



ONTARIO SPINAL CORD INJURY  
— SOLUTIONS ALLIANCE —  
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**Response to: *Final Report of the Catastrophic Impairment  
Expert Panel to the Superintendent***

Submitted to the Financial Commission Services of Ontario

May 13, 2011

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## Executive Summary

This letter is being submitted on behalf of the Ontario Spinal Cord Injury Solutions Alliance in response to the expert panel's proposed changes to the definition of catastrophic impairment specific to spinal cord injury (SCI). The Ontario Spinal Cord Injury Solutions Alliance is a network of key SCI stakeholders from 70+ organizations including people with SCI, researchers, service providers, physicians, and funders from across Ontario that spans the continuum of care from injury onset through to community reintegration.

It is our opinion that a spinal cord injury resulting in either complete or incomplete paraplegia or tetraplegia is a catastrophic impairment and should be treated as such. Our recommendation therefore is to leave the definition of catastrophic impairment specific to SCI untouched.

Spinal cord injuries are chronic, lifelong disabilities that have devastating consequences on the health and well-being of individuals and their surrounding families. Spinal cord injuries cost the government of Ontario over \$1.38 billion per year.<sup>1</sup> The leading cause of spinal cord injury in Canada is motor vehicle collisions.<sup>2</sup>

The proposed changes would immediately eliminate 55% of the SCI patient population who are not admitted into in-patient rehabilitation from accessing funds they are justly entitled to. An additional percentage of the SCI patient population would also lose access to funding they are justly entitled to due to the erroneous recommendation that clinical tools (or simply one measure within a tool) should be utilized for purposes for which they were never intended.

It is the hope of the Ontario Spinal Cord Injury Solutions Alliance that the points identified throughout this document are seriously considered prior to any changes to the definition of catastrophic impairment specific to SCI.

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<sup>1</sup> Krueger, Hans. The Economic Burden of SCI in Canada. Report commissioned by the Rick Hansen Institute.

<sup>2</sup> Pickett GE, Campos-Benitez M, Keller JL et al. Epidemiology of traumatic spinal cord injury in Canada. *Spine*. 2006; 31(7): 799-805.

## Introduction

The Ontario SCI Solutions Alliance was established in 2007 through the combined efforts of the Ontario Neurotrauma Foundation, the Canadian Paraplegic Association Ontario, and the Rick Hansen Institute. The Alliance is a network of key SCI stakeholders from 70+ organizations including people with SCI, researchers, service providers, physicians, and funders from across Ontario that spans the continuum of care from injury onset through to community reintegration. Please refer to appendix 1 for membership list but do note that not all members have endorsed this response simply due to tight time constraints. Many of the stakeholders that make up our alliance maybe greatly impacted if the proposed changes to the definition of catastrophic impairment specific to SCI are to be implemented. More importantly patients with SCI may be disadvantaged in their opportunity to attain the fullest possible benefit from the services available to them to assist with optimizing their physical health, function and well-being. Please consider the arguments outlined in this document when determining whether changes to the definition of catastrophic impairment specific to spinal cord injury are necessary.

## Recommendation

The proposed changes to the definition of catastrophic impairment are significant and will inevitably lead to the loss of crucial support for many people. The Ontario Spinal Cord Injury Solutions Alliance strongly opposes the expert panel's proposed changes to the definition of catastrophic impairment specific to SCI. **It is of the opinion of the Ontario Spinal Cord Injury Solutions Alliance that a spinal cord injury resulting in either complete or incomplete paraplegia or tetraplegia, is a catastrophic impairment and should be treated as such.** Our recommendation is to leave the definition of catastrophic impairment specific to SCI untouched. If it is deemed necessary to modify the current definition we would appreciate the opportunity to be involved in the consultation process.

## Impact of Spinal Cord Injury

Spinal cord injuries are chronic, lifelong disabilities that have devastating consequences on the health and well-being of individuals and their surrounding families. In addition to the personal tragedies caused by SCI it is also an injury that carries with it substantial economic costs shouldered primarily by the government of Ontario. In Ontario there are an estimated 17,000 people living with traumatic spinal cord injuries with close to 600 new traumatic injuries occurring each year. Spinal cord injuries cost the government of Ontario over \$1.38 billion per year.<sup>3</sup> The leading cause of SCI in Canada is motor vehicle collisions.<sup>4</sup>

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<sup>3</sup> Krueger, Hans. The Economic Burden of SCI in Canada. Report commissioned by the Rick Hansen Institute.

<sup>4</sup> Pickett GE, Campos-Benitez M, Keller JL et al. Epidemiology of traumatic spinal cord injury in Canada. *Spine*. 2006; 31(7): 799-805.

## Expert Panel's Proposed Changes

### 4.1.3 2 (a) – Paraplegia/ quadriplegia

#### **Current Definition**

(2) For the purposes of this Regulation, a catastrophic impairment caused by an accident is,

(a) paraplegia or quadriplegia;

#### **Proposed Revision:**

2. For the purposes of this Regulation, a catastrophic impairment caused by an accident is,

2(a) paraplegia or quadriplegia that meets the following criteria i and ii, and either iii or iv:

- i. The Insured Person is currently participating in, or has completed a period of, in-patient spinal cord injury rehabilitation in a public rehabilitation hospital; and
- ii. The neurological recovery is such that the permanent ASIA Grade can be determined with reasonable medical certainty according to the American Spinal Injury Association Standards (Marino RJ et al. ASIA Neurological Standards Committee 2002. International standards for neurological classification of spinal cord injury. J Spinal Cord Med 2003; 26(Suppl 1): S50–S56)62 and
- iii. The permanent ASIA Grade is A, B, or C or,
- iv. The permanent ASIA Grade is or will be D provided that the insured has a permanent inability to walk independently as defined by scores 0–3 on the Spinal Cord Independence Measure item 12 (indoor mobility, ability to walk <10 m) (Catz A, Itzkovich M, Tesio L, et al. A multicenter international study on the spinal cord independence measure, version III: Rasch psychometric validation. Spinal Cord 2007;45: 275–91) and/or requires urological surgical diversion, an implanted device, or intermittent or constant catheterization in order to manage the residual neuro-urological impairment.

#### **Limitations with Section 2 (a) i**

The panel's recommendation is that in order for the patient to be considered one with a catastrophic impairment the patient must have completed, or be in the process of completing, a period of in-patient rehabilitation at a public rehabilitation hospital. This criterion is a considerable oversight.

A 2010 Rick Hansen Institute report reviewed all qualifying data, both Canadian and international, which estimates actual SCI incidence and prevalence.<sup>5</sup> Based on this evidence it was determined that during 2010 578 people will have suffered traumatic spinal cord injuries in Ontario.

The Health Analytics Branch of the Ministry of Health and Long-Term Care reports that between 2003/2004 and 2007/2008 an average of 261 patients were admitted annually to public rehabilitation hospitals with traumatic SCI.<sup>6</sup> Assuming that these levels remain relatively constant through 2010 when we compare them with the annual incidence estimates a huge disparity presents itself. Only 45% of people having suffered a SCI will go on to complete in-patient rehabilitation! Should this mean that 55% of traumatic spinal cord injuries are considered non-catastrophic? Traumatic SCI patients are not being admitted into in-patient rehabilitation at all for some of the reasons listed below.

- There are only six specialized public rehabilitation hospitals in Ontario (Ottawa, Kingston, Toronto, Hamilton, London, Windsor) that serve the complex needs of patients with spinal cord injuries. Many patients come from rural communities and once their bodies become stabilized following their injury they may choose to complete their rehabilitation at home closer to family in alternate hospital settings.
- Patients with high-level cervical lesions (i.e. C4) are in many cases judged not to be suitable for in-patient rehabilitation due to their extreme limits in functional capability. Also patients with high-level cervical lesions resulting in the need for constant ventilation are not admitted to in-patient rehabilitation simply because the rehabilitation hospitals are not equipped to care for patients with these specific complex needs. These two patient groups, with severely catastrophic injuries, would not legally be considered catastrophic. The lifetime funding these highly dependent patients stand to receive for attendant care would change drastically from \$ 1 million to \$ 36 thousand resulting in a significant decrease in quality of life placing the burden of care on volunteer and family members.
- Often lengthy admission wait-lists exist for specialized rehabilitation hospitals. These delays prevent timely rehabilitation, which may cause frustration and annoyance on the part of the patient. Ultimately the patient may choose alternative options for post-acute care rehabilitation. The Ministry of Health and Long-Term Care reported on wait times for specialized in-patient rehabilitation. Mean wait time in days for traumatic spinal cord injury was 4.3 days. However, 5.7% of admissions waited between 15 and 30 days, and 2.7% of admissions waited more than 31 days.<sup>7</sup>

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<sup>5</sup> Rick Hansen Institute / Urban Futures Institute, The Incidence and Prevalence of Spinal Cord Injury in Canada: overview and estimates based on current evidence, December 2010

<sup>6</sup> Health Analytics Branch. Utilization of Adult In-Patient Rehabilitation Services in Ontario Hospitals 2003/2004 – 2007/2008. MOHLTC, April 2010

<sup>7</sup> Health Analytics Branch. Utilization of Adult In-Patient Rehabilitation Services in Ontario Hospitals 2003/2004 – 2007/2008. MOHLTC, April 2010

As demonstrated above the requirement that patients must be admitted or have completed in-patient rehabilitation at a public hospital fails to capture everyone for whom it is intended. Several groups of patients representing 55% of annual spinal cord injuries do not fit easily into this category. The end result is the level of funding for the crucial services people with SCI require will be significantly compromised creating a marginalized sub-population.

### **Limitations with Section 2 (a) IV**

International standards for the neurological classification of spinal cord injury (ISNCSCI) scores do not represent an absolute; rather, they are more accurately described as indicative. Relying on the ISNCSCI in combination with one spinal cord independence measure (SCIM) item to decipher between catastrophic and non-catastrophic impairment specific to SCI is highly problematic. These criteria will not capture everyone for whom they are intended and again several patient groups would be at risk of losing access to funding for critical services. We have identified the following flaws with the panel's recommended use of ISNCSCI and SCIM.

- Although the ISNCSCI system describes each severity category as “mutually exclusive” there is, in fact significant overlap across the ASIA Impairment Scale (AIS) C & D scores in terms of functional ability. Ultimately the AIS Classification should not be used to differentiate catastrophic vs. non catastrophic SCI as the classification in itself does not differentiate the population discretely. Please refer to appendix 2 (Figure 2, Chapter 6 ISNCSCI Manual<sup>8</sup>), which clearly illustrates this overlap. An alternative method to determine the economical, functional, vocational, and social burden on the individual, family and the healthcare system should be employed to determine catastrophic vs. non-catastrophic SCI.
- Additional contributing factors that accompany SCI but are not captured through ISNCSCI include neuropathic pain, autonomic dysfunction, pressure sores etc. These secondary health complications are a significant contributor to one's dependence following injury. Pressure sores are often acquired in those patients with significant co-morbidities and require significant home care nursing resources. This common secondary health complication must be serviced as it can be life threatening.
- The decision to use the SCIM indoor locomotor item 12 to determine extent of impairment provides an incomplete and inaccurate diagnosis. This item only reflects the ability to walk 10 metres indoors; it does not take into consideration walking speed (e.g. speed of 0.8 m/s is required to cross a street), nor does it consider an individual's ability to walk for longer than 10 metres or outdoors in the community. Lerner-Frankiel, Vargas, Brown, Krusell, and Schoneberger (1986)<sup>9</sup> demonstrated that someone must be

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<sup>8</sup> American Spinal Injury Association, Reference Manual for the International Standards for Neurological Classification of Spinal Cord Injury, Rev. 2003

<sup>9</sup> Lerner-Frankiel MB, Vargas S, Brown M, Krusell L, Schoneberger W. Functional community ambulation: what are your criteria? Clin Management 1986; 6: 12–15.

able to walk for at least 342 metres to be able to access services in their community. Furthermore, the four areas that the SCIM covers (self-care, respiration, sphincter management, mobility) provide a more comprehensive picture of one's ability. To extract and rely on only one indicator (mobility) from four areas that have been validated in the international literature to assess and predict ability is erroneous.

- If one is to differentiate between individuals in the AIS D subgroup more than just an impairment measure **MUST** be employed. An impairment measure will define the injury; however, it will not correlate well with the impact of impairment on one's physical capacity, function and independence. Cost to the individual and the healthcare system is ultimately based on **level of functional ability, independence, co-morbidities, age, pre-existing medical status and body type**. The individual as a whole must be considered rather than one small aspect of daily functioning and the ISNCSCI. The SCIM is one beneficial measure to use to differentiate the AIS D subgroup; however, all three subscales should be used and a threshold for each subscale defined a priori. The threshold should be based on a consensus decision made by knowledgeable rehabilitation specialists who understand the financial demands of the functional deficits acquired as a result of SCI and by specialists who understand how to administer the ISNCSCI and SCIM. For example an individual scoring 7 on item 12 of the SCIM would require third party assistance in acquiring the orthoses for their lower extremities. Thus choosing 0-3 does not differentiate the AIS D subgroup adequately enough to determine eligibility for funding.
- Many types of spinal cord injury, including central cord syndrome, cauda equine, Brown Sequard's syndrome, may potentially be classified as non-catastrophic. This is inaccurate and should never occur because an individual with central cord syndrome for example may easily be able to walk 10 metres; however, the inability to manipulate their hands means they are more dependent compared to someone who cannot walk 1 metre. In differentiating the AIS D subgroup the potential upper extremity deficits that can remain are not considered in this proposal and must be included. Upper limb function is essential for a significant proportion of activities of daily living performance and vocational ability. If upper limb impairment and its impact on functional ability for those who can ambulate is not considered this will leave many individuals with a poor quality of life without adequate third party resources.
- Length of stay (LOS) in both acute care and in-patient rehabilitation has been significantly reduced in the last 5 years, particularly for those individuals who are most functionally and medically stable (AIS D patients). These individuals often have a very short acute care LOS arriving at rehab in some cases within a week of their injury. Canadian Institute for Health Information (CIHI) provides target LOS for specific rehab patient groups based on their diagnosis and functional mobility on admission to rehab.

Patients with traumatic SCI classified as AIS D would likely be given a projected rehab LOS of 44 days. At this time, they would be discharged to the community with a significant need for ongoing medical and rehabilitation services. Although AIS D patients eventually walk, they need substantial out-patient rehabilitation to maximize their functional ability. When discharged from in-patient rehab, most are referred for community or out-patient physiotherapy and occupational therapy, with those who have alternate funding (MVA) often seeking private therapy. Access to publicly funded, specialized out-patient SCI rehabilitation is extremely limited in Ontario, particularly in rural areas where in some cases no such services exist. The result is significant waiting lists for services. If AIS D patients were no longer classified as catastrophic, this would push more individuals into the public system adding more strain and increasing wait times. Denial of services to this group is sub-optimal especially considering the Excellent Care for All Act 2010.

## **Conclusion**

The Ontario Spinal Cord Injury Solutions Alliance strongly opposes the proposed changes to the definition of catastrophic impairment specific to SCI. A traumatic spinal cord injury is by definition a devastating injury that requires support, financial and otherwise, in order to achieve optimal recovery. The additional conditions to the definition of catastrophic impairment specific to SCI the expert panel has recommended are flawed. If implemented, the proposed changes will lead to miscategorising many SCI patients ultimately resulting in significant decreases in quality of life for this population.

The proposed changes would immediately eliminate 55% of the SCI patient population who are not admitted into in-patient rehabilitation from accessing funds they are justly entitled to. What's more an additional percentage of the SCI patient population would lose access to funding they are justly entitled to due to the erroneous recommendation that clinical tools (or simply one measure within a tool) should be utilized for purposes they were never intended to.

It is the hope of the Ontario Spinal Cord Injury Solutions Alliance that the points identified throughout this document are seriously considered prior to any changes to the definition of catastrophic impairment specific to spinal cord injury.

**Exhibit 1: Ontario & Regional SCI Solutions Alliance Membership**

<b>Provincial &amp; Regional SCI Solutions Alliance Membership</b>		
<b>Name</b>	<b>Role</b>	<b>Organization</b>
<b>Michael Johnson</b>	<b>Executive Director</b>	<b>ON SCI Solutions Alliance</b>
Bill Adair	Executive Director	Canadian Paraplegic association Ontario
Kent Bassett-Spiers	CEO	Ontario Neurotrauma Foundation
Dr. Milos Popovic	Chair - Spinal Cord Injury Research	Toronto Rehabilitation Institute
Lee Harding	Director Independent Living	Ontario March of Dimes
Dr. Keith Hayes	Professor	University of Western Ontario
Dr. Tara Jeji	SCI Program Director	Ontario Neurotrauma Foundation
John Shepherd	Person with SCI	
Natalie Cournoyea	Executive Director Patient Care	Toronto Rehabilitation Institute
Dr. Kathy Boschen	Rehab Scientist	University of Toronto
Dr. Terry Bates	Family Doctor	Anne Johnston Health Station
Peter Athanasopoulos	SCI Networks and Service Manager	Canadian Paraplegic Association Ontario
Pamela Berg	Interim Director Community Partnerships Program	Rick Hansen Institute
Sara Guilcher	PhD Candidate	University of Toronto
Wayne Archibald	Operations Manager	Canadian Spinal Research Organization
Lynda Staples	Regional Independent Living Manager	Ontario March of Dimes
Michael Clarke	Person with SCI	
Glenn Barnes		Tetra Society
Lynda Charters	Executive Director	Ontario Wheelchair Sports association
Dr. Charles Tator	Professor of neurosurgery	Toronto Western Hospital
Dr. Anthony Burns	Medical Director Spinal Cord Rehabilitation Program	Toronto Rehabilitation Institute
Dr. Cathy Craven	Physiatrist	Toronto Rehabilitation Institute
Dave Shannon	Human Rights Lawyer	

Ian Parker	Manager Direct Funding	Centre for Independent Living
Dr. Michael Fehlings	Neuro Surgeon	Toronto Western Hospital
Anoushka Singh		Toronto Western Hospital
Gillian Bone	Director Client Services	Canadian Paraplegic Association Ontario
Dr. Nathania Liem	Physician	Windsor Hospital
Dr. Sukhvinder Kalsi-Ryan	Post-Doctoral Fellow Spinal Program	Toronto Western Hospital
Dr. Joseph Lee	Chair and Lead Physician	Kitchener / Waterloo Centre for Family Medicine
Kim Donaldson	Principal	Capital Hill
Gillian Bone	Director Client Services	Canadian Paraplegic Association Ontario
<b>Peter Athanasopoulos</b>	<b>Solutions Alliance Coordinator</b>	<b>Southwest SCI Solutions Alliance</b>
Dr. Dalton Wolfe	Associate Scientist	Lawson Health Research Institute
Jennifer Flemming	Co-Principal / Acute Coordinator	Rick Hansen SCI Registry
Judi Fisher	Executive Director	Cheshire Homes
Nancy Dool-Kontio	Senior Director - Strategic Planning and Integration	Southwest CCAC
Sharon Jankowski	Director of Rehabilitation	Parkwood Hospital
Janet Hickey	Person with SCI	
Mike Mulligan	Person with SCI	
Rebecca McKee	Planning and Integration Specialist	Southwest LHIN
Julie Gagliardi	Coordinator - Rehab and ABI program	Parkwood Hospital
<b>Nathan Hauch</b>	<b>Solutions Alliance Coordinator</b>	<b>HNHB SCI Solutions Alliance</b>
Patti Leonard	Director - Neuroscience Trauma	Hamilton Health Sciences
Jennifer Kodis	Director - Rehab and Seniors	Hamilton Health Sciences

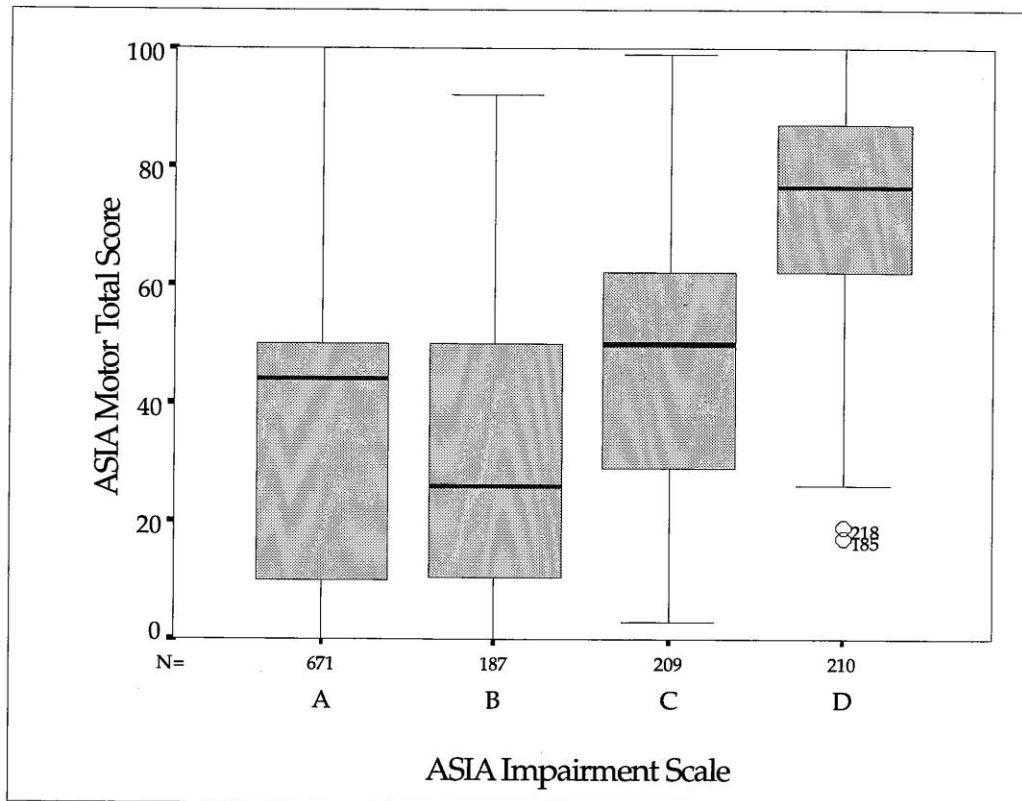
Carol Mishaw	Senior Manager Regional Services	Canadian Paraplegic Association Ontario
Lina Santagiuna	Professor	McMaster University
Rob Murphy	SCI Pilot	Hamilton Health Sciences
Aznive Mallet	SCI Pilot	Hamilton Health Sciences
Paul Rice	Regional Service Coordinator	Canadian Paraplegic Association Ontario
Dr. Brian Drew	Neuro Surgeon	Hamilton Health Sciences
Lucas Milinovich	Manager Spine Unit	Hamilton Health Sciences
Lori Petrie Mulrain	Manager Discharge Planning	Brant Community Health System
Rhonda Caminiti	Discharge Planner	Brant Community Health System
Teri Czajka	Manager Rehabilitation	Hamilton Health Sciences
Dr. Agnes Chmiel	Physiatrist	Hamilton Health Sciences
Chris Pollard	Manager Neurology	Hotel Dieu Shaver, St. Catherines
Sherry Parsley	Director Client Services	HNHB Community care Access Centre
Carol Burgess	Manager Client Services	HNHB Community care Access Centre
Deb Langlois	Manager CCC	St. Joseph's Health Care Hamilton
Liz Mersereau	Program Director CCC	St. Peters Hospital Hamilton
Ernie Jodoin	Advisor Planning and Integration	Hamilton Niagara Haldimand Brant LHIN
Dr. Audrey Hicks	Professor	McMaster University
Garth Greaves	Employment Systems Support Manager	Ministry of Community and Social Services
Kathi Carroll	Chronic Disease Prevention and Management Program Director	Hamilton Family Health Team
Sarah Wojkowski	Chronic Disease Prevention Facilitator	Hamilton Family Health Team

Donna Boyce	Regional Independent Learning Centre	Ontario March of Dimes
Peggy Brown	Supportive Housing	March of Dimes
Cindy McKinnon	CEO	Abel Living Hamilton
Sherry Kerr	Executive Director	Participation House Brantford
Brad Spencer		PATH Employment Services
Mark Mindorff	Passenger Services	DARTS
Marg Whalman	Passenger Services	DARTS
Marla Adams	Manager Tennant Support Services	City of Hamilton
Jake Lawless	Community Rep.	Canadian Paraplegic Association Ontario
Darlene Burkett	Community Rep.	Canadian Paraplegic Association Ontario
Troy Fraser	Community Rep.	Canadian Paraplegic Association Ontario
Ron Rattie	Community Rep.	Canadian Paraplegic Association Ontario
<b>Nathan Hauch</b>	<b>Solutions Alliance Coordinator</b>	<b>Champlain SCI Solutions Alliance</b>
Helen Zipes	Clinical Director of Rehabilitation Services and Family Health Teams	Ottawa Hospital
Kevin Babiluc	Director Client Services	Champlain Community Care Access Centre
Serge Felardeau	Ottawa Community Support Coalition	
Wanda MacDonald	Executive Director	Champlain Community Health Centre
Richard Ruest	Community Link Worker	VHA Health and Home Support
Dr. Vidya Sreenivasan	Physiatrist	Ottawa Hospital
Deborah Andrews	Executive Director	South East Ottawa Community Health Centre
Dr. Lynne MacGregor	Physiatrist	Ottawa Hospital

Toba Miller	Advanced Practice Nurse	Ottawa Hospital
Madelyn Scanlan	Regional Service Coordinator	Canadian Paraplegic Association Ontario
Jane Boardman	Acute Physiotherapist	Civic Hospital Ottawa
Kathy Brett	Flow Coordinator	Ottawa Hospital
Angela Clair	Regional Service Coordinator	Canadian Paraplegic Association
Christine Cercena	Clinical Manager	Ottawa Hospital
Lillina DeSouza-Burr	Co-Coordinator	Rick Hansen SCI Registry
Monique Leburn	Quality Coordinator	Ottawa Hospital
Jossette Naim	Case Manager	Champlain Community Care Access Centre
Nathan Rusthoven	Social Worker	Ottawa Hospital
Terry Gilhen	Community Developer	The In Community
Kathy Riley	Transportation Accessibility Specialist	OC Transpo
Diane Breton	Chair	Senior Transportation Committee
Leanne Anderson	Client Services Manager	MS Society
Candice Botha	Program Manager	Ottawa Independent Living Resource Centre
Bernard Bouchard	Executive Director	Council of Aging of Ottawa
Brian Tardiff	Executive Director	Citizen Advocacy of Ottawa

## Appendix 2: Distribution of ASIA motor scores by ASIA impairment scale grade

Reference Manual for the International Standards for Neurological Classification of Spinal Cord Injury (Rev. 2003)



**Figure 2. Distribution of ASIA motor scores by ASIA Impairment Scale grade. The bar represents the interquartile range (25th-75th percentiles), the black horizontal line is the median value, and the circles indicate outlier values.**