and learning better compensation strategies were necessary. Adaptation of assistive devices and learning better compensation strategies were examples of interventions that were identified for each intervention target and assigned to selected members of the rehabilitation team.

## Assignment and Intervention



While the nurse, physical therapist (PT) and occupational therapist (OT) were responsible for most of the interventions during Stefan's three-week rehabilitation programme, a number of intervention targets were also addressed by the physician, psychologist and other health professionals.

### Interventions Targeting Mobility

**Specific interventions to improve mobility were performed by both the OT and the PT. While the PT focused on addressing intervention targets from the body functions perspective, the OT provided interventions that targeted activities and participation.** For example, the PT performed manual therapy to improve joint mobility (b710), guided Stefan in completing regular circuit training to increase muscle power (b730), especially in his arms, and muscle strength training to improve

supportive functions of his arms (b7603). The PT also provided body balance training to help Stefan enhance his ability to maintain a sitting position (d4153). These intervention targets, in turn, were essential for improving Stefan's transferring skills. Transferring to and from the wheelchair (d420) – a crucial skill for being independent in daily living – was addressed by the OT, as well as by the PT and nurse, through instruction and regular transfer training.

*“...the interventions provided also aimed at optimising the amount of time Stefan needed for indoor and outdoor mobility.”*

The OT also provided city training, in both individual and group sessions, to help Stefan improve

his outdoor mobility, specifically his abilities to manoeuvre the wheelchair in different locations

(d460) such as streets, railway stations, trains, elevators. The group activities included Stefan's participation in a wheelchair club, weekly group counselling sessions during brunch, and visits to the circus, a zoo and a local lakeside café. Additionally, Stefan contributed to a group project that helped train his ability to plan tasks and actions, effective communication, and cooperation with others toward achieving a common goal.

Using public transportation (d470), specifically the train, was difficult for Stefan. Getting into an elevator at the train station with the Swiss-Trac™ was almost impossible since it took too much time to completely manoeuvre his wheelchair and Swiss-Trac™ into the elevator before the

doors closed. Once inside the train Stefan took a lot of time to undock the Swiss-Trac™ and take a place in the wheelchair compartment. Moreover, he was afraid of moving around in his wheelchair in the train. **These are among the mobility problems that slowed Stefan down in everyday life.** Thus, the interventions provided also aimed at optimising the amount of time Stefan needed for indoor and outdoor mobility.

In addition to the PT, OT, and the nurse, the physician also provided interventions to address Stefan's mobility issues i.e. the physician prescribed medication to reduce the spasticity Stefan had been experiencing.

### Interventions Targeting Self-Care

*“Shaving with the electric shaver is difficult for Stefan, since he doesn't know how much pressure is needed. It takes him about ten minutes to finish shaving – much longer than another person would require.”*

*Stefan's OT at the time of assessment*

The physician together with the nurse also contributed to addressing the problems Stefan had with toileting (d530), specifically the body functions aspects of toileting. The physician conducted regular clinical examinations, while the nurse assisted Stefan with using a device to clear

his bowel and in applying the condom catheter, and provided related instruction. **The nurse was also instrumental in addressing other intervention targets in self-care together with the OT.**

To improve Stefan's independence in self-care, the nurse and OT provided instruction and self-management training in caring for body parts (d520), dressing (d540), eating (d550), and looking after his health (d570). The OT assisted Stefan in finding compensation strategies to independently perform self-care activities and in a time-efficient manner.

### Interventions Targeting Contextual Factors

Members of the rehabilitation team coordinated their interventions to address contextual (environmental and personal) factors that impacted Stefan's independence in mobility and self-care. For example, both the PT and OT were involved in clarifying the ideal assistive devices for use in daily living (e1151).

*“Stefan had difficulties docking the Swiss-Trac™ to his wheelchair. Subsequently, a special funnel was attached that facilitated his handling of the wheelchair.”*

*Stefan's OT*

With regard to Stefan's personal factors, a psychologist provided counselling to help improve Stefan's assertiveness and self-confidence. This

### An Overview of Assignment and Intervention

Each of the intervention targets was assigned to one or more of the rehabilitation team members. The **ICF Intervention Table** provided an at-a-glance overview of the assignment of intervention targets to the respective team member(s) as well

was supported by the group activities led by the nurse, PT and/or OT.

as the ICF qualifier values defined for the first value and goal value as documented on the ICF Categorical Profile. See *"Table 3: ICF Intervention Table" on page 36 at the end of this booklet.*

## Evaluation



Shortly before Stefan's three-week rehabilitation programme ended, a final assessment took place to see whether the goals Stefan and the rehabilitation team set at the beginning of the programme were achieved.

**Overall, Stefan made significant progress towards gaining independence in his daily routine. Although he only met the cycle goal of improved mobility, there was still some improvement in the area of self-care.** Stefan's progress in the intervention targets was documented using the **ICF Evaluation Display**, an extended version of the ICF Categorical Profile that visually shows (as a bar graph) the rating given to each of Stefan's

intervention targets during the final assessment as well as from the initial assessment. Note that a comparison of the initial and final ratings only shows that there was a change, but not whether the change was due to the interventions. The ICF Evaluation Display also indicates whether the goals set were achieved or not. See *"Table 4: ICF Evaluation Display" on page 38 at the end of this booklet.*

### Goal Achievement in Mobility

Cycle goal 1 'improved mobility' was crucial to Stefan's overall independence in daily routine and specifically in order to participate in the one-year vocational preparatory course he had been planning to take upon finishing school.

At the end of the rehabilitation programme, Stefan was able to transfer himself (d420) from the bed to his wheelchair with supervision or with only

minimal assistance. While other transfers required more support, he improved his transferring skills as a whole. He also improved his ability to maintain a sitting position (d4153). However, due to his fear of falling backwards Stefan leaned on his left hand for support. Nevertheless, the rehabilitation team considered the goal they set for maintaining a sitting position as achieved.

*“...a new set of “faster” wheels allowed Stefan to manoeuvre his wheelchair more quickly.”*

With regard to moving around using equipment (d465), **Stefan was able to dock the Swiss-Trac™ to his wheelchair independently** following a simple technical adaptation. Although he still required assistance to overcome little steps and

uneven surfaces, at the end of the rehabilitation programme Stefan was able to move his wheelchair independently on even ground. Moreover, a new set of “faster” wheels allowed Stefan to manoeuvre his wheelchair more quickly.

*“Unfortunately, using the train remained a challenge.”*

Unfortunately, using the train remained a challenge. Stefan was still unable to use the elevators at train stations, since he was still too slow in moving into the elevator before the doors closed. In addition, he continued to take a considerable amount of time to undock and re-dock the Swiss-Trac™. As a result, Stefan blocked the train’s door, preventing the train from departing. Thus, the goal of using public transportation independently (d470) was not achieved.

Other mobility-related goals that were not achieved included improving mobility of the right elbow (b710), increasing muscle power in the arms (b730), and changing basic body positions (d410). In addition, spasticity (b735) remained a problem.

### Goal Achievement in Self-care

Although cycle goal 2 ‘increased independence in self-care’ was not achieved, Stefan took less time to care for body parts than at the beginning of the rehabilitation programme. Nevertheless, Stefan required help from others to care for his body parts (d520). Shaving remained a time-intensive task. However, the rehabilitation team felt that Stefan would become more efficient in shaving with additional practice.

At the end of the rehabilitation programme, Stefan was able to dress himself (d540) independently despite taking an average of 30 minutes to finish dressing.

Unfortunately no significant improvements were made in Stefan’s ability to look after his health. Forecasting that Stefan would continue to need support in performing self-care activities at home, the rehabilitation team involved Stefan’s mother in a therapy session to help her optimise the support she gives Stefan in these activities.

### Goal Achievement in Contextual Factors

The goals related to maximising the assistive products and technology for everyday use (e1151) and for mobility (e1201) were both achieved.

In terms of personal factors, the psychologist recognised the complexity of Stefan’s strategies for dealing with daily challenges and his life in general. On one hand, Stefan described himself to others as “dependent and lazy”; the psychologist saw this more as a strategy to maintain the status quo of dependency. On the other hand, Stefan possessed a personality trait that is goal-oriented

and driven, as evident by his intention of attending a one-year vocational preparatory course far from home as well as his mastery of playing the panpipe.

While Stefan’s personal factor goal of increasing his self-assurance was achieved, his goal of becoming more assertive was not.

*“He says that he is dependent and lazy. But he hides behind this.”*

*Psychologist at final assessment*

## Discussion

While few studies have specifically explored the temporal aspects of living with a spinal cord injury (SCI) or a spinal cord disease (SCD), this case of Stefan, a person living with spina bifida and additionally with a SCI, highlights that the factor of time is an issue that persons with SCI/SCD, as well as others around the person, must grapple with on a day-to-day basis.

For Stefan, before participating in the three-week inpatient rehabilitation programme his daily life was underscored by dependency and difficulties in performing everyday activities, such as transferring from the wheelchair to another place and back, and self-care. This was partly due to his

slowness in completing these activities. At the end of the rehabilitation programme, Stefan was able to perform some activities better and a bit faster. However, he continued to struggle with time issues and dependency.

### Time Factor and Participation in Major Life Situations

Stefan's experience with dependency and the time factor is not an isolated case. A few studies found that **persons living with SCI/SCD need more time**

**to perform everyday activities. This, in turn, can limit the person's participation in major life situations, such as work, school or social life.**<sup>13,14,15</sup>

*“Stefan's experience with dependency and the time factor is not an isolated case.”*

In Stefan's case, the time factor had a major impact on his ability to use public transportation. This, in turn, was considered a limiting

factor toward Stefan's plans to participate in a vocational preparatory course that took place in a location far from his home.

### Independence and Time Factor

Stefan's dependency on assistance for indoor and outdoor mobility and to perform self-care activities contributed to the excessive amount of time he needed to complete these activities. This is consistent with the study by Gribble et al. who found that children and youth with spina bifida who were independent in toileting spent less time

to complete toileting activities.<sup>15</sup> They also found that **independence had an impact on time spent but not the other way around.** Given this, it would be essential that children and youth gain as much independence in toileting and other daily activities as early as possible.<sup>15</sup>

*“...it would be essential that children and youth gain as much independence in toileting and other daily activities as early as possible.”*

This finding is contrary to Pentland et al., who found no predictive relationship between independence and time spent on leisure activities, productive activities, self-care, and sleep.<sup>13</sup> Note, however, that independence in this study was assessed using the Functional Independence Measure<sup>4,5</sup>, an assessment instrument that has

shown to have limitations in its use with persons with SCI/SCD.<sup>4,6,7</sup> Moreover, the differences in the findings may have also reflected the differences in the study populations in Pentland et al. (adult males with SCI) versus in Gribble et al. (children and youth with spina bifida).

### Time Factor and Family Life

The amount of time a child or young person with spina bifida (like Stefan) needs to complete daily activities can pose many challenges for the family as well. **The need for assistance and the time the child needs for basic activities can restrict family life and result in stress and conflicts among family members.**<sup>21</sup> While teenagers without disabilities generally become more independent as they transition into

adulthood, teenagers with spina bifida often need continued care from parents. Providing teenage children with assistance in performing physical activities, such as involved in self-care, also becomes increasingly more difficult as the child gets physically bigger and heavier. In addition, conflicts can arise when parents limit the teenager's possibilities for gaining independence.<sup>22,23,24,25</sup>

*“The amount of time a child or young person with spina bifida (like Stefan) needs to complete daily activities can pose many challenges for the family as well.”*

In Stefan's case, the primary caretaker was his mother. She tended to perform the activities that Stefan should have been doing himself, since her full schedule of daily activities allowed her limited

time to wait until Stefan carried out everyday tasks. The consequence was a cycle of dependency and a feeling of dissatisfaction for both Stefan and his mother.

## Implications for Rehabilitation and Care

The case of Stefan illustrates the time-related challenges of living with SCI/SCD and the quest for increased independence, including the dynamic interaction between the time factor in performing daily routine and independence. **Stefan's case also highlighted the importance of optimising the time necessary for completing daily activities in order to achieve the highest possible level of independence.** Efforts toward optimising the time allocation for an activity could include but not limited to:

- reducing impairments in body functions and/or body structures e.g. reducing spasticity or increasing muscle power to support transferring skills
- optimising procedures, e.g. developing and adapting compensation strategies

- enhance the social environment and support of others e.g. instructing parents and caregivers to empower the person with disability to perform activities independently as early and as often as possible, whereby allowing the person to take the necessary time required to complete the activities
- optimising the physical environment e.g. clarifying and employing appropriate assistive devices

Although Stefan only achieved one of three goals at the end of the rehabilitation programme i.e. improved mobility, his participation in the three-week inpatient programme brought him one step closer toward his ultimate goal of gaining independence in daily routine.

## Annex

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- *Table 1: ICF Assessment Sheet*
- *Table 2: ICF Categorical Profile*
- *Table 3: ICF Intervention Table*
- *Table 4: ICF Evaluation Display*
- *Literature*
- *Questions*

Table 1: ICF Assessment Sheet

ICF Assessment Sheet			
Patient Perspective	<ul style="list-style-type: none"> <li>- The sensitivity in my body decreases more and more the lower the body location</li> <li>- I can't sense any pressure when sitting</li> <li>- Sometimes I have a little pain in my stiffened spine</li> <li>- I have been less able to breathe deeply since the spinal surgery</li> <li>- The mobility in my right arm is reduced</li> <li>- I have different degrees of muscle power on the left and right side.</li> <li>- My spine is stiffened</li> <li>- I don't have any problems with my skin</li> </ul>	Activities & Participation	<ul style="list-style-type: none"> <li>- Time management is a problem for me</li> <li>- I am quite slow in performing tasks</li> <li>- I have some learning difficulties</li> <li>- I am dependent on others for transferring from bed to wheelchair – with more time I am able transfer more independently</li> <li>- I can't transfer in and out of the car</li> <li>- When I fall out of the wheelchair I am unable to get back by myself</li> <li>- I can't get dressed by myself</li> <li>- My mother helps me to check my skin</li> <li>- I visit the regular school</li> <li>- I play the panpipe very often</li> <li>- I also listen to music, read books, and work on the computer</li> </ul>
Health Professional Perspective	<ul style="list-style-type: none"> <li>- Severely impaired proprioceptive functions</li> <li>- Moderately impaired touch functions</li> <li>- Severely impaired defecation functions</li> <li>- Severely impaired urination functions</li> <li>- Moderately impaired mobility of joint functions</li> <li>- Severely impaired muscle power functions</li> <li>- Moderately increased spasticity</li> <li>- Severely impaired sensations related to muscles.</li> <li>- Extremely stiff cervical and lumbar spine</li> </ul>	Activities & Participation	<ul style="list-style-type: none"> <li>- Has severe difficulty carrying out daily routine</li> <li>- Has moderate difficulty handling stress and other psych. demands</li> <li>- Has severe difficulty changing basic body positions</li> <li>- Has severe difficulty maintaining a sitting position</li> <li>- Has severe difficulty transferring himself</li> <li>- Has severe difficulty with fine hand use</li> <li>- Has severe difficulty moving around using equipment</li> <li>- Has severe difficulty using transportation</li> <li>- Has moderate difficulty washing himself</li> <li>- Has severe difficulty toileting</li> <li>- Has moderate difficulty dressing</li> <li>- Has moderate difficulty eating</li> <li>- Has severe difficulty looking after his health</li> </ul>
Environmental Factors		Personal Factors	
<ul style="list-style-type: none"> <li>- Medication helps substantially</li> <li>- Lower leg splints help considerably</li> <li>- The two wheelchairs and SwissTrac™ also help substantially</li> <li>- Receives considerable support from his family, especially his mother</li> <li>- Continuous assistance unintentionally led to dependency</li> <li>- Perceives that his family is often too fast for him</li> <li>- Although he lives in a wheelchair-accessible home, the physical environment often poses a barrier</li> </ul>		<ul style="list-style-type: none"> <li>- 17 year-old male</li> <li>- Living with family (parents, one brother and a sister)</li> <li>- Has been visiting the regular school</li> <li>- Describes himself as a loner and a lazy person</li> <li>- Is afraid of falling</li> <li>- Has poor self-esteem</li> <li>- Likes listening to music, reading books, and working on the computer</li> <li>- Plays the panpipe very well</li> <li>- Is eager for knowledge, specifically history</li> <li>- Aims to participate in a vocational school</li> </ul>	

Table 2: ICF Categorical Profile

ICF Categorical Profile									
Assessment									
ICF categories									
ICF Qualifier	0	1	2	3	4	Goal Relation	Goal value		
	problem								
Global Goal: None set							-		
Service-Program Goal: Increased independence in daily routine							2		
Cycle Goal 1: Improved mobility							2		
Cycle Goal 2: Increased independence in self-care							2		
ICF categories									
b130	Energy and drive functions						-		
b134	Sleep function						-		
b152	Emotional function						-		
b260	Proprioceptive functions						-		
b265	Touch functions						-		
b28010	Pain in head and neck						-		
b415	Blood pressure functions						-		
b440	Respiration functions						-		
b455	Exercise tolerance functions						-		
b525	Defecation functions						2	3	
b530	Weight maintenance functions						-		
b620	Urination functions						2	3	
b710	Mobility of joint functions						1	1	
b715	Stability of joint functions						-		
b730	Muscle power functions						1	2	
b735	Muscle tone functions						1	1	
b755	Involuntary movement reaction functions						1	2	
b760	Control of voluntary movements						-		
b7603	Supportive functions of arm or leg						1	1	
b765	Involuntary movement functions						-		
b770	Gait pattern functions						-		
b780	Sensations related to muscles and movement functions						1	2	
b810	Protective functions of the skin						-		
s12000	Cervical spinal cord						-		
s12002	Lumbosacral spinal cord						-		
s430	Structure of the respiratory system						-		
s610	Structure of the urinary system						-		
s760	Structure of trunk						-		
s810	Structure of areas of skin						-		
d230	Carrying out daily routine						SP	2	
d240	Handling stress and other psychological demands						-		
d410	Changing basic body positions						1	2	
d4106	Shifting the body's centre of gravity						-		
d4153	Maintaining a sitting position						1	2	
d4154	Maintaining a standing position						-		
d420	Transferring oneself						1	2	
d440	Fine hand use						-		
d445	Hand and arm use						-		
d450	Walking						-		
d455	Moving around						-		
d460	Moving around in different locations						1	2	
d465	Moving around using equipment						1	2	
d470	Using transportation						1	2	

ICF categories		ICF Qualifier							Goal Relation	Goal value			
		4+	3+	2+	1+	0	1	2	3	4			
		facilitator				barrier							
d475	Driving											-	-
d510	Washing oneself											-	-
d520	Caring for body parts											2	1
d530	Toileting											2	2
d540	Dressing											2	2
d550	Eating											2	1
d560	Drinking											-	-
d570	Looking after one's health											2	2
d760	Family relationships											-	-
d920	Recreation and leisure											-	-
e110	Products or substances for personal consumption											-	-
e1151	Assistive products... for personal use in daily living											2	4+
e1201	Assistive products--for personal...mobility ...											1	4+
e155	Design, construction...of buildings for private use											-	-
e310	Immediate family											-	-
e320	Friends											-	-
e355	Health professionals											-	-
e460	Social attitudes											-	-
e680	Health services, systems and policies											-	-
pf	Self-assurance											SP	0
pf	Motivation											-	-
pf	Assertiveness											SP	0
pf	Motives											-	-

**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 and 2 refer to Cycle goal 1 and 2; SP refers to Service-Program Goal; Goal value refers to the ICF qualifier to achieve after an intervention.

Table 3: ICF Intervention Table

ICF Intervention Table											
	Intervention target		Intervention					First value	Goal value	Final value	
			Doc	Nurse	PT	OT	Psych	Others			
Body functions/structures	b525	Defecation functions		X					3	3	3
	b620	Urination functions	X						3	3	3
	b710	Mobility of joint functions			X				2	1	2
	b730	Muscle power functions			X				3	2	3
	b735	Muscle tone functions			X				2	1	2
	b755	Involuntary movement reaction functions			X				3	2	3
	b7603	Supportive functions of arm or leg			X				2	1	1
	b780	Sensations related to muscles and movement functions			X				3	2	2
	d230	Carrying out daily routine		X					3	2	2
	d410	Changing basic body positions		X	X	X			3	2	3
d4153	Maintaining a sitting position			X				3	2	2	
d420	Transferring oneself		X	X	X			3	2	2	
d460	Moving around in different locations				X			2	2	2	
d465	Moving around using equipment							X	3	2	
d470	Using transportation				X			3	2	3	
d520	Caring for body parts			X	X			2	1	2	
d530	Toileting			X				3	2	3	
d540	Dressing			X	X			3	2	2	
d550	Eating			X	X			2	1	1	
d570	Looking after one's health			X	X	X		3	2	3	
								X			
Environmental factors	e1151	Assistive products and technology for personal use in daily living			X	X			3+	4+	4+
	e1201	Assistive products and technology for personal indoor and outdoor mobility and transportation				X		X	2+	4+	4+
Personal factors	pf	Self-assurance					X		2	0	0
	pf	Assertiveness					X		2	0	2

**Table 3:** ICF Intervention Table; Doc = physician; PT = Physical Therapist; OT = Occupational Therapist; Psych = Psychologist; Others = Sports Therapist, Dietary Specialist, or Orthopaedic Technology Specialist. The first value refers to the rating at the initial assessment, the goal value refers to the rating that should be achieved after the intervention, and the final value refers to the actual rating at the second assessment or evaluation. ICF qualifiers were used to determine these ratings (0 = no problem to 4 = complete problem) in the intervention targets. For the intervention targets representing the environmental and personal factors, the plus sign next to the value indicates a facilitator.

Table 4: ICF Evaluation Display

ICF Evaluation Display																							
Assessment						Evaluation																	
Global Goal: None set																							
Service-Program Goal: Increased independence in daily routine																							
Cycle Goal 1: Improved mobility																							
Cycle Goal 2: Increased independence in self-care																							
ICF categories																							
	ICF Qualifier	Goal relation	Goal value	ICF Qualifier				ICF Qualifier				Goal achievement											
				problem				problem															
				0	1	2	3	4	0	1	2	3	4										
b525	Defecation functions	2	3												+								
b620	Urination functions	2	3												+								
b710	Mobility of joint functions	1	1												-								
b730	Muscle power functions	1	2												-								
b735	Muscle tone functions	1	1												-								
b755	Involuntary movement reaction functions	1	2												-								
b7603	Supportive functions of arm or leg	1	1												+								
b780	Sensations related to muscles and movement functions	1	2												+								
d230	Carrying out daily routine	SP	2												+								
d410	Changing basic body positions	1	2												-								
d4153	Maintaining a sitting position	1	2												+								
d420	Transferring oneself	1	2												+								
d460	Moving around in different locations	1	2												+								
d465	Moving around using equipment	1	2												+								
d470	Using transportation	1	2												-								
d520	Caring for body parts	2	1												-								
d530	Toileting	2	2												-								
d540	Dressing	2	2												+								
d550	Eating	2	1												+								
d570	Looking after one's health	2	2												-								
				facilitator				facilitator				barrier											
				4+	3+	2+	1+	0	1	2	3	4	4+	3+	2+	1+	0	1	2	3	4		
e1151	Assistive products... for personal use in daily living	2	4+																				+
e1201	Assistive products--for personal... mobility ...	1	4+																				+
pf	Self-assurance	SP	0																				+
pf	Assertiveness	SP	0																				-

Table 4: ICF Evaluation Display: 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 and 2 refer to Cycle Goal 1 and 2; SP refers to the Service-Program Goal; Goal value refers to the ICF qualifier to achieve after an intervention. Goal achievement: + means achieved, - means not achieved.

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## Questions

- Q1. Explain how dependency and temporal aspects of functioning pertain to disability. *(Refer to page 8 for the answer.)*
- Q2. Give examples in which the aspect of time is reflected in the International Classification of Functioning, Disability and Health (ICF)? *(Refer to page 9 for the answer.)*
- Q3. Considering this case of Stefan, which of the examples you provided in Question 2 most reflect the time issues he faced? *(Refer to page 16 for the answer.)*
- Q4. Identify the intervention targets that were defined for cycle goal 2 'increased independence in self-care', the rehabilitation team member(s) responsible for addressing these intervention targets and the respective interventions. *(Refer to page 36 for the answer.)*
- Q5. What is the relationship between the time factor and family life? *(Refer to page 27 for the answer.)*



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