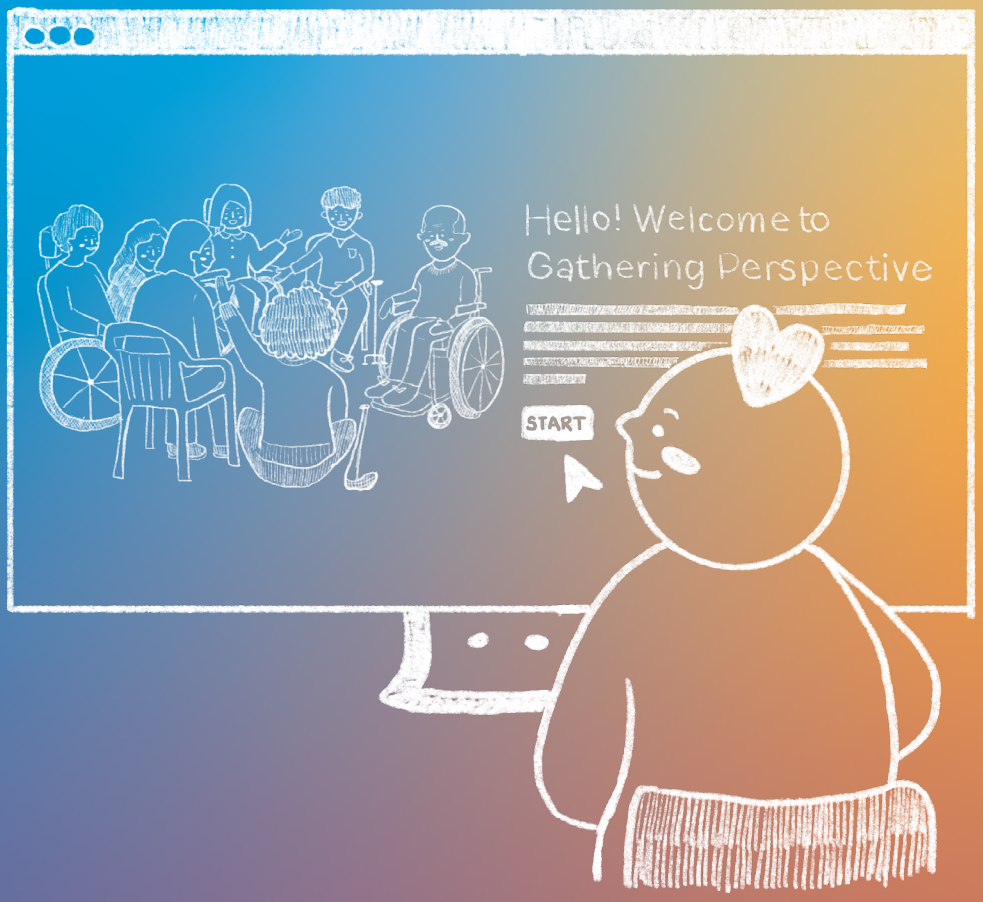

Gathering Perspective

POLICY RECOMMENDATIONS SURVEY SUMMARY

Reshaping Rehabilitation & Recovery of Stroke, Brain Injury, and Spinal Cord Injury in BC through community engagement

BC Rehabilitation+ Recovery

JULY 2023

PROJECT STEERING COMMITTEE:

Heart & Stroke

Mary Stambulic, Director, Health Policy and Systems, BC + Yukon

Jeff Sommers, Former Director, Health Policy and Systems, BC + Yukon

After Stroke BC/March of Dimes Canada

Brent Page, Executive Director

Spinal Cord Injury BC

Chris McBride, Executive Director

BC Brain Injury Association

Geoffrey Sing, Manager of Brain Injury Services the Cridge Centre for the Family

Robin Bienvenu, Member of the Board of Directors

BC Brain Wellness Program

Sally-Ann Stelling, Team Lead, Exercise Programs & Education

GF Strong Rehabilitation Centre

Jennifer Yao, MD, FRCPC Physical Med & Rehab, UBC Clinical Associate Professor

Centre for Health Services and Policy Research

Jason Sutherland, Director

Person With Lived Experience

Jennifer Monaghan, Patient Partner

Health Design Lab , Emily Carr University of Art + Design

Nadia Beyzaei, Manager

Blair Muxiang Yu, Research Assistant

Mark Hanbunjer, Research Assistant

Yutaan Lin, Research Assistant

This project is funded by a Vancouver Foundation Systems Change Grant.

The development of this report took place in Vancouver, British Columbia, located within the unceded lands of the Musqueam, Skxwú7mesh-ulh Úxwumixw (Squamish) and Tsleil-Waututh peoples. We practice these land acknowledgments not only as acts of recognition, but also as a reminder to attune ourselves to the real, and lived impacts of colonial systemic forces, as we work towards engaging in processes that look to better support people who have experienced a stroke, spinal cord injury and/or brain injury.

For more information, please contact:
Mary Stambulic at: mary.stambulic@heartandstroke.ca

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Introduction

The 'BC Rehabilitation and Recovery Strategy and Advocacy Plan 'is a collaboration between community organizations, health professionals, and people with lived experience aimed at improving rehabilitation and recovery services for people living with stroke, spinal cord injury, and brain injury in BC. The aim of the initiative is to:

- Work closely with people with lived experiences, rehabilitation and recovery professionals and researchers, and community organizations to gather and translate their experiences into recommendations for concrete policy changes.
- Build the case for a client-centered, systematic, integrated, and organized province-wide approach to rehabilitation and recovery services; and
- Vigorously press that case to all levels of relevant decision-makers in the province over the next two years and beyond.

Phase one of the initiative involved a community engagement series with people with lived experience, as well as health care professionals and researchers through a community engagement series. Around 50 participants and 16 facilitators were engaged in 12 virtual workshops, with over 4,600 individual notes collected and synthesized, informed the phase one report.

Phase two involved sharing the phase one report with the community and gathering feedback on policy recommendations informed by that report and existing literature. Outreach was conducted by an online survey; results are summarized in this document with opportunity questions for further discussion.

Survey

DEMOGRAPHICS

In total, 61 people participated in the BC Rehabilitation and Recovery Policy Recommendation Validation Survey. Out of all the participants:

- 65.6% (n=40/61) are people living with a stroke.
- 16.4% (n=10/61) are rehabilitation and recovery professionals.
- 9.8% (n=6/61) are community organization volunteers.
- 9.8% (n=6/61) are people living with a brain injury.
- 6.6% (n=4/61) are people with lived experience's family members.
- 6.6% (n=4/61) are rehabilitation and recovery professionals.
- 4.9% (n=3/61) are care partners.
- 4.9% (n=3/61) are community organization professionals.
- 3.3% (n=2/61) are people living with a spinal cord injury.
- 3.3% (n=2/61) are people who identify as other.

The steering committee reached out to both people with experience and professionals and researchers through the organizations represented by the steering committee. The survey results represent 12 Local, community-based organizations, 3 Provincial, allied/dotted line organizations with an interest in stroke/brain injury, 3 National, allied/dotted line organizations with an interest in stroke/brain injury, and 9 other key stakeholders.

LOGISTICS

This survey was hosted online via the survey platform *Typeform* and open from April 28th to June 20th, 2023.

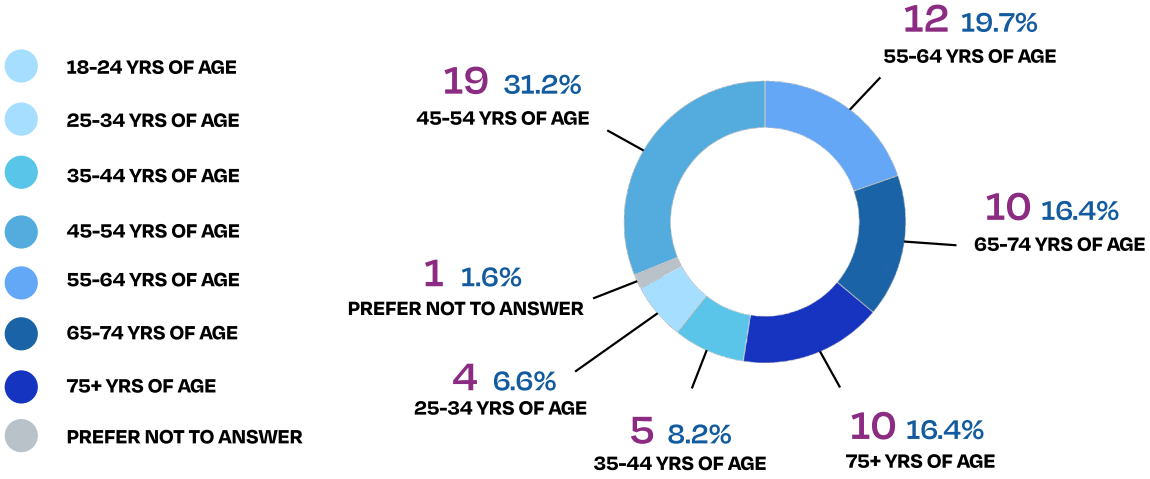
Survey Participant Demographics

Summary of who joined

	NO. OF PEOPLE	%
PERSON LIVING WITH A STOKE	40	65.6%
REHABILITATION AND RECOVERY PROFESSIONAL	10	16.4%
COMMUNITY ORGANIZATION VOLUNTEER	6	9.8%
PERSON LIVING WITH A BRAIN INJURY	6	9.8%
FAMILY MEMBER	4	6.6%
REHABILITATION AND RECOVERY RESEARCHER	4	6.6%
CARE PARTNER	3	4.9%
COMMUNITY ORGANIZATION PROFESSIONAL	3	4.9%
PERSON LIVING WITH A SPINAL CORD INJURY	2	3.3%
OTHER	2	3.3%

Age

NO. OF PEOPLE IN EACH AGE RANGE %



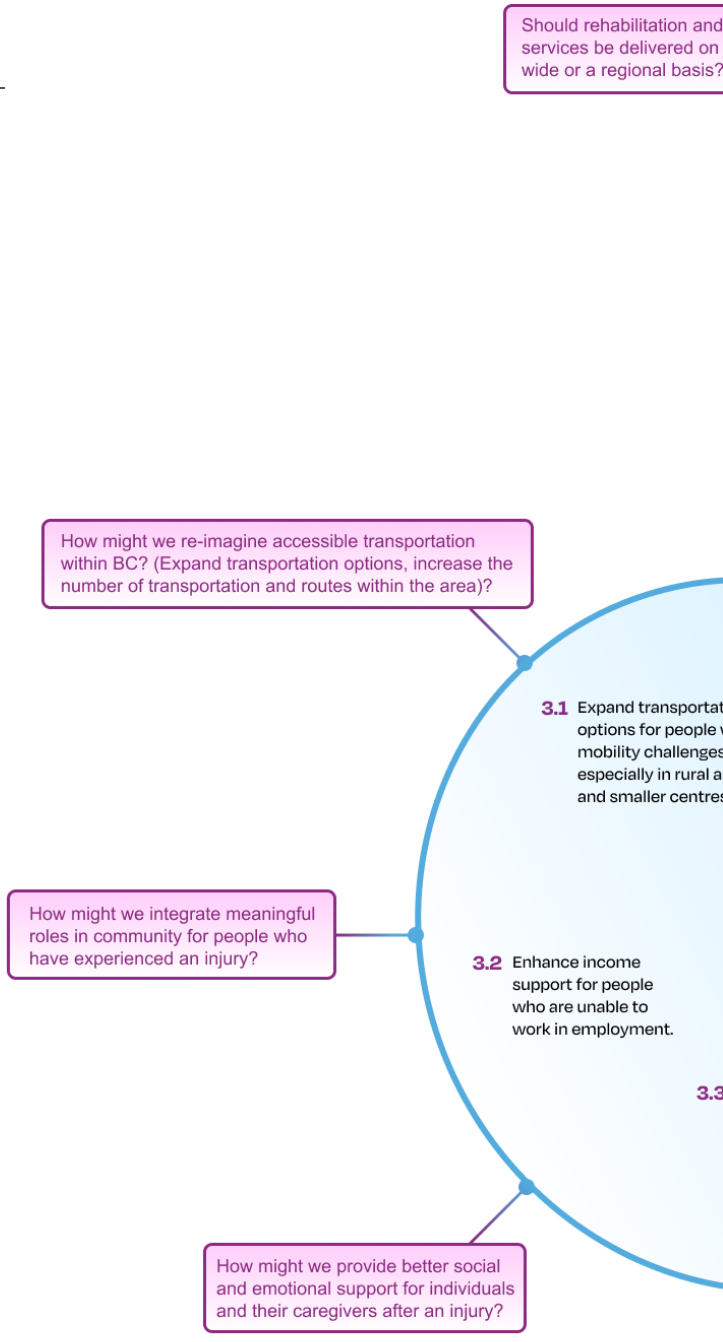
The Policy Recommendations

OVERVIEW

The policy recommendations for this Rehabilitation and Recovery initiative span 3 overarching themes:

1. System Access, Coordination, and Infrastructure
2. Community Services and Support
3. Supports & Infrastructure for Daily Living

Within each theme, there is a set of three recommendations (See Figure 1).



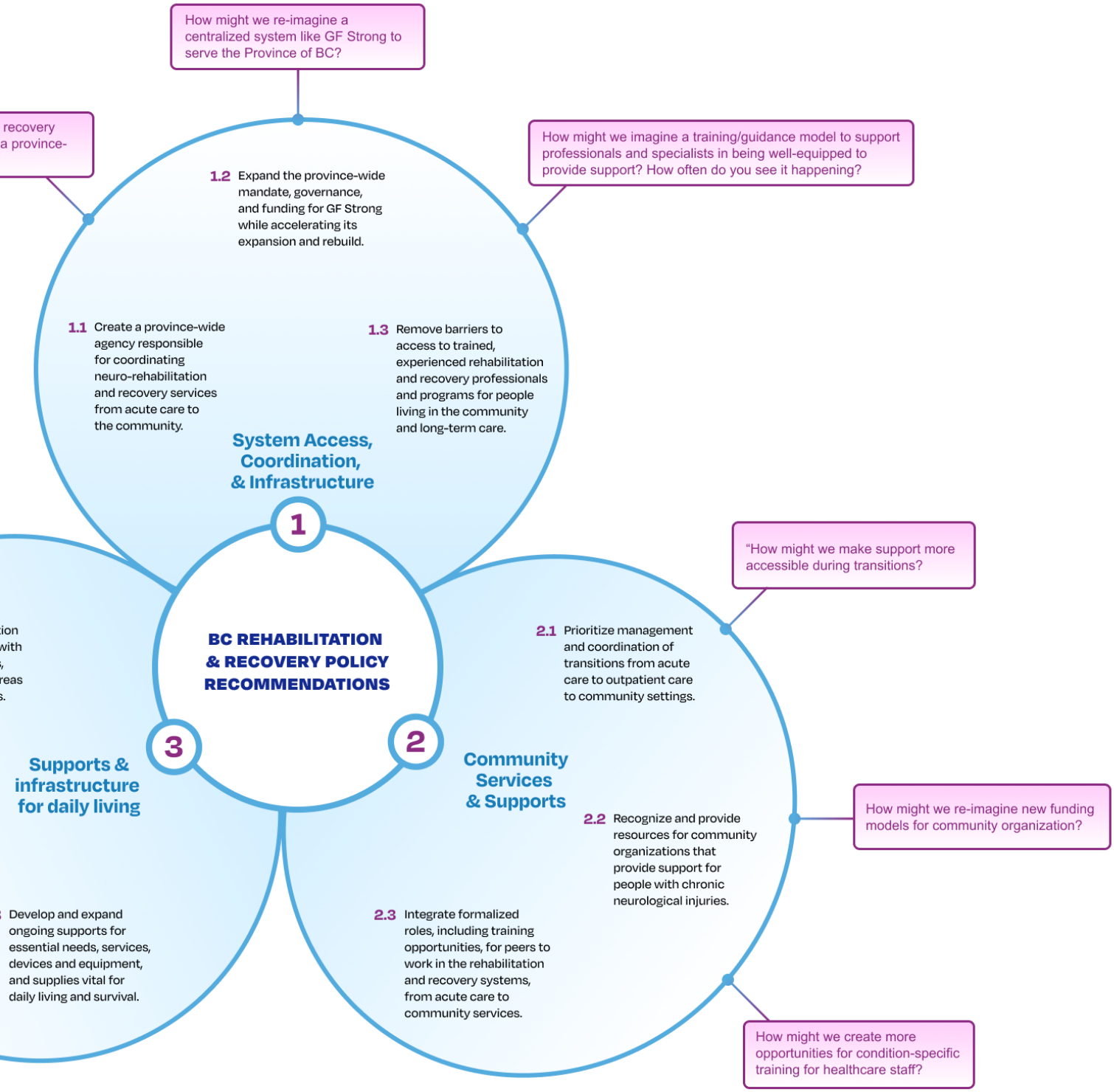


Figure 1: Overview of policy themes (i.e. 1,2,3) recommendations (i.e. 1.1, 1.2) and opportunities (i.e. questions in purple)

RECOMMENDATIONS AND FEEDBACK

1. System Access, Coordination, and Infrastructure

These three key changes in the health care system will provide the basic framework for improving overall coordination and integration of rehabilitation and recovery services and programs and enhance the potential for linkages between that system and the community.

1.1 Create a province-wide agency responsible for coordinating neurorehabilitation and recovery services from acute care to the community.

The Ministry of Health should create and fund an agency responsible for coordinating neurorehabilitation and recovery services, that span the distance from acute care into the community. A single agency with a mandate to coordinate and renew rehabilitation and recovery services will help overcome the current state of administrative fragmentation and geographical disparities in services by working across institutional/systemic boundaries with Health Authorities and community organizations to direct resources to resolve challenges, address gaps, and promote innovation. This agency could also be responsible for the collection of data, currently a major lacuna in the rehabilitation and recovery system in BC, to better monitor and evaluate system effectiveness, and to coordinate training and mentoring for rehabilitation professionals, a key gap that was identified by professionals working with people who live outside the major centres.

KEY INSIGHTS:

- From the Gathering Perspective survey, 93% (n=57/61) of the participants support establishing a province-wide centralized system to promote better accessibility and equity, especially for people who are outside of the urban areas. Having a centralized, province-wide agency could help with knowledge translation, information/ resource-sharing, service consistency, and to prevent breakdown in communication. From the survey, one physiotherapist shares: "It would be helpful to have a central coordinating entity, since people often have to travel between cities/communities for their care, whether when first injured or for follow-up appointments, etc. It would also relieve some of the pressure on the individual professional (who might have other competing priorities on their caseload, or might not know all the provincial resources)." Currently, our healthcare system is centred on acute services: there is a need to bring more attention to post-acute care services and ensure patients have access to knowledgeable services at any time of their recovery stage.

- 6.5% (n=4/61) of participants prefer having region-wide services instead of province-wide. "Province-wide gets too clunky... The resources are spread too thin." says a person living with a stroke. This suggests that some people are interested in a localized healthcare services.

OPPORTUNITY QUESTION

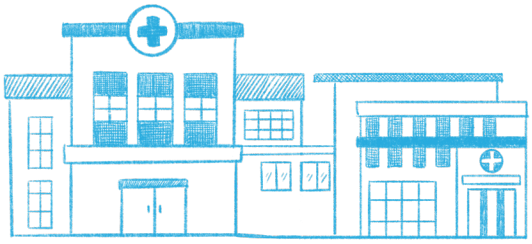
Should rehabilitation and recovery services be delivered on a province-wide or a regional basis?

1.2 Expand the province-wide mandate, governance, and funding for GF Strong while accelerating its expansion and rebuild.

As the main centre for neurorehabilitation in BC, GF Strong Rehabilitation Centre, originally constructed in 1949, with renovation and expansion in the early 1970s, is long overdue for a new, updated building and a review and renewal of its governance and purpose. There is an existing conflict between its governance as a service provided by Vancouver Coastal Health Authority, and its mandate to provide province-wide services. At the same time, neither available funding for rehabilitation staff nor the condition of the building itself are able to support the level of service required to address province-wide needs. Not only is the facility unable to accommodate the number of people who need its services for the length of time required, but staffing shortages and structural challenges frequently create situations that are not conducive to successful service delivery.

KEY INSIGHTS:

- Many participants (85%, n=52/61) said that GF Strong is a well-established centre for rehab and should be expanded to allow for a greater role in providing and supporting province-wide services. Increased funding and support for GF Strong "would allow for increased support and knowledge translation to health professionals in their home community, [and] will help to further improve service delivery and resources available. GF Strong is the provincial rehab hospital and it is in need of upgraded equipment." says occupational therapist and SCI Educator. We also heard that not many services and programs are available to people outside of Lower Mainland, there are no follow-ups, with minimum support for people who are post-discharge. One participant living with stroke shares: "The specialized facility is a recovery game changer, and it shouldn't feel like you need to win the health care lottery to get treatment there." It is a top priority to ensure access to specialized care centres and programs, and the services and expertise should not only be accessible through one rehab centres across the entire province.



- 14.7% (n=9/61) of the participants had different opinions on this policy. People state that specialized health care centres like GF Strong should be re-established within every healthcare region to provide access to local patients without the need for them to travel to the Lower Mainland. One PhD candidate and Registered Nurse shares: "I agree with expanding the funding for GF Strong but it is equally essential to ensure that neurorehabilitation is not centred in an urban area that removes stroke survivors from their communities (especially those living in the rural areas)."

OPPORTUNITY QUESTION

How might we re-imagine a centralized system like GF Strong to serve the Province of BC?

1.3 Remove barriers to access to trained, experienced rehabilitation and recovery professionals and programs for people living in the community and long-term care.

People living with chronic neurological diagnoses, whether they live at home or in long-term care, face a range of barriers that impede access to trained, experienced health professionals. BC has a dire shortage of rehabilitation professionals – especially in the public system. As the province expands the number of places for health trainees in BC through its Health Human Resources Strategy, it will be vital that rehabilitation professionals are included in those efforts and that increased post-secondary training places includes physiatrists and allied health professions such physio- and occupational therapists as well as speech language pathologists. Such an expansion could also take advantage of the need for student practicums to enhance low-cost access to rehabilitation programs.

KEY INSIGHTS:

- In policy recommendation 1.3, 100% (n=61/61) of participants report that expansion of healthcare staff (especially of highly trained, specialized workers) is needed. People should be recruited for all BC healthcare regions. Available training programs need to be provided for professionals and healthcare staff. Currently, many patients are not able to access ongoing rehab programs when transitioning out of acute care. One occupational therapist shares: "it is a very difficult transition as there is limited access to services and health professionals as patients undergo intensive rehabilitation and then have minimal, if any, services in the community... begs the question if it's worth the investment in some of the rehab process if it is not maintained, sustained, or continued to work upon in the community or long-term care." Some participants find that most of the public rehab services needs to be waitlisted, while accessing private ongoing rehab programs or support often requires substantial financial resources.

OPPORTUNITY QUESTION

How might we imagine a training/guidance model to support professionals and specialists in being well-equipped to provide support? How often do you see it happening?

RECOMMENDATIONS AND FEEDBACK

2. Community Services and Support

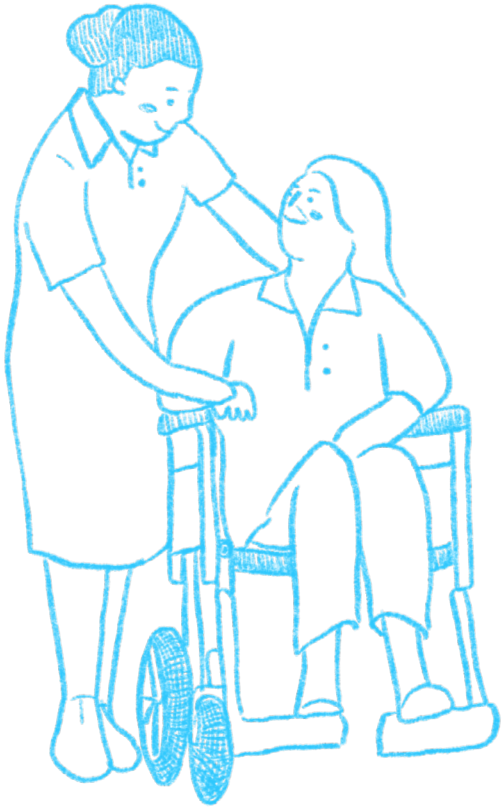
Providing more focused, coordinated activation of community support and peer-driven organizations will improve transition support for people living with stroke, spinal cord injury, and brain injury. Strengthening and coordinating community-based groups will help generate more consistent channels between health care providers working both in and out of the hospital setting and individuals and their families providing a foundation for life-long recovery support.

2.1 Prioritize management and coordination of transitions from acute care to outpatient care to community settings.

Transitions from hospital to home or long-term care, from one set of health care providers to another, from one type of facility or program to another, is difficult, especially for people who are facing an entirely new and unexpected future. Some programs have processes and procedures for managing some transitions but systemic pressures, including staff shortages, often mean that these are not always used adequately. In other cases, people and families are left to manage entirely on their own. One solution to this problem is implementation of a program of system navigation to support people with lived experience and their families to make the transitions from hospital to community, and to facilitate connections with health and community care services and programs. Navigators would operate at the interface of the health system, community health programs, and organizations, and individuals and families, providing backward and forward linkages as well as facilitating connections to social programs such as income and housing support and transportation options.

KEY INSIGHTS:

- For policy recommendation 2.1, 100% of participants (n=61/61) mentioned that navigating through transition stage is difficult for people with lived experience with many falling through healthcare gaps and finding themselves with minimal knowledge, direction, and support available. "There needs to be some formal check-in and update process so patients know the plan while they are on a waitlist for outpatient services. Perhaps there needs to be a resource/person/service that links patients to bridging services while they are on a waitlist so that they are not sitting idle waiting for rehab. Rehab should not be paused after being discharged from acute/inpatient care," wrote a rehabilitation and recovery researcher. The need to establish formalized roles and check-ins to assist people with lived experience at each stage of their recovery journey and to follow-up with them post-acute stage is absolutely essential.



OPPORTUNITY QUESTION

"How might we make support more accessible during transitions?

2.2 Recognize and provide resources for community organizations that provide support for people with chronic neurological injuries.

BC has a broad network of community groups– often peer-driven – that work directly with people living with stroke, SCI, and brain injury, as well as their families. Many of these organizations operate with some provincial and/or federal funding. However, most of this funding is not permanent, nor is it systematically integrated into a broader strategy for post-hospital care and support. While a key advantage of community groups is their autonomy and on-the-ground knowledge/experience, which provides them with a far greater level of flexibility than government programs, the lack of a coordinated, integrated strategy means the province is not fully leveraging the opportunities presented by these networks of organizations to improve quality of life for people living with chronic neurological diagnoses.

KEY INSIGHTS:

- 100% (n=61/61) of participants believe that community organizations are an invaluable resource both emotionally and physically to people with lived experience and should receive more funding and support. An Occupational therapist from the survey suggested: "Community organizations and healthcare system must work together to optimize the care and support provided to clients. [It] can offer a different lens and angle to help clients in the community."It would be ideal for people to access to services and support from their local organizations instead of traveling away from their communities. In order to provide better service to people, there should be a better communication system established between hospital and community organizations to ease transition of care, provide clearer navigation of resources, and to create infrastructure of support for people with lived experience.

OPPORTUNITY QUESTION

How might we re-imagine new funding models for community organization?

2.3 Integrate formalized roles, including training opportunities, for peers to work in the rehabilitation and recovery systems, from acute care to community services.

The opportunity to meet with and learn from people who have had similar experiences can be a significant boost for a person's recovery. Both the transition management process and community organizations offer channels for providing peer support. Health organizations, including hospitals, should explore ways of incorporating peer counselors into their teams and identify other avenues for using peers, up to and including – when possible and appropriate – professional training so there are people working and volunteering in programs who have lived through similar experiences as the people in the programs.

KEY INSIGHTS FROM THE SURVEY:

- 98% (n=60/61) participants spoke about the need to establish peer-led programs in an organized fashion in both hospital and community care settings. Peer support/ mentorship programs offer valuable insights to PWLE and allow them to connect with relevant communities. We heard from a person living with stroke that: "There is [a lack of] peer support in an organized fashion. Peer support is essential in the stroke group [and] this type of group needs to be run by other than strictly volunteers because it is a great responsibility as well as a great resource." Creating roles for PWLE can also help guide patients and support them both physically and mentally. It was also mentioned that having access to trained and experienced professionals and enhancing training opportunities are essential. Currently there are not enough rehabilitation and recovery professionals in the healthcare systems, especially in rural areas.

OPPORTUNITY QUESTION

How might we create more opportunities for condition-specific training for healthcare staff?

RECOMMENDATIONS AND FEEDBACK

3. Support and infrastructure for daily living

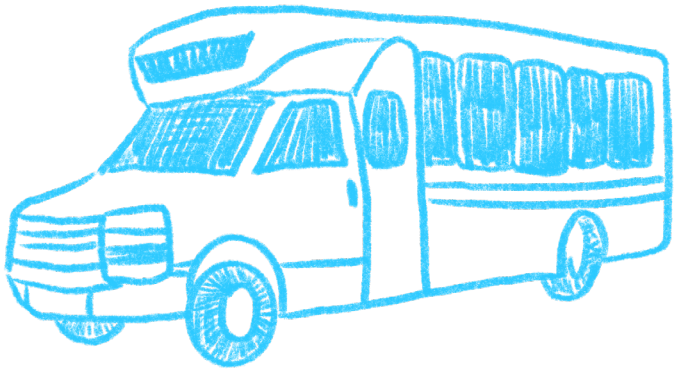
Key infrastructure and program changes could help people living with stroke, spinal cord injury and brain injury, and their families, to participate fully in their communities and avoid disengagement.

3.1 Expand transportation options for people with mobility challenges — especially in rural areas and smaller centres.

Most, if not all, municipal/regional transit services in BC have at least some accessible buses on regular routes. In addition, TransLink and BC Transit support HandyDart services across the province. However, the levels of service vary, often with long lead times and thus advance planning required for booking the service. Travel beyond service areas, or between communities and regions can be very difficult – almost impossible without personal transportation - for people living with major mobility challenges. Despite the major improvements made to municipal pedestrian infrastructure over the past 30 years, there are still many barriers faced by people who need support to get around outside. With an aging population, maintaining social inclusion will demand ongoing, and accelerating changes to infrastructure to support mobility.

KEY INSIGHTS:

- "We are constantly struggling to assist patients to get to the appointments they require in order to support recovery." says by Speech Language Pathologist. 100% (n=61/61) participants mentioned that current programs of accessible transportations are mainly limited to urban areas, with the needs of rural areas outweighing the capacity of services. PWLE who are homebound or lacks accessible transportation and mobility often faces isolation, depression, and limited access to social participation and quality of life. To create more accessible transportations, funding needs to be increased especially for rural areas, and other options of transportation may be considered, such as the implementations of health bus, services and modes that supports different disabilities, including visual impairment, etc. We also heard from the survey that many people find HandyDart is insufficient, unreliable, and difficult to use.



OPPORTUNITY QUESTION

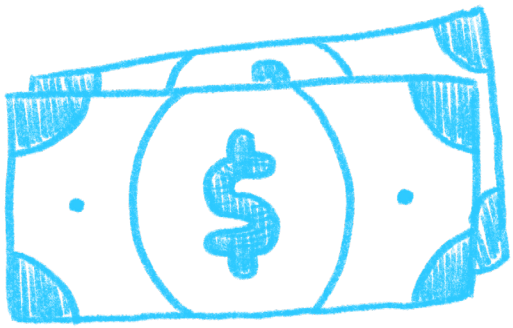
How might we re-imagine accessible transportation within BC? (Expand transportation options, increase the number of transportation and routes within the area)?

3.2 Enhance income support for people who are unable to work in employment.

The economic burden of chronic neurological injuries at a social level is well documented, especially for stroke. What is less well understood is the household burden. Canadian data shows clearly that for people of working age, post-stroke income falls dramatically. While some British Columbians living with, mainly, SCI or TBI may have income through WorkSafe or ICBC settlements, most people living with chronic neurological injuries who are under 65 and unable to work must rely on Disability Assistance or Canada Pension – Disability. Provincial support pays less than $1400/month for single people and just over $2100/month for couples with one child. Federal support ranges from $1000/month to just over $1500/month. These are mutually exclusive, i.e., receipt of one precludes receipt of the other. The income available through such programs is much less than minimum wage, which is highly problematic given living costs, especially high in BC, often increase because of mobility and/or cognitive challenges.

KEY INSIGHTS FROM THE SURVEY:

- 100% (n=61/61) of people with lived experienced find it difficult to return to work. More income support should be provided to support people with lived experience due to expensive medical charges for services and equipment needed for accommodation of a new lifestyle. Access to these funding and disability support qualifications also needs to be adjusted, with the current system having unrealistic standards of qualification. As one participant living with a stroke states: "To get any kind of disability [support] is practically impossible. The limits set are so ridiculous that hardly anyone qualifies for them plus nowhere close to their original income." Furthermore, the province should create employment opportunities and integration of roles for people with lived experience.



OPPORTUNITY QUESTION

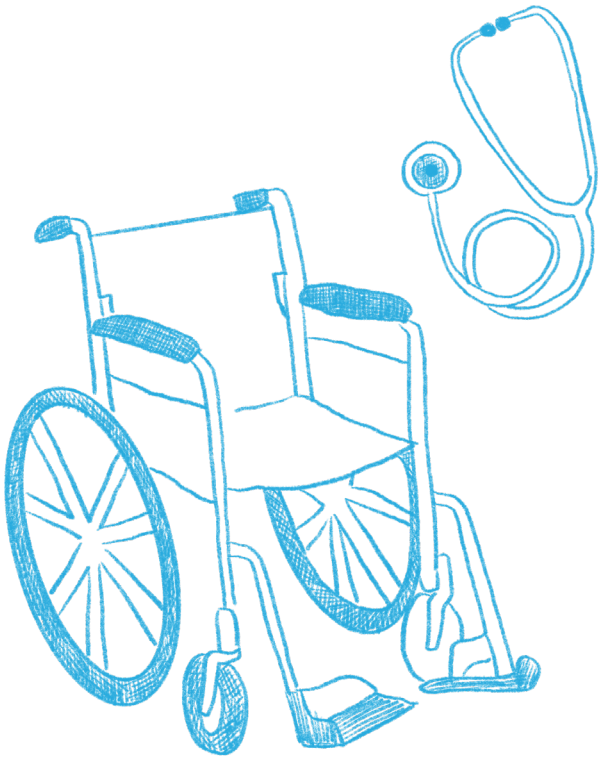
How might we integrate meaningful roles in community for people who have experienced an injury?

3.3 Develop and expand ongoing supports for essential needs, services, devices and equipment, and supplies vital for daily living and survival.

People living with mobility and other physical challenges often require a range of devices, resources, and other types of support that are basic necessities for their survival. However, in many cases, they are often required to pay for these items or services. While urinary catheters for people living with spinal cord injury are perhaps the most egregious example, the list of items ranges from shower/bathtub rails to wheelchairs (manual and electric) and walkers to a plethora of Musculo-skeletal and cognitive therapeutic services that are rarely, if ever, available through MSP. At the same time, the availability of home support and services are often restricted, increasing the responsibility and burden of family caregivers to provide services for free that should be covered by the public system.

KEY INSIGHTS FROM THE SURVEY:

- Having essential support throughout the entire recovery journey is a must. 100% (n=61/61) participants expressed that current ongoing support programs can be very competitive and expensive. One participant with lived experience of a stroke shares: "Because I don't qualify for disability benefits, I had to pay out of pocket for devices required for my home therapy program. It was difficult to manage shopping, meals and housekeeping tasks." Many people are in need of equipment to be able to navigate their everyday life, however, the expenses that come with it does not make it easy. People told us that Disability benefit qualifications should provide more coverage, especially with helping the cost of assistive devices and equipment. Ideally, the community organizations can on the role and support patients with the right equipment.



OPPORTUNITY QUESTION

How might we provide better social and emotional support for individuals and their caregivers after an injury?

Next Steps

OVERVIEW

This is not the first time these issues have been raised in BC. Earlier reports and processes have made recommendations for improving rehabilitation and recovery without success. To catalyze change in the health system. It will be necessary to have a broader conversation about the importance of rehabilitation and recovery services, not only for the well-being of individuals and families but also for the resilience of our communities and our province. But change must happen not only in communities, but also within the health system, and at the policy level. Over the next year, the BC Rehabilitation and Recovery Strategy will be having those conversations, bringing together people with lived experience, and their families with people who work in the health system, and with policymakers. Through this process, we want to advance the changes needed to ensure that people living with stroke, SCI, and TBI have the services and programs they need when they need them along the course of their recovery journeys.

OPPORTUNITY DECK: PROMPTS FOR DISCUSSION

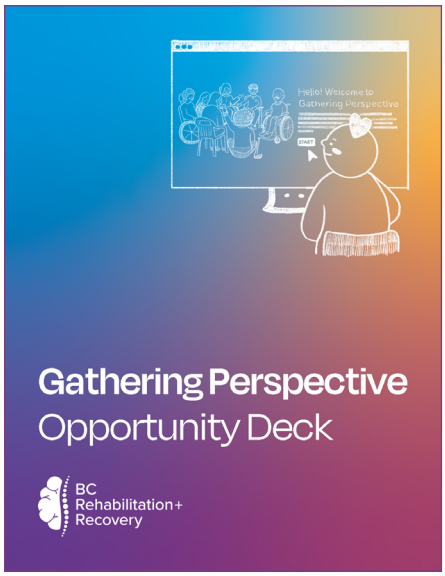
Gathering Perspective Policy Recommendation Survey Report', to spark further conversatons about Rehab and Recovery in BC for people who have experienced a stroke, spinal cord injury and/or brain injury!

The cards are organized into three overarching policy recommendation categories:

- System Access, Coordination, & Infrastructure
- Community Services & Supports
- Supports & Infrastructure for Daily Living

Each card highlights quotes from the community, gathered from our survey conducted between April 28th to June 20th, 2023. On the reverse side of each card, we pose a question for further discussion about opportunities for change.

Our hope is that this supports you in having conversations that shape the future of care!



Appendix A:
Policy Recommendation Survey

If you would like to view ***The Gathering Perspective Policy Recommendation Survey***, two versions are available via the QR codes below.

Archived web version

PDF version

BC Rehabilitation+ Recovery

Gathering Perspective

The BC Rehabilitation and Recovery team conducted a community engagement series alongside people with lived experiences of Stroke, Spinal Cord Injury, and Brain Injury, health professionals, and researchers to map out current experiences and identify gaps within the BC rehabilitation and recovery system.

Take a look at our community engagement summary and fill out our survey to share your feedback on our policy recommendations

Start the survey

Appendix B:
Policy Opportunity Deck

If you would like to view ***The Gathering Perspective Policy Opportunity Card Deck,*** two versions are available via the QR codes below.

PDF version
optimized for digital viewing

Gathering Perspective Opportunity Deck

BC Rehabilitation+ Recovery

Let's do this.

This card deck was created as a supplementary resource to the 'Gathering Perspective Policy Recommendation Survey Report', to spark further conversatons about Rehab and Recovery in BC for people who have experienced a stroke, spinal cord injury and/or brian injury!

The cards are organized into three overarching policy recommendation categories:

System Access, Coordination, & Infrastructure
Community Services & Supports
Supports & Infrastructure for Daily Living

Each card highlights quotes from the community, gathered from our survey conducted between April 28th to June 20th, 2023. On the reverse side of each card, we pose a question for further discussion about opportunities for change.

Our hope is that this supports you in having conversations that shape the furture of care!

With care,
BC Rehab + Recovery Team

Policy Rec. Recap

System Access, Coordination, & Infrastructure
1.1 Create a province-wide agency responsible for coordinating neuro-rehabilitationand recovery services from acute care to the community
1.2 Expand the province-wide mandate, governance, and funding for GF Strong while accelerating its expansion and rebuild
1.3 Remove barriers to access to trained, experienced rehabilitation and recovery professionals and programs for people living in the community and long-term care

Community Services & Supports
2.1 Prioritize management and coordination of transitions from acute care to outpatient care to community settings
2.2 Recognize and provide resources for community organizations that provide support for people with chronic neurological injuries
2.3 Integrate formalized roles, including training opportunities, for peers to work in the rehabilitation and recovery systems, from acute care to community services

Supports & Infrastructure for Daily Living
3.1 Expand transportation options for people with mobility challenges, especially in rural areas and smaller centres
3.2 Enhance income support for people who are unable to work in employment
3.3 Develop and expand ongoing supports for essential needs, services, devices, equipment, and supplies vital for vdaily living and survival

"I feel well supported, but many in B.C. are not."
— Person living with a stroke

Policy Rec. 1.1

Create a province-wide agency re
coordinating neuro-rehabilitation
services from acute care to the c

How might we create access to equitable care throughout different healthcare regions within BC?

System Access, Coordination & Infrastructure

"Due to the pressures in hospitals, clients are often needing to navigate and find support in community and outpatient settings. There needs to be assistance and focus on this piece and clinicians are often not able to do it in a timely way."
— Rehab & Recovery Professional, SLP

"The quality of care from Outpatient to community settings can be improved. I felt rushed in this transition and lack of support once
outpatient (ie. social worker, vocati
Strong has these services on outpa
people outside coastal health regio
access to such services."
— Person living with a stroke

Policy Rec. 2.1

Prioritize management and coordi
transitions from acute care to outp
to community settings

How can we relieve pressure within hospitals/rehab centres while maintaining a high standard and quality of care?

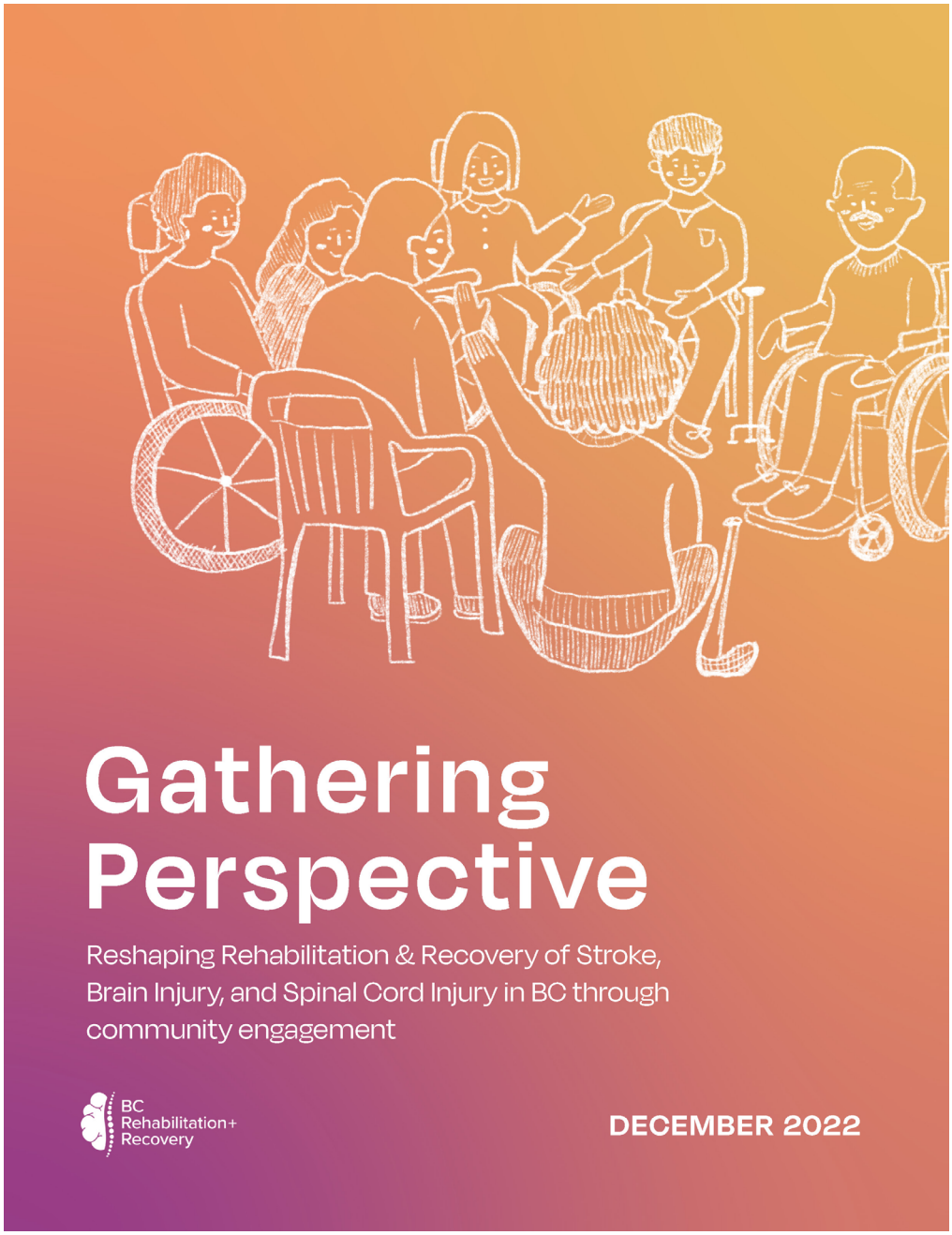
Community Services & Supports

Appendix C: Community Engagement Report

If you would like to view the full or the summary of ***The Gathering Perspective*** phase 1 report, the documents are available via the QR codes below.

Summary Report

Full Report


Gathering
Perspective
Reshaping Rehabilitation & Recovery of Stroke, Brain Injury, and Spinal Cord Injury in BC through community engagement
BC Rehabilitation+ Recovery
DECEMBER 2022

Notes

BC
Rehabilitation+
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