

Contents

Preface	vii
Acknowledgements	ix
Contributors	xi
1. Understanding spinal cord injury	1
Aim and scope of this report	4
What is spinal cord injury?	4
The medical dimension	4
The historical dimension of spinal cord injury	6
Spinal cord injury as a challenge to health systems and to society	7
Tools for understanding the spinal cord injury experience	7
Overview	9
2. A global picture of spinal cord injury	11
What do we know about spinal cord injury?	13
Prevalence of spinal cord injury	15
Incidence of spinal cord injury	17
Traumatic spinal cord injury	17
Non-traumatic spinal cord injury	22
Mortality and life expectancy	22
Costs of spinal cord injury	26
Data and evidence for spinal cord injury	28
Data sources	28
Information standards	30
Data issues and concerns	31
Definitions and standardization of data	31
Underreporting	31
Other issues	31
Conclusion and recommendations	32
3. Prevention of spinal cord injury	43
Causes of traumatic spinal cord injury	45
Road traffic crashes	46
Falls	49
Violence	49
Causes of non-traumatic spinal cord injury	51
Activities, places and circumstances associated with spinal cord injuries	52

Occupational injuries	52
Sport and recreation-related injuries	55
Natural disasters	58
Conclusion and recommendations	59
4. Health care and rehabilitation needs	65
Understanding the health impact of spinal cord injury	68
Potential complications	69
Health care needs	72
Pre-hospital and acute care	72
Post-acute medical care and rehabilitation	73
Assistive technology	78
Health maintenance	81
Conclusion and recommendations	83
5. Health systems strengthening	93
Unmet needs	95
Health care	95
Rehabilitation	96
Health systems strengthening	97
Leadership and governance	97
Service delivery	98
Human resources	103
Health technologies	105
Health information systems	107
Financing and affordability	109
Research	110
Conclusion and recommendations	112
6. Attitudes, relationships and adjustment	121
Attitudes	124
Wider community attitudes	124
Attitudes of health professionals	125
Assistance and support	126
Informal care	126
Formal care	128
Personal assistants	128
Family relationships	129
Partners	130
Parent and sibling relationships	131
Adjustment to spinal cord injury	132
Conclusion and recommendations	137

7. Spinal cord injury and enabling environments	147
Barriers for people with spinal cord injury	149
Housing	150
Transportation	150
Public buildings	151
Addressing the barriers	151
Cross-cutting measures	151
Housing	153
Transportation	156
Public buildings	157
Conclusion and recommendations	160
8. Education and employment	167
Spinal cord injury and participation in education	170
Addressing barriers to education	171
Legislation and policy	171
Support for children with spina bifida	172
Returning to school after injury	172
Transitions from school	173
Reducing physical barriers	174
Reasonable accommodations	174
Funding education and accommodations	175
Social support	175
Addressing attitudinal barriers	176
Spinal cord injury and participation in employment	177
Addressing barriers to employment	178
Vocational training and supported employment	179
Overcoming misconceptions about spinal cord injury	182
Ensuring workplace accommodations	182
Self-employment	184
Social protection	185
Conclusion and recommendations	186
9. The way forward: recommendations	195
Key findings	197
1. Spinal cord injury is a significant public health issue	197
2. Personal and social impacts of spinal cord injury are considerable	198
3. Barriers to services and environments restrict participation and undermine quality of life	199
4. Spinal cord injury is preventable	199
5. Spinal cord injury is survivable	200
6. Spinal cord injury need not prevent good health and social inclusion	201
Recommendations	201

1. Improve health sector response to SCI	201
2. Empower people with SCI and their families	201
3. Challenge negative attitudes to people with SCI	202
4. Ensure that buildings, transport and information are accessible	202
5. Support employment and self-employment	202
6. Promote appropriate research and data collection	202
Next steps	202
Conclusion	204
Technical appendix A	207
Technical appendix B	211
Technical appendix C	213
Technical appendix D	215
Glossary	217
Index	221