



# International Perspectives on Spinal Cord Injury



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## Preface

The international symbol of disability is the wheelchair and the stereotype of a person with disability is a young man with paraplegia. While these images are very familiar, at the same time we know that this is not an accurate picture of the diversity of global disability. Whereas 15% of the population are affected by disability, less than 0.1% of the population have spinal cord injury.

However, spinal cord injury is particularly devastating, for two reasons. First, it often strikes out of the blue. A driver is tired and inebriated late at night, and veers off the road, resulting in a roll-over crash and consequent tetraplegia. The teenager dives into a pool, only to break her neck. A workman falls from scaffolding, and becomes paraplegic. An earthquake strikes and a person's back is injured by falling masonry. A middle aged woman is paralysed due to pressure from a tumour. In all these examples, someone in the prime of their life becomes disabled in an instant. None of us are immune from this risk.

Second, the consequences of SCI are commonly either premature mortality or at best social exclusion. Trauma care systems are frequently inadequate. For many, access to high quality rehabilitation and assistive devices is unavailable. Ongoing health care is lacking, which means that a person with spinal cord injury is likely to die within a few years from urinary tract infections or pressure sores. Even when individuals are lucky enough to receive the health and rehabilitation care they require, they are likely to be denied access to the education and employment which could enable them to regain their independence and make a contribution to their families and their society.

None of these devastating outcomes is necessary. The message of this report is that spinal cord injury is preventable; that spinal cord injury is survivable; and that spinal cord injury need not prevent good quality of life and full contribution to society. The report contains the best available scientific evidence about strategies to reduce the incidence of spinal cord injury, particularly from traumatic causes. The report also discusses how the health system can respond effectively to people who are injured. Finally, the report discusses how personal adjustment and relationships can be supported, how barriers in the environment can be removed, and how individuals with spinal cord injury can gain access to schools, universities and workplaces.

We can turn spinal cord injury from a threat into an opportunity. This has two dimensions. First, spinal cord injury challenges almost every aspect of the health system. So enabling health systems to react effectively to the challenge of spinal cord injury will mean that they can respond better to many other types of illness and injury. Second, a world which is hospitable to people with spinal cord injury in particular will inevitably be more inclusive



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of disability in general. Improved accessibility and greater availability of assistive devices will help millions of the world's disabled and older people. And finally, of course, the word “opportunity” signals the better lives and the productive contribution to which people with spinal cord injury rightly aspire, and which we can help them to attain, if only we have the political will and the organizational commitment. As earlier with the *World report on disability*, so now with *International Perspectives on Spinal Cord Injury*, this report has potential to change lives and open doors. I urge the world's policy-makers to pay attention to its findings.

Dr Margaret Chan

Director-General

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In 2003, Brian Kellett developed T4 complete paraplegia after a mountain bike accident. Through the arts, he was enabled to accept and adapt to his injury. As an adjunct instructor at his undergraduate college, and in his artwork, he is thankful that his disability gives him a unique narrative to reflect on and share with others. He works as a freelance photographer and designer and is also continuing his academic studies at Ohio State University in the Art Education PhD program. His goal is to create a non-profit organization, working with disabled veterans teaching them therapeutic photography.



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## Chapter 1

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# Understanding spinal cord injury



“Before the SCI, I was a very independent person, with a very busy social life with a lot of friends, working very hard, travelling a lot, concluding my law course, dating... my life was identical to any other young female, with a lot of desire to live. After the SCI, everything changed and many dreams were interrupted – to live alone, finish the university, start a family.”

(Claudia, Brazil)

“While my father was cycling his tricycle and my mother sat and carried me in her arms, a car ran into the tricycle. They were both killed. I survived but became paraplegic at the age of 2. I was looked after by my grandfather who lived in a slum in Bangkok. Later, I was sent to a school for disabled children. Now I am 11, I quit from school. My brain is not good. I have bad memory but can manoeuvre a wheelchair without difficulty. Luckily, Mr B, a tetraplegic business-man, and his wife met me and agreed to look after me. Now I live with them. They gave me a sport wheelchair and planned for me to be a national wheelchair athlete in the future, and I think I can.”

(Anonymous, Thailand)

“When I returned from rehab(ilitation), I was welcomed back to the community at the airport and entered into another phase of my life in a chair. I was thinking that I couldn’t live my life like it was before. I was embarrassed and didn’t really want to see my friends – I was different now – I had changed. I couldn’t play football, run, go camping, ride my bike to the local river. All I wanted to do was stay inside and hide. It took about 6 months of convincing me by my first community OT before I would step out of the house. Prior to me arriving back to the community, she had already arranged for the school to construct ramps and made sure the bathrooms were accessible for me. Very slowly my confidence began to build up. Basketball was a favourite pastime for me before my accident, and while I was in rehab(ilitation) I learnt to play wheelchair basketball. I showed some of my friends how to do some tricks in my chair. Teachers started to encourage participation in school and my community by going on local excursions walking around the community identifying bush plants, as well as travelling to Cairns on a school excursion. The support from the teachers, friends and family was encouraging.”

(Alfred, Australia)

# 1

## Understanding spinal cord injury

Spinal cord injury (SCI) is a medically complex and life-disrupting condition. Historically, it has been associated with very high mortality rates. Yet today, in high-income countries, SCI can be viewed less as the end of a worthwhile or productive life and more as a personal and social challenge that can be successfully overcome. This change reflects better medical provision, which means that people are able to survive, live and flourish after injury. For instance, people who develop SCI can now usually benefit from improved emergency response, effective health and rehabilitation interventions, and technologies such as respirators and appropriate wheelchairs, together with more extensive social services and more accessible environments. As a result, lives can be saved and functioning can be maximized. Many people with SCI can now anticipate not just a longer life, but also a fuller and more productive life, than they would have had in previous generations.

In low-income countries the situation is very different. Traumatic SCI often remains a terminal condition. Most people with SCI in a country such as Sierra Leone die within a few years of injury (1). In low-income countries, and in many middle-income ones, the availability of quality assistive devices such as wheelchairs is very limited, medical and rehabilitation services are minimal, and opportunities to participate in all areas of personal and social life are constrained (2). The situation in many developing countries today is comparable to what it was in Europe and North America in the 1940s (3). Poverty makes life even harder for people with SCI (4). Yet the fact that such dramatic progress in survival and participation has been seen in high-income countries over a relatively short period of time should be a reason to be optimistic for other parts of the world. With the right policy responses, it should be possible to live, thrive and contribute with SCI anywhere in the world.

But no one lives in a vacuum, and essential to our understanding of how people with SCI live is the overall physical, social and attitudinal environment in which they experience their day-to-day lives. The quality of life with SCI depends greatly on whether the environment is facilitating – appropriate resources and services are available, there are supportive relationships and community inclusion – or whether it acts as a barrier when people have to confront discriminatory attitudes and other obstacles, including the failure to provide supportive and facilitating services and resources.

The overall impact of SCI on the individual, and also on society at large, therefore depends on a range of factors, including:

- the age at which the injury occurs (whether early or late in a person's productive life);
- the extent of the injury;
- the availability and timing of resources and services;
- the environment in which the person lives – physical, social, economic and attitudinal.

Policy changes that ensure prompt and effective medical response and sustained rehabilitation towards full reintegration into community life are highly cost-effective and socially beneficial. The cost of providing immediate emergency and medical care is offset by the fact that this care directly saves lives. Since SCI disproportionately affects younger people with many productive years remaining, failure to allocate resources to their rehabilitation results in a substantial social waste that can be avoided through cost-effective measures. Expenditure on the medical and rehabilitative responses to SCI is money well spent. More importantly, saving lives, promoting the quality of life and retaining productivity are social and humanitarian imperatives. The recommendations of this report highlight the changes in policy and practice that, as shown by evidence, can bring about large improvements in the health and quality of life of people with SCI.

Steps to improve the lives of people affected by SCI must be accompanied by measures to prevent SCI. This report shows that many of the high-prevalence causes of traumatic SCI – road traffic injuries, falls, sporting and leisure injuries, and violence – can be understood, anticipated and, to a large extent, prevented.

### Aim and scope of this report

The aim of *International Perspectives on Spinal Cord Injury* is to:

- assemble and summarize information on

SCI, in particular the epidemiology, services, interventions and policies that are relevant, together with the lived experience of people with SCI across the life course and throughout the world;

- make recommendations for actions based on this evidence that are consistent with the aspirations for inclusion and participation as expressed in the *United Nations Convention on the Rights of Persons with Disabilities (CRPD)* (5).

This report documents the magnitude of and trends in SCI, explores prevention strategies, analyses the situation of people with SCI around the globe, and gives examples of solutions across a range of economic settings that can enhance the lived experience of SCI. These solutions range from inclusive health and rehabilitation services to improving access to education and employment, and enhancing support for family and community life.

This opening chapter offers a general orientation to SCI, including a short review of the medical dimension of SCI for non-specialists and a history of SCI. It also includes a discussion of how SCI, and the systems and services that are required for enhancing the experience of living with SCI, can help the wider evaluation of the adequacy of the social response to the needs of people with health conditions and associated disabilities.

## What is spinal cord injury?

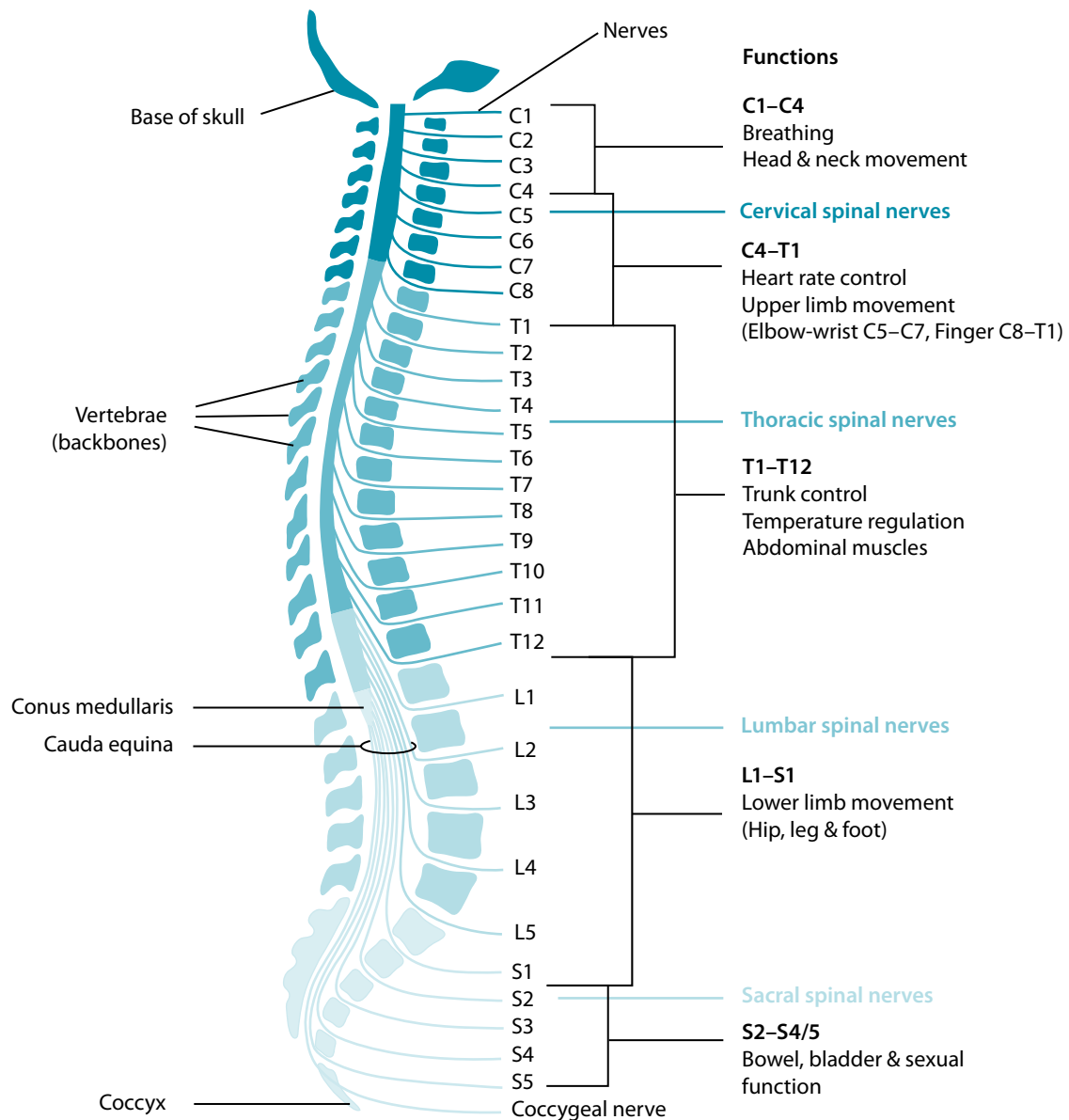
### The medical dimension

Understanding the basic anatomy and physiology is important, even though the experience of living with SCI varies greatly depending on environmental factors. The spinal cord is situated within the spinal column (see [Figure 1.1](#)); it extends down from the brain to the L1–L2 vertebral level, ending in the *conus medullaris*. Continuing from the end of the spinal cord, in

the spinal canal, is the *cauda equina* (or “horse’s tail”). The spinal cord itself has neurological segmental levels that correspond to the nerve roots that exit the spinal column between each of the vertebrae. There are 31 pairs of spinal nerve roots:

8 cervical, 12 thoracic, 5 lumbar, 5 sacral and 1 coccygeal. Owing to the difference in length between the spinal column and the spinal cord, the neurological levels do not necessarily correspond to the vertebral segments.

**Figure 1.1. Longitudinal organization of the spinal cord (with cervical, thoracic, lumbar and sacral segments shaded), spinal vertebrae, and spinal nerves and a rough representation of major functions of the spinal cord**



## International Perspectives on Spinal Cord Injury

While there is debate about what is classified as “spinal cord injury,” all lesions to the spinal cord, *conus medullaris* and *cauda equina* are considered within the context of this report. Damage to the spinal cord may be traumatic or non-traumatic. Traumatic SCI can result from many different causes – including falls, road traffic injuries, occupational and sports injuries, and violence. Non-traumatic SCI, on the other hand, usually involves an underlying pathology – such as infectious disease, tumour, musculo-skeletal disease such as osteoarthritis, and congenital problems such as spina bifida, which is a neural tube defect that arises during development of the embryo.

The symptoms of spinal cord lesion depend on the extent of the injury or non-traumatic cause, but they can include loss of sensory or motor control of the lower limbs, trunk and the upper limbs, as well as loss of autonomic (involuntary) regulation of the body. This can affect breathing, heart rate, blood pressure, temperature control, bowel and bladder control, and sexual function.

In general, the higher up the spinal cord the lesion occurs the more extensive the range of impairments will be. Cervical SCI commonly causes sensory and motor loss (paralysis) in the arms, body and legs, a condition called *tetraplegia* (the alternative term *quadriplegia* is now less used). Someone with C4 or higher lesions may require a ventilator to breathe because the lesion directly interferes with autonomic control. Thoracic SCI commonly causes sensory and/or motor loss in the trunk and legs, a condition called *paraplegia*. Lumbar SCI typically causes sensory and motor loss in the hips and legs. All forms of SCI may also result in chronic pain.

The extent and severity of sensory, motor and autonomic loss from SCI depends not only on the level of injury to the spinal cord, but also on whether the lesion is “complete” or “incomplete.” According to the International Standards for Neurological Classification of SCI, with the American Spinal Injury Association (ASIA) Impairment

Scale (AIS), an SCI is considered complete if there is no sensory and motor function at S4–S5. While some sensory and or motor function is preserved below the level of injury in incomplete SCI, including the lowest sacral segments S4-S5, it is no less serious and can still result in severe impairments.

## The historical dimension of spinal cord injury

The beginning of effective SCI care can be dated to the work of the American neurosurgeon Dr Donald Munro at Boston City Hospital in the 1930s (6). His approach was emulated by Sir Ludwig Guttmann who founded the SCI unit at Stoke Mandeville Hospital in the United Kingdom in 1944 (it became the National Spinal Cord Injury Centre in 1952). The prevailing 80% mortality rate of SCI began to decline, thanks to 2-hourly turning and skin care, together with better bladder management. Improved functional outcomes were achieved with physical and occupational therapy, and more holistic care responded to the socioeconomic needs of the patients (7, 8). Guttmann emphasized sport as a method of therapy and was the founder of the Stoke Mandeville Games, which expanded to become the Paralympic Games in 1960 (9). These early centres became the model for SCI care in the United Kingdom, USA and other countries.

The changing experience of SCI also reflects wider developments in the understanding of disability in general. The social response to disability has profoundly changed in the last few decades, primarily because of the advocacy of people with disabilities themselves. The disabled people’s movement has fought to achieve full inclusion and participation in all areas of society. Conceptually, **the focus has shifted from disability as an individual deficit to disability as an outcome of complex interactions between features of the individual’s health and functioning and aspects of his or her physical, social and attitudinal environment.** In parallel with this conceptual change, disability has become understood as

a human rights concern. This well documented transformation (10–12) has resulted in the CRPD (5). People with SCI have played leading roles in the disabled people’s movement in many countries, beginning with the early pioneers of Independent Living in Berkeley, California, USA, in the late 1960s and 1970s (10).

## Spinal cord injury as a challenge to health systems and to society

The complexity of the lived experience of SCI and the variations in that experience around the world mean that, despite being a comparatively low-prevalence condition, SCI has wider implications for monitoring health care. In principle, an individual with SCI will experience nearly every clinical setting that his or her country provides: emergency services, intensive care, surgery, stabilizing medical care, and particularly rehabilitation, including return to the community, vocational rehabilitation and ongoing primary care. SCI care thus provides evidence about the adequacy of a country’s services, systems and policies. It can also help clinicians, health professionals, researchers and policy-makers to understand the strengths and weaknesses of their health-care system. SCI care is a good indicator of how the overall health system works – or fails to work.

Beyond the health sector, the individual with SCI will require services, resources and access to the social, educational and economic sectors to lead a full and rich life. Turning to civil society, self-help groups, patient groups and other advocacy and disabled people’s organizations play a crucial role in offering knowledge, advice and support, and in lobbying for policy change.

If governments and societies fail people with SCI, it is likely that they will fail people with other health conditions as well. Research and data on the experience of SCI is generally relevant to sound public health policy and to wider efforts to remove barriers to care.

The reverse is also true: SCI clinicians and researchers can benefit from research into other more prevalent conditions that share some or many of the impairments and daily challenges that confront people with SCI. Given that research into, for instance, accessible public transportation or return-to-work services will tend to concentrate on higher-prevalence health conditions and disabilities, the best evidence available may not involve SCI directly but may focus on people with “mobility problems” or “wheelchair users.” This report takes advantage of all relevant high-quality research, whether directed specifically at SCI or taking a broader disability focus.

## Tools for understanding the spinal cord injury experience

United Nations Convention on the Rights of Persons with Disabilities (CRPD)

Two tools are indispensable for comprehending the experience of SCI: the CRPD, which provides a moral compass by elaborating disability as a human rights and development issue, and WHO’s *International Classification of Functioning, Disability and Health (ICF)*, which provides a model of functioning and disability for conceptual clarity as well as being an epidemiological classification for data collection and clinical practice (see [Box 1.1](#)).

The CRPD provides the human rights orientation of this report. It specifies the civil, cultural, political, social and economic rights of people with disabilities, including people with SCI. The CRPD resulted from several years of detailed drafting with the sustained participation of disabled people’s organizations and other civil society groups. The Convention outlines not only broad aspirations – “...to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity” – but also detailed and concrete human rights entitlements in health, education, employment and family life.

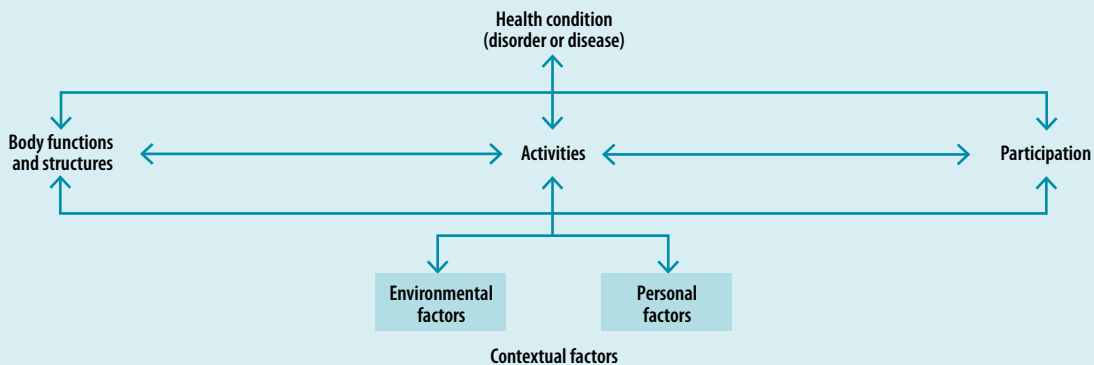
**Box 1.1. International Classification of Functioning, Disability and Health (ICF)**

The ICF was developed through a long process that involved academics, clinicians and people with disabilities (13). The ICF recognizes as determinants of disabilities not only underlying health conditions but also environmental factors (products and technology, the natural and built environment, support and relationships, attitudes and services, systems and policies). The ICF also recognizes personal factors, such as motivation and self-esteem, that can influence a person’s participation in society. It further distinguishes between a person’s capacities to perform actions and the actual performance of those actions - a distinction that highlights the essential role of the person’s environment.

In the ICF, problems with human functioning are categorized in three interconnected areas: impairments are problems in body function or alterations to body structure (e.g. paralysis or loss of bladder and bowel control); activity limitations are difficulties in executing activities (e.g. walking or eating); and participation restrictions are problems with involvement in any area of life (e.g. discrimination in employment or transportation).

Health conditions are understood as diseases, injuries and disorders, while impairments are specific decrements in body functions, such as paralysis associated with health conditions. Environmental factors can be barriers that worsen the experience of SCI (e.g. wheelchair-inaccessible transportation), or facilitators that improve that experience (e.g. wheelchairs and rehabilitation services). Disability is used in the ICF to refer to difficulties encountered in any or all of the three areas of functioning; it arises from the interaction of health conditions with contextual factors, both environmental and personal, as represented in the figure below.

**Representation of the International Classification of Functioning, Disability and Health**



Source (14).

As will become clear in later chapters, the CRPD sets out in very detailed language the precise areas in which human rights reform is required by the Convention. The central topics of this report – the impact of stigma and attitudes, the degree to which the environment is accessible, the availability of health and social services, and the extent to which people with SCI can participate in education, employment, and family and community life – are also the focus of the articles of the CRPD. Furthermore, and unique

to this United Nations human rights treaty, the CRPD mandates that States Parties should collect statistical data (Article 31) and should establish independent human rights monitoring mechanisms (Article 33) to ensure that progress in the implementation of the obligations of the CRPD can be demonstrated with evidence. Countries are obliged not merely to reform laws and practices with respect to disability, but are also obliged to provide evidence that they are doing so. This report has been designed to make

available to countries and their agencies the evidence base for unmet obligations to people with SCI, as well as the best practices for fulfilling those obligations.

## Overview

The report follows the publication of the WHO/World Bank *World report on disability* in 2011, and explores one major health condition in greater detail than was possible in that wide-ranging study (15). The audiences for this report are policy-makers, health service managers, professionals, representatives of nongovernmental organizations and disabled people's organizations, and all those concerned with improving services for people with SCI, particularly in low- and middle-income countries.

After this introductory chapter, the report reviews in Chapter 2 the best epidemiological evidence available on prevalence and incidence of SCI around the world. Chapter 3 examines the main causes of SCI and surveys prevention programmes that respond to these causes and risk factors. The report then turns to a comprehensive review of the medical and rehabilitation dimension of SCI in Chapter 4. This is coupled with a health systems discussion in Chapter 5 that matches best practices in interventions and treatment strategies with the evidence on the systems that are required to make these available. The report next focuses on the lived experience of SCI, beginning with relationships and attitudes in Chapter 6, moving on to general fea-

tures of SCI-enabling environments in Chapter 7, and then an in-depth look at two of the most important areas of participation – education and employment – in Chapter 8. The report concludes with cross-cutting recommendations in Chapter 9.

*International Perspectives on Spinal Cord Injury* offers a practical guide to improving the lives of people with SCI worldwide. It summarizes evidence on needs and unmet needs, and highlights practices across service settings and countries that have been successful in overcoming barriers and addressing service shortfalls.

The key messages of this report are the following.

- SCI is a relatively low incidence but very high-cost health condition.
- Incidence of traumatic SCI can be greatly reduced through a range of preventive strategies.
- Mortality rates in the aftermath of SCI can be reduced through appropriate and timely health care, which also reduces the need for readmissions with secondary complications.
- Dependency as a consequence of SCI can be avoided through provision of rehabilitation and assistive devices.
- Poverty and social exclusion associated with SCI can be minimized through removing barriers and providing adequate support.

While SCI will always have a life-changing impact, it need not end life, nor need it impose undue cost on families and societies if appropriate health and social responses are forthcoming.

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## Chapter 2

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# A global picture of spinal cord injury

“One day I woke up and stared at the ceiling. I wanted to turn my head but I couldn’t. I wanted to lift my arm but could not. Nothing was moving. I heard a lot of noise but could not see anything. A nurse appeared beside me. I wanted to say something but she couldn’t hear me. I wanted to scream but no sounds came out. I closed my eyes. I opened them when I heard my name being called, looked up and saw my parents. Even though it seemed to me like one second between closing my eyes and opening them again, a whole day had passed. My parents told me that I had tetraplegia. My parents told me that I was in a Brussels hospital and I had a work-related injury. My neck was broken, I was totally paralysed and I could not breathe on my own. I was thirsty and asked for some water. I couldn’t drink out of the cup with a straw that was handed to me because I could not swallow. I had been working at a house. I fell off a ladder or I shifted off a ladder, I’m not quite sure anymore. I fell six metres down and landed on the concrete.”

(Gunther, Belgium)

“I was injured (C5–C6) in a car accident when I was 19 and have now been in a wheelchair for 30 years. I live in the most northerly city in the world, Hammerfest. Living in the North brings with it some great physical challenges with streets draped in snow for up to five months of the year and low temperatures making it hard to go outside in a wheelchair. I was among those with the greatest need of assistance when I was injured, at a time when the community really had just started to develop its home-based services. Since then I have had the privilege to participate and shape the services related to my needs, and my demands to live as normally as possible as a citizen.”

(Kjell, Norway)

“I was injured in the Sichuan earthquake four years ago when I was 30 years old. Now I use a wheelchair for daily movement.”

(Chen, China)

“I am 51 years old and I am a T–6 complete paraplegic caused by a blood clot compression. I was shocked when I first became paralysed because I had received the wrong diagnosis from a physician in 1984. I don’t think it is easy getting into the mainstream of independent living after being disabled. In the years since my diagnosis, a lot of things have helped me come to terms with my disability.”

(Nipapan, Thailand)

“In early November 2002 I fell from a friend’s horse while competing at a horse trials event. I am an incomplete C6–7 with good arm control. Despite not having grip ability, my hands are functional enough to perform several tasks like holding a glass of wine (very important!) and signing my name.”

(Anonymous, New Zealand)

# 2

## A global picture of spinal cord injury

Article 31 of the *Convention on the Rights of Persons with Disabilities* (CRPD) requires States Parties to collect statistical data that enable them to formulate and implement policies that give effect to the rights in the Convention, so that people with spinal cord injury (SCI), and other disabilities, can fully participate in all areas of society, from family life, education and employment to community and country. Valid and reliable data about SCI are essential for informed decisions about programmes and policies designed to prevent the occurrence of SCI, to improve the lives of people with SCI and to anticipate future SCI service needs.

To appreciate the socioeconomic impact of SCI, a complete epidemiological picture of SCI is required, both in terms of data about the overall number of people living with SCI (prevalence), the number of new cases that arise (incidence), and the causes of SCI (see [Table 2.1](#) for definitions of indicators). This information needs to be collected at regular intervals to make predictions about future trends. Evidence-based policy and programming at the national level also require information about the environmental factors that influence the experience of living with SCI, the socioeconomic circumstances of people with SCI, their met and unmet needs, and the costs of SCI.

This chapter presents basic epidemiological information using indicators (see [Table 2.1](#)) of prevalence, incidence, mortality, causes and costs of both traumatic and non-traumatic SCI (TSCI and NTSCI) and discusses SCI data and evidence and how they can be improved. The information presented is derived from peer-reviewed journal articles, governmental publications, and reports from prospective and retrospective studies using data from spinal cord injury registries, population registries, hospital admission and discharge data, and health survey data. Specifically for the report, systematic reviews were carried out of publications on the epidemiology of SCI published between January 2000 and August 2012. Meta-analysis was done where appropriate. A fuller explanation of the methodology used to assess the data and its limitations can be found in Technical Appendices A and B.

### What do we know about spinal cord injury?

Data on the magnitude and costs of SCI are limited. Only a handful of high-income countries are able to provide national statistics. Other data sources

**Table 2.1. Examples of commonly used national, epidemiological indicators for spinal cord injury**

Indicator	Description	Use and limitations
<b>Incidence of SCI</b>	Incidence data reflect how many people have become spinal cord (SCI) injured in a given population over a specified period of time. It is generally reported as several new SCI cases per million population per year. Incidence is a direct measure of SCI risk. Stratified estimates of incidence rates by etiology, and further by demographic (sex, age), occupation or geographical location (urban, rural) variables may differentiate/identify risk groups, thereby informing effective prevention policy and programmes.	Variation occurs as to whether: <ul style="list-style-type: none"> <li>– population at risk (i.e. source population for SCI cases) is well defined;</li> <li>– case definition of SCI;</li> <li>– completeness of case ascertainment, which is the extent to which all the incident SCI – as defined by the case definition – is included. For instance, TSCI incidence may not include those people with SCI that died at the scene of injury; NTSCI incidence may not include people incurring SCI during end-of-life care (e.g. spinal metastasis).</li> </ul>
<b>Prevalence</b>	The numbers of people in the population living with SCI at a given time point. It is measured as number per million population. Prevalence is influenced by risk and duration of a condition and the latter is determined by recovery or death. Regular collection of data, disaggregated by age, sex and socioeconomic categories, such as occupation and wealth status, can uncover important patterns and trends in the lived experience of SCI.	Prevalence is an indicator of the effectiveness of secondary prevention and the need for health care and social support.
<b>Etiology</b>	Absolute figure indicating the number of people that are spinal cord injured by mechanism, intent, place and activity.	Useful for planning at the local level for primary prevention, trauma care and rehabilitation services. Useful for calculating the cost of health care.
<b>Standardized Mortality Ratio (SMR)</b>	The SMR gives a standardized estimate of mortality in people with SCI with regard to the general population. When the SMR equals 1.0, then there is no increased risk of death for people with SCI; if larger than 1.0 then there is. The requirements for calculating SMR for a cohort are: <ul style="list-style-type: none"> <li>– the number of people with SCI by age group and sex;</li> <li>– observed deaths in people with SCI;</li> <li>– the age- and sex-specific mortality rates of the general population.</li> </ul>	To determine if mortality of people with SCI is higher or lower than in the general population. Limitation: Variation in SMR estimates between populations may partly reflect variation in mortality of the general population and completeness of mortality ascertainment.
<b>Case fatality rates</b>	Absolute figures of the number of people who died after SCI. If disaggregated by etiology, relevant responses can be identified and implemented.	Shows the relationship between SCI and fatalities. For comparison, the information needs to be standardized into the following groups: number of people with SCI, including those with TSCI that die at the incident scene; fatalities in hospital; and fatalities after discharge: 30 days, 1 year, 5 years, etc.

are so few and so methodologically varied that it is not possible to calculate reliable point estimates for global prevalence or incidence. The best available SCI data provide a general picture that is summarized below and explored in detail in the remainder of this chapter.

SCI is a relatively rare but life-altering and costly condition, with a mortality risk that varies widely by country income status and depends heavily on the availability of quality clinical care and rehabilitation services. It is unclear how many people in the world are currently living

with SCI, but international incidence data suggest that every year between 250 000 and 500 000 people become spinal cord injured. The majority of these cases are traumatic SCI, the leading causes of which are road traffic injuries, falls and violence. Recent studies show an increase in the age of SCI onset and a gradual increase in the proportion of non-traumatic SCI cases – partly attributable to the world's ageing population.

Current data also show that SCI is associated with an elevated risk of death. People with SCI are most at risk of death in the first year after SCI onset, but even in high-income countries where advances in care have meant that survival has improved, they still face an elevated mortality risk and are more likely to die earlier than the general population. People with SCI in low-income countries continue to die from preventable secondary conditions that are no longer a leading cause of death in high-income countries.

The costs of SCI varies widely depending on the context, and few comparable data are available. From existing data it is clear that SCI carries substantial direct and indirect costs, and that much of these costs are borne by people with SCI. The level

and severity of SCI have a significant influence on cost. Direct costs appear to be highest in the first year after SCI onset and, over a lifetime, indirect costs are likely to exceed direct costs.

There is an urgent need to improve the quantity and quality of data collection on SCI. Issues with SCI data and recommendations for improving the evidence are discussed at the end of this chapter.

## Prevalence of spinal cord injury

Data on the prevalence of SCI are important for gauging demand for health care and social support, and for assessing the impact of secondary prevention measures; unfortunately, data on the prevalence of SCI are sparse. Currently there are no reliable global or regional estimates of all-cause SCI prevalence. Estimates from six countries are presented here (see [Tables 2.2](#) and [2.3](#)). Some estimates found in the literature are not included because they either suffer from methodological problems or are considerably older and may not reflect the current situation.

**Table 2.2. Prevalence of TSCI**

Country	Locality	Year of estimate	Study design and reference population	Paediatric /adult SCI	Prevalence per million population
Islamic Republic of Iran	Tehran	2008	Prospective, cross-sectional, national registry	Adult, paediatric	440
Finland	Käpylä Rehabilitation Centre, Helsinki; Helsinki University Central Hospital, Helsinki	1999	Retrospective, registry of hospital data	Adult, paediatric	280
Norway	Hordaland and Sogn og Fjordane counties	2002	Retrospective, longitudinal/cohort using hospital data	Adult, paediatric	365
Iceland	Landspítali University Hospital, Reykjavík	2009	Retrospective, longitudinal/cohort using hospital data	Adult, paediatric	526
Canada	Nationwide	2010	Retrospective, cross-sectional, national registry, modelling study	Adult, paediatric	1298
Australia	Nationwide	1997	Retrospective, national registry, modelling study	Adult	681

Sources (1–6).

**Table 2.3. Prevalence of NTSCI**

Country	Locality	Year	Study design and reference population	Paediatric / adult SCI	Prevalence per million population
Canada	Nationwide	2010	Retrospective, cross-sectional; national registry	Adult, paediatric	1227
Australia	State of Victoria	2010	Retrospective, cross-sectional, national registry	Adult, paediatric	367 (455 for adults 16 years and over)

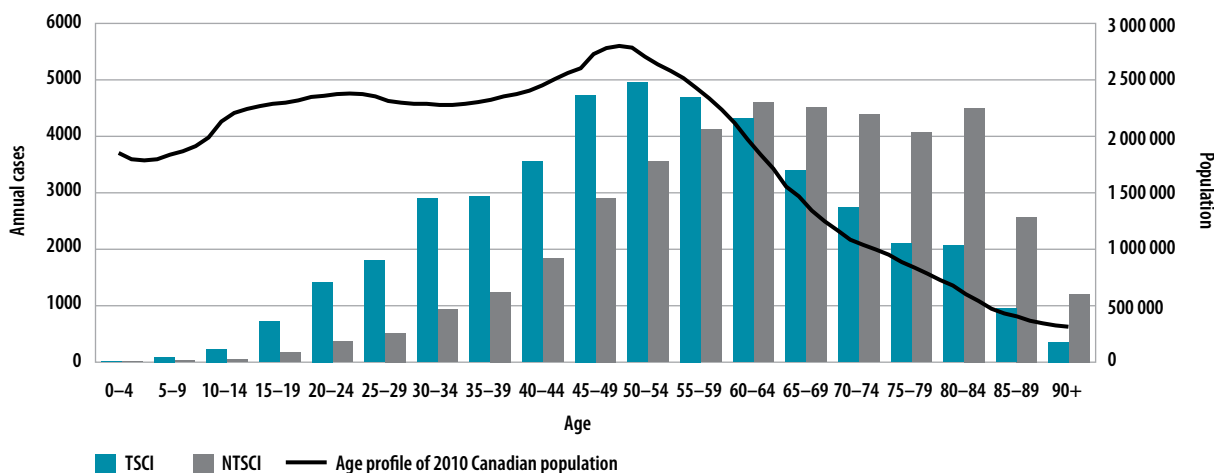
Sources (1, 7).

Canadian data yield an overall SCI prevalence rate (traumatic and non-traumatic combined) of 2525 per million population, or 85 000 people, in 2010. Age-specific prevalence estimates of SCI in Canada indicate that TSCI is concentrated in younger populations while NTSCI is concentrated in older age groups (see Figure 2.1).

TSCI prevalence figures (see Table 2.2) range from 280 per million population in Finland (5) to 1298 per million in Canada (1), although this variation is more likely due to differences in methodology than to a true fivefold difference in prevalence. The Australian and Canadian prevalence estimates derive from a modelling technique that incorporates incidence data

and information on disease duration. The higher rates in Canada might be indicative of a North American trend or it may be that current best-evidence assumptions used in Canada lead to overestimation of incidence while those employed in Australia underestimate the incidence rate. The other countries present available data from hospital and national registries and cross-sectional and longitudinal studies. To better understand prevalence estimates between these countries, more data are needed regarding demographic differences, both cause-specific incidence rates by age and sex and associated life expectancies, information that is not currently available.

**Figure 2.1. Age-specific prevalence estimates of SCI in Canada for 2010**



Source: Adapted from (1) with permission from S. Karger AG, Basel.

NTSCI prevalence data (see Table 2.3) are available only for Australia (367 per million population) and Canada (1227 per million population) (1, 7). The Australian data are drawn from a study in the state of Victoria, based on life expectancy and national rehabilitation outcomes data, and extrapolated to the rest of the country (7). The results show a prevalence of 455 per million population for adults 16 years and above, suggesting that ageing demographics may be the primary driver for increasing NTSCI prevalence. The higher Canadian prevalence estimates may be a result of the assumptions made in the study rather than a true difference in prevalence.

## Incidence of spinal cord injury

Estimated global SCI incidence is 40 to 80 new cases per million population per year, based on quality country-level incidence studies of spinal cord injury from all causes. This means that every year, between 250 000 and 500 000 people become spinal cord injured.

Studies that report incidence data for both traumatic and non-traumatic causes of SCI provide information about the overall constitution of SCI populations. This information is important to collect since the resource needs and characteristics of traumatic and non-traumatic populations are different. The proportion of TSCI varies within a wide range and appears to differ across regions (8–11). Historically, up to 90% of SCI has been traumatic in origin, but data from the most recent studies indicate a slight trend in recent years towards an increase in the share of NTSCI (12). The NTSCI population is generally older, with progressive diseases requiring more expensive care, although for a shorter period.

Most studies of SCI incidence cover either TSCI or NTSCI, perhaps because of differences with data sources and data collection methods. The incidence and etiology of TSCI and NTSCI are therefore examined separately below. Data for NTSCI are limited compared to those for TSCI.

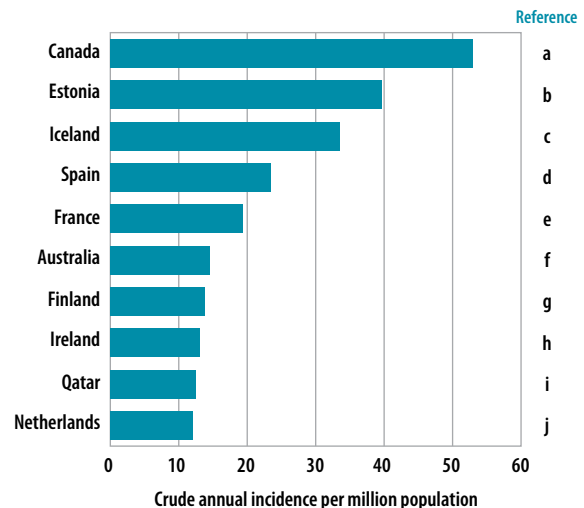
## Traumatic spinal cord injury

### Incidence

Given the available data, it is not possible to derive meaningful regional point estimates for the incidence of TSCI. Statistical modelling is precluded because of the lack of reliable predictors.

Country-level TSCI incidence rates vary widely across the world – from 13 to 53 cases per million population, as illustrated by Figure 2.2. TSCI incidence rates tend to be higher in North America than in Europe, possibly due to higher rates of violence in the USA. Incidence data from other regions either do not exist or fluctuate too widely between and within countries that it is difficult to provide valid summary statistics. For example, data from the Municipality of Beijing in China show a high of 60.6 per million (21), while the region of Tianjin reports an incidence of 23.7 per million (22).

**Figure 2.2. Global variation in country-level estimates of annual incidence of TSCI**



Sources: a (1); b (13); c (2); d (14); e (15); f (16); g (17); h (18); i (19); j (20).



The considerable country-level variations in TSCI incidence are due to several factors:

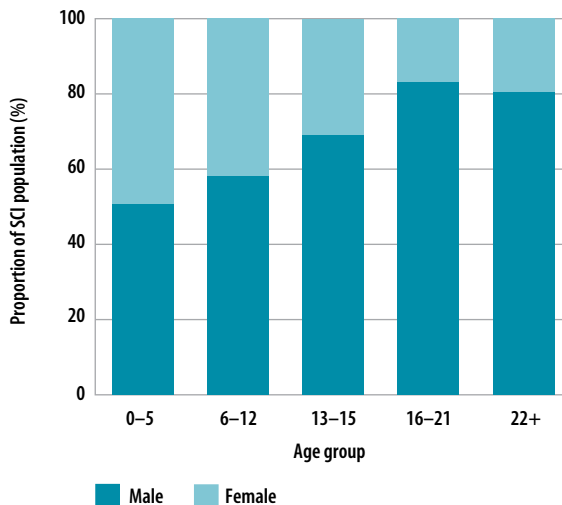
- Genuine country-level differences in incidence related to differences in risk.
- Differences attributable to methodological approaches.
- The population (adults, children or both) under study. TSCI in children is low. Studies reporting only adult incidence overestimate the overall population rate and make comparison difficult with studies reporting merged adult and child incidence data.
- Representativeness of the data. With the exception of a few countries that have a country-wide SCI registry system, such as Finland, incidence estimates are extrapolated from city or regional data that may not be representative of the country as a whole.

Despite these variations, a few trends emerge from the TSCI country-level incidence data:

**1. Incidence of TSCI is decreasing in some countries, but staying stable or increasing in others.** Studies in the USA, Finland and Australia have noted a decrease in incidence of TSCI resulting from road traffic crashes. However, this result is not evident in all developed countries. Data from two Norwegian counties showed a steady increase in the incidence of TSCI by decade between 1952 and 2001, from 9.9 to 34.5 per million in men and from 1.9 to 8.2 per million in women (3). Although France has shown a marked decrease in the incidence of road traffic crash fatalities, the incidence of SCI has remained stable (23). This reflects a changing profile, with the incidence of SCI for car users dropping but the incidences for motorcyclists, pedestrians and cyclists increasing.

**2. There are consistently higher incidence rates of adult TSCI among males.** Whereas paediatric studies typically report a balanced male-to-female ratio (24, 25), adult studies mainly show a minimum male-to-female ratio of 2:1, with some reporting much higher rates. For example, excessively high male-to-female

**Figure 2.3. Distribution of TSCI by sex and age group**

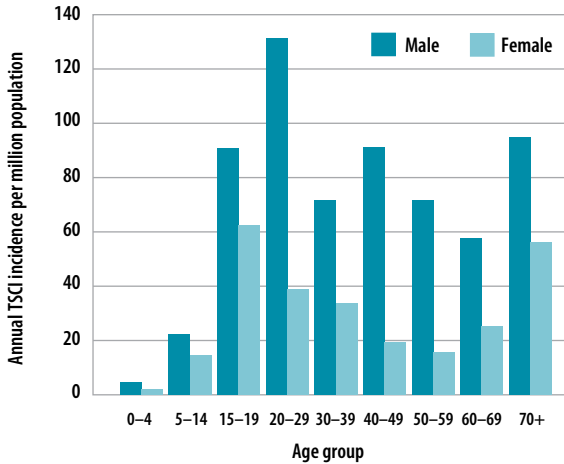


Sources (27, 28).

ratios have been reported in the Thessaloniki region of Greece (7.3:1) (26), Ireland (6.7:1) (18), Qatar (8.3:1) (19), and Stockholm, Sweden (3.3:1) (26). TSCI incidence data from the USA show that males have higher rates of TSCI across all age groups, with a peak from ages 16 to 21, with 82% of TSCI cases in this age group occurring to males (see Figure 2.3). These results support the view that SCI incidence is in part a function of gender roles – alcohol consumption, driving behaviour and participating in high-risk sports – that manifest after childhood (13, 29–31).

**3. TSCI is most likely to occur in young adults and the elderly.** Two common age-associated peaks occur in TSCI incidence rates– in young adults (males: 20–29 years; females: 15–19 years) and in older people (males 70+; females 60+), see example of age- and sex-specific TSCI incidence rates for Canada in Figure 2.4 (1). The increased incidence after age 65 is a pattern only recently observed. A study in Canada showed a 51.4 per million incidence for people over 60 (32), which is supported by studies in China and Australia (16, 33). In Australia over the past 25 years the proportion of SCIs among people 65 and older

**Figure 2.4. Age- and sex-specific incidence rates for TSCI in Canada**



Source (1).

has increased from 4% to 12% (34). These findings reflect the higher incidence of falls among the elderly (see Figure 2.4 and Figure 2.7). Paediatric TSCI incidence rates are low (e.g. 4–8 per million) in most countries for which there are estimates (24, 25, 36), with the notable exception of the USA, where one study reports a paediatric TSCI

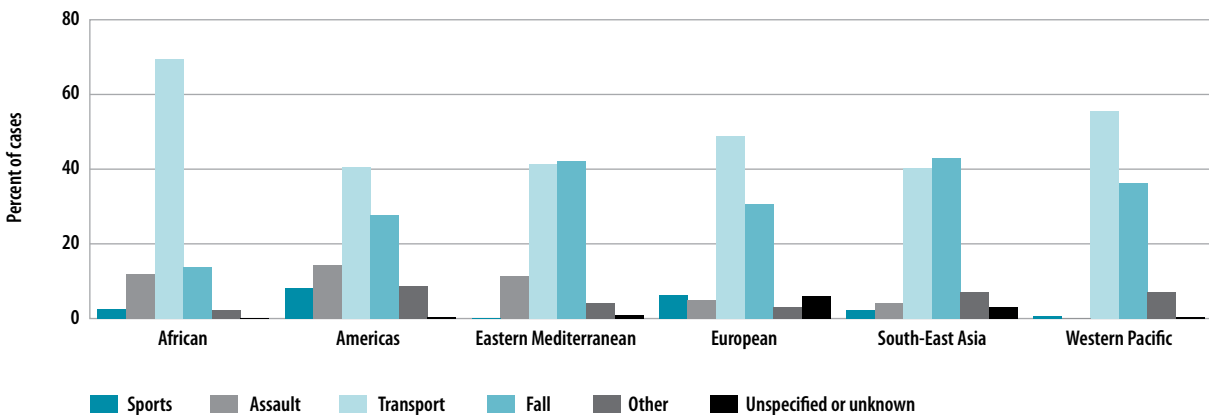
incidence of nearly 20 per million (37). Studies typically show intermediate incidence rates for adolescents and middle-aged adults (1–3). There is some evidence that age at time of injury is increasing. In Norway, for example, the mean age of TSCI increased from 40.2 years to 48.9 years between 1952 and 2001, with the greatest change in average age at injury seen among women – an increase from 24.7 years to 57.7 years (3).

### Etiology

Based on available evidence on the etiology of TSCI across WHO regions, the three most common causes are transport (road traffic crashes in particular), falls and violence (see Figure 2.5). While the summary estimates in Figure 2.5 capture regional differences, they may not adequately illustrate country-level variation in causes or the context of the injury.

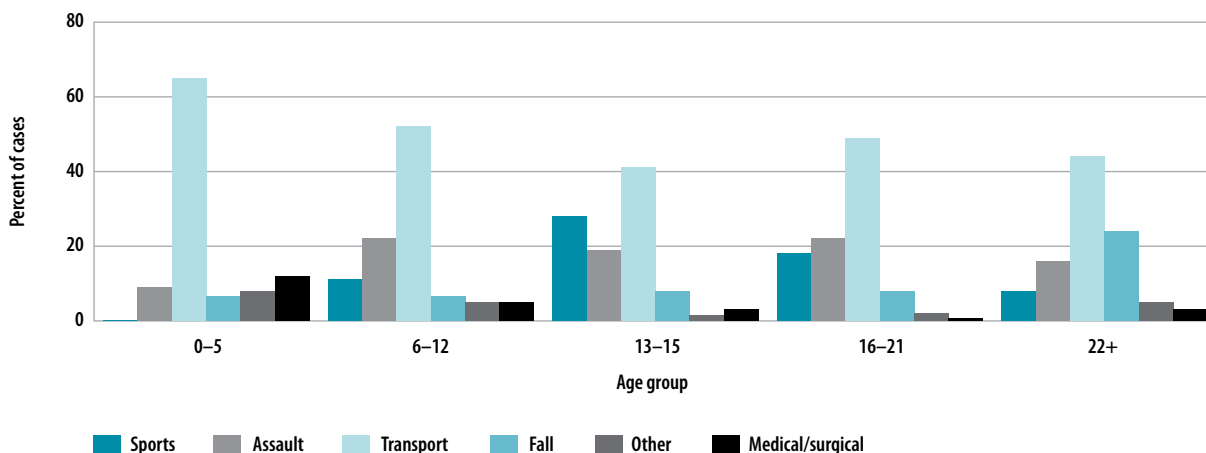
Road traffic crashes are the leading cause of TSCI. In the African Region, transport accounts for nearly 70% of cases. In the other WHO regions transport, as a percentage of all cases, ranges from 40% in the South-East Asia Region to 55% in the Western Pacific Region. A study in Mississippi, USA showed that seat-belts were

**Figure 2.5. Distribution of TSCI by WHO region**



Note: The numbers of countries providing data for regional summary are as follows: African 3 countries; Americas 4; Eastern Mediterranean 5; European 13; South-East Asia 3; and Western Pacific 3 countries.  
Sources: African – (38–45); Americas – (12, 30, 32, 35, 46–52); Eastern Mediterranean – (4, 53–56); European – (2, 3, 9, 13, 17, 18, 20, 26, 57–67); South-East Asia – (68–72); Western Pacific – (16, 21, 22, 34, 73–80).

**Figure 2.6. Etiology of SCI by age group (in young people)**



Sources (27, 28).

not available or not used in at least 75% of vehicle crashes resulting in SCI (31). Similarly, a study of SCI in Nigeria reported that none of the 63 reported traffic-injured patients used a seat-belt (38), which illustrates the importance of seat-belt use to reduce SCI among vehicle occupants (see Chapter 3 for further details).

Falls are the second leading cause of TSCI. Falls account for just over 40% of all cases in the Eastern Mediterranean and South East Asia Regions. For example in Nepal a study reported that 40% of spinal injuries resulted from falls from trees while cutting leaves for fodder and 28% resulted from falls from buildings (81). The African Region reports the lowest percentage (14%) of falls, with the other WHO regions showing percentages between 27% and 36%.

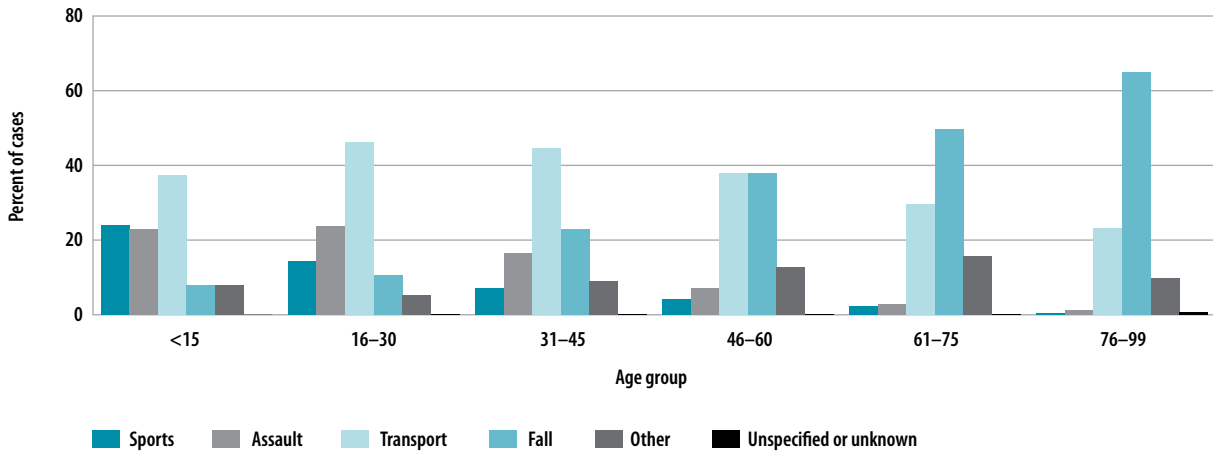
Violence, including self-harm, is the third most common cause of TSCI. The relative proportion of violence as a cause of TSCI varies considerably, with the Americas, African and Eastern Mediterranean Regions reporting the highest percentages of 14%, 12% and 11%, respectively. Some country-specific data – notably from countries affected by war – show much higher rates, such as Afghanistan, which reports 60% of all cases of TSCI being related to violence (56). The percentage of violence-related TSCI cases is also

high in Brazil at 42% (10), Turkey at 25% (64), and South Africa at 21% (44). In the USA, 11.7% of SCI cases are caused by firearms (82), with as much as 28% due to firearms among some age and ethnic groups (27). Western European averages are around 4% (59), and some countries such as Norway, Canada and Australia report an average of less than 2% (3, 16, 30). Finally, attempted suicide has been shown to contribute to over 10% of TSCI cases in Israel and Finland (5, 8).

Across all regions, sport and leisure activities contribute less than 10% of all cases of TSCI, with the Region of the Americas reporting the highest percentage of sport-related TSCI (8%). However, in some cases country-specific data show higher rates, such as 28% in the USA (27), 25% in the Republic of Korea (83) and 22% in France (84), or lower rates such as in Nigeria where sports contribute only 1.7% of all TSCI cases (43).

Causes of TSCI may also be related to activities, places and circumstances. Work-related injuries contribute to at least 15% of all TSCI cases (2, 8, 16, 18, 26, 60, 85). Alcohol or drug use has been identified as a contributing factor to TSCI in 34% of all cases in British Columbia, Canada (30) and 34% of all transport-related trauma in Mississippi, USA (31).

**Figure 2.7. Etiology of SCI by age group (all age groups)**



Source (35).

### Demographic trends

Age and sex influence the etiology of TSCI throughout the life-cycle. Drawing on data of SCI among children and young adults in the USA (see Figure 2.6) – data that are supported in the literature from other countries – medical and surgical causes of SCI are most prevalent under the age of one year. Between birth and five years of age, four-wheeled motor vehicle crashes account for as much as 65% of all TSCI cases (28). Transport (i.e. road traffic crashes) remains the most common cause of TSCI among children and young adults, accounting for a higher percentage of SCI in girls than for boys. Violence is shown to cause more SCI among males in all age groups, although these differences are statistically significant only in ages above five years. Sports cause more TSCI in boys than girls after the age of 13 years.

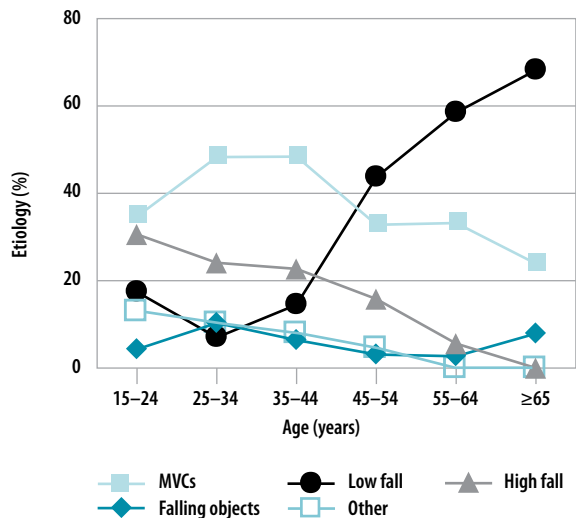
These trends are reflected in data from other countries with a couple of exceptions. Two studies of children with a mean age of nine showed higher rates of violence and assault in Brazil and higher rates of falls in the United Kingdom (10, 86).

While transport remains a significant cause of SCI in all age groups, falls become the most common cause after the age of 60, as seen in Figure 2.7 in US data taken from the 2011 National Spinal Cord Injury Statistical Center

(NSCISC) Annual Statistical Report (35).

A study from China, which looked specifically at the height of falls, found that high falls were more common for those between 15 and 44 and that low (less than a metre) falls were most common for people over 45 (80), as shown in Figure 2.8.

**Figure 2.8. Distribution of etiology by age group in China**



Note: MVCs = Motor vehicle crashes

Source: Reproduced from (80) with permission from Maney Publishing.

## Non-traumatic spinal cord injury

### Incidence

There are far fewer studies on NTSCI incidence than TSCI incidence, with the exception of specific studies on spina bifida (see [Box 2.1](#)). Global and regional incidence rates cannot be estimated because existing studies are not representative or comparable, owing to methodological issues such as different inclusion/exclusion criteria, incomplete case ascertainment, or inadequacies in reporting population at risk (87). The NTSCI incidence rate in Canada is estimated to be 68 per million (1). Australian estimates, using data from the State of Victoria, report an incidence of 26 per million (87–89). Data from a hospital with a specialized SCI unit in Spain (90) report 11.4 per million.

The incidence of NTSCI varies by both age and sex. As with TSCI, incidence rates of NTSCI are higher among males than females. In contrast to TSCI, NTSCI incidence increases steadily with age (see [Figure 2.9](#) for example), with risk probably influenced by the increase of ill health with increasing age. Since NTSCI is more common in older age groups (89), and given global ageing,

NTSCI incidence will increase and may overtake that of traumatic TSCI in the next decades (7).

### Etiology

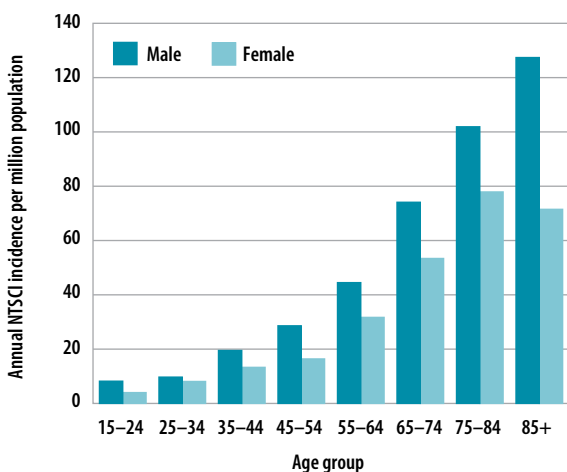
There are few reliable national data concerning the etiology of NTSCI, but studies suggest that the leading causes are neoplastic tumours and degenerative conditions of the spinal column, followed by vascular and autoimmune disorders (11, 59, 62, 122–124). In countries such as India, Peru and Sweden, where there are high levels of tuberculosis and other infectious diseases, these dominate all causes of NTSCI except tumours (123, 125, 126). Congenitally and genetically caused cases such as spina bifida are not recorded in these studies, as these are typically collected in different settings.

### Mortality and life expectancy

This section summarizes what is known about the impact of SCI on mortality risk and life expectancy – essential information for effective planning and resource allocation. Improvements in SCI recognition, evaluation, pre-hospital management, trauma care services, general clinical care and rehabilitation service have resulted in longer life expectancy for people with SCI in high-income countries, alongside a decreased risk of mortality from secondary conditions. People with SCI remain more likely to die – and to die earlier – than people without SCI. They are also more likely to die from certain health conditions than people in the general population. In most cases, the first year after injury holds the highest risk of death for people with SCI, and many people with SCI in low-income countries are dying from preventable secondary conditions.

**People with SCI die earlier than people without SCI.** Overall, studies have indicated that people with SCI are 2 to 5 times more likely to die prematurely than people without SCI (see [Table 2.4](#)). Another way to assess the effect of SCI is to consider its impact on life expectancy, how long a life someone can expect to live. Few

**Figure 2.9. Age- and sex-specific incidence rates for NTSCI in Australia**

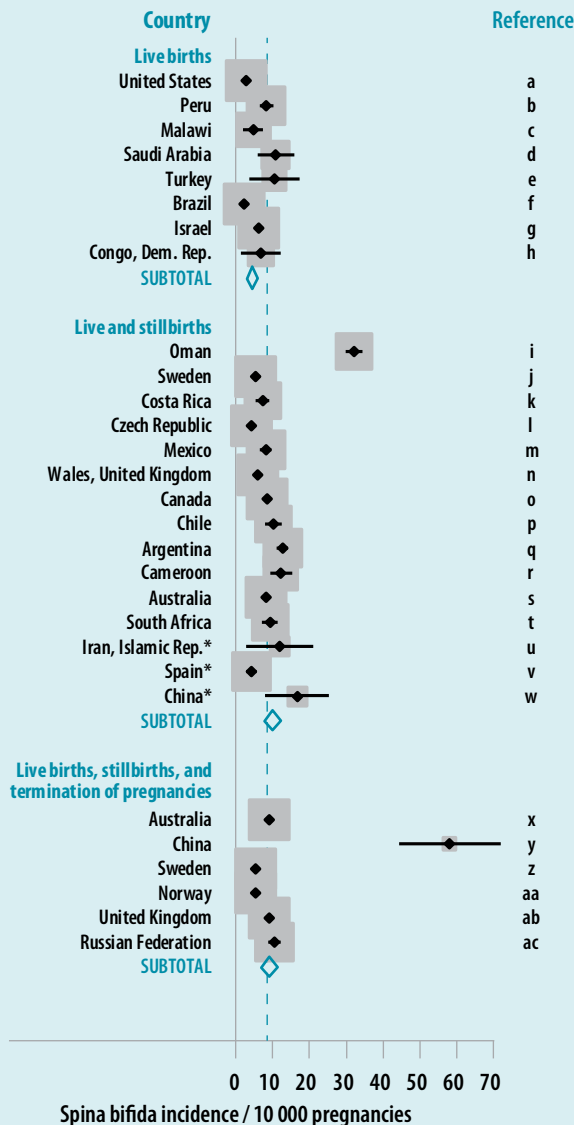


Source (89).

**Box 2.1. Spina bifida incidence**

The majority of studies estimate spina bifida incidence to be between 2 and 12 per 10 000 live births. A few studies indicate much higher rates, including those from Oman (32 per 10 000) and China (58 per 10 000). A meta-analysis carried out for this report found an overall incidence rate of spina bifida of about 4.5/10 000 (95% CI: 3.7–5.3) in studies that use live birth data, while those that use live and stillbirth data or live, stillbirth and termination of pregnancy (TOP) data reported incidence rates of about 10.0/10 000 (95% CI: 8.1–11.8) and 9.1/10 000 (95% CI: 6.7–11.4), respectively (see Technical appendix C for methods and terminology used). It would be reasonable to expect that country studies reporting incidence rates based on live, stillbirth and TOP data would have higher incidence rates. However, as illustrated in the figure below, this is not the case. This may be due to the variation in data sources used for calculations, as well as the variation between countries of spina bifida incidence.

**Spina bifida incidence**



Note: This figure is a Forest plot that provides a graphical summary, plus the summary statistic, of a meta-analysis on incidence rates of spina bifida as reported globally. The data used in the meta-analysis were extracted from studies identified in a systematic review of relevant literature. The size of the grey squares for each study is proportional to the weight assigned to the study for the meta-analysis. Each study is shown with 95% confidence intervals, depicted by black horizontal lines going through the point estimates of spina bifida incidence. The summary incidence rate of spina bifida is represented by the diamond shape, whose width represents the 95% confidence interval, centred on the summary statistic.

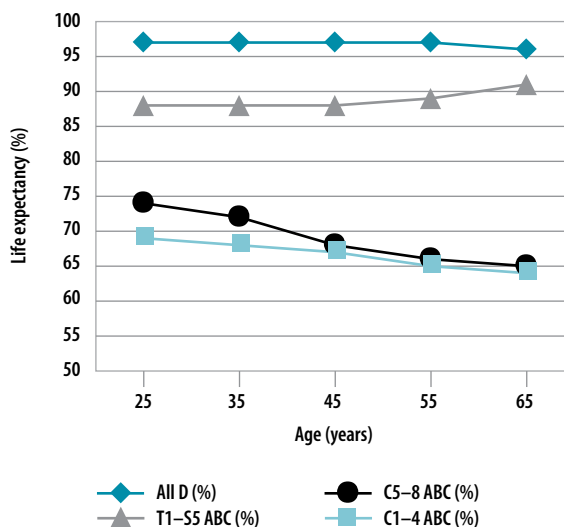
Note: \* = subgroup meta-analysis  
 Sources: a (91); b (92); c (93); d (94); e (95); f (96); g (97); h (98); i (99); j (100); k (101); l (102); m (103); n (104); o (105); p (106); q (106); r (107); s (108); t (109); u [(110); (111)]; v [(112); (113)]; w [(114); (115); (116)]; x (117); y (118); z (119); aa (120); ab (121); ac (120).

studies compare people with SCI to the general population. However, one Australian study showed that individuals with a spinal cord lesion level between C1 and C4 have only 70% of the life expectancy of the general population at the age of 25 (see Figure 2.10) (34). The first year after injury has the highest risk of mortality for people with SCI (57, 129).

**Among people with SCI, mortality risk depends on the level and severity of the injury.** Tetraplegics die earlier than paraplegics (34, 127, 130). A Finnish study found that the SMR for paraplegia was 2.3 as compared to 3.0 for tetraplegia (127), while in Australia the SMR for paraplegia is 1.7 as compared to 2.2 for tetraplegia (34). The Finnish study also showed that mortality is higher in people with complete lesions as compared to incomplete, with a complete injury nearly doubling the mortality rate of people with paraplegia, and nearly tripling it for those with tetraplegia (127).

**In developed countries life expectancy has increased since the 1950s.** Longitudinal studies in high-income settings have shown a steady increase in life expectancy for people with SCI. A study in the USA on TSCI observed a 40% decrease in mortality between 1973 and 2004 during the first 2 years post-injury, while mortality beyond 2 years post-injury remained fairly stable (131). Similarly, between 1981 and 1998 a study showed there was a 3% annual decrease in TSCI mortality rate; in particular mortality rates declined among males, whites and victims of motor vehicle crashes (132). This progression reflects the improvements in clinical care and

**Figure 2.10. Life expectancy in Australia by attained age for people with SCI in comparison to general population**



Note: A: complete paralysis; B: sensory function only below the injury level; C: incomplete motor function below injury level; D: fair to good motor function below injury level. Source (34).

rehabilitation medicine for people with SCI over the past 60 years.

**Secondary conditions of SCI are no longer the main cause of death of people with SCI in high-income countries.** In high-resource countries, there has been a shift in principal causes of death from urologic complications, such as urosepsis or renal failure, to causes of death similar to the general population, such as respiratory problems, especially pneumonia and influenza (11, 50, 130, 133, 134). Some studies have found high rates

**Table 2.4. Standardized mortality ratios for TSCI in four countries**

Country	Locality	Years	Paediatric/adult TSCI	SMR
Finland	Helsinki	1976–2005	Adult	2.7
Norway	Hordaland and Sogn og Fjordane counties	1997–2001	Adult and paediatric	1.9
Estonia	Nationwide	1997–2001	Adult and paediatric	5.0
Australia	Nationwide	1986–1997	Adult	2.1

Sources (127–129).

of mortality caused by heart disease, suicide, and neurological problems (11, 50, 127, 130, 133).

People with SCI however die of these conditions more frequently than people in the general population. For example findings from a study in Norway indicate an overall increased mortality risk from respiratory diseases among SCI cases compared to the general population, with a SMR of 1.96 (135). In Australia, a study found a cause-specific SMR of 17.11 for pneumonia and influenza, 4.37 for suicide, and 6.84 for diseases of the urinary system (34). One Norwegian study found respiratory disease, ischaemic heart disease, cancer and suicide as the most common causes of death (57).

***In low-income countries, people with SCI continue to die from preventable secondary conditions, e.g. urologic complications and pressure sores.*** In low-resource countries, although there are few data because of the extremely high rate of “lost to follow-up” (41), anecdotal evidence indicates that urologic complications remain a common cause of death (136). Fatal infections from untreated pressure ulcers, because of the absence of adequate medical care, are a common cause of death in low-income countries (45, 136).

***Mortality rates among people with SCI are strongly affected by the capacity of the health-care system, especially emergency care.*** Transportation and time of admission post-injury are important factors affecting survival. The first 24 hours after a SCI are the most critical for survival. A study in Nigeria found that predictors of mortality after 6 weeks include being in a crouched position during transfer (odds ratio of 23.52), and presenting 24 hours or more post-injury (odds ratio of 5.48). While overall in-hospital mortality in the high-resources settings of Canada and the USA are 11.6% and 6.1%, respectively (137, 138), Sierra Leone has an average mortality rate of 29% (45) and Nigeria of nearly 35% (41).

This underscores the importance of quick recognition, early evaluation and appropriate management of suspected SCI (139). In a large retrospective study of the outcomes of 324 patients in Australia who had been transported by ambulance and admitted to a SCI unit, it was only because the ambulance crews had been trained to spot vital physiological signs of SCI that these patients were directed to a SCI unit, where nearly 88% were diagnosed as SCI ((75), see Box 2.2). Generally, mortality rates in hospitals reflect the

### **Box 2.2. Appropriate pre-hospital management in the immediate post-injury period reduces deaths and secondary complications**

A large retrospective study in Australia of the outcomes of 324 patients who had been transported by ambulance and admitted to a spinal cord injury unit was conducted between 2004 and 2008. Most individuals, at the scene of the injury, had vital physiological measurements that were within normal limits, but because of the nature of the injury were treated by the ambulance crew as potentially SCI. This protocol saved many lives as 88% were diagnosed as SCI when admitted to a spinal cord injury unit. The median time to reach the injury unit post-injury was under 12 hours. However, if first admitted to a general trauma centre, it often took more than 24 hours before the patient was treated by SCI specialists, and these individuals were 2.5 times more likely to develop secondary complications compared with those admitted directly to the injury unit.

Significantly, the study also showed that when the injury was caused by a low fall, the patients were invariably older but were much less likely to be treated by the ambulance crew as potentially spinal cord injured. This increased inter-facility transfers so that less than half of this group reached the spinal cord unit within 24 hours and suffered a substantially higher rate of death and secondary complications. Given the increasingly ageing population and the increase in incidence of SCI from age-related low falls, the study suggests that injuries from low falls among the elderly should be more cautiously accessed as potentially SCI.

Source (75).



importance of good quality care for the survival of people with SCI, and these rates may be linked to the overall resource level of the country.

### Costs of spinal cord injury

The costs of SCI – direct and indirect – are important in assessing the economic and social impact of SCI. *Direct costs* can include health and rehabilitation services, more expensive transportation options, special diets, and personal assistance. *Indirect costs*, both economic and non-economic costs, can include lost productivity due to premature death or disability, social isolation and stress.

The cost of SCI is influenced to a large extent by the following factors:

- The nature of the initial injury or underlying health condition. For TSCI, cost is affected by the level and severity of the lesion (140–144), and for NTSCI it is influenced by the severity of the underlying health condition (145, 146).
- The timeliness of treatment, notably the length of time between the injury and first appropriate medical response.
- The length of stay in the hospital – including initial admission (146) and any re-hospitalization caused by a failure to prevent or manage the health consequences of secondary conditions. Evidence suggests that there are no gender-based differences in cost (147).
- Direct medical costs – including wheelchairs and ventilators.

Care must be taken in comparing cost data across countries. Direct country comparisons of the “cost estimates of SCI” are difficult. Different categories of direct and indirect costs are used and estimates of costs rely on different statistical techniques and data of variable quality. Even within a country, estimates of direct health care costs vary depending on the source of data (148–150). A general picture of the costs of SCI emerges from available data, even if no regional or global estimates can be calculated:

1. The level and severity of the injury have an important influence on costs, with higher costs associated with injuries higher up on the spinal cord (e.g. tetraplegia versus paraplegia), and higher costs associated with complete SCI compared to incomplete SCI.
2. The costs of NTSCI tend to be lower than those for TSCI, largely because of age of onset.
3. Direct costs are highest in the first year after SCI onset and then decrease significantly over time.
4. Indirect costs, in particular lost productivity, may exceed direct costs.
5. Much of the cost is born by people with SCI.

These points are discussed in greater detail below.

**1. The level and severity of the injury have an important influence on costs** (134, 151, 152). Tetraplegia is associated with higher costs than paraplegia (42, 153, 154). Data from the National Spinal Cord Injury Statistical Center in the USA estimated that in 2013, lifetime costs for a person injured at age 25 are US\$ 4.6 million for high tetraplegia compared to US\$ 2.3 million for paraplegia. In Australia the lifetime costs per incident case were estimated to be 5.0 million Australian dollars for a person with paraplegia and 9.5 million for tetraplegia (154). This Australian study also compared costs across a range of neurological conditions, such as dementia, multiple sclerosis, cerebral palsy and bipolar disorder, and found that the costs associated with tetraplegia were between 2 and 20 times higher than those for the other conditions (154). In terms of severity, some studies have found that costs are higher for complete SCI compared to incomplete SCI. For example, data from Canada on average direct costs, which included hospitalizations, physician services, home care, and long-term care, found that mean attributable costs in the first year were \$121 600 (2002 Canadian dollars) per person with a complete SCI, and \$42 100 per person with an incomplete injury. In

the subsequent 5 years, annual costs were \$5400 and \$2800 for people with complete and incomplete SCI, respectively ((144), see Figure 2.11).

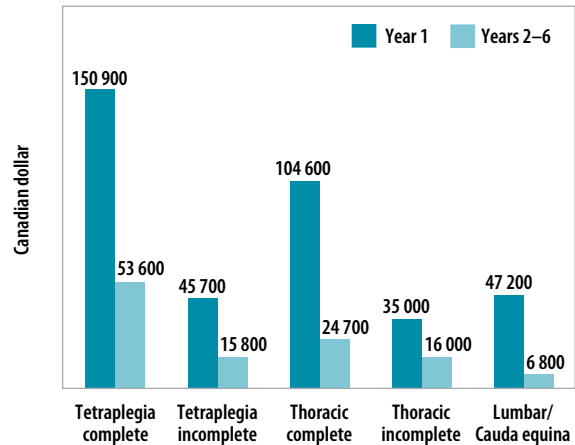
2. *The costs of NTSCI tend to be lower than those for TSCI, largely because of age of onset.* NTSCI typically affects older populations who incur fewer indirect costs over their remaining life, primarily because they are no longer in the workforce. The exception to this is spina bifida, not only because it begins in infancy, but also because of high expenditures in developmental and behaviour services and home health services (155–157).

3. *Direct costs are highest in the first year after SCI onset and then decrease significantly over time* (134, 151, 152). The National Spinal Cord Injury Statistical Center Database in the USA estimates of care costs in 2013 are given in Table 2.5.

The on-going costs of aids and equipment and long-term care, such as assisted accommodation, respite care, personal assistance, and supported community services, tend to be high even after the initial high direct health care costs begin to decrease (154). Figure 2.12 illustrates this cost development for tetraplegia in Australia.

4. *Indirect costs may exceed direct costs.* Although direct medical and rehabilitation costs are expensive and are increasing (158), indirect costs, and especially costs associated with loss of productivity across the lifespan, can be well in excess of all direct expenditure (159). A study of acute care costs (over 6 weeks) in 34 individuals

**Figure 2.11. Direct annual health care costs per person by level and severity of SCI for people injured in Alberta, Canada, 1992–1994 (2002 Canadian dollars)**



Source (144).

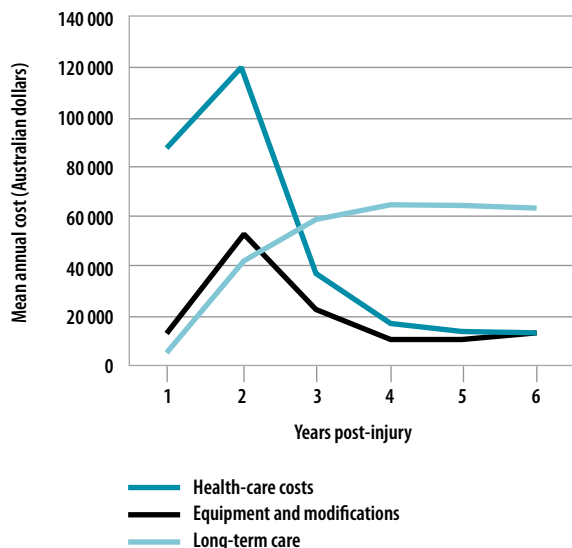
with SCI in Nigeria found a 6-fold difference between the mean direct care costs (an average of US\$ 239 including nursing and medical care, including operative procedures, accommodation, medication and laboratory charges), and the indirect costs (US\$ 1360, including the sum of income lost and costs of vehicle replacement and repair) (42). The total cost of the treatment represented more than 50% of the annual income of the patient (42).

**Table 2.5. Average yearly expenses of TSCI by severity of injury**

Severity of Injury	Average yearly expenses (2013 US\$)	
	First year	Each subsequent year
High tetraplegia (C1–C4)	1 044 197	181 328
Low tetraplegia (C5–C8)	754 524	111 237
Paraplegia	508 904	67 415
Incomplete motor functional at any level	340 787	41 393

Source (153).

**Figure 2.12. Direct mean annual cost over time by cost type, tetraplegia**



Source (154).

© VNI, based on TAC data for the years 2004–2008

The Report by Access Economics Pty Limited for the Victorian Neurotrauma Initiative June 2009 entitled “The economic cost of spinal cord injury and traumatic brain injury in Australia” quoted above is not an official publication of WHO. This and other related publications are available free of charges by visiting [www.tac.vic.gov.au](http://www.tac.vic.gov.au).

**5. Much of the cost is born by people with SCI.** The Victorian Neurotrauma Initiative calculated the total annual cost of SCI for Australia to be nearly AUS\$ 2 billion (1.3 billion for tetraplegia and 689.7 million for paraplegia), 40% of which was paid by the SCI individuals themselves. The state government covered 44% and the federal government a further 10% of the costs (154).

## Data and evidence for spinal cord injury

It is important to advance knowledge on people with SCI and strengthen the evidence base for prevention, support and care of people with

SCI. This section discusses issues and concerns related to SCI data and evidence, with a more detailed explanation of data limitations found in Technical appendix B.

Data on SCI may be obtained from information sources specific to SCI or may be related to general disability data collection with links to external causes of injury. The source, data type and standard/tool for information collection are discussed below and outlined in Table 2.6.

## Data sources

**Health settings.** A wide variety of health settings can be the source of SCI data, including patient records from hospital inpatient services, ambulance services or emergency departments, health clinics and family doctors. Health setting data are only relevant to the population served by these services and may not be representative of the overall SCI population of the country.

**Central registry of people with SCI.** Some high-income countries have established a central registry of spinal cord injuries that applies scientific criteria for the collection, management and analysis of SCI information, for example the Rick Hansen Spinal Cord Injury Registry in Canada (see Box 2.3), the Australian Spinal Cord Injury Register (162) and the Spinal Cord Injury Model database administered by the National Spinal Cord Injury Statistical Center in the USA (163, 164). These registries have varying degrees of representativeness. No low- or middle-income country currently has a national SCI registry.

**National surveys.** National disability data come from censuses or population health and social surveys, which all rely on self-reporting. Although these surveys usually ask questions about mobility, if the data are not disaggregated by impairment or health condition these surveys will have limited value for SCI-specific information. Several tools exist or are under development that can support national data collection. These include the questions developed by the Washington Group on Disability Statistics, those in

**Table 2.6. Source, data type and standard/tool for collection of information on SCI**

Source	Type of data	Standards/tools for information collection
<b>Health settings</b>	Age at injury	ICD
	Sex	ASIA/ISCoS International SCI Data Sets
	Injury	SHA
	Neurological level and extent of lesion (paraplegic, tetraplegic, complete, incomplete) Costs of treatment	
<b>Central registry</b>	Age at injury	ICECI
	Sex	ASIA/ISCoS International SCI Data Sets
	Race, ethnicity	SHA
	Occupation status	ICD
	Etiology	
	Neurological level and extent of lesion (paraplegic, tetraplegic, complete, incomplete) at discharge	
	Type of residence the person is discharged to	
	Length of stay in hospital	
	Costs of treatment	
	Causes of death	
<b>National surveys</b>	Census	Washington Group 6 Questions (Census only)
	National health and social surveys	WHO Disability Assessment Schedule
	National disability survey	WHO and World Bank Model Disability Survey
<b>Insurance firms</b>	Age at injury	
	Sex	
	Etiology of injury	
	Neurological level and extent of lesion (paraplegic, tetraplegic, complete, incomplete) at discharge	
	Occupation status	
	Cost of claim	

**Box 2.3. An example of a SCI registry**

The Rick Hansen Spinal Cord Injury Registry is a Canada-wide database of patients admitted to 31 major trauma and rehabilitation facilities across all provinces. Currently NTSCI and incomplete TSCI (D) cases are not captured as they are often treated in community hospitals not covered by the Registry. The Registry is funded by the Canadian and provincial governments, participating registry sites and the Rick Hansen Foundation. Diverse funding sources provide a consistent and dependable funding base, which is the key to a sustainable registry.

Each participating facility recruits patients, obtains their consent and collects data stored centrally in an anonymous format. A total of 260 data elements from pre-hospital, acute and in-patient rehabilitation, and post-discharge to the community are collected along with sociodemographic factors, medical history, injury details, diagnosis and interventions, neurological impairment, complications and patient-reported outcomes. Participants are contacted 1, 2, 5 and 10 years post-discharge and then every 5 years thereafter to complete an outcome questionnaire. Data elements are aligned to the International Core Data Sets and the International Standards for Neurological Classification of SCI and linked to other registries to prevent duplication.

The Registry has improved clinical care by:

- standardizing assessment and coding in clinical procedures enhancing comparability of outcomes;
- identifying trends over time for staffing requirements;
- providing staff and patients with information during community follow-up assessments.

*continues ...*

... continued

The Registry has also facilitated clinical research by:

- identifying individuals interested in participating in research studies;
- reducing respondent burden by supplementing information for clinical trials;
- providing a feasibility assessment of facilities participating in clinical trials;
- showing how patients flow through the Canadian health-care system and the differences in care provided and funded between provinces.

Sources (160, 161).

the WHO World Health Survey, and the proposed questions in the Model Disability Survey currently under development by WHO and the World Bank.

**Insurance firms** provide insurance coverage against several risks, such as poor health, vehicle crashes, occupational and sports injuries. Insurers collect and use statistics to help estimate the rate of future claims based on a given risk, including, where relevant, the number of new and existing cases of SCI. These data are used as a basis for determining premiums and hence may be hard to obtain.

### Information standards

**There are three main generic health information standards** relevant to SCI. The most widely used standard diagnostic tool is the **International Classification of Diseases (ICD)**, which can be used to classify diseases and other health problems for health and vital records, including death certificates and health records, and monitor the incidence and prevalence of diseases. In many countries ICD-based records are also used for reimbursement and resource allocation decision-making (165).

The **International Classification of External Cause of Injury (ICECI)** is used to describe, measure and monitor the circumstances of occurrence of injuries including the mechanism of injury, the objects or substances producing injury, place of occurrence, activity when

injured, the role of human intent, use of alcohol and other psycho-active drugs. It also has other modules for collecting data on violence, transportation, place, sports and occupational injury.

The **System of Health Accounts (SHA)** is a standardized framework for collecting internationally comparable health financial accounts, organized by intervention, for public and private sector applications (166).

**There are also three SCI-specific standardizations.** The American Spinal Injury Association (ASIA) **International Standards for Neurological Classification of SCI** is a standard for assessing and classifying the neurological level and extent of SCI. The classification system contains three elements: ASIA Impairment Scale (AIS A-E); motor score (based on the neurological examination of muscle function); and sensory score (based on the neurological examination of sensory function). This standard recently revised jointly by ASIA and ISCoS, provides reliable data for clinical care and research studies (167–170).

The **International Spinal Cord Injury (SCI) Data Sets** were developed by ISCoS to facilitate comparisons of injuries and outcomes between patients, centres and countries (171, 172). The Data Sets include the International SCI Core Data Set (173) and the International Spinal Cord Injury Non-traumatic Data Sets (174). These are the primary data sets for the standardization of basic epidemiological data, including SCI etiology, and its reporting (175). Relevant here is the

ISCoS initiative to standardize data reporting of global epidemiological SCI trends (176).

The **ICF Core Sets for SCI** (Comprehensive and Brief) are international data sets that can be used in clinical and research work on SCI (177). Core Sets for post-acute and long-term care settings were developed in 2010 using the *International Classification of Functioning, Disability and Health (ICF)* to further ensure comparability with other areas of disability statistics (177–179).

## Data issues and concerns

Given the paucity of data on SCI, there is a serious need to collect more data on a worldwide basis. There is also a need to improve the quality of data. The following section discusses some common limitations within SCI data collection.

### Definitions and standardization of data

There are variations in case definitions of SCI and inclusion criteria that affect comparability of data across settings, within and between countries. General medical definitions are clinically functional but lack the comprehensiveness needed for epidemiology, e.g. “Spinal cord injury is damage to the spinal cord that causes loss of sensation and motor control” (180). The clinical SCI definition used by the US Centers for Disease Control (CDC) – “an acute traumatic lesion of the neural elements in the spinal canal, resulting in temporary or permanent sensory deficit, motor deficit, or bowel/bladder dysfunction” – includes traumatic cases that involve an external event to trigger the injury, rather than disease or degeneration. As such it excludes intervertebral disc disease, vertebral injuries in the absence of SCI, nerve root avulsions and injuries to nerve roots and peripheral nerves outside the spinal canal, cancer, spinal cord vascular disease, and other non-traumatic spinal cord diseases (181).

## Underreporting

Underreporting of both SCI and deaths from SCI is a substantial problem in low- and middle-income countries (130, 182, 183). TSCI, like most severe traumas, has a high mortality rate. If emergency trauma care services are not required to report death by ICD code, or are overwhelmed during an emergency, this information will be lost (55, 184, 185), which will artificially lower the incidence and case fatality rates (186).

Even in high-resource settings, reliable information for prevalence and incidence estimates can be difficult to get. Few countries in the world have SCI registries and the existing registries have incomplete coverage. Even in countries with good statistics on SCI, the data tend to focus on TSCI and there is a significant underreporting of NTSCI cases (89). A registry for NTSCI, as with TSCI, would be expensive, time consuming and impractical because people with NTSCI – owing to the diverse etiologies – are treated and rehabilitated in multiple care settings and often do not receive specialized SCI rehabilitation services (88).

## Other issues

Studies have uncovered several other problems related to SCI data and evidence. These include the following issues.

- Medical record keeping, which results in missing or incorrect information within individual records. For example incorrect ICD coding can cause an over-reporting of SCI cases when fractures of the spine or contusions without neurological symptoms are mistakenly coded (20).
- Most data, for incidence and prevalence, come from single centre hospital-based surveys, which may not be generalizable to the rest of the country.
- Appropriateness of tools. The ICD-10 does not specifically define SCI but uses several codes to identify fractures, traumatic rup-

tures, vertebral dislocations, and complete and incomplete lesions. In practice the data collected using these codes is unreliable for epidemiological research (187).

- Inconsistent use of terminology, e.g. in the spina bifida literature.
- Relatively small sample sizes.
- Scientific soundness of the methods used for determining incidence/prevalence.
- Lack of data on exposure to causes of SCI.

## Conclusion and recommendations

Using the best available data from across the world, this chapter provides information on incidence, prevalence, trends and costs of SCI. The conclusions are tentative given the quality and paucity of the data from some regions of the world.

Reliable data and evidence are essential for describing the numbers of people affected and the impact on their lives, assessing causes, developing and evaluating interventions, providing information for policy-makers and decision-makers, and raising awareness. Without reliable information, the priorities for prevention, medical and social care cannot be rationally or satisfactorily determined.

There is a global need for more robust and reliable, comparable and comprehensive SCI data that can be used for research, clinical care and policy, and in particular to be able to fully include the SCI population in country-level monitoring of the implementation of the provision of the CRPD.

In this light, the following recommendations can contribute to enhancing the availability and quality of data on SCI.

## Improve comparability by using international standards for data collection

As well as the *International Standards for Neurological Classification of Spinal Cord Injury*, the World Health Organization's *International Classification of External Cause of Injury* (ICECI) and *International Classification of Functioning, Disability and Health* (ICF) should be consistently used to provide a universal framework for all health and disability data. The International SCI Data Sets, freely available from the ISCoS web site, further contribute to the comparability of SCI data.

Countries can:

- formally adopt the ICECI and ICF as essential standards for national data collection in all health data collection;
- ensure that all SCI data are collected using the terminology of ICECI and the model of disability in the ICF;
- ensure that all SCI data are reported using the International SCI Core Data Set as a minimum.

## Improve national spinal cord injury statistics

The best way of collecting SCI data is by means of a SCI registry that assembles data directly from hospitals and other health service locations and centralizes the data in a databank that is best maintained by a government authority, such as the NSCISC in the United States. Registries provide longitudinal data essential for identifying incident trends that are important for prevention programmes and other policy responses to SCI and the needs of people with SCI.

In the absence of a SCI registry, the following strategies would greatly improve data collection.

- Collect within the country's health and disability data collection system internationally comparable SCI information, ensuring that data can be disaggregated into standard-

ized categories relevant for incidence trend analysis, and at a minimum by sex, age and etiology.

- Make SCI data available in annual reports published on the Internet in a searchable manner so that data can be easily located.
- Encourage and support hospitals and other health-care settings to collect SCI data, with minimal additional expense, through appropriate record-keeping and the use of formats based on international data standards.
- Include SCI-relevant questions in population health and disability surveys, notably censuses, national household and health surveys, and general social and economic surveys.
- Collect SCI-specific data through specific surveys after natural disasters such as earthquakes.
- Use the resources of ISCoS and other SCI professional organizations to explore the possibility of developing a standard recording method for NTSCI and a prospective SCI registry for both TSCI and NTSCI.

## Encourage and improve spinal cord injury research

To have robust local data, countries in all regions must encourage and seek to improve the quality

of SCI research, including especially longitudinal and cohort studies.

- SCI topics should be included in the curriculum of medical and allied health professionals to raise awareness about SCI and to encourage young health researchers to consider SCI research.
- Researchers can be encouraged to collaborate with agencies in charge of prevention programmes, informing prevention strategies with incidence data, and be involved in the monitoring and evaluation of prevention campaigns.
- A comprehensive framework should be developed that identifies and standardizes direct and indirect costs of SCI. These data items should then be incorporated in administrative and national data collection instruments to enable a better understanding of the social cost of SCI.
- Involve people directly affected by SCI in devising questions for surveys and other data collection strategies that collect data on the lived experience of SCI. The data so collected can be harmonized with the data sets on SCI that already exist.
- Research into NTSCI should be supported to expand the evidence base in terms of incidence, survival rates, prevalence, etiologies and health care management strategies.

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## Chapter 3

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# Prevention of spinal cord injury

“I am a 52-year-old male with an incomplete but severe spinal cord injury (C4). The spinal cord injury was caused by a traffic accident in 1973, when I was 16 years of age. The traffic accident was my own fault; I was driving too fast without a driver’s license and a little bit drunk. I can move my arms a little bit and use my hands a little. I can stand, but I cannot walk. I cannot type on the computer, but I can use a speech-to-text programme to be able to write on a computer. To move around I use my electric wheelchair. To handle my personal needs, I have round-the-clock personal assistance.”

(Stig, Denmark)

“Between rice planting seasons, I worked as a labourer on construction sites in Hanoi to make additional money, both to ensure that I could afford a good stock of seeds for the rice season and so that I could cater to the needs of my children for their schooling and their future. One day in the city my whole life collapsed literally on me when I lost control while carrying a load of bricks on a wet plank.”

(Anonymous, Viet Nam)

“I fell from the roof of my house in 1976 resulting in a spinal cord injury (C5–6) that left me unable to move my legs and limited my control of fingers and arms.”

(David, USA)

“In 1998, I suffered a gunshot wound that caused a spinal cord injury at the T6–7 level.”

(Robert, Uganda)

“I was injured in October 1997 while bodysurfing at Noosa Heads, Queensland, Australia. As a result of my spinal cord injury (C4–5) I am able only to move my head and have absolutely no functional movement in any limbs. Many challenges suddenly arose when launched into this sticky situation requiring interesting problem-solving abilities to maximize independence and also to help reduce the burden on others.”

(Brad, Australia)

“I am a tetraplegic who sustained a spinal cord injury many years ago in 1974 playing rugby when I was 15½ years old.”

(Richard, New Zealand)

# 3

## Prevention of spinal cord injury

When spinal cord injury (SCI) follows a traumatic incident such as a road traffic crash or a fall, the transition is often from good health to permanent disability in a matter of seconds. Whether the origin is traumatic or non-traumatic, the good news is that a large proportion of these injuries are preventable.

Primary prevention involves actions to avoid or remove the cause of SCI in an individual or a population before the problem arises, e.g. actions to reduce road traffic injuries. Secondary prevention comes into play once a SCI has occurred. The aim is to provide early diagnosis and treatment, and to limit disability (see Chapter 4: Health care and rehabilitation needs: Pre-hospital and acute care). Early recognition of the possibility of SCI following an injury, including proper transportation to an appropriate facility, and access to acute rehabilitation is part of secondary prevention. Tertiary prevention focuses on rehabilitation post-SCI and environmental interventions to reduce complications and promote successful inclusion of the injured person in family and community life (1).

All forms of prevention are required. People with disabilities have emphasized access to health, together with human rights and social inclusion, as solutions to the predicament of health conditions associated with disability (2). Human rights principles of respect and dignity, as highlighted by the *Convention on the Rights of Persons with Disabilities* (3), entail that prevention strategies are undertaken in ways that do not demean people living with SCI (4).

This chapter discusses primary prevention interventions to reduce the occurrence of SCI, predominantly those of traumatic origin. It highlights interventions with proven effectiveness and points to those where more research is needed. Secondary and tertiary prevention are covered in subsequent chapters.

### Causes of traumatic spinal cord injury

Traumatic SCI can result from several different mechanisms, e.g. road traffic crashes, falls, violence, while undertaking different activities, e.g. at work, during sport or while at home. Prevention strategies tend to relate to the specific setting where there is increased risk of an injury occurring. This section discusses traumatic SCI prevention by cause.

## Road traffic crashes

While the contexts and precise mechanisms vary between and within regions, road traffic crashes are the most common cause of SCI worldwide. As with the global road crash statistics (see Chapter 2), the incidence of SCI is higher among young adults and among males (5–7). Reducing the incidence of road traffic crashes is therefore a significant element in preventing SCI and can be addressed in the pre-crash, crash and post-crash phases first described by Haddon (8) (see Table 3.1).

### The safe systems approach to crash prevention

The adoption of a safe systems approach to road traffic crash prevention has been central in reducing death and disability associated with road traffic crashes in high-income countries (Figure 3.1) (9, 12). This approach recognizes that the interaction of vehicles of all kinds with different types of road users in a shared space is likely to result in collisions, and that if the components (vehicles, people and roads) and their interactions are not properly managed (system design) this will contribute to crashes resulting in severe injury and fatalities (9). The safe

systems approach seeks to identify and rectify the major sources of “error” within each of the pre-crash, crash and post-crash phases. For example, the main risk factors for vehicle occupants are well known: excessive or inappropriate speed, non-use of seat-belts and child restraints, and driving while under the influence of alcohol or recreational drugs (13).

The development and implementation of action plans with reduction targets informed by crash data and evidence-based interventions are key components of the safe systems approach (12, 14). The successful implementation of road safety action plans requires effective advocacy, broad-based community acceptance, multisectoral intragovernmental cooperation with an identified lead agency (for example a stand-alone agency within the Ministry for Transport), and the cooperation of industry and nongovernmental organizations (NGOs) such as automobile associations, the medical profession and road safety advocacy groups (9).

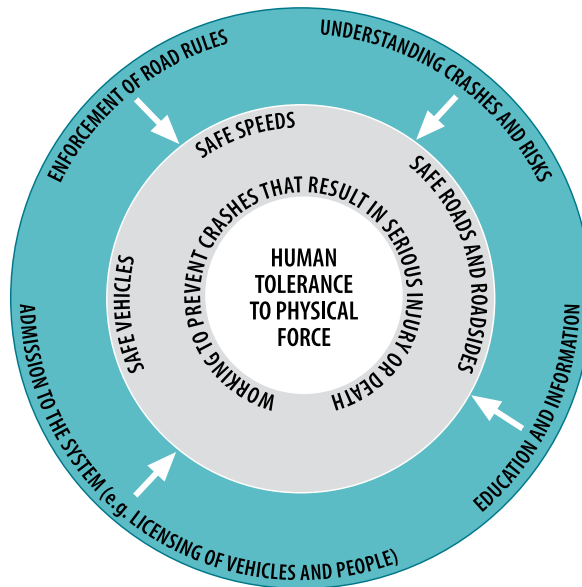
The safe systems approach is holistic and cyclical, comprising:

- problem identification;
- formulation of strategies;
- implementation of selected policies;
- evaluation, fine-tuning and re-evaluation.

**Table 3.1. The Haddon matrix applied to road traffic injury prevention**

Phase		Factors		
		Human	Vehicles and Equipment	Environment
Pre-crash	Crash prevention	Information Attitudes Impairment Police enforcement	Roadworthiness Lighting Braking Handling Speed management	Road design and road layout Speed limit Pedestrian facilities
Crash	Injury prevention during the crash	Use of restraints Impairment	Occupant restraints Other safety devices Crash-protective design	Crash-protective roadside objects
Post-crash	Life sustaining	First-aid skill Access to medics	Ease of access Fire risk	Rescue facilities Congestion

Source (9).

**Figure 3.1.** The “safe systems” approach to road safety

Sources (10, 11).

The measures involved may include:

- promulgating and enforcing appropriate laws around drinking and driving, speeding, seat-belt and helmet use, etc.;
- educating the public about road safety through social marketing, public relations activities, etc.;
- engineering safety countermeasures, including airbags, restraint systems and road design.

The safe systems approach has proved critical to the observed reductions in road traffic crashes, and a road safety systems evidence base is being continually updated (9, 12).

Knowledge and technology transfer from high-income countries to middle- and low-income countries – taking into account the differences in the road environment, vehicle fleet, vehicle uses and unique resource constraints – is critical for addressing projected future increases in crash-related mortality and morbidity (15).

### Specific interventions to reduce spinal cord injury among vehicle users

While individual interventions specific to SCI should be implemented (16, 17) (see Box 3.1), the greatest gains will be made by implementing a systems approach – focusing on the road environment holistically (e.g. land use, access to and for communities, proximity to housing and other amenities) – taking into account the needs and abilities of all road users, and designing and promoting vehicles that protect not only their occupants but also the well-being of other road users who may make contact with the vehicles in the event of a crash (9, 12). A summary of interventions for road traffic crashes is shown in Table 3.2.

While these interventions mainly concern vehicles, a typical environmental modification would be traffic calming measures (e.g. roundabouts, rumble strips, vehicle separation, and so on) that have the potential to reduce the rates of all types of road traffic crashes in urban areas.

### Box 3.1. Rollover crashes increase the risk of spinal cord injury

Matilda was driving her boyfriend's car alone on a Sunday morning following a 30th birthday party at a friend's farm. She had been drinking alcohol into the early hours and had very little sleep. The car drifted onto the hard shoulder of the road, which was poorly constructed with a significant drop. Within a fraction of a second, the vehicle was out of control. The inside front tyre caught the edge, causing the car to roll over. The crash was severe, as were Matilda's injuries – a neck fracture and dislocation that left Matilda tetraplegic.

Matilda's story is typical. Crashes where the car rolls over are associated with severe injuries. An occupant's head can come into contact with the roof of the vehicle when the vehicle is turned over and the occupant is upside down, with the weight of the body resting on the neck (16, 18, 19). The resulting axial compression is associated with cervical spine fracture-dislocations. Rollover crashes are relatively common, particularly in rural areas where high speeds and poorly maintained vehicles and infrastructure are risk factors.

Measures to reduce the incidence and impact of rollover crashes include:

- regulatory approaches that include the introduction of rollover protection standards for vehicles (20);
- the use of electronic stability control within cars, i.e. a computerized technology that improves the safety of a vehicle's stability by detecting and reducing skidding (21, 22);
- the installation of barrier systems and road shoulder sealing to promote safe roadsides (23);
- interventions to counter speeding, fatigue and drink-driving.

Specific interventions include:

- Mandatory standards for the design of vehicle seating that specify height requirements for head restraints, as well as sophisticated seat design, can mitigate the likelihood and severity of cervical spine soft-tissue sprains, i.e. whiplash-type injuries (24–26).
- Correctly used three-point seat-belt systems prevent severe head strikes against interior vehicle structures, which are associated with tension-flexion injuries (24, 27, 28), prevent ejection from the vehicle (29), and are effective in reducing thoraco-lumbar injuries. Enforcement, coupled with behavioural interventions such as seat-belt reminder systems, has been shown to ensure high levels of seat-belt use (20, 30).
- Child restraint systems that are appropriate to the age and weight of the child are critical in decreasing the risk of injury to infants and children, and are preferable to two-point lap-belts, which have been associated with thoraco-lumbar and abdominal injuries (13, 31–33).
- While the role of motorcycle helmets in preventing traumatic brain injury is now well accepted, their role in preventing cervical spinal cord injuries is unclear. More research is needed to determine whether they offer protection (34).

### Protecting other road users

The challenges of preventing SCI and other injuries for vulnerable road users (motorcyclists, pedestrians and cyclists) are complex and rely on behavioural interventions that are designed to reduce crash risk and to provide safe road environments that ensure the appropriate separation of pedestrians and cyclists from vehicles.

These challenges are particularly pressing in low- and middle-income countries where the level of motorization is increasing rapidly and yet the

dominant modes of transport remain walking, cycling and unsafe vehicles such as overcrowded pick-up trucks with no occupant restraint measures (9). This higher traffic volume is associated with an increased exposure to crash risk, while the problem is compounded if the pace of infrastructure development is slow. It is within this context that technology transfer and adoption of “safe system” interventions have considerable scope to bring about rapid reductions in traffic-related mortality, morbidity and disability (44).

**Table 3.2. Summary of interventions for road traffic crashes**

Interventions that work and should be implemented widely	Promising, more evaluations needed	Ineffective or detrimental, should be discouraged
Legislating and enforcing drink-driving laws (including a blood alcohol concentration limit of 0.05 g/dl for all road users and lower for novice drivers, the use of random breath-testing, minimum age for purchase of drinks, point-of-sale control) (9)	Use of booster seats for children that have outgrown child seats (35)	Road safety education without accompanying legislative changes or measures to make road environments or vehicles safer
Use of seat-belts (36)		School-based driver education (37, 38)
Use of child passenger restraints (35)		Putting babies or children on a seat with an airbag (39)
Motorcycle helmets (34, 40)		
Setting and enforcing speed limits (including use of speed cameras, reduced speeds around schools, hospitals, etc.)		
Daytime running lights for motorcycles (9)		
Road designs that separate pedestrians and two-wheelers from cars and heavier vehicles (9, 12, 41)		
Area-wide traffic calming measures (42)		
Graduated driver licensing systems (43)		

## Falls

In addition to road traffic crashes, falls also contribute significantly to SCI. Four patterns have been recognized as resulting in SCI, namely:

- falls on the same level (e.g. playing sports, tripping over a carpet, falling while carrying a heavy load [see [Box 3.2](#)]);
- falls from heights of less than one metre (e.g. falling down stairs, falling off a low wall);
- falls from heights of one metre or more (e.g. falling from a building or a horse);
- being struck or crushed by a falling object (e.g. collapse of a mine shaft).

Many severe falls occur while at work or playing sport, or in unsafe homes or residences. In the home, falls can occur on stairs or because of other obstacles, and are especially prevalent among the elderly and the very young. The prevention of falls can be improved by alterations to the living environments of older people, such as the elimination of clutter, loose carpets and uneven floor surfaces, and the provision of good

lighting, hand rails and appropriate level seats, toilets and beds (48). Programmes to assess balance can identify those at risk and can lead to the implementation of measures to improve balance and prevent falls, such as exercise classes and the provision of appropriate assistive devices (e.g. walkers) and training of users in their use and maintenance.

Fall prevention includes modifying the environment, putting in place laws and regulations, educating the population with regard to risks, and providing immediate post-fall management. A summary of interventions can be seen in [Table 3.3](#).

## Violence

The use of firearms (used both for assaults, for self-harm or unintentionally fired) is one of the most common causes of injuries to the spinal cord, with sub-Saharan Africa having the highest reported proportion of violence-related SCI in the world (38% of all cases of SCI) (52). Knives and other sharp objects can also be used



### Box 3.2. Falls while carrying a load on the head

In many low-income countries people carry loads on their heads. Porters regularly carry weights as heavy as 100 kg on their heads. This practice has been observed in Bangladesh (45), Ghana (46) and Sierra Leone (47).

In Bangladesh the people who sustain cervical SCI caused by falling while carrying a heavy load on the head – in most cases a load of farm produce, fertilizer or rice – are often poor young men working as porters, and farmers.

The risk of SCI due to falling while carrying a heavy load on the head is greatly increased for new and unskilled carriers, for children, and when the load exceeds 50 kg (45).

As the carrier must keep his or her head erect at all times to maintain the balance of the load, it is very difficult to observe the path or road on which he or she is walking. Uneven or slippery surfaces often cause falls. Sixty per cent of cases occur in rural locations, on farmland or muddy tracks. The falling individual loses balance and the combination of the force of the fall and the force of the heavy load combine to result in a high-energy incident. The person is unable to push the heavy load off his or her head, or to control the abnormal neck movement caused by the weight and momentum of the load. This effectively converts a low-energy fall into a high-energy fall, resulting in SCI.

Governments may easily overlook the extent of this problem, because these injuries typically occur in rural communities and affect poor individuals with no influence. Unemployment is often rife and injured workers are easily replaced. The profound impact of these injuries to the individual and his/her family, however, is incalculable.

Prevention can be achieved by moving to an alternative method of carrying the load. Wheelbarrows can carry heavier loads and are durable and safer. Promotion of the wheelbarrow as an alternative would require government regulation and support, and possibly also subsidies to make wheelbarrows an attractive alternative for employers.

The process of identifying situations in which there is scope for injury prevention in occupational settings involves careful analysis both of the mechanics underlying the falls and of the sequence of events that ultimately leads to injuries.

**Table 3.3. Summary of falls interventions**

Fall category	Interventions that work and should be implemented widely	Promising, more evaluations needed	Ineffective or detrimental, should be discouraged
Falls on the same level	Floor clear of clutter and loose rugs, provision of good lighting, hand-rails and appropriate level furniture		Educational programmes working in isolation
Falls from more than one metre, e.g. high-rise buildings, rooftops, trees	Window guards in high-rise buildings, barriers on roofs (49) Safe harvest equipment*	Enforcement of building regulations (50) Education of parents of young children on risk of falls related to specific products (51)	Educational programmes working in isolation
Struck or crushed by heavy object, e.g. carrying objects on head	Wheelbarrows where applicable	Workplace regulations that limit weights carried on head and ages of workers*	

\* The interventions are unlikely to be applicable in all settings, especially in low-income countries where labour laws may be lacking or not enforced.

to inflict penetrating injuries that result in SCI (53). Injuries to the spinal cord resulting from bomb explosions have also been reported (54). A small proportion of falls from height are also caused by intentional self-harm.

There is some evidence to suggest that, as would be expected, jurisdictions with restrictive firearms legislation and lower firearms ownership tend to have lower levels of gun violence. Restrictive firearm licensing and purchasing policies – including bans, licensing schemes, minimum ages for buyers, background checks – have been implemented and appear to be effective in countries such as Australia, Austria, Brazil and New Zealand. Studies in Colombia and El Salvador indicate that enforced bans on carrying firearms in public may reduce homicide rates (55). Multifaceted strategies are also needed to reduce demand for guns – for instance, by diverting vulnerable youth from gang membership.

With regard to knives and other sharp objects, governments need, in addition to control measures, broad strategies to reduce socio-economic factors that underlie the violent use of these weapons. Less evidence is available on the impact of efforts to reduce violence associated with sharp objects, e.g. knives, than on that of efforts to reduce violence associated with firearms. Until now concerned authorities have focused on similar measures to those used for the control of firearms. In the United Kingdom these have included legislative reforms (e.g. bans on flick-knives, a minimum age for purchasers), stiffer enforcement (“stop-and-search” initiatives) and weapon amnesties. However, the impact of these measures is not yet clear (55).

Strategies to prevent violence, other than those aimed at reducing access to lethal means such as guns and knives described above, include the following: developing safe, stable and nurturing relationships between children and their parents and caregivers to prevent child maltreatment and other forms of violence later in life; developing life skills in children and adolescents to prevent future involvement in youth vio-

lence; reducing the availability and harmful use of alcohol, which is a risk factor for all forms of violence; promoting gender equality to prevent violence against women; changing cultural and social norms that support violence; and victim identification, care and support programmes.

## Causes of non-traumatic spinal cord injury

Prevention of non-traumatic SCI depends on wider measures for both public health and disease control. Preventable non-traumatic causes of spinal cord dysfunction include:

- communicable diseases – tuberculosis (TB) and human immunodeficiency virus (HIV);
- noncommunicable conditions – cancer, degenerative diseases such as osteoarthritis leading to spinal stenosis, cardiovascular disease;
- nutritional deficiencies – neural tube defects, vitamin B<sub>12</sub> deficiency (56);
- complications of medical care.

Some prevention strategies related to each group of conditions are discussed below and summarized in [Table 3.4](#).

Infections such as TB are more prevalent in low- and middle-income countries than in high-income ones. Spinal tuberculosis occurs in about 1–2% of people with TB and, given the prevalence of TB, may account for up to 20% of spinal conditions seen in some settings (58, 64). The prevalence of spinal TB has increased with the rise of HIV infection (65–67). Common clinical presentations include back pain, fever, weight loss and neurological deficit (68). Preventing SCI from arising as a result of TB depends on early detection and treatment (69). Spinal TB can be identified through biopsy or magnetic resonance imaging (MRI). However, these services may not be readily accessible in low- and middle-income countries, thus delaying diagnosis (70). Treatment for spinal TB includes taking a complete

**Table 3.4. Summary of interventions to prevent non-traumatic spinal cord injuries**

Cause	Interventions that work and should be implemented widely	Promising, more evaluations needed
Infections (e.g. TB, HIV)	Vaccines (Bacille Calmette–Guérin for TB) Early identification and drug treatment of spinal TB (58)	Treatment with highly active antiretroviral therapy (HAART) for HIV (57)
Cancer	Early diagnosis and treatment	
Spina bifida	Fortification of wheat and maize flours with folic acid and other micronutrients (59); oral daily folic acid supplementation three months before and after conception (60, 61).	Intermittent iron and folic acid supplementation during the reproductive years (62, 63)
Degenerative conditions of the spinal cord	None known	

course of anti-tuberculosis medication and may, if indicated, include spinal surgery.

Cancer that spreads to the spine can compress the spinal cord and nearby spinal structures. If this is not treated, it can lead to pain, paralysis and incontinence. Prevention of cancer spreading to the spine depends on early detection and treatment, particularly of cancers involving breast, lung and prostate (71). Treatments to reduce the pressure on the spinal cord when spinal tumours occur can include radiotherapy, surgery, pharmacotherapy and chemotherapy (72, 73).

Although several influencing factors have been associated with neural tube defects, increased folic acid intake has been shown to be a viable, economic nutritional intervention in their prevention (74, 75). A meta-analysis of available data underlines these findings (see Box 3.3).

About 63 countries mandatorily fortify wheat flour with folic acid (91), which has resulted in documented reductions in incidence of spina bifida (77, 92, 93). Periconceptional folic acid supplementation (three months before and after conception) has been shown to reduce the rate of infants born with neural tube defects, including spina bifida (60, 61). For example, an Israeli study demonstrated that three years after implementing folic acid supplementation (2002 and 2004) the incidences of spina bifida decreased from 14.4 to 8.9 per 10 000 live births

(84). Awareness campaigns can raise knowledge of folic acid levels significantly (94) but sustained campaigning to promote periconceptional consumption is necessary for success.

## Activities, places and circumstances associated with spinal cord injuries

### Occupational injuries

A significant proportion of accidents leading to SCI occur in the workplace (95, 96), particularly in the construction, agriculture and mining industries (95, 96). The most frequent external causes in work environments are falls from heights and being struck or crushed by a falling object (96).

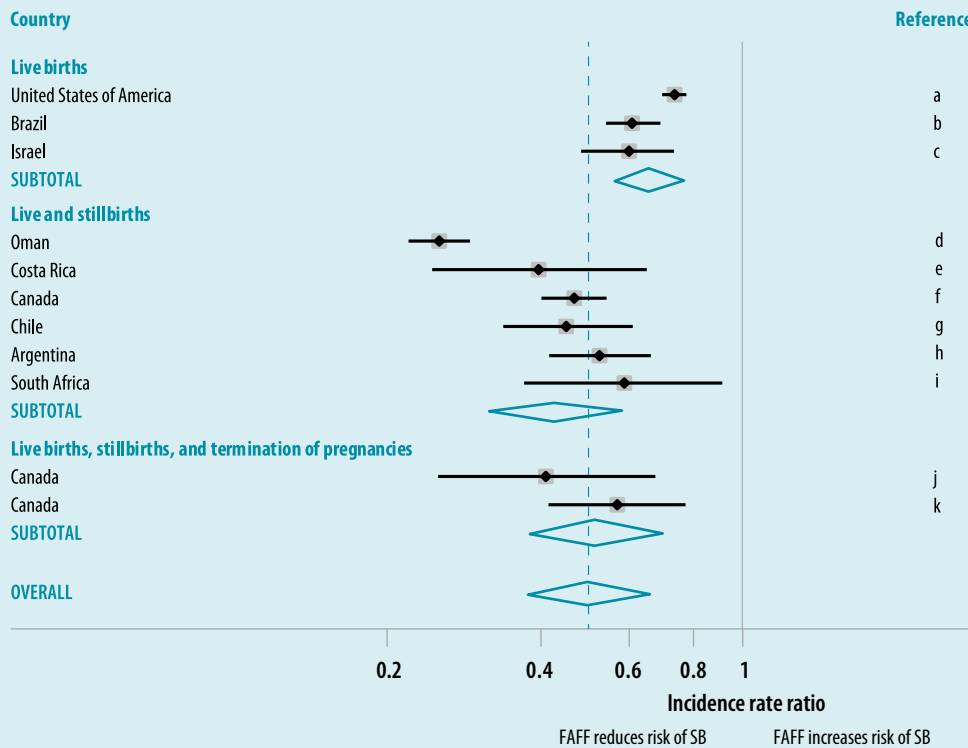
Spinal cord and other major injuries frequently occur in underground mining, where the main working area is a horizontal tunnel while initial access into the earth is either vertical or sloping. While mining activities in high-income countries are often well organized and highly regulated (97–99), low-income countries with poverty, high unemployment, weak law enforcement, and corruption may have unsafe mining practices. For example in Africa there are increasing numbers of small and informal sector mining operations that have inadequate health

**Box 3.3. Interventions to prevent spina bifida**

Spina bifida is a birth defect that affects pregnancies worldwide. A systematic review of spina bifida incidence found a range of incidence rates, from 2.3 per 10 000 in Brazil (76) to 32.1 per 10 000 in Oman (77). A meta-analysis conducted for this report calculated an overall incidence rate of 8.4 per 10 000 (see Technical appendix C for methods and terminology used). This overall incidence rate does not reflect the variation in incidence rates from studies reporting different pregnancy and birth type data (see Chapter 2). Overall incidence rates of spina bifida are about 4.5/10 000 in studies that use live birth data, while those that use live and stillbirth data or live, stillbirth, and termination of pregnancy (TOP) data report incidence rates of about 10.0/10 000 and 9.1/10 000 respectively.

Consumption of folic acid supplements has been shown to significantly reduce the risk of pregnancies affected by spina bifida or other neural tube defects (NTDs) by around 50% (78). As the neural tube closes early in embryonic development (28 days after conception), the ideal time period for consumption of folic acid is before pregnancy (79). Many pregnancies are unplanned, and unfortunately educational campaigns aiming to encourage women to increase their supplement use have been ineffective at reaching populations of higher risk, i.e. low socioeconomic status, poor education, immigration status, unplanned pregnancy, etc. (80). To counteract this issue, some countries have chosen to introduce legislation implementing mandatory folic acid food fortification (FAFF) for a variety of foods (81). FAFF has been proven to improve folic acid status; since mandatory FAFF, the USA, Canada and Western Australia have seen reductions in the prevalence of NTDs of 15–50% (82). Despite the proven efficacy of FAFF legislation, FAFF has not been implemented worldwide, and legislation for mandatory FAFF exists only in the Americas (with the exception of Venezuela) and Australia. There is also partial coverage in the African, Western Pacific and South-East Asia Regions, as well as in the majority of the Eastern Mediterranean Region. Some coverage for FAFF exists in the European Region, but only in eastern European countries (i.e. Republic of Moldova, Kazakhstan, Uzbekistan, Kyrgyzstan and Turkmenistan).

**Meta-analysis of the effect of folic acid food fortification on spina bifida incidence rates**



Sources: a (83); b (76); c (84); d (77); e (85); f (86); g (87); h (88); i (89); j (90); k (80).

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The figure above shows the results of a meta-analysis that used data collected from studies reporting on incidence rates pre- and post-FAFF. The meta-analysis shows an overall effect size (incidence rate ratio) of 0.43 (95% confidence interval 0.39–0.63) when using only those studies that included live births and stillbirths in their study population. With these considerations, worldwide FAFF legislation could potentially reduce spina bifida births by roughly 38 000 per year (see Technical appendix D for methods used).

Although there are proven advantages to FAFF, many countries, especially those in western Europe, have been reluctant to introduce FAFF legislation, as a result of possible health concerns regarding increased folate consumption, coupled with the lack of autonomy some view as implicit in mandatory FAFF. Currently many countries without mandatory FAFF have recommendations for women of reproductive age to take folic acid supplements, and, although this has proved to provide some benefit, it has mainly been restricted to women of higher socioeconomic status. Therefore, additional research needs to be conducted to support informed policy decisions and adequately address concerns of adverse effects.

and safety mechanisms (100, 101). Mining injury incidents may not be reported to the authorities, and statistics may not be well maintained. The mining industry, however, offers an example of a prevention programme (see Box 3.4).

Strategies for injury prevention in the workplace may include developing and implementing labour laws, a code of practice on safety and health specific to each sector, and the implementation of science-based prevention activities (103–106).

### Box 3.4. Preventing fatalities and injuries associated with mining in South Africa

In South Africa, the availability of data on mining fatalities and injuries has made it possible for the outcomes of the injury prevention programme to be measured, for milestones to be identified, and for future prevention targets to be set. This systematic public health approach used by the Government included:

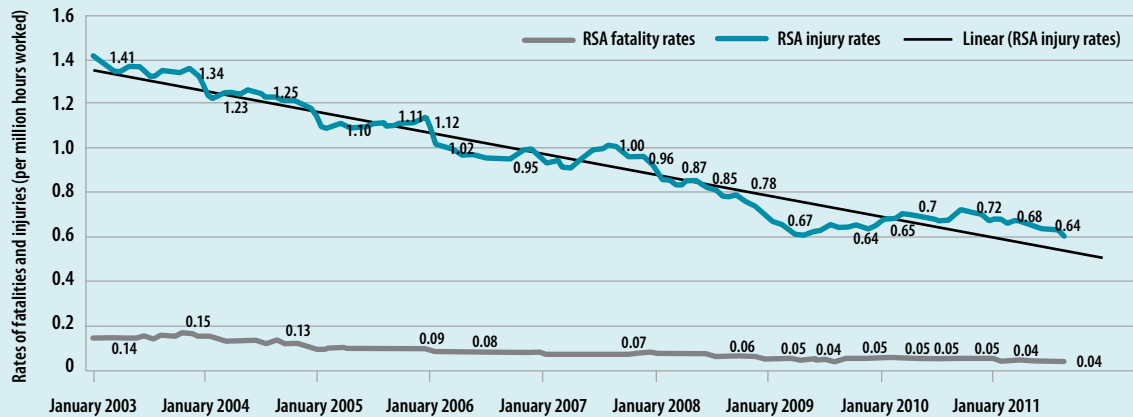
- **Obtaining data on the magnitude of the problem:** i.e. the number of mining fatalities and injuries, for example by mine location and commodity (gold, coal, etc);
- **Hazard identification:** geological, hydrological, seismological and rock evacuation processes;
- **Risk analysis and assessment:** including the identification for each hazard of *how* people are exposed, the *likelihood* and *frequency* of exposure and the possible *consequences* (including serious injury such as SCI); risk assessment involves determining the level of risk and ranking in order of severity;
- **Identification of protective factors:** those actions that can eliminate or reduce the risk;
- **Design and implementation of interventions to control risk:** e.g. modify the working environment, address equipment design, institute new rules to reduce exposure to risks, and provide information and training, for example on inspections and safety audits;
- **Strengthen enforcement provisions and address offences**
- **Monitor and review:** to ensure that changing circumstances do not alter the effectiveness of control measures.

As a result of this process, there has been a significant reduction in both fatal and serious workplace injuries in the South African mining industry. The figure below shows the fall in the rate of fatalities from collapsing mine roofs – the largest single cause of injuries – from 0.14 per million hours worked in January 2003 to 0.05 per million hours in 2011. Injuries from the same cause decreased by 51% from 1.41 per million hours in 2003 to 0.72 per million hours in January 2011.

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### South Africa (RSA) mining fatalities and injuries due to roof collapses (2003–2011)



Source: Reproduced from (102) with permission from Republic of South Africa, Department of Mineral Resources.

## Sport and recreation-related injuries

SCI has been reported in several sporting and recreational activities. The mechanisms for SCI in sporting and recreational settings include:

- vehicle crashes, such as with motorcycles, quad bikes and racing cars;
- falls on the same level, such as during rugby and skiing;
- falling/stumbling/jumping from a height of less than one metre, such as diving into shallow water (see [Box 3.5](#)) and falling from a child-sized pedal cycle;
- falling / stumbling / jumping / pushed from heights of one metre or more, such as in rock climbing, paragliding, falling from a horse or from an adult-sized pedal cycle, or falls from playground equipment.

### Box 3.5. Diving as a cause of spinal cord injury

Cervical SCI – commonly at neurological level of C4 with resulting tetraplegia – is the most common form of diving-related SCI (107–109). This type of diving injury is most often seen in men under the age of 35 (110–112).

Factors associated with diving-related SCI include a lack of diver awareness and education, diving into shallow water (1.5 m or less), lack of depth indicators and safety regulations, characteristics of the upslope in swimming pools, and consumption of alcohol (111, 113, 114). For instance, 63% of SCI in in-ground pools in Canada resulted from the diver striking the upslope between the deep and shallow ends of the pool (111).

Correctly designed pools with appropriate design features can reduce the risk of SCI. Olympic pools that meet a required minimum depth of 2.7 m of water below the diving board have not reported any incidence of diving-related SCI (114). In 2010, the International Swimming Federation introduced new minimum depths of 3.2 m from a 1 m platform, and 5 m from a 10 m platform in Olympic diving facilities (115).

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Research in Australia shows that education (seven 10-minute sessions) covering suitable diving conditions (e.g. known water depth greater than three metres, absence of objects in the water, not diving into above-ground pools) and dive positions (locking thumbs, extending arms beyond the head, and steering and gliding skills) are effective in reducing dive depth and creating safer hand and arm positions (116). Follow-up to the diving education programme demonstrated that participants retained the information and that dives remained shallower 20 months after the initial diver education programme (117, 118).

Key areas that need to be improved to reduce the amount of diving-related SCI (111, 114) include the following.

- National and international evidence-based design parameters for private and public pools should be established and enforced to promote diving safety.
- Vendors and buyers of home pools should be trained in pool safety, stressing the dangers of diving and of head-first entry into shallow water.
- At-risk individuals in schools and in communities should be reached through comprehensive, evidence-based education in water safety.

Research shows that sporting injuries globally account for between 7% and 18% of all SCI (119–121). The prevention of spinal cord injuries

in rugby represents a compelling example of prevention that has been successfully implemented in the context of a major team sport (see [Box 3.6](#)).

### **Box 3.6. New Zealand leading the way in preventing rugby-related spinal cord injury**

Rugby is a high-contact team sport. From the mid-1990s, awareness grew in rugby-playing nations such as New Zealand and South Africa that serious nonfatal injuries, including SCI, were occurring on the field during matches. Consequently data were collected (injury surveillance) to quantify the problem.

The Accident Compensation Commission (ACC) and the New Zealand Rugby Union collaborated with a view “to eliminate spinal injuries within the context of a contact sport.” A study of the circumstances in which injuries occurred identified the following risks: high-risk phases in the game (the scrum, tackle, and ruck/maul); high-risk conditions and behaviours, including poor level of player fitness, high tackles, dropping the chin during a tackle; and inadequate field-side first aid (122).

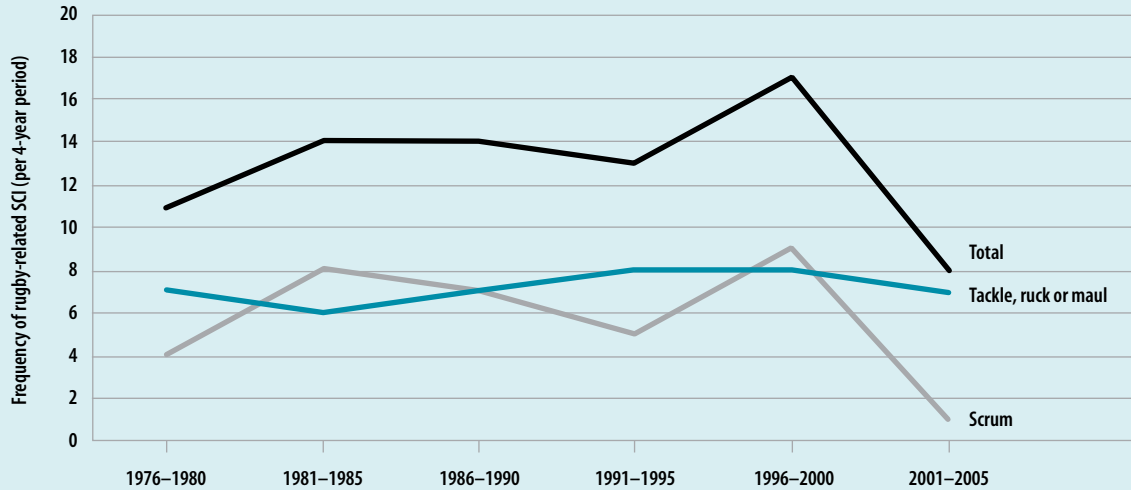
The frequency of rugby-related SCI in New Zealand between 1976 and 2005 is depicted in the first figure below. In response to these patterns, a comprehensive prevention programme called RugbySmart started in New Zealand. It included the following interventions: compulsory safety workshops for coaches, referees and players; compulsory seminars in which safety information and resources were disseminated; a dedicated web site; and provision of injury prevention tools such as a sideline concussion check card for coaches and referees. All coaches were required to complete RugbySmart on an annual basis, resulting in the programme reaching almost 100% of coaches and referees in the country (123).

The introduction of RugbySmart correlated with a reduction in the frequency of SCI, with eight spinal injuries between 2001 and 2005 compared with 17 during the period 1996–2000 (123). As noted in the second figure below, this frequency continued to stay low, with an average of two serious injuries per year in the 11 years during which RugbySmart has been implemented.

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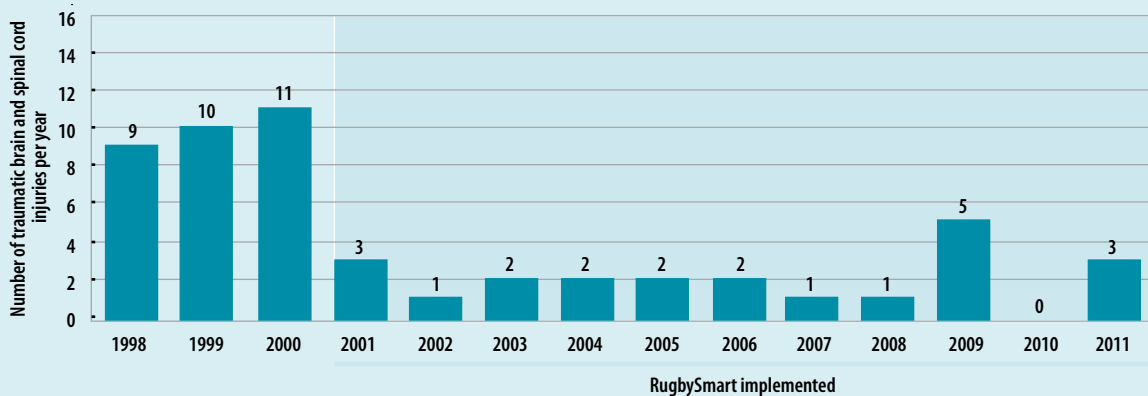
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**Frequency of rugby-related SCI according to high-risk phases in the game**



Source: Reproduced from (123) with permission from BMJ Publishing Group Ltd.

**Reduction in serious rugby-related injuries in New Zealand following the introduction of RugbySmart**



Source: Adapted from (124) with permission from RugbySmart, published by the New Zealand Rugby Union in conjunction with Accident Compensation Corporation.

This approach has also been adapted to the South African context. BokSmart was introduced by SA Rugby and the Players Fund in 2008. This led to improved training and provision of medical support staff or trained people able to provide field-side first aid and equipment to prevent the aggravation of injuries through poor immediate care. Other changes include improvements in coaching and selection policy, changes to the rules of the game (such as rules of scrum engagement to introduce “crouch, touch, pause and engage”) and the adoption of safety equipment (125).



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As with most educational interventions, the degree of effectiveness remains a matter of debate and continuing research. Prevention strategies include minimizing risk through standardized requirements, providing education, and enacting and enforcing appropriate legislation and standards. An overview of prevention approaches for several sports is shown in [Table 3.5](#).

### Natural disasters

Several factors influence the extent to which earthquakes and other natural disasters, such as landslides and volcanic eruptions, can cause SCI. These include the type of buildings, the

time at which the disaster occurs, and the density of the population in the affected area (131, 132). People who are inside buildings made from dry stone or unreinforced masonry at the time of an earthquake have an increased risk of injury compared to those inside buildings with wooden frames (131). Earthquakes that occur when the majority of people are inside high-risk buildings are more likely to result in higher numbers of injuries. While natural disasters may not be preventable, building collapse can be reduced, for instance by enforcing appropriate building codes to ensure that the infrastructure is resistant to earthquakes.

**Table 3.5. Summary of interventions to prevent spinal cord injuries in sporting activities**

Sport	Interventions that work and should be implemented widely	Promising, more evaluations needed	Ineffective or detrimental, should be discouraged
Rugby	Mandatory safety training for coaches and referees (123)	Safer rules for high-risk phases (122, 125)	
Skiing and snowboarding		Education and training in safety measures, e.g. Alpine Responsibility Code (126) Marking ski track dangers and barriers around hazards (126)	
Horseback riding		Safety vests (127)	Tying child riders to the saddle
Diving	Legislation and enforcement of safe pool design, e.g. depth, lighting, diving board height and elasticity (114), prohibiting use of alcohol around water sports	Educational interventions, diving instruction (116–118, 128)	
General field sports	Playground standards for the depth of appropriate surface material, height of equipment and maintenance (129)		
Deep sea diving	Early access to decompression chamber (130)		

## Conclusion and recommendations

SCI is largely predictable and preventable. Substantial research and development over the past 30 years has resulted in interventions proven to reduce incidence of SCI due to a variety of causes – road traffic crashes, falls, violence – and due to activities such as working and playing sport.

The gap between what is known to be effective and what is practised is considerable.

Despite attempts to find and document examples of good SCI prevention programmes in low- and middle-income countries, examples are few. This does not mean that the interventions presented in this chapter will not work in low- and middle-income countries; indeed many do. The strategies, however, need to be tested and adapted to local contexts and conditions.

Governments and others involved in prevention are encouraged to consider the following areas for action:

- *Continue to invest in primary prevention programmes* that have been shown to be effective, taking SCI into consideration (e.g. by requiring mandatory standards that specify height requirements for head restraints in vehicles). Furthermore, implement specific actions to prevent or control SCI in activities such as high-risk occupations and sports (e.g. educational programmes for rugby injury prevention).
- *Strengthen the health system* to identify and treat people at risk of non-traumatic SCI related to communicable diseases, non-communicable conditions and nutritional deficiencies.
- *Raise awareness* about how to prevent SCI in ways that are not demeaning to those who already have SCI.
- *Define priorities for research on the prevention of SCI.* Many widely practised prevention interventions lack a firm evidence base (e.g. diving lessons). Risk factor analysis and intervention evaluation are key to determining which interventions are effective and therefore should be promoted, and which ones are ineffective or harmful and should be discouraged.
- *Involve all relevant sectors and stakeholders.* Preventing SCI involves multiple sectors – such as infrastructure, health, industry, sport and education – in addressing the different causes, activities or settings associated with SCI. One entity needs to take the lead to ensure that implementation goes ahead and that the contributions from different sectors are delivered and sustained.
- *Encourage agencies* in charge of prevention programmes to collaborate with researchers so that incidence data can inform prevention strategies and researchers can be involved in the monitoring and evaluating of the resulting prevention campaigns.

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## Chapter 4

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# Health care and rehabilitation needs



“At age 15 I was diagnosed with acute lymphoblastic leukaemia and other complications. Following my 16th birthday in hospital, I developed a rapidly progressive paraplegia with a sensory level at T6 together with a neurogenic bladder and bowel. The cause of the paraplegia remains unclear; however an adverse reaction to chemotherapy was the most likely explanation. After medical care at home and continuing complete marrow remission, I was well enough in July 1990 to commence rehabilitation at a spinal unit. Life in the spinal unit was difficult. As a younger, female patient I did not have support from peers of my age or gender to talk with. My strong desire to leave the unit was my inspiration to work hard and learn to live in a wheelchair. After three months I was able to return home and start living more independently.”

(Anne, Australia)

“In intensive care I awoke to find a man, a doctor – his face, adorned with beard, close to mine. In an almost threatening but absolute way he stated to me, ‘You do know that you’ll never walk again.’ I looked quizzically and with disbelief at him. He wanted me to reply that I did understand – but I was in shock and incredibly naïve about spinal injury. I absolutely didn’t know what it meant and, even if I did, I still wouldn’t believe that they could tell me then what the prognosis was because I couldn’t take it on. It was too early to hear such a life sentence...”

(Joanna, New Zealand)

“Everybody is encouraged to exercise daily, so why would a spinal cord injury make us any different to everybody else? I find that actively trying to exercise helps me prevent many potential complications that may affect me and maintains my body and mind for today and into the future. Getting out in the paddocks or on the beach with my wife and our kids in my chin-control wheelchair is my favourite exercise.”

(Brad, Australia)

“I received therapy daily, which was a big relief. I loved the nurses, especially the one who taught me bladder and bowel care (remember until now I still had an indwelling catheter). I had to be put on a very high bed to reduce the electric shocks every time someone came near or touched my bed. Slowly I learned techniques to help me bathe, transfer, and wheel. Barriers between the residents of the spinal unit were quickly eliminated as the trousers of those who dared to stand would fall to their ankles and we would laugh until there was no longer anything to laugh about.”

(Angela, Uganda)

“I got the bladder calculi after discharging from the hospital 2 years ago, and then I was admitted to the hospital for surgery. The pressure ulcer always appeared in my hips each time there was a delay in turning over. Now I pay enough attention to the prevention of pressures sores and urinary system infection under the guidance of rehab teachers. I will try to keep good health, but I can’t promise it.”

(Chen, China)

# 4

## Health care and rehabilitation needs

Whether traumatic or non-traumatic in origin, spinal cord injury (SCI) is a very significant health condition. While SCI will always be life-changing, it does not have to undermine the possibilities of a good and fulfilling life for individuals. The social impact of SCI does not necessarily depend on the severity or level of the injury, but on social and environmental factors, particularly the availability of appropriate and accessible health care. With the right treatment, SCI does not have to be a terminal condition, nor does it need to prevent anyone from having an education, finding employment, having a family, and having a successful and productive life. While subsequent chapters explore other social barriers and facilitators, this chapter focuses on health care and rehabilitation including assistive technologies.

The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) establishes the human right of people with disabilities to the highest attainable standard of health in Article 25, the provision of rehabilitation (including assistive technologies) in Article 26, and personal mobility (including assistive technologies) in Article 20 (1).

This chapter analyses the impact that SCI can have on an individual's health, the complications that they can experience and how these can be managed across three key phases of health care provision, namely:

- *pre-hospital and acute care* – the need to ensure immediate survival and stabilization. Without the right initial response, SCI can be life-threatening and can undermine the possibility of future function and independence.
- *post-acute medical care and rehabilitation services* – to ensure that functioning is maximized and that the individual can be as independent as possible so as to return to education or resume employment. Appropriate assistive devices are a vital part of this. Without access to rehabilitation and assistive devices, the person with SCI has little hope of participating in society.
- *maintenance of health care* – so that the individual can avoid or survive the complications of SCI, such as urinary tract infections, pressure ulcers and overuse injuries, remain healthy and enjoy a long life. Without access to basic health care, a person with SCI is more likely to die prematurely.

Constraints of space mean that this chapter cannot address all the health care needs of people with SCI. The goal is to inform policy-makers and service

managers of the potential complications of SCI and the main services that are required across the three phases of care.

### Understanding the health impact of spinal cord injury

The neurological damage caused by both traumatic and non-traumatic SCI prevents sensory and motor information from travelling to and from the brain below the level of the injury. The impact of SCI on function will depend on the level and severity of injury and the available health care. The International Standards for Neurological Classification of Spinal Cord Injury are often used in health-care settings to describe the extent of injury (including type and level of injury) on the basis of a systematic sensory and motor examination of neurological function (2).

SCI can be divided into two types of injury on the basis of **severity** (2), namely:

- Complete injury – people who experience a *complete injury* have no sensory or motor function below the level of the SCI and specifically at S4–S5.
- Incomplete injury – people who experience an *incomplete injury* retain some function (i.e. sensory and muscular) below the neurological level of injury, including at the lowest sacral segments S4–S5. There are different types of incomplete SCI, such as anterior, central and posterior cord syndrome, and Brown-Sequard syndrome, which can influence residual function.

The **level** at which the spinal cord is damaged determines which parts of the body may be affected by paralysis, i.e. loss of muscle function and sensation (2):

- Paraplegia – refers to an injury to the thoracic (T2–T12), lumbar (L1–L5) or sacral (S1–S5) segments of the spinal cord, which includes the *conus medullaris* (distal bulbous part of the spinal cord) or to the *cauda*

*equina* (collection of nerve roots which fan out from the spinal cord at L1–L2). It results in a loss of varying degrees of control of the lower limbs and trunk without involvement of the upper limbs. For example, people with complete injuries between T2 and T8 will have poor trunk control, due to a lack of abdominal muscle control, and total loss of function in the lower limbs; people with complete lower level injuries between T9 and T12 will have good trunk and abdominal control and total loss of function in the lower limbs; while people with lumbar and sacral injuries will have some control over their lower limbs. Figure 1.1 in Chapter 1 shows the location of the different segments of the spinal cord.

- Tetraplegia – is used to describe an injury to the cervical segments of the spinal cord, i.e. between C1 and T1. Depending on the severity and level of injury, tetraplegia results in varying degrees of functional loss in the neck, trunk, and upper and lower limbs. For example, people with complete C1–C3 injuries will require the assistance of a ventilator to breathe; people with complete C5 injuries will have shoulder/upper arm control but no wrist/hand control; people with complete C6 injuries will have wrist extension but no hand/finger function; and people with complete C7–C8 injuries will be able to control their upper limbs but will experience problems with hand/finger dexterity.

In addition to the motor-sensory loss, SCI affects the autonomic neurologic function of the body, resulting in multiple impairments such as loss of bowel, bladder and sexual functions (3). People with SCI also experience a range of activity limitations and participation restrictions in areas such as mobility (e.g. changing body position, transferring, walking), self-care activities (e.g. bathing, dressing, toileting, eating), domestic activities (e.g. cleaning, cooking, caring for others), education, employment, maintenance of

social relationships, and participation in leisure activities (4).

## Potential complications

People with SCI are at risk of a range of secondary conditions, which can be a major cause of morbidity and mortality. While some of these complications occur primarily within the pre-hospital and acute care phase after injury, others may appear at any stage. There is evidence that, with appropriate management, many of these secondary conditions are preventable.

### Circulatory system

*Autonomic dysreflexia:* This condition is characterized by a sudden increase in blood pressure and commonly occurs in people with SCI at or above the T6 level (5). Other signs and symptoms include severe headache, heavy sweating, flushed or reddened skin, blurred vision, body hair “standing on end,” and cardiac arrhythmias (5–7). Triggers can include any noxious stimulus, most commonly a distended or blocked bladder or bowel. Autonomic dysreflexia is a medical emergency that, if left untreated, may result in serious consequences such as stroke, seizures and death. Education on prevention and management strategies is essential for all people with tetraplegia or high-level paraplegia as well as for their family members and caregivers (6).

*Deep vein thrombosis (DVT):* People with SCI are at a high risk of DVT, particularly during the acute and post-acute phases of injury when changes in the normal neurological control of the blood vessels and immobility can result in stasis (8). Additional risk factors include age, obesity, the presence of lower limb fractures, pregnancy and a previous history of DVT. Signs and symptoms include pain, swelling, tenderness, skin discoloration and warmth of the affected limb (8). DVT can lead to pulmonary embolism and potentially to death, and therefore require rapid treatment with anticoagulant medication (8). Preventive measures such as anticoagulant med-

ication or the wearing of compression stockings are extremely important and should be a part of general hospital policy (8, 9).

*Hypotension:* Orthostatic hypotension is a significant drop in blood pressure when a person moves from a lying to upright position. It affects people with both paraplegia and tetraplegia and is common during the acute phase of injury, although some symptoms may continue to occur later (10, 11). Symptoms typically include fatigue, light-headedness, dizziness, blurred vision, muscle weakness, and even temporary loss of consciousness (12). Management involves close monitoring, gradual changes in posture and, where appropriate, provision of medication and salt tablets (13).

### Genitourinary system

*Urinary tract infections (UTIs):* UTIs are common among people with SCI and have been cited as a major reason for re-hospitalization in high-income countries and premature mortality in developing countries (6, 14–16). SCI has an impact on bladder function, and many people use catheterization as a means of management (see below). There is some evidence that the type of bladder management method and also the types of catheters used may have an impact on the risk of UTIs (14, 16). Other factors associated with an increased risk of UTIs including fluid intake, personal hygiene, pregnancy, social support systems and access to health-care services (17).

Noticeable signs and symptoms of UTIs include episodes of urinary incontinence, pain during urination, cloudy urine with increased odour, fever, malaise or lethargy, as well as an exacerbation of other SCI-related complications such as increased spasticity, neuropathic pain and autonomic dysreflexia (6, 15, 16). Laboratory investigations (analysis of urine cultures) are used to confirm the presence of UTIs and to determine the best course of treatment (6, 15, 16). Prevention of UTIs is a major goal of bladder management. Education on proper catheterization techniques and care is essential. Other

management approaches include routine follow-up, adequate fluid intake, good standards of personal hygiene, and proper care of medical devices associated with bladder management (6, 15).

### Neuromusculoskeletal system

*Spasticity/spasms:* Spasticity is a common secondary condition for people with SCI (13, 18). It can lead to involuntary movements and the development of contractures in joints, which restrict their range of motion and thereby hinder functioning. Management measures include: passive movement or stretching, which can be applied manually by therapists, self-administered or achieved through positioning, splinting and/or serial casting; active movement and exercise; electrical, mechanical or thermal techniques to stimulate the muscles or nerves; and antispasmodic medications (18–20).

*Sublesional osteoporosis:* Following SCI there is an immediate loss of bone mass, thus increasing the risk of osteoporosis below the level of injury (21). Inadequate calcium in a person's diet, insufficient vitamin D, ageing and inactivity may also contribute to changes in bone density (21). If osteoporosis is present, people with SCI are at a higher risk of bone fractures, which may be sustained easily during everyday activities such as transfers. Given the immediate loss of bone mass following SCI, early management of bone health is particularly important. Examples of interventions are: biophosphonates (medications to prevent or treat decline in bone mass), together with vitamin D and/or calcium; weight-bearing activities; and electrical stimulation. However, evidence regarding their effectiveness is limited (21–25).

*Heterotopic ossification:* Heterotopic ossification is a condition that results in abnormal bone formation in the soft tissues around affected joints below the level of SCI. Commonly affected joints include the hips, knees and, in cervical injuries, the shoulders and elbows (13). Heterotopic ossification restricts the range of movement in joints and therefore can have a significant impact

on functional outcomes for people with SCI. Early detection through bone scans or X-rays is important. As the cause of heterotopic ossification is unclear, its management can be challenging. The limited evidence available suggests that early provision of anti-inflammatory medication can be effective in reducing the risk of developing heterotopic ossification. Treatment such as medication and radiotherapy may help to stop the progression of heterotopic ossification, and surgery may be useful in improving the range of motion of affected joints (26).

### Respiratory system

*Respiratory function:* Lung capacity, ease of breathing and the ability to cough and clear secretions are often compromised following SCI as a result of paralysis of muscles associated with breathing (27, 28). People who experience high-level tetraplegia are particularly vulnerable. People with an SCI at and above C3 may require constant mechanical ventilation or implantation of a phrenic or diaphragm pacemaker to maintain adequate breathing (29–31). Some people may have a tracheostomy inserted during the acute stage of care to maintain an adequate airway and to facilitate secretion clearance and ventilation (13).

*Respiratory complications:* Pneumonia, atelectasis (“collapsed lung”), aspiration and respiratory failure remain major causes of morbidity and mortality in people with SCI. However, with good management, such complications are preventable. Measures include annual influenza vaccination, five-yearly pneumococcal vaccination, prompt treatment of upper respiratory tract infections with antibiotics, and early implementation of assisted coughing for people with high-level SCI. Longer-term management requires: regular assessment and review of respiratory and lung function; short- or long-term mechanical ventilation aids; respiratory muscle training; aerobic exercise; psychological support to develop coping skills, particularly for those dependent on a ventilator; and education for

people with SCI and their family members (29). In some situations a pacemaker can be surgically implanted to help stimulate some of the key respiratory nerves and muscles (e.g. diaphragm) and allow ventilator-free breathing (29, 32).

## Pain

Most people with SCI experience chronic pain, which can have a significant impact on their quality of life (13, 33–35). The *International Spinal Cord Injury Pain Classification* has recently been developed to assist clinicians and researchers to classify pain following SCI (36, 37). A significant proportion of people with SCI experience neuropathic pain as a result of damage to the spinal cord, usually characterized as burning, stabbing, aching, and/or electric-like stinging sensations (13, 33, 38). People with SCI may also experience musculoskeletal pain as a result of overuse, e.g. shoulder pain from constantly pushing a manual wheelchair, muscle spasms, mechanical instability or poor posture (39).

Experiences of pain are different for each individual and therefore consideration needs

to be given to biomedical, cultural and psychosocial factors (35, 40–42). Multidisciplinary approaches are required for pain management programmes, which may involve measures such as medication, exercise, massage, acupuncture, psychotherapy, meditation and relaxation, provision of assistive technology (see [Box 4.1](#) for definition), review and modification of seating systems, and education about alternative methods of carrying out activities such as transferring (13, 33, 34, 38).

## Skin

*Pressure ulcers:* People with SCI are at high risk of developing pressure ulcers as a result of impairments in sensation and mobility. The presence of other behavioural, socio-demographic and medical factors – smoking, nutritional deficiencies (malnutrition, being underweight, anaemia), infection, moisture from sweating or incontinence, or co-morbid conditions such as diabetes and pulmonary disease – can increase the risk of pressure ulcers (46–48). Pressure ulcers may occur at any time and can have a significant

### Box 4.1. Definitions

*Assistive technology:* Assistive technology can be defined as “any piece of equipment, or product, whether it is acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities” (43).

*Environmental modifications:* The accessibility of the physical environment has an impact both on the functional performance of people with disabilities and on their ability to use certain types of assistive devices. Environmental modifications, whether focused on the individual level (such as installing a grab rail to assist someone to transfer on or off the toilet, or adapting the width of a door to accommodate a wheelchair) or on the societal level (such as ramps and elevators in public buildings), can help individuals to overcome barriers in their home, school and work environments.

*Universal design and mainstream technology:* Universal design is defined in the CRPD as “the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design...” (1). While the focus of this section is on products that are specifically designed for use by people with SCI, it is important to be aware that there are many technologies available on the market with universal design features that may also be useful (e.g. mobile telephones, computers and kitchen appliances). See Chapter 7 for further details.

*Appropriate technology:* This term is used to describe technology that is appropriate for the needs of the user in his or her environment (44, 45). It includes technology that is acceptable to its users, provides proper fit and where appropriate postural support, is safe and durable, is available in the country, and can be obtained and maintained at an affordable cost (45).

impact on an individual's health, functioning and quality of life (46), as well as placing a significant strain on the health-care system due to increased rates of hospitalization and longer lengths of stay (49).

Preventing the development of pressure ulcers is one of the most important aspects of health care for people with SCI and is more cost-effective than treatment (47). As a result, individuals with SCI and their family members require education and training on management techniques as part of their life long care (47, 50). Prevention includes simple measures such as regular skin checks, pressure-relieving methods, adequate bowel and bladder care, provision of appropriate assistive devices, and good nutrition (46–48, 51). Treatment measures may include appropriate wound care, pressure-relieving measures, antibiotics for infections, and surgery (46–48, 50).

## Health care needs

### Pre-hospital and acute care

Care provided during the first 24 hours and the first few days following a traumatic SCI is critical and can significantly influence outcomes for an injured person (51). Pre-hospital management requires: a rapid evaluation, including measurement of vital signs and level of consciousness; initiation of injury management, including stabilization of vital functions, immobilization of the spine to preserve neurological function until long-term spinal stability can be established, and control of bleeding, body temperature and pain; and prompt and safe access to the health-care system (48, 51–55).

People with SCI should ideally arrive at an acute care setting within two hours of injury (54). Interventions in the acute phase, in addition to the techniques applicable in all major injuries (e.g. infusion, bladder drainage, monitoring of vital signs) focus on: prioritizing and

treating life-threatening injuries to maximize survival; treating potentially disabling injuries so as to minimize impairment; and minimizing pain and psychological suffering (54). Accurate diagnosis of the SCI and any co-occurring conditions (e.g. traumatic brain injury, limb fractures, chest or abdominal injuries, wounds and penetrating injuries) is essential so that appropriate medical care and rehabilitation can be provided. Assessment should commence immediately on arrival at hospital and include: a medical history; signs and symptoms, e.g. weakness, sensory and motor deficits, bowel and bladder dysfunction, anatomical deformity, localized tenderness; a neurological (motor and sensory) examination; radiological imaging, i.e. X-ray, computerized tomography, and/or magnetic resonance imaging; and laboratory testing, e.g. blood, microbiology.

Conservative and/or surgical interventions are required if the spine is unstable or there is ongoing compression of the spinal cord. For both traumatic and non-traumatic SCI, there are benefits and complications to both conservative treatment and surgery. Many factors should be taken into consideration to determine the most appropriate management approach, including level of injury, type of fracture, degree of instability, presence of neural compression, impact of other injuries, surgical timing, availability of resources such as expertise, and benefits and risks. In all cases people with SCI should be given an informed choice between conservative and surgical management.

Conservative management involves measures to immobilize the spine and to “reduce” a dislocation with, for instance, bed rest, traction of the spine or the wearing of orthoses (e.g. a halo vest) to immobilize the spine, which usually takes place over a period of six weeks or more. Surgical management can be used to (i) decompress the spine by the “reduction” of a dislocation and/or by removal of fracture fragments that are causing compression of neural structures, and (ii) stabilize the spinal column by implantation of

hardware and the use of bone grafts. Recent evidence from one prospective, multicentre study in North America of 313 patients with injuries between C2 and T1 has indicated that early surgical decompression, i.e. in the first 24 hours following SCI, can improve neurological outcomes (56). Both conservative and surgical management have potential benefits and complications and there is limited research and agreement on which approach promotes better neurological outcomes, has fewer complications, enables earlier mobilization and rehabilitation, and is more cost-effective (13, 51, 57–61).

Acute care for non-traumatic SCI is similar to that for traumatic SCI, with some variation according to the cause. Surgery may be considered for: degenerative conditions, if there is a significant impact on the spinal canal (62, 63); spinal tumours, often followed by radiotherapy or chemotherapy (64); and spinal vascular conditions, with the exception of infarction (65, 66). Non-traumatic SCI caused by infectious conditions may also require surgery, but typically needs immediate treatment with medication such as antibiotics, antivirals or antiparasitics (67).

## Post-acute medical care and rehabilitation

Appropriate medical care and rehabilitation can prevent complications associated with SCI and can assist the person towards a fulfilling and productive life. Rehabilitation, defined as a “set of measures that assist individuals to achieve and obtain optimal functioning in interaction with their environments” (44), should commence in the acute phase for people with SCI, continue to be available to promote functioning, and be available in a range of different settings from the hospital through to the home and community environments.

Regaining functioning is a high priority for people with SCI. Studies indicate that regaining upper limb function is a high priority for people with tetraplegia and regaining sexual function is a high priority for people with paraplegia, while

recovery of bladder and bowel function is important to both groups (68–71). The following section explores what works in improving body and mental functions.

### Management of bladder function

Loss of normal bladder function is one of the most significant consequences for people who have sustained an SCI. Poor management of bladder function can result in secondary complications such as UTIs, urinary retention, incontinence, stones in the kidneys and urinary tract, and reflux of urine (15). When any of these problems occurs over a protracted period of time, life-threatening conditions such as renal failure may develop (13, 16).

Methods used to assist people with SCI to empty their bladders include (15, 16):

- Intermittent catheterization – involves inserting a catheter into the bladder to drain the urine and then immediately removing it on completion. This is done regularly throughout the day, and either “sterile” (i.e. single-use) or “clean” (i.e. sanitization and storage of the catheter for multiple use) systems can be used.
- In-dwelling catheterization – involves inserting a catheter into the bladder and leaving it there on a short-term or long-term basis. The two main types of in-dwelling catheters are 1) the urethral catheter and 2) the suprapubic catheter, which involves inserting the catheter through a small surgical incision above the pubic bone.
- Other methods – include manual methods to trigger voiding or condom catheterization, which involves an external condom-type catheter attached to a drainage bag (for males only); medication; electrical stimulation; and surgery to create a urinary diversion or abdominal stoma for catheterization.

Each individual requires a customized bladder management programme that takes into consideration factors such as sex, bladder function, mobility, sitting balance, hand function and lifestyle. Consideration should also be given



to the advantages and disadvantages associated with each method of bladder control and their appropriateness and availability in the individual's context. Manual methods are generally discouraged and using them as the only means for bladder emptying in the long-term is not considered best practice (16, 72). Evidence suggests that intermittent catheterization is a preferable option as it is generally associated with fewer complications, particularly compared to in-dwelling catheterization (16). A randomized controlled trial carried out in the USA demonstrated that a brief education programme (consisting of an experienced nurse observing catheterization techniques, medical counselling on how to improve bladder management and when to access health care, provision of written information on management of UTIs and one follow-up call to discuss questions that arose after the educational session) brought about a reduction in reporting of symptoms, antibiotic treatment episodes and the number of UTIs (14). Research has also shown that clean intermittent catheterization (CIC) can be a safe, efficient and cost-effective method to use in low-resource settings (72–74).

### Management of bowel function

Neurogenic bowel is a common condition following SCI and is associated with a large number of gastrointestinal problems, including poor colonic motility, prolonged bowel transit time, chronic constipation, abdominal distension and faecal incontinence (75–77). People with SCI who experience a neurogenic bowel are often afraid of possible bowel incontinence, which can have a major impact upon an individual's ability to return to former social roles and activities (75, 76). Adequate management of bowel function can be particularly difficult where resources are limited. For example, a study carried out in Pakistan following the 2005 earthquake found that limited access to appropriate health care, medical devices and toilet facilities had an impact on the ability of individuals to maintain proper bowel care (78).

As with bladder management, a bowel management programme must be developed for each person. A comprehensive assessment, development of an individualized bowel programme, monitoring and education are important aspects of the process (76). Establishing an effective bowel programme may involve measures such as:

- ensuring adequate and appropriate nutritional and fluid intake;
- use of dietary supplements and oral medications when necessary;
- selecting appropriate methods to assist defecation and evacuation, such as physical techniques (i.e. manual evacuation, digital stimulation of the rectum and anal canal and positioning) and stimulants such as suppositories, enemas or laxatives;
- surgery to form a stoma to manage bowel emptying; and
- strategies to manage complications (75, 77, 79–81).

### Management of sexual function and reproductive health

SCI and its associated impairments can affect the physiological, practical and psychological aspects of sexual function – arousal, response, sexual expression and fertility. Both men and women may experience a decrease in or loss of sensation, difficulties in achieving orgasm, difficulties in moving and positioning themselves, and lowered self-esteem and confidence (82–84). In addition, men may experience complete or partial impairment of penile erection and ejaculation, which has implications for fertility (85). For women, menstruation may be disrupted following injury, though it usually returns to normal within a few months (86).

Changes in sexual function can have a major impact on quality of life for people with SCI (69, 82). These psychological and social aspects of sexuality are discussed in Chapter 6. Resuming sexual activity is an important priority for people with SCI. A web-based study carried out to determine the impact of SCI on

sexual function reported that the main reasons people wanted to pursue sexual activity were intimacy, sexual need, self-esteem and keeping a partner (69). Sexuality is often overlooked in the context of rehabilitation as health professionals may feel uncomfortable addressing this issue and may lack the necessary knowledge and skills (82).

Management of sexual function requires respectful discussion at the appropriate time with the involvement of both the individual and his or her partner. Medical care and rehabilitation measures need to be relevant to the individual and should consider age, gender, physical, psychosocial, and cultural factors (82, 83). These measures include: (i) the provision of education and information on preparation and positioning for sexual activity, birth control, prevention of sexually transmitted infections, and management strategies should issues such as incontinence or autonomic dysreflexia arise; (ii) provision of assistive devices for arousal or to enhance positioning; treatment of erectile dysfunction in men (e.g. vibratory stimulation, oral medications, penile injections, vacuum devices and, as a last resort, surgical options such as

penile implants); and (iii) assisted fertility if required (13, 82, 83).

When women with SCI become pregnant, consideration needs to be given to the potential impact of medications for SCI on the fetus, the increased risk of complications (such as UTIs, pressure ulcers, deep vein thrombosis and respiratory problems) associated with pregnancy, functional changes associated with weight gain (e.g. difficulties transferring towards the end of pregnancy), and complications during labour, including autonomic dysreflexia (86).

**Management of difficulties in functioning**

SCI results in limitations in many activities. Rehabilitation should aim to assist people to overcome those limitations by: improving trunk and limb function; modifying the person’s immediate environment; and providing assistive devices and other reasonable accommodations to enable individuals to continue family and work roles.

Although there is variation between individuals, Table 4.1 provides a broad summary of the functional outcomes (mobility, self-care and domestic activities) desirable for different levels of complete SCI.

**Table 4.1. Projected functional outcomes for motor complete tetraplegia at 1 year post-injury and for people with complete paraplegia**

Projected functional outcomes for complete tetraplegia					
Measure	C1–4	C5	C6	C7	C8 – T1
<b>Feeding</b>	Dependent	Independent with assistive technologies	Independent with or without assistive technologies	Independent	Independent
<b>Grooming</b>	Dependent	Requires assistance to independent with assistive technologies	Requires assistance to independent with assistive technologies	Independent with assistive technologies	Independent
<b>Upper extremity dressing</b>	Dependent	Requires assistance	Independent	Independent	Independent
<b>Lower extremity dressing</b>	Dependent	Dependent	Requires assistance	Requires assistance to independent with adaptive equipment	Usually independent

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Projected functional outcomes for complete tetraplegia					
Measure	C1–4	C5	C6	C7	C8 – T1
<b>Bathing</b>	Dependent	Dependent	Requires assistance to independent with assistive technologies	Requires assistance to independent with assistive technologies	Independent with assistive technologies
<b>Bed mobility</b>	Dependent	Requires assistance	Requires assistance	Requires assistance to independent	Independent
<b>Weight shifts</b>	Independent in power chair with power tilt or recline mechanism	Requires assistance unless in power chair with tilt or recline features	Independent	Independent	Independent
<b>Transfers</b>	Dependent	Requires assistance	Requires assistance to independent on level surfaces	Independent with or without transfer board for level surfaces	Independent
<b>Wheelchair propulsion</b>	Independent with power chair; dependent in manual wheelchair	Independent with power chair; independent to some extent in manual wheelchair with adaptations on level surfaces	Independent with manual wheelchair on level surfaces	Independent in manual wheelchair, except for curbs and uneven terrain	Independent
<b>Driving</b>	Dependent	Independent with adaptations	Independent with adaptations	Independent with adaptations	Independent with adaptations
Projected functional outcomes for complete paraplegia					
	T2–9	T10–L2	L3–S5		
<b>Activities of daily living (grooming, feeding, dressing, bathing)</b>	Independent	Independent	Independent	Independent	
<b>Bowel and bladder Transfers</b>	Independent	Independent	Independent	Independent	
<b>Walking</b>	For exercise only and using orthotics and crutches/walking frame	In the house with orthotics; outdoors with orthotics and crutches	Independent yet may require orthotics and crutches/cane		

Terms:

*Dependent* – the person with SCI requires another individual to carry out the task.

*Requires assistance* – the person with SCI can carry out the activity when assisted by another individual. The level of assistance can be minimal, moderate to high.

*Independent* – the person with SCI can carry out the task with or without assistive technologies and without any form of personal assistance.

Source: Adapted from (87) with permission from Wolters Kluwer and Lippincott Williams & Wilkins.

A wide range of rehabilitation measures can be used to enhance function or compensate for loss of function; some of these are described in the following section.

*Exercise to improve, restore or maintain function:* Exercise is a key rehabilitation measure for improving muscle strength and function in the upper limb and may include interventions such as massed practice (highly repetitive movement) and electrical stimulation (19, 88–90). Interventions used for the lower limb include: passive and active exercises for stretching, range of motion and strengthening; electrical stimulation of muscles; and various gait retraining strategies in conjunction with the use of assistive technology such as orthoses, crutches, walking frames and parallel bars (13, 19, 91, 92). Exercise is important for people with SCI as it is associated with several psychological and physiological benefits, including improved muscle strength and endurance, reduced spasticity, improved joint range of motion, reduced pain and improved cardiovascular fitness (93–95).

*Teaching new strategies and techniques:* Rehabilitation provides support and guidance for people to learn and master new and alternative ways of carrying out activities. A wide range of alternative strategies and techniques can be used by people with SCI to overcome activity limitations, including: learning new dressing techniques that utilize residual muscle function; wearing clothes that allow greater ease of dressing; learning to eat with different utensils to enable independence; modifying routines, e.g. personal care routines, to maximize efficiency and conserve energy; and re-allocating tasks to others where appropriate. Successful rehabilitation ensures that individuals are able to generalize their learning across a range of different environments. Therefore opportunities to practise new strategies and techniques outside the therapy environment, e.g. in the home and community, are essential.

*Provision of assistive technology (including modifications to the individual's immediate environment):* Assistive technology is an important

element of rehabilitation, and is essential for people with SCI, as it can enable them to perform everyday activities such as eating, dressing and moving around at a higher level of independence than would otherwise be possible. Environmental modifications similarly remove barriers to functioning and should be considered before discharge, as discussed below and in Chapter 7. Users and caregivers require training in the proper care and use of assistive technology; for instance, wheelchair users who received training have been shown to be more likely to report better functional outcomes and satisfaction (96). The provision of appropriate assistive technology empowers individuals with SCI and can lead to significant gains in their independence and participation in all areas of life, e.g. education, employment and recreation.

*Consideration of surgical interventions:* When no further neurological or functional improvement is expected in the upper limb, reconstruction may be an option, although it is not relevant to all people with SCI and for many people it is not available (97). Surgery can involve transfer of one or several muscles or tendons to improve elbow or wrist extension, hand grasp or finger grip (13). Surgery is followed by a period of immobilization and targeted exercise. For many people with cervical SCI, surgery has led to improved upper limb movement and functioning; however, individual circumstances need to be considered, as do the benefits and disadvantages of surgery and the availability of appropriate rehabilitation (89, 98, 99).

### Management of mental health issues

During the post-injury period, individuals and their family members will often experience grief and a range of emotions including denial, sadness, fear, frustration or anger as they begin the process of adjustment, as discussed further in Chapter 6. Personal factors – including gender, age, personality, coping style – and pre-morbid mental health conditions (e.g. depression, anxiety, alcohol or substance abuse) and associated

conditions such as post-traumatic stress disorder (PTSD) will influence how well an individual adjusts to the injury. Environmental factors – including cultural beliefs and values, attitudes, social supports, provision of appropriate assistive technology, and socioeconomic status – also have an influence on adjustment (13, 48, 100–104).

Depression is a common mental health condition to which people with SCI are particularly vulnerable in the post-injury phase. A recent review has estimated that 20–30% of people with SCI show clinically significant symptoms of depression (105). Depression can have far-reaching consequences for both individuals and their family members, and also for health systems. Depression is associated with fewer improvements in functioning, increased health complications such as pressure ulcers and UTIs, high rates of suicide, increased rates of hospitalization, and higher medical expenses (101, 104, 106).

Mental health conditions such as depression are often regarded as a natural consequence of SCI and are therefore inadequately addressed (101). Management of the adjustment process requires early screening and assessment, timely provision of management measures such as education, information regarding available support services and resources, counselling and potentially medication, and sustained monitoring in the long-term (13, 48, 104, 106, 107). Peer mentoring and support is becoming an important component of rehabilitation programmes for people with SCI, and there is evidence that it contributes to improved adjustment and functioning (108–111).

### Assistive technology

The term “assistive technology” and other terms relating to it are defined in [Box 4.1](#).

#### Need for assistive technology

The need for assistive technology usually begins at the onset of an SCI and continues throughout the person’s life. The type of assistive technology required is influenced by the level of the SCI and

associated impairments, environmental factors (e.g. the physical environment, support, relationships) and personal factors (e.g. age, fitness, lifestyle) and any co-morbid health conditions.

Wheelchairs, environmental control systems and computer technology appear to be the most widely used assistive technologies (112). Wheelchairs are one of the most important types of mobility device used by people with SCI (113, 114). For example a Danish study found that only 3.4% of a sample of 236 individuals followed up for 10–45 years since traumatic SCI reported that they did not require a mobility device, while 83.5% used manual and 27% used powered wheelchairs (115). Similarly, in an Australian study many people with SCI reported that mobility equipment was an important or very important area of need (116). A study in the USA showed that devices for mobility and independent living were the most common devices owned by participants with SCI, with a smaller proportion using computer technology, prosthetics, orthotics, and augmentative and alternative communication devices (117). People with a high level of SCI, i.e. tetraplegia, own significantly more assistive devices than people with paraplegia (117).

Assistive technology needs may change during transition phases, as when an individual returns to community living or work, begins school, has a change in living situation or health status, or experiences gains or losses in function (118). As individuals with SCI age, they experience a decline in functional independence, which may necessitate changes to assistive technology, e.g. they may need a powered wheelchair instead of a manual one (119).

#### Types of assistive technology

[Table 4.2](#) provides a comprehensive overview of the assistive technologies relevant to people with SCI. Assistive technologies are often grouped according to functional need and therefore include mobility devices, communication devices, aids for self-care, aids for domestic activities and environmental control systems.

**Table 4.2. Types of assistive technologies for people with spinal cord injuries**

Activity areas	Examples	Purpose/Benefit
<p><b>Mobility</b></p> <p>This area includes all those activities related to movement and travel, such as changing and maintaining body position, transferring, walking and moving, carrying and handling objects, hand and arm use, and using transportation.</p>	<p><i>Spinal orthoses:</i> the type required is dependent on the level and severity of SCI and includes cervical collars, sternal occipital mandibular immobilizers and thoraco-lumbar-sacral orthoses.</p> <p><i>Lower limb orthoses:</i> include braces/splints to support the hip, knee, ankle and foot. The most common example is the ankle-foot orthosis (AFO).</p> <p><i>Other walking aids:</i> include crutches, canes and walkers.</p> <p><i>Wheelchairs:</i> include manual (self- or attendant-propelled, three- or four-wheeled) and powered wheelchairs (head-, chin- or hand-controlled), hand-powered tricycles, and scooters.</p> <p><i>Transfer aids:</i> slide sheets, transfer boards, and hoists.</p> <p><i>Seating and positioning systems:</i> include adapted forms of seating; cushions for pressure relief and comfort; supports for the head, thorax, pelvis, hips and legs; standing tables; and positioning belts.</p> <p><i>Upper limb orthoses:</i> splints to support the shoulder, elbow, wrist, and/or hand. Examples include resting splints, tenodesis splints (support the wrist and allow for functional grasp), short hand splints and functional use splints (feeding, writing, typing splints).</p>	<p>Spinal orthoses are used in the acute phase after injury to stabilize the spinal column, allow for healing of bones or soft tissue, prevent further injury, and reduce pain (120). In the recovery phase they are designed to prevent deformity, improve posture and limit movement.</p> <p>Lower limb orthoses can provide fixed positioning of the limb to control spasticity and prevent deformity. They also compensate for muscle weakness or joint instability and provide support for people who have adequate lower limb strength to ambulate (121).</p> <p>Walking aids provide extra stability during ambulation to compensate for muscle weakness, poor coordination and reduced balance.</p> <p>Wheelchairs are used when lower limb strength is insufficient to allow walking and can be adapted to suit a vast range of movement abilities (122). For example, manual wheelchairs may be controlled using the upper limbs while powered wheelchairs can be controlled by using very small movements of the fingers on a control stick, or even by using head control (123) for those with inadequate hand movement.</p> <p>Transfer aids enable caregivers to assist people with SCI to change their body position and to move from one place to another, minimizing the risk of injury for both parties.</p> <p>Seating and positioning systems aim to facilitate optimal function in daily activities, prevent contractures and deformities by maintaining joint mobility and muscle length, and prevent skin breakdown and pressure ulcers (46, 48, 124).</p> <p>Static (fixed) splints provide hand positioning to prevent contractures and deformity. Dynamic (moveable) splints support weak or paralysed muscles, thus increasing hand and upper limb function. For example, a wrist-driven wrist-hand orthotic (or flexor hinge splint) allows someone with weak fingers to grasp using wrist strength. It has been found to improve hand function significantly for people with C5, C6 or C7 injuries (125). A mobile arm support can be fixed to a table or wheelchair to support a person's arm against gravity while allowing the arm to move horizontally. It allows them to perform tasks such as feeding, hygiene and writing (126).</p>

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Activity areas	Examples	Purpose/Benefit
<p><b>Communication</b></p> <p>This area includes all those activities related to communication, such as receiving and producing messages and engaging in conversations (4). Accessing information in all its forms is also considered under communication.</p>	<p><i>Driving and transportation:</i> include vans with ramps or lift systems to accommodate wheelchairs; customized hand controls on motor vehicles for accelerating, braking and turning; and accessories such as car door openers, handles and swivel seats to assist with transfers.</p> <p>Devices for communication are often categorized as “augmentative and alternative communication” (AAC) devices and include communication boards, speech amplifiers, speaking valves, electronic speech output devices and computer speech programmes with eye tracking or head tracking technology.</p> <p><i>Computer technology:</i> examples include alternative input devices such as joysticks and touch screens, which enable control of the cursor on the computer screen (128); expanded and modified keyboards; mouth stick controls; voice input switches (129); eye gaze switches that use eye movements to select targets on an on-screen keyboard; and brainwave technology that responds to excitation of a waves to trigger the selection (130).</p>	<p>People with SCI often identify transport as a major barrier. Driving an adapted vehicle facilitates community reintegration, access to employment, access to health-care services, and small health-related quality-of-life gains (127).</p>
<p><b>Self-care</b></p> <p>This area includes activities related to caring for oneself, such as washing oneself, caring for body parts, toileting, dressing, eating and drinking.</p>	<p><i>Bathing and showering:</i> shower chairs, bath benches, transfer boards, grab bars, bath mitts, long-handled bath sponges and brushes.</p> <p><i>Grooming and hygiene:</i> hairbrushes, combs, toothbrushes, razors, mirrors with built-up, extended or angled handles.</p> <p><i>Toileting:</i> bedpans, commode chairs, adapted toilet seats.</p> <p><i>Dressing:</i> dressing sticks, buttonhooks, zipper pulls, long-handled sock, stocking and shoe aids.</p> <p><i>Eating and drinking:</i> plates and bowls with raised edges; utensils with built-up, weighted, angled handles; cups with lids, straws, modified handles or two handles.</p>	<p>High-level SCI can affect the respiratory muscles, and mechanical ventilation may be required via a tracheotomy. Speaking valves can assist people with tracheotomies to produce speech. If speech is weak or cannot be produced, AAC will enable people to express themselves.</p> <p>Computer technology allows people to access information on the Internet, offers an alternative or additional means to communicate, and enables participation in education, work and leisure.</p>
<p><b>Domestic life</b></p> <p>This area includes activities related to domestic and everyday actions and tasks such as preparing meals and doing housework.</p>	<p><i>Bathing and showering:</i> shower chairs, bath benches, transfer boards, grab bars, bath mitts, long-handled bath sponges and brushes.</p> <p><i>Grooming and hygiene:</i> hairbrushes, combs, toothbrushes, razors, mirrors with built-up, extended or angled handles.</p> <p><i>Toileting:</i> bedpans, commode chairs, adapted toilet seats.</p> <p><i>Dressing:</i> dressing sticks, buttonhooks, zipper pulls, long-handled sock, stocking and shoe aids.</p> <p><i>Eating and drinking:</i> plates and bowls with raised edges; utensils with built-up, weighted, angled handles; cups with lids, straws, modified handles or two handles.</p> <p>Examples are extensive and include: nonslip mats to prevent plates and boards from slipping; modified cutting boards to stabilize food while chopping; cooking utensils with angled, comfortable handles; jar and bottle openers; kettle tippers; tap and knob turners. Where food is cooked over a fire or on the ground, low trolleys to move items from place to place, non-tip pots and pans, and reachers to push or pull hot items can be useful.</p>	<p>Self-care devices enable people with limited physical function (both upper and lower body difficulties) to perform self-care activities with little or no assistance. Weak grip, poor coordination or limited ranges of motion are compensated for to allow a person to move and manipulate objects. Appropriate management of self-care activities is essential for individuals returning to social roles such as school or work. Devices such as mirrors play an important role in the early identification of pressure ulcers.</p> <p>The technologies enable people with limited physical function (both upper and lower body difficulties) to perform domestic activities with little or no assistance.</p>

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Activity areas	Examples	Purpose/Benefit
<b>Other</b>		
Environmental control units	Examples include: remote controls and special adaptations to switches to make them accessible (e.g. switches that can be activated by head position, chin, eyebrows or breath).	People living SCI may lose the ability to control devices in their immediate environment such as the television, computer, telephone, lights and doors. Environmental control systems enable them to re-establish this control (131).

### Outcomes associated with assistive technology

Access to a broad range of assistive technology can enable people with SCI to perform everyday activities that they would otherwise be unable to perform (115, 117, 126, 132–135). Assistive technology can assist people with SCI to achieve greater independence and autonomy in their daily lives, e.g. wheelchairs allow people with SCI to be mobile in their communities (136). Environmental control systems can enable people to re-establish control over devices in their immediate environment, such as the television, computer, telephone, lights and doors (131). A Canadian study showed that people who used environmental control systems had greater functional abilities for 75% of tasks associated with activities of daily living, which had a very positive psychosocial impact on their lives (137).

Use of assistive technology has been associated with greater participation in community, social and civil life (138–140). Assistive technology can play a vital role for children with SCI in promoting learning and development (141) and in enabling mobility, education and social engagement (142). Assistive technology contributes to successful employment outcomes (117) and can help ensure the reintegration and inclusion of people with SCI in society (122, 133).

Assistive technology can also improve quality of life. For instance, studies have shown that the use of environmental control systems has a positive impact on user's perceptions of their competency, adaptability and self-esteem (137,

143) and can result in higher levels of satisfaction with quality of life than that of non-users (144).

People with SCI who do not use assistive technology may experience functional limitations and increased dependency on others for assistance (144). Assistive technology can reduce the level of dependence on caregivers (145) and can reduce the time and physical burden for caregivers (132), as reported by caregivers of children with neuromuscular conditions in Guatemala (139). Economic benefits from assistive technology include reduction of costs associated with family assistance, such as wage loss, and the costs of formal support services (44, 132, 146, 147).

### Health maintenance

As outlined in Chapter 2, life expectancy of people with SCI has steadily improved over time as a result of advances in medicine and improved access to medical care, rehabilitation and systems of support (148–150). While life expectancy is beginning to approach that of the general population in developed countries, it is far from equal in developing countries, where morbidity and mortality rates are likely to remain high without increased investment.

There is evidence that, as a population, people with disabilities experience poorer health outcomes than the general population (44). This is also true for people with SCI, who experience what is often referred to as a “narrower or thinner” margin of health. This is strongly influenced by the nature of the SCI, i.e. the severity and level of injury (150). As indicated previously,



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people with SCI are at a high risk of secondary conditions such as pneumonia, pressure ulcers and UTIs (49, 151). These conditions frequently lead to hospitalization and can also result in increased costs for care, reduced employability, decreased quality of life and lowered life expectancy (49, 152–155).

People with SCI are also at risk of the same chronic health conditions as the general population, e.g. heart disease, stroke, diabetes. However, there is evidence that people with SCI may have a higher prevalence of these diseases than the general population (156–160). Ischaemic heart disease has been cited as a leading cause of death in the SCI population in Australia, at a rate significantly higher than that in the general population (157). Chronic conditions in people with SCI are linked to changes in body composition, such as reduced muscle mass and increased adipose tissue, lower activity levels as a result of paralysis, autonomic dysfunction, and metabolic changes (152, 156, 158, 161). There may also be links to other risk factors, such as poor diet, smoking and alcohol use, which may be heightened in the SCI population (159, 162, 163).

Maintaining the long-term health status of people with SCI requires recognition that:

(i) they are at risk of health issues that are specifically related to their SCI, and they therefore require ongoing access to both general and specialist services (151); and (ii) they are also at risk of developing the same health issues as the general population and therefore require access to mainstream services such as health promotion, preventive care (immunization, health screening), and treatment for acute and chronic illness (44). Involvement in physical activity has benefits for physiological health and well-being, but adherence to a regular exercise programme may be hard to maintain (164) if environmental barriers exist, since they are strongly associated with reduced physical activity (165).

Table 4.3 provides some of the specific and mainstream health maintenance measures that are relevant to people with SCI. It should be noted that this table provides an overview only and that consideration must be given to specific guidelines and standards within each country. Health-care providers, people with SCI and family members should all be involved in the development and implementation of a health maintenance plan.

**Table 4.3. Examples of health maintenance measures**

Health area	Measure
Genitourinary	Review bladder management programmes regularly. Investigate further if there are changes in bladder function (e.g. urinary retention, episodes of incontinence, UTIs, blood in urine). Test renal function. Carry out regular imaging of the urinary tract. Conduct prostate cancer screening for men.
Bowel	Review bowel management programmes regularly. Investigate further if there are changes in bowel function (e.g. constipation, diarrhoea). Perform a digital rectal exam routinely from middle age. Encourage a high-fibre diet and regular daily fluid (water) intake. Carry out regular monitoring of bowel function, including the frequency, colour and consistency of stools.

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Health area	Measure
Cardiovascular	Check cholesterol, lipids and blood pressure regularly. Review risk factors (e.g. diet and smoking). Provide education and support for control of risk factors. Encourage regular aerobic exercise each week.
Mental health and well-being	Screen and monitor psychosocial functioning (e.g. depression). Review capacity of caregivers to provide and sustain support. Provide education and support on appropriate diet and exercise. Encourage community participation.
Neurological/ musculoskeletal	Review neuromusculoskeletal function, particularly if there are changes in sensation, muscle strength/tone, joint range of movement, or increased pain. Provide education and training to prevent injuries due to overuse, particularly in the upper limbs. Encourage regular exercise each week. Review assistive technology to ensure proper fit and function.
Respiratory	Provide education on strategies to prevent and manage infection. Perform regular respiratory tests (e.g. vital capacity, peak flow). Immunize against influenza and pneumococcal pneumonia. Provide support and encouragement for cessation of smoking.
Sexual and reproductive function	Conduct pap smear and gynaecological examination for women. Conduct mammogram for women.
Skin	Provide education on how to perform daily skin checks. Provide advice on appropriate nutrition. Provide education on changing posture every two hours. Review assistive technology regularly to ensure proper fit and function (e.g. wheelchair/seating systems).

Sources (47, 76, 95, 152, 156, 157, 159, 164).

## Conclusion and recommendations

The provision of appropriate and timely medical care and rehabilitation (including assistive technology) can have a significant impact on mortality, morbidity and disability in people with SCI. Access to both specialized and mainstream health care can lead to better outcomes and a productive and enjoyable life for people with SCI.

It should be stressed that this chapter is intended to provide only a broad overview of the health needs of people with SCI. Should comprehensive clinical guidance be required, it

should be sourced from peer-reviewed journals, medical/rehabilitation textbooks, manuals and guidelines, relevant health workers and professional organizations, and adapted for use to the specific country and context.

Chapter 5 explores what countries can do to improve the capacity of their health systems to meet the needs of people with SCI. The policy and practice implications of the analysis of health needs of people with SCI given in Chapter 4 are that the following issues should be addressed.

- There must be prompt access to specialized health-care services immediately after injury to address complex issues associated

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- with SCI and to preserve neurological function where possible.
- Access to rehabilitation should be as early as possible, i.e. during the acute phase of injury, and provided on a continuum to maximize functional outcomes and facilitate transition to community living.
  - Access to a range of assistive technologies will help accommodate changes in function and will maximize independence.
  - Follow-up care should be provided to address issues that may arise following discharge from rehabilitation services, particularly during the first 12 months after injury.
  - It must be recognized that people with SCI are at high risk of secondary complications, such as pneumonia, UTIs and pressure ulcers, and therefore require access to ongoing mainstream or specialized medical care.
- People with SCI also require access to mainstream health-care services – including health promotion, prevention and medical care – to address acute and chronic illnesses that are also present in the general population.
  - A coordinated, integrated and multidisciplinary approach that includes people with SCI and their family members will help ensure a smooth transition between inpatient, outpatient and community-based care.
  - People with SCI and their family members must be educated and empowered to ensure that they are able to look after their own health to the greatest extent possible.
  - There must be ongoing clinical research to determine the best possible rehabilitation measures to restore function in different contexts.

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## Chapter 5

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# Health systems strengthening

“I got my injury at a time when my community’s main hospital was in a state of ruin. The surgery theatre was not working and therefore surgery could not take place! My family tried all they could to ask the hospital to transfer me to a neighbouring country but their efforts were in vain. The head of orthopaedics at that time was so barbaric that his words destroyed my will to fight. He came into my hospital room one day, rudely called my mother and family around, and said that I would be a vegetable for the rest of my life and would never be able to sit or walk again!”

(Angela, Uganda)

“I have positive experience with the doctors such as full detailed explanation of my disability, which makes it easier for me to understand my injury and help me to face it, plus encouragement from the doctors to live happily with my disability so that I can positively live with it. I find it challenging especially for long-term health maintenance because, for the spinal cord injury, we have to deal with many complication such as bowel, bladder, limb movement, and it will be a very hard task to achieve my health maintenance.”

(Suliman, Saudi Arabia)

“One of the major problems that I faced after leaving the rehab centre was finding doctors who were familiar with the specific needs and problems of SCI patients. With the spasms it is difficult to travel, transfer and be in the examination chair. Because the spasms tended to be less frequent in the morning I generally asked for a morning appointment. But not many doctor’s offices were willing to do a favour like that. By the time I was eventually seen, my legs would be dancing around. Another problem was autonomic dysreflexia (AD). Almost 90% of the doctors outside the rehab centre were unaware of such a phenomenon. So, almost every time I had to explain that I will have AD when my leg bag is full or if the position is uncomfortable. Even after mentioning it, they forgot to regularly check the leg bag and I often wound up AD. I used to take my brother along to regularly check for the signs of AD.”

(Alexis, India)

“During the 2010 Haiti earthquake, I was hit by a wall and severely injured. My injuries were diagnosed as tetraplegia at the level of C6. Five months following the earthquake, I was re-admitted to Haiti Hospital Appeal for rehabilitation. There I received my first wheelchair. However this wheelchair did neither fit to my size (I am very tall) nor to the level of my spinal cord injury. In Haiti, the health system does not care for wheelchair provision, therefore you have try by yourself – and you have to pay by yourself. One year after the onset of my spinal cord injury, I received a new manual wheelchair, provided by an American organization.”

(Samuel, Haiti)

# 5

## Health systems strengthening

Chapter 4 gave an overview of the health care, rehabilitation and assistive technology needs of people with Spinal Cord Injury (SCI), and this chapter demonstrates how health systems can respond to these needs. Currently, the health system response to people with SCI is inadequate in many countries. As a result, mortality is needlessly high. Investment in the right facilities and skills can enable people with SCI to survive, thrive and access their human rights.

WHO promotes a “systems strengthening” approach to improve the performance of health systems, with consideration given to six “building blocks,” namely: leadership and governance, service delivery, human resources, health technologies, information systems, and financing (1). While this chapter addresses each component separately, it should be recognized that it is the interaction of these components – as well as coordination across other sectors such as education, employment and social welfare – that enables people with SCI to access the care they need. SCI is relevant to almost all aspects of a health system. Therefore, measures to ensure that the needs of people with SCI are met effectively have the potential to benefit not just people with disabilities but also other people using the health system. The chapter concludes with a series of recommendations that provide general guidance to countries willing to strengthen the capacity of their health systems to meet the needs of people with SCI.

### Unmet needs

#### Health care

The *World report on disability* showed that people with disabilities seek more inpatient and outpatient care than people without disabilities, and that people with disabilities also report not receiving care more than people without disabilities (2). For example, people with disabilities have been found to receive fewer screening and preventive services such as mammograms, pap smears and tobacco advice than the general population (3, 4).

Specific data on the utilization of health-care services and the unmet needs of people with SCI are often difficult to obtain, particularly in low-income

countries. However, available evidence supports the findings of the *World report on disability*, showing that people with SCI often have substantial and unmet needs for follow-up services (5), as well as primary care (6), once they have completed their initial rehabilitation period. For example, a cohort study carried out in Canada showed that people with SCI were more likely to have contact with the health-care system (including having higher rates of hospitalization) than the general population during the six-year follow-up period (7). A Danish register-based study, which included patients with SCI nine years after injury, found that they were being admitted to hospital 0.5 times a year, which represented three times more admissions than for a control group; the same SCI patients used general practitioners and physiotherapists six times more than the controls (8).

The unmet primary care needs of people with SCI include health promotion, prevention services and medical treatment (9). In particular, information needs and concerns related to psychological, sexual and reproductive health are poorly addressed (9). A study in the Netherlands showed that people with SCI living at home had significant unmet needs for care, including information and psychosocial care (10). Participants in the Netherlands study also considered that secondary conditions associated with SCI were largely preventable. For instance, 50% of pressure sores and 25% of bladder, bowel and sexuality problems were perceived to be preventable, particularly by providing access to quality care and information, and through self-management of one's own health and behaviour (10).

## Rehabilitation

Global data are also very limited on unmet needs for rehabilitation services, including assistive technology (2). National studies carried out in Malawi, Mozambique, Namibia, Zambia and Zimbabwe on the living conditions of people with disabilities, including people with SCI,

indicated that there were gaps in the provision of services for medical rehabilitation and assistive devices (11–15).

In the absence of data on need and unmet need, research that explores consumer perspectives and experiences of rehabilitation can be helpful in providing information as to whether services are meeting the needs of people with SCI. People with SCI have reported that rehabilitation does not adequately prepare them for the transition to living in the community and that there are gaps between the skills taught in rehabilitation settings and those required in the “real world” (16, 17). The Netherlands study cited above reported that 72% of participants indicated a need for additional care, including consultation at the rehabilitation centre, re-evaluation at the rehabilitation centre, telephone consultation and home visiting (10).

Assistive technology is an important issue: in low- and middle-income countries, it is estimated that only 5–15% of people with disabilities who have a need for assistive devices have access to them (18). The research in southern Africa cited above revealed that only 17–37% of people who expressed a need for assistive device services actually received them, with more men than women reporting use of assistive devices (Malawi: men 25.3%, women 14.1%; Zambia: men 15.7%, women 11.9%), and a greater percentage of urban dwellers than rural dwellers reporting use of assistive devices.

People living in high-income countries may also have unmet needs for assistive technology. A national survey of people with SCI, multiple sclerosis and cerebral palsy in the USA found that more than half (56.5%) of those surveyed reported that they had needed assistive technology during the preceding year, but 28.4% of those who said they had needed it did not receive it every time it was needed (19).

In a SCI study in the Netherlands, the majority of respondents (56.7%) indicated that they had problems obtaining their wheelchairs and that, in consequence, discharge from rehabilitation

centres was often delayed due to waiting times. In addition, 35.9% of people who used manual wheelchairs and 47.5% of those who used power wheelchairs had complaints about their wheelchairs. The same study also reported that, while a high proportion of respondents (78.3%) agreed that their home had the appropriate modifications, a significant proportion (38.1%) reported they did not receive all the modifications they requested (20).

## Health systems strengthening

### Leadership and governance

The *Convention on the Rights of Persons with Disabilities* (CRPD) states that “all people with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” and that States Parties must undertake appropriate measures to ensure access to health services, including rehabilitation as described in both Article 25 and Article 26 of the Convention (21). The CRPD also explicitly mentions the responsibility of States Parties to ensure access to assistive technology for people with disabilities.

Meeting these obligations will require national legislation, policies and strategies. However, in many low- and middle-income countries these are not in place and the provision of and access to health-care and rehabilitation services, including assistive technology, cannot be assured (2). For example, a global survey on the implementation of the United Nations *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* highlighted that 50% of the 114 respondent countries had not enacted legislation relating to rehabilitation; 42% did not have rehabilitation policies in place; 48% did not have policies in place specifically relating to the provision of assistive devices; and 40% had not established rehabilitation programmes (22). Where government legislation and policies do exist, they often

impose restrictions on the type and range of care provided, which can make it difficult for people with SCI to access the care they need. Conflicting definitions of disability, eligibility criteria for assistance and complicated processes can make it difficult for people to obtain or advocate for the resources they need (23).

Without appropriate legislation, policies and strategies it will be difficult to ensure that people with SCI have adequate access to health-care and rehabilitation services. Specific policies on disability (inclusive of people with SCI) should be in place, as well as ensuring that the health and rehabilitation needs of people with SCIs are addressed across other government sectors, including housing, transportation, education, recreation and leisure, employment and social welfare. Plans should also be in place in case of humanitarian disasters, such as earthquakes, which may result in a large number of traumatic SCIs and may overwhelm already weak systems (see [Box 5.1](#)).

Countries need to adopt an incremental approach to building the capacity of health systems to meet the needs of people with SCI. Recognition of the needs and benefits of health care and rehabilitation for people with SCI is a critical first step. Engaging people with SCI in the planning process is also essential, as they are directly affected by policy decisions, and their views, knowledge and experience can provide invaluable insight.

While governments are responsible for ensuring that policies and strategic plans are supported and implemented, a range of stakeholders – including specialist SCI centres, hospitals, professional associations, universities and national and international development agencies – can play a significant role through partnership and collaboration and by providing financial and technical support. Where countries have limited resources they can be supported through the provision of technical assistance, which may include the development of relevant guidelines, the organization of regional and country capac-



### **Box 5.1. Organization of rehabilitation services after the Sichuan earthquake, China**

In May 2008, a devastating earthquake in the Sichuan Province of China resulted in an estimated 86 000 dead or missing people, and left many more people injured and homeless. There were an estimated 200 hospital admissions with injuries to the spinal cord that required intensive medical management. After the earthquake, the Chinese Association of Rehabilitation Medicine (CARM) partnered with local government health officials and the Caring for Children Foundation (a national NGO) to organize the “NHV” approach to address the rehabilitation needs of people with SCI and other traumatic disabling injuries. This approach combined NGO funding (N), resources from local health departments (H), and commitment from professional rehabilitation volunteers (V) to provide a comprehensive continuum of services from institutional-based rehabilitation (IBR) to community-based rehabilitation (CBR). The Law of the People’s Republic of China on the Protection of Persons with Disabilities 2008 (24) and the CRPD (21) provided the legislative framework for the NHV model.

As a result of the severely disrupted health-system infrastructure in the provincial capital of Chengdu and neighbouring areas and the overwhelming number of traumatic SCIs and other disabling injuries following the earthquake, mass evacuation of medically stable patients took place to hospitals in other parts of China (25). Within several months, infrastructure was sufficiently restored for most people to return directly to their homes and displacement camps, or to be transferred to hospitals in the Chengdu area for continued medical care. In anticipation of the rehabilitation needs of people returning to the community, CARM in partnership with local government health officials and the Caring for Children Foundation developed a project to provide second-stage fracture surgery and rehabilitation for people with fractures, SCI, amputations, traumatic brain injuries, and peripheral nerve injuries.

An area rehabilitation needs assessment was conducted with the assistance of Handicap International and the Caring for Children Foundation to identify people who would benefit from IBR. Following piloting, IBR was implemented at the health department hospital in Mianzhu County.

After discharge to the community, the emphasis shifted to CBR and in particular to its health component – promotion, prevention, medical care, rehabilitation and assistive devices. Other components of CBR were also addressed, including the livelihood, social and empowerment components, through the provision of employment services, personal assistants and peer group support.

People who sustained injuries as a result of the earthquake received “fee-free” IBR along with coverage for basic living needs such as expenses for transport to the hospital. Overall, the cost-effectiveness of the NHV model was facilitated by providing IBR at nearby county hospitals as opposed to the more distant provincial hospitals.

The effectiveness of the NHV model for SCI rehabilitation has been shown by Li (26) who demonstrated an average improvement of 30 points in the Barthel Index, a measure of activities of daily living, in 51 earthquake victims with SCI who were treated under NHV modalities. Medical complications were managed effectively in most patients. Moreover, Hu (27) showed improvements in self-reported quality of life, overall health, and satisfaction with social relationships, as well as physical independence and mobility, in 26 subjects with SCI who had been discharged to the community under the NHV model.

ity building and training workshops, and assistance for the development of national policies and programmes.

### **Service delivery**

Systems for the delivery of health-care and rehabilitation services (including assistive technology)

vary throughout the world. In terms of pre-hospital care, several different models exist, ranging from advanced systems of care that utilize highly skilled health personnel to volunteer-based systems that are common in areas where there are few resources. Regardless of what system is in place it is essential that pre-hospital care is integrated into the existing health-care system (28).

Acute and post-acute medical services for people with SCI are usually provided through inpatient facilities such as trauma centres, general hospitals and specialist SCI units or centres, while rehabilitation services can be provided through inpatient, outpatient and/or community settings. In high-income countries, specialized and integrated systems of care for SCI are usually the preferred option – i.e. services are provided “under one roof” or there is an organized system that enables seamless transition between each stage of care, as discussed in Chapter 4.

A policy statement released by the European Spinal Cord Injury Federation (ESCIF) advocates the centralization of treatment, rehabilitation and lifelong care for people with SCI and the development of dedicated centres that are able to manage all aspects of a person’s care (29). Early intervention through specialized centres or dedicated teams within general hospitals has been reported to result in better outcomes for people with SCI (2). A shorter length of stay in a specialist centre/unit or overseen by a dedicated team has been shown to reduce costs, lead to fewer complications, and result in fewer rehospitalizations following discharge, compared to alternative or nonspecialized services (2, 30–42).

A study in nine countries across the world, including two developing countries, found that SCI units are usually led by a physician trained in physical and rehabilitation medicine (43). Services required in the rehabilitation phase included physiotherapy, occupational therapy,

counselling, assistive technology provision, overview of rights, and psychological and psychosexual support. Patients received between two and five hours of therapy a day, usually five days per week, although there was considerable variation in treatment time and length of stay (43, 44).

The provision of assistive technology involves the design, production and distribution of products, and the delivery of relevant services such as assessment, fitting and training (45). Depending on the model of service delivery, people with SCI can acquire assistive technology through a range of different stakeholders, including government services, international agencies, NGOs, the private sector or a combination of these (public–private partnerships). Where government resources are limited, other stakeholders may play a greater role in the provision of assistive technology. National studies on the living conditions of people with disabilities in five African countries indicated that the majority of assistive devices were provided by sources outside the government, although some countries, e.g. Namibia, in this group had a much higher proportion of government-provided assistive technology than others (see Table 5.1).

People with SCI, in association with their family members, need also to be empowered with bladder and bowel management and skills such as transferring, wheelchair skills and self-care. Vocational rehabilitation, sports and cultural activities may follow.

**Table 5.1. Provision of assistive technology by stakeholder**

Country	Government	NGO	Private	Other source
Malawi	19%	9%	34%	38%
Mozambique	47%	4%	36%	13%
Namibia	60%	3%	30%	7%
Zambia	14%	9%	44%	33%
Zimbabwe	28%	8%	31%	33%

Sources (11–15).

### Barriers

People with SCI frequently encounter barriers to maintaining a healthy lifestyle and accessing health-care services. Some of those barriers are described below.

### Availability

Given the multiple health care needs of people with SCI, a comprehensive range of services is required. The delivery of services through specialist centres, while preferred for people with SCI, requires a substantial investment of resources, and such health-care and rehabilitation services are often centralized with limited availability in rural and remote areas (2). A study investigating factors that influence the utilization of health care by former military personnel with SCI in the USA found that distance from general health-care facilities had an impact on utilization – i.e. those who lived further away from inpatient and outpatient services used them less (46). A study carried out in rural and remote areas of Australia found that specialized services such as pain management and wheelchair seating were typically difficult to access, as were diagnostic testing and specialized equipment (47). Owing to the low incidence of SCI, it is very difficult to create sustainable specialized health-care services in rural and remote areas (47).

### Accessibility

People with disabilities often report difficulty in accessing health-care facilities. A lack of accessible and appropriate equipment may cause doctors and other health-care professionals to forego, omit or fail to consider appropriate (and otherwise routine) procedures for people with disabilities (2). A survey of physicians in the USA revealed that, although they were aware of some physical barriers in their offices, they continued to use inaccessible equipment (48).

Systems for the delivery of health-care and rehabilitation (including assistive technology) services can be difficult for people with disabilities and their family members to negotiate: com-

plicated processes and service fragmentation have been found to be major barriers to meeting needs (5). There is rarely a “one-stop shop” to support access to assistive technology, and there are often competing interests among designers, manufacturers, suppliers, fitters and funding sources. In some countries assistive technology services may be separate from health services, making coordination difficult. In one study consumers cited that delays in service delivery, the number of organizations and officials involved, and poor treatment by professionals were contributing factors to unmet needs for assistive technology (20).

### Acceptability

In many instances people with SCI report that rehabilitation programmes do not meet their needs – i.e. they are standardized and are not tailored to individual requirements (17). For example, assistive technology is frequently “prescribed” without consideration of the individual requirements of users and their living environments. Attitudes such as “something is better than nothing” and “one size fits all” are common where resources are limited (49–51).

Inadequate assessment of user needs may result in individuals being matched with inappropriate equipment (52), resulting in negative consequences. For example, where wheelchair systems are not tailored to individual need, people with SCI are at risk of secondary conditions such as pressure areas, repetitive strain injuries, and shoulder injuries (53, 54).

People with SCI often have limited access to the information and support required to make informed decisions about health care and rehabilitation. Individuals may be particularly vulnerable during the early stages of their injury, as their lack of experience and knowledge can limit their insight into their own needs (55). Low user involvement may explain why a large number of wheelchairs provided in low- and middle-income countries are not appropriate for users in their environment (56, 57) or are abandoned (55).

## Addressing barriers

### Coordination of services

As multiple stakeholders are involved in the delivery of services for people with SCI, a systematic and unified approach to service delivery is vital. Regardless of which type of service delivery model is in place, services should be coordinated to ensure smooth transitions between the different stages and settings of care (39, 58). Care coordination promotes a collaborative interdisciplinary team approach to service delivery, linking people with SCI to appropriate services and resources, and ensuring a more efficient and equitable distribution of the resources (2). It involves identifying a care coordinator, developing an individual care plan, and providing appropriate referral and effective information transfer to other services (2). A study involving Sweden and Greece compared similar groups of people with SCI and concluded that better outcomes were achieved with fewer complications when there was a predefined process for managing a person over the first year following traumatic SCI (59).

### Using alternative and complementary models for service delivery

Where dedicated specialized services for people with SCI are not possible, other models of service delivery can be considered to meet their needs. Some alternative models are outlined below. It should be emphasized that these are not stand-alone models; they should form part of a coordinated system of care.

#### *Smaller dedicated units or teams*

SCI units or teams can be set up within the framework of general hospitals. For example, a specific SCI team in Brazil and a small unit in Afghanistan were established in surgical hospitals and orthopaedic centres and supported by a home-based follow-up programme (2, 60). In Viet Nam, the National Rehabilitation Centre partnered with Handicap International in a project to decentralize SCI services by establishing specialist units in existing rehabilitation centres.

#### *Specialist support for mainstream health services*

Mobile consultation teams have been proposed as a way of supporting people with SCI who are in acute care hospitals that do not have specialist SCI units (38). These teams can assist with the prevention and management of complications associated with SCI, advise on timely referrals to rehabilitation services, assist with discharge planning, and provide education to hospital staff. SCI centres could have a role providing consultancy and education to strengthen the capacity of primary health care and social services to follow up issues affecting people with SCI living in the community (5).

#### *Outreach models*

Outreach models enable people with SCI to maintain contact with specialist health-care providers following discharge from tertiary centres. In these models, services are delivered closer to where people live, thus overcoming barriers such as distance and transport costs. Outpatient clinics and home visiting together with “flying clinics” (see Box 5.2) are examples of outreach models that can provide access to specialist medical and rehabilitation services for people with SCI living in rural and remote communities, and they are recognized and supported by people with SCI as alternative forms of service delivery (5).

#### *Telemedicine/telerehabilitation*

Information and communication technology has been used to deliver ongoing support services for people with SCI (61, 62). Teleconsultation and web-linked guidance for medical care and rehabilitation has been used for the treatment of specific SCI complications such as wound care, with suggestions that it may be an appropriate service delivery model for other areas such as bladder management (63). The use of telecommunications is also a potential solution to delivering assistive technology services in rural and remote areas (64).

#### *Community-based rehabilitation (CBR)*

CBR is a broad development strategy that is currently implemented in over 90 countries around

### **Box 5.2. Flying clinics to East Arnhem aboriginal communities in Australia**

Providing ongoing access to health-care and rehabilitation services for people with SCIs in rural and remote areas of Australia presents a significant challenge. In Australia's Northern Territory many indigenous people who sustain an SCI are unable to return to their communities because of inadequate health-care and support services.

Major spinal cord trauma and severe non-traumatic lesions are treated at one of the major SCI units in the southern part of the country – usually by the South Australian Spinal Cord Injury Service (SASCIS) in Adelaide. Medical treatment and rehabilitation for people who sustain less severe lesions of the spinal cord are provided through the Royal Darwin Hospital Rehabilitation Service (RDHRS) in Darwin in the Northern Territory. SASCIS holds several outreach clinics in Darwin and Alice Springs each year to provide follow-up for people living in the Northern Territory. For indigenous people living in areas such as East Arnhem Land, attending these clinics is often difficult, as they live in communities on islands or in remote locations from which lengthy travel via bush tracks is necessary to reach major towns.

Targeted programmes are required to address the needs of people with SCI who live in the isolated communities in northern Australia. In 1994, the Territory Insurance Office Motor Accident Scheme provided funding for an SCI rehabilitation physician from Adelaide and a spinal nurse from the Northern Territory to visit two communities in East Arnhem Land (Yirrkala and Gapuwiyak). Over time the number of communities visited and people seen have increased, with up to 12 clients and seven communities per visit. Since 2002, an allied health professional (occupational therapist, physiotherapist and/or rehabilitation aboriginal liaison officer) has also accompanied the doctor and nurse, and funding has been provided by the RDHRS and the Territory Health Service. Where possible, the spinal outreach team consults with members of the Rural and Remote Allied Health team, who may be involved with individual clients, and community health staff such as doctors, nurses and aboriginal health workers. When not making a community visit, the spinal outreach team is accessible by telephone, telefax and e-mail.

Costs include commercial flights between Darwin and Gove, overnight accommodation in a motel or community guest house and flights with the local charter airline. The costs compare favourably with the alternative, which is to bringing each person and designated caregiver to Darwin for a minimum of two nights.

Apart from the economic benefits for the health system, there are other benefits for people with SCI, their family members and health-care workers. These include the development of a trusting relationship between the person with SCI, family members and the specialist SCI team, as well as the ability to provide opportunistic (and planned) education for the person with SCI, family members, aboriginal health workers and remote nursing and medical staff. The outreach team also gains knowledge about the difficulties and needs of people with SCI living in remote communities and about local solutions to problems, which may benefit other communities.

the world. It has the potential to increase access to health care, rehabilitation and assistive technology for people with disabilities who live in communities with few resources (65). Research from Uganda found that while the mortality of children under five with spina bifida often approaches 50%, districts with CBR programmes had a mortality rate of 16%, approaching that of non-disabled children. Survival rates are associated with parental behaviour, which can be supported and encouraged by visits from CBR workers (66). The development of partnerships between existing specialist services and CBR programmes provides an opportunity for con-

tinued and coordinated care for people with SCI. With appropriate training and supervision, CBR workers have demonstrated in many settings that they are able to provide ongoing support to people with SCI. Many CBR programmes have also supported people with SCI through peer support initiatives such as self-help groups (67).

#### **Adopting person-driven approaches**

A collaborative approach is required in which people with SCI (and their family members, where appropriate and relevant) are able to contribute to planning and decision-making (55, 68). A meta-synthesis of qualitative research examining peo-

ple's experiences of rehabilitation following SCI highlighted that they felt valued and respected when health-care workers: (i) treated them as partners throughout the rehabilitation process; (ii) had a direct and open style of communication; (iii) shared information; and (iv) included them in problem-solving and decision-making (17).

Self-management approaches are critical for ensuring that people with SCI are able to maintain their health in the long-term (54). Constraints within health-care systems serve to further emphasize the importance of these approaches. People with SCI have highlighted that bowel, bladder and skin care are some of the most important topics for which they require education to facilitate self-management (54). In addition to the training and education provided by health and rehabilitation personnel, there are various ways in which people with SCI can gain knowledge and skills. The Internet can be a good source of information and may be a useful means for people with SCI to learn about their condition and to empower themselves to play an active role in their health care and rehabilitation. For instance, the New Zealand Spinal Trust has developed "Spinal Essentials," an online interactive course designed to educate people with SCI about spinal anatomy, medical terms associated with SCI and issues that they may face (69).

Research has demonstrated that people with SCI value input from their peers, whether on an informal basis such as meeting other patients during hospital admissions or on a more formal basis through peer mentoring, peer support and peer training programmes (17, 70). Peer-based programmes have the potential to improve outcomes for people with SCI and for their family members. For example, a comparative study of an SCI peer mentoring programme in the USA showed there was a decreased trend in medical complications following completion of the peer mentoring programme (71).

Peer mentors have a common characteristic (i.e. SCI) and provide needed support and assistance by sharing their experiences, knowledge

and skills. Peer mentors can be used to: build confidence in people who have recently sustained an SCI; address issues related to psychosocial adjustment; provide training and education about self-care and mobility; provide information and advice about health maintenance strategies and the prevention of secondary conditions such as pressure ulcers and urinary tract infections; and initiate referrals to health-care workers where required.

Peer-based training can be incorporated into the various stages of health care and rehabilitation and can be used in many different settings. NGOs, disabled people's organizations and CBR programmes have successfully used this type of training in low-income countries. Organizations such as Motivation run peer training for wheelchair users in countries such as Malawi, Mozambique, Romania and Sri Lanka. Groups for both adults and children promote wheelchair skills, health and awareness of disability rights (72).

### Improving physical access to health-care facilities

The CRPD (21) defines reasonable accommodation as "necessary and appropriate modification and adjustment not imposing a disproportionate or undue burden, where needed in a particular case, to ensure that persons with disabilities enjoy or exercise, on an equal basis with others, all human rights and fundamental freedoms." Reasonable accommodations such as wide automatic doors, large examination rooms, height-adjustable examination tables, wheelchair-accessible scales, and low check-in counters would improve the physical access to health-care facilities for people with SCI.

### Human resources

People with SCI require access to a wide range of skilled personnel who are able to provide both general and specialist health-care and rehabilitation services. These personnel include medical doctors (e.g. emergency physicians, general

practitioners, neurologists, rehabilitation physicians/physiatrists, surgeons, urologists), nurses, paramedics, prosthetists and orthotists, psychologists, rehabilitation engineers, therapists (occupational therapists, physiotherapists, speech therapists), social workers and a variety of support staff, including community-based health and rehabilitation personnel.

### Barriers

There is insufficient information to allow an adequate commentary on the global challenges relating to human resources in the area of health care and SCI. However, the global shortages of human resources for health and rehabilitation, particularly in low- and middle-income countries and in rural and remote locations (2, 65, 73, 74), would suggest that the number of personnel trained in SCI is inadequate to ensure that people with SCI can access the care they need.

There are few formal training programmes for rehabilitation professionals in low- and middle-income settings. A survey of 114 countries showed that 37 had not taken action to train rehabilitation personnel (22). Where courses for rehabilitation professionals exist, curricula often fail to cover the area of SCI adequately. Anecdotal evidence suggests that, while many training programmes include SCI in their curricula, information is usually delivered through a series of lectures, less time being devoted to practical aspects of care.

Lack of expertise among service providers is reported to be a significant barrier to people with disabilities receiving appropriate assistive technology (75). Rehabilitation professionals indicated in a study in Maine, USA that they had no, or only very basic, knowledge in areas related to provision of assistive technology (76). Paediatric occupational therapists reported that they had received inadequate training and technical support, and that they lacked confidence in areas relating to provision of assistive technology (75).

The low incidence of SCI also means that health workers who encounter people with SCI

are often inadequately trained to deal with those people's ongoing care needs. A study carried out in Australia showed that the majority of participants perceived limited local specialist knowledge of SCI to be a major barrier to needs being met (5). Several studies have shown that the lack of knowledge about SCI among primary care physicians, who are for many people with SCI the preferred health-care provider, is a barrier to the provision of preventative and ongoing health care for SCI (48, 77–80).

### Addressing barriers

Articles 4 and 26 of the CRPD highlight the obligations of States Parties to promote the training of professionals and other staff working with people with disabilities (21). To meet the needs of people with SCI, countries need to consider a range of strategies to build capacity in the health and rehabilitation workforce. These strategies include education and training, developing specialist SCI expertise within the country, using alternative methods to provide SCI expertise where it is not available locally, developing collaborative practice between health workers, improving quality and efficiency in service delivery, and introducing incentives to retain health workers in remote areas.

### Establish and strengthen training programmes for rehabilitation professionals

There is a worldwide need to establish training programmes to address the significant shortage of rehabilitation personnel. Training programmes should be established at all levels, including higher education (undergraduate and postgraduate), mid-level education (certificate) and entry-level education (targeting disciplines such as community health and CBR). Training programmes for rehabilitation personnel should be reviewed in collaboration with professional associations, training providers and spinal injury societies/associations to determine the best way to integrate information on SCI, health and rehabilitation including assistive technology.

### Support continuing professional development

Ongoing professional development (including supervision) is needed to maintain or upgrade the knowledge and skills of existing health-care and rehabilitation personnel, and can be linked to registration and a licence to practice. In Australia a service model, whereby rural health professionals were provided with education and professional support, was found to improve their confidence in managing people with SCI (47). Various delivery modes can be used, including face-to-face, on-the-job or Internet-based training, and also telemedicine/tele-rehabilitation. The particular mode used will depend on the context and model of service delivery (73).

While some health care needs are unique to people with SCI (e.g. autonomic dysreflexia), many other health care needs (e.g. bowel, bladder and pressure management) are also relevant to other health conditions. Consideration can be given to integrating and expanding training on issues that are relevant to a wide range of health conditions, as well as on strategies to promote collaborative practice between health-care and rehabilitation personnel (73, 81). E-learning packages, such as the one launched by the International Spinal Cord Society (ISCoS) in 2012, can help provide essential information and support for health-care and rehabilitation personnel working in the field of SCI (82). International, regional and national professional networks such as the International Network of Spinal Cord Injury Physiotherapists (SCIPT) may also help to facilitate the exchange of ideas, knowledge and resources (83). “Observerships”, an initiative of the International Spinal Cord Society Educational Committee, are designed to provide eligible health professionals with opportunities to observe management practices in SCI centres for a period ranging from three weeks to three months (84).

### Utilize non-health professionals to deliver services

As inpatient rehabilitation periods become shorter, rehabilitation professionals face the chal-

lenge of providing services within shorter time frames (71). As highlighted under the section on service delivery above, peer support, mentoring, counselling and training can be helpful in providing guidance and assistance to people with SCI and can help to overcome underlying weaknesses in the health system. Many organizations, such as community-based NGOs and disabled people’s organizations, have established peer-based support programmes. Specialist SCI services have also included peer-based programmes and integrated them into medical care and rehabilitation services. Provision of training and supervision is essential to the success of programmes delivered by non-health professionals (71).

### Ensure that family members receive adequate training and support

Family members can be valuable resources by, among other things, assisting people with SCIs to access care, supporting the implementation of rehabilitation programmes, and providing assistance with activities of daily living. In Nigeria an intensive 12-week programme was developed for the management of SCI. The orthopaedic hospital had limited beds and could not accommodate people for lengthy inpatient stays. Family members were trained in blocks of time to complement and overcome the lack of experienced and available personnel (85). NGOs can also provide training and support to the caregivers of people with SCI in developing countries, with a focus on health care maintenance, manual handling and challenging emotional issues (86).

## Health technologies

Health technologies are required across all phases of health care for people with SCIs, and they are essential for safe and effective prevention, diagnosis, treatment and rehabilitation (87). Health technologies can be broadly categorized under the following areas: emergency and essential surgical care; diagnostics and laboratory technology; diagnostic imaging; and medi-



cal devices (including assistive technology). Although also discussed elsewhere, assistive technology and wheelchairs are the particular focus of this section.

### Barriers

Many countries may be unable to respond to the assistive technology needs of people with SCIs due to barriers associated with production, distribution and maintenance. In many low- and middle-income countries, production and distribution of assistive technology is small-scale or in some instances non-existent (50, 88). Many countries have limited access to the materials and equipment needed to produce assistive devices. The demand for assistive technologies in developing countries may be limited due to the decreased purchasing capacity of potential users and limited awareness among the users of the existence and benefits of devices.

Many countries with limited resources also rely on donations from international organizations and NGOs. This model is commonly used to supply and distribute new or refurbished wheelchairs in low-income countries. While this approach is well-intentioned and enables the distribution of a large number of wheelchairs in a cost-efficient manner, it has several limitations, as outlined below, and is unsustainable in the long term as it does not build local capacity (89). Assistive technology is not applicable across all contexts; for instance, wheelchair designs that are appropriate for people with SCI in high-income countries may not be useful for those in low-income countries (18). In addition, the level of service delivery that accompanies the donation of assistive technology may also vary between different organizations (88). Devices are also often prescribed without the provision of adequate training and support for users (56, 90), which can have a range of consequences.

The abandonment or non-use of assistive technology can be an indicator of unmet needs. Rates of assistive technology abandonment have been shown to be highest during the first year

of use, and then again after five years of use (91). Assistive technology may be abandoned as a result of changes in the needs of users, poor device performance (in terms of effectiveness, reliability, durability, comfort, safety or ease of use), and lack of involvement of users in the selection process (91). The type of device and the level of SCI are likely to play a role in the abandonment of technology (92).

### Addressing barriers

Low-cost sustainable strategies are required for the provision of appropriate assistive technologies in developing countries. The suitability of each approach will depend on the context in each country and may vary for different types of assistive technologies. Factors for consideration include input (financial and technical requirements), sustainability (the potential for established production without external input or with long-term stable external input), appropriateness (how well the technology meets the needs of the user) and impact (quantity that can be produced and delivered in a given period of time) (88).

### Design of appropriate technology

Appropriate technology requires that design features are customized to the user's environment, needs and preferences (93). Local issues, such as rough terrain, limited access to electricity and supply of device components when a breakdown occurs, need to be considered (18, 88, 94). Several organizations have developed mobility devices for developing countries that overcome many of the local issues (72, 95). Standards can improve the quality of assistive technology, increasing the reliability of products and reducing potential risks for users (96). The International Standards Organization (ISO) has standards for manual and powered wheelchairs and scooters, and transportation standards that relate to the transportation of people in wheelchairs in buses or vans (96). However, these standards are not necessarily applicable in all contexts, and it is important to develop national standards that

take into account factors such as the local environment and user characteristics (18, 97).

### Selection of suitable models for production and distribution

Different models for production can be used in low-income countries to increase the availability of assistive technology. For example, small-scale workshop models involve the establishment of local fabrication facilities that may increase sustainability, provide employment for local people (including people with disabilities), and offer products that can be more affordable and appropriate for the local environment (89, 98). However, such models have had varying levels of success in low-income countries, as they require significant time and financial investment to set up and sustain. In addition, they are often limited in their ability to respond to the total needs of the population (88). Some countries like India and China have the capacity to undertake production on a larger scale, supplying products at national, regional and local levels.

### Comprehensive service delivery

Appropriate services are required to assist people to select, acquire and learn to use assistive technologies. Such services include: assessment and prescription; selection and fitting; user training and support on device use; follow-up to ensure safe and efficient use; and ongoing maintenance, repair and replacement. Without comprehensive services in place, users' needs that change over time cannot be accommodated, outcomes will be compromised, and assistive devices may be abandoned (89). A study in Guatemala that evaluated the perceptions of caregivers receiving donated wheelchairs for their children with disabilities (94) showed that, while they perceived the wheelchairs to be beneficial, the caregivers noted the need to provide wheelchairs in collaboration with local services to support wheelchair use (see also [Box 5.3](#)).

Publications such as the *Guidelines on the provision of manual wheelchairs in less-resourced*

*settings* provide useful information and recommendations on service delivery (18).

Many lessons can also be learned from countries with comprehensive delivery systems (45). For instance, in the USA the *Assistive Technology Act* of 1998 funds programmes in each state to provide a range of services, including demonstration centres, loan schemes, technical assistance and outreach to rural populations (103). Demonstration centres and loan banks have the potential to increase user awareness about available assistive technology (104), as well as to improve the knowledge and skills of practitioners and support decision-making processes (104). People are able to try out assistive devices in their own environments before making decisions about whether they are suitable for their needs (91).

## Health information systems

As highlighted in Chapter 2, many countries lack basic information about SCI (105). Information about SCI at the individual, service and population levels is imperative to facilitate health sector planning and budgeting, to guide injury prevention and health promotion efforts, to assist with directing further research and to improve outcomes of rehabilitation (29, 106).

Information should be collected at the individual, service and population levels, as follows:

1. At the level of the individual, information should include age, gender, the mechanism or cause of injury, date of injury, days hospitalized, complications, associated injuries, types of services received, treatment outcomes, neurological status, place of discharge and rehospitalizations (106–110).
2. At the medical and rehabilitation service level, information is required on services, service outcomes, and the cost and benefit of medical and rehabilitation services at facility level (2, 65, 111). The information may include costs, human resources, facility resources (e.g. beds), type of services, frequency of service, referral and waiting

### Box 5.3. Wheels of change: towards appropriate wheelchair user services in Romania

The need for appropriate wheelchair services in Romania continues to increase every year. In 2010 it was estimated that “one in every five persons who need a wheelchair does not have such equipment ... Those not served are either completely immobilized, or have to fend for themselves” (99).

The Motivation Romania Foundation (MRF) was established in 1995 to provide sustainable programmes to increase the quality of life of Romanians with disabilities and has supported over 9000 children and adults with mobility-related impairments in Romania to access a comprehensive package of services.

MRF's wheelchair programme has grown from an initial 20 wheelchair users to approximately 1000 served annually, with peer-group training in the use of appropriate mobility equipment and independent living. MRF's wheelchairs were initially funded through donations and grants. Now, however, they are also partially funded by the National Health Insurance Agency (NHIA), which covers 16–30% of the total demand.

In 2004, 2009 and 2011, funding from the United States Agency for International Development (USAID) was crucial to increasing the capacity of MRF's wheelchair user service. The funding supported seven regional teams, each including one wheelchair technician/independent living trainer (wheelchair user) and one physiotherapist, to provide the following services:

- *Assessment and prescription of wheelchairs:* this includes personalized measurements to ensure that wheelchairs fit the individual needs of each user.
- *Provision of wheelchairs and specialized seating:* wheelchairs both with and without adaptations are provided to a wide range of wheelchair users, and special seating equipment is provided specifically to children with cerebral palsy.
- *Independent living training:* peer-led training is available for wheelchair users and includes training in wheelchair skills, personal hygiene, self-management (e.g. prevention and management of pressure ulcers and urinary tract infections), sexuality and inclusion, counselling and peer support groups.
- *Wheelchair sports*
- *Architectural accessibility:* the first national electronic resource of wheelchair-accessible buildings in Romania (100, 101).

Important challenges need to be overcome before more Romanians with mobility impairments are able to access appropriate wheelchairs together with the necessary training. Romanians who need wheelchairs are entitled to receive one every five years at a basic price paid by the NHIA to certified distributors. Approval for funding can take many months and the individual needs of each user are not considered as this price does not include assessment, adaptations or wheelchair skills training. MRF has attempted to overcome these challenges in several ways, namely:

- The awareness of appropriate wheelchair provision has been increased among prescription specialists. In 2010, MRF introduced the WHO-ISPO-USAID *Guidelines on appropriate wheelchair provision in less resourced settings*. In 2011 MRF organized the first WHO training workshop for wheelchair prescription professionals and plans to expand this training countrywide to increase appropriate wheelchair provision in Romania. In 2012, MRF introduced into the Romanian Code of Occupations (COR) a new profession – that of Wheelchair Assessment, Prescriptions and Adaptations Technicians, and are working to develop an officially recognized training curriculum and course for this profession, based on the WHO wheelchair service training package (102).
- A wheelchair fund has been established with the help of donors to ensure appropriate provision and rapid delivery.
- Funds have been raised from international donors to cover the need in the medium term.

By working to overcome the challenges of wheelchair provision in Romania, MRF is enabling more people with mobility impairments to access the wheelchairs they need and to develop the skills and confidence to participate in education, employment and community life.

Source (101).

lists. All information can be used and aggregated with individual progress data both to identify the economic benefits and efficacy of services and to assist in developing priorities for health research, funding and resource allocation (112–115). There should also be periodic evaluations of the outcomes and the impact (cause and effect) of policy, programmes and medical and rehabilitation services (116).

3. At the population level, data collection can be used to determine the incidence, prevalence and etiology of SCI and to map trends.

It is also important to produce information on the barriers and facilitators a person experiences in terms of legislation and policies, organizational structures, services beyond health and rehabilitation (e.g. transport), and attitudes (109, 117).

Establishing regional and/or national SCI registers is important (29). Countries need to work towards developing information systems by identifying gaps in data availability and quality and by prioritizing the types of information required. To facilitate the collation and comparison of data at the international, regional and national levels, consistency is needed in the framework and terminology used (106). Chapter 2 provides details of international frameworks developed to assist health systems to collect information on SCI.

## Financing and affordability

### Barriers

People who have sustained SCI require ongoing access to medical care and rehabilitation from the time of injury. Therefore both the initial and ongoing costs associated with SCI can be significant (40, 118). These costs vary according to the context and type required (40) and cannot be generalized across settings due to differences in health system structures and funding. Chapter 2 provides further details.

People with SCI often face additional health service expenditures and out-of-pocket payments, which can place undue stress on individuals and their families (79). In general, people with disabilities experience higher rates of poverty than nondisabled people (2) and are therefore unlikely to be able to afford the costs associated with health care, rehabilitation and assistive technology. A study in Nigeria (one of the few carried out in a low-income country) reported that, for 41.1% of people with SCI participating in the study, acute treatment costs represented more than 50% of their annual income (119). In this study, “cost” took into account both direct costs (e.g. hospital charges) and indirect costs (e.g. loss of income).

Where the costs of assistive technology are not covered or subsidized by third parties, products can be inaccessible for people with SCI, and particularly for those living in low- and middle-income settings (120). A study carried out among people with physical impairments (including SCI) in Uganda showed that the primary barrier to assistive devices was financial – the purchase, maintenance and replacement costs were too expensive (121). An individual with traumatic SCI who has just incurred high costs of medical and rehabilitation care may have no funds left to buy and maintain an appropriate wheelchair.

Financial barriers are also relevant in high-income settings. For example in the USA almost one half of all assistive technology is obtained without the help of a third-party payer (19). Governments, NGOs or health insurance companies typically pay for, or underwrite, the provision of “medically necessary” assistive technology, but service costs and coverage limitations may restrict access to this technology (19). People with disabilities are often confronted with eligibility requirements, restrictions, paperwork, rules, regulations, and denials and refusals. This can result in inequities in the types of technology people from lower socioeconomic backgrounds are able to acquire. For example, people with SCI from low socioeconomic backgrounds were

more likely to receive standard wheelchairs than wheelchairs customized for their needs (93).

### Addressing barriers

Countries need to ensure adequate funds are available to finance health-care services to ensure that all people, including those with SCI, can access the services they need.

Various financing options have the potential to increase the availability of health-care services for the general population, as well as for people with SCI (2). These options include: raising sufficient resources for health by increasing the efficiency of revenue collection; reprioritizing government spending; innovative fundraising; and improving the overall efficiency of the health system. Streamlined and coordinated service delivery, for instance, can minimize administrative costs, avoid duplication, and avoid delay in health care and rehabilitation, which may result in the need for protracted and more expensive health care (e.g. pressure ulcers).

Strategies to improve access to assistive technology include promoting local production, reducing duty and import tax, and improving economies of scale based on established need (2). The causes of the abandonment of technology and the cost implications associated with it suggest that consideration could be given to the loan, rental or recycling of equipment during the period in which abandonment is most likely (91). Funds saved through loan or rental programmes could be used to support funding systems for long-term needs (91).

In some countries national or state insurance schemes, compulsory third party insurance or voluntary donation models provide compensation for people who sustain traumatic SCI, for example as a result of road traffic injuries. In Switzerland, membership in a benefactors' association run by the Swiss Paraplegic Foundation, requiring a small yearly donation, entitles the individual to a substantial coverage of costs in the case of a traumatic SCI. Membership is open to anyone regardless of place of residence,

location of accident or treatment (122). In New Zealand, the Accident Compensation Corporation provides comprehensive, no-fault personal injury cover (regardless of cause) for all New Zealand residents and visitors to New Zealand (123). It is funded through levies on people's earnings, businesses' payrolls, the cost of vehicle fuel and vehicle licensing fees, as well as through other government funding.

As there are many causes associated with SCI, other mechanisms need to be in place to ensure that people are protected from the financial risks associated with the use of health-care and rehabilitation services. Given the high costs associated with SCI, affordable health insurance is essential to minimize the need for direct payment at the point of care. Disability insurance schemes can provide a secure and consistent pool of support for services and for people with disabilities (e.g. (124).

International cooperation is needed as many developing countries may lack the resources required to establish specialist services for people with SCI. Article 32 of the CRPD highlights the need for States Parties to undertake measures with other States, together with international and regional organizations and civil society, to provide economic and technical assistance to facilitate access to health care, rehabilitation and assistive technologies (21).

## Research

### Emerging treatments

Research relating to the medical care and rehabilitation of SCI has taken place for decades and, as a result, there have been many gains that have enabled people with SCI to maintain a high quality of life and to live as long as the general population.

There have been remarkable innovations in assistive technology, which have been of benefit to those people with SCI who can access them. For example, advances in wheelchair technology have meant that the needs of people with SCI are better accommodated through tilt-and-

recline mechanisms and elevating leg-rests that address postural alignment, function (including physiological functioning), spasticity, contractures, pressure management, comfort and other issues (125). The development of virtual environments and robotics (126, 127), as well as computer technology such as the use of speech or eye movements to type and the introduction of alternative keyboards (128, 129), has helped to facilitate rehabilitation and engagement in life activities. Research on the neurological control of devices has resulted in the development of prosthetic arms that people can move by thinking about what they want to do (120).

Several potential treatments for SCI are beginning to emerge. Some of these treatments are still undergoing animal trials, while others are at the preclinical stage of research and some treatments that are showing potential are currently being

trials in humans (130–133). Treatments such as stem cell therapy are highly controversial because of the scientific, safety and ethical issues involved (see Box 5.4). Despite the efforts of researchers there are currently no known treatments capable of restoring or repairing the injured spinal cord. Biomedical researchers generally share the belief that it is likely that, in the future, a combination of new treatments combined with existing medical care and rehabilitation will achieve real and significant progress towards restoring or repairing the spinal cord (133). People with SCI and their families seeking new treatments in the hope of a cure need to be aware of the complexity and uncertainty in this field. They should be encouraged to seek advice from multiple sources, including clinical experts, reputable researchers and people with SCI who might have experienced some of these treatments.

#### **Box 5.4. Stem-cell treatment: hope or hype?**

The discovery of nervous system stem cells and rapid advances in stem cell biology have raised hope that stem-cell treatments could contribute to the reversal of severe neurological diseases, including SCI. These discoveries have also created a business opportunity for entrepreneurs in less regulated jurisdictions to sell stem-cell treatments to people with serious diseases who are desperate for recovery, which has become known as “stem-cell tourism.” Such treatments have not been thoroughly tested and evaluated in properly designed clinical trials, nor has regulatory approval been given by recognized bodies such as the United States Food and Drug Administration.

Several variables have contributed to the rapid development of stem-cell tourism (134). These include the existing successful uses of stem-cell treatments for haematological diseases such as leukaemia. Thus entrepreneurs with access to clinical-grade cell-processing facilities can prepare and deliver cells for a variety of unsubstantiated indications. In addition, access to the Internet has created unprecedented advertising opportunities (135), and the availability of treatments in countries such as China and India has increased medical tourism (136).

Stem-cell entrepreneurs argue that people with SCI are being denied effective treatment due to obstructive regulatory requirements, overly cautious scientists and rigid research designs, including randomization and controls (137). However, other than anecdotal reports, such entrepreneurs have contributed little to the vital data that must be gathered before stem cells can be used safely and effectively. Comprehensive long-term follow-up to determine the actual consequences of the treatments is often lacking. When stem-cell treatment is offered along with renewed rehabilitation, it becomes difficult to determine whether it was the stem cells or the rehabilitation that was responsible for any functional improvements.

One of the first published papers critical of stem-cell tourism involved neurological examinations of people with SCI who had received fetal cells before and after direct spinal cord implantation (138). Subsequent reports from this trial by the Chinese investigators have sought to clarify which individuals can benefit from the transplantation procedure (139). Serious complications occurring after fetal stem cell transplantation have been described (140). Numerous not-for-profit and government entities issued statements describing the risks of stem-cell tourism and created educational tools for people with SCI and their families to consider before undergoing stem-cell treatment.

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Key consensus principles emerging include: clinical trials should never involve payment from patients or their families; treatments need to be adequately characterized; pharmacological or toxicological data need to be improved to establish reasonable evidence of safety and efficacy; and a key indicator that a stem-cell treatment is questionable is when a single treatment is advertised as having efficacy for a spectrum of diseases (141).

There is a danger that legitimate stem-cell research will become discredited due to the rogue researchers who offer unsubstantiated therapies. As a result of increased government scrutiny, some stem cell clinics have been closed, including some following serious adverse events (142), while others have been fined for fraudulent advertising. Educational information is now available to advise individuals about the risks of stem-cell treatments (143), and considerable attention has been directed towards the ethical problems and difficulties with informed consent that arise in the context of therapeutic misconception (130). Attempts are underway to distinguish valid medical innovation from the unfounded application of stem cells as treatments (144, 145). Nevertheless, the lure of a potential cure is a powerful enticement, especially when combined with anecdotal reports of remarkable changes in patients. Thus, those with SCI may continue to purchase hope-inducing treatments (146) until potent scientifically validated treatments for acute and chronic SCI are a reality.

### Other research

Insufficient evidence is available on the most appropriate models of service delivery for people with SCI. Further health service research is required to determine rates of access (19) and to identify cost-efficient and equitable service delivery models for improving access. Evidence-based guidelines are also needed by a wide range of stakeholders, including people with SCI, health-care personnel, governments and funding bodies. Without such guidelines, health-care personnel and others will have limited ability to make informed clinical decisions about appropriate interventions and will be unable to support people with SCIs to make informed choices about their care. In the area of assistive technology, there is currently very little empirical evidence regarding the impact on outcomes for people with SCI (147, 148). Without outcomes research in the area of assistive technology for people with SCI, it will be difficult to determine what works, how well it works, and for whom it will work.

### Conclusion and recommendations

This chapter has provided a broad overview of the ways in which health systems can be strength-

ened to ensure that people with SCI can access the health services (including rehabilitation and assistive devices) they need. On the basis of the evidence presented in this chapter, the following recommendations should be considered. A broad range of stakeholders have roles to play and should be consulted in efforts to apply these recommendations.

### Leadership and governance

- Conduct a comprehensive situation analysis to provide a baseline for sustainable national planning.
- Develop or revise national policies and plans in accordance with the situation analysis and the best available research evidence and best practices.
- Develop partnerships with other relevant sectors (e.g. education, employment, transport, social sectors) to increase the possibility of improved health outcomes for people with SCI.
- Engage in policy dialogues with key stakeholders to capitalize on the evidence from research and the knowledge, experience and views of people involved or affected by future policy decisions.
- Multilateral and bilateral donors should provide adequate financial and technical support

for developing countries through sustainable and transparent international cooperation.

## Service delivery

- Map existing services relevant to people with SCI, identify barriers to access and build the capacity of these services, avoiding duplication or the establishment of parallel services.
- Ensure that appropriate systems are in place for the delivery of services for people with SCI. Where resources are adequate this should include access to specialized services. In less well-resourced settings, SCI units or teams in generalized hospitals should be developed. In all settings, systems need to be put in place to ensure a continuum of treatment for individuals when discharged to the community.
- Establish effective communication and referral systems to ensure coordination across the three phases of care: (i) pre-hospital and acute medical care; (ii) post-acute medical care and rehabilitation; and (iii) health maintenance.
- Engage people with SCI and their family members as partners in service delivery: provide them with information and include them in decision-making, planning, goal-setting, and monitoring and evaluation.

## Human resources

- Promote access to specialist training to ensure an adequate supply of suitably trained physical and rehabilitation medicine physicians; occupational therapists; physical therapists; prosthetic and orthotic technicians, speech and language therapists, rehabilitation engineers and wheelchair personnel.
- Strengthen existing training curricula to ensure adequate coverage of SCI and assistive technology.
- Support opportunities for continuing professional development for both rehabilitation and mainstream health-care personnel.

- Utilize non-health professionals such as peers to assist in the delivery of a comprehensive range of health-care and rehabilitation services.
- Ensure that family members, as well as people with SCI themselves, are provided with opportunities for training and support.

## Health technologies

- Establish transparent and fair eligibility guidelines to enable people with SCIs to access assistive technology.
- Identify cost-effective models for the provision of assistive technology.
- Ensure that assistive technology services respond to individual needs, allow choice and accommodate ageing and other changes in life situations.
- Allow local assistive technology producers in low-income settings to contribute to national standards for health technology along with international industry groups.

## Health information

- Ensure that appropriate and standardized health information systems are in place for data collection within health services.
- Collect and analyse data on the causes of injury, together with clinical, management and outcome data, to inform planning and decision-making for both the individual and the services.

## Financing and affordability

- Allocate sufficient funding for specialized services for people with SCI.
- Ensure that appropriate pre-injury and post-injury insurance schemes can protect people against the costs of injury.
- Ensure that people with SCI can access comprehensive and affordable health insurance.



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- Develop international partnerships to secure technical and financial assistance to sustain services for people with SCI in the long term.

## Research

- Support the implementation of rigorous evidence-based research.
- Disseminate objective information on new developments in SCI care to relevant stake-

holders, including people with SCI and their families.

- Conduct health systems research to determine rates of access to health-care and rehabilitation services, and to identify the most cost-effective and efficient models for service delivery.
- Ensure that evidence-based guidelines are available and are used by health-care and rehabilitation personnel.

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## Chapter 6

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# Attitudes, relationships and adjustment



“As wheelchair users, we often prompt a certain curiosity among the non-disabled, in the sense that many wonder why a ‘normal’-looking body would be sitting on a wheelchair. Soon an opportunity is seized to start a conversation by saying: ‘Hope you get well soon!’ followed by the question: ‘Was it an accident?’. The gazer will listen to the story of the person in the wheelchair, realize that this able-bodied-looking person in fact really cannot stand up, feel sincere sorrow and then turn around and go. As he leaves, he will be thankful that it is not him who goes through this ‘suffering.’ He will walk faster and think: ‘My biggest fear in life is to become disabled.’ Yet, that nightmare moment of the spectator might be an ordinary snapshot of the happy but not so easy life of the wheelchair user.”

(Bulent, Turkey)

“Their attitudes make me very miserable. It comes from their myths and beliefs. And yes my SCI happened accidentally, but for our Samoan people not all the people are educated – only 8% are educated. Everyone must work, so you are seen as ‘a waste of time’ because all you do is sit. Especially because I am the age I am – I should work hard for my family and I am not – so I must be useless. Personal care is very hard in Samoa. Your wife will be your main carer but you are lucky if you have a mother too. Without a wife or mother you would have to stay in the hospital. The family will not take you home. There is no knowledge. There is no equipment. I am lucky that my wife loves me very much.”

(Pene, Samoa)

“I acquired a T10 spinal cord injury when I was very young and being a wheelchair user was a natural part of my life. Growing up in a rural part of the USA, I felt comfortable with myself and had a very positive self-identity. However I was never sure if I would find a partner and often felt discouraged about not dating as much as my friends. Now, I am in a loving, stable relationship and plan to be married in the coming year. Looking back, I realize that the only limitations I truly faced are the ones I placed on myself due to a lack of self-confidence regarding dating and sexuality. As a woman with a disability, I had to be even more open, up-front, honest, and confident with men because there were many questions inherent to the process, such as: ‘How will this work?’ or ‘Can you have sex?’ Once these questions were answered, then things proceeded naturally as they would with any relationship!”

(Cheri, USA)

“I received 25 hours per week with a personal assistant for different tasks. I have a few professional people (nurses) with whom I have had a good chemistry and who I can ask to accompany me when I see a trip coming up. I always plan well and put in the time for an enjoyable course of the trip, so that my assistant will have a positive experience when accompanying me. I am extremely pleased with this special type of ‘personal assistant.’”

(Kjell, Norway)

# 6

## Attitudes, relationships and adjustment

The attitudes and behaviours of family members, friends, health-care providers, neighbours and strangers contribute to the environmental factors that influence the lives of people with spinal cord injury (SCI), both as barriers and as facilitators (1). At the same time, the degree to which people with SCI are able to adjust to their situation, which in turn relates to their beliefs and perceptions of themselves, can also influence the attitudes and behaviours of others in their social network (2). For many with SCI, the respect and acceptance expressed by family, friends, neighbours, colleagues and service providers – especially those social reactions that reduce anxiety and fear – are powerful positive forces that can help make adjustment to SCI possible (3). Assistance and support provided by nondisabled people, as well as peer support from other people with disabilities, represent vital help to many people with disabilities.

In the *Convention on the Rights of Persons with Disabilities* (CRPD), Article 3 (General Principles) stresses the importance of respect for inherent dignity, individual autonomy, respect for difference, and acceptance of people with disabilities as part of human diversity and humanity (4). Specific Articles of the Convention that are relevant to a discussion of attitudes and social relationships include:

- Article 8 Awareness-raising;
- Article 19 Living independently and being included in the community;
- Article 23 Respect for home and family;
- Article 30 Participation in cultural life, recreation, leisure and sport.

Other articles, such as Article 26, Habilitation and rehabilitation, highlight important enabling factors in promoting positive relationships.

This chapter reviews the attitudes and relationships that structure the lives of people with SCI. The chapter discusses inclusion in the wider community as well as the attitudes of health-care professionals. It considers the provision of assistance and support – formal institutional and home care, informal unpaid care from family and friends, and consumer-controlled paid personal assistance. Next, the section on family relationships explores relationships with and support from parents, spouses and children. Finally, the chapter examines how individuals adjust to SCI and build positive self-esteem. In each section, a problem statement is followed by examples of interventions and evidence on what works to improve the situation.

## Attitudes

### Wider community attitudes

Cultural representations of and attitudes to disability influence every social interaction in the lives of people with disabilities (5). Staring, ignoring, evading, stereotyping and marginalizing are actions manifesting negative attitudes (6–8). Attitudinal barriers can be just as inhibiting as physical barriers (9). Many non-disabled people are ignorant of the reality of life for people with disabilities. Instead, they base their attitudes on stereotypes and negative imagery (10, 11). Typically, disability is associated with dependency and passivity, though in some cultures it is associated with witchcraft, sin or negative karma (12). Even when nondisabled people avoid these prejudices, disability is still considered to be incompatible with a good quality of life; for example, the general public often views tetraplegia to be worse than death (13, 14). A Kenyan study of families with children with spina bifida revealed that only six of 40 families found their community very helpful; seven had been shunned, while nine felt that they were cursed because of the birth of a disabled child (15). In Bangladesh, even family members themselves had negative attitudes and low expectations about their relatives with disabilities (16).

Attitudes of others can also be a positive force. A survey on the facilitators and barriers for people with mobility impairments in the USA indicated that the attitudes of family, friends and personal assistants had a large positive influence on recovery, while the attitudes of physicians and therapists were viewed as being barriers to receiving health care (17). However, this may differ according to the severity of injury: a Canadian study found that while about two thirds of people with SCI in excellent health identified the attitudes of their family and friends as facilitating their social participation, 25% of those in

poor health cited attitudes of family and friends as obstacles to their social participation (18).

People may be unaware of what a positive attitude towards people with SCI is (19). They may assume, for instance, that people with SCI want special treatment and respond accordingly. Alternatively, they may think of independence in terms of what tasks people with SCI can perform, rather than the independence which comes from having control over one's life. Surveys of people with SCI have found that they perceive their lives more positively than do health-care professionals and the general public (19–21).

### Addressing barriers

Contact with people with disabilities improves attitudes (22). In general, the more that people with SCI go to mainstream schools, travel on public transport, live in ordinary neighbourhoods and work in mainstream workplaces, the more that children and adults without disabilities will learn to understand and respect them as part of the diversity of society (23). When private homes, bars, restaurants and cultural venues are made more accessible, it becomes possible for people with disabilities to attend social gatherings and be included in mainstream leisure options, all of which will tend to improve attitudes.

Targeted interventions – such as disability equality/awareness training delivered to service providers – can challenge negative attitudes and increase understanding (24, 25). Classroom interventions – such as visits from disabled role models or advocates – can improve children's awareness and understanding (26–28). The presence of more varied and positive disability role models in the media may also influence attitudes (29), and individual awareness-raising efforts can profit from media coverage on major events, as the example from Haiti in [Box 6.1](#) shows.

Actions by governments to promote awareness of the CRPD will tend to challenge negative attitudes to disability and promote acceptance.

**Box 6.1. Changing attitudes in Haiti**

While the initial medical care required to support SCI patients after the earthquake on 10 January 2010 posed a huge task, perhaps the greatest challenge for rehabilitation in Haiti has been the issue of reintegration.

In a country where people with disabilities are often called *cocobai* – Haitian Creole for “worthless” – SCI centres have faced significant challenges in transforming attitudes and developing successful reintegration programmes. In an ICF (International Classification of Functioning, Disability and Health) study undertaken at the Haiti Hospital Appeal (HHA) after the earthquake, nearly all patients showed severe problems in moving around using equipment and transportation. The environment had a major impact on these limitations, since the area around the hospital and existing transportation services were not wheelchair-accessible (30).

However, aside from infrastructural reintegration, which has been the main focus of most recommendations, perhaps the greatest obstacle for countries such as Haiti is the cultural stigma associated with disability. Of 62 Haitian families surveyed, 45 stated they faced abuse or discrimination because of their child’s disability, 39 on a daily basis (31). Cultural and religious beliefs contribute to discrimination, since in Haiti disability is often viewed as supernatural in origin. Even crop failure can be blamed on children with disabilities (32).

While national infrastructural change is generally too expensive for NGOs to implement, cost-effective advocacy efforts for achieving more rapid short-term change are attainable. HHA has launched a campaign that uses sport for the advancement of disability inclusion. The universal popularity of sport and its physical, social and economic development benefits make it an ideal tool for fostering the inclusion and well-being of people with disabilities (33). HHA’s strategy focuses on grassroots sport, and also professional Paralympic development. Leon G. lost his wife and eight of his children in the 2010 earthquake, as well as suffering an SCI. Yet, his subsequent determination to use sport to overcome disability has generated widespread attention, giving hope, courage and vision to many people in Cap-Haitien (Haiti’s second largest city) and helping to eradicate the social stigma of disability, according to Istvann Papp (Chief of the North Haiti United Nations Community Violence Reduction Team).

In addition to the awareness opportunity for nondisabled spectators as Leon handcycles publicly around his district, his achievement of becoming Haiti’s first competitive handcyclist at the Parapan Games in 2011 has presented a perfect challenge to the stigma of disability. Leon has been featured on Haitian and international television, has spoken at public events, and supported the effort to have the 2012 Paralympic Games broadcast on Haitian television for the first time. His story has shown how sport can transcend linguistic, cultural and social barriers, providing an excellent platform for strategies of inclusion and adaptation in a way that more traditional forms of reintegration may struggle with (33).

While physical infrastructural change is undoubtedly a critical need, a nation needs first to appreciate, understand and care for the needs of people with disabilities before it is likely to respond appropriately. Once people with disabilities are viewed as equal, it will be easier for them to achieve their human rights. Leon’s experience is just one example of how individual stories of personal sporting achievement can significantly improve relationships and attitudes.

**Attitudes of health professionals**

Health professionals may sometimes be prejudiced against people with disabilities or may fail to treat them with respect (34). For example, one study found that 8.2% of general practitioners in south-western France felt discomfort with regard to people with physical impairments, and these attitudes were associated with less experience, lack of medical training about disability

and inadequate consultation time (35). An Australian study found that occupational therapy students’ attitudes were no better than those of business students (23). Another study found that nurses working in acute SCI care had more negative attitudes to older people with SCI than did either nurses working in SCI rehabilitation or people with SCI (36), perhaps because they always see individuals in a critical state, experiencing high dependency. This phenomenon may

also explain the negative attitudes found among emergency care providers (37) and some rehabilitation workers (19). These studies were mainly conducted in high-income countries. Less is known about the attitudes of health professionals in low- and middle-income countries (38), although analysis of the World Health Survey found that, compared with nondisabled people, people with disabilities were twice as likely to find health-care provider skills and equipment inadequate to meet their needs, three times as likely to be denied care, and four times as likely to be treated badly (39).

### Addressing barriers

Health-care professionals with supportive attitudes were seen by people with SCI as being central to their recovery, well-being, autonomy and hope (40). It has been found, for instance, that the positive attitudes of physicians can have more influence on patient attitudes towards their disability and rehabilitation than education of patients on their treatment options (41). Therefore it is critical to help professionals to develop positive attitudes and better understanding.

Efforts to improve the attitudes of health professionals include measures such as lectures and modules on the health needs and human rights of people with disability in undergraduate training, including exposure to people with disabilities or to disabled peoples' groups (23, 42). Workshops and participative activities may have a greater long-term impact than lectures (25). In-service training and other forms of continuing education can help influence the thinking of doctors, nurses and other professionals after they have qualified (43). Encouraging the training and recruitment of health professionals with disabilities can also challenge the prevailing stereotype that people with disabilities are always patients (44).

## Assistance and support

The topic of assistance and support refers to non-medical personnel who assist people with disabilities with activities of daily living. Needs might occur in the home, in school, in the workplace, while travelling between locations, or in social and community activities. Environmental barriers generally increase the need for assistance; better accessibility and more assistive devices generally decrease the need for assistance. People who cannot obtain assistance, particularly in inaccessible settings, may be confined to the home, or even to one room in the home. Generally speaking, people with more complex needs – such as tetraplegia – will require more assistance than people with paraplegia.

As demonstrated in the *World report on disability* (39), in general the majority of needs for assistance and support for all people with disabilities are met by family members and friends, also referred to as informal caregivers, who are unpaid. For high-income settings, or sometimes for individuals with high incomes who are living in lower income settings, paid support may be available. This may be supplied by the state, by a voluntary organization or on a commercial basis. This new and potentially very empowering phenomenon is discussed below in the section on personal assistants.

### Informal care

Studies of informal caregivers, typically family members, have looked at the type of tasks performed, the effects on the health of the family, and the effect on relationships (45, 46). The majority of adults with SCI are male, and their caregivers are more likely to be female. For example, one Brazilian study found that more than 80% of caregivers of people with traumatic paraplegia were female, generally wives or sometimes sisters, and more than half of the caregivers were sole caregivers (47). Another significant group of informal caregivers are the parents of children and

young people with spina bifida or acquired SCI: again, women generally perform the majority of caregiving tasks.

Family and friends may feel untrained or inadequate to provide the assistance needed. Other research has found problems of isolation and lack of support for caregivers (48). Depending on the level of need, supporting an individual with SCI can be physically and emotionally demanding. This can have psychological impacts that affect the care that is provided. For example, spouses who fulfil caring roles may have more symptoms of stress and depression than their SCI partners (46). A study in the Netherlands using the Barthel Index found that the perceived burden of support in partners of people with SCI was high in nearly 24.8% of partners of people with serious disabilities, compared to 3.9% of partners of people with minor disabilities, and concluded that prevention of caregiver burn-out should be part of the care of people with SCI (49). A Brazilian study found that caregivers of people with paraplegia reported low scores on SF36 quality of life measurement, particularly for the dimensions of bodily pain and vitality (47). A study in Fiji of caregivers of people with SCI found significant caregiver burden and psychological distress (50). In Fiji, paid care support is almost non-existent, with the extended family being the main source of assistance for people with SCI. A small study of the quality of life of families with spina bifida in Kenya found pervasive social, financial, emotional and spiritual impact on parents, with these stresses being heightened when children also had urinary incontinence (15).

### Addressing barriers

Social support is a key factor in the lives of adults with SCI as they return to their homes and communities after the initial period of rehabilitation has ended. Strategies and programmes are needed to provide informal personal assistance networks to people with SCI before they leave rehabilitation facilities so that they will be able to

live in the community (51). During inpatient care, not only patients but also their families should be involved in educational activities (52): needs for information on medical, psychosocial and emotional, community/integration, employment/financial and ADL (activities of daily living)/self-care issues were all highlighted in this Canadian study. Adaptation to SCI during the first three years after onset is improved if social and educational support is provided to family members, and not just to the person with SCI (53). A randomized controlled trial in the USA found that psychosocial interventions that targeted both the caregiver and the person with SCI were most effective in reducing health symptoms and social exclusion of caregivers (54). Family support interventions may include face-to-face problem-solving training sessions, support via telephone or video conference, and educational materials. These have been shown to improve functioning and problem-solving and, in some cases, to reduce caregiver depression (55, 56).

Comprehensive support services during rehabilitation for families of children with traumatic injury have been found to be effective. This includes coordination of discharge care, education protocols, implementation of support groups, and peer support programmes for families (57). Both interventions and research are lacking for families of children with spina bifida (58). Respite care is a common solution in high-income countries where family members have caring responsibilities for children or older adults with disabilities and require a break from delivering caring tasks to reduce psychological distress (59). In less-resourced contexts, community-based rehabilitation (CBR) programmes can be an important source of support for families with disabled children (60, 61). Voluntary organizations are another source of help. Parents in Bangladesh reported benefits from meeting other parents when they attended a rehabilitation centre (16). In a Kenyan study of families having children with spina bifida, three quarters of families had been befriended by someone

from their church, and half of them knew other families with disabled children, which suggests that sources of mutual aid and support are available (15). However, geographical coverage of both NGO and CBR projects remains patchy.

### Formal care

Formal assistance and support services cover several different areas, including residential support services, community support, respite care and others. Formal services may be delivered by means of public or private for-profit and private not-for-profit sectors, or by a combination of these (39). Formal care can benefit both people with disabilities and informal caregivers (62, 63). For low-income countries, however, resources may not be available for this type of service or the cost to the consumer may be too great (64). Residential provision, which has been the traditional approach to formal care in high-income countries, undermines the choice and freedom of people with disabilities to lead normal lives.

### Addressing barriers

Informal assistance and support have been shown to be more effective when combined with several formal care systems and services. For instance, respite care allows families to take a break from the stresses associated with informal caregiving to children with spina bifida or SCI (62).

High-income countries have seen a move from residential care (65, 66) to community-based care in recent decades. Support workers in the community allow individuals of all ages with SCI to remain in their own homes rather than enter a residential institution, a solution that is regarded as preferable by most individuals and is mandated by Article 19 of the CPRD. Community support can assist with self-care, mobility and participation, and has been associated with better health and functioning in individuals with SCI (67, 68). Home-based assistance and support is important for people who have little or no mobility. Lack of mobility is associated with

higher rates of medical complications and highlights the need for workers to have formal training in health-related support tasks (13, 69). When implemented correctly, it has been demonstrated that formal care in a community setting is not only cost-effective (70, 71), but can also improve the management of neuropathic bladder, reducing the risk of secondary complications associated with SCI (67) and thus improving quality of life. Collaboration with NGOs, as has happened in South Africa, for instance, is one way in which formal care can be made available to people in low- and middle-income countries (72).

### Personal assistants

In high-income countries, for those who have no family support or who prefer to alleviate the stress on informal caregivers by paying for assistance, or who favour greater control and flexibility, the personal assistant model is widely seen as a good solution. Personal assistance in this context refers to human help provided to individuals, under their control, so that they can perform basic activities necessary for living in the community (e.g. dressing, bathing, toileting, doing laundry, housekeeping and shopping) (73).

Formal assistance and support supplied by agencies may entail strict rules on the number of hours worked and on the range of tasks that workers are allowed to perform, which may limit the ability of consumers to negotiate services outside those specifically authorized by the agency (74). In contrast, consumer-directed personal assistance programmes have been found to result in increased well-being, decreased hospitalization, and enhanced overall satisfaction of consumers (51, 74–76).

Personal assistants enable individuals with SCI to participate more in community life (77), in school, volunteering, active employment and engagement in social and recreational activities (51). The availability of a personal assistant may also influence the amount of exercise a person has. One study in the USA found that less than

half of manual wheelchair users met recommendations of 150 minutes moderate or strenuous physical activity per week (78). Kehn and Kroll (79) interviewed exercisers and non-exercisers with SCI about their physical activity levels and found that having a personal assistant to help with use of exercise machines and equipment was the primary reason for exercising.

Barriers to widening the personal assistance model are lack of funding (80), inadequate arrangements for assessment, and the need for training of both personal assistance users and the personal assistants themselves. Employing or managing a personal assistant requires the person with disability to have the necessary skills to manage budgets and perform employer tasks, which may not be possible or desirable for all (81).

### Addressing barriers

Except for individuals with access to private resources, the provision of personal assistance services is usually dependent on a country's health and social security system. However, a systematic review of evidence found that the personal assistance approach can be cost-effective in high-income countries, particularly when compared to the cost of institutional care for people with high dependency needs (63). In Sweden, for instance, a personal assistance programme makes it financially possible for people with severe impairments to hire a personal assistant, either directly or through a provider, and thereby to receive support that is adapted to the individual and optimizes the person's influence over how the support is arranged (82). Most people with SCI in low- and middle-income countries cannot afford to pay for their own assistants, and they are unlikely to receive support from the state. However, informal assistance and support can still be delivered in ways that reflect human rights values of empowerment and respect, rather than fostering dependency (83, 84).

Provision of personal assistance should start with an assessment of need. For example,

in New Zealand the publicly funded Accident Compensation Corporation (ACC) National Serious Injury Service aims to encourage independent living and a return to employment by appointing a case manager to help coordinate the individual's community requirements (85). An assessment of needed assistance hours is usually conducted by an independent ACC-funded occupational therapist, who will, following standard guidelines, consider the amount of function present in an individual with SCI and what that individual requires in a typical day.

Support from disabled people's organizations (DPOs) and other intermediary organizations may be critical in empowering people with disabilities to recruit and manage their own assistants and fulfil the role of employer (86). Consumers generally prefer to train their assistants themselves, or sometimes to have current assistants train their replacements. There may be specific needs for training on issues such as ventilator use, lifting and carrying, and other health needs such as monitoring of skin, blood pressure, respiratory infections and urinary tract infections. Personal assistance training increases the knowledge of both the consumer and the personal assistant (87) and can help reduce the occurrence of secondary conditions, which contribute to morbidity and mortality as well as increasing health care costs (88).

### Family relationships

The impact of support tasks is one of the factors that may make personal relationships more difficult. The discussion above focuses on the provision of tasks to support children and adults. The emotional aspect of family, however, is equally important to people with SCI. Availability of social support – particularly emotional support and problem-solving support – has been shown to be important for the life satisfaction of people with SCI in the early phase of injury (89). Feelings of dignity, pride, confidence, hope and joy in



their social interactions provide people with SCI with a firm foundation for a successful life (37, 90). These positive attitudes have been linked to the magnitude and type of support from family and friends. Family and friends can be very important in aiding recovery and taking on new life roles, although there is a risk of over-assistance (91), particularly for children with SCI. There is also evidence that, whereas social support is important, having companions who are solicitous about pain symptoms actually makes it harder for people with SCI to cope with pain (92).

Several studies have found that adjustment to disability or serious chronic illness results in enhanced spiritual well-being (93, 94). Numerous studies have demonstrated strong associations between spirituality and quality of life among people with SCI (95, 96), and involvement in religion can provide social support (97, 98).

People with SCI should not be seen simply as passive recipients of support, but as active and autonomous agents who consciously shape their relationships and environment by using their psychological “equipment,” – i.e. their social skills, coping skills, strengths and resources. For example, an Iranian study found that self-confidence, religious beliefs, social networks and positive thinking were facilitators of coping (99). People with SCI not only receive but can also provide support, and providing support can be more beneficial than receiving it for the person with SCI (68).

### Partners

SCI can have a negative impact on relationships, and many studies find a higher risk of divorce after the injury (100–105). However, this may be a short-term effect; one study found that more than 80.7% of married people were still married five years after their injury compared to the rate of 88.8% in the general population (106). Another study found no difference in divorce rates between people with SCI and the general population (107). A clue to this divergence

of results comes from research conducted in Taiwan, China, which found that traumatic SCI led either to family resilience or family breakdown (108). There may even be positive influences on relationships arising from more time spent together (109). Yet, results from these studies are difficult to compare, as the time frame after injury for divorces and separations varies, as does the definition of marriage (in some studies people who are cohabiting without being married are sometimes included and sometimes not) (110). Interpreting the varying results of the studies is even more challenging due to culture differences, changes in family life in society in general and the different methodologies used.

Sexuality is an important dimension of partner relationships that is often negatively affected by SCI. For instance, studies in the United Kingdom and the Netherlands found that sexual satisfaction was frequently rated very low by a sample of people with SCI 12–18 months after discharge (111, 112). Studies of partnered men with SCI linked sexual satisfaction to factors such as partner satisfaction and relationship quality more than to biological factors such as erectile function (113, 114), although, for some people, concerns about bowel and bladder incontinence are a deterrent to sexual activity (115). Studies in Greece, India and China have found stigma and other negative beliefs to be the major obstacle to sexuality and marriage for people with SCI (116–118). Dating was rated as one of the most difficult aspects of transition for adults with paediatric-onset SCI (119).

Sexuality may not always be a problem: in a Swedish study, 84% of partners of people with SCI considered their relationship to be satisfying, and 45% considered their current sex life to be as good as or better than before injury. Feelings of emotional closeness, variety of sexual activities and mutual concerns were more important for partners than were physiological aspects (120). A study of 545 Scandinavian women with SCI found that 80% had engaged in sex after injury. Half of the women with SCI were in relationships and 85% felt their relationships were very good or rather good. However, there

were lower levels of activity, desire, arousal and satisfaction in women with SCI than in controls (121).

### Addressing barriers

Support for intimate relationships is very important to promote the well-being of people with SCI. Having a close relationship with a partner has a positive effect on quality of life (103) and well-being (122). Several studies have shown that marital status is a powerful predictor of outcome variables of independent living (100, 107, 123, 124). Good sexual adjustment after SCI is positively associated with better physical function, higher income, more participation in work and community, and higher morale (125).

All members of the rehabilitation team have a role and a responsibility to address issues of sexuality with people with SCI. In the previously mentioned Scandinavian study, 61% of women had received no information about sexuality after SCI. Respondents wanted both information and support, not too soon after the injury, but when the need arose (121). Young people with disabilities should also have access to appropriate sex education (126). Programmes to improve the sexological competence of multidisciplinary teams and individual disciplines in rehabilitation have shown effectiveness (127, 128). People with SCI particularly appreciate sexuality counselling from peers (129). The key period during which sexual health interventions are important is the interval between inpatient rehabilitation and six months after discharge (130). Relationship counselling has been found effective in supporting couples in which one partner has SCI, because it can promote reciprocity and improve communication skills. Useful approaches emphasize the development of new mutually enjoyable activities (131, 132). The attitude of sharing responsibilities rather than providing care has been reported by wives as a reason for successful marriage to men with SCI (124).

For those whose relationships break down after the onset of SCI, there is hopeful evidence regarding new relationships. People in post-

injury marriages have been found to be more satisfied with their living arrangements, relationships and health, and to have had improvements in their sex lives (113, 133). This may be partly because this is a subgroup of people with SCI who are more active, better adjusted and content to start with, and also because marriage further improves their quality of life (133).

### Parent and sibling relationships

SCI in a young person can be traumatic for the whole family. Reviews of evidence find that 12–13% of families of children with spina bifida have clinical levels of “family dysfunction” (134), and these problems are exacerbated when families come from lower socioeconomic backgrounds. One North American study found that 25% of paediatric patients, 41% of mothers and 35.6% of fathers had post-traumatic stress disorder (PTSD) (135). However, other evidence suggests that families often also show resilience, and that coping with spina bifida may even strengthen the parental marriage (134).

Evidence highlights both positive and negative impacts on siblings of children with spina bifida – for instance, anxiety and concern for the health and social well-being of their disabled sibling, but also increased empathy for the disabled sibling and a greater appreciation of their own physical abilities (134). There is some evidence of anxiety and depression in siblings of disabled children, but this is by no means inevitable (136) and depends on how well the family copes with the situation (137). The disabled child should be treated as part of the family in the same way as other children.

Men and women with SCI can have children (138). A Scandinavian study found that 18% of women with SCI had had children post-injury (121). Evidence shows no significant parenting differences between mothers with SCI and non-disabled mothers, nor in outcomes for children raised by mothers with SCI compared to non-disabled mothers (139, 140). Similar evidence is

available for children of fathers with SCI (141). However, there may be a need to redefine parenting roles as a result of disability (142). Children are usually comfortable with a parent's disability, and open discussion is believed to be a key to acceptance (143). There are risks where children are expected to take up caring roles for parents or siblings with SCI, which may not be age-appropriate (144).

### Addressing barriers

Health-care providers should identify those families of children with SCI who are in need of psychosocial support (134). Social networks are very important for people with disabilities (145) and for the families of disabled children. A Swedish study of people who had acquired SCI in their teenage years found that parents and peers were a crucial network. Parents were advocates in interactions with health-care providers, and they were supporters, helping to deal with sorrow, frustration and anger. Peers were important in promoting activities and identity development. Health-care providers should use the patient's own social networks effectively (146). Education of parents can influence perceptions and help them develop realistic goals for their children (16). A Kenyan study on quality of life for people with spina bifida concluded that family, caregiver and community education about the condition would contribute to improving physical, psychological and communicative development outcomes (147).

Transition to adulthood is a major issue for children with spina bifida (134, 148) and has been the subject of considerable work in North America (149) based on a life-course model, which maps out developmental stages and topics that have most impact on a successful adult life (150). Parents may need education to foster independence in their children so that they can move on to participation in post-school education, independent living and employment wherever possible (148). Social groups can be helpful in assisting with leisure and friendship networks. Young people with spina bifida should be

encouraged to be independent (151) and to do household chores, use public transport (where accessible and available) and participate in community activities (152). To help young people with SCI in their transition to adulthood, appropriate sex education is also very important (126).

With regard to nondisabled children, social workers and other supporters should help the siblings of children with spina bifida to navigate the complex emotions associated with having a brother or sister with this condition (153), and should help them develop their own strengths and resources to cope. Rehabilitation centres should consider the needs of children visiting a parent with newly acquired SCI, both to provide appropriate facilities, but also to facilitate the understanding and emotional adjustment of these children (154).

### Adjustment to spinal cord injury

Acquiring SCI can be a challenge to an individual's self-esteem (155). A previously independent person may now not be in control of his or her own life, or even body, and may be dependent on help from others. Those with traumatic SCI may also have concurrent traumatic brain injury that complicates adjustment (156). Many variables have been associated with quality of life after SCI. In addition to motor impairment, experiencing secondary health complications such as incontinence, spasticity and pain is associated with lower life satisfaction (111, 112, 122, 157, 158). Furthermore, moving around in a wheelchair may be difficult in non-adapted environments, and experiencing environmental barriers is associated with lower life satisfaction (90). Adjustment to disability is a dynamic process whereby people with SCI move towards a better fit with their environment (159).

A narrative review of studies of life satisfaction of people with SCI (160) confirmed that people with SCI experience, on average, higher levels of distress and lower levels of life satis-

faction compared with the general population. However, there is considerable variation and most people with SCI adapt well to their condition. For example, in a Dutch study, 75% of participants experienced a decrease in life satisfaction after SCI, but one year after SCI, 50% of participants were satisfied or very satisfied with their lives (112).

A review of evidence on mental health has shown that 20–30% of people with SCI show clinically significant symptoms of depression, which is substantially higher than the general population (160). Some evidence indicates that depressive symptoms reduce as time passes, although this is uncertain. Similarly, most studies show that 7–27% of people with SCI experience post-traumatic stress disorder (160). Yet this evidence proves that, despite a higher-than-average risk of mental health problems, the majority of people with SCI adjust well to their condition.

Longer-term studies find good adjustment and high quality of life among people ageing with SCI (158, 161). A large study in France of tetraplegic people, for instance, found that almost three quarters of respondents rated their subjective well-being as fairly good or better (122).

People with SCI who make successful adjustment, like other people with acquired disability, are those who are successful in adapting mentally to their new situation. This may include devaluing unattainable goals and altering criteria for success (155). It is this mental shift, as much as the material possibilities, which enables people to have satisfaction in life (101). Appraisal theory suggests that the way people feel about themselves depends on their cognitive response to a situation. People use different coping strategies according to their appraisal of the situation and their behavioural preferences. An integrative conceptual framework of adaptation to health problems has been described by (162), highlighting personal resources (e.g. personality, intellect), health-related factors, social and physical context (e.g. family, environment), cognitive appraisal and adaptive tasks (e.g. man-

aging symptoms, positive self-image, relating to others): each of these sets of factors is a potential target for intervention.

A recent review of psychological factors associated with mental health and life satisfaction after SCI, based on 48 studies, shows that the factors consistently associated with life satisfaction or mental health are perceived control in life, sense of coherence, positive factors such as hope and purpose in life, feelings of self-worth such as self-efficacy and self-esteem, positive and negative affect, and post-traumatic cognitions (163).

While the coping strategy of acceptance is a consistent determinant of adjustment, the majority of emotion-focused coping styles are not associated with life satisfaction or mental health. Although active problem-focused coping is generally considered a favourable strategy, this is not consistent in the scientific literature. It may be that where goals are blocked, as is the case with SCI, adjusting personal preferences and goals to situational change is more effective and more positively related to adjustment than trying actively to adjust life circumstances to one's personal preferences (164).

## Addressing barriers

### Rehabilitation

Access to rehabilitation services should result in accessing appropriate assistive technologies and being able to self-manage bowel and bladder, as well as receiving other information and support, all of which represent important steps in adaptation. A small Sri Lankan study provides evidence of improved health and psychological and social outcomes for men with SCI who accessed rehabilitation (165). Since the way people view themselves is predictive of how they adjust to physical disability (166, 167), perceptions of the injured person's body should be reworked during the process of rehabilitation to recapture positive self-esteem. Rehabilitation professionals can have a significant impact on the patient's self-image by, for example, providing information and creating opportunities such as group out-

ings, which have been reported to be beneficial in overcoming fears of being stared at (167).

Evidence on psychological interventions following SCI is growing but is still incomplete. The most frequently studied intervention to reduce depressed mood in people with SCI is cognitive behavioural therapy (CBT), which incorporates a variety of techniques to facilitate emotional and behavioural change on the part of the person with SCI (104, 168). CBT can include addressing “irrational” or negative thoughts, increasing opportunities for participating in rewarding activities, and instruction in relaxation. Issues of assertiveness, social skills and sexuality have also been included. Providing CBT in a group setting can also be a cost-effective opportunity for peer support, for practice of social skills and for gaining additional viewpoints (169, 170).

Coping effectiveness training (CET) may also be effective in people with SCI (171, 172), and especially in those with more severe mental health disorders at baseline. The intervention may work by changing participants’ negative appraisals of the implications of SCI and increasing their perceived manageability of its consequences, thereby improving their mood. Supportive group therapy (SGT), which emphasizes the sharing of experiences and information on topics related to injury, the exploration of emotional and cognitive reactions, and the opportunity for support and education from peers and psychologists, is also effective in reducing depression and anxiety (173).

A group of positive psychological factors, including self-efficacy (belief in ability to succeed in a situation) and self-esteem (a person’s sense of self-worth or personal value), are consistently related to better quality of life. These variables may be seen as psychological resources that help people to regain their quality of life after SCI. For example, people with high self-efficacy and high self-esteem might be more likely to take personal control of their future than people with low self-efficacy, since the former have a stronger belief in their ability to influence their situation for the better. Positive

psychology interventions aimed at cultivating positive feelings, behaviours and thinking have shown effectiveness in other populations (174), and could be tested in people with SCI.

Evidence exists for the effectiveness of multidisciplinary, multimodal interventions targeted at enhancing self-efficacy (175). General and specific self-efficacies – such as for active living – have been found to be enhanced by active/independent living programmes (176, 177) or by physical activity or sports programmes (178–180). Knowledge was enhanced in a multimodal intervention programme (181) and was significantly correlated with perceived control after one-year follow-up.

While health professionals often recognize the importance of hope, they appear to find it problematic to balance patients’ “unrealistic” hopes with what they perceive as more “realistic” ones (182). However, from an attitudinal perspective in the initial period post-SCI, “hope for recovery” may be an effective coping mechanism in the face of an otherwise intolerable health crisis (182, 183). It may therefore be beneficial to keep the person’s hope alive as long as hope for recovery from SCI does not stand in the way of active participation in the rehabilitation programme.

Screening for mental health problems in the early phase of SCI will identify those in need of psychological support. Psychological treatment for depressed people with SCI in initial hospitalization needs to be available as part of the functions of the multidisciplinary rehabilitation team. There are strong indications that psychological interventions at this stage are helpful and may prevent long-term adjustment problems (160).

### Self-help groups

People with SCI usually value group learning situations in which they can meet other people who are similarly affected and thus feel less isolated (184, 185), e.g. self-help groups and other forms of peer support. Organizations such as the Back-Up Trust in the United Kingdom and the Spinal Injury Trust in New Zealand offer training,

support and confidence-building activities such as abseiling and kayaking (see Box 6.2). In a study in France, participation in community activity and meeting friends frequently were positively associated with well-being for people with tetraplegia (122), although the direction of causality was not proven. In low- and middle-income countries, NGOs can play an important

role in supporting the capacity development of social networks, regional networking platforms and consumer organizations such as those supported by Livability Ireland in South and South-East Asia (190). The United Kingdom NGO called Motivation runs peer group training and training-of-trainers courses in Malawi, Mozambique, Romania and other low- and middle-income

### Box 6.2. Spinal cord injury consumer organizations and networks

Consumer and advocacy organizations for and of people with SCI can be sources of invaluable peer support and advocacy. SCI consumer organizations and networks can be found in various parts of the world at national, regional and global levels, united in their efforts both politically and practically to improve living conditions and enhance participation of people with SCI.

These groups may focus on single topics, such as sports activities (often with a view to recruiting elite sportsmen and women who could compete internationally), or specific demographic groups (e.g. veterans, children). They may cater to the needs of people with SCI in all major areas of life from education and employment to home modifications and peer support. SCI organizations may operate as stand-alone organizations or may be part of larger organizations or networks. In many low- and middle-income countries, such specific SCI organizations may not exist and the interests of people with SCI are promoted as part of cross-impairment disability organizations. However, SCI organizations have been established in some low-income countries, including Nepal and Uganda.

In some countries, local small initiatives of former patients have evolved as a result of personal need for assistance and proper accommodation, and they have combined to create national network organizations, such as Spinal Cord Injuries Australia (SCIA), which provide accommodation and care services, employment and social service counselling. SCIA also hosts an advocacy department that works to promote inclusiveness and lobbies for specific programmes or legislative change by, for instance, submissions to government committees (e.g. on supply of health services and medical professionals in rural areas) or by providing input to policy review processes (e.g. review of the tables for the assessment of work-related impairment for disability support pension) (186). SCIA has in the past supported individual claims, as in the case of a taxi discrimination complaint (187).

Regional networks can be a means of sharing experiences and success factors in implementing change and can provide support to initiatives seeking to establish national organizations. The European Spinal Cord Injury Federation (ESCIF) was founded in 2006 and represents 26 national SCI organizations throughout Europe. Its role is to share information, hold annual conferences and conduct its own research on topics such as SCI registries or the provision of specialized SCI care and rehabilitation (188).

Building on these successful experiences at national and regional level, the Global Spinal Cord Injury Consumer Network (189) was started by ESCIF and the Asian Spinal Cord Network's (ASCoN) consumer network in 2012, with the aim of bringing together existing SCI consumer groups, establishing new groups in underserved countries and regions, and expanding their activities. The main activities and plans of the Global SCI Consumer Network are to:

- formalize community channels (e.g. web site, news updates);
- link organizations and key people to support and promote local initiatives;
- generate funding and other support for the activities of the global network;
- appoint SCI "ambassadors" throughout the world;
- organize a corps of SCI volunteers to assist SCI groups in other countries/world regions;
- organize global SCI consumer network meetings;
- in the long run, formalize the network as a global federation or organization.

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countries, with the aim of creating a network of skilled peer counsellors and trainers who can help recently paralysed people adjust to their new situation (191).

The disabled people's movement has helped many people with disabilities to develop their friendship networks and even to meet partners (192, 193). SCI consumer organizations and networks play an important role beyond providing valuable guidance and services in the form of advocacy, sports, employment and accommodation support (see Box 6.3). However, evidence from a study of French people with tetraplegia found that, while 56% of respondents felt that disabled people constituted a community, only

a third of them felt that they belonged to the community (194). Women in particular were less likely to be involved. It was those who were more socially excluded and who often experienced worse symptoms who expressed a sense of belonging to disability networks (194).

### Physical activity and sport

Regular physical activity can have substantial social benefits, providing a means of establishing new friendships, sharing experiences, developing social support networks, and improving overall functioning (195, 196). Participation in sports has been reported to re-establish contact with the world at large by aiding community

### Box 6.3. Peer support in Sri Lanka

The Spinal Injuries Association (SIA) of Sri Lanka was started by individuals with SCI and has implemented many useful programmes in addition to peer group training. On a monthly basis, members of SIA visit the general hospital and meet with people who have recently incurred SCI. They serve as role models and help newly injured individuals to overcome the initial shock of their trauma, giving them information and demonstrating that it is possible to live a useful life even with SCI. Anecdotal reports indicate that this peer counselling has helped many individuals who had given up hope, thinking that their life ended after paralysis due to SCI. As noted in the following testimony, this programme appears to be successful and may serve as a model for others wishing to adopt and further develop peer counselling programmes.

"I had a motor traffic accident in September 1980 and sustained a SCI at the T4 level. After treatment for wounds in a general hospital for three months I was transferred to the only hospital available at that time for rehabilitation of people with SCI, the Ragama Rehabilitation Hospital. I was shown by another patient in the hospital how to make an improvised condom catheter which I started using after giving up the indwelling catheter that had been provided previously. For bowel movements you just sat on the commode and hoped for the best. I had small wounds on the buttock which were a nuisance.

My life changed in 1998. Motivation United Kingdom set up an office in Sri Lanka to train the nurses in the rehabilitation hospital how to manage patients with SCI and to set up a wheelchair manufacturing workshop. They also conducted a training programme for peer group trainers, which I attended. The five-day training programme included lessons on what SCI is, the prevention of pressure sores, the importance of using a good wheelchair cushion, bowel control, bladder management, skin care, sexuality, wheelchair skills, wheelchair maintenance and other topics.

Here I learned digital stimulation and manual evacuation of stools to manage the bowel. Earlier I had a lot of anxiety when travelling due to uncertainty regarding my bowel movements. After the training I changed the wheelchair cushion I had been using and this prevented pressure sores. The fact that the training was given by another person with SCI had a big impact. Following the training, my activities of daily living became so much easier. I felt at ease and confident when travelling both locally and overseas. Later the Spinal Injuries Association of Sri Lanka (SIA) continued with peer group training and it was satisfying to see the improvement in the quality of life of people with SCI who underwent training."

Cyril, Sri Lanka

integration and improving family relationships (197–199). A meta-analysis found a small- to medium-sized positive association between physical activity and subjective well-being (200). A review of literature has revealed psychological as well as physiological benefits of participation in recreation and physical activity (201), such as increased social interaction. Research in the USA shows that people with SCI involved in sports score higher in physical independence, mobility, occupation and social integration than non-athletes (197), with psychological benefits particularly evident for those engaged in team sports (202). A German study found that individuals who were actively involved in sport had a higher employment rate and better quality of life (203). People other than therapists tend to be the source of the motivation to become involved in sports (204). Specialized equipment allows people with SCI to practice a wide range of sports (205–207). In recent years low-cost wheelchairs for basketball and tennis have become available for developing countries (208).

## Conclusion and recommendations

People with disabilities commonly rate their own quality of life higher than nondisabled people rate the quality of life of disabled people (20, 147). Feelings of dignity, pride, confidence, hope and joy in social interactions provide a person with SCI with a firm foundation for a successful life (37, 90). These positive attitudes have been linked to the magnitude and type of support from family and friends.

Interventions to challenge negative attitudes towards people with SCI and other disabilities should be a priority, as mandated by Article 8 of the CRPD. In particular, health professionals and other service providers should receive training to ensure that they treat people with SCI and other disabilities with respect and dignity.

Provision of appropriate services, both during rehabilitation and for subsequent community living, can facilitate adjustment and improved quality of life for people with SCI. Adequate information and psychological support are particularly important. While needs for assistance are generally met by relatives, provision of home care, respite care and personal assistance can liberate individuals with SCI and their family members. Participation in sporting, cultural and spiritual activities can increase self-confidence and improve well-being.

The following recommendations show specific ways forward.

### Provide support

Support children and adults with SCI to achieve positive self-esteem and adjustment by, for instance:

- providing access to counselling and information in rehabilitation settings and in the wider community, including sexuality information;
- supporting development of peer networks and self-help organizations;
- helping people access sporting, religious, cultural, political and leisure opportunities, as well as education and employment.

Support family members and caregivers of people with disabilities by providing:

- counselling, information and advice for family members and caregivers;
- opportunities to meet other people in similar situations by, for example, supporting the development of self-help groups;
- marriage guidance, counselling and other interventions for couples affected by disability, including information and advice about intimate relationships;
- emotional and social support for siblings of children with spina bifida and SCI, including services at the transition to adulthood;



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- respite care and other support for families of children with spina bifida and SCI where necessary and appropriate.

### Develop assistance services

Where possible, support the development of personal assistance services by:

- developing community care contracting and assessment procedures in support of consumer-directed care schemes;
- developing legal and financial frameworks to enable direct payments for personal assistance;
- empowering people with SCI and other disabilities to use personal assistance by, for instance, fostering infrastructure organizations that can support personal assistance users.

### Change attitudes

Help to ensure that professionals, other key service providers and members of the general public develop positive attitudes to disability by:

- ensuring that human rights issues related to disability are included in undergraduate curricula for teachers, doctors and professions allied to medicine;
- providing disability equality training to staff with customer care responsibilities, such as in transport, social and housing services;
- supporting public awareness, information and education initiatives that challenge negative attitudes to disability through, for example, schools and the media.

### Foster research

Increase the evidence base for interventions by fostering research on topics such as:

- effective interventions to challenge negative attitudes to disability;
- cost-effectiveness and consumer satisfaction of consumer-directed care schemes;
- effectiveness of psychological interventions to support adjustment to SCI;
- the role of interventions such as sports, social media and self-help groups in supporting people with SCI to develop positive self-esteem and to form relationships.

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## Chapter 7

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# Spinal cord injury and enabling environments

“After some months in hospital and some rehabilitation, I was confronted by many challenges when I returned to my community. First, I could not get to my place of work, which was on the third floor of a five-story building. I couldn’t use stairs anymore and there were no elevators. Second, I could not access many services because of the way buildings were structured in my community. I had to travel long distances in search of accessible places to get services. I had lost my car when I was shot, and so I had to rely on public transportation, and the many operators were not willing to accommodate a person in a wheelchair. A lot needs to be done by the government to enforce laws in these areas.”

(Robert, Uganda)

“Accessibility to the hospitals was another problem. While all the big hospitals were wheelchair accessible, clinics like those of a dentist, ophthalmologist, etc. were not. Some were even on the second or third floors of buildings that did not have elevators. In these instances, I often had to be carried in my wheelchair up the stairs, which was a difficult and dangerous adventure. But I had to do it many times. The toilets in many hospitals were not wheelchair friendly. I guess the attitude towards the lack of accessible toilets was: ‘There aren’t many Spinal Cord Injury (SCI) patients, so why waste space?’”

(Alexis, India)

“When I go out to do something in my electric wheelchair, I could take a taxi, the public transportation system, or a high-speed train. However, these options are expensive, even with the discount disabled persons receive. There are only a few public buses with lifts in them, and they must be ordered a week in advance. So if there is an emergency, one cannot depend on being able to use a public bus for transportation. In addition, only a few lines have bus stops without steps. Because of this, I usually use a taxi to commute and the fare is very expensive.”

(Co-Han Yee, Taiwan, China)

“It is very difficult for me to leave my house. Sidewalks are very uneven and in bad condition. I always depend on other people to move around. Public transport in the part of the city where I live is in bad condition and it is very difficult for me to take it even with help. I cannot be independent. How can I participate in a society like this? I feel frustrated. I take cocaine and marijuana. I play guitar.”

(Diego, Argentina)

“I rebuilt my house after the earthquake since the original house was totally damaged. But my family and I had no idea how to make the environment convenient for my movement. The NGO adapted my washroom and kitchen to make it easier for me to move around. I couldn’t even go into the washroom before the adaptation but now I can take a bath by myself. I can cook meals sitting in the wheelchair. Everything is convenient and I encounter no major problems when I am in my house.”

(Chen, China)

# 7

## Spinal cord injury and enabling environments

Physical environments may facilitate the participation of people with spinal cord injury (SCI) or may act as barriers to participation. Accessibility is one of the cross-cutting general principles listed in Article 3 of the *Convention on the Rights of Persons with Disabilities* (CRPD) while Article 9 specifically highlights the importance of accessibility, including buildings and transportation (1). Accessibility underwrites the right to live independently in the community (Article 19) and to participate fully in all areas of life; failure to ensure accessibility can constitute discrimination. This chapter focuses on the housing, transportation and public accommodations necessary to achieve these outcomes.

The physical environment and transportation are among the key environmental barriers for people with SCI (2–6). Evidence for the impact of these factors on participation is still sparse (7). Accessibility measures need to respond to the range of needs of people with SCI: making a home wheelchair accessible is vital but, if accessibility ends at the front door and the individual cannot move around the community, use transportation and participate in education, employment or other social activities, then the environment still remains a barrier. Accessibility strategies are constrained by cost and human resources, but incremental improvement is always feasible (8). For countries that have ratified the CRPD, evidence of progress towards full accessibility is required by the concept of “progressive realization.” Ensuring accessibility for people with SCI makes the world easier to navigate for everyone else too.

### Barriers for people with spinal cord injury

Community reintegration will depend on the extent to which a person with SCI can overcome environmental barriers. In this section, environmental barriers are explored progressively, beginning with *housing* – to which a person who recently developed SCI will have to return after rehabilitation – then continuing with *transport*, which will be vital to participating in the community, and finishing with *public buildings* – such as schools and workplaces – where access is needed to fulfil rights to education and employment.

## Housing

Home is the most important environment in life (9–11). For adults with SCI, leaving the rehabilitation hospital may be difficult if their accommodation has barriers such as stairs, small bathrooms and inaccessible kitchens (12–14), which in effect make them “prisoners in their own homes” (15). The result may be what is often called “bed-blocking,” when patients fit enough to go home are forced to stay in the hospital due to insufficiently accessible housing (16, 17).

The unmet need for accessible housing is a global problem for people with disabilities, particularly those with mobility impairments such as SCI, although only limited data are available. Evidence from surveys in southern Africa shows that disabled people generally live in housing that is inferior to that of nondisabled people (18). Studies in different regions of the world suggest that, across most low-income countries, people with mobility and other restrictions have limited independent housing, although it should be noted that living together with families is more common for everyone in these settings (19, 20). Even in countries where there are high levels of home ownership, financial support for home adaptation may be inadequate (21). In the United Kingdom, for instance, research has shown that provision for people with disabilities is insufficient in terms of accessible housing and funding for adaptation costs (22–24). Some 78 000 wheelchair users in the United Kingdom are estimated to have unmet housing needs (25).

If a person with SCI cannot afford his or her own home, and living with relatives is not an option, social housing may be an alternative (26, 27). In Europe, provision ranges from less than 2% of total housing stock (Estonia, Greece, Spain) to 35% (Netherlands) (28). The demand for social housing is generally far greater than the supply (26). Even when social housing is available, it is rarely sufficiently accessible. This shortfall remains even when social housing operates a quota for people with disabilities, as in coun-

tries such as El Salvador, India and Thailand (19, 20). Ironically, accessible social housing is often occupied by nondisabled people: in England only 22% of wheelchair standard homes were let to households containing wheelchair users (25).

## Transportation

Access to transport is required to participate in education, employment and social activities outside the home. Public transport is often inaccessible to people with SCI (6, 29). Ramps, lifts and safety lock-down systems may be absent, poorly maintained or unsafe (30), and transport personnel may not be trained in the accessibility features (31). In fixed-route buses and rail systems, the desired destination may not be close to the bus or train stops (30). Public transport systems that operate on demand, such as wheelchair-accessible taxis, may require appointments to be made several days in advance, thus reducing flexibility (30). A private car can be an alternative if sufficient resources (financial and technical) exist, as the costs of modified driving controls or vehicle adaptations can be prohibitive. Airports and airlines should have provisions enabling people with SCI to fly. However, toilets on aircraft are often inaccessible and, in some cases, regulations prevent individuals who cannot move about independently from travelling by themselves (32).

Underlying these practical problems are systemic failures. For example, a break in the “travel chain” (i.e. when part of the journey is not accessible) can mean that wheelchair users cannot reach their destination (33). Even where laws explicitly require mobility accessibility for public transportation, they may not be effective, especially in developing countries, because there are insufficient resources for enforcement (34). If regulations require taxi companies when purchasing new vans to ensure that they are accessible for disabled people, a company may avoid this by buying only used vans (35). Since accessible taxis and accessible minibuses on para-

transit/special transport services are expensive to purchase, it may be a challenge to make the service cost-effective and sustainable (35–37).

## Public buildings

The inaccessibility of public buildings can hinder participation for people with SCI (38, 39). Studies show that the five major areas in which accessibility is essential for participation of wheelchair users are parking, routes to public buildings, ramps, entrances and restrooms/toilets (40, 41). For instance, a survey in South Africa found that less than 10% of hospitals had a fully accessible toilet for people with disabilities (42). Doors are often too heavy for people with SCI to open easily, handrails – essential for people with SCI who can walk with crutches – may be missing, and uneven sidewalks or cobbles, narrow pathways, and steep terrain and lack of curb cuts all limit accessibility to public accommodation for people in wheelchairs (43–45). Unsafe road crossings and pavements/sidewalks contribute to the high rate of injuries caused to wheelchair users by cars (46–48).

Progress in addressing issues of accessibility is often uneven. In some cities in the USA, compliance rates for buildings constructed after 1980 were very high – 97% in one city (49). Elsewhere, however, as in Turkey, United Arab Emirates and Zimbabwe, the rates are less than half that, and progress towards accessibility is reported to be very slow (50–52). Sometimes the situation is dire: in Ibadan, Nigeria, less than 18% of public buildings were found to be wheelchair accessible (53), while in Bangkok, Thailand, a survey found that almost no public or commercial building was fully accessible to wheelchair users (54).

As with transport, it is not enough to have laws, policies and standards if they are not enforced. In a recent survey of 36 countries in Asia and the Pacific, 25 had regulations about accessibility to public buildings and transport, yet none of these laws and standards were mandatory or were supported by enforcement

mechanisms (55). A United Nations survey of 114 countries found that, while nearly half had policies on accessibility to public buildings, most lacked public educational programmes to explain accessibility and many had not allocated financial resources to implement the policies or had no official agency to enforce or monitor these policies (1). Across domains, factors standing in the way of accessibility include:

- the absence of regulatory frameworks and accessibility standards;
- the lack of enforcement mechanisms;
- the lack of financial resources or public procurement policies focusing on accessibility;
- institutional limitations (such as lack of interagency and public–private cooperation, or inadequate planning capacity);
- a general lack of awareness of the need and benefits of accessibility at all levels;
- the absence of user participation in the development and implementation of policy.

## Addressing the barriers

Almost all the barriers that people with SCI confront daily in the physical environment, transportation and other facilities and services open or provided to the public, both in urban and rural areas, can be addressed. Moreover, innovative and economically feasible good practices are available for doing so.

## Cross-cutting measures

The following measures are relevant across the environmental domains of housing, transport and public buildings.

**Adoption of universal design** has the potential not only to ensure access for people with disabilities but also to benefit older people, parents and others who have difficulties with mobility in buildings, transportation and around the community (14, 33).

***Development of accessibility standards can ensure access for people who use wheelchairs, including people with SCI.*** The CRPD requires States Parties to develop, promulgate and monitor the implementation of minimum standards for public accommodation (1). For wheelchair users these should include access to buildings – curb cuts, safe street crossings, and accessible entries – as well as accessibility within buildings, particularly toilets. Although removing the major obstacles makes an important difference to people in wheelchairs, full accessibility should always remain the goal. Detailed standards are readily available nationally and internationally (e.g. (41, 56)). This increasingly includes low- and middle-income settings. In Uganda, for example, the National Union of the Disabled Persons of Uganda together with the Ministry of Gender, Labour and Social Development produced access standards (57). Standards may need to be revised to respond to changes in technology and needs (e.g. wheelchair design, increasing prevalence of obesity).

***Enforcement of accessibility standards.*** In the USA, voluntary standards were created by law in 1961, but soon proved to be ineffective and were replaced with mandatory standards in 1968 (58), which were reinforced a decade later by a procedure in which individuals could bring complaints against public buildings that were inaccessible. This approach was further strengthened by the provisions of the *Americans with Disabilities Act 1990*. Municipalities and businesses now incorporate accessibility into their plans for new construction to avoid the prospect of complaints. Enforcement requires a responsible agency or other focal point to monitor compliance with standards.

***Involvement of people with SCI, along with other disability groups, in prioritizing investments to promote access and in monitoring access outcomes.*** People with disabilities should be involved in standards development, in auditing access, researching compliance (e.g. (59)), monitoring access and campaigning for improvements

(60). The *Council of Canadians with Disabilities*, for instance, has for nearly 30 years worked with cities and provinces in monitoring the implementation of accessibility standards and advising on issues such as space requirements for wheelchair use in buildings (61). In Latin America, disabled people's organizations such as Mexico's *Libre Acceso* and Brazil's Center for Independent Living have actively campaigned for accessibility in transportation, participated in the development and promulgation of access guidelines, and have promoted their use (62). In Japan and the USA people with disabilities have played a key role in monitoring the implementation of accessibility through audits and through contribution to consultations (63).

***Training for stakeholders on accessibility issues facing people with disabilities.*** Awareness of and knowledge about accessibility in the public sphere is vital. Disability awareness training or disability equality training helps change attitudes and improves respect for people with disabilities who use facilities. Basic technical information about accessibility needs and solutions is useful for those who develop and enforce policy. University and in-service training courses for architects, engineers and planners should include exposure to the principles and practices of universal design and accessibility as standard course elements (60). For example, since the passage in 2008 of Malaysia's *People with Disabilities Act*, Malaysian universities have been encouraged to introduce "barrier-free architecture" courses to encourage research, to disseminate accessibility solutions and to increase public awareness. In Colombia, the National University prepared a manual on accessibility to the built environment and the means of transportation (19).

***Private entities that offer facilities and services that are open or provided to the public must take into account all aspects of accessibility for people with disabilities.*** Commercial industries involved in home construction and furnishings should be encouraged to implement the principles of universal design in their

own design and development processes, and to share this information with policy developers at national level (64, 65).

**Further research on what works in improving accessibility is required.** Despite expertise in universal design, there are still gaps in knowledge about what works to increase accessibility in all contexts, from homes to communities. We know little about how exactly the physical environment limits, and how it can be altered to facilitate, the participation of people with disabilities (6, 7, 66–69). Although there have been some significant advances, among the most urgent research priorities is a reliable and valid instrument for assessing the extent to which the built environment constitutes a barrier for people with mobility limitations (3, 68, 70–74). Assessment and measurement of the extent of inaccessibility (69) is the first step to a more evidence-based approach to developing standards. Evidence is also needed to show the economic and social benefits of making environments accessible.

## Housing

The solutions to housing barriers need to include modifications to existing housing (including social housing) and accessible new housing construction.

**Appropriate home modifications for people with SCI have wide-ranging social benefits.** Home adaptations enable people with SCI to leave hospitals and other high-cost care settings. In addition they can also help reduce strain on caregivers, prevent accidents, improve overall health and functioning, and reduce social exclusion (14, 75–78). Modifications to the home environment to facilitate functioning can vary widely and may change over time. Basic features may include ramps, low-friction floor surfaces and lowered working surfaces. More expensive modifications can include stair lifts or elevators, and an intercom or other control system (77). Assessments of interactions between person and environment over time may be needed to maximize functioning in the home (79). It is always

sensible to fit with cultural norms of desirable housing and avoid “institutional-style” design solutions (24).

**Modifications to existing accommodation can be cost effective.** A study in Sweden of people with SCI found that up to 30% of moves to nursing homes could have been avoided if housing had been made accessible (80), a result that has been reproduced in England (81). Providing owner occupiers, landlords and tenants with “disabled facilities grants” to finance home modifications across the United Kingdom has been shown to be cost-effective when compared with the costs of moving individuals to other living arrangements (82). In Canada, the Residential Rehabilitation Assistance Program for Persons with Disabilities, administered by the Canada Mortgage and Housing Corporation, offers financial assistance to allow homeowners and landlords to pay for access improvement to their properties (83).

**Information is needed to promote accessible housing.** In the USA, the State University of Colorado has produced detailed technical pamphlets and a web site that can be used by builders to learn about space needs and other details for wheelchair home retrofitting (84). Resources available from Community-based Rehabilitation (CBR) programmes in India, using guidelines for care and community integration after SCI produced by the Government of India and the WHO *Community-based rehabilitation: CBR guidelines* (85), provide basic information on low-cost modifications in the home and simple tips for improving access in low-income settings.

**Collaboration between government, disability organizations, and the private sector (for profit and not-for-profit) can help make housing accessible.** Since 1997, the National Cooperative Housing Union in Kenya has linked the government, disability groups and the private sector to identify available land and provided technical assistance and loan capital to facilitate accessible housing construction (86). Rebuilding in Sri Lanka after the 2004 Indian Ocean earthquake and tsunami is another example that illustrates



### **Box 7.1. Sri Lanka: recovery after the 2004 Indian Ocean earthquake and tsunami**

The Indian Ocean tsunami of 2004 cost tens of thousands of lives in Sri Lanka and destroyed countless buildings. However, the reconstruction provided an opportunity to develop more inclusive environments. Disabled and elderly people in rural areas of Sri Lanka often find it difficult to move around in their own homes, let alone in their neighbourhoods. People with mobility difficulties often rely on others to assist them, which affects the independence of other family members including their ability to undertake full-time employment. No reliable statistics on disability exist for Sri Lanka, but decades of civil war have increased the number of people experiencing disability.

After the tsunami, a local disability organization, in partnership with an international organization, undertook to rebuild one destroyed village as a model inclusive village, recruiting an architect and an occupational therapist to advise on accessibility. No national standards or guidelines on accessibility were available. European guidelines were used, which proved problematic due to their urban and “European” bias.

With limited financial resources, 55 simple but adaptable homes and an accessible community centre were completed according to specifications set out by the government. Ramped access or stepped access with railings was provided as needed. Inside, all homes had level access, doorways at a specified minimum width, and minimum turning-circle space in all rooms. A combined level-access toilet and washing area was added at the side of each house. Where required, handrails and an over-toilet commode, which doubled as a shower chair, were provided. Switches, handles and taps were all located within specified ranges of reach.

Before the construction, the elderly and disabled villagers and their caregivers were reluctant to accept the new style of housing, especially the attached toilet, but afterwards they were relieved to have better facilities. People without mobility restrictions often converted the attached bathroom into another bedroom and constructed an alternative washing area outside. The community centre, with ramped access and accessible toilets, enabled people with disabilities, less mobile older people and caregivers who might not normally be involved in social activities to participate in community events.

Important lessons were learned, namely:

- Inclusive design must take careful account of cultural and economic circumstances.
- The use of guidelines developed for high-income countries may not be appropriate in low-income countries, particularly in rural areas. Better solutions can be found that fit local conditions.
- Close supervision was needed at the construction stage, as the builders were unfamiliar with the main elements of the design.

how housing can be made accessible for people on low incomes when different sectors collaborate (see [Box 7.1](#)).

***Making new housing accessible is much cheaper than retrofitting existing homes and provides the widest choice.*** To increase the stock of accessible homes, an integrated and coordinated public- and private-sector effort is required that combines regulation and funding, the development of a market for accessible homes, incentives, interagency coordination, information and protection from discrimination (87, 88). Policy can help make a proportion of new housing accessible (10, 89). In the United

Kingdom, a response to population ageing – “Lifetime Homes” – has produced dwellings meeting a wide range of mobility requirements at minimal additional costs (90). Another important aspect of housing accessibility, called “visitability,” involves enabling people in wheelchairs to access the homes of relatives or friends who may or may not themselves have mobility limitations. “Visitability” mandates features such as at least one no-step entrance, wide doorways and ground-floor bathrooms (91, 92).

***A range of financial mechanisms can be used to increase accessible housing.*** These include tax incentives and low-interest loans to

private builders of housing projects to encourage them to build accessible homes – as required by the USA’s *Fair Housing Act 1988* and similar legislation. Also in the USA, the Housing Act of 1959 provides capital grants to not-for-profit organizations to cover the costs of building, rehabilitating or buying property. The state-run Norwegian Housing Bank, under its Lifecycle Housing programme, similarly offers low-cost loans to builders to encourage them to build accessible homes. Greater market acceptance of Lifecycle Housing has been achieved by linking accessibility with quality design and encouraging partnerships between architects, disability groups and builders (80, 89). By May 2004, the programme in Oslo had produced 260 873 housing units, 85% of which were occupied by elderly people and 15% by nonelderly people with disabilities (93). When it was later discovered that community groups interested in contracting builders for accessible housing lacked access to sufficient capital, the Disability Opportunity Fund was created in the USA in 2007 to supplement the incentives in legislation (88).

***Other mechanisms – such as explicitly labelling homes “accessible” or providing design awards – may encourage construction of accessible housing.*** Labelling homes “accessible” may assist in combating the stigma associated with living in a “special” home and may stimulate consumer demand. In a community-led housing project in British Columbia, Canada, for example, the concept of “flex housing” was used to design, and increase demand for, wheelchair-accessible homes in the Seabird Island community (94). Flex housing designs allow residents to easily change the connections between rooms and the size of rooms to increase accessibilities. National awards to designers and architects, and community service awards for accessible housing projects have been used in Australia and the United Kingdom to encourage the building of accessible housing (89).

***Improving accessible social housing is important for people with SCI who have limited financial means.*** The complex funding and coor-

dination requirements for providing high-quality social or subsidized housing create challenges, even in the wealthiest of countries (26, 27). Many innovative approaches to making social housing accessible have developed in countries across Europe over the past 20 years (95–97), often driven by population ageing (81). These include:

- In Denmark, a cooperative housing company has built blocks of apartments linked by common areas for people with mobility difficulties. The Government of Denmark funded the construction costs, while private finance paid for the extra disabled facilities and the local authority pays the care costs. “Special-needs housing” (for people with disabilities, older people and large families) makes up 50% of new social housing in Denmark (98).
- In Sweden, a housing scheme in Stockholm was built on former industrial land provided by a private firm that worked with city planners to design and build accessible cooperative housing developments with a community centre, a kindergarten, a youth centre and health clinic (96).
- In the Netherlands, since 1997 all new homes in the private and social housing sectors have been required to be designed according to adaptable homes standards laid down in the national building code, which covers such issues as thresholds, space requirements for wheelchairs, door widths, and heights of electric sockets and working surfaces.

***The gap between consumer demand and government supply can be reduced by providing information.*** In the United Kingdom, the London Accessible Housing Register is designed to encourage owners of social housing to make accessibility adaptations (91). The register not only acts as an information conduit to people who need accessible housing, but also sets criteria of accessibility by categorizing available social housing according to detailed standards of wheelchair accessibility that cover the entire

home (99). Accessible housing registries have also been developed by local government and disabled people's organizations in parts of Canada and Australia (100). Similar approaches have been successfully developed in Rwanda as part of an extensive programme to provide accessible housing for ex-combatants and civilians disabled as a result of the 1994 genocide (101).

It is important that housing solutions do not segregate people with disabilities. Thus universal design and the inclusion of accessible housing within mixed residential settings are the preferred solutions.

### Transportation

Usable public transportation is one of the most important facilitators for people with disabilities (102). Transportation policy should be a component of a national disability strategy, while access should be part of any national transport strategy. Transport accessibility is best addressed with a comprehensive policy that can be monitored by a responsible agency with the participation of people with disabilities. It is more effective and less costly to build accessibility into transportation from the beginning rather than to retrofit (8). The challenges are not merely structural and financial; they are also often psychological – such as fear for one's safety (34, 36, 62, 103).

Strategies that can be used to promote accessibility across a range of transport options are outlined below.

#### Fixed-route bus, tram, subway and rail systems

The renovation of an existing public system presents technical and financial problems (104), such as ensuring space requirements for wheelchairs, overcoming the height difference between street and vehicle levels, and limiting the gap between vehicle and platform (105, 106). “Kneeling buses,” automatic lifts, elevators and ramps can transform accessibility. Subways in major cities of the world are becoming increas-

ingly accessible (107), and rapid transit systems in cities such as Calgary, Canada; Beijing, China; and Dar es Salaam, United Republic of Tanzania, have implemented universal design principles (104, 108–110). The goal should be to implement solutions that address the widest spectrum of mobility difficulties, rather than relying on ad hoc remedies such as folding ramps or portable lifts that depend on staff availability (111).

#### Special transport services

The need for transport that is seamlessly accessible for wheelchair users (33, 112) has led to a move to demand-responsive approaches, such as paratransit services found in both high-income and low-income settings (113, 114). However, such special transport services (STS) can be perceived as “special treatment” for a few, or as too costly and unsafe (35, 36). To address these perceptions, the Swedish “Brukslinjen” project started in 2001 to bring rural and urban municipalities together to fully integrate the existing public transport system – including school buses and other regular route traffic – with the flexible route STS. The Brukslinjen project has been extended throughout the country (35, 37). Sweden relies extensively on taxis for STS (35). A more technological solution was implemented with RegioTaxi KAN in the Netherlands and the FLIPPER initiative in Bologna, Italy. Both of these use a telemetric-based demand-responsive system in which travel dispatch centres use computer booking and automatic vehicle location systems. This information is then run through route-optimizing software that integrates the paratransit system with the public system, private taxis, and other services. Using a single voucher, an individual can order a route and then be directed to a series of interlocking transport options (115).

#### Taxis, minibuses, cycle rickshaws

Some large cities favour accessible private taxis. The taxi fleet in London, United Kingdom, for example, is 75% accessible (approximately

24 000 vehicles) (35). Although in low-income settings the cost of accessible taxis, as well as the infrastructure for a coordinated network, may be out of reach, lower-cost options such as rickshaws, minibuses and pedicabs can be cheaply adapted for people with disabilities (62). In some contexts, and for people with SCI who are able to transfer out of their chair, these forms of transport may be a good option. The minibus-taxis in South Africa, the *chapa 100s* in Mozambique, and the *micros* in Mexico all provide good curb-to-curb mobility because of their smaller size and ubiquitous presence (62).

### Public–private collaboration

Many transportation solutions rely on public–private collaboration. When the public sector faces cutbacks and formal public transportation degenerates, the gap is often filled by private taxis, minibuses or other vehicular services that compete for a market share. A case study of transportation in Georgia, Ghana and Kazakhstan indicated that once private services enter the transportation market they tend to displace the public system and, once entrenched, resist regulation or adherence to accessibility requirements (116). Increased consumer mobilization in collaboration with government has been successful in increasing accessible transportation in the Integrated Rapid Transit systems in Cape Town and Johannesburg, South Africa (111), as well as in the Dar es Salaam Rapid Transit Project in the United Republic of Tanzania, which fully integrates the public transport networks with private paratransit operators (113). As early as the 1970s, Brazil was a leader in the implementation of high-flow bus priority schemes, but economic constraints made it harder for cities to finance public infrastructure. Instead of downgrading accessible services, however, and stimulated by protests from groups representing elderly and disabled people, cities in Brazil have opted for public–private partnerships for bus rapid transit with full accessibility (117).

### Education

The success of any of these strategies depends on the cooperation of knowledgeable and well-informed transportation personnel. Safety lockdown systems in buses are of little use if the bus operator has not been trained to use them. Taxi drivers may have accessible vehicles, but may still avoid people in wheelchairs because of the perceived inconvenience. Even managers and policy-makers may not understand the importance of accessibility or the need for well-researched guidelines about low-cost access solutions (108).

### Private transportation

For many people in high-income countries, privately owned and adapted vehicles promote independent living, community participation and higher life satisfaction (118–120). Article 20 of the CRPD on personal mobility mandates access to mobility aids and devices to promote independence, and requires training and specialist staff. For those who can transfer into a car, and have a wheelchair that can be stowed, the cost of modified driving controls for a vehicle with automatic transmission may be relatively modest. In countries such as China, Malaysia, Thailand and Viet Nam, adapted motorcycles are a lower-cost popular solution for some people with paraplegia (121).

For those who cannot transfer to a vehicle, wheelchair-accessible vehicles are a more costly solution, particularly for tetraplegic people (122), who may also require a friend or assistant to drive (30). Nevertheless, important innovations are being made in assistive technology policies in some countries that offer possible solutions such as subsidies and grants (123–126). In Finland, for example, the purchase of adapted private vehicles is supported by a reduction in tax.

### Public buildings

Success in achieving accessibility cannot be reduced to one factor: enforceable laws and good policies need to be combined with strong lead-

ership, plus cooperation between sectors, and a commitment to progressive realization of appropriate accessibility standards.

Structural and political measures such as legislation, regulations, building standards and policies are required to meet the complex challenge of achieving accessibility in public buildings, public spaces and private facilities such as shopping centres, stores, restaurants and hotels. However, political will and institutional support are also required to bring these components together. Most importantly, these measures need to be enforceable. Surveys show that, even when there are laws and policies governing accessibility, if they are voluntary, compliance is minimal (19–21).

In countries such as Australia, Canada, Germany, India, New Zealand, the United Kingdom and the USA, where accessibility requirements are linked directly to antidiscrimination legislation with complaint provisions, a successful challenge made by an individual on grounds of inaccessibility can lead to fines or court orders. A young wheelchair user in the United Kingdom won a substantial award against a major bank in 2007 because the bank's premises were inaccessible (127). Although such victories are important, using antidiscrimination legislation has drawbacks. Bringing a complaint is costly and, even when successful, victories do not always translate into systemic change. If antidiscrimination law recognizes the "undue hardship" defence to reasonable accommodation, accessibility changes from being a human rights issue to a question of cost-effectiveness, which is harder to argue and less clear-cut.

Any coercive enforcement strategy may lead to perverse results, such as partial compliance, by which the easiest and most visible accommodation is made – a ramp to the main entrance of a shopping centre, for example – but nothing else is changed, leaving the wheelchair-user stranded once inside the building (128). All access improvements are of course welcome, but expensive, and token accommodations can exhaust the allocated budget and fail to achieve

comprehensive accessibility. Accessibility solutions must also be practical, non-demeaning and user friendly. One study found that the designated "accessibility elevators" were all freight elevators – some of which were designed to carry garbage – and were located in inaccessible parts of the building (49). A more effective approach, although limited in scope, is Germany's *Act on Licences for Restaurants, Cafes and Bars* that makes accessibility a condition of obtaining an operating licence.

In light of the difficulties with the enforcement approach, some countries have tried inducement:

- The "Warsaw without Barriers" campaign in Poland offers prizes for the most innovative and effective accessibility solutions in the city centre.
- The "Map of Accessible Sofia" project in Bulgaria highlighted and advertised shops and facilities that were accessible.
- An integral part of Ireland's National Disability Strategy regarding public accessibility is to convince developers and builders that accessible buildings will provide them with a good return on their investment by improving market values, broadening potential usage, promoting a better image, and improving ease of use and safety (56) (see [Box 7.2](#)).
- In the Canadian province of Ontario, the Association of Municipal Managers, responding to the provisions of the *Accessibility for Ontarians with Disabilities Act* of 2005, organized a "municipal accessibility toolkit" web site that showcased innovative ways of meeting requirements under the Act. The web site fostered a sense of competition between municipalities in identifying feasible ways of making buildings and public spaces accessible (129).

A key indicator of success for any programme of public accessibility is the extent to which it is comprehensive and integrated. An accessibility programme for public buildings and spaces and

**Box 7.2. An accessibility maintenance audit****Externally**

Check that:

- designated parking bays are reserved for the use of disabled drivers;
- ramps and circulation routes are free from parked bicycles and other obstructions;
- circulation routes and escape routes from buildings to places of safety are on surfaces that are free of obstruction and well lit;
- areas being serviced or repaired are adequately protected and alternative routes are provided as necessary and are clearly marked;
- route surfaces are well maintained, clean, free of gravel, grit, mud, ice, snow and moss;
- battery supplies to platform lifts are permanently charged;
- aids to evacuation are in place.

**Entrances**

Check that:

- turning space at the top of ramps is kept free of obstruction;
- approaches to bells, letterboxes and door handles are free of obstruction;
- doors are easy to open, and closing devices are set at the minimum force needed to shut the door;
- entrance lobbies are free of obstruction, both permanent and temporary.

**Horizontal circulation within the building**

Check that:

- door mats are recessed and, along with rugs, are securely fixed so as not to cause tripping;
- slip resistance of floor finishes is maintained, spillages are cleaned up promptly and appropriate cleaning agents and polishes are used;
- worn floor finishes are replaced;
- artificial lighting is at adequate levels;
- doors are easy to open, and door closers are set at the minimum force needed to close;
- doors are kept closed when not in use;
- wheelchair spaces in waiting rooms and elsewhere are kept free of obstruction;
- circulation routes are free of obstruction (e.g. toolboxes, boxes of files, vending machines, photocopiers);
- refuges are kept free of obstruction;
- adequate headroom is maintained throughout the building, with no trailing cables on floors or at heights below 220 cm;
- approaches to and egress from all lifts and stairs are kept free of obstruction.

Source (56).

private buildings open to the public should strive to achieve full accessibility in manageable steps and avoid the “all-or-nothing” trap in which important initial improvements are deferred because complete accessibility is not immediately achievable.

All components of the strategy – technical guidelines, professional knowledge and

expertise, legislative and policy framework, public awareness, political will and economic resources – need to be brought together into a single accessibility programme with a designated focal agency. The strategy should earmark funding for accessibility and should ensure that professional training institutions (for architecture, town planning, design and related professions)

are encouraged to teach about accessibility (14, 104). There should be formal liaison between people with disabilities, relevant professionals (rehabilitation professionals, politicians, developers, engineers, architects and planners) and other stakeholders to ensure continuing participation in the accessibility programme.

The tragedy of a natural disaster can also present an opportunity to rebuild with accessibility in mind. In New Zealand the “Accessible Christchurch” project was launched in July 2011 to promote the needs of disabled people and to ensure the use of lifetime design standards in the rebuilding after the devastating earthquakes of that year. After the 2004 Indian Ocean earthquake and tsunami, housing in Sri Lanka was rebuilt to be more accessible (see [Box 7.1](#)). Thus, even governments facing economic constraints can make substantial moves towards accessibility, as has also happened in Haiti (130).

## Conclusion and recommendations

The physical environment that surrounds people with SCI can either facilitate or impede their participation and inclusion in social, economic, political and cultural life. There is a broad spectrum of barriers, and most people with SCI experience at least some of these barriers to participation each day of their lives (3, 6). Improving accessibility improves the daily life of a person with SCI considerably. Yet accessibility also has value for others, such as older people, parents with strollers/pushchairs, and people with other restrictions (temporary or permanent) on their mobility. Accessibility helps everyone.

Appropriate accessibility policies and laws, coupled with effective enforcement, are essential for the creation of a “culture of accessibility.” The following recommendations highlight measures that can help to create this culture.

## Cross-cutting recommendations

- Adopt universal design as the conceptual approach for the design of buildings, transportation systems and homes that are accessible for people with SCI and promote awareness of accessibility at all levels.
- Develop locally appropriate accessibility standards, responding to local cultures, settings and needs. Then include accessibility as a criterion in planning and permissions in housing, the built environment and transport, and monitor compliance with accessibility laws to ensure that universal access standards are met.
- Directly involve organizations of people with SCI, as well as other disability organizations, in accessibility efforts, including the design and development of policies, products and services, the assessment of user needs, and the monitoring of progress.
- Make incremental improvements to environments, starting with basic barriers and slowly raising standards and goals as resources become available. Begin with crucial public buildings such as hospitals, government offices and schools. In resource-constrained contexts, strategic planning is needed to highlight priorities and to set out a series of ever-expanding goals, based on pilot studies to learn from experience what is successful and in what context.
- Raise awareness to reduce misperceptions and prejudice regarding SCI and other disabilities. Ensure that personnel working in public and private services are trained to provide access and to treat disabled customers and clients with respect and sensitivity.

## Housing

- Provide information on the cost-effectiveness and feasibility of home adaptation and retrofitting, and improve affordability by providing grants or tax incentives.

- Provide public–private incentives to increase the stock of accessible housing. Encourage associations of people with SCI, local authorities, housing cooperatives and other stakeholders to work with developers to design and build accessible housing.
- Create a register of accessible housing to enable people with SCI to easily locate appropriate accessible housing.
- Aim for complete continuity of accessibility throughout the travel chain by including improvements in pavements and roads, intersections, and access to buses, trams, trains and other vehicles.

## Public buildings and spaces

### Public transportation

- Make accessibility in public transportation an integral part of a country's overall transportation policy, monitored by a responsible agency with representation by people with mobility requirements and other access needs.
- Ensure compliance with standards for new or renovated public buildings and spaces by a combination of legal regulation, fines and licensing preconditions, together with public awareness.
- Aim for a maximum circulation path for priority public buildings and facilities, as determined locally.
- Establish an auditing process and designate a lead government agency to be responsible for implementing the accessibility programme.

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## Chapter 8

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# Education and employment

“My school teachers, friends and family are supportive because they know what I am capable of. Kids from other schools tease me just because I am in a wheelchair. Anyway they got over teasing me because I had some pretty good comebacks ... If I wanted to change anything it would be people’s attitude towards disabled people, to treat us as normal people instead of feeling sorry for us or thinking we are dumb.”

(Kiringawa, New Zealand)

“Lecturers and administrative staff frequently failed to understand the necessity to schedule a lecture in a wheelchair-accessible venue. They had difficulty comprehending why approximately 300 students had to be inconvenienced to accommodate one student with a disability. Moreover, my fellow able-bodied students tended to perceive reasonable accommodation as unfair advantage... [Now] a Disability Officer has been employed at the university. Consequently, administrative staff, lecturers and students are continually sensitized with regards to the reasonable accommodation of students with disabilities in accordance with current South African legislation.”

(Lizelle, South Africa)

“When I got sick I was working delivering food to people’s houses. I thought I was going to lose my job because of the wheelchair. The owner of the shop was always telling me that I could keep my job. When I was able to come back to work, I became the person in charge of the shop: I control products, I attend to providers of products, I control the employees and also the money that comes in. Working makes me feel good, it allows me to relate to other people, to leave my house, to have a future. It really helps a lot to forget the worries caused by the injury.”

(José, Argentina)

“Six years ago, at the age of 30, tuberculosis of the spine made me a paraplegic. During the first year I felt down and depressed. I refused to do anything except lie in bed. One day, my mother pushed me to visit a neighbour. When I saw him lying in bed and could not move any limbs but he still smiled, I looked at myself and realized that I still had normal arms and hands and could do more. Thereafter, I started doing self-care by myself and attended a vocational course for disabled persons. Now I run a small electronics shop at home and earn about 3000 baht a month, which to me is sufficient for living.”

(Boonpeng, Thailand)

“Once I had accepted my disability and proven myself through sports as well, the door to life was opened. The desire to be employed was crucial. I received a great deal of assistance from the Employment Service, which found me a job in a government-owned company... I soon discovered that I wanted to achieve more and I started to look for another job. I got a job at a privately-owned company and acquired a lot of experience there. I was lucky to have come into an environment where people were judged by their ability not their disability. I became the managing director in a couple of years.”

(Janez, Slovenia)

# 8

## Education and employment

Education is about becoming an active member of society, not just simple learning. Work is about belonging, not just about income. People with spinal cord injury (SCI) are entitled to participate in education and employment on an equal basis with others. Article 24 of the United Nations *Convention on the Rights of Persons with Disabilities* (CPRD) (1) emphasizes the need for governments to ensure equal access to an “inclusive education system at all levels” and to provide reasonable accommodation and individual support services to facilitate education. Article 27 prohibits all forms of employment discrimination, promotes access to vocational training and opportunities for self-employment, and calls for reasonable accommodation in the workplace.

Education will be a step to employment and social participation for:

- the child who was born with spina bifida and needs to navigate through all levels of education, from primary school to university and beyond;
- the young adult who wishes to complete school or university after an acquired SCI;
- the adult with acquired SCI who needs to retrain or upgrade skills to open the door to alternative careers.

Inclusion in the general education system may require some environmental adaptations. A young person may also require counselling and other preparatory supports to overcome feelings of low self-esteem or self-consciousness that might stand in the way of returning to school or taking the next steps to higher education.

Acquiring and keeping a meaningful job or returning to a pre-injury employment can also be a challenge for a person with SCI. Yet with vocational rehabilitation, counselling and preparation, with appropriate assistive technology, and with adjustments and accommodations on the part of the employer, people with SCI can perform most jobs. Work is not merely important as a source of economic security; it also provides a foundation for a meaningful life, offering social contacts and a sense of purpose and self-worth.

Full participation in education and employment for people with SCI depends on dispelling misconceptions about the condition. When teachers, school administrators and fellow students learn about SCI, this knowledge facilitates the transition or return to education of the child or young adult with SCI. In the



employment context, assumptions about what a worker with SCI cannot do may well prevent a well-qualified individual from getting a job or, if employed, of having the respect of co-workers. Often the best way of confronting misperceptions about SCI is through direct experience of a person with SCI as a fellow student or co-worker, learning or working side-by-side.

### Spinal cord injury and participation in education

Children with disabilities are generally less likely to start school and often have lower rates of staying in school and of being promoted there (2). In low-income countries, there is limited access to education at all levels (3), and almost no access to higher education for young people with disabilities (4–6). Household data in Malawi, Namibia, Zambia and Zimbabwe showed that between 9% and 18% of children aged five years or older without a disability had never attended school, but between 24% and 39% of children with a disability had never attended one (7–10). A study from Cambodia estimates the non-attendance figure to be as high as 45% (11).

In many low-income countries, the general lack of educational resources makes it very difficult to accommodate children with SCI or any other disability (12). A persistent lack of funding leads to chronic understaffing, absence of medical assistance, and lack of equipment and facilities (13). Evidence from Kenya, for instance, highlights barriers to higher education ranging from the lack of available post-secondary institutions to physical inaccessibility, lack of transition services from secondary education, attitudinal barriers such as stigma, and the generally poor economic background of disabled students (4). The challenges facing low- and middle-income countries to include all children with disabilities in education are formidable, but progress can be made, especially by listening more closely to the voices of students with disabilities and their parents (14).

Although evidence is available on educational participation for children and young adults with disabilities, it is rare for these data to be disaggregated to provide information about SCI. Sometimes it is possible only to infer from data on “orthopaedic disabilities” or even “physical disabilities” to obtain any sort of picture. The majority of children with SCI return to school after injury and rehabilitation, which creates distinct service needs (15).

Since SCI incidence rates are high for people in their late teens and early twenties (see Chapter 2), the focus has been on returning to secondary and post-secondary education (16). The paediatric age group starting in education consists almost exclusively of children with spina bifida (17), who have special challenges that distinguish them from those who are returning to school after injury. However, the distribution of age at injury is shifting upwards, due to the rise in late-onset traumatic and non-traumatic SCI, (16, 18, 19), with the implication that older adults with SCI may be returning to education or training to develop new skills to return to work in a different kind of job than the one they had before.

Relatively more is known about children with spina bifida than about other cohorts because these children have complex educational needs linked to the variety of associated physical, mental and emotional issues they may experience. Spina bifida accompanied by hydrocephalus may lead to limitations in cognitive functioning in at least one third of affected children, including attention and concentration difficulties (20) that require, where available, special educational resources (17, 21, 22). Recent studies have also noted the presence of depression and anxiety among young adults with spina bifida, which contributes to poor educational performance (23). Despite these challenges, a longitudinal study of children with spina bifida in the USA indicated that nearly half had successfully reached tertiary-level education (24). This supports evidence that indicates a steep decline in drop-out rates during the period

of increased resource funding targeted at these children in the USA (25).

For most children and young adults with SCI, the challenge is navigating a return to secondary or post-secondary school. Aside from some research with small samples in Europe and the USA (26–29), there is little reliable information about overall success or failure of the school experience of children with SCI, as compared to children with other disabilities or the nondisabled population. Qualitative research from the United Kingdom has highlighted how return to school can be a traumatic transition (30). Return was most successful when it began as early as possible, and preferably while the child was still undergoing rehabilitation in a hospital. All students agreed that the major problems were physical accessibility and the staff's lack of training in how to accommodate the child's needs for full participation in all school activities, including sports and school trips.

Transition to post-secondary education at universities and colleges generally seems to be less of a challenge, possibly because the students are more mature, have had more experience with their SCI and know what they need. In the USA, for example, 45% of young adults with mobility-related impairments go to college or university after secondary education, compared to 53% of the general student population (31). One study found that 82% of participants went on to college (32). The United States National Longitudinal Transition Study 2 had similar findings, but also showed a difference from the 77% of students who are blind or deaf who continue to post-secondary education (31). In Europe the numbers are comparable, although the rates of college attendance of mobility-impaired students has been decreasing in Europe in recent years (33).

## Addressing barriers to education

To understand and address the myriad barriers to education that children and adults with SCI

confront, it is important to begin by distinguishing three groups: children with spina bifida; children and young adults who are returning to school after rehabilitation; and adults who return to education to acquire the skills and knowledge for new employment prospects after SCI.

## Legislation and policy

Article 24 of the CRPD gives clear and detailed guidance on what is required at the legislative, policy and programming levels to give effect to the right to education at all levels and for all people with disabilities (1, 12).

Some high-income countries have legislation and policy in place to implement the principles of educational inclusion, including general anti-discrimination provisions such as the *Disability Discrimination Act* in the United Kingdom, to address individual complaints of educational exclusion. However, legislation is more effective if it is proactive. In Denmark, for instance, legislation requires the Ministry of Education to provide the compensatory aids that people with disabilities require to follow the same educational courses as their peers so that they can succeed academically. In France, schools are required to take positive measures for students with disabilities and to adapt academic pathways physically as well as pedagogically (33).

In low- and middle-income countries there are often legislative barriers, including laws that explicitly permit children with disabilities to be excluded from education (34–36). UNESCO has concluded that the biggest obstacle to inclusive education in these countries is the failure to enact a legislative and policy framework that is supportive of inclusive education (37). Even in countries such as South Africa, where the government has taken the lead in identifying obstacles to fully accessible education, the absence of legislation and funded programming has allowed little progress (38). Top-down approaches that fail to take into account the local situation in rural communities are less likely to succeed (39).

Countries need to take practical steps to prepare the ground for a workable education policy, as well as making a general commitment to the rights of disabled children to be educated. These steps include: identifying the number of disabled children and their needs; developing strategies for making school buildings accessible; revising curricula, teaching methods and materials to meet these needs; and developing educational capacity, both by providing educators trained in the needs of children with disabilities and by tapping into the resources of parents and communities. All of these measures must be supported by appropriate and sufficient financing (36).

### Support for children with spina bifida

Approximately half the children and young adults with a myelomeningocele accompanied by hydrocephalus are likely to be put into special education programmes and to have poor educational outcomes, while the remainder have outcomes similar to students without disabilities (17). The challenge is to create conditions within the normal school setting that optimize learning for all children with spina bifida. Despite the medical complications to which children with spina bifida are prone – including seizures and bladder and bowel incontinence – in well prepared and resourced educational settings, these students can access primary and secondary education and can have graduation rates equal to those of the general population of children (24, 40).

More research is needed on how to provide a supportive environment for children with spina bifida. Work is also needed to build self-confidence and independence among these children (41). A small-scale study about integrating self-management, goals development and other independence skills in a week-long camp showed that efforts to overcome lack of self-confidence can be extremely successful (42). Most children with spina bifida can successfully participate in mainstream schools and achieve good educational outcomes. Thus

a coordinated effort is needed involving teachers, school administrators and parents to assist these children by fostering intrinsic motivation and independence as a basis for building positive social relationships in mainstream schools (43, 44). Although the situation for children with spina bifida in the poorest parts of the world can be extremely difficult, progress has been achieved in East Africa by bringing together community supports and parents in a culturally sensitive manner (45).

### Returning to school after injury

Returning to school as soon as possible after injury must be a primary goal of rehabilitation, and a commitment to the continuity of education should be part of the rehabilitation goal-setting process (26, 32, 46, 47). Education has consistently been found to be associated with increased community participation, employment, higher levels of independent living, and higher life satisfaction in adults who experienced SCI during their primary or secondary schooling years (48, 49). The best option for any child is to go to mainstream school. Home schooling or individual instruction alone or besides regular classwork is a second-best option that should be considered only if a child with SCI needs more educational support or misses instruction because he or she has to leave classes too frequently for physical or occupational therapy (29).

A recent study on the school experience of children with SCI in London (30), emphasized the following key factors of success:

- early contact between child, parent and school personnel, with the involvement of rehabilitation professionals;
- adaptations and accommodations, planned and carried out in advance of the child's arrival and in non-stigmatizing ways, to ensure complete access to all areas of the school;
- full-access programming, by which school officials ensure that the student is included

in all school activities, including in particular physical education classes (50) and school trips;

- education on spinal cord injury and associated conditions provided on-site for all staff, together with age-appropriate educational programmes for school peers, to encourage the acceptance of difference.

This and similar studies (29, 32, 51) have confirmed that mechanisms need to be put in place for students and their parents to raise concerns and deal with problems in an informal setting (e.g. an evening social event) well before the student enters school. Rehabilitation professionals should attend these events, since evidence suggests that their encouragement to the child is an important factor for successful re-entry into school and participation in school life (52, 53). Peer mentoring has also been shown to be a good way to motivate young adults to return to or continue with their education after an injury (54). Overprotection should be discouraged (30).

## Transitions from school

For children with disabilities, transition from school to post-secondary education is more stressful than for other children, due to challenges concerning adaptation and accommodation to new settings and situations. People with multiple sources of support adjust to transition better than those without (25). The availability of appropriate assistive technology is also essential for smooth transition (55). Parents can play an important motivating and confidence-building role during transition. Peer mentoring to address the trauma of transition for children with SCI (54) and web-based resources that the family and child can use together to increase confidence and boost independence (41) are promising developments for emotional and psychological preparation.

In its 2004 summary report (56), the United States National Center on Secondary Education

and Transition (NCSET) outlined some potential solutions for major transition challenges, namely:

- promoting students' self-determination and self-advocacy by incorporating career development skills in the general education curriculum;
- ensuring that students have access to the general education curriculum by employing universal design principles to make classrooms, curricula and assessments usable by the largest number of students possible without the need for additional accommodations or modifications;
- increasing the school completion rates of students with disabilities by developing methods and procedures for identifying and documenting research-based information on best practices in dropout prevention and intervention;
- increasing informed parent participation and involvement in educational planning, life planning and decision-making;
- using methods such as cross-training between general education teachers and those in special education to promote collaboration between general education and special education in student assessment, individual education plans and instruction.

An OECD report on issues of transition to universities and colleges stated that bridging the gap between secondary and tertiary (or higher) education requires cooperative efforts from both levels of education (33):

- Secondary schools must provide counselling and other resources, which have been shown to be highly effective (57).
- Colleges and universities need to revisit their admissions strategies and education accommodation to facilitate the access and success of students with disabilities.

Transition should be coordinated both centrally by university-wide disability support services and within the relevant university

departments, and advance planning for adjustments should be put in place. Relevant adjustments include note-takers, tutors, technology aids, physical adaptations to classrooms and independent living support (31, 58, 59).

With regard to low- and middle-income countries, the Consortium for Research on Educational Access, Transitions and Equity (CREATE), was established in 2006 as a partnership between research institutions in Bangladesh, Ghana, India, South Africa and the United Kingdom. The first CREATE monograph set out a research agenda based on a classification of “zones of exclusion” of children with disabilities – from total exclusion to entry into secondary school but at risk of dropping out before completion – and made the case for education policies targeted to these different situations (60). A follow-up monograph highlighted the specific teaching challenges and potential strategic responses across Africa (14), and pointed out how gender disadvantage complicates the challenge faced by children with SCI.

### Reducing physical barriers

Research has shown that barriers to basic mobility are key factors restricting the participation of pupils with paraplegia in South Africa (61) and children with spina bifida in Malaysia (62). In the United Republic of Tanzania, access is difficult because many schools are built on plinths to protect them during the rainy season, and, inside the school, toilet facilities are not accessible and doorways are rarely wide enough to accommodate wheelchairs (63). In the United Kingdom, a study highlighted barriers such as steps or ramps that were too steep, lack of appropriate toilets, and lack of reserved parking spaces that were all obstacles preventing students with wheelchairs from using classrooms, dining halls, libraries and sports facilities (30). Access detours and delays hinder students from reaching classes on time (64). Inaccessible transportation is particularly burdensome for children with mobility dif-

ficulties who cannot get to school by themselves because the distances are too great or because of uneven rural pathways or flooded roads during the rainy season (61).

Many of these barriers can be overcome with better policy and planning (33, 65, 66). Even where resources are constrained, it is possible to make a difference by prioritizing the removal of physical barriers over a period of time, as in Kenya where the government plans by 2015 to begin the task of installing ramps and other accommodations in its local schools (67). In 2003, the city of Lisbon, Portugal, launched a programme called *Escola Aberta* (“open school”) that included a wide-ranging strategy for gradually eliminating physical barriers in primary schools (68).

### Reasonable accommodations

Although needs vary considerably, some children with SCI can only achieve the level of independence required to attend school and get the full benefit of an education with some form of accommodation. This may be a classroom assistant or may take the form of assistive technologies ranging from low-technology devices such as pencil grips to high-technology tools such as optical character recognition systems or to a highly sophisticated robotic arm for children with limited upper-body control (69). All these can enhance, or simply make possible, a child’s educational performance and classroom participation. The best source of information about what is needed and what technology actually works is the experience of people who use the equipment. A Canadian project offers a discussion guide to help peers share information on different assistive technology solutions (70) and to enable newly disabled people to think through the issues. Although computers and other technologies will greatly benefit a child with SCI, this often requires a well-trained teacher or classroom assistant to help the child to use them (29, 71).

## Funding education and accommodations

Accommodations, whether equipment or support personnel, require secure funding. In high-income countries, there are many potential sources of funds set aside for students with disabilities, e.g. government education grants or loans, state-run scholarships and supplementary funding, university competitive scholarships, private educational funds and scholarships, and private insurance (33). In the USA, 78% of the budget for disability support for tertiary education went to financing scholarships or loans for people with disability (33), and a variety of federal plans exist from which educational assistive technology can be funded (72). In the United Kingdom, the Disabled Students Allowance provides direct tax-exempted payments for specialist educational equipment, personal assistants and extra travel costs (73). In Ireland, government funds are distributed to colleges and universities, which are primarily responsible for allocating these funds to students (74). Another approach is to ensure that the extra costs of a student with SCI are offset by individual loans or partial bursaries awarded on a case-by-case basis, as in France and Norway, with provisions for these loans to be converted into outright grants should the graduating student be unable to repay the loan (33).

In low-income countries, specialized funding arrangements are unlikely to be available for the student with disabilities. Although studies have shown that integrating children with disabilities into regular schools is cost-effective, even taking into account the extra costs of accommodations (see the review of studies in (75)), many countries are not able to take advantage of these potential savings. In principle, low-income countries at least have the benefit of being able to see how various funding strategies have worked, or failed to work, in high-income settings (76). Uganda, for example, pieced together components of several inclusive education funding

approaches from Europe and the USA to produce good results for its disabled children (37). Adopting funding approaches from high-income countries may not always be the best approach, however, since the primary goal of education in a rural setting may be to prepare individuals with disabilities for living and working in their communities, which may mean that the best funding arrangements are more closely tied to the needs of that community (39).

## Social support

For any young person in secondary or higher education, independence usually depends on the presence of a network of social support from families, friends and peers. The disruption caused by SCI may mean that a young person loses contact with friends, and the time away from school can lead to a general detachment from society. Social support generally is a determinant of life satisfaction, health and even mortality in people with SCI (77). Informal mentoring systems have been shown to be helpful to children with SCI as they return to their schools and social life (54, 59), and interaction with peers with SCI is especially important (78). Advocacy groups, SCI support groups and NGOs are vital components of a social network that can, by sharing common experiences, play an important role in assisting students and their families. In the United Kingdom, the Back Up Trust runs a mentoring service for people with SCI, and matches mentors with those who need advice about adjusting to life with SCI, going back to school and other issues (79). A similar role is played by other groups in other countries, including some that have limited resources to spend on any aspect of living with a disability. India's National Resource Centre for Inclusion, which is a part of Able Disabled All People Together (ADAPT), is based in Mumbai from where it has provided support and mentoring to children with disabilities since 1972.

## Addressing attitudinal barriers

The obstacles that children and young adults experience when they return to school from rehabilitation, or when they enter school for the first time with spina bifida or paediatric SCI, are not merely physical and institutional, they are also attitudinal. Successful educational participation requires that ignorance and misperceptions about what SCI means need to be dispelled. Children and young adults with SCI, and their families, also need to learn about SCI and what they should expect when they return to school, or move from secondary to post-secondary education.

### Students with spinal cord injury and their families

When contemplating returning to school, children with SCI may worry that they will not be accepted by their peers, and there is some evidence that children may have difficulty coping with their SCI and may experience symptoms of maladjustment, anxiety and depression (23, 80), or even a sense of loss of control (81). If not addressed, this may progress into increased isolation, loneliness, absence of friends, anxiety about the future and, as a result, poorer educational outcomes (27). Children with SCI coming back to school need to know about features of the school they are entering, and the regular activities they will be participating in – i.e. things that matter to them, rather than what matters to parents or teachers (51). This means that input from children with SCI on what they need to know may be more important than what their parents, teachers or other professionals believe they ought to know. Later in their educational careers, students with SCI, like their peers, will need counselling and career services that will facilitate their transition to higher education, and then to employment (53).

Children with SCI and their families can profit from web-based resources that provide basic medical information about SCI or spina bifida, including in particular practical infor-

mation about self-management (41). SCI support groups exist in many countries and share information and common concerns that are important to families. Parents may be understandably worried about their child's safety at school or whether their child will be socially accepted by peers (27) but, since overprotection can further isolate the child with SCI (26), parents should be advised by rehabilitation professionals and teachers to seek out support groups to allay their fears.

### Teachers, school administrators and peers

Attitudes of principals and teachers are crucial in facilitating and managing an inclusive environment, and attitudes can be influenced positively by well-planned information and supportive strategies (39, 50, 61, 82). Teacher attitudes are generally more positive towards students with mobility impairments than towards students with intellectual impairments (83). Very basic “disability awareness” programming for teachers, administrative staff and students has been found, in a review of the literature, to be almost as important for successful social integration as an adapted setting (84). This has been confirmed in Botswana and Lebanon (85, 86). For example, the Center for Assistive Technology and Environmental Access at the Georgia Technology College of Architecture offers free online courses for high-school mathematics and science teachers so that they may learn about classroom accommodations, adapted tests and laboratories, assistive technology, and laws and policies (70).

Lacking understanding of what SCI entails, or how to be supportive, both teachers and pupils would benefit from exposure to basic information about disability in general and SCI in particular. There are easily accessible resources that can be used, both for basic information about disability in the schoolroom and for SCI issues in particular. For example, UNESCO has produced a toolkit for creating inclusive learning-friendly environments (87), while OECD offers resources that describe the steps that need to be taken by teachers, school administrators and students to support diversity in the school environment (88).

Teachers play a direct and decisive role in making inclusive education a reality. This is especially true of physical education instructors, who often face the challenge of integrating a child with serious impairments into a mainstream physical education class in a manner that balances the goal of integration, exercise activities that are appropriate for functional limitations, and safety considerations. A Swedish study showed that success in meeting this challenge is a result of adequate training, support from the school administration and adequate resources (50). There is now growing acceptance that teacher training institutions must ensure that new teachers are trained to teach effectively in classrooms where there are students with disabilities (89).

There is also evidence that teachers will more readily assimilate information about a child's disability, and will use that information to help integrate the child into school activities, when the information is not presented in terms of diagnostic labels e.g. child with spina bifida, but in terms of functional problems and assets that will make a practical difference to how they teach the child (83). Generally, it is not basic medical information about SCI that is required, apart from health conditions such as autonomic dysreflexia that may be life-threatening for some individuals with SCI (15). Teachers should also be made aware of the health complications linked to spina bifida or those associated with concomitant traumatic brain injury (19).

Teachers need to know that children with SCI often struggle for self-determination and independence and that they will not readily be able to talk openly about these problems (90). This is a phenomenon that rehabilitation therapists should be prepared for (78). Classroom assistants, who often interact with children with disabilities more directly in primary school, should receive training and information about SCI and its implications, including its emotional and psychological impact (30).

## Spinal cord injury and participation in employment

Most people with SCI can work and can be productive members of society if there are appropriate work accommodations where required. Unfortunately, many people with SCI and other disabilities are excluded from work and livelihood opportunities, with the result that they and their families live in poverty and are marginalized from the mainstream of society. This exclusion is a hardship for people with SCI, but it is also problematic for other reasons:

- Exclusion is a waste of valuable human resources. Estimates of the economic impact of the unemployment and underemployment of people with disabilities in representative low- and middle-income countries range from 3% to 5% of gross domestic product (91).
- Employment is a key rehabilitation outcome for people with SCI (92) because it is positively associated with adjustment to SCI, life satisfaction, a sense of purpose, mental stimulation, social contact and well-being (93–96).
- Low income associated with unemployment or underemployment is linked to higher mortality rates after SCI (77, 97) and generally poorer health (93, 98–100).

A recent systematic review of 50 studies on SCI and unemployment found that the average global employment rate of people with SCI was only 37%, although the figure for having been employed at some point post-injury was 68% (101). The average current employment rate of people with SCI by continent was highest in Europe (51%) and lowest in North America (30%). For the OECD countries, these averages are comparable to the unemployment rates of people with the most serious disabilities (102). Another review of the literature on the return to work of people with SCI around the world for the years 2000–2006 reported return-to-work levels ranging from 21%



to 67%, and overall employment levels ranging from 11.5% to 74% (103). The wide range of results in both systematic reviews is mainly attributable to differing definitions of employment.

Although there are good data on the employment rates of people with SCI in high-income countries, equivalent data for low- and middle-income countries are sparse (104) and reveal variable employment rates. Some studies find approximately half the respondents with SCI returning to work: 57% in Malaysia (105), 50% in Bangladesh (106) and 41% in India (107). However, evidence from other settings is much worse. For example, a follow-up study on 136 people with SCI admitted to the National Rehabilitation Centre in Zimbabwe showed that only 13% of the participants, only one of whom had tetraplegia, were employed (108). Seemingly good statistics may obscure the fact that available work may often pay poorly (109). Provision of support with return to work is a major factor in differential outcomes.

Because non-traumatic SCI is more likely to be late onset, employment-related information applies mostly to traumatic SCI. The exception is young people with spina bifida, who are especially hard hit by unemployment. Although information is available only from Europe and the USA, the rates of full-time or part-time employment of young people with spina bifida range from 36% to 41%, as compared to 75% for those without disabilities (40, 44) or those with other serious chronic conditions (110). A large study in the Netherlands found a relatively high rate of employment (62.5%), but many respondents were in sheltered employment settings rather than in the general workforce (43).

While SCI employment data for low- and middle-income countries is scarce, it is clear that, even in high-income settings, unemployment is very high for people after SCI. More research is needed on the causes of persistent unemployment, as well as to distinguish, if possible, the barriers to employment that are associated with SCI from the barriers associated with disability in general (111).

## Addressing barriers to employment

There is good evidence from high-income countries on determinants of employment and the factors that prevent people with SCI from returning to work after injury or from acquiring their first job (96, 103, 112–115). Although gender is not a reliable determinant of employment (92, 98), age at injury and level of pre-injury education are stable predictors (48, 98, 116–120). The younger, more educated and less injured a person is, and the sooner the person can get to work after the injury, the more likely it is that the person will be employed (120, 121). Race is also a reliable determinant in the USA, with whites being far more likely to be employed than other groups (81, 120–123).

The more serious the injury and the more functional difficulties a person has, the less likely it is that the person will be employed (48, 98, 117, 124–127). For all levels of injury severity, employment rates improve over time (81, 128–130). Nevertheless, secondary conditions, especially when requiring hospitalization, reduce the chances of job acquisition and job retention (100, 122, 131).

However, the main barriers to employment are environmental rather than demographic, biomedical or psychological (132). The literature review and evaluation of reported evidence on determinants of return to work conducted by the Spinal Cord Injury Rehabilitation Evidence (SCIRE) project rank discrimination and inaccessibility at the workplace as the most important negative factors for employment (115). Even studies that emphasize health issues such as functional inability to perform job tasks, lack of stamina or lack of endurance, point out that these issues are only problems if the nature of the work or workplace cannot be modified to enable the person with SCI to perform the preferred job (98, 133, 134).

Overall, research has consistently shown that people with SCI are often prevented from working because of the lack of accessible transporta-

tion to work (43, 103, 115). This is a worldwide problem, especially in rural areas, which consistently have higher unemployment of people with SCI than urban areas (34, 131, 135, 136).

The causes of unemployment of people with SCI are complex, as are the causes of failure to achieve economic self-sufficiency. There is considerable variability across studies, and predicting return to work or access to financial support is challenging because, even if all obstacles preventing a young person from returning to work are overcome, a seemingly trivial environmental or logistic obstacle at the workplace may make it impossible to do so (112, 114). However, the four categories of employment and economic security predictors seem to be: vocational training and employment supports; misconceptions about, or discrimination against, people with SCI; workplace accommodation; and securing economic self-sufficiency.

## Vocational training and supported employment

Vocational rehabilitation, which is a multidisciplinary approach that aims to return a worker to gainful employment or to facilitate participation in the workforce, usually includes more specialized services such as vocational guidance and counselling, vocational training, and job placement to optimize the chances of employment (137). It has been shown to be highly effective for return to work and first-time “work-ready” preparation for a wide variety of disabling conditions (138, 139).

Functional recovery after traumatic SCI may take up to 12 months after injury, and the individual with the injury will need time to deal with medical needs and adjustment to family and home. It may seem unrealistic to begin active vocational planning during inpatient comprehensive rehabilitation or in the first months after discharge (113). Yet there is strong evidence that vocational rehabilitation that begins early and is coordinated with efforts to promote

adjustment to life in the community has a better chance of enabling the individual to obtain and sustain employment (48, 138, 139). Vocational goals and expectations of a productive lifestyle should therefore be incorporated into the overall rehabilitation plan at an early stage to prepare for the more concentrated efforts of vocational counsellors later (140). Unfortunately, even in high-income countries, vocational rehabilitation and counselling is not always available for people with SCI (96, 141), and the case for the need for these services has to be made at the policy level.

People with SCI may need specialized services that address specific ergonomic and technical issues that they may confront (142, 143). There is also strong evidence in the case of SCI that an important factor in return to work is the availability of job placement services provided by vocational counsellors: particularly job search and networking; making job descriptions available to match job requirements with the individual’s functional strengths and weaknesses; job application skills; and preparation for job interviews (118). An important part of these services is the provision of information about employment opportunities, including vocational and educational prerequisites, to help with vocational decision-making (94, 143).

The need for general social support for people with SCI is recognized as a significant factor for successful re-entry into employment (132). After a traumatic injury, many believe that they are no longer capable of performing tasks necessary for work (124, 144, 145). Psychological factors ranging from reduced sense of control of life and self-esteem to depression may make re-employment harder (146–148). Serious mental illnesses such as depression may require professional help, but in most cases psychosocial support from SCI peers, family members and close friends can be highly effective in encouraging the individual to continue the journey back to employment (149, 150). This is very relevant in low-resource settings where there is generally more reliance on informal support networks (109).

## International Perspectives on Spinal Cord Injury

For children and adolescents, especially those with spina bifida, vocational counsellors must be integrated into a large programme of transition from school to work. Although the ultimate goal is to develop strategies that will lead to employment in the future, typically the primary focus is to keep young people in school so that they can stay on the path to employment (26, 54).

To meet the challenge of returning to work for people with serious injury-related disability such as SCI, there are two overall types of vocational rehabilitation programmes in high-income countries. Transitional programmes offer streamlined services focused on helping people to obtain and hold competitive jobs, also known as “supported employment” (143, 151). The emphasis is on training in job skills,

job readiness counselling, and job placement services, with post-placement support and follow-up by vocational counsellors (96, 128, 152, 153). Transitional services are by their nature resource-intensive and costly, but these costs are considerably reduced if the services are begun as soon as possible and are integrated with other rehabilitation services (96, 137). The Kaleidoscope vocational rehabilitation programme described in [Box 8.1](#) is an example of such a programme for SCI.

Supported employment programmes build on the job-seeker’s strengths and abilities. These programmes tailor support to address specific needs in searching for and selecting suitable employment, provide on-the-job support and advocacy with the employer as the individual

### **Box 8.1. Kaleidoscope, Burwood Hospital, Christchurch, New Zealand**

Kaleidoscope is an early-intervention vocational rehabilitation programme that started in response to the high unemployment rate among people with SCI. Kaleidoscope is based on the supportive employment model and has four characteristics, namely:

1. **Early access to people with serious spinal injuries and their families.** This generally begins within the first week or two of an acute admission. Spinal injuries often result in very lengthy hospitalization so there is ample opportunity to get together with those who are injured and their families. The primary focus during this time is, of course, a person’s medical rehabilitation. However, valuable foundations are laid for future vocations, and expectations are raised that continuing employment is both realistic and likely.
2. **Detailed career planning.** This gives people the opportunity to design a future path that they are motivated to follow. If it is no longer possible for people to do their previous jobs, they may be unsure of what the future holds. Planning a person’s employment future on the basis of motivation, experience, skills and the many thousands of job possibilities that exist helps to give that person the desire to get back into full and active participation in the workforce.
3. **Post-placement support.** This support is central to ensuring that the transition back into the workforce is as smooth as possible. A key aim of the support provided is to empower the employee sufficiently so that the requirement for ongoing regular support will gradually cease. However, all parties will be clear that support will be provided should it be required at any time or if an ongoing support regime becomes necessary again.
4. **A motivated and supportive local business community.** The local business community has a huge amount to offer people who wish to return to the workforce after a serious injury or illness. Kaleidoscope has a business network of over 40 local businesses in a variety of industries. These employers have made themselves available to meet face-to-face to share information on their industry and to help identify a job search strategy that will assist people to gain a position within that industry.

The Oho Ake (“awaken” and “rise up”) programme is based on the same principles and includes people with chronic SCI who have experienced unemployment.

Source (154).

begins to fit into the job, and provide ongoing long-term support throughout the employment (155). The key to the approach is individualized services, given that each person with SCI is different in terms of functioning, job skills, experience and transportation requirements, and requires different employment accommodations. Although highly individualized assessment is time-consuming, there is some evidence that this approach not only makes it possible for the professional counsellor to better tailor services to individual needs but it also empowers people with SCI to take control over their lives (151). Although the supportive employment model is primarily used in high-income countries, one of the most successful examples of it is the Centre for the Rehabilitation of the Paralysed in Bangladesh (see Box 8.2).

The sheltered workshop model of employment is the second of the two types of vocational rehabilitation programme. It is the traditional approach where people with severe disabilities are given tasks to perform in a workshop setting that is managed by vocational specialists. This option is sometimes perceived to be more realistic for people with complex needs and is often offered as

the first step towards open employment. Box 8.3 gives an example of such a programme in operation in southern India. Sheltered workshops that are not directly linked to programmes for transition to competitive employment foster segregation and are therefore not the optimal approach to realizing the human rights of people with SCI.

SCI peer counselling has long been advocated as an essential component of vocational programmes (140). Although early vocational approaches were controlled by rehabilitation professionals, research has suggested that a high level of professional support could be intrusive and that more coordination is needed between the clients and the businesses and other workplaces that they were hoping to enter. The role of vocational rehabilitation professionals is to liaise between employer and client, and to counteract any employer prejudice against employing people with severe disabilities (141, 157). Rehabilitation professionals should emphasize the employment goals of the person with SCI, assess the work-related functional capacity of the individual in view of available support, and accept that work career planning is an ongoing process that does not end with the attainment of a specific job (143).

### **Box 8.2. Centre for the Rehabilitation of the Paralysed (CRP) in Bangladesh**

Bangladesh is a poor country, with nearly half of its 150 million people living below the poverty line. There is no general social security network, and most people with disabilities receive no financial aid to assist them with their impairment-related expenses. The Centre for the Rehabilitation of the Paralysed (CRP), an NGO specializing in the rehabilitation of people with SCI, was founded in 1979 in response to the desperate need for rehabilitation services for people with spinal injury. CRP has since developed into an internationally respected organization that provides a full range of supportive employment services, including physical and psychological rehabilitation, job placement counselling, vocational retraining, assistance in securing microcredit loans for self-employment, planned reintegration into the community, ensuring that home environments are safe, and educating local residents on the nature and consequences of SCI.

CRP's headquarters is in Savar. It also runs two residential vocational retraining centres (CRP-Gonokbari for women and girls, and CRP-Gobindapur for outpatients and community-based services) as well as a centre for medical, therapy and diagnostic services in the capital Dhaka. CRP operates 13 community-based rehabilitation projects that are involved in accident and disability prevention programmes as well as advocacy and networking activities to promote SCI issues. Additionally CRP runs awareness-raising and publicity campaigns to break down the barriers and stigma against people with SCI and other disabilities.

Sources (34, 106, 156).

### Box 8.3. Sheltered workshops for veterans with SCI in India

Two paraplegic rehabilitation centres at Kirkee and Mohali, with 109 and 34 beds respectively, are run for the rehabilitation of paraplegic and tetraplegic ex-servicemen. The centres are charitable trusts that are funded by Kendriya Sainik Board (which is part of the Department of Ex-Servicemen in the Ministry of Defence) and the Ministry of Social Justice and Empowerment. All individuals in these centres are given vocational training in skills such as weaving, knitting, tailoring and candle-making. They are employed in on-site sheltered workshops and given small monthly salaries so they can be relatively economically independent. Sheltered workshops at these centres are considered to be permanent or semi-permanent vocational placements for these individuals because it is assumed that they would be unable to find jobs in the community. An ex-serviceman's activity at a workshop is to be considered a job and a place to go to work every day. The centres also provide medical treatment, physiotherapy, physical exercise, sports and computer training to enable inpatients to become self-reliant.

Source (107).

## Overcoming misconceptions about spinal cord injury

Misconceptions about SCI and the ability of people with SCI to work in competitive employment, especially among employers and co-workers, have often been cited as a significant factor that negatively affects the employment prospects of people with disabilities in general and those with SCI in particular (114, 124, 140, 152, 158, 159). A study from Bangladesh reported that some employers generally perceived potential employees with SCI to be “sick” and “less productive” (34). In the Netherlands, 57% of young adults with spina bifida reported that they had problems finding employment because of negative attitudes among employers (43), a result confirmed by similar findings in other studies (25, 41, 160). In a classic study of workplace discrimination, nondisabled candidates were 1.78 times more likely to be hired than their disabled counterparts. It is argued that the more visible the physical problem (e.g. the presence of a wheelchair), the more likely it is that employers will be reluctant to hire (161).

Overcoming employment discrimination requires commitment to antidiscrimination legislation, plus legal processes for redress. Laws such as the *Americans with Disabilities Act 1990* (as amended in 2007) are increasingly common around the world. A study of the application of

this act in the case of SCI has shown that, although the success rate is very low, people with SCI tend to be more successful in their complaints than other disability groups (162).

Antidiscrimination legislation is not the only way forward. Research reveals a trend towards very positive employer attitudes about workers with disabilities, but this has not always translated into positive attitudes when specific workers are assessed for jobs (163, 164). A follow-up study found that employers who had experience of people with disabilities, or whose knowledge of disability had increased with disability awareness programmes conducted by vocational counselors, hired people with disabilities far more readily (158). This suggests that employment outcomes for people with disabilities can be enhanced if the rehabilitation community plays an active role in providing support to employers with less experience of disability. A recent study found, contrary to expectation, that perceived discrimination was not associated with a lower likelihood of returning to work, which suggests that people with SCI may be growing more aware of, and more successful in overcoming, discriminatory and prejudicial attitudes of employers (145).

## Ensuring workplace accommodations

Successful return to work depends on workplace accommodation (95, 99, 101, 103, 113, 165).

Though accommodation begins with issues of physical accessibility, the need is more extensive and includes integration of assistive technology into employment, and modifications to the nature or location of the work. Practical examples of SCI-relevant accommodations derive from people with SCI themselves: in a recent qualitative study of 266 people with mobility and sensory problems who had entered employment, a total of 1553 specific and detailed accommodations was identified (166).

Ample information is available on ways to make the workplace physically accessible, including free web-based resources that provide very detailed and practical information, such as the USA-based Jobs Accommodation Network (JAN), a portal to practical information for innovative and tested accommodations for individuals with impairments, including those resulting from SCI (167). Since 2004, JAN has also conducted a study of employers to determine the costs and benefits of worksite modifications, consistently demonstrating the benefits to employees and showing that the benefit employers receive from workplace accommodations far outweighs their cost (167).

Examples of workplace modifications relevant to the needs of people with SCI include: wheelchair accessibility from the point of entry (in all weather conditions) to the workstation and all other areas needed for the job tasks; widened doorways and path clearance for wheelchair users; modifications to the workstation, including height-adjustable desks or tables; accessible filing systems and other work areas; and accessible amenities such as toilets, conference areas, and lunch and rest areas (168).

For workers with SCI, accommodations for wheelchairs are crucial, but for most jobs it is of equal importance to have access to assistive technology that overcomes both lower-body and upper-body functional limitations associated with SCI. In a study of people with SCI who are working, a majority reported using adapted telephones, magnifiers and other assistive technologies to perform

their job functions, saying that these technologies substantially increased their productivity and self-esteem (144). In particular, many studies have shown that people with SCI who are employed use a computer at work more often than the general population (169–172). This makes the availability and accessibility of such equipment essential for a successful return to work. For those with upper-body difficulties, recent developments such as a head-movement image-controlled mouse, for which the user with SCI wears a headset and moves his or her head to control the movement of the mouse cursor, may be needed.

For assistive technology to be useful for a person with SCI, it must be fully integrated into the workplace. In part this is a matter of physical accessibility, but vocational rehabilitation specialists have increasingly noticed that it is also important to make sure that co-workers and employers understand the need for the specialized equipment, that they provide users with enough information about how to use it, and that they know why technical assistance is required to maintain or repair it so that the user's work is not disrupted (169, 173). Sometimes sophisticated technology is neither available nor needed, such as when the job can be performed by providing an assistant to help with job-related tasks. In some cases that role can be provided by service animals that are trained to carry and bring objects to make it easier to perform basic job tasks (174).

Since the injury is very likely to have some impact on the kinds of tasks that can be performed, "reasonable accommodation" may also include making changes to the nature of the job. The manner in which the tasks required are performed may be changed, the job may become part-time, or the work schedule may be modified, including allowing the worker to leave when necessary for bladder and bowel management or for rest. A recent European study showed that, while 60% of young people with SCI returned to work after their injury, nearly all of them took advantage of job modifications, including reduction of time pressure, flexible work schedules and, in some cases, cutting work hours by up to half (141).

An era of technological and economic changes, together with an emphasis on work-life balance, means that people with disabilities are not the only ones who wish to work differently. In some countries, governments are actively encouraging programmes of flexible working hours and job-sharing, which can equally benefit people with SCI (152).

Telework, in which work is conducted from a remote location using a variety of information and communication technologies, can be a way of overcoming transportation obstacles, physical environmental barriers and health limitations such as fatigue created by SCI or secondary conditions (170). The advantages of telework need to be weighed against the potential danger of social isolation and the risk of employment segregation. Teleworking might also undermine efforts to make transportation systems, buildings and communities more accessible to people with mobility limitations. More research into benefits and disadvantages in this area is needed (111).

### Self-employment

In many low-income countries, self-employment in the form of small-scale arts and crafts manufacturing or selling of farm produce is often a source of income for people with disabilities and is a relevant work option for people with SCI (109). In high-income countries too, self-employment has potential benefits for the people with SCI: working from home or in the immediate community avoids barriers of access and transportation, workplace discrimination and negative co-worker attitudes, and allows for flexible working hours and conditions. Evidence suggests that people with mobility and musculoskeletal problems in particular are likely to be self-employed (159). The disadvantages of self-employment are isolation and lack of skills development, lower income levels, and the fact that the cost of employment-related assistive devices has to be borne entirely by the individual (171).

The most significant barrier to self-employment is the initial financial burden of starting

the business, whether capital or for equipment or training costs. An extensive study of self-employment options in Europe found that, because individuals with disabilities were generally viewed by private financial lenders as poor risks, they turned to their families for funds. In countries such as the United Kingdom, people with disabilities were able to take advantage of tax credits and other disability-related income supports, and sometimes small business loans available through employment agencies (159). However, even in Canada and the United Kingdom, which offer relatively generous financial assistance in the form of grants, loans and tax credits, there is low take-up because of the lack of accessible information (159, 175).

Access to funding to set up a small business can prove to be a major challenge for people living with SCI in low-income settings. In these countries microfinance arrangements have been instrumental in enabling people with disabilities to earn a living. Microfinance refers to provision of standard financial services, including business loans, to individuals and small businesses otherwise lacking access to affordable banking. An extensive review of literature and practice from Africa and Asia concluded that people with disabilities have not been able to benefit equally from existing microfinance programmes (176, 177). Handicap International in 2006 conducted a thorough study of access to microfinance organizations across the poorer countries of Africa and Asia and found that only 0.5% of the clients of these funding organizations had disabilities (178). Pointing to successes with Asociación de Discapacitados de la Resistencia Nicaragüense in Nicaragua and with the International Committee of the Red Cross in Afghanistan and elsewhere, the report argues that the involvement of NGOs with strong capacity-building power is needed to resolve this complex problem. Other research argues that community-based saving and lending groups have the potential to increase the employment rates of people with disabilities, and that disability organizations can play an

important role by joining forces with these community financial groups (177).

## Social protection

Disability is strongly linked with extreme poverty worldwide, and SCI is no exception. An Australian study estimated the average annual income of employed people with tetraplegia to be approximately half of the mean annual earnings of the general population (179). In a Malaysian study, post-injury earnings for the 50% who had jobs were considerably less than what they earned before (105). In southern India most of SCI patients were found to be living below the poverty line (109, 135), and in Nepal less than half of the study population earned any income at all a few years after discharge from rehabilitation (180). In Zimbabwe, a study reported that one third of those who survived SCI had no income whatsoever and relied on family and friends for financial support (108). In Ghana, it is reported that people with mobility restrictions have resorted to illegal begging because of the lack of employment options or social services (181).

Apart from these isolated studies, very little is known about how many people with SCI are economically self-sufficient. It is likely that many people rely on social security programmes, disability pensions, income support, family assistance, or in-kind transfers. Social safety nets are vulnerable to economic downturns and are lacking in most of the poorer parts of the world. In some countries, including India, there are benefits restricted to government service workers or military personnel, which help people from those sectors who develop SCI (182, 183).

Most high-income countries, and an increasing number of middle-income countries such as Brazil, Namibia and South Africa, have two forms of social protection. One is temporary and means-tested to sustain income until permanent employment is re-established (e.g. unemployment insurance, temporary disability benefits). The other is a permanent form of social assistance

or welfare when the individual is deemed to have a permanent disability of such severity that he or she is no longer employable. In the Netherlands, for example, unemployment insurance is compulsory. As a result, 97% of people with SCI and without a post-injury job are funded, and most of those who do have employment remain entitled to a supplementary social benefit based on 70% of their salary before SCI (127). In Canada, by contrast, a long-term disability insurance (DI) scheme will pay 65–70% of a person's salary for two years post-injury until an alternative job is found. If there is no possibility of returning to work, this payment will continue for an extended period and will eventually be replaced by some form of social assistance (152).

The downside of social protection schemes is that they can operate as a “benefit trap”. This refers to a situation where, because income maintenance and other programmes are means-tested (or simply end once a permanent job is acquired), people with SCI who have continuing health and rehabilitation needs, including the costs of assistive devices, are reluctant to take jobs. The reason for this is that the income they would receive, minus the health care and other costs caused by the SCI, would be less than if they stayed in the temporary income replacement programme (184). There is conflicting evidence about how extensive a problem this is. A large study in the USA showed that, for people with SCI not in employment, higher disability benefits were strongly associated with a lower chance of being employed in subsequent years (129). DI beneficiaries do not appear to price themselves out of the labour market. Half of them would want a wage that is 80% or less of the last wage earned before receiving DI. It is estimated that approximately 7% of long-term DI beneficiaries might return to work if they search for jobs and are offered a wage with a distribution mean of 80% of their last wage (185).

The most straightforward, if costly, solution to the benefit trap is to modify the means test so that an individual with high health care and



impairment costs retains some portion of the benefit after having secured employment. The perceived difficulty with this solution is that, when there is widespread unemployment, people will seek to take advantage of disability support to secure health care costs. OECD has recommended radical changes that would greatly benefit people with SCI (102, 186), arguing that disability benefits should be a single component of a larger “participation package”, adapted to individual needs and capacities and designed primarily to return people to work. The package would include rehabilitation and vocational training, job search support, and cash or in-kind benefits for preparation to return to work. The package must directly involve employers, who should be given a substantial incentive to hire these workers and a disincentive to fire them if the need for further workplace accommodations is discovered later. In this way, disability benefits would be transitory payments acting as a step towards full employment.

The OECD-recommended changes to disability and employment policy would probably benefit people with SCI more than other disability groups. The typical person with traumatic SCI is young and, prior to injury, was either preparing for a career or starting one. Vocational rehabilitation, as a transitory package of work-related services, complements the OECD proposal.

## Conclusion and recommendations

Education is an essential step towards employment and full membership in society but, for children with spina bifida or young adults with SCI returning to school, full participation in mainstream education can be difficult because of barriers, both physical and attitudinal. Institutional and school-level change is required to remove these barriers and to provide accommodation and support services so that every child and young adult with SCI can fully ben-

efit from education. Older adults, who may want to retrain for new jobs, also require customized support and accommodations from training institutes, vocational or technical schools, colleges and universities.

People with SCI, where qualified, can perform the requirements of many jobs and be productive. However, obtaining employment and staying employed are often made more difficult by: lack of access to relevant education, training, vocation rehabilitation and job placement services; lack of access to financial resources for self-employment opportunities; disincentives and delays created by the structure of some social protection benefit schemes; the absence of workplace accommodation and assistive technology; and employers’ and co-workers’ misperceptions about what a person with SCI can and cannot do.

Many individuals and groups – from families, school administrators, teachers, vocational rehabilitation and other specialists to governments, employers and SCI organizations – need to be involved and to coordinate with each other to overcome the obstacles to full participation in education and employment. Critical areas that need to be addressed by these stakeholders are summarized in the following recommendations.

### Enhancing educational participation

- Ensure that laws and policies guarantee that children with SCI can enrol and attend any level of schooling appropriate to their needs and abilities, and on an equal basis with others.
- Ensure that college and university admission strategies do not exclude potential applicants with SCI and that they have in place strategies for making the environment accessible.
- Plan the return to school after injury, bringing together education and rehabilitation staff.
- Ensure the availability of health, rehabilitation and support services, as required by the child.

- Ensure that teachers are trained to meet the needs of children with disabilities.
- Where feasible, provide peer mentoring to the child returning to school or making a transition between levels of education.
- Include parents and children in decision-making.
- Use SCI organizations to provide information and awareness on issues relating to SCI.

## Securing employment and economic self-sufficiency

- Enact, enforce and publicize effective anti-discrimination legislation, so that employers

are aware of their duties not to discriminate and to provide reasonable accommodation.

- Ensure access to vocational rehabilitation to help people with SCI prepare for work and to address psychosocial concerns.
- Promote access to microfinancing or other sources of credit for people with SCI who wish to develop a self-employment opportunity.
- Depending on the setting, provide social protection that supports individuals and families affected by SCI but does not act as a disincentive to work.
- Collect statistics on the employment experiences of people with SCI and other disabilities.

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## Chapter 9

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# **The way forward: recommendations**



# 9

## The way forward: recommendations

Spinal cord injury (SCI) is a medically complex and life-disrupting condition. SCI has costly consequences, both for individuals and society. People are left dependent, are excluded from school, and are less likely to be employed. Worst of all, they risk premature death. SCI is both a public health and human rights challenge. However, with the right policy responses, as demonstrated in this report, it is possible to live, thrive and contribute with SCI anywhere in the world. People with SCI are people with disabilities and are entitled to the same human rights and respect as all other people with disabilities. Once their immediate health needs have been met, social and environmental barriers are the main obstacles to successful functioning and inclusion for people with SCI. Ensuring that health services, education, transport and employment are available and accessible to people with SCI, alongside other people with disabilities, can make the difference between failure and success. SCI will always be life-changing, but it need not be a tragedy and it need not be a burden.

### Key findings

#### 1. Spinal cord injury is a significant public health issue

- ***The global incidence of SCI, both traumatic and non-traumatic, is likely to be between 40 and 80 cases per million population.*** Based on the 2012 world population estimates, this means that every year between 250 000 and 500 000 people suffer a spinal cord injury (1). The incidence of traumatic SCI (TSCI) reported in country-level studies ranges from 13 per million to 53 per million. Historically, up to 90% of SCI has been traumatic in origin, but data from the most recent studies indicate a slight trend towards an increase in the share of NTSCI. Available studies report an incidence of non-traumatic SCI (NTSCI) of 26 per million.
- ***No global estimates of SCI prevalence are available.*** Data on SCI incidence and prevalence are inadequate and inconsistent. Even in developed countries, figures vary due to differences in case ascertainment and modelling methodology, as well as to real differences in epidemiology. For countries where data are available, TSCI prevalence figures range from 280 per

million population in Finland (2) to 681 per million in Australia (3) to 1298 per million in Canada (4). NTSCI prevalence for adults and children in Australia is 367 per million (5) and in Canada 1227 per million (4). Overall combined TSCI and NTSCI prevalence for Canada in 2010 was 2525 per million population.

- **Increasing prevalence of SCI in some countries.** There is a trend towards increasing prevalence of SCI in high-income countries due to increases in survival rates, which have reached approximately 70% of general population life expectancy for tetraplegics and 88% for people with complete paraplegia (6). However, survival rates in low- and middle-income countries remain poor – as low as 1 to 2 years after injury in some settings – and this contributes to lower prevalence (7). Global ageing is likely to increase rates of NTSCI, and there is a slight trend for NTSCI to increase as a proportion of total SCI.
- **Changing profile of victims.** The SCI incidence rate peaks in young adulthood and, to a lesser extent, in old age. While young males dominate the statistics, the profile is changing to include more older people and more women. Overall, age at time of injury is increasing.
- **Road traffic crashes, falls and violence are the main three causes of SCI.** Road traffic injuries predominate in the African Region, accounting for nearly 70% of cases, and are a prominent underlying cause of SCI in other WHO regions as well, ranging between 40% in the South-East Asia Region and 55% in the Western Pacific Region. Falls, the second leading cause, account for just over 40% of all cases in the South-East Asia and Eastern Mediterranean Regions. The African Region reports the lowest percentage (14%) of falls, with the other WHO regions showing percentages between 27% and 36%. Rates of assault, including violence and self-harm, mostly from firearms, as a cause of SCI vary

considerably across regions, the Americas, African and Eastern Mediterranean Regions reporting the highest percentages of 14%, 12% and 11%, respectively. Work-related accidents contribute to at least 15% of all TSCI cases. Across all regions, sport and leisure activities contribute less than 10% of all cases of TSCI. Attempted suicide has been shown to contribute to over 10% of TSCI cases in some countries. A third of NTSCI is linked to tuberculosis in sub-Saharan Africa.

- **People with SCI die earlier.** Studies have indicated that people with SCI are 2 to 5 times more likely to die prematurely than people without SCI. People with tetraplegia are at higher risk than people with paraplegia, and people with complete lesions are at higher risk than people with incomplete lesions. Mortality is particularly high in the first year after injury (8), and mortality rates are strongly affected by the capacity of the health-care system, especially emergency care.
- **In low-income countries, preventable secondary conditions remain the main causes of death for people with SCI (9).** In high-income countries, the main causes of death for people with SCI have changed over recent decades (10, 11), with urological complications in decline and the leading cause of death shifting to respiratory problems, pneumonia or influenza in particular. Heart disease, suicide and neurological problems are other associated causes of death.

## 2. Personal and social impacts of spinal cord injury are considerable

- **SCI has a debilitating psychological impact.** 20–30% of people with SCI show clinically significant symptoms of depression, which is substantially higher than the general population (12), although the majority of people eventually adapt well to SCI.

- **People with SCI have a narrower margin of health**, due partly to preventable complications such as urinary tract infections and pressure sores.
- **SCI is associated with family breakdown, but also family resilience.** Immediately after injury, SCI can have a negative impact on personal relationships and is associated with a higher rate of divorce. However, post-SCI relationships generally do better. Carers of children and young people with spina bifida or traumatic SCI typically experience isolation and stress.
- **Lower participation in school.** Children and young people with spina bifida or acquired SCI are less likely to attend school and less likely to participate in tertiary education. They face obstacles in the transition between school and tertiary education, and between education and employment.
- **SCI is associated with lower rates of economic participation.** Average global employment rates for people with SCI are only 37%, with a high of 51% in Europe (13).
- **Costs of SCI are higher than for comparable conditions** such as dementia, multiple sclerosis, cerebral palsy and bipolar disorder. In Australia the lifetime costs (including the financial costs and burden-of-disease costs) were estimated to be AUS\$5 million for a person with paraplegia and AUS\$9.5 million for a person with tetraplegia (14). Indirect costs, such as lost earnings, generally exceed direct costs.

### 3. Barriers to services and environments restrict participation and undermine quality of life

- **Inadequate policy and provision.** Often appropriate policies and services are lacking in areas such as inclusive education, accessible environments and rehabilitation. For example in low- and middle- income coun-

tries, only 5–15% of people have the assistive devices that they need (15). In a Netherlands study, more than half of respondents with SCI were delayed leaving in-patient rehabilitation due to delays in obtaining wheelchairs (16).

- **Lack of funding.** One Nigerian study, for instance, showed that for more than 40% of respondents with SCI, acute treatment costs represented over 50% of their annual income (17). Similarly, cost is one of the main barriers when it comes to assistive devices.
- **Physical access barriers.** Homes, schools, workplaces and even hospitals are often inaccessible to people who use wheelchairs. Inaccessibility of transport is a major obstacle to participating in society, particularly for those who live in rural areas. This prevents people with SCI leaving hospital or nursing home and becoming independent.
- **Negative attitudes.** It may be perceived for example, that tetraplegia is a fate worse than death, or that people in wheelchairs cannot work or cannot have intimate relationships. Even family members may have negative attitudes and low expectations. Often, prejudice arises from lack of knowledge and lack of contact.
- **Lack of knowledge.** Rehabilitation providers may lack knowledge and skills relevant to SCI. For example, lack of expertise among service providers can hinder people with SCI receiving appropriate assistive technologies. Primary care staff may not know about preventable complications in SCI, and diagnostic overshadowing can mean that people with SCI do not receive screening or treatment for their general health needs.

### 4. Spinal cord injury is preventable

- **Death and disability associated with road traffic crashes can be reduced** through the safe systems approach, which highlights what can be done to improve road environments,

vehicle safety and driver behaviour (18). For example the world's first compulsory seat-belt laws were introduced in Australia in 1970, and, in conjunction with government efforts to improve road design and regulations on car safety, the incidence of SCI from road traffic crashes has been reduced from 60 to 25 cases a year (19).

- **Workplace codes on health and safety can reduce injuries** caused in mining, construction and agriculture.
- **Limiting access to guns and knives prevents injuries** and reduces cost to society. Measures for limiting access include bans, licensing schemes, a minimum age for buyers, background checks and safe storage requirements. These measures have been successfully implemented in Austria, Brazil and some states in the USA.
- **Injuries from sporting and leisure activities can be minimized** through better design (e.g. of swimming pools, play equipment and ski runs), safety information (e.g. dangers of diving into shallow water, training of rugby coaches) and sports-wide awareness.
- **Early detection and treatment can reduce the prevalence of spinal TB** (20), as well as spinal tumours arising from cancer.
- **Improved nutrition reduces the incidence of spina bifida and other neural tube defects** (21). Voluntary periconceptional oral folate supplementation (three months before and after conception) has been shown to reduce the rate of infants being born with neural tube defects, including spina bifida (22, 23). Many countries that have a policy of supplementation of wheat flour with folic acid have also seen a fall in the incidence of spina bifida (24–27).

### 5. Spinal cord injury is survivable

- **Appropriate pre-hospital care is vital for immediate survival.** Quick recognition, early evaluation and appropriate manage-

ment of suspected SCI are required. Pre-hospital management in traumatic SCI requires: a rapid evaluation, including measurement of vital signs and level of consciousness; initiation of injury management, including stabilization of vital functions, immobilization of the spine to preserve neurological function until long-term spinal stability can be established, and control of bleeding, body temperature and pain; and prompt and safe access to the health-care system. People should **ideally arrive in an acute care setting within two hours**, which relies on adequate emergency and rescue services.

- **Acute care ensures stabilization.** Acute care may involve surgical intervention or conservative management, but accurate diagnosis of SCI and co-occurring conditions is the vital first step. Many factors should be taken into consideration to determine the most appropriate management approach, including level of injury, type of fracture, degree of instability, presence of neural compression, impact of other injuries, surgical timing, availability of resources such as expertise and appropriate medical and surgical facilities, and benefits and risks. In all cases, people with SCI and their family members should be given an informed choice between conservative and surgical management.
- **Ongoing health care maintenance is required for survival and quality of life.** An individual **can avoid or survive the complications of SCI, such as urinary tract infections and pressure ulcers, remain healthy and enjoy a long and full life with** access to ongoing health care. People with SCI often have a narrower margin of health, for example, a raised risk of chest infections and cardiovascular disease. Without access to basic health care, together with products such as catheters and appropriate cushions followed up by advice on healthy living, a person with SCI is more likely to die prematurely.

## 6. Spinal cord injury need not prevent good health and social inclusion

A person with SCI who has access to health care, personal assistance if required, and assistive devices should be able to return to study, live independently, make an economic contribution, and participate in family and community life.

- ***Once stabilized, there is a need for access to relevant acute and post-acute medical care and rehabilitation services***, to ensure that functioning is maximized and that the individual can become as independent as possible. There are different models of service delivery, but specialist centres have been shown to reduce costs, result in few complications, and result in fewer rehospitalizations, compared to nonspecialized services. People with SCI give high priority to achieving control of bladder and bowel functions. Therapy can enhance function in lower and upper limbs and teach techniques for achieving independence in everyday activities. Mental health services and advice are important: depression is associated with fewer improvements in functioning and increased rate of health complications. Information and support with sexual and reproductive health needs should also be part of rehabilitation.
- ***Appropriate assistive devices are a vital component of rehabilitation***. For example, more than 90% of people with SCI require some form of wheelchair. These must be appropriate for the individual and for the setting. Other assistive technology needs include modifications in and around the home, environmental control, and sometimes communication systems for people with tetraplegia.
- ***Services should support return to education and employment***. Self-help groups, accessible buildings and transport, vocational rehabilitation and antidiscrimination measures can ensure that children and adults can

return to study, live independently, make an economic contribution and participate in family and community life.

## Recommendations

### 1. Improve health sector response to spinal cord injury

This requires: building capacity of the health and rehabilitation workforce; strengthening prevention and early response services; ensuring that appropriate medical services and rehabilitation services are available and accessible; improving coordination to enhance effectiveness and save costs; extending health insurance coverage so that SCI does not lead to catastrophic health expenditure; and identifying strategies for the supply of appropriate assistive technology and health products.

### 2. Empower people with spinal cord injury and their families

People with SCI need information so that they can take responsibility for their own health care after discharge. Information should be shared with family members during rehabilitation. Support for family members and other caregivers can prevent stress and burnout.

In high-income countries, an independent living model of personal assistance can be empowering and cost effective for people with SCI who have high support needs. Community-based rehabilitation (CBR) is important in low-income settings. In all settings, social networks, self-help groups and disabled people's organizations can promote empowerment and participation. Access to physical activities and sport can promote both physiological and psychological well-being.



### 3. Challenge negative attitudes to people with spinal cord injury

As part of general disability awareness campaigns, this can involve a range of interventions, including undergraduate education for doctors and other health professionals, classroom activities to reduce stigma, and awareness campaigns through media.

### 4. Ensure that buildings, transport and information are accessible

This requires: enforceable national access standards; teaching architects and designers about universal design; improving access to social housing; promoting “universally designed” bus rapid transport; mandating accessibility for private taxis; and using organizations of persons with disabilities to consult on accessibility and monitor progress.

### 5. Support employment and self-employment

Vocational training, flexible working hours, supported employment, and community-based rehabilitation projects with a focus on livelihood are all promising options for people with SCI returning to work. Social protection schemes should be available, depending on the setting and the economic status of the individual, but should not act as a disincentive to return to work.

### 6. Promote appropriate research and data collection

There is a pressing need to both increase and improve routine data collection and research on SCI. Disaggregated statistics on SCI, using standardized ICECI terminology, can assist incident trend analysis and help in monitoring of policy responses. SCI registries, which compile data directly from hospitals, together with longitudinal population-based cohort studies covering major life areas, are the best ways of collecting

SCI data. At service level, data are required on costs, outcomes and cost/benefits.

## Next steps

Implementing the recommendations requires the involvement of different **sectors** – health, education, social protection, labour, transport and housing – and different **actors** – governments, civil society organizations (including organizations of persons with disabilities), professionals, the private sector, and people with SCI and their families. Sectors and actors need to work together because multidisciplinary teamwork will maximize success. It is essential that countries tailor their actions to their specific contexts. Where countries are limited by resource constraints, some of the priority actions, particularly those requiring technical assistance and capacity-building, can be included within the framework of international cooperation on disability and development.

## Governments can:

- invest in effective primary prevention programmes, which are evidence-based and respectful of people with SCI;
- improve provision of health, rehabilitation and support services for people with SCI;
- promote standards for national SCI data collection, including centralized SCI registries;
- ensure that appropriate insurance schemes exist that can protect people against the costs of injury;
- support public awareness, information and education initiatives that challenge negative attitudes to disability;
- adopt appropriate accessibility standards, covering housing, transport and public buildings;
- ensure that education policies enable children and adults with SCI to attend school and university on the same basis as others;

- ensure access to vocational rehabilitation to help people with SCI prepare for work;
- adopt antidiscrimination legislation in line with the CRPD.

### **Health and social care professionals and their organizations can:**

- offer appropriate SCI health care, with a coordinated multidisciplinary approach that includes people with SCI and their family members;
- empower people with SCI and their family members so that they are able to look after their own health to the greatest extent possible;
- include SCI topics in the training curriculum for medical and allied health professionals to raise awareness about SCI and promote SCI research;
- undertake research to determine the best possible rehabilitation measures to restore function in different contexts.

### **Disabled people’s organizations and nongovernmental organizations can:**

- promote development of peer networks and self-help organizations, including support for personal assistance schemes;
- contribute to public awareness, information and education initiatives that challenge negative attitudes to disability;
- support people with SCI to access sporting, religious, cultural and leisure opportunities;
- help educate and empower people with SCI and their families on topics of health maintenance, assistance and support, housing, accessibility and mobility, education and employment;
- develop community-based rehabilitation initiatives in resource-poor and remote settings.

### **Service providers can:**

- help strengthen existing (and support the

establishment of new) resource-sensitive, appropriate and timely SCI health-care services;

- collect internationally comparable SCI information and make these data available in annual reports published on the Internet in a searchable manner so that data can be easily located;
- help ensure a smooth transition between inpatient, outpatient and community-based care through establishment of a coordinated, integrated and multidisciplinary service approach;
- engage people with SCI and their family members as partners in service planning and delivery, provide them with information and include them in decision-making, planning, goal-setting, and monitoring and evaluation.

### **Academia can:**

- increase the evidence base for interventions by fostering SCI research;
- engage with policy-makers and other key stakeholders to promote the implementation of the Report’s recommendations;
- promote access to specialist training to ensure an adequate supply of suitably trained health professionals;
- ensure that human rights issues related to disability are included in undergraduate curricula for teachers, doctors and professions allied to medicine;
- remove barriers to the participation of people with SCI in tertiary education and research.

### **The private sector can:**

- invest in the development of appropriate and affordable assistive technologies;
- ensure that products and services are accessible to people with disabilities, including people with SCI, in sectors such as health, sport, education;

- adopt universal design for new products and services;
- employ people with SCI, ensuring that recruitment is equitable, that reasonable accommodations are provided, and that employees who become SCI are supported to return to work.

### People with spinal cord injury and their families can:

- educate themselves about SCI health maintenance issues;
- participate in peer support and self-help programmes;
- contribute to community education and awareness activities;
- avail of opportunities to make an early return to education and employment;
- where appropriate, consider re-training and developing self-employment activities to improve livelihood opportunities.

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## Conclusion

While the incidence of traumatic and non-traumatic SCI can and should be reduced, there will always be new cases of SCI. SCI will continue to affect mainly individuals in the prime of life. Ensuring an adequate medical and rehabilitation response, followed by supportive services and accessible environments, will help minimize the disruption to people with SCI and their families. These measures will also reduce the overall costs to society, in terms of dependency and lost productivity, and to the individual, in terms of lower self-esteem and impaired quality of life. SCI is preventable, survivable and need not preclude health and social inclusion. But action by governments and other stakeholders is urgently required. Without effective action, SCI will remain, all too often, a catastrophe.

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### Methods used in systematic reviews on epidemiological outcomes (incidence, prevalence, etiology, mortality, cost)

The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement was used as guideline to ensure a transparent and comprehensive reporting of the systematic review and meta-analyses (1). PRISMA is endorsed by leading organizations and medical journals (2).

#### Search strategy

The Pubmed/Medline and EMBASE, the Latin American and Caribbean Health Sciences Literature (LILACS), the Indian Medlars Centre (IndMed) and the African Index Medicus (AIM) databases were searched for relevant publications between January 1<sup>st</sup> 2000 and August 15<sup>th</sup> 2012. In this review, spinal cord injuries with traumatic and non-traumatic origin were included as defined in Chapter 4 and classified by the International Spinal Cord Injury Data sets (3–5). The databases were searched using the free search terms ‘*spinal cord injuries*’, ‘*spinal cord injury*’, ‘*spinal cord lesion*’, ‘*paraplegi\**’, ‘*tetraplegi\**’, ‘*quadriplegi\**’, ‘*traumatic spinal cord injury*’, ‘*spinal cord damage*’ and ‘*spina bifida*’ and the abbreviations ‘*SCI*’, ‘*TSCI*’ and ‘*NTSCI*’. Further outcome-related free terms included ‘*prevalence*’, ‘*incidence*’, ‘*epidemiology*’, ‘*cause of*’, ‘*cause of death*’, ‘*cost\**’, ‘*aetiology*’, ‘*etiology*’ and ‘*mortality*’. The full text was searched using the MeSH terms and subject headings for SCI ‘*spinal cord injury*’, ‘*paraplegia*’, ‘*quadriplegia*’ and ‘*spinal dysraphism*’, and outcomes ‘*causality*’, ‘*epidemiology*’, ‘*incidence*’, ‘*prevalence*’, ‘*mortality*’, ‘*etiology*’, ‘*cause of death*’ and ‘*costs and cost analysis*’ if the databases allowed. The literature search was performed without any language restrictions, the MeSH term search was restricted to humans, the free term search was without restrictions, and only papers with abstracts available were included.

In addition reference lists of systematic reviews and literature summaries retrieved were screened for further publications, and an online hand search was performed for epub, ahead of print, online first papers in journal issues from 1 August 2012 to October 2012 (as available online on 8 October 2012). Journals screened were *Spinal Cord*, *Journal of Spinal Cord Medicine*, *Spine*, *Journal of Rehabilitation Medicine*, *Journal of Neurotrauma*, *Archives of Physical Medicine and Rehabilitation*, *PM&R (American Journal of Physical Medicine & Rehabilitation)*, *Epidemiology*, *International Journal of Epidemiology*, *American Journal of Epidemiology*,

*European Journal of Epidemiology, Journal of Epidemiology & Community Health, Journal of Clinical Epidemiology, European Spine Journal, Journal of Bone & Joint Surgery, Acta Orthopaedica Scandinavica, Asian Spine Journal, Global Spine Journal, Journal of Neurosurgery: Spine, Neurology India, International Journal of Technology Assessment in Health Care, Journal of Evaluation in Clinical Practice, and Journal of Health Services Research & Policy.* Finally SCI registry web sites were searched for data. Relevant publications with a publication date after 1 January 2000 that were found by random hand searches during the further development process of the report were used to supplement information in the corresponding sections. In isolated cases regarding the outcome 'cost', particularly important publications from before 2000, which were retrieved by screening the reference list of publications, were also included.

### Inclusion criteria

After a duplicate check, titles and abstracts of the obtained results were screened by two reviewers to determine eligibility for inclusion in the systematic review. In case eligibility could not be resolved based on the abstract, full length articles were obtained, translated where necessary and reviewed. Uncertainties were resolved by group consensus consisting of five researchers. For the outcome 'incidence' and 'prevalence', papers were included in the review if they: (1) described the population in the context of the general population; and (2) included main etiological subgroups (paraplegia, tetraplegia, TSCI, NTSCI, SB). For 'mortality' papers had to at least define one or more of the following: (1) mortality rates (stratified or not); (2) relative mortality; (3) standardized mortality ratios (SMRs); and (4) life expectancy. In the case of 'etiology', studies were included if they reported on: (1) TSCI or NTSCI; (2) distribution of TSCI and

NTSCI cause of injury by subspecifications (i.e. car crashes, sport, violence); and (3) percentages of subgroups. For comparative analysis, etiology data were reclassified using the classification recommended by ISCoS (3, 5) where needed.

### Exclusion criteria

For all outcomes, studies were excluded if they exclusively reported on one SCI condition subgroup (osteochondrodysplasia, neurosyphilis, poliomyelitis, HTLV-infection, hereditary spastic paralysis, locked-in-syndrome, flaccid paralysis, Brown-Sequard syndrome, central cord syndrome, SCIWORA, malignant spinal cord compression), specific complications or co-morbidities (after vascular or spine surgery, cancer), ethnic minorities and employment backgrounds (veterans), single specific circumstances (work-related SCI) if not representative of the whole population, and costs treatment comparisons or sub-treatments (thrombosis, cauterization, drugs). The same was applied for single case registries (e.g. car crash in trauma registries) or case studies. In the case of spina bifida, data were only extracted from papers reporting incidence data and, when available, from pre- and post-fortification studies. Studies were further excluded if data reporting was incomplete (i.e. number of deaths and SCI cases missing).

For the US Spinal Cord Injury Model System data were primarily extracted from the 2011 report as this proved to be richest and most detailed data presentation in terms of stratification across sociodemographic and time domains (6). In the case of foreign language papers that had met the eligibility criteria, the group screened the English abstracts and decided on the most representative studies to be translated for data extraction. Where there were duplicate or overlapping publications, the most recent and/or comprehensive study was included in the systematic review.

## Data extraction

Data were extracted from the full-length papers on main study characteristics, information regarding the inclusion and exclusion criteria, and all relevant data towards the outcomes (incidence, prevalence, etiology, mortality, cost). The quality of the data extraction was tested using existing systematic reviews retrieved by the search to cross-check data reported. Final summary table data were again cross-checked and compared to the original reporting papers by three group members. Where relevant data were only available graphically (e.g. a Kaplan–Meier plot for cumulative survival), scanned graphs were converted to data using the graph digitizer software. Furthermore, for studies that provided information on the total number of TSCI or NTSCI cases over a given time period in a well defined catchment area (mostly country), but not incidence rates, country-specific population size estimates were obtained from available Internet resources (country-specific National Statistical Office or Global Burden of Disease database) to estimate crude incidence rates.

## Recalculation of estimates

In cases where population averages were not available, we derived population average estimates using reported stratified estimates that were weighted for the relative population of the respective strata.

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## Figure 2.5. Distribution of traumatic SCI by WHO region

Studies reporting on TSCI etiology in adult and mixed adult/paediatric populations were selected for calculation of regional etiology sum scores based on a variety of criteria. When available, nationwide or largest studies from most recent years were selected, but only those that reported on both road traffic crashes and falls. Overlap in years reported led to exclusion of studies with lesser stratification across etiologies or reporting of etiology type in the category 'other'. For the USA the most-recent NSCISC 2011 annual report (6) was used as primary data source, also to avoid issues of data overlap by year and subgroups used in specific studies relying on Model Systems data.

Regional estimates for the overall etiology of TSCI were derived in two steps. First, a country-specific TSCI etiology was derived using the weighted-average distribution of causes by factoring in the sample size of the available studies. Second, a regional estimate of TSCI was calculated using the weighted-average distribution for cause-specific TSCI by country by factoring in the 2011 population size of countries that provided data. Population data were taken from the online resource of the United Nations statistical office (7). Of note, available data for Taiwan, China (8), were used to calculate the estimate for China, but they had little impact on the overall estimate given the relatively small sample size.



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8. Wu JC et al. Effects of age, gender, and socio-economic status on the incidence of spinal cord injury: an assessment using the eleven-year comprehensive nationwide database of Taiwan. *Journal of Neurotrauma*, 2012, 29:889-897. doi: <http://dx.doi.org/10.1089/neu.2011.1777> PMID:21510819

### Limitations of the data sources used in Chapter 2

While all efforts have been made to use the best available data, there are several limitations in the data used in this chapter notably:

- variation in SCI case definition and the inclusion criteria;
- variation in representativeness of the available SCI data. The actual representativeness of the data is not always evident, i.e. whether national statistics draw on national, regional or subregional data;
- variation in the level of completeness of the collected (local or national) data;
- inadequate quality of methodological reporting.

Several specific limitations were identified related to the main indicators used in this report. They are as follows:

- *Incidence*: Source population of cases (catchment area) is often poorly defined, particularly in studies reporting on regional data, multicentre or single centre data (e.g. it is not always known if the hospital is the only regional referral centre for SCI). Furthermore, for incidence of TSCI, it is often unclear whether individuals that die from SCI at the time of injury are included. For NTSCI incidence, it is frequently unclear if people identified with SCI at the end-of-life care are included.
- *Prevalence*: The reference population of cases is often poorly defined. Most countries do not have direct prevalence data available, and proxy data are difficult to access (e.g. insurance data, disability benefit data). As a result prevalence estimates are frequently derived from modelling studies that rely on a weak evidence base, involve bold assumptions, and hence have a large level of uncertainty.
- *Mortality*: Methodological criteria and procedures for inclusion and exclusion of cases in the evaluation of cumulative mortality (e.g. Kaplan–Meier method) or modelling of mortality rates or risk factors for mortality (time to event analysis, Cox regression) are commonly not described. In particular, few studies report on loss to follow-up and the completeness of mortality ascertainment (right censoring). Furthermore, it is often not clear if early mortality cases are included in analysis (left censoring).
- *Etiology*: Future studies should more strictly adhere to the international recommendations of ISCoS on the classification and hierarchical reporting of TSCI and NTSCI etiology. In addition, TSCI cases related to work and self-harm (suicide attempts) need systematic documentation (i.e. on top of the ISCoS classification; falls stratified by work and suicide, etc).



## Technical appendix C

### Meta-analysis of spina bifida data

A random effects meta-analysis on the extracted annual incidence\* data for spina bifida was conducted to derive a summary estimate for three types of available data. Data types, in increasing order of completeness and preferential usage in the analysis, included live birth data only; live and stillbirth data; and live, stillbirth, and termination of pregnancy data. Meta-analyses were conducted with the statistical package STATA, version 12.1, using the command 'metan'. The annual incidence rates with standard errors were used as point estimates and measures of variance for individual studies, respectively. Results of the analyses are graphically displayed as Forest plots and are stratified by data type.

Some of the variation observed among reported incidence rates could be due to several factors, including race, socioeconomic status, measurement techniques, and cultural influences (1, 2). To identify the impact of the observed variation on overall rates, a sensitivity analysis was conducted by excluding those studies that appeared to be particularly heterogeneous compared to the majority of studies, namely the study conducted by Alasfoor et al. in Oman (3) and studies for China conducted by Li et al. (4, 5). When excluding only the Oman study, the incidence rate of spina bifida dropped to 7.4/10 000. Exclusion of the two studies by Li et al. resulted in an overall incidence rate of 8.4/10 000, while exclusion of both the Oman study and the two China studies resulted in an incidence rate of 7.2/10 000.

A subgroup analysis was performed, in addition to the meta-analysis results, that considered the impact of the type of data used in each study included in the meta-analysis for incidence rate of spina bifida. The subgroup analysis revealed that the incidence rate observed among those studies using live birth data only was 4.5/10 000, compared to the incidence rate calculated including all studies regardless of data type, which was 8.4/10 000.

\* *Note:* In the literature on spina bifida, the terms 'prevalence' and 'incidence' are used inconsistently. Rothman et al. (6) define the proportion of babies born with some malformation as a prevalence proportion and not an incidence rate. The incidence of malformations is then the occurrence among the population of embryos. Nonetheless, for this report the term 'incidence' is used when reporting rates of spina bifida, as studies which used different data types, including data on terminations of pregnancy, were included.

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## Technical appendix D

### Meta-analysis of the effect of folic acid food fortification on spina bifida incidence rates

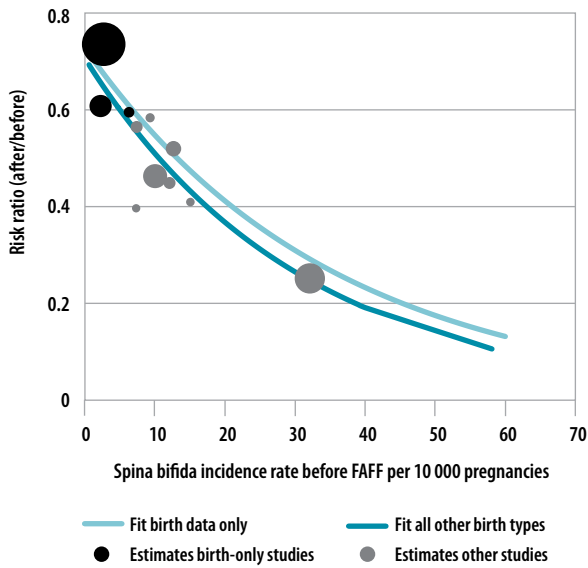
The burden (additional cases of spina bifida pregnancies due to the lack of folic acid food fortification (FAFF)) was estimated under the following assumptions and considerations: the global number of live births serves as a proxy for all pregnancies (including spontaneous abortions, stillbirths, and terminations of pregnancy (TOPs)) because spina bifida is a relatively rare condition. Therefore undetected cases would not have a large effect on the estimated incidence and FAFF would have a similar impact on incidence of spina bifida worldwide. For the calculation of burden, regional estimates of spina bifida background incidence rates were calculated to address regional variation so as to obtain a more precise estimate.

The estimated number of potentially preventable spina bifida pregnancies was based on the effect size of FAFF calculated from only those studies that reported incidence rate (IR) of spina bifida in live births, because worldwide birth data were only available for live births.

Additionally, a meta-regression was performed to determine if any of the between-study heterogeneity could be explained by certain measured covariates, namely incidence rate pre-FAFF and type of data used (live birth only, live, stillbirth or TOPs). The meta-regression was performed using STATA, version 12.1, with 'metareg' command. Results from meta-regression suggested that the incidence rate of spina bifida before FAFF legislation was significantly associated with effect of FAFF. However, no significant association was observed between type of birth data used and effect of FAFF. Overall, the model explained 92% of the heterogeneity seen in the original meta-analysis (see [Figure D.1](#)). The impact of background incidence rate pre-FAFF on the effect size of FAFF was taken into consideration when calculating the number of potentially avoidable spina bifida pregnancies; this information was obtained from the meta-regression. Therefore, if the burden of spina bifida was estimated using incidence rates and effect sizes calculated from live birth data only, potentially 37 979 pregnancies with spina bifida could be prevented.

Since only live births were included, it is likely that the number of potentially preventable pregnancies is underestimated for several reasons. For example, a pregnancy may be more likely to be terminated if there is a case of spina bifida. Also, although the literature does not suggest that there is an increased risk of stillbirths in pregnancies with spina bifida, the lack of information on stillbirths affected by spina bifida might cause an attenuation of the true incidence.

**Figure D.1. Spina bifida incidence rates before FAFF and the effect of FAFF (risk ratio)**



## ***Accessibility***

The extent to which an environment, service or product can be used by as many people as possible, and in particular by people with disabilities.

## ***Accessibility standard***

A standard is a level of quality accepted as the norm. The principle of accessibility may be mandated in law or by treaty, and then specified in detail according to regulations, standards or codes, which may be compulsory or voluntary.

## ***Assistive device or technology (AT)***

Any item or piece of equipment, whether acquired commercially, modified or customized, that is used to increase, maintain or help a person to perform a task or activity.

## ***Community-based rehabilitation (CBR)***

A strategy within general community development for rehabilitation, equalization of opportunities, poverty reduction, and social inclusion of people with disabilities, that is implemented through the combined efforts of people with disabilities, their families, and relevant governmental and nongovernmental health, education, vocational, social and other services.

## ***Co-morbidity***

An additional health condition that an individual may also experience, which is independent of and unrelated to the primary health condition.

## ***Convention on the Rights of Persons with Disabilities (CRPD)***

An international treaty, adopted at the United Nations in 2006, that specifies both general human rights principles of dignity, nondiscrimination, participation, accessibility and equality for persons with disabilities, as well as specific human rights relating to all areas of social life – family and community, education, employment and access to health and social resources. CRPD has an explicit social and economic developmental dimension.

## ***Disability***

In the ICF, an umbrella term for impairments, activity limitations and participation restrictions, denoting the negative aspects of the interaction between an individual with a health condition and environmental and personal factors.

## ***Enabling environments***

Physical and human-built environments that support a person's participation



through the removal of barriers and the provision of facilitators.

### **Environmental factor**

In the ICF, any feature of the physical, social and attitudinal environment in which people live and conduct their lives, e.g. products and technology, the natural environment, support and relationships, attitudes and services, systems and policies.

### **Functioning**

In the ICF, a term for body functions, body structures, activities and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors). The term 'function' refers only to the functions of the body.

### **Health condition, secondary**

An additional health condition that an individual with a primary health condition may experience and that arises from an increased susceptibility or vulnerability caused by the primary health condition, e.g. pressure ulcers.

### **Impairment**

In the ICF, a significant deviation in body structure or physiological function of body systems (including mental functions), based on statistical population norms.

### **Incidence of SCI**

The number of new cases of SCI during a specified time period.

### **International Classification of External Causes of Injury (ICECI)**

A WHO classification that classifies types of injuries, their circumstances and their causes and that is used for measuring and monitoring the occurrence of injuries.

### **International Classification of Functioning, Disability and Health (ICF)**

A WHO classification that provides a standard language and conceptual framework for the description of health and health-related states of functioning associated with the experience of health conditions.

### **International SCI Data Sets**

Data sets composed of data about core categories of SCI-related physiological and psychological features and quality of life, which are appropriate for use in trials to test novel therapies and rehabilitative strategies and devices.

### **Kneeling buses**

Buses designed to laterally lower on the passenger entrance side for easier access for people with mobility difficulties.

### **Mortality rate**

The proportion of deaths in a defined population or group of individuals in a defined area and period of time.

### **Non-traumatic spinal cord Injury (NTSCI)**

Any damage to the spinal cord from a non-traumatic cause, e.g. congenital/genetic malformations such as spina bifida or acquired damage caused by infection, loss of blood supply (infarction), compression by a cancer

or tumour, or by slow degeneration of the vertebrae because of osteoarthritis.

### **Paratransit**

An alternative mode of flexible private or public transportation (e.g. mini-buses or taxis) that does not follow fixed routes or schedules, designed to meet the transportation needs of people with disabilities, the elderly, or anyone who is unable to use mainstream modes of transportation. Also known as Special Transport Services (STS).

### **Pressure ulcers (sores)**

Localized injuries to the skin and underlying tissue, usually over a bone, that result from pressure alone or in combination with friction and that range from mild sores or wounds to serious tissue destruction.

### **Prevalence of SCI**

The sum total of all cases of SCI found in a given population and at a given time.

### **Progressive realization**

A principle of human rights law that acknowledges that some economic and social human rights – such as the right to health – may be difficult for states to achieve in a short period because of resource constraints, but that requires them to achieve what they can within their means, and to achieve progressively more as resources become available.

### **Prosthetist–orthotist**

A health professional who provides prosthetic and orthotic care and other mobility devices designed to improve functioning. Orthotic care involves external appliances designed to support, straighten or improve

the functioning of a body part; prosthetic interventions involve an artificial external replacement of a body part.

### **Reasonable accommodation**

Necessary and appropriate modifications or adjustments, not imposing a disproportionate or undue burden, to ensure that people with disabilities can exercise their human rights on an equal basis with others.

### **Rehabilitation**

A set of measures that assists individuals who experience disability (or are likely to experience it) to achieve and maintain optimal functioning in interaction with their environment.

### **Respite care**

The provision of short-term, temporary professional replacement caregiving for informal caregivers, such as family members, for people needing care who might otherwise need to be permanently placed in a facility outside the home.

### **Schools – inclusive, integrated, special**

In *inclusive schools*, children with disabilities attend regular classes with age-appropriate peers, follow the curriculum to the extent that is feasible, and are provided with additional resources and support according to need. In *integrated schools*, children with disabilities are provided with separate classes and additional resources within mainstream schools. In *special schools* (also called segregated schools), children with disabilities are provided with specialized services in separate settings from mainstream educational institutions.

## ***Social housing***

Social housing is housing provided, usually by local governments or NGOs, at low cost and on a secure basis to people with housing needs (also called “affordable housing” or “public housing”).

## ***Social protection***

Social programmes that aim to reduce deprivation and unmet need arising from conditions such as poverty, unemployment, old age and disability.

## ***Spinal cord injury (SCI)***

Any injury to the spinal cord from traumatic and non-traumatic causes (see also definitions of traumatic and non-traumatic SCI in this glossary). Damage or trauma to the spinal cord that results in an impairment or loss of function.

## ***Spinal cord injury registry***

A database that collects uniform clinical and other information about spinal cord injury in a population over time to evaluate outcomes for a population for scientific, clinical or policy purposes.

## ***Traumatic spinal cord injury (TSCI)***

Any injury to the spinal cord that is caused by trauma or damage resulting from the application of an external force of any magnitude, e.g. in the event of road traffic crashes, falls or acts of violence.

## ***Travel chain***

All elements that make up a journey, from starting point to destination, including

the pedestrian access, the vehicles and the transfer points.

## ***Universal design***

Principles for the design of products, environments, programmes and services that can be used by all people, to the greatest extent possible, without the need for additional adaptation or specialized design.

## ***Vocational rehabilitation***

Programmes designed to restore or develop the capabilities of people with disabilities to secure, retain and advance in suitable employment, e.g. job training, job counselling, and job placement services.

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“Spinal cord injury need not be a death sentence. But this requires effective emergency response and proper rehabilitation services, which are currently not available to the majority of people in the world. Once we have ensured survival, then the next step is to promote the human rights of people with spinal cord injury, alongside other persons with disabilities. All this is as much about awareness as it is about resources. I welcome this important report, because it will contribute to improved understanding and therefore better practice.”

SHUAIB CHALKEN, UN SPECIAL RAPPORTEUR ON DISABILITY

“Spina bifida is no obstacle to a full and useful life. I’ve been a Paralympic champion, a wife, a mother, a broadcaster and a member of the upper house of the British Parliament. It’s taken grit and dedication, but I’m certainly not superhuman. All of this was only made possible because I could rely on good healthcare, inclusive education, appropriate wheelchairs, an accessible environment, and proper welfare benefits. I hope that policy-makers everywhere will read this report, understand how to tackle the challenge of spinal cord injury, and take the necessary actions.”

TANNI GREY-THOMPSON, PARALYMPIC MEDALLIST AND MEMBER OF UK HOUSE OF LORDS

“Disability is not incapability, it is part of the marvelous diversity we are surrounded by. We need to understand that persons with disability do not want charity, but opportunities. Charity involves the presence of an inferior and a superior who, ‘generously’, gives what he does not need, while solidarity is given between equals, in a horizontal way among human beings who are different, but equal in their rights. We need to eliminate the barriers, construct a way to liberty: the liberty of being different. This is true inclusion.”

LENÍN MORENO, FORMER VICE-PRESIDENT OF THE REPUBLIC OF ECUADOR

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