Insights Report

Hearing from People with Lived Experience of Spinal Cord Injury

HEALTH STANDARDS ORGANIZATION
PRAXIS SPINAL CORD INSTITUTE

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Overlap Associates

HSO

PRAXIS Spinal Cord Institute

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“I can’t stress enough that hearing from others who have lived that experience is so important and helpful, especially people who returned to their community.”

– PARTICIPANT

Introduction

Project Objectives

HSO has partnered with Praxis Spinal Cord Institute to develop updated Canadian health standards in response to the needs of people with spinal cord injuries (SCI). The driving principle behind this project approach has been to collaborate with and centre the voices of people with lived experience of SCI in the development of these standards.

To support in the early stages of this project, Overlap Associates worked with the project team to facilitate three co-design workshops with people with spinal cord injuries, from across Canada. The purpose of this engagement was to gain a deeper understanding of people's experiences transitioning out of their primary rehabilitation following their SCI and back into their communities–including their goals and needs, challenges and barriers, and recommendations for improving the overall experience.

Engagement Methods

Overlap and the project team hosted three 2.5-hour workshops held remotely online. These workshops were designed to engage participants living with SCI around the images and stories they had collected as part of the Photovoice engagement method.

Photovoice is a qualitative research method that can be used to understand people's lived experience through photos and sharing stories. The HSO and Praxis team selected the Photovoice method for participants to collect and share stories that were relevant to them and to the project objectives. As part of the Photovoice method, participants collected 3 or more images to share at the workshops. These images helped participants tell a particular story about their experiences transitioning out of rehab and back to their community. Images could be of themselves, photos they had taken, or images they found on the internet.

The online workshops enabled participants to share their stories and discuss themes and insights across their shared experiences. Activities during the workshops included:

- Introductions and an icebreaker activity
- Developing Community Guidelines for the group
- Sharing individual Photovoice stories and images
- Developing a timeline of experiences from 0 to 18-months after leaving rehab and transitioning back to their home communities
- The participants for these workshops were recruited previously by the HSO and Praxis team. Prior to the co-design workshops, participants also attended an orientation session hosted by the HSO and Praxis team to provide information about the Photovoice engagement method.

Context

Individual experiences are shaped by context and identity.

The insights and Experience Map presented in this report aim to describe the common experiences, as well as differences, that participants shared when describing their experience from 0 to 18 months after leaving rehab. While there were many similarities that participants found among their stories, they also found that each person's experience was shaped by their context and identity.

The core factors that contributed to people's different experiences transitioning out of rehab and into their community were:

IDENTITY

People's experiences were affected by their age and gender. This showed up in the specific challenges people faced, as well as feeling a mismatch between their needs and the programs or services available to them. Although this was not discussed during the sessions, public health implications of racialization, gender, class, and other aspects of identity, will certainly also impact their experience during the transition out of rehab.

TYPE OF INJURY AND IMPACT OF INJURY

The specifics of each person's injury, as well as the impact that injury had on their body and recovery, has a significant impact on their experience of returning home from rehab. These factors led to different needs for equipment, care, and living spaces.

“Living in a smaller town, I am the only person in this level of the situation…I really wanted to reach out and meet others in the same situation, similar to me, but that wasn’t possible in a smaller town.”

– PARTICIPANT

FAMILY, RELATIONSHIPS AND COMMUNITY

Participants highlighted the key role that family, friends and neighbours played in their transition from rehab to home. These relationships, many of which existed before a person's injury, provided levels of care that were important during times of transition–from primary caregiving from spouses to community belonging through friend groups. These unique networks contributed to different experiences of support participants noted in their journeys.

LOCATION

People's experiences were affected by the location of their home, particularly the size of their town or city. Participants who lived in small towns or suburban areas talked about having restricted access to services or practitioners with experience of working with clients with spinal cord injuries. Smaller towns also were also less likely to have opportunities for peer support. Even in larger urban centres, the style and age of buildings had an impact on the accessibility of people's living spaces or public spaces they wished to visit.

INSURANCE CONTEXT

Each person's injury and insurance situation had a significant impact on the financial support they received in the transition period out of rehab. This depended on how the injury was acquired, if insurance was a job benefit, and what level or type of insurance they had. Some participants also mentioned that their insurance company assigned them a case worker who had supported them with some coordination of care, in addition to financial support.

COVID-19

Depending on when participants were transitioning home, people felt greater or lesser impacts of COVID-19 on their transition. The pandemic impacted people's access to physiotherapy, support services, and access to exercise and recreational activities. Especially for participants just coming out of rehab, this had a big impact on their plans for healing and adjusting to life at home.

Insights

The Experience Map *(see next section)* outlines specific activities, goals, needs, and recommendations from participants laid out in a timeline from 0 to 18 months after leaving rehab. As participants were sharing their stories and developing this timeline, however, there were certain experiences and topics that were important across the full 18-month timeline, and beyond. These topics are highlighted in this Insights section.

Insights

EXPERIENCES AND TOPICS SHARED BY PARTICIPANTS

INSIGHT 1

When people leave rehab, they have to rebuild their identities, routines, and relationships.

In describing the transition from rehab to their homes or communities, participants talked about an important and challenging process of reinventing themselves and their lives.

As a result of their injury and the new barriers they encountered, participants had to:

- Change their living spaces or move to a new/temporary home
- Find new hobbies and let go of old ones that had previously been a source of fulfillment and community
- Negotiate changing friendships, particularly if common activities, like skiing or golf, were not feasible at the time
- Establish new self-care and hygiene routines, like getting prepared in the morning
- Develop a new wardrobe and sense of style
- Find new "usual" spots to spend time in their communities, because previous favourites, like restaurants and shops, were inaccessible
- Find new work or figure out technologies and routines to continue previous work
- These changes can be dramatic, difficult, and challenging to people's identities. In very few other life circumstances do all of these changes happen at once. These changes also occur over a long period of time, starting the moment when people left rehab.

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"In the last couple years, I've had to reinvent my life." – PARTICIPANT

"I'm not a fashionable person, but one thing that struck me when checking out of rehab is a lack of idea of what to wear … it was kind of a big deal. What in your wardrobe will fit and represent who you are? How confident will you be when you go out … " – PARTICIPANT

"Finding who your friends were again…Because I couldn't do what I did before, play hockey, play tennis, do construction, I was completely excluded … " – PARTICIPANT

INSIGHT 2

People have to rediscover their relationship with their bodies and health, once they leave rehab.

In the transition from rehab to home, participants talked about the different ways that their relationship to their body, health, and safety changed. They also identified that programs during rehab had not prepared them well enough for these changes, in some cases.

These changes included:

- Gastrointestinal issues that were unexpected and made it difficult to navigate daily routines or going outside
- Risk or experiences of urinary tract infections
- Risk or experiences of pressure sores that can lead to significant health challenges, as well as being on bedrest for extended periods of time
- Fear of getting injured from falling out of their wheelchair or accidents during other daily activities

Some participants described these changes as adding more pressure and uncertainty during their transition home. In some cases, these changes also caused significant disruption to participants' ability to do daily tasks or achieve some of their goals. Participants also experienced challenges adapting to moving around and activities with adaptive equipment. This was especially frustrating during the early stages of being home, when participants did not have the right equipment or did not have a customized wheelchair yet. One participant described their experience with a wheelchair that was slightly too wide, causing repeated mild injuries and damage to the door frames and walls of their house. This transition can last for months as equipment is produced or delayed.

"[It's] very difficult emotionally – it's not a broken arm. [There's a] realization that I've got what I've got." –PARTICIPANT

"[A barrier was] GI issues, having that in the back of my mind whenever travelling." –PARTICIPANT

"It took a long time to get a [personalized] wheelchair after discharge...the [standard] wheelchair was too big and I couldn't get to most bathroom doors for almost 5 years. It didn't reflect my body or my needs." –PARTICIPANT

"I broke a bone and that resulted in a pressure injury that required surgery … led to more bed rest and doing nothing....It teaches you to be very careful and do your due diligence." –PARTICIPANT

"Like going out into the world is obviously much more dangerous, and [I] had a couple of close calls falling out of the chairs … " –PARTICIPANT

INSIGHT 3

Access and navigation of care is a significant challenge when people transition out of rehab.

Throughout the transition out of rehab, participants highlighted the challenges they faced finding, organizing, and accessing the different care and services they needed. Participants often had to do a lot of research on their own to find out about clinics or services that would be useful for them. They also described the challenges of coordinating care from different practitioners and services, such as support workers, physiotherapists, nutritionists, and more. This experience of fragmented services and care was particularly frustrating after having been in rehab facilities where practitioners are centralized and easily accessible.

Some participants had also experienced high turnover of support workers or physiotherapists, which made it difficult to establish a relationship and have continuity of their care. Participants described how frustrating and tiring it is to have to constantly explain their specific experiences and needs to new practitioners as a result of this turnover.

Another common experience across the transition period was that participants encountered significant financial barriers or burdens when looking for essential equipment. One participant described their process of designing and asking a relative to build their own set of parallel bars, since purchasing this equipment was necessary for their exercises, but too expensive. Another participant was in the process of

designing their own platform scale to help with weight management, since they could not find one in a reasonable price range.

While the creativity of these participants is commendable, these financial barriers could prevent them, or others, from accessing necessary services or activities.

"You're on your own after [the] rehab experience." –PARTICIPANT

"It would be interesting if there would be…suggestions for things that people can do on their own rather than purchasing these very expensive material, like parallel bars." –PARTICIPANT

"When I first moved, we were getting a different helper [personal support worker] – the medical system was issuing a different person every day, so we had to retrain somebody on a daily basis. It was crazy." –PARTICIPANT

INSIGHT 4

When people encounter physical barriers, their routines and sense of belonging or community are disrupted.

During the transition out of rehab, every participant could relate to the experience of discovering key places in their communities were inaccessible to them. People encountered physical barriers everywhere from local restaurants and businesses, friends' houses, community centres, and their children's schools, as well as hotel rooms and amenities when travelling. Broken accessibility features, such as pool lifts and automatic door openers also created significant barriers. To add to this challenge, participants noted that many staff in restaurants and hotels cannot provide accurate information about the accessibility of the business. This makes it difficult to check ahead of time and avoid barriers.

The lack of physical accessibility of public and private spaces will continue to be a challenge and frustration for participants. However, this is particularly relevant during the transition period from rehab to home, as participants were forced to change plans and often experience exclusion from family, social, or community activities that would bring them joy or a sense of belonging.

"Losing my routine because places aren't accessible [was a pain point]." –PARTICIPANT

"I could not go swimming with my family...I worked so hard to get back to go on that vacation. It is very frustrating and things are not accessible as they were supposed to be." –PARTICIPANT

""Those are both restaurants in [town] that I used to frequent quite a bit before my accident. Unfortunately, those restaurants have stairs … so there is no way I can actually go to these restaurants if nobody picks me up. I can't go there anymore." –PARTICIPANT

"It is very frustrating that I cannot get into my daughter's school and see her do any activities." –PARTICIPANT

INSIGHT 5

The ignorance and behaviour of the general public contributes to challenges as people are transitioning out of rehab.

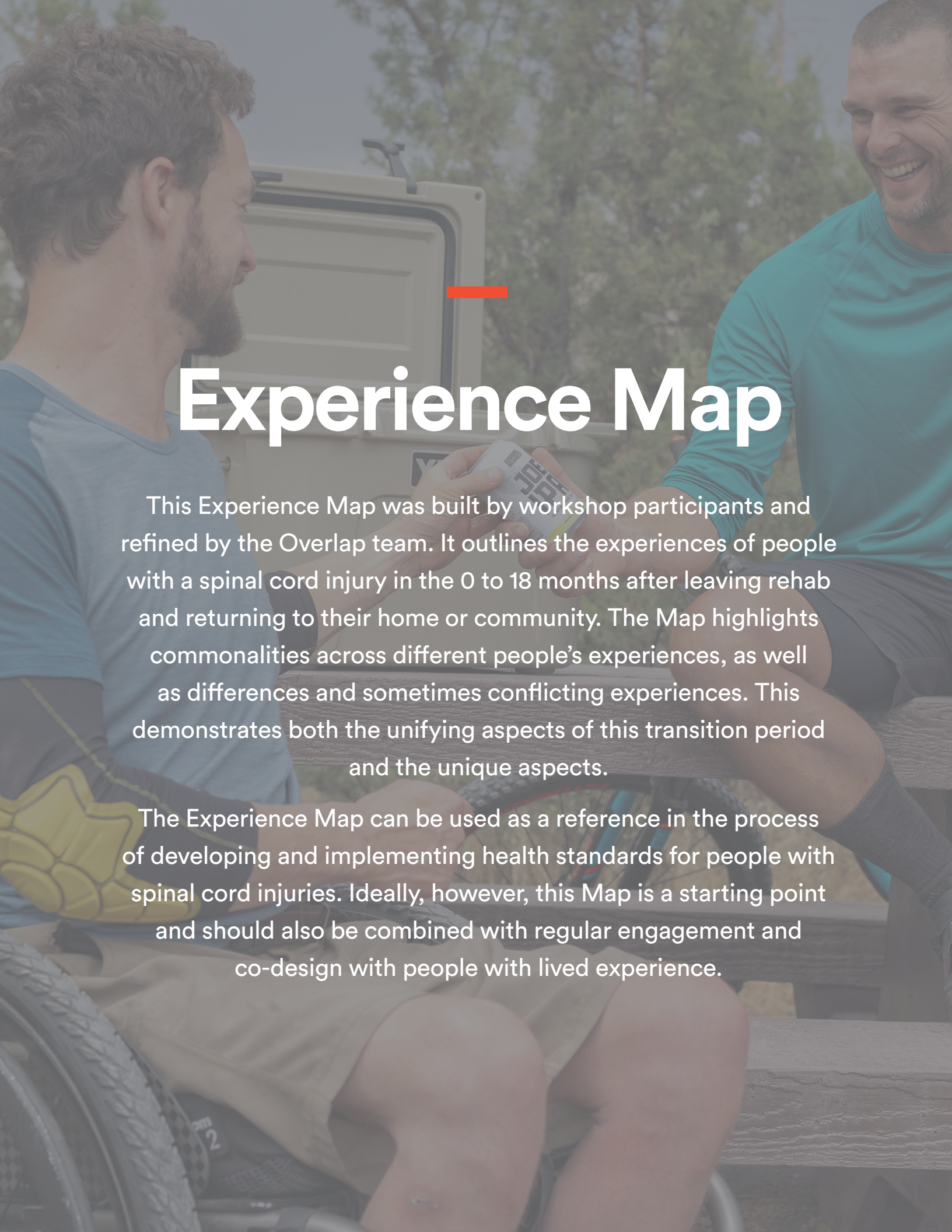
As they spent more time out in public places, many participants talked about the challenge of interacting with strangers. Stories emerged of people staring, asking questions, and acting in unhelpful ways. These responses show that many people are ignorant about people who use wheelchairs, their capabilities, needs, and experiences. Participants described being frustrated by having to navigate these sometimes uncomfortable social situations, on top of daily activities like grocery shopping or crossing the street.

These experiences can also feel demeaning, since strangers are giving the impression that the person in the wheelchair is fragile or incapable of doing a specific task. This can be especially challenging when transitioning out of rehab, because independence and self-sufficiency are top goals for many people during this time.

"People [look] at you like an invalid needing constant care and attention." –PARTICIPANT

"[It's] curiosity and ignorance mixed in one." –PARTICIPANT

"[I have to say,] 'it's ok, I got this.'" –PARTICIPANT



Experience Map

This Experience Map was built by workshop participants and refined by the Overlap team. It outlines the experiences of people with a spinal cord injury in the 0 to 18 months after leaving rehab and returning to their home or community. The Map highlights commonalities across different people's experiences, as well as differences and sometimes conflicting experiences. This demonstrates both the unifying aspects of this transition period and the unique aspects.

The Experience Map can be used as a reference in the process of developing and implementing health standards for people with spinal cord injuries. Ideally, however, this Map is a starting point and should also be combined with regular engagement and co-design with people with lived experience.

The Journey from Rehab to Home and Community

AN EXPERIENCE MAP CO-DESIGNED WITH PEOPLE LIVING WITH SPINAL CORD INJURIES

Time

The time in months following the transition from rehab into community and home.

Feelings

The range of emotions participants felt during these phases of transition. These feelings range between more negatively associated emotions to more positively associated emotions, and demonstrate the spectrum of emotions at any given phase.

Goals and Activities

The major goals and activities participants were trying to achieve during different phases of their transition. These activities reflect themes found across different participant goals and activities.

Pain Points, Gaps and Barriers

The pain points, gaps and barriers in the lives of participants that made their experiences difficult. These points reflect themes found across different participant pain points.

Ideas for Improving Experience

The ideas generated by participants that would have made a positive impact on their experiences.

Early (0–3 months)

Feelings

- **I feel vulnerable and scared** — Fear and vulnerability coming out of rehab and experiencing fewer supports, fear of falling out of the wheelchair or getting injured, feeling intimidated by the world outside home.
- **I feel disconnected from myself and others** — Feeling disconnected from wheelchair and other standard equipment, social supports like friends and family, feeling dehumanized by insurance and medical system processes.
- **I feel frustrated and stressed** — Stress around reconnecting with friends, frustrations adapting home and routines to new abilities, frustrations experiences during travel, experiencing barriers in the community and being excluded from usual routines and activities.
- **I feel accomplished leaving rehab** — Accomplishment around new milestones and overcoming obstacles, such as navigating travel for the first time and getting back to work.

Goals and Activities

- **Focusing on physical health and safety** — Attending to the needs of my physical body to feel safe as I continue to recover and gain my strength.
- **Establishing new routines and independence at home** — Creating and planning new ways of doing everyday activities setting up my home to be more accessible, managing time to leave my home, and learning how to be mobile, etc.
- **Re-adapting to old routines and activities** — Coming back to activities that were part of my life before my injury and understanding my limits-learning what it would mean to get back to work, recreation and sports, and community events.
- **Reconnecting with friends** — Re-establishing friendships and learning what my friendships mean as I continue to transition back into my home and community settings.
- **Preparing to and travelling in community and beyond** — Learning what I need to do in order to travel safely, and researching the accessibility of places in the community and beyond.

Pain Points, Gaps and Barriers

- **Accessibility barriers and challenges at home** — Not having a home that works for my new needs or a person to help me navigate these challenges.
- **Delays and challenges accessing care and equipment** — Long processes to get equipment like personalized wheelchairs, and to access care like outreach therapy and home care workers.
- **Lack of mental health and social support** — Not having the resources to help me with my feelings and emotions, and not having the guidance to help me navigate the changes in my personal and community relationships.
- **Challenges with accessibility during travel and transit** — Physical spaces not being accessible to my mobility needs and lack of understanding from service providers on accessibility standards.
- **Losing aspects of identity** — Challenges in coming to terms with how my injury has affected important aspects of my life that have been shaped by my lifestyle before my injury.
- **Lack of peer support and information** — Not having connections with other people who live with SCIs to learn from them, and not having health care providers with first hand experience of SCIs.
- **Challenges adapting to wheelchair and equipment** — Difficulty in adapting to my mobility equipment as it damages my body, and the places I use it in.

Middle (4–6 months)

Feelings

- **I feel broken** — Emotional impacts of adapting to mobility, continued frustration and challenges around accessibility and community that restrict activities, from room around access to equipment and physiotherapy.
- **I feel curious** — Curiosity in approaching aspects of self and life that need to be redefined. For example, shopping a new wardrobe and exploring dating relations from others with lived experience.
- **I feel happy returning to normalcy** — Finding joy in returning to activities and errands that feel "normal," like grocery shopping, parenting activities, driving, sports, and hobbies.
- **I feel a sense of liberation** — Feeling more comfortable and confident leaving home and navigating public spaces independently in a wheelchair, feeling more adventurous from a sense of freedom, particularly from starting to drive again.

Goals and Activities

- **Preparing to drive** — Learning the requirements for driving with my abilities, getting hand controls and practicing driving on a new way.
- **Adapting to the accessibility of places** — Learning and managing the physical barriers of the different places like restaurants, public spaces, and hotel rooms.
- **Re-adapting to old routines and activities** — Continuing the process of returning to activities that were part of my life before my injury like parenting, getting back to work, and household chores.
- **Exploring mobility supports and sporting equipment** — Learning about the types of mobility and sporting equipment that is financially accessible to me and that would help me in the future.
- **Navigating interpersonal relationships** — Learning how to manage my relationships with family, friends, and neighbours, and how to manage romantic relationships.
- **Managing physical safety and accidents** — Continuing to focus on the recovery of my physical well-being and handling new accidents that happen.
- **Figuring out my clothing and wardrobe** — Figuring out what I can wear that will work for me and help me feel like me.

Pain Points, Gaps and Barriers

- **Challenges in my relationships with family members** — Difficulty in managing my needs in my journey and my role in relationships with family-as a child, as a parent or as a sibling.
- **Lack of peer support and information** — Not having connections with other people who have had SCIs to learn from them, and not having health care providers with first hand experience of SCIs.
- **Lack of support for family caregiver** — Family caregivers not having access to resources to help them learn about the role of caregiving, or mental and emotional supports to help them meet their unique needs as caregivers.
- **Delays and challenges accessing care and equipment** — Financial barriers and long processes prevent access to equipment that would help me in my journey.
- **Inaccessible public and private spaces** — Lack of accessibility to public and private spaces-no alternatives to stairs, broken door buttons, cramped spaces, etc.
- **Disruption from COVID-19** — Disruption in services like physiotherapy due to COVID-19.
- **Challenges with outdoors and seasonal activities** — Difficulty in adapting to the changing seasons and the activities it necessitates-new ways of travelling and mobility and household chores like yard maintenance.
- **Challenges in my relationship with my body and how I care for it** — Difficulty in managing how I care for my body when challenges unexpectedly affect me-ranging from gastrointestinal issues to new emotional triggers around my clothing.
- **Over-reactive strangers** — Social reactions and stigma when encountering people in public-lack of awareness about accessibility, over-reaction from strangers to my needs, and ignorant and harmful comments, etc.

Late (7–18+ months)

Feelings

- **I am still struggling** — Continued challenges in physically navigating spaces, rebuilding daily life, managing emotionally and accepting that my life has changed because of my injury.
- **I feel nostalgic** — Nostalgia around habits, routines, and passions from before injury, missing homes and other spaces that are not currently accessible.
- **I feel agile** — Experimenting with different physical activities and sports, gaining confidence with these activities, and finding routines to stay active and physically fit.
- **I feel hopeful** — Anticipation of new milestones, like getting back to a home, starting to drive again, or getting back to work. Focusing on optimism as a way to stay hopeful and motivated day-to-day.
- **I feel proud** — Pride in participating in sports and other rewarding activities, sometimes enabled by specialized equipment or overcome barriers, specialized equipment or overcome barriers. Being able to take risks and have fun.

Goals and Activities

- **Exploring capabilities and limits** — Testing my boundaries with longer travel and day trips, participation in research projects, and experimentation with different mobility equipment as I increase my strength.
- **Gaining new independence through activities and responsibilities** — Increasing the level of independence I can manage with activities like staying at home with my kids, gaining more responsibility at work, and/or driving on my own.
- **Living and adapting to routines** — Continuing to live out the established routines and patterns I created during the transition process.

Pain Points, Gaps and Barriers

- **Managing through accidents with mobility device** — Challenges in maintaining and repairing equipment after an accident has occurred.
- **Lack of access to and knowledge of resources** — Not knowing how to find resources, or who to go to for that information as I continue my journey.

Ideas for Improving Experience

- Provide support through a centralized care navigator or coordinator
- Support holistic wellbeing with access to a broad range of specialists, care providers, and support organizations
- Peer support during and after rehab on broad range of topics
- Provide support materials in easily accessible formats and channels
- Provide a focus during rehab on reconnecting with support networks (partner, family, friends, community)
- Connect people to centralized resources before leaving rehab
- Provide training and health supports for caregivers
- Create accessible public infrastructure and transit
- Strengthen peer support and networks
- Create access to clear and known resources that accomodate accessibility need
- Provide personalized training for individual needs (like navigating personal homes, etc)
- Create a central repository of resources to support across the lifespan of an individual with an SCI
- Connect with social and mental health supports

HSO

PRAXIS Spinal Cord Institute

Next Steps

This HSO/Praxis Experience Map will be used to inform a National Standard of Canada on SCI rehabilitation care and services. The standard will present best practices for the co-design and delivery of an integrated, people-centred SCI rehabilitation program that spans the full rehabilitation journey of a person with lived experience of SCI – from acute care to re-integration into the community.

The standard will provide health and social services organizations and their teams with recommendations on how to work collaboratively with one another and with people with lived experience of SCI to co-design SCI rehabilitation care and service pathways that can be delivered at any time and in any setting, always with the needs of the person of lived experience in mind. The standard will be informed by the holistic needs of persons with lived SCI experience and the gaps they identified through this Experience Map process.

This Insights Report has been developed collaboratively with Health Standards Organization and Praxis Spinal Cord Institute and Overlap Associates.

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Better is absolutely possible.

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