Swiss Paraplegic Research

Swiss Paraplegic Centre

ICF Case Studies

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

SCI in Adolescence and Peer Relationships

Case Study 13

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Content

SCI in Adolescence and Peer Relationships

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.

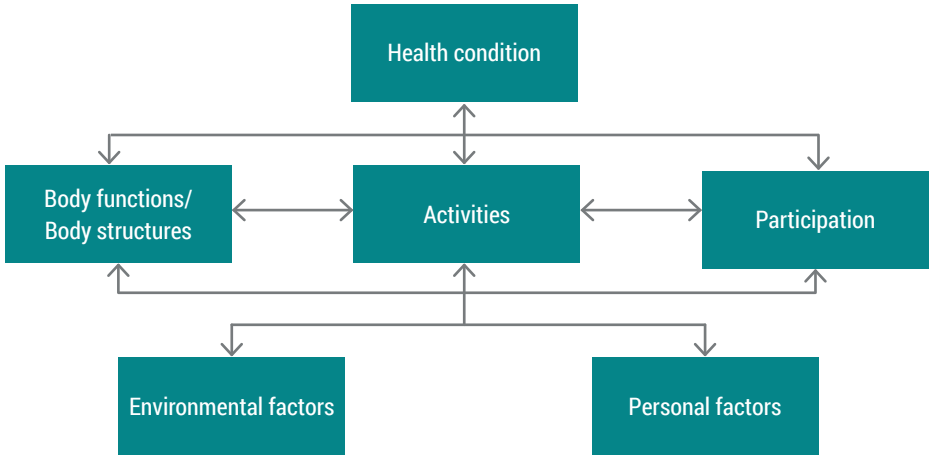

Figure 1: *Bio-psycho-social model of functioning, disability and health*

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.

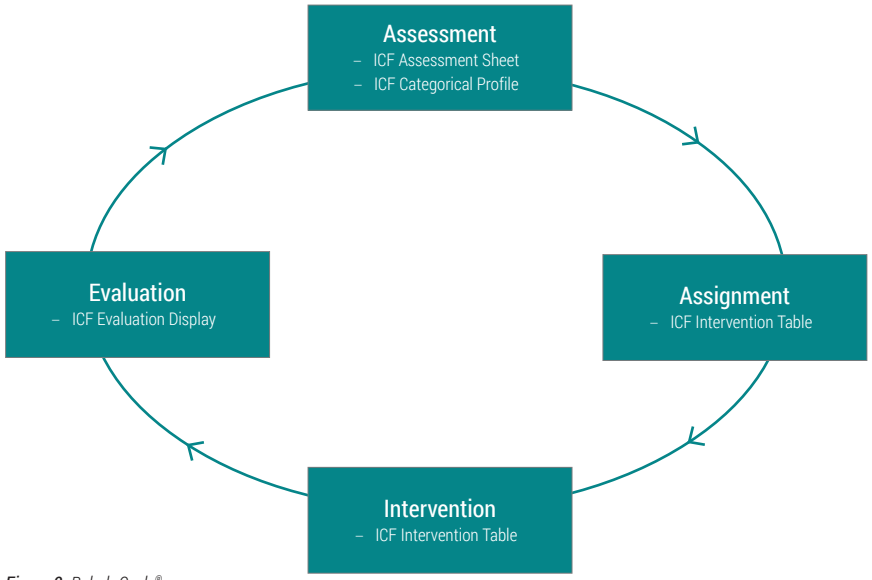

Figure 2: *Rehab-Cycle®*

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

For most teenagers, with or without disabilities, adolescence is a period of time full of rapid and dramatic changes that present many challenges. However, teenagers with disabilities face unique challenges that have implications for personal development, family and peer relationships, and healthcare.

Adolescence is a time of biological development, as well as significant cognitive, psychological and social change.[1,2] It is a time of transition that prepares each young person for adult life, and involves completing the following developmental tasks:[2,3]

- Developing a self-identity (including values, personality and sexual identity)
- Reducing physical, emotional and financial dependence on parents and caregivers
- Developing social relationships (with peers and with the opposite sex) through appropriate behaviour and communication skills
- Acquiring a profession
- Engaging in hobbies and other significant ways of spending time

In the process of completing these developmental tasks, peer relationships become increasingly important as the teenager attempts to find a sense of belonging and an identity beyond the immediate family, while the direct role of the family in shaping the person's life is significantly reduced.[2,4] In addition, teenagers face many challenges that accompany these developmental tasks.

Being a Teenager with Spina Bifida

The challenges that all teenagers face are often intensified when the teenager has a disability such as spina bifida (see box 1). This can also include body image concerns, low self-esteem, social isolation, and stigma.[2,4,5] Moreover, parents and caregivers are confronted with new adolescence-associated aspects of living with a person with spina bifida. Due to advances in medical care and better management of the condition, the life expectancy of persons with spina bifida have greatly increased i.e. over 85% of children born with spina bifida survive into adulthood.[3,5] Given this, **it is important to address the issues persons with spina bifida and their families face in the transition from childhood to adulthood.**

Box 1 | Spina Bifida

Spina bifida is a congenital condition resulting from an incomplete closure of the neural tube within the first 28 days of pregnancy, causing malformations of the spine. The abnormal development of the neural tube is most often accompanied by damage to the nerves and spinal cord. While the exact cause of spina bifida is still unknown, heredity, nutrition (notably insufficient intake of folic acid) and environmental factors are thought to play a role. Although spina bifida can be surgically treated at birth, the damage to the nervous system is permanent and there is no cure at present.[6,7]

Spina bifida is the most common congenital condition affecting the central nervous system. According to the International Perspectives on Spinal Cord Injury (IPSCI), there are an estimated 4.5 cases of spina bifida per 10,000 live births worldwide, with some variations in country incidence rates due to different data sources used.[8] According to the International Federation of Spina Bifida and Hydrocephalus, neural tube defects affect approximately 320,000 newborns a year.[9]

Types of Spina Bifida[6,7]

- Spina bifida occulta: a mild, symptom-free form of spina bifida, in which the spinal cord remains in the body with abnormally developed lower back bones.
- Meningocele: a moderate form of spina bifida, in which a small cerebrospinal fluid (CSF)-filled cyst (or sac) protrudes from the spinal canal and is visible on the person's back, often covered by a thin layer of skin.
- Myelomeningocele: the most common and severe form of spina bifida, in which the CSF-filled cyst also contains parts of the spinal cord and nerves that develop outside of the body. This type of spina bifida is often accompanied with hydrocephalus, an abnormal build-up of CSF in the brain causing increased pressure within the skull and an enlargement of the skull.

When the term "spina bifida" is used, it most often refers to myelomeningocele rather than the other types of spina bifida. Myelomeningocele results in a range of

impairments in body functions and structures including some degree of paralysis, loss of sensation and muscle weakness in the lower extremities (hip, legs and feet), and bowel and bladder control problems. Persons with spina bifida often experience limitations in executing activities involving the lower extremities e.g. mobility and balance, often requiring assistive devices. The extent of problems a person experiences varies depending on the location and level of damage. For example, persons with damage high on the spine may have more extensive paralysis and require a wheelchair, while others with damage lower on the spine may need to only use crutches or leg braces.[6,7]

In addition to hydrocephalus, spina bifida may also cause other abnormalities of the brain. For example, most persons with myelomeningocele have Chiari II malformations, an abnormal displacement of the lower part of the brain – much lower than normal – into the upper part of the spinal canal. This part of the brain is responsible for sensory input and controls, coordination and motor control, including maintaining balance. Symptoms include headache, upper body weakness, sensory disturbance, shooting pain, double vision and other visual disturbances, swallowing difficulties, speech problems, as well as poor coordination when walking. Persons with spina bifida have normal intelligence, but may encounter learning disabilities.[6]

"Navigating the critical developmental stages and successfully acquiring the necessary skills to enter adulthood may prove problematic."

For teenagers with spina bifida navigating the critical developmental stages and successfully acquiring the necessary skills to enter adulthood may prove problematic. Indeed, beyond the physical and cognitive effects of the condition lay an array of psychosocial and participation issues as well as issues related to education that confront teenagers with spina bifida. Young people often compare themselves with other peers. **Teenagers with spina bifida have reported seeing themselves different from their non-disabled peers, contributing to the difficulties they experience in forming friendships with peers without disabilities.** Incontinence and being identified with the wheelchair also contributed to altered body image and social isolation.[2,3,4,5,10] Teenagers with spina bifida have even reported experiencing teasing by peers in a qualitative study on the transition of young adults with spina bifida.[5]

Participation is also often hindered by environmental barriers – inaccessible streets, public transportation, and meeting locations such as sporting facilities or places where teenagers often meet.[2,4,5,10]

Implications for the Family

The transition of children with spina bifida into young adulthood has implications for the family as well. For parents with teenagers with disabilities like spina bifida, this transition period is often a time of greater stress. While teenagers without disabilities generally become more independent and leave home at a certain point, teenagers with spina bifida often need continued care from parents, and almost half of them continue to live with their parents in adulthood. Providing care to teenage children becomes more physically burdensome – assistance with physical activities such as transferring, bathing, dressing, etc. gets more difficult as the child gets physically bigger and heavier. In addition, young adults with spina bifida often continue to be financially dependent on their parents due to difficulties in entering the job market.[4,5,10]

Alongside the increased stress parents feel during this transition period, conflict between parents and the teenager with spina bifida can arise as a result of overprotectiveness or when parents provide insufficient opportunities for the teenager to gain independence.[4,5,11]

Independence is a topic that becomes more prominent during adolescence. Another is sexuality. Parents of teenagers with spina bifida are less likely to discuss issues of sexuality with their children.[11]

Despite the stress experienced by parents and other family members as the child with spina bifida transitions into young adulthood, families have shown great resilience in tackling the challenges they face.[11]

"Despite the stress experienced by parents and other family members as the child with spina bifida transitions into young adulthood, families have shown great resilience in tackling the challenges they face."

Implications for Healthcare Provision

As with parents, health professionals who have been caring for a patient with spina bifida since a young age also have to adjust to the changing needs of that child as he or she matures into adulthood. Parents and health professionals may have difficulty giving up a trusted relationship to transition the maturing teenager's healthcare to adult providers. In addition, a level of trust between the paediatric and adult healthcare provider is also essential for smooth transition into adult healthcare.[3,6,12,13]

"Ideally, the paediatric and adult healthcare provider work together during this transitional period..."

Transition of care does not only mean transfer of patient and documentation to another facility. Ideally, the paediatric and adult healthcare provider work together during this transitional

period, especially considering that adult providers have been slow in establishing healthcare protocols that are adapted to the special healthcare needs of persons with spina bifida. Given the complexity of healthcare provision of spina bifida, a multidisciplinary approach, including the establishment of multidisciplinary clinics, would be ideal for addressing the range of healthcare issues related to spina bifida.[3,6,12,13]

In addition, enabling the teenager with spina bifida to take over more responsibility for managing his or her care e.g. for catheterisation, is also part of this healthcare transition.[5,12]

This case study aims to illustrate some specific challenges to independence and peer relationships face by Gabi, a 15 year-old girl living with spina bifida, and show how these challenges were addressed in a comprehensive rehabilitation programme.

Gabi's Story

For 15-year old Gabi, living with spina bifida also meant living with paraplegia. Over the years she had learned to cope with many of the functional limitations associated with her health condition as well as to manage their impact on her lived experience.

Born with spina bifida, Gabi's paraplegia at the 3rd lumbar vertebra with American Spinal Injury Association (ASIA) Impairment Scale grade A means that **she has loss of sensory and motor function in her hip and legs, and impaired bowel and bladder functioning. She is also a wheelchair user.**

Medically, she had had problems with a number of secondary and/or related health conditions, most of which were treated successfully. At the age of three, Gabi was diagnosed with Chiari II malformation (see box 1), and she required a shunt to treat both the hydrocephalus and the mild neurological deficits that it caused. When she was 8 years old, she suffered from epileptic seizures, that were successfully treated with medication. Since the age of ten, Gabi has been seizure-free without medication.

Also at ten years of age, Gabi began to experience luxations of the hip joint (i.e. dislocation of the bone from the joint)[14] , and she developed scoliosis (i.e. an abnormal side-to-side curving of the spine).[14] The scoliosis decreased her respiratory functions among other things. Both problems were treated surgically, and Gabi's spine was fixed from the 4th thoracic level (breast area) to the 1st sacral level (bottom) of the spine, greatly limiting her available range of motion and mobility.

Moreover, Gabi suffered from a number of accompanying disorders. These included autonomic dysregulation of bowel and bladder, sexual dysfunction and short-sightedness.[14]

Over the years of living with spina bifida, Gabi had come to view her health condition as both normal as well as limiting. Although she has only ever

known life with specific limitations posed by the spina bifida, she has discovered that peers without disabilities experience limitations in their lives as well. Thus, living with limitations is normal.

With regard to school education, Gabi had been enrolled in regular public schools, where most of her peers did not have a disability.

Gabi lived at home with a supportive family that included an older brother and sister. Like other teenagers, she was social, often meeting friends from swimming and unihockey clubs for persons with disabilities. She even took part in swimming and unihockey competitions. Gabi also enjoyed painting, reading, listening to music and playing the flute, and like all teenagers, communicating with friends via text messages. It is important to note that Gabi's closest friends were other teenagers with disabilities, who were not peers from school.

"Over the years of living with spina bifida, Gabi had come to view her health condition as both normal as well as limiting."

For Gabi at the time, there were two **outstanding problems in her life – dependency on others and peer relationships**.

"I can't move because of the plate in my back. And I can't even put on pants by myself after using the toilet…every time I have to go, someone has to accompany me."

"I have to say that I'm much more open and happy to be around others in wheelchairs."

"School is one of my biggest problems… sometimes it is really depressing. I am always reminded that I am not the same as the others. I have to admit that I haven't felt like learning anymore in this environment."

Gabi on living with spina bifida

Due to continued functioning limitations Gabi had been experiencing, her health insurance agreed to pay for a three-week intensive inpatient rehabilitation programme specifically created for adolescents with spinal cord disorders/injuries. The explicit goal of this specialised rehabilitation programme was to increase the independence of adolescents with congenital or traumatic spinal cord injuries – a programme well-suited to Gabi's needs.

Assessment

At the beginning of the rehabilitation programme (or Rehab-Cycle®) a comprehensive assessment was performed to identify Gabi's and the rehabilitation team's perspective of her functioning status. The assessment later helped to define the goals that Gabi and her rehabilitation team decided to address during the intervention phase of rehabilitation.

The Assessment Phase of the Rehab-Cycle®

The assessment of Gabi's functioning included an interview with Gabi as well as tests and examinations performed by individual rehabilitation team members. The results were documented in the **ICF Assessment Sheet**, a comprehensive overview of Gabi's functioning status presented according to the International Classification of Functioning, Disability and Health (ICF) components of body functions and structures, activities and participation, and environmental and personal factors.[15] Some of Gabi's statements during the interview were also included in the ICF Assessment Sheet. Having this overview helped Gabi and the rehabilitation team to identify her needs, and to support the planning of interventions for the Rehab-Cycle®.

See "Table 1: ICF Assessment Sheet" on page 28 at the end of this booklet.

Gabi expressed her wish to decrease her dependency on her family. She required much assistance in executing daily activities, particularly in dressing. Problems with dressing further resulted in complete dependency on others when toileting, since she was unable to put on her pants by herself after using the toilet. This, in turn, meant that she was unable to be left alone for any extended period of time.

She also experienced limitations in mobility due to her stiffened spine. Despite Gabi's view that her muscle power was normal (considering that she

had never experienced it otherwise), her mobility with the wheelchair was limited as a result of the spinal fixation and the relatively short length of her arms. Additionally, she was unable to dock and undock the wheelchair-handbike independently and required constant assistance in transferring from the ground to the wheelchair. In sum, Gabi felt mobility and self-care were critical factors for gaining independence. As an essential part of the efforts toward independence, Gabi's emotional (in)stability also had to be addressed.

"Gabi felt mobility and self-care were critical factors for gaining independence."

Gabi's experience of limitations in activities was not only related to movement, but also to mental acuity. She felt that she was "slow in understanding," normally needing more time than others to complete her homework – a fact that further reinforced the idea that she was "different" from her other classmates. In fact, her perceived learning difficulties were confirmed by poor grades.

Related to school was also the aspect of social participation and peer relationships. Gabi expressed a number of her concerns regarding her relationship with non-wheelchair using classmates, or "walkers" as she called them. She found her interactions with walkers to be stressful. She was subject to regular teasing, and was often excluded from activities. Gabi recognised that there was a real and qualitative difference between her relationship with walkers and with wheelchair-using peers. The difference was dramatic – with wheelchair-using peers, Gabi was more open and was able to communicate better. She also enjoyed their company.

"Gabi recognised that there was a real and qualitative difference between her relationship with walkers and with wheelchair-using peers."

However, it was not just peer relationships that caused Gabi stress in school. She was beginning to have concerns about her future i.e. about possible vocational training. At the time of assessment, Gabi was soon to start her final year of school.

Gabi's assessment of the problems in functioning was supported by the rehabilitation team. From their point of view, the three main areas to be addressed during rehabilitation were mobility, self-care and peer relationships.

Factors such as pain, limited joint mobility, problems in changing body positions, transferring, moving around outside of the home, use of the wheelchair, and transportation all reduced Gabi's mobility. The factors that decreased Gabi's ability to perform adequate self-care were urinary system dysfunction, difficulties in carrying out a daily routine, changing her body position, transferring herself, caring for body parts, toileting, dressing, and looking after her own health. Finally, the rehabilitation team felt that peer relationships were closely related to her emotional functions, and that these influenced each other.

Case Study 13 | SCI in Adolescence and Peer Relationships | Assessment

Accordingly, Gabi indicated limitations in interpersonal interactions and informal social relationships, primarily with persons without disabilities. Also relevant to her social functioning, Gabi was thought to have low assertiveness and low self-esteem, both of which tended to further restrict her participation at school.

With the completion of the ICF Assessment Sheet, the first step in the assessment phase of the Rehab-Cycle® was also completed. The next step in the assessment phase was to consider this "laundry list" of needs, limitations, environmental and personal factors, and set long- and short-term goals as well as define the intervention targets that Gabi and her rehabilitation team needed to address during the intervention phase.

Goal-setting/Determination of Intervention Targets

Having a comprehensive overview of Gabi's functioning based on the rehabilitation team's assessment and Gabi's own statements about her situation helped the rehabilitation team to identify intervention targets and concrete goals to achieve during the three-week Rehab-Cycle®.

Based on the results of the assessment, Gabi and her rehabilitation team set 'community integration' as the **global goal**. Although not explicit, this also included improvement in peer relationships. To help achieve the global goal, a **service-program goal**, that is, the goal to achieve at the end of this Rehab-Cycle®, was defined as 'increased overall level of independence'. In turn, as small steps toward reaching the service-program goal three **cycle goals** – 'increased independence in mobility', 'increased independence in self-care', and 'enhanced peer relationships' were set. These goals were documented on the **ICF Categorical Profile**. In addition to the goals, the ICF Categorical Profile lists the corresponding categories of the International Classification of Functioning, Disability and Health (ICF)[15] that correspond to the aspects of functioning identified during the initial assessment of Gabi's functioning.

The extent of the problem Gabi had in the respective ICF categories was visually displayed with a bar graph that reflected the rating given using ICF qualifiers. To help compare Gabi's functioning at the initial assessment and at a later time point, ICF qualifiers were also used to indicate the goal value i.e. the ICF qualifier that was intended to be reached after the intervention phase. *See "Table 2: ICF Categorical Profile" on page 30 at the end of this booklet.*

"While emotional functions referred to Gabi's feelings and her ability to control them, complex interpersonal interactions and informal social relationships referred to her behaviour toward others, particularly peers, and how she interacted with them."

The ICF categories (and personal factors) that corresponded to any of the goals set and were associated with a goal value were considered **intervention targets**. Intervention targets were those categories intended to be addressed with specific interventions. For example, for cycle goal 3 'enhanced peer relationships' Gabi and her rehabilitation team defined the following intervention targets: b152 Emotional functions, d720 Complex interpersonal interactions and d750 Informal social relationships. While emotional functions referred to Gabi's feelings and her ability to control them, complex interpersonal interactions and informal social relationships referred to her behaviour toward others, particularly peers, and how she interacted with them. The personal factors of social competencies and assertiveness were also designated as intervention targets.

Case Study 13 | SCI in Adolescence and Peer Relationships | Goal-setting/Determination of Intervention Targets

At the time of the initial assessment these personal factors neither enabled nor hindered Gabi in her interactions and relationships with others. However, Gabi and the rehabilitation team decided that these personal factors should become facilitators at the end of the Rehab-Cycle®. Social competencies and assertiveness were seen as skills and personal traits that supported positive relationships and interactions with others. Although not specified on the ICF Categorical Profile, the intervention targets for cycle goal 3 were intended, among other things, to support Gabi's management of stress related to her interactions with non-wheelchair using peers at school.

"Social competencies and assertiveness were seen as skills and personal traits that supported positive relationships and interactions with others."

To assist Gabi in addressing these intervention targets a psychologist was invited to join the rehabilitation team. The psychologist was one of a team of eight health professionals who provided interventions in the next stages of the Rehab-Cycle®.

Assignment and Intervention

Every intervention target that was determined during the assessment phase was allocated to corresponding member(s) of Gabi's rehabilitation team during the assignment phase of the Rehab-Cycle®. The respective team member was then responsible for addressing the targets with specific interventions during the intervention phase.

Gabi's multidisciplinary rehabilitation team for the three-week Rehab-Cycle® included a physician, a nurse, physical, occupational and sports therapists, a psychologist, and a music therapist. Additionally, a vocational trainer was available to address her vocational needs. Each intervention target that was documented on the ICF Categorical Profile during the assessment phase was assigned to one or more of these health professionals. **The ICF Intervention Table** provided an at-a-glance overview of the assignment of the intervention target to the respective team member(s) as well as the ICF qualifier values determined during the assessment phase (first value, goal value) and the actual qualifier rating given at the re-assessment of Gabi's functioning after interventions. *See "Table 3: ICF Intervention Table" on page 34 at the end of this booklet.*

Gabi's rehabilitation programme was comprehensive, and each day included a full schedule of both individually-focused activities and interventions, as well as numerous group activities. *See "Table 4: Gabi's Rehabilitation Schedule" on page 36 at the end of this booklet.*

Case Study 13 | SCI in Adolescence and Peer Relationships | Assignment and Intervention

Individual Sessions

Gabi's rehabilitation schedule included interventions that were performed solely by one health professional. For example, the physical therapist conducted active movement therapy to alleviate pain, music therapy was provided to improve Gabi's respiration functions, and the nurse provided skin care as well as instructed Gabi on how to optimally care for skin herself. The nurse also instructed Gabi on how to use an assistive device to independently manage her catheterisation.

There were also intervention targets that were addressed with various interventions. This was intended to address the same intervention target from different angles. The nurse, for example, shared the responsibility with the occupational therapist for many self-care interventions, such as to address problems with toileting, dressing, and looking after one's health. In addition, the nurse, physical and occupational therapists all provided Gabi, in separate sessions, self-management training to improve her ability to carry out her daily routine. City training (in a group) to improve Gabi's ability to move around outside and to use transportation was also led by both the physical and the occupational therapist in individual sessions.

In addition to interventions to increase Gabi's independence in mobility and self-care, measures to meet Gabi's psychological needs also played a central role during the intervention phase of rehabilitation. The psychologist met with Gabi once a week to work on her emotional (in)stability, to build or strengthen Gabi's interpersonal interaction skills, as well as the skills she needed to enhance informal social relationships, especially with non-wheelchair using peers. During the counselling sessions, the psychologist also discussed issues related to Gabi's academic problems, including those associated with interpersonal interactions and informal social relationships.

"The adolescent-tailored rehabilitation programme went beyond one-to-one interventions. Besides the individual sessions, Gabi also participated in group activities."

Group Activities

The adolescent-tailored rehabilitation programme went beyond one-to-one interventions. Besides the individual sessions, Gabi also participated in group activities. According to table 4, almost half of Gabi's rehabilitation schedule comprised of group activities.

These **group activities provided Gabi an opportunity to strengthen her interpersonal interactions and improve peer relationships**, even if mostly with other wheelchair users. Group excursions to a nearby city was also intended to further strengthen Gabi's confidence in using public transportation. In group activities as well as in individual sessions, Gabi's need to be more assertive and to improve her social competencies were addressed.

The group activities were organised not only to address problems, but also to foster strengths and interests. For example, Gabi participated in a swimming group simply to encourage and build upon one of her favourite leisure activities. Many group activities were just for fun e.g. an outdoor picnic with a barbeque, a wellness evening with a massage, etc. There was even a workshop offered, in which parents were able to participate.

"The group activities were organised not only to address problems, but also to foster strengths and interests."

Gabi and her rehabilitation team were hopeful that the individual sessions as well as the group activities all contributed to reaching the goals they set in the assessment phase of the Rehab-Cycle®. In the next phase of the Rehab-Cycle®, the evaluation phase, the rehabilitation team re-evaluated Gabi's functioning and the status of the contextual factors to determine whether the goals that they set were reached.

Evaluation

At the end of the three-week Rehab-Cycle® a final assessment was completed, and Gabi's progress in the intervention targets was evaluated to see whether the goals that she and her rehabilitation team set in the beginning of the Rehab-Cycle® were achieved.

"Gabi also achieved her service-program goal of increased overall level of independence..."

After three weeks of rehabilitation in individual sessions and in group activities, Gabi was successful in reaching her cycle goal of increased independence in self-care. She was now able to dress herself independently, including putting on her pants without the help of others. She also developed some techniques for managing catheterisation by herself. Both this **self-management of catheterisation and independent dressing allowed her to use the toilet without assistance**, even if she still required a lot of time to finish. Moreover, Gabi took more personal responsibility for looking after herself.

Gabi also achieved her service-program goal of increased overall level of independence, despite the fact that the cycle goal of increase independence in mobility was not achieved. **Her mobility did improve a little but still remained a moderate problem.** For example, in spite of improvements in her transferring skills i.e. transferring herself from the ground up to the wheelchair, Gabi still required assistance for transferring due to her lack of arm power, knee pain, and the ill-suited wheelchair design. In addition, her ability to change body positions and move around outside the home with her wheelchair remained unchanged.

Nevertheless, due to progress in reducing pain and in respiratory functions, as well as gains in carrying out her daily routine, the rehabilitation team felt that Gabi's overall level of independence did improve.

The **psychologist also concluded that Gabi had made significant improvement**, specifically in finding strategies to deal with complex interpersonal interactions and in being able to better deal with stress and other psychological demands related to informal social relationships. The psychologist also commented that Gabi learned to communicate her fears and wishes. They discussed her interactions with others at school quite a bit. The psychologist did suggest that Gabi continue regular psychological counselling after discharge from the rehabilitation centre, since feelings of uncertainty and inferiority may appear again after the programme.

"Gabi was well-integrated in the group and was motivated in everything she was involved with. She always arrived in a good mood, and brought ideas of her own. In thtis context, she really enjoyed being one of the "stronger" persons in the group, in contrast to her experience at school. The experience here has no doubt made her more assertive."

Gabi's physician

It is important to note that the comments made by the psychologist and the physician were based upon observations within the context of a three-week rehabilitation programme designed specifically for adolescents with disabilities. Whether the skills Gabi gained in the programme along with the assertiveness and social competencies she demonstrated at the end of the three weeks would be maintained at home and at school remained to be seen. **Evaluation of real improvement in developing and maintaining peer relationships and better community integration was only possible outside the context of the rehabilitation centre.**

This was also the case for Gabi's emotional stability. Whether Gabi's enhanced social skills would result in increased emotional stability in her normal environment, particularly at school, could only be evaluated in that environment.

Gabi's progress in the intervention targets were documented on the **ICF Evaluation Display**, an extended version of Gabi's ICF Categorical Profile that visually shows (as a bar graph) the rating given to each of Gabi's intervention targets during the final assessment as well as the ratings from the initial assessment. Note that a comparison of the initial and final rating 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 5: ICF Evaluation Display" on page 38 at the end of this booklet.*

Discussion

Those born with spina bifida are living longer. This means that more and more children with spina bifida are living into adulthood. Consequently, specific issues related to the transition from childhood to adulthood arise, and these issues need to be addressed.

Being a teenager with spina bifida presents a range of unique challenges, not only for the body functions and structures, but also for activities and participation. Environmental and personal factors also play an important role in the dynamic interaction between these bio-psycho-social components. This translates into the need for specialised medical/rehabilitation and psychosocial support for teenagers with spina bifida and their families during this period of transition.[2,3,4,5,10]

This case of Gabi illustrates how a comprehensive inpatient rehabilitation programme can bring a 15 year-old girl with spina bifida one step closer to adulthood by helping her gain more independence. Gabi's case also highlights the importance of dealing head-on with psychosocial issues faced by teenagers with disabilities, in this case with spina bifida, in daily life.

Compared to teenagers without disabilities, young persons with spina bifida or other physical disabilities may struggle more than non-disabled peers in gaining independence, developing peer relationships and participating in activities with peers, and possibly finding their way toward a future profession.[4,5,10] In Gabi's example, she struggled with developing friendships with peers from school, specifically classmates without disabilities. Gabi stated that she felt more comfortable with others like herself i.e. teenagers who use a wheelchair. In addition, continued dependency on her family or personal assistants for activities of daily living like dressing and toileting further dampened her perceived quality of life.

"Continued dependency on her family or personal assistants...dampened her perceived quality of life."

During a three-week rehabilitation programme, Gabi and a multidisciplinary rehabilitation team tackled the challenge of increasing Gabi's overall level of independence, specifically independence in mobility and self-care, with individual interventions and group activities. They also honed in on improving Gabi's interpersonal skills, specifically in dealing with peers with and without disabilities. Although not all of the goals set were achieved, she completed the rehabilitation programme with increased independence, particularly in self-care, and seemed to be more assertive and confident. The group activities also helped Gabi to build up self-esteem and learn skills that support interpersonal relationships. Furthermore, she developed friendships among peers with a common and shared life experience.

> *"She has made significant improvements in creating strategies to deal with complex interpersonal interactions and informal social relationships. She was also able to deal with stress and other psychological demands better."*
>
> *Gabi's psychologist*

The rehabilitation programme that provided Gabi the opportunity to become more independent and to further develop personal and social skills reflects the type of healthcare programmes recommended in several publications on the transition from paediatric to adult healthcare for adolescents with spina bifida.[3,6,12,13] In these publications, the authors indicate that a comprehensive multidisciplinary approach would help ensure that the complex spectrum of health and health-related issues related to spina bifida is addressed adequately. It has also been suggested that the development of designated programmes within adult clinics would facilitate the collaboration between paediatric and adult healthcare providers and ultimately the smooth transition into adult healthcare. The rehabilitation programme, in which Gabi participated, was not only comprehensive, goal-oriented and multidisciplinary, it was specifically designed for adolescents with spinal cord disorders like spina bifida, and was also integrated within an adult spinal cord injury rehabilitation clinic.

Empowering transitioning patients, using evidence-based guidelines, providing outreach and care coordination, continuity of care, etc...are seen as essential to quality and person-oriented healthcare provision, including rehabilitation.[12,13]

Since the lived experience of teenagers with spina bifida go beyond biological health concerns, it is essential that rehabilitation and other healthcare providers additionally explore the social context of the young adult, evaluate the risk factors for social isolation and barriers to psychosocial development, and provide appropriate resources and interventions accordingly.[16]

Although it was unclear whether the progress Gabi made in the rehabilitation programme would be maintained at home and at school, in the end, the rehabilitation programme was a success for Gabi – she took significant steps towards greater independence and potentially toward improving her relationship with peers, including non-wheelchair users.

> *"I am convinced that she will find her way."*
>
> *Gabi's psychologist*

Annex

Table 1: ICF Assessment Sheet

ICF Assessment Sheet

		Body Functions & Structures	Activities & Participation
Patient Perspective		– I am not very fast in understanding – I can sense something in my right lower leg – I have less pain in my back – Breathing is no problem – My whole spine is not as flexible as before the surgery; I can't bend my spine anymore – My muscle power is normal – I can extend and bend both legs – Everything takes more time – I have been able to sit more upright since the surgery	– I can transfer from the bed to the wheelchair without a problem, but I can't transfer from the ground to the wheelchair – I love to move around with the wheelchair over obstacles and in the city – I go to school by taxi, and I also use public transportation – I can't go to the toilet on my own; someone else has to help me with my pants – Dressing myself is cumbersome, and it is difficult for me to put on a panty liner – The relationship with other wheelchair users is different than with non-wheelchair users – Dealing with classmates stresses me out – I don't feel like learning, and this causes me to get bad marks – I need more time to do my homework – I find it difficult deciding what I want to do after I finish school – I play unihockey and swim in a club – I play flute
Health Professional Perspective		– Emotional functions – moderately impaired – Pain – moderately impaired – Respiratory functions – mildly impaired – Defecation functions – completely impaired – Urination functions – completely impaired – Mobility of joints (Spine and knee) – severely impaired – Muscle power functions – severely impaired – Muscle tone functions (hypotone) – mildly impaired – Protective functions of the skin – moderately impaired – Supportive functions of the arms – mildly impaired – Spinal cord and related structures – moderately impaired – Structure of respiratory system – mildly impaired – Structure of urinary system – moderately impaired – Structure of the skin – moderately impaired	– Severe difficulty in carrying out daily routine – Severe difficulty in handling stress and other psychological demands – Moderate difficulty in changing basic body positions – Severe difficulty in transferring oneself – Mild difficulty in fine hand use – No difficulties in hand and arm use – Moderate difficulty in moving around outside the home – Moderate difficulty in moving around using equipment – Mild difficulty in using transportation – Severe difficulty in caring for body parts – Severe difficulty in toileting – Moderate difficulty in dressing – Moderate difficulty in looking after one's health – No difficulties in basic interpersonal interactions – Moderate difficulty in complex interpersonal interactions – Moderate difficulty in informal social relationships – Moderate difficulty in school education – No difficulties in recreation and leisure

Environmental Factors	Personal Factors
– Has several assistive devices that considerably support her – Manual wheelchair supports her substantially – Many houses have stairs; they pose a mild barrier for her – Home is adapted; this is extremely helpful, but it is in a hilly area – The fact that people are reserved and have prejudices poses a mild barrier for her – Extremely helpful public transportation systems – Physical therapy once a week help her considerably	– 15 year-old female – Lives with her parents and three siblings – Has a very positive attitude – Prefers being around wheelchair than with non-wheelchair users – Has various hobbies – Unsure about goals – Not that assertive – Poor self-esteem

Table 2: ICF Categorical Profile

ICF Categorical Profile											
Assessment											
Global Goal: Community integration											1
Service-Program Goal: Increased overall level of independence											1
Cycle goal 1: Increased independence in mobility											1
Cycle goal 2: Increased independence in self-care											2
Cycle goal 3: Enhanced peer relationships											2

ICF categories		ICF Qualifier									Goal Relation	Goal value
						problem						
						0	1	2	3	4		
b134	Sleep functions											
b152	Emotional functions										G,3	1
b265	Touch functions											
b280	Sensation of pain										1	1
b415	Blood vessel functions											
b440	Respiration functions										2	0
b455	Exercise tolerance functions											
b525	Defecation functions											
b530	Weight maintenance functions											
b620	Urination functions											
b710	Mobility of joint functions											
b715	Stability of joint functions											
b7300	Power of isolated muscles and muscle groups										1	0
b7303	Power of muscles on lower half of the body											
b7353	Tone of muscles of lower half of the body											
b755	Involuntary movement reaction functions											
b760	Control of voluntary movements*											
b7603	Supportive functions of arms										1	0
b810	Protective functions of the skin											
s120	Spinal Cord and related structures											
s430	Structure of the respiratory system											
s610	Structure of the urinary system											
s810	Structure of areas of skin										2	0
d230	Carrying out daily routine										2	2
d240	Handling stress and other psychological demands											
d410	Changing basic body positions										1	1
d415	Maintaining a body position											
d420	Transferring oneself										1	2
d430	Lifting and carrying objects											
d440	Fine hand functions											
d445	Hand and arm functions											
d450	Walking											
d455	Moving around											
d4601	Moving around within buildings other than home											
d4602	Moving around outside the home a. other buildings										1	1
d465	Moving around using equipment										1	1
d470	Using transportation										1	0
d510	Washing oneself											
d520	Caring for body parts										2	2
d530	Toileting										2	2

Table 2: ICF Categorical Profile continued

ICF categories		ICF Qualifier									Goal Relation	Goal value
						problem						
						0	1	2	3	4		
d5302	Menstrual care					■	■	■	■			
d540	Dressing					■	■	■			2	1
d550	Eating					■						
d570	Looking after one's health					■	■	■			2	1
d710	Basic interpersonal interactions					■						
d720	Complex interpersonal interactions					■	■	■			3	0
d750	Informal social relationships					■	■	■			3	0
d760	Family relationship					■						
d820	School education					■	■	■			G	0
d920	Recreation and leisure					■					G	0
		facilitator					barrier					
		4+	3+	2+	1+	0	1	2	3	4		
e110	Products or substances for personal consumption		■	■	■	■						
e115	Assistive products... for personal use in daily living		■	■	■	■						
e120	Assistive products---for personal...mobility ...		■	■	■	■					1	4+
e150	Design, construction...of buildings for public use					■	■					
e155	Design, construction...of buildings for private use	■	■	■	■	■						
e310	Immediate family	■	■	■	■	■						
e320	Friends		■	■	■	■						
e355	Health professionals		■	■	■	■						
e420	Individual attitudes of friends	■	■	■	■	■						
e425	Individual attitudes of acquaintances, peers, ...					■	■					
e540	Transportation services, systems and policies		■	■	■	■						
e555	Associations and organizational services, systems...		■	■	■	■						
e580	Health services, systems and policies		■	■	■	■						
pf	Positive attitude towards own disability			■	■	■						
pf	Social competencies					■					3	2+
pf	Assertiveness					■					3	2+
pf	Goal orientation					■					G	2+

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, 3 refers to Cycle goal 1, 2, 3; G refers to the Global Goal; Goal value refers to the ICF qualifier to achieve after an intervention.

Table 3: ICF Intervention Table

ICF Intervention Table														
	Intervention target		Intervention	Doc	Nurse	PT	OT	Spo	Psych	Others	First value	Goal value	Final value
Body functions/structures	b152	Emotional functions	Psychological counselling						x		2	1	1
	b280	Sensation of pain	Active movement therapy			x					2	1	0
	b440	Respiration functions	Diagnostic	x							1	0	0
			Music therapy							x			
	b7300	Power of isolated muscles and muscle groups	Circuit training					x			1	0	1
	b7603	Supportive functions of arms	Circuit training					x			1	0	1
			Prop-up training			x							
	s810	Structure of areas of skin	Skin care and instruction on optimal skin care		x						2	0	1
Activities / Participation	d230	Carrying out daily routine	Self-management training		x	x	x				3	2	2
	d410	Changing basic body positions	Repetitive functional training			x	x				2	1	2
	d420	Transferring oneself	Transfer training (wheelchair-ground)			x					3	2	2
	d4602	Moving around outside the home and other buildings	Wheelchair training, City training with group			x					2	1	2
	d465	Moving around using equipment	Wheelchair training			x					2	1	2
	d470	Using transportation	City training with group				x				1	0	1
	d520	Caring for body parts	Self-care training		x						3	2	3
	d530	Toileting	Instruction for optimally using assistive devices		x						3	2	2
			Dressing training specifically related to toileting		x		x						
	d540	Dressing	Dressing training		x		x				2	1	1
	d570	Looking after one's health	Self-care training		x		x				2	1	1
	d720	Complex interpersonal interactions	Psychological counselling						x		2	0	1
	d750	Informal social relationships	Psychological counselling						x		2	0	1
			Group activities		x	x	x						
	d820	School education	Psychological counselling						x		2	0	0
	d920	Recreation and leisure	Swimming group					x			0	0	0
Environmental factors	e1201	Assistive products and technology for personal indoor and outdoor mobility and transportation	Check of wheelchair			x	x				3+	4+	3+
Personal factors	pf	Social competencies	Psychological counselling						x		0	2+	1+
			Group activities		x	x	x	x					
	pf	Assertiveness	Psychological counselling						x		0	2+	1+
			Group activities		x	x	x	x					
	pf	Goal orientation	Vocational counselling							x	0	2+	2+

Table 3: ICF Intervention Table; Doc = physician; PT = Physical Therapist; OT = Occupational Therapist; Spo = Sports Therapist; Psych = Psychologist; Other = Music Therapist or Vocational Counsellor. 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: Gabi's Rehabilitation Schedule

Rehabilitation Schedule							
Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
7:00	Nursing Interventions Dressing training	Nursing Interventions Dressing training	Nursing Interventions Dressing training	Nursing Interventions Dressing training	Nursing Interventions Dressing training		
7:30							
8:00	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Nursing Interventions	Nursing Interventions
8:30							
9:00	Physical Therapy	Physical Therapy	Physical Therapy	Physical Therapy	Group Activity – Brunch	Breakfast	Breakfast
9:30		Occupational Therapy		Psychological Counselling			
10:00			Occupational Therapy			Group Activity – Project	Group Activity – Surprise Event
10:30							
11:00	Swimming Group	Swimming Group	Swimming Group	Swimming Group			
11:30							
12:00	Lunch	Lunch	Lunch	Lunch	Lunch	Lunch	
12:30							
13:00							
13:30	Self-management/ Independence Training	Independence Training	Self-management/ Independence Training	Independence Training	Independence Training	Group Activity – Project	
14:00							
14:30	Occupational Therapy		Group Activity – Wheelchair Group	Occupational Therapy			
15:00	Physical Therapy	Physical Therapy					
15:30				Group Activity – Dietary Counselling	Group Activity – Beach Bar		
16:00		Music Therapy				Group Activity – Wellness and Games	
16:30							
17:00							
17:30							
18:00	Dinner	Dinner	Dinner	Dinner	Dinner	Dinner	Dinner
18:30							
19:00	Group Activity – Project	Group Activity – Rhythm and Music	Group Activity – Art Atelier	Group Activity – Project	Group Activity – Barbeque and Fireworks		
19:30							
20:00							
20:30							
21:00							

Table 5: ICF Evaluation Display

ICF Evaluation Display																						
	Assessment											Evaluation										
Global Goal: Community integration											1					Not evaluated yet						
Service-Program Goal: Increased overall level of independence											1											+
Cycle goal 1: Increased independence in mobility											1											-
Cycle goal 2: Increased independence in self-care											2											+
Cycle goal 3: Enhanced peer relationships											2											+

ICF categories		ICF Qualifier									Goal relation	Goal value	ICF Qualifier									Goal achieve-ment
						problem											problem					
						0	1	2	3	4							0	1	2	3	4	
b152	Emotional functions										G,3	1										+
b280	Sensation of pain										1	1										+
b440	Respiration functions										2	0										+
b7300	Power of isolated muscles and muscle groups										1	0										-
b7603	Supportive functions of arms										1	0										-
s810	Structure of areas of skin										2	0										-
d230	Carrying out daily routine										2	2										+
d410	Changing basic body positions										1	1										-
d420	Transferring oneself										1	2										+
d4602	Moving around outside the home a. other buildings										1	1										-
d465	Moving around using equipment										1	1										-
d470	Using transportation										1	0										-
d520	Caring for body parts										2	2										-
d530	Toileting										2	2										+
d540	Dressing										2	1										+
d570	Looking after one's health										2	1										+
d720	Complex interpersonal interactions										3	0										-
d750	Informal social relationships										3	0										-
d820	School education										G	0					Not evaluated yet					
d920	Recreation and leisure										G	0										+
		facilitator					barrier						facilitator					barrier				
		4+	3+	2+	1+	0	1	2	3	4			4+	3+	2+	1+	0	1	2	3	4	
e120	Assistive products---for personal... mobility ...										1	4+										-
pf	Social competencies										3	2+										-
pf	Assertiveness										3	2+										-
pf	Goal orientation										G	2+										+

Table 5: 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, 2, 3 refers to Cycle goal 1, 2, 3; G refers to the Global 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. **What are the developmental tasks involved in the transition from childhood to adulthood.** *(Refer to page 8 for the answer.)*

Q2. **Name the types of spina bifida, and describe the differences between them.** *(Refer to page 9 for the answer.)*

Q3. **Identify at least three challenges faced by persons with spina bifida during adolescence.** *(Refer to page 9 for the answer.)*

Q4. **What are the two main issues Gabi would like to address in the three-week rehabilitation programme?** *(Refer to page 14 for the answer.)*

Q5. **List the ICF categories that correspond to each of the main issues you identified in question 4.** *(Refer to page 30 for the answer.)*

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