Acquired Brain Injury Provincial Services Evaluation Initiative: Phase 1 Report

EXECUTIVE SUMMARY

With generous support from the Rick Hansen Foundation, the British Columbia Brain Injury Association (BCBIA) launched an initiative called *Acquired Brain Injury (ABI) Provincial Services Evaluation Initiative.* The purpose of this initiative was to answer the following question: "What excellent programs and services for people with ABI[i] exist in BC?" The focus was on quality programs and services that demonstrate excellence in the area of transitioning people living with acquired brain injury to be active participants in their communities. Rather than identifying areas of deficiency or weakness, BCBIA wanted to identify areas of strength and opportunities to expand on those strengths. Given timing and resource constraints, the project was split into two phases:

- Phase 1 – Quantitative Information Collection (March - June, 2015)
- Phase 2 – Building on Results from Phase 1 (June, 2015 + TBD)

The project was guided by a Steering Team consisting of ABI Leads and Stroke Leads from each of the regional Health Authorities, Provincial Stroke Leads from the Provincial Health Services Authority, and representatives from BCBIA. The health authority representatives each identified two programs/services for inclusion in the evaluation. In making their selection, they considered the following four criteria: 1) *Community engagement* (helps individuals transition successfully to community); 2*) Peoples' experiences* (displays high levels of satisfaction for clients and families); 3) *Quality outcomes* (demonstrates positive individual goal attainment and functional outcomes); and, 4) *Economic value* (shows positive return on investment).

Limitations of the Evaluation

Selection of Services for Inclusion in Evaluation

It was recognized that there would be limitations inherent in asking the Steering Team members to identify the services, most notably that they would likely put forward services with which they were most familiar, and that others might be missed in the process. It was agreed, however, that in the absence of a comprehensive overview of all existing ABI services in BC, it would serve as a good place to start. It should be noted, however, that of the 10 programs/services included in this evaluation: 7 are led by Health Authorities; 2 are led by stroke or brain injury associations; and, 1 is led by a private deliverer of brain injury services.

Availability of Data

There was great variation in the size, budgets and nature of the 10 programs/services evaluated. All of the 10 programs/services had information and statistics to share, although there was great variability in quantity and quality of the available data.

Privacy Challenges

The original project plan had identified the desire to conduct focus groups and interviews with individuals and families utilizing the 10 programs/services. Each health authority has privacy and ethics processes that projects like this must be vetted through. A number of questions and concerns were raised by privacy officers from the health authorities that would have required a significant amount of time to address. Given timing and resource constraints, a decision was made to split the project into two phases. In Phase 1 (March – June, 2015) we chose to gather, collate and summarize existing aggregate information for the programs/services; we did not collect any line level data or data of a personal nature. During the data collection process, 1-2 hour conversations were had with eighteen key service contacts/key informants.

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[i] This project adopted the World Health Organization's definition of ABI: "Damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease. These impairments may be temporary or permanent and cause partial or functional disability or psychosocial maladjustment" (Geneva 1996).

Programs/Services Included in the Evaluation

Of the 10 programs/services that were evaluated:

- 5 are based solely in an institutional/direct care setting (e.g., hospital, rehab centre, or clinic); 2 are split between hospital and community/home, 1 is in a private, community-based residential care setting; and 2 are based entirely in non-institutional settings (i.e., community health unit or brain injury association);
- 7 are led by Health Authorities; 2 are led by stroke or brain injury associations; 1 is led by a private deliverer of brain injury services; and,
- 2 are stroke specific; 3 are ABI specific, 1 is traumatic brain injury (TBI) specific and 4 are for eligible clients, of whom people with ABI represent a significant proportion.

Table 1: List of the 10 Programs/Services Included in the Evaluation

Region	Lead	Program/Service Name & Brief Description
FHA	FHA	**Community Rehab Early Discharge Initiative (REDi)** An outpatient service designed to provide coordinated rehabilitation to clients who have realistic, achievable functional goals, who no longer need to stay in hospital and are able to be supported at home.
FHA	FHA	**Concussion Clinic** An early intervention and follow-up service for clients living with the effects of a recent concussion/mild traumatic brain injury.
IHA	CONNECT	**CONNECT Lake Country Specialized ABI Transitional Rehabilitation Program and Residential Services** Complex and specialized services for people living with brain injury and stroke provided in a nurturing, innovative and empowering community environment.
IHA	IHA	**Acute ABI Coordinator Role** A role that serves as one point of contact for patients and families. The Coordinator provides education and orientation to the system within acute care and community to support maximum independence.
Island Health	SRABC	**Community Stroke Recovery Navigator (CSRN)** A post-hospital, community-based stroke recovery navigation service that links stroke survivors and caregivers with community resources based on co-created goals, and provides educational sessions.
Island Health	Island Health	**Hospital to Homes (H2H) Committee** A multidisciplinary Island Health committee that collaborates to find community placements for clients who have long hospital stays because they have complex needs and often co-occurring disorders (e.g., brain injury and mental health or substance use issues).
NHA	NHA	**Two Stroke Workshops: 1) "Understanding Stroke"; and, 2) "Building Community Connections"** Workshop #1 offers a chance for survivors, families and friends to learn about how the brain works, stroke and recovery and to talk about life after a stroke. Workshop #2 is an opportunity for the same target audience to learn about some of the services and programs available in their communities.
NHA	PG BIG	**Two Group Programs: 1) "Rebuilding After Brain Injury"; and 2) "Connect, Learn and Grow" (CLG)** Program #1 is a 24-week, 1.5 hour in-depth course. It looks at strategies of daily living and dealing with the effects of brain injury. Program #2 is a weekly 1.5 hour session that provides education and tools, and develops skills and personal connections necessary for personal growth following brain injury.
VCH	VCH	**Intensive Rehab Day Program (IRDP)** An intensive, 4-5 days/week, 4-6 week, team-oriented outpatient program as an alternative to inpatient care.
VCH	VCH	**Intensive Rehab Outpatient Program (IROP)** A coordinated early discharge service that helps clients transition from hospital to home sooner. Clients attend one-to-one therapy (and group activities when appropriate) as outpatients.

The most common success factors identified through the evaluation include the following values/approaches:

- **Recovery-oriented** – Is goal based, not just focused on clinical outcomes
- **Client-centered** – Meets people where they are at
- **Based on best practices** – Engages in continuous improvement based on best practices and client feedback
- **Flexible** – Is flexible and does "whatever it takes" in order to meet the unique needs of clients
- **Coordinated, collaborative approach** – Works closely with all appropriate service providers
- **Dedicated program management or project support -** Invests in and/or allocates a program manager, program coordinator or project manager to lead and/or support the initiative
- **Links to other services** – Makes links to other community services essential to supporting clients upon discharge
- **Marketing** – Educates other parts of the system about its purpose and services
- **Group education sessions** – Offers group education sessions as a means to provide information & support
- **Value-add** – Offers something complementary to other parts of the system
- **Evaluation** – Provides dedicated resources for data collection, analysis, evaluation and reporting where possible
- **Supportive leadership** – Has support from organizational leaders and decision-makers (especially those in health authorities), demonstrated through words and actions

During the data collection process, the Consultant also explored key informants' thoughts regarding how they would "in a perfect world" like to move their own initiatives forward and also how they would like to see the system as a whole advance in order to more effectively support people with ABI. Potential actions that were proposed included the following:[ii]

Potential Actions at a Provincial or Regional Level:

1) Develop a strategy to enhance public education
2) Establish a mechanism for ongoing communication, information sharing & joint action
3) Collect, analyze, report & share data more effectively
4) Demonstrate supportive leadership
5) Explore opportunities to create new and build on existing partnerships with others
6) Build on this evaluation
7) Link more effectively with research community
8) Use evaluation results to support decision-making about ABI services
9) Explore opportunities to align these options for next steps with key Ministry of Health priorities

Potential Actions at an Individual Program/Service Level:

1) Establish dedicated program coordination and/or leadership roles or mechanisms
2) Educate and connect more effectively with health service providers across the entire continuum of services
3) Orient programs/services more to client goals rather than strictly clinical goals
4) Place more focus on metrics and evaluation
5) Continue to build on and enhance effectiveness of group programming
6) Encourage and inform supportive leadership

[ii] The potential actions are loosely prioritized in the sense that they are listed in order based on how frequently they were mentioned by key informants (i.e. #1 = most frequently mentioned; #9 = least frequently mentioned).

Everyone Has a Role to Play

This document provides stakeholders with a snapshot of some of BC's excellent programs/services, offers learnings from the experience and expertise of those programs/services, and serves as a solid foundation on which to build. It identifies areas of promising practices and others that are showing early signs of success but merit further exploration. Embracing the challenge of strengthening the network of ABI services and supports in BC can feel overwhelming – there are many steps that need to be taken. This document is intended to provide a foundation to help readers start to identify and implement manageable steps specific to their context. Everyone has a role to play...at a micro level, readers are encouraged to view this document through the lens of their own role in the system and think about what they can do within their circle of influence. There may be some small changes they can make immediately in their day-to-day work, as well as some big changes they would like to try to encourage in the long-term. At a macro level, readers are encouraged to think about how this document could be used to inform strategic planning at a provincial level. A structure, process and plan will need to be developed to operationalize the actions in this report going forward.

A package of various communication materials has been created to use with a wide range of target audiences. Newsletters are being sent to all the health authorities. This executive summary is being shared with the Ministry of Health, the Board Chairs of all the health authorities, key physician groups and some of the relevant provincial programs such as Trauma Services BC. This executive summary will also be posted on www.brainstreams.ca. The full report will be shared with representatives from the 10 highlighted programs/services, representatives from the additional programs that were noted in the report but not included in the analysis, and the project's Steering Team members, which includes brain injury and stroke leads from each health authority.

NEXT STEPS: MOVING FORWARD FROM THE REPORT

A strategy is being developed to address the priorities for moving forward identified by the Steering Team, including:

1) Establishing a formal partnership with Stroke Services BC (Provincial Health Services Authority);
2) Continuing to work closely with our partners at the Rick Hansen Foundation, each of the 5 regional Health Authorities and with the non-profit and private service providers in our province;
3) Showcasing the 10 programs/services identified as excellent through this initiative; and,
4) Anchoring the ABI Provincial Services Evaluation Initiative to best practice.

Comments or Questions?

If you have comments or questions about this initiative or would like a copy of the full report, there are three ways to contact the BCBIA:

- Call us at 604-984-1212
- Email us at info@brainstreams.ca
- Send us a message via the contact form located at www.brainstreams.ca/contact

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