

Prioritizing Solutions to Improve Health and Quality of Life for People with Spinal Cord Injury

Findings from the Community Forum, March 30, 2022

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Prepared by:

Habib Chaudhury, Ph.D.	Professor, Department of Gerontology, Simon Fraser University (SFU) Email: chaudhury@sfu.ca
Ben Mortenson, Ph.D.	Associate Professor, Department of Occupational Science and Occupational Therapy, University of British Columbia (UBC) Email: ben.mortenson@ubc.ca
Shreemouna Gurung, M.P.P.A.	Ph.D. Candidate/Research Assistant, SFU
Hailey-Thomas Jenkins	Ph.D. Student/Research Assistant, SFU
Alfiya Battalova, Ph.D.	Research Coordinator, UBC
Olatioluwase Olatona	MSc Student/Research Assistant, UBC

Praxis Project Community Advisory Committee (CAC) Members:

Chris McBride, PhD

Executive Director
Spinal Cord Injury BC
Executive Director, BC Paraplegic Foundation
Chair, SCI Canada Executive Directors Council
CMcBride@sci-bc.ca

Rachel Abel, OT

Occupational Therapist
GF Strong Rehabilitation Centre
Inpatient SCI Program
Rachel.abel@vch.ca

Cynthia Morin, OT

Occupational Therapist
Spinal Cord Injury Outpatient Program
GF Strong Rehabilitation Centre
Cynthia.Morin@vch.ca

Jamie Borisoff, PhD

Canadian Research Chair, Rehabilitation Engineering Design, British Columbia Institute of Technology
Adjunct Professor, Department of Occupational Science and Occupational Therapy, Faculty of Medicine, University of British Columbia
Research Director, British Columbia Institute of Technology
Jaimie_Borisoff@bcit.ca

Ryan W Clarkson

Research Director, British Columbia Institute of Technology
Peer Support Program Coordinator, Metro Vancouver
Spinal Cord Injury BC
RClarkson@sci-bc.ca

Vivian Ng, BSPT, MSc

Project Leader
Fraser Health Rehabilitation Network
Vivian.Ng@fraserhealth.ca

Sam Douglas

Global Research Platform & BC Programs Support
Sdouglas@praxisinstitute.org

Summary

Based on data collected from interviews of people with spinal cord injury a forum was held to allow participants to discuss and prioritize recommendations to improve the quality of life of people with spinal cord injury (see Appendix 1). The forum opened up a space for discussion among various stakeholders to prioritize the recommendations for putting them into action. This forum was part of a larger project entitled, *“Improving the experience of coping and managing health and function among people with Spinal Cord Injury”*, which was funded by the Praxis Spinal Cord Institute.

Objective

The primary objective of this community forum was to discuss the identified set of recommendations in 7 domains: 1) Equipment & Assistive Technology, 2) Financial, 3) Healthcare, 4) Access to Information, 5) Community Programs & Services, 6) Physical Environment and 7) Social Environment, and prioritize specific strategies within each of those domains. The community forum also identified ways in which the prioritized recommendations could be made actionable.

Methods

The community forum was conducted virtually for pandemic safety and to allow participants to attend from outside Metro Vancouver. In a series of break-out groups, participants were invited to discuss recommendations within each of the 7 domains. Following breakout room discussions, participants were asked to prioritize two recommendations per domain. Results were collated and shared with participants in real-time.

Eight were selected for further discussion. Within breakout rooms, identified ways that the prioritized recommendations could be made actionable.

Results

Demographic Data

Twenty-eight people registered for the event and 19 attended. The majority of the participants were females below the age of 50. In regard to race, most were Caucasian (of European descent). The participants represented various health regions in British Columbia, with the majority in the Fraser Health and Vancouver Coastal Health regions. Most of the stakeholders in attendance were either healthcare providers/professionals or people with lived experience.

Findings

The findings have been organized based on discussion related to each of the seven domains.

1. Equipment and Assistive Technology

In this domain, the two most prioritized recommendations were: (1) ensure awareness of the variety of assistive technology and equipment available, and (2) aid with assistive technology and equipment set up including customization, modification, and training. The main focus of the discussion was on limited knowledge about available technologies and necessary financing. Participants identified a wide range of newly available technologies that could increase the quality and quantity of life for individuals with SCI, however, the financial barrier prevents many from accessing appropriate technologies. Many existing programs only support equipment intended to support volunteering, education, or some form of employment. However, equipment for more discretionary activities (e.g., recreation or leisure) would not be covered. Participants recommended people with SCI could be supported more effectively if programs worked with individuals to determine what technology would be most relevant and beneficial to them. For example, one participant with lived experience explained that being able to change the thermostat or close the blinds remotely would play a large role in reducing the effects caused by other comorbidities. Although GF Strong has an Assistive Technology program, people may not be aware of it or may have difficulty attending to it if they live outside Metro Vancouver. Furthermore, participants emphasized the need to improve funding access to new and relevant technology.

2. Financial

The financial domain resonated strongly with all participants. Participants highlighted the following two recommendations: (1) improve access to financial support by reviewing and expanding eligibility criteria, and (2) provide or increase financial support for allied health and alternative health services, vitamins, and supplements. Participants emphasized issues of poverty among people with SCI. Quite often how an individual with SCI was injured, determines how they will be funded: Workplace injuries are funded by WorkSafe BC and car accidents by ICBC. This means that access to funding resources are not evenly distributed across the population. Many people with SCI are living below the poverty line, with some only receiving about \$1,400 a month (Ministry of Social Development and Poverty Reduction, 2022). Ultimately, this requires most to rely heavily on community resources for food, clothing, and other necessities. One participant suggested that to save money in the future, it would be good to implement proactive and preventative support for people with SCI. For example, a participant indicated that a \$500 cushion to reduce the risk of pressure injuries could save taxpayers thousands of dollars per patient in the future if pressure injuries could be avoided (Chan et al., 2013). Unfortunately, not everyone who needs pressure relief is able to get equipment funded or easily access assessment services.

Participants emphasized that access to funding for basic necessities and preventative care is necessary for the overall functioning and success of individuals with SCI.

3. Healthcare

Healthcare contained the largest number of recommendations across the seven domains with the following recommendations prioritized: (1) consider other models of care including integrated health and holistic care and (2) increase physicians' awareness of available alternatives and community services and programs so they can refer appropriately. Though most people resonated with these two recommendations, there was broad discussion across all recommendations. There was a wide range of opinions regarding the utility of nurse practitioners in a care setting. Participants noted that access to care in a timely manner has the potential to be lifesaving. Therefore, booking follow-up appointments regularly may help avoid long wait times for necessary services. In addition, it may help solve the backlog caused by the one issue per visit rule that is currently in place for many physicians. Many participants believed that physicians would benefit from receiving specialized training relevant to people with SCI. This training may include information about services relevant to SCI or ways to better triage patients to relevant services.

4. Access to Information

Participants stated that access to information keeps many SCI patients alive, but one needs to be motivated to learn and do the necessary research. This statement partially encompasses the two most prioritized recommendations for this domain: (1) develop a standardized information forum for SCI-specific information & resources from reliable sources, and (2) create strategies to develop awareness about the information forum. Currently, there is a wide array of online resources that provide people with information, but there may be challenges with people knowing which sites are relevant to them. In addition, many SCI patients accessing these sources are laypeople, hence, the available information may not be clear or effective, unless explained. Many participants had similar sentiments regarding access to information, echoing that although the information may be accessible, it may be challenging to navigate, understand and apply the information. Additionally, there is a role of advocacy and promotion of relevant information.

5. Community Programs and Services

Community programs and services had the fewest number of recommendations with one main priority (1) provide affordable and accessible leisure and physical activity programs through a variety of sources (SCI specific, community, adapted sports). The COVID-19 pandemic has changed how community programs and services are offered to help slow the spread of the virus. Others are no longer able to help with tasks such as transferring, so patients have been forced to adapt to different activities themselves. One participant spoke

about how her local gym was not accessible, which led her to purchase her equipment to be able to exercise at home. The lack of accessible leisure and physical activity programs leads to yet again another reason why adequate funding is necessary for people with SCI. Though many participants understand that the SCI population in BC is rather small, many echoed that even if stand-alone services specific to SCI persons aren't available, it would be beneficial to incorporate them with services for a larger, but similar population.

6. Physical Environment

In this domain, participants prioritized the following recommendations: (1) ensure that accessibility standards developed for the Accessible British Columbia Act are enforceable, and (2) promote features in the lived environment that contribute to aging in place. More emphasis was placed on ensuring that accessibility standards were enforced. Much can be improved in the physical environment, but it all depends on whether the land is privately owned or owned by the municipality. Oftentimes, there are curb cuts located in the wrong places, ramps are much steeper than necessary and a lack of accessible parking stalls. Some participants suggested that legislation may be the best way to solve issues in the accessibility of the physical environment. Building construction should have policies in place to promote accessibility, and once built, should be approved based on accessibility requirements in addition to regular building requirements. Since the inception of COVID-19, touchless buttons to open doors have been beneficial, while they have cut down colds and other easily transmittable things.

7. Social Environment

This domain focused on participants prioritizing: (1) raising awareness and educating the public about SCI to establish disability etiquette, and reduce stigma, stereotypes, and discrimination and (2) providing sensitivity training to service providers. Most participants agreed that more training is needed for the clinicians and for the general public to ensure the success of people with SCI.

Actionable Approaches to Selected Prioritized Recommendations

Participants identified actionable approaches for 6 recommendations. The following table contains the suggested actionable approaches to address some of the highest-ranked recommendations for each domain.

Actionable Approaches	
Equipment & Assistive Technology	
<i>Ensure awareness of the variety of assistive technology and equipment available</i>	No Suggestions
Financial	
<i>Improve access to financial support (e.g., disability assistance) by reviewing and expanding eligibility criteria</i>	<ul style="list-style-type: none"> • Potentially utilize the WorkSafe model to allow people with SCI to get back to work with fewer barriers – Many worry that by going back to work and contributing to society may lead to the loss of some of their benefits
Healthcare	
<i>Consider other models of care including integrated health and holistic care</i>	<ul style="list-style-type: none"> • Integration of healthcare needs to occur- Doctors need to be made aware of relevant therapies and triage patients accordingly • Create a system, using electronic charting, where health data is shared across all providers • Utilize nurse practitioners often – they have access to a lot of information and can also triage cases easily • Work towards finding ways to better subsidize or cover the cost of supplements as there are necessary for nutrition and overall health • Create a pipeline system to put people with SCI through which allows doctors to see all of the various interventions and apply the ones that are relevant
<i>Decrease wait times for physician, diagnostic, allied health, and alternative health services</i>	<ul style="list-style-type: none"> • Develop a system with criteria to better prioritize appointments
Access to information	
<i>Create strategies to develop awareness about the information forum</i>	<ul style="list-style-type: none"> • Create a working group (On a provincial level) that is connected across health authorities to create resource packages for the SCI population • Connect and utilize the cities disability committees

	<ul style="list-style-type: none"> • Focus on marketing and advocating through various media streams such as magazines, websites, etc. • Create resources that are available in multiple languages
Community Services & Programs	
<i>Provide affordable and accessible leisure and physical activity programs through a variety of sources (e.g., SCI specific, community, adapted sports)</i>	No Suggestions
Physical Environment	
<i>Ensure that the accessibility standards developed for the Accessible British Columbia Act are enforceable</i>	<ul style="list-style-type: none"> • Rewrite portions of the Accessible British Columbia Act, specifically those related to building codes • Work towards accessible and affordable housing for people with SCI
Social Environment	
<i>Raise awareness (e.g., media representation) and educate the public about SCI to establish disability etiquette, and reduce stigma, stereotypes, and discrimination</i>	<ul style="list-style-type: none"> • Create infographics that can be put up in places like emergency departments where physios and other people can see them • Host workshops to provide training to clinicians and to the general public

Discussion

Most participant groups at the community forum focused heavily on the Equipment & Assistive Technology, Financial and Healthcare domains. Hence, we need to prioritize these domains to improve the experience of people with Spinal Cord Injury coping and managing health and function.

In contrast, the Physical and Social Domains received the least amount of feedback and concern. This could have been attributed to a few different things. These domains were slightly smaller than others, and as stated in the coming paragraphs, there was not a significant amount of time allotted to discussing each domain. Alternatively, the recommendations within these domains, may not be a large priority for the participants in attendance. Though there were still

recommendations prioritized via the survey, there were few, if any comments regarding their importance or ways to implement them.

Even across prioritized recommendations, most suggestions for action were to support the consideration of other models of care including integrated health & holistic care and to create strategies to develop awareness about the information forum. The most prominent issues overall seem to be regarding access to necessary resources e.g., information, funding and adequate healthcare. Without access to these resources, many individuals with SCI run the risk of being left behind with no pathways to improve their quality of life.

Limitations and Future Considerations

Following the community forum, the research team discussed the positives and negatives of the event overall and the following were agreed upon. In future community forums, it would be beneficial to have more time to discuss the given content. Although most of the recommendations were discussed, we may have benefitted from more time to further discuss the recommendations that participants resonated with the most. Providing participants with the recommendations prior to the forum would have also given participants the option to formulate thoughts and ideas prior to the discussion. In regard to the ranking system, we found that it was successful in ranking recommendations, nevertheless, ranking at the end of all discussions could have yielded better results. Finally, there were a couple of administrative pieces considered such as providing all participants and discussion leaders with a way to contact the moderator as well as a minute-by-minute schedule to keep the group on time for the duration of the event.

APPENDIX A

Revised Suggestions for Improving Quality of Life from the Perspective of People with SCI

Domain	Suggestions for Improvement
Equipment and Assistive Technology	<ul style="list-style-type: none"> ○ Ensure awareness of the variety of assistive technology and equipment available ○ Aid with assistive technology and equipment set up including customization, modification, and training. For example, GF Strong has an Assistive Technology program, but people may not be aware of it or may have difficulty attending if they live outside Metro Vancouver. ○ Provide ongoing support with assistive technology and equipment
Financial	<ul style="list-style-type: none"> ○ Improve access to financial support (e.g., disability assistance) by reviewing and expanding eligibility criteria ○ Address application barriers (e.g., technological, procedural, language) ○ Provide or increase financial support for: <ul style="list-style-type: none"> ○ Allied health and alternative health services, vitamins and supplements, housing and home modifications, cleaning services, the appropriate wage for homecare providers, assistive technology ○ Reduce financial barriers for obtaining mobility assistive devices (e.g., manual and power wheelchair), medical supplies (e.g., catheters), assistive technology, and aids for activities of daily living ○ Develop and implement financial literacy programs for people with SCI
Healthcare	<ul style="list-style-type: none"> ○ Decrease wait times for physician, diagnostic, allied health, and alternative health services ○ Create an exception for people with SCI related to the restriction of addressing one issue per visit with a physician ○ Allow for hybrid delivery of care and sustain virtual care post pandemic ○ Consider other models of care including integrated health and holistic care ○ Integrate nurse practitioners into the provision of standard care ○ Provide sufficient access to healthcare professionals and services in rural and sub-urban areas ○ Provide after hour nursing and care aide services ○ Increase training and support to reduce the shortage of care aides and LPNs

	<ul style="list-style-type: none"> ○ Increase physicians’ awareness of available alternatives and community services and program so they can refer appropriately ○ Provide incentive for healthcare workers to accept people with SCI into their practices and treat them on an ongoing basis ○ Promote transparency and accountability within the healthcare system ○ Expand the pharma care program ○ Provide advanced interpersonal skills training to physicians so preconceived notions about people with SCI, including ageism, can be removed and they can collaborate with them to manage health ○ Improve the SCI-specific knowledge by providing training for healthcare professionals, including considerations for services targeted towards people with quadriplegia
Access to Information	<ul style="list-style-type: none"> ○ Develop a standardized information forum for SCI specific information and resources from reliable sources ○ Create strategies to develop awareness about the information forum ○ Use simple and clear language to ensure information is understandable and accessible
Community Programs and Services	<ul style="list-style-type: none"> ○ Provide affordable and accessible leisure and physical activity programs through a variety of sources (e.g., SCI specific, community, adapted sports) ○ Integrate SCI specialty services into communities using their existing municipal infrastructure (e.g., ensuring accessible gym equipment is available in all municipal gyms)
Physical Environment	<ul style="list-style-type: none"> ○ Improve indoor and outdoor accessibility (e.g., wider elevators that account for the presence of a caregiver, adjustable medical examination tables and plinths in community clinics and hospitals) ○ Create a system for indicating the current accessibility status of locations and buildings ○ Regularly cleaning sidewalks (e.g., remove debris and snow) ○ Increase the availability of accessible transportation ○ Promote features in the built environment that contribute to aging in place ○ Provide incentives and subsidies to small businesses for improving accessibility ○ Ensure that the accessibility standards developed for the Accessible British Columbia Act are enforceable
Social Environment	<ul style="list-style-type: none"> ○ Raise awareness (e.g., media representation) and educate the public about SCI to establish disability etiquette, and reduce stigma, stereotypes, and discrimination

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| | <ul style="list-style-type: none">○ Consider the impact of Covid-19 around the visibility of people with SCI and its relationship to awareness and public attitudes○ Provide sensitivity training to transit service providers |
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References

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