

# SCIO:

A CENTRALLY-FUNDED PROVIDER FOR ONTARIO HEALTH TEAMS



Peer to peer. Strength to strength.

## Viola's Story

*"I thought I was stuck in that hospital forever... When they reached out, it was a blessing. Doors opened for me; opportunities came forward."*

After fracturing her back in three places, Viola Lalonde feared that she would never be able to live an independent life again. A grandmother who was extremely active in her community, Viola wanted to continue to enjoy the freedom and family time she had before sustaining her spinal cord injury (SCI). Her hopes were put in limbo during her recovery process, where she was perpetually moving from hospital to hospital.

*"I was looking into suicide; I was looking at the [hospital] room with no more hope."*

Fortunately, Viola's story changed thanks to Spinal Cord Injury Ontario (SCIO). She met Angela, her Regional Services Co-ordinator, in July of 2018. As Viola says, "she was my angel."

With the help of Angela and SCIO, Viola regained her independence and returned home. SCIO helped her navigate the complex process of applying for funding and making her home accessible, helping with everything from washroom accessibility to cleaning services.

As Viola says, "Before SCIO, I tried social workers – they didn't understand. They kept telling me to sell my home, sell my stuff. But what I wanted was to go home." SCIO made that a reality for Viola, helping her to return to home in a way that worked for her.

SCIO's services and support were delivered with the sensitivity and expertise that comes from lived experience. Through the care she received from SCIO, Viola was able to see the possibility of a new future after spinal cord injury.

*"They gave me life, they honestly did. I feel human again."*

Today, Viola lives a full, independent life in the greater Ottawa area. She spends her time in her community shopping, attending support groups, and staying active through sport. Viola volunteers with SCIO's Peer Support services and is committed to doing all that she can to bring hope and help to others as SCIO and Angela did for her.

## Executive Summary

It is a transformational time with the creation of the Ontario Health Teams (OHT). As a member of an OHT, you find yourself responsible for providing a full and coordinated continuum of care, aimed at improving patient and population health outcomes – as well as patient, family and caregiver experience – all while delivering better value.

Within the diverse populations your OHT will serve, you will invariably be responsible for caring for those with complex conditions such as a Spinal cord injury (SCI). Individuals with a SCI often have a challenging journey through the medical system, from acute care to rehabilitation to community living. They consistently report that while the health care system cares for them clinically, it does not adequately address the complexities of their journey. Spinal Cord Injury Ontario's (SCIO) specialized offering is uniquely positioned to fill this gap.

The costs of managing individuals with SCI are significant. The annual SCI-related health costs in Ontario for hospitalization, physician services, long-term care, home care, and prescriptions are estimated at \$719.3 million. If the typical OHT is serving 175,000 people, we can expect to see approximately 20 new incidences of SCI each year, while serving approximately 440 individuals managing an SCI. This would amount to an **estimated annual cost of \$8.8 million for a typical OHT.**

As a specialist community provider since 1945, **Spinal Cord Injury Ontario effectively optimizes care pathways for individuals managing an SCI.** As a **centrally funded organization**, building a partnership with your OHT means that we can ensure every Ontarian with a SCI has access to the comprehensive care and support they need to live independent, healthy lives post-injury.



At SCIO, we have a proven track record of delivering meaningful quality of life improvements – and lower health care utilization – for individuals living with SCI.



We operate within the clinical setting – embedded in rehab centres – and beyond to improve independence, prevent social isolation, and overall quality of life for patients living with an SCI. For over 75 years, we have been there for our clients and their families, offering support from a genuine, relatable perspective that helps people live a fulfilling life.

With our wraparound services – from peer support to help adjusting to life with a disability – we look at the whole person to improve health outcomes, patient and caregiver experience, and overall wellness. SCIO addresses key social determinants of health to empower people living with SCI and equip them with the skills and support to live an independent life and avoid secondary health complications.

We drive value for Ontario's health care system: by supporting individuals in their return to independence from clinical care; and by preventing secondary complications with individual support between doctor appointments. Our centrally funded services keep individuals healthier and out of hospital, at no additional cost to individual OHTs.

**Working together, we can amplify the effectiveness of your OHT, resulting in people with SCI living fulfilling lives** in their communities, contributing their unique skills and strengths to building a better Ontario for all.

## Spinal Cord Injury in Ontario

Spinal cord injury (SCI) is a complex medical reality that each Ontario Health Team (OHT) must be prepared to manage.



**There are an estimated 36,036 Ontarians currently managing a spinal cord injury**, with an annual incidence of 1,715 Ontarians<sup>1</sup>. This means that an OHT serving 175,000 people can expect to serve over 440 people with an SCI.

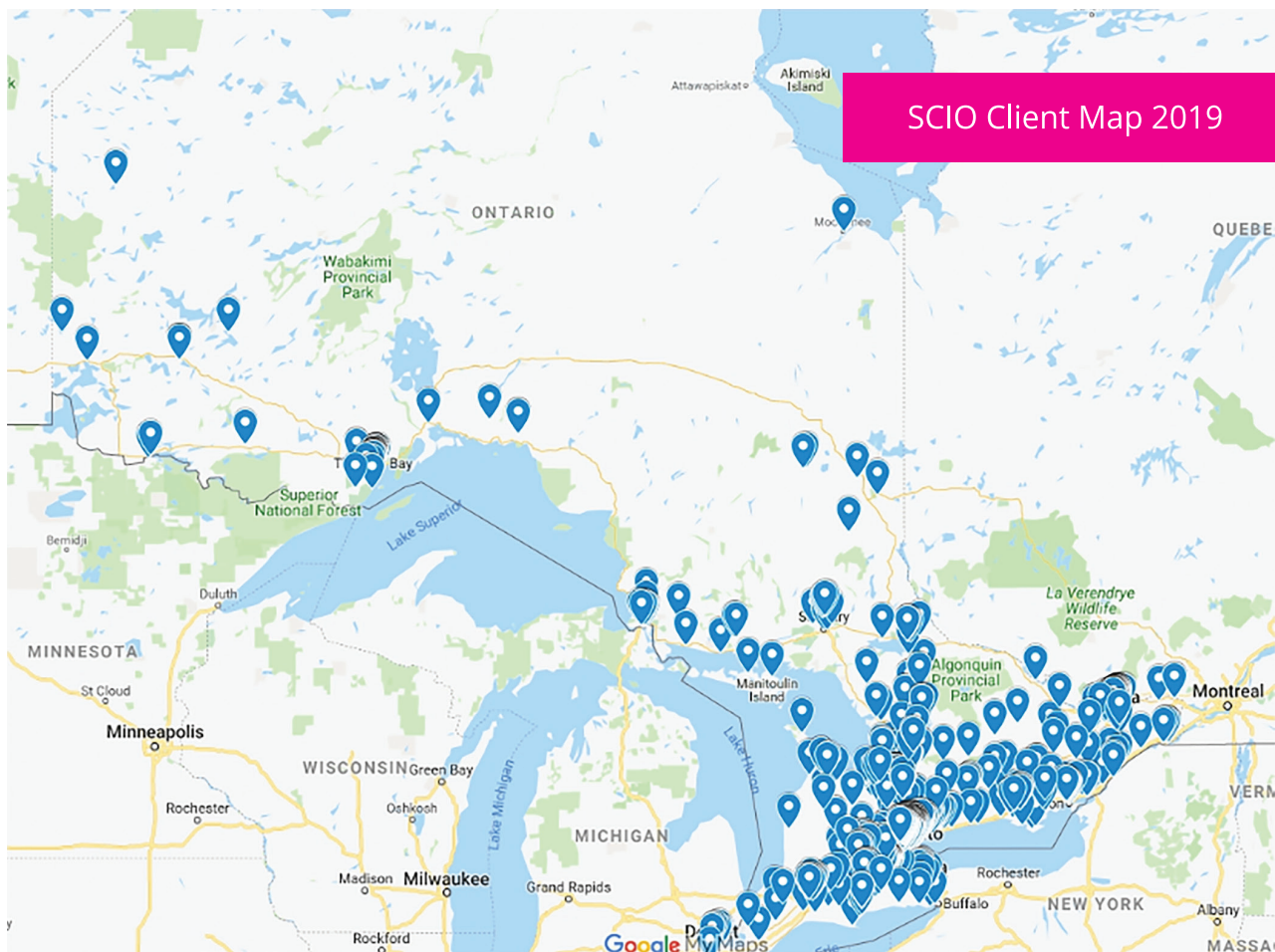
Due to the specialized care required to manage an SCI, **the net lifetime health costs for a patient with an SCI start at \$336,000**. In the incident year for an SCI, the per-case health costs total an estimated \$124,000, with each subsequent year costing approximately \$13,700.<sup>2</sup>

There are also high rates of rehospitalization after an SCI, as **27.5% of patients with SCI are readmitted to hospital due to preventable secondary health complications**; within the first year of injury, more than 50% of people discharged with an SCI may require re-hospitalization due to a secondary complication. Overall, studies have shown that emergency department visits for the SCI population ranges from 110 visits per 100 persons in the first year post-injury to 72 visits per 100 persons in the fifth year.<sup>3</sup> Managing cases involving SCI places a heavy cost on individual hospitals and the health system as a whole<sup>4</sup>, but some of these costs can be avoided with a comprehensive and supportive system of community care.

In total, including some home care and prescriptions, the annual **SCI-related health costs in Ontario for hospitalization, physician services and long-term care are estimated at \$719.3 million**, excluding outpatient rehabilitation, assistive devices, and home and vehicle modifications.<sup>5</sup> Although the highest annual cost is in the first post-injury year, 76% of total costs to the system relate to ongoing care.<sup>6</sup>

This is where SCIO comes in. Our services fill in the gaps between clinical care and hospital visits to improve the overall holistic health and well-being of individuals with an SCI, contributing to better patient and caregiver experiences, and, ultimately, better health outcomes as individuals with SCI are able to re-enter their communities and live more independent lives.

# SCIO: A Community Specialist Provider



Based in Toronto at the Lyndhurst Centre, Spinal Cord Injury Ontario (SCIO) has been serving individuals with spinal cord injury (SCI) and other physical disabilities since 1945, when our founders, having sustained SCI, returned from the Second World War and rejected institutionalization as their lot in life.

SCIO's mission was, and still is, to assist individuals with SCI and other physical disabilities to achieve independence, self-reliance and full community participation with measurable success.

**Funded by Ontario Health, the support provided by SCIO comes at no cost to your OHT.**

With 142 staff, relationships with five dedicated rehabilitation centres, and more than 75 partnerships with local service providers and resources, SCIO is a known and respected entity within the disability field with a reputation for high standards of service delivery and accountability.

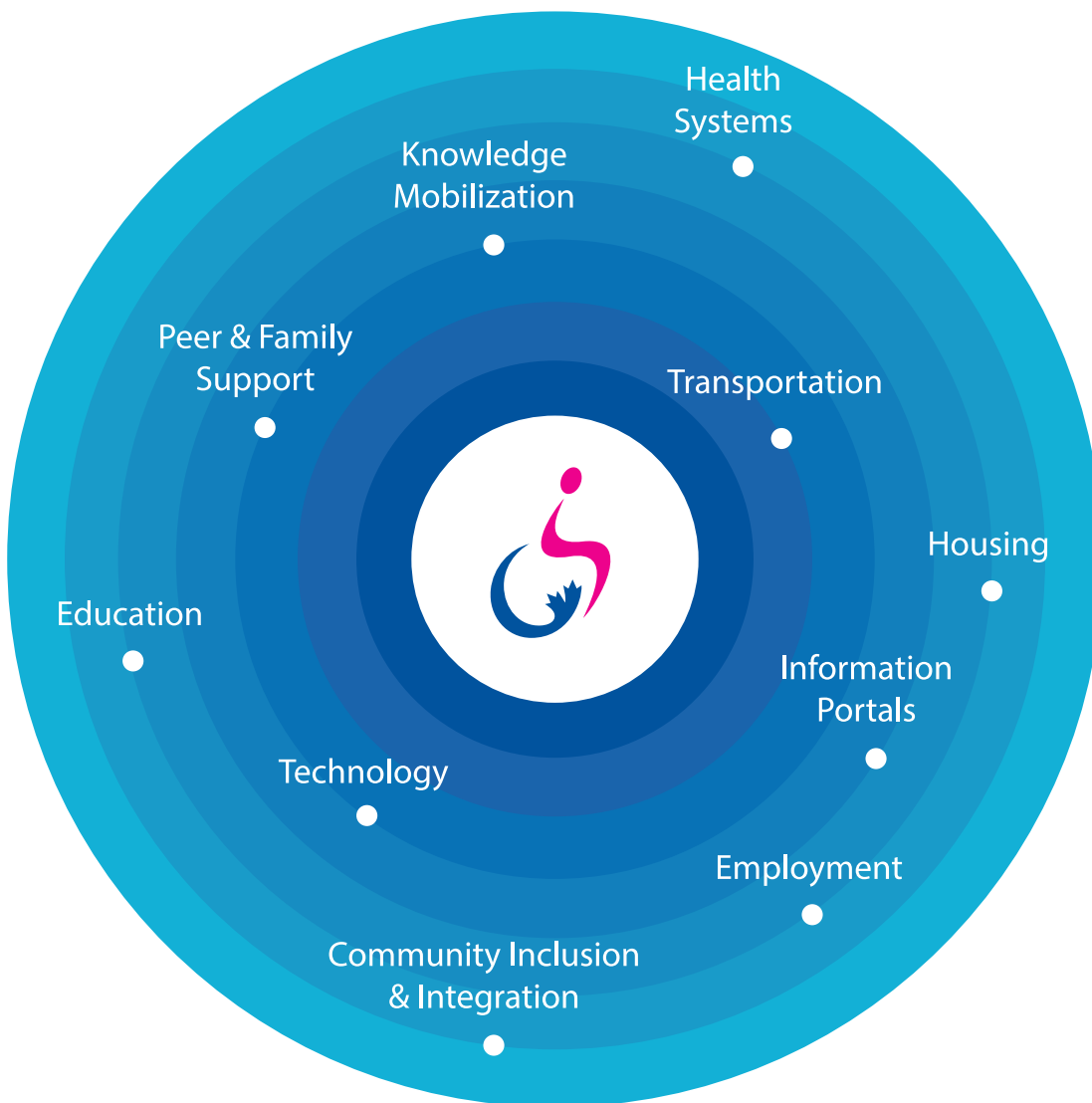
SCIO has served thousands of families and patients with SCI, and we hope to continue our impactful work through a provincial partnership with every Ontario Health Team.

## Holistic Supports for Independent Living

At SCIO, our goal is to support our clients and help them, like Viola, to improve their quality of life. Clinical care is only one part of that equation; **SCIO is there to fill the gaps, providing valuable, holistic supports to clients between and after clinical visits, to help people with an SCI maintain long term health, combat social isolation, and regain their independence.**

Our wraparound services address **key social determinants of health** to supplement and complement the clinical services that will be provided by the OHTs: together, we form a comprehensive health team that improves patient outcomes and experiences.

Wraparound services are key to integrated care and independent living.



## Support Throughout the Client Journey

SCIO's support and services for patients, caregivers, and practitioners span the journey for an individual with SCI.



For many individuals with an SCI, the ultimate goal is to be able to return home and live as independently as possible.<sup>7</sup> However, community barriers in accessibility, transportation, and societal attitudes make it difficult to return to productive life without intervention and key supports.<sup>8</sup>

For someone with an SCI, a home that was once comfortable may now be inaccessible; a job that was once fulfilling may now be out of reach. Facing these challenges alone can be difficult – emotionally, physically, and financially – and can impede an individual's ability to live a rewarding, independent life. SCIO's services, which provide assistance with and information about housing, transportation, employment, and specialized equipment, address these difficulties holistically and respectfully.

*“There is convincing evidence that comprehensive SCI systems of care result in fewer complications, better functional outcomes and lower mortality”<sup>9</sup>*

“

*“SCIO secured a hospital bed and accessible side tables, donated a garage lift, a shower chair and washroom outfitting, and found a contractor to complete the renovations so that I could live independently.”*

- Viola

SCIO's Regional Services Co-ordinators provide a comprehensive system of support. They facilitate needs analysis and goal-setting processes with patients and co-develop rehabilitation plans; they provide counselling, as well as support and resources; and they are there for regular follow-up to ensure that patients' needs continue to be met even after discharge. They maintain relationships with their clients to monitor and evaluate case development on an ongoing basis, including re-assessing and re-evaluating goals and assisting the person with SCI and their family with accessing services based on needs and goals. In short, they are a point-person and provide ongoing support for people with SCI and their families, through their journey.<sup>10</sup>



**Patients with an SCI consistently report that the formal health care system, while effective from an acute care and physical rehabilitation perspective, lacks a “customer-centric” perspective, and does not adequately address the complexities of their journey.** SCIO’s wraparound services are uniquely positioned to fill this gap in the health care system, leveraging decades of specialized experience to amplify the effectiveness of Ontario Health Teams.

SCIO offers a range of services. We are there for our clients and their families, every step of the way. (For a full list, please see the Appendix.)



Expert **regional service co-ordinators** assist with everything from system navigation and referrals, to transportation, to accessing equipment and funding support.



**Virtual information portals** provide province-wide monthly workshops, and SCIO’s **secure virtual integration platform** allows patients to digitally connect with their network of care using a computer, tablet, or mobile phone.



Trained **peer support volunteers** provide an experience-based point of contact, knowledge translation, and supportive advice for clients and family members from point of injury onwards.

## Peer Support

Research has shown that after sustaining an SCI, many people – like Viola – experience social isolation and depression.<sup>11</sup> Often, these issues emerge in full force after discharge, when patients are faced with the often lonely and frightening reality of returning home.<sup>12</sup> At SCIO, we actively work to combat these issues through our Peer Support system: we match our clients with trained volunteers who have lived experience with similar SCI to ensure they and their family are supported throughout their journey.

**80%**

**Of people with SCI experience significant limitations in social participation.**

*“Peer mentoring services from fellow SCI patients...has been shown to promote coping post-SCI”<sup>13</sup>*

Peer mentors help people with SCI understand how to live and work with SCI. They provide information and emotional support related to health care, self-care, employment opportunities, knowledge translation, and coping mechanisms for trauma. They also support the transition to/from rehabilitation and, finally, back home. Peer support has **“been reported as crucial in adjusting to post-discharge life”<sup>14</sup>**

Our Peer Support is unique and targets areas often overlooked by other parts of the health system. Studies show that **“peer-led interventions are usually run outside the formal system of care and fill an important service gap in long-term SCI management”** – “peer mentors provide hope for the future and enable people to **visualize possibilities that they may not have thought achievable, [including]...improving self-efficacy,** perceptions of competence and self-determination.”<sup>15</sup> In fact, research shows that “informal networks serve as essential key players in filling in the gaps that exist within the formal health care system”<sup>16</sup> and are crucial to long term health maintenance.

In the whirlwind of care that follows an SCI, family members struggle as well: feelings of isolation, confusion, and their own trauma can mark their role in a patient’s journey. We understand that a strong and capable support system is essential to a successful patient journey, which is why we expanded our Family Support Program to provide direct services to families in need. **Studies have shown that relatives of people with an SCI benefit equally or more so from peer support than the patient with SCI and should not be overlooked in the recovery process.**<sup>17</sup>

“

*“The person who has sustained an SCI is going to be facing many challenges, but their partners will also be facing challenges. They need support as much as their loved ones.”*

- Sam Russo

*“It’s such a trying time in your life when you find yourself with a spinal cord injury. The future is truly unknown. Being able to see someone who has been at it for a while and has been very successful was extremely reassuring.”*

- Gary Luker  
SCIO Client, Volunteer &  
Tennis Canada Team Athlete

## Benefits of SCIO Support



## Enhanced Impact for Ontario Health Teams



Keep Patients in  
Communities and  
Reduce Hallway  
Medicine



Improve Patient and  
Caregiver Experience



Improve Physical,  
Social, and Mental  
Health Outcomes

For the OHTs, Spinal Cord Injury Ontario's (SCIO) wraparound services support individuals with spinal cord injury (SCI) in transitioning out of clinical care, and keeping them their communities, contributing to the reduction of hallway medicine and to more positive health outcomes.

Studies show that **positive patient self-efficacy is linked to lower health care utilization<sup>18</sup>**, and that **rehospitalizations are preventable through health maintenance strategies like self-management<sup>19</sup>**. SCIO's services are uniquely designed to promote self-efficacy and ensure that clients enter community care with the supports and skills necessary to practice proper health maintenance strategies.

**By complementing primary care services, SCIO's wraparound offerings allow patients to independently manage their injury from their communities, thereby reducing the likelihood of secondary complications and costly rehospitalizations.**

## Conclusion

*"It would have been nice if the hospital came to you directly and said, 'hey, there's this organization that can help you'... patients could feel: 'oh, this is where I could go for help.'"*

We've helped thousands of individuals like Viola, and their families; helping them through their hospitalization, rehabilitation, return to the community, and milestones in between. Unfortunately, when Spinal Cord Injury Ontario (SCIO) is not involved in an integrated and coordinated continuum of care, people with spinal cord injury (SCI) can fall through the cracks.

While OHTs are able to provide excellent clinical care for individuals with SCI, for many in this population, long term health maintenance and wellbeing are dependent on a range of factors, including access to "health information, health promotion/prevention activities, safe housing, nutritious food, a convenient and safe space for physical exercise, social support, and financial resources."

Studies have shown that "individuals who are at greater risk of developing medical complications and secondary conditions... should be targeted for health promotion counseling during every phase of care" and that **"one of the ways rehabilitation**

**professionals and counsellors can provide health promotion service is by partnering with community-based organizations"** who can initiate, organize and facilitate health promotion programs for people with SCI.<sup>21,22</sup> These are precisely SCIO's strengths.

Integrating SCIO as a centrally-funded, province-wide, specialized community provider will improve the patient and caregiver experience while strengthening the overall quality of care and breadth of services that your OHT can offer individuals with an SCI.

By partnering with SCIO, you can help ensure that people like Viola Lalonde make their way out of hospital care and back into their communities, finding new hope and possibility in the process.

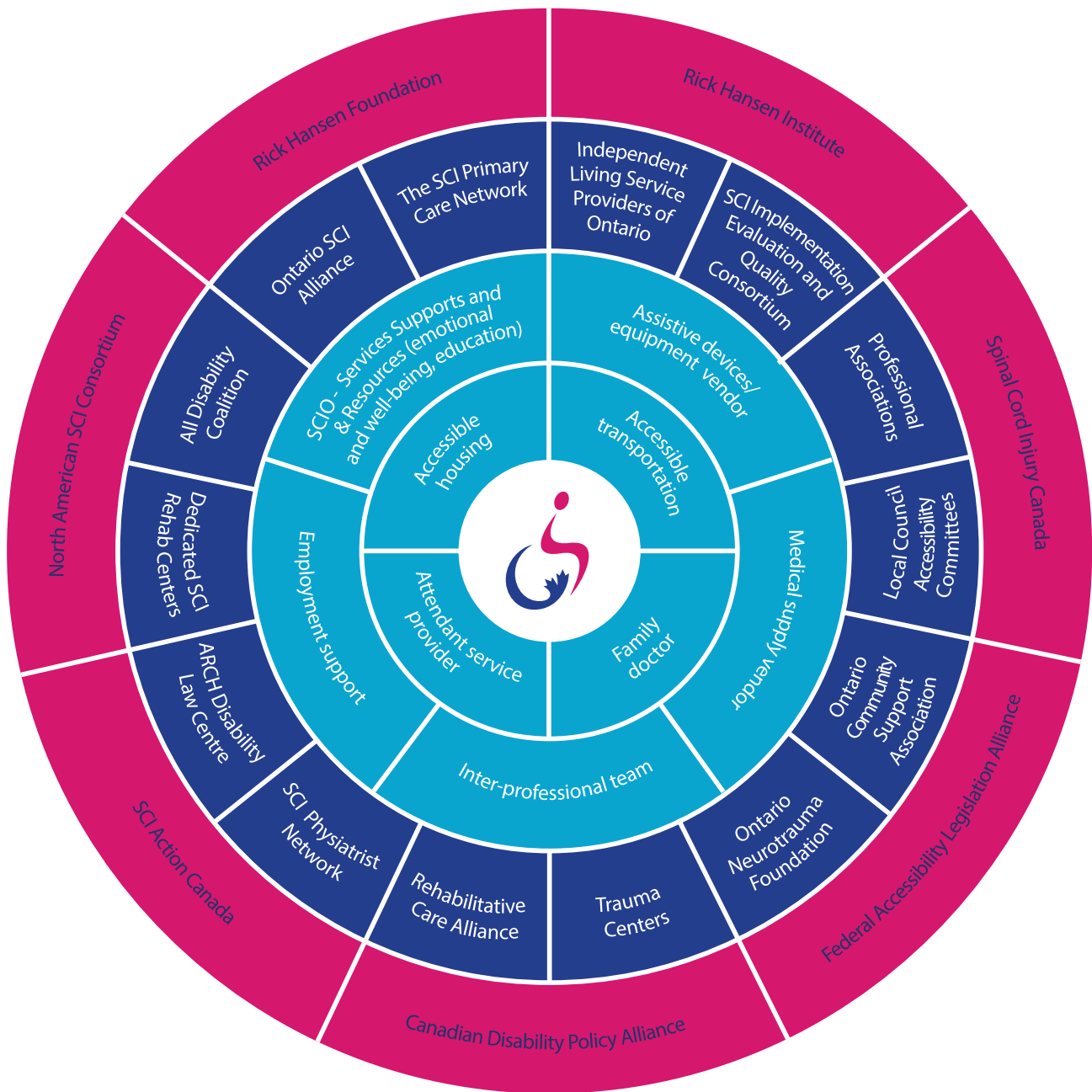
“

*"I just love the organization. I stand 100% behind it."*

-- Viola



## Appendix A: Better Care for Ontarians



To support a connected health care system in partnership with OHTs, SCIO brings to the table a respected and established community presence, expertise characterized by lived experience and a long history of service innovation in the area of SCI. Select core offerings below represent the unique value we bring to patients, OHTs and the Ministry:

- **Direct patient support**

- Expert regional service co-ordinators with case manager role to access community resources

- Trained peer support volunteers for patients and family members from point of injury and beyond
- Employment services for job searchers
- Attendant services (GTA patients at this time)
- **Information Portals**
  - Province-wide monthly workshops (Bowel & Bladder Care, Travel, Adaptive Sports, Vehicle Modification Fair, Adaptive Cooking, Community Reintegration, Direct Funding Program, Osteoporosis & Nutrition, Taxes)
  - VIP4SCI - a virtual integration platform for patients to digitally connect with their network of care using a computer, tablet or mobile phone
  - sciontario.org – a growing online source of information and opportunities for patients, family members, health care partners and community members
  - SCIO connections to provincial, national and international networks expand the scope of influence and support for each patient/client
- **Health Systems and Knowledge Mobilization**
  - Emergency Preparedness Plan
  - Materials and initiatives to improve patient awareness, skills and knowledge on specific health issues and complications (UTI, autonomic dysreflexia, pressure sores, respiratory supports)
  - Materials and initiatives to encourage effective communication between patients and health care professionals
  - Disability training to increase awareness, skills and knowledge of inclusivity and equity in the health care setting and workplace
- **Community Referral**
  - Established networks between SCIO and SCI dedicated rehab clinics and SCI professionals will complement OHT roles
  - SCIO involvement can identify vulnerable people with an SCI to prevent a crisis scenario, avoiding the emergency room
- **Access to SCI Community and SCIO Resources**
  - Used equipment program increases access and reduces costs
  - Funding supports for medical supplies and assistive devices
  - Event and education opportunities
  - Participation in SCI and disability research
  - Volunteering opportunities
  - Skill development
  - Integrated virtual supports mean consistency of service

- Opportunities to leverage national and global opportunities
  - Primary Care Networks for SCI
  - Independent living service providers
  - SCI Canada, national umbrella agency for SCI provincial charities
  - Ontario SCI Alliance - co-led by SCIO and the Ontario Neurotrauma Foundation (ONF), 250 key provincial stakeholders and strategic partners of researchers, service providers, policy makers, funders and people with spinal cord injury
  - Provincial, national and international community stakeholders committed to SCIO's vision and mission
- Pathways of Care
  - We've partnered up with The Ontario Neurotrauma Foundation (ONF) and the Ontario Brain Injury Association (OBIA) to develop a framework that supports integrated, more efficient, equitable co-ordination of care for people living with spinal cord and acquired brain injury. Known as Neurotrauma Care Pathways, this approach will effectively create a **"roadmap of care"** within the health system and improve the health care experience of those living with neurotrauma. The **"roadmap"** will make best use of services and supports regardless of where the individual lives and how the injury occurred, all of which currently affect how treatment and services are delivered and paid for. Neurotrauma Care Pathways reflects the Ontario government's goal to create a more integrated and patient-centred health care system in alignment with the health system transformation efforts now underway.

A neurotrauma pathway of care will help ensure consistent, best practice, medical care and community support



# References

- <sup>1</sup> Note: extrapolated from 2010 Canadian incidence, prevalence figures from Noonan V, K, et. al.: Incidence and Prevalence of Spinal Cord Injury in Canada: A National Perspective. *Neuroepidemiology* 2012; 38:219-226. Population figures from Statistics Canada.
- <sup>2</sup> Note: extrapolated from Chan, Brian et al. The lifetime cost of spinal cord injury in Ontario, Canada: A population-based study from the perspective of the public health care payer. *The Journal of Spinal Cord Medicine* 2019, 42:2, 184-193 and Noonan V, K, et. al.: Incidence and Prevalence of Spinal Cord Injury in Canada: A National Perspective. *Neuroepidemiology* 2012; 38:219-226.
- <sup>3</sup> Guilcher, SJT, BC Craven, A Calzavara, MA McColl, and SB Jaglal. Is the emergency department an appropriate substitute for primary care for persons with traumatic spinal cord injury? *Spinal Cord* 202; 3.
- <sup>4</sup> Munce, Sarah EP, et al. Barriers and facilitators to self-management in individuals with traumatic spinal cord injury: a qualitative descriptive study. *BMC Neurology* 2014; 14:4
- <sup>5</sup> Note: extrapolated from Chan, Brian et al. The lifetime cost of spinal cord injury in Ontario, Canada: A population-based study from the perspective of the public health care payer. *The Journal of Spinal Cord Medicine* 2019, 42:2, 184-193 and Noonan V, K, et. al.: Incidence and Prevalence of Spinal Cord Injury in Canada: A National Perspective. *Neuroepidemiology* 2012; 38:219-226.
- <sup>6</sup> Note: extrapolated from Chan, Brian et al. The lifetime cost of spinal cord injury in Ontario, Canada: A population-based study from the perspective of the public health care payer. *The Journal of Spinal Cord Medicine* 2019, 42:2, 184-193 and Noonan V, K, et. al.: Incidence and Prevalence of Spinal Cord Injury in Canada: A National Perspective. *Neuroepidemiology* 2012; 38:219-226.
- <sup>7</sup> Boschen, Kathryn A., Mark Tonack, and Judith Gargaro. Long-term adjustment and community reintegration following spinal cord injury. *International Journal of Rehabilitation Research* 2003; 26:157-164.
- <sup>8</sup> Boschen, Kathryn A., Mark Tonack, and Judith Gargaro. Long-term adjustment and community reintegration following spinal cord injury. *International Journal of Rehabilitation Research* 2003; 26:157-164.
- <sup>9</sup> Divanoglou, A. and M. Georgiou. Perceived effectiveness and mechanisms of community peer-based programmes for Spinal Cord Injuries – a systemic review of qualitative findings. *Spinal Cord*. 2017; 55: 225.
- <sup>10</sup> Boschen, Kathryn A., Mark Tonack, and Judith Gargaro. Long-term adjustment and community reintegration following spinal cord injury. *International Journal of Rehabilitation Research* 2003; 26:157-164.
- <sup>11</sup> Note: 80% of individual experience significant limitations in social participation (Craig, Nicolson Perry, Guest, Tran and Middleton, 2015) and 15-35% experience clinically significant depressive symptomatology (Elliott and Frank, 1996). In addition, suicide has been reported as the leading cause of death in spinal injured individuals under the age of 55 years (Dijkers, 1996) and is two-six times higher in the SCI population than in the wider community (Charlifue & Gerhart, 1991).
- <sup>12</sup> Divanoglou, A. and M. Georgiou. Perceived effectiveness and mechanisms of community peer-based programmes for Spinal Cord Injuries – a systemic review of qualitative findings. *Spinal Cord*. 2017; 55: 225.
- <sup>13</sup> Dickson, Adele, Richard Ward, Grainne O'Brien, David Allan and Ronan O'Carroll. Difficulties adjusting to post-discharge life following a spinal cord injury: An interpretative phenomenological analysis. *Psychology, Health, and Medicine*. 2011; 16.4: 482.
- <sup>14</sup> Divanoglou, A. and M. Georgiou. Perceived effectiveness and mechanisms of community peer-based programmes for Spinal Cord Injuries – a systemic review of qualitative findings. *Spinal Cord*. 2017; 55: 225.
- <sup>15</sup> Barclay L and Hilton G M. A scoping review of peer-led interventions following spinal cord injury. *Spinal Cord*. 2019; 57:626-635.



- <sup>16</sup> Guilcher, Sara J. T., Tiziana Casciaro, Louise Lemieux-Charles, Catharine Craven, Mary Ann McColl, Susan B. Jaglal. Social networks and secondary health conditions: The critical secondary team for individuals with spinal cord injury. *The Journey of Spinal Cord Medicine* 2012; 35.5: 339.
- <sup>17</sup> Haas, BM, L. Price, and JA. Freeman. Qualitative evaluation of a Community Peer Support Service for people with spinal cord injury. *Spinal Cord* (2013) 51, 295–299.
- <sup>18</sup> Gassaway, Julie, et al. Effects of peer mentoring on self-efficacy and hospital readmission after inpatient rehabilitation of individuals with spinal cord injury: a randomized controlled trial. *American Congress of Rehabilitation Medicine* 2016; 0003-9993/17/\$36.
- <sup>19</sup> Ronca, E., A. Scheel-Sailer, HG Koch, A Gemperli, and SwissSCI Study Group. Health care utilization in persons with spinal cord injury: part 2—determinants, geographic variation and comparison with the general population. *Spinal Cord* 2017; 55, 828–833.
- <sup>20</sup> Umeasiegbu, Veronica. Determinants of Health Care Access after Spinal Cord Injury. *Journal of Applied Rehabilitation Counseling* 2013; 44:2.
- <sup>21</sup> Umeasiegbu, Veronica. Determinants of Health Care Access after Spinal Cord Injury. *Journal of Applied Rehabilitation Counseling* 2013; 44:2.
- <sup>22</sup> Peeler, Andrew W. Strategies for Cost Saving Through Social Determinants of Health. *Foundation of the American College of Healthcare Executives* 2019; 64:4, 222-230.

CONTACT  
Dr. Stuart Howe  
CEO, SCIO  
[stuart.howe@sciontario.org](mailto:stuart.howe@sciontario.org)

[www.sciontario.org](http://www.sciontario.org)