

COMPLETED:

Stroke Recovery Association of British Columbia / March of Dimes Canada - Survey of Stroke Recovery-related Organizations in Canada

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1.0 Introduction

Stroke Recovery Association of British Columbia (SRABC) is the largest provincial association devoted to Stroke Recovery in Canada. Stroke Recovery Canada is a program of March of Dimes Canada (MODC) which seeks to support Stroke Recovery in each province and across the country. Tim Readman, Executive Director of SRABC, and Brent Page, National Manager for Regional Development at MODC, have been exploring opportunities to work together. They are aiming to host a National Symposium to bring key stakeholders in post-hospital stroke recovery and community reintegration to a virtual table to:

- Discuss the definition of 'Stroke Recovery' in the context of community-based programs;
- Build consensus on what elements comprise a stroke recovery program;
- Provide a forum for dialogue on best practices; and,
- Identify specific targets for joint National and Provincial advocacy.

Key stakeholders in post-hospital stroke recovery and community reintegration were identified and invited to participate in an online survey. The survey is used to collect baseline information on organizations working in the stroke recovery/community reintegration field. This report will summarize the results of the survey.

2.0 Methods

A total of 115 stroke recovery-related organizations were identified using mainly Google. The key stakeholders and contact information were recorded in an Excel database. The organizations were then categorized into three groups based on their involvement in the stroke recovery/community reintegration field.

The groups are:

- Green – The key stakeholders that are invited to the National Symposium as well as to complete a 10-15 minute survey. Twenty-six organizations are in this group.
- Yellow – The organizations that have been contacted to gather more information about key stakeholders in each province. Seventy-six organizations are in this group.
- Red – The organizations that are not specifically involved in stroke recovery and community reintegration. No contact has been made at this stage of the project. Thirteen organizations are in this group.

The survey is created using SurveyMonkey and is comprised of 14 questions. The survey is used to collect baseline information on these organizations. In order to keep anonymity, the responses are only used by MODC and SRABC for the purposes of this project.

Twenty-two surveys were sent to the key stakeholders in the green group. One survey was sent to an interested organization in the yellow group.

3.0 Results

Thirteen responses (out of twenty-three surveys sent) are received.

3.1 Offered Programs

The most offered programs are health promotion/ wellness/ secondary stroke prevention and system navigation services. Both of these services are offered by five organizations. The least offered programs are community-based adapted fitness and exercise and also cognitive stimulation and memory exercise services. More detailed results can be observed in Figure 1.

Five organizations do not provide direct stroke recovery services. Some of these organizations conduct research, provide financial support to other stroke recovery programs, or act as a go-to agency that connects stroke survivors to available services.

3.2 Statistics

Out of thirteen responses, five of them indicated that they keep some form of statistics and/or records. These statistics include number of participants in stroke recovery programs, number of printed resources, number of inquiries, number of stroke cases, and descriptions of brain injury (including stroke).

Another five key stakeholders claimed they do not keep any statistics. Three respondents skipped this question.

3.3 Definition of Stroke Recovery

Nine respondents strongly agree while two respondents agree with the following definition of stroke recovery:

Stroke Recovery is the process by which people who have had a stroke recover to the best of their ability; improve their independence and quality of life; and have respect, inclusion, and support as they become reintegrated into their home community.

Some suggestions to improve this definition include:

- Include the family unit/caregiver in the definition
- Change "best" to "to the full extent of their ability"

Two respondents did not answer this question nor provide suggestions.

3.4 Impact

Out of a rating from one to five where one represents the lowest impact and five represents the highest impact, most key stakeholders rate their organization's impact in the stroke recovery and community reintegration fields with a score of 3. Only two key stakeholders rated themselves with a score of 5. One of key issues that was highlighted by three key stakeholders is the lack of funding needed to grow and develop. More detailed results can be observed in Figure 2.

3.5 Elements of Stroke Recovery Program

In general, all elements listed in this question seem to be important to be included in a community-based Stroke Recovery program. In particular, there is more emphasis on professional input and supervision. The elements that receive the least weight are: physical exercise and mobility, social interaction and recreation, system navigation, cognitive stimulation, and emotional support.

3.6 Regionally-Based Stroke Groups

Out of eight responses, five organizations do not offer regionally-based stroke groups. Some indicated that they do not provide direct services, but they work with other stroke recovery groups.

Three organizations offer regionally-based stroke groups, but most of them are independent to their organizations.

3.7 Program Planning

Five organizations are involved in Stroke Recovery program planning. The reference materials highlighted in the responses include:

- Canadian Best Practice Recommendations for Stroke Care
- Heart and Stroke Foundations materials
- Canadian Stroke Network materials
- Evidence Based Review for Stroke Rehabilitation (EBRSR)
- Stroke Engine
- Surveys from participants in Stroke Recovery programs
- Other Stroke Strategy materials
- Other fact books about Stroke

3.8 Challenges

The most significant challenge/barrier that hinders the organization's ability in achieving its goal is the lack of funding. Five out of ten respondents indicated that lack of funding is one of their major issues. Human resource shortage is another issue that is revealed from the responses. This issue is sometimes directly related to funding cutbacks. Some organizations rely mainly on their volunteers. Two respondents believe they received insufficient support from the government, such as Ministry of Health and provincial health regions.

3.9 Opportunity

The question aims to comprehend what key stakeholders believe as an untapped opportunity that they should be involved in. The responses from this question are all varied. Many key stakeholders focus on developing a well-established organization in which they will use available resources more effectively, provide support to stroke recovery groups, and provide useful and practical resources for all stroke survivors and caregivers.