

Dear Participant,

Thank you for your interest in this very important project! Before you begin, please take the time to learn more about this project, and your participation.

Depending on who you are (a survivor, family member/caregiver or professional), you will be asked questions about life before and after brain injury, services utilized, and unmet service needs. Your input will assist us in developing and delivering brain injury related services in Nova Scotia.

The survey has a special focus on issues related to housing, education, and employability. We encourage you to express any concerns not covered in the survey.

The survey should take you no longer than 30 minutes to finish. All information is confidential, and there is no way for us to link your name to your answers. Your participation is completely voluntary. You are not required to answer all the questions and you may stop at anytime.

If you begin the survey and have difficulty answering some of the questions, please ask someone to help you, or maybe they can answer the questions on your behalf. You can also save your place in the survey and return to it at a later time.

We would like to thank you by offering you a chance to enter your name for a prize draw to be held after the survey ends. Prizes have been donated by a number of businesses serving Nova Scotia.

If you have more questions about the survey and your participation, or if you are interested in participating in a focus group in your community, please contact Nancy Green at (902) 473-5199 or send an email to bianssurvey@gmail.com. Focus groups will be held in Halifax, Truro, New Glasgow, Bridgewater, Kentville, Sydney, and Yarmouth during late June and early July.

Thank you for your support!

Sincerely,



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Family Member/Caregiver Questionnaire

Please take a few minutes to tell us about your experiences as a family/member or caregiver to a survivor of brain injury. We ask that you also complete the survivor portion of the questionnaire on his/her behalf if he/she is unable to complete the questionnaire.

Circle your answers for multiple choice questions and mark an "X" for the questions where multiple options exist.

1. Are you:

- a) Male
- b) Female

2. To which age group do you belong?

- a) 0-17
- b) 18-25
- c) 26-35
- d) 36-45
- e) 46-55
- f) 56-65
- g) 65+

3. In what community do you live? (If you live in a community listed, please select it as your answer, if you live in a rural area, please select the county.)

- | | | | |
|----------------------------|---------------------|---------------|----------------|
| a) Annapolis County | ___ Middleton | | |
| ___ Bridgetown | | | |
| b) Antigonish County | | | |
| ___ Antigonish | | | |
| c) Cape Breton County | | | |
| ___ Glace Bay | ___ New Waterford | ___ Sydney | |
| d) Colchester County | | | |
| ___ Truro | | | |
| e) Cumberland County | | | |
| ___ Amherst | | | |
| f) Digby County | | | |
| ___ Clare | ___ Digby | | |
| g) Halifax County | | | |
| ___ Bedford | ___ Dartmouth | ___ Halifax | ___ Sackville |
| h) Guysborough County | | | |
| ___ Canso | ___ Guysborough | | |
| i) Hants County | | | |
| ___ Windsor | | | |
| j) Inverness County | | | |
| ___ Inverness | ___ Port Hawkesbury | ___ Port Hood | |
| k) Kings County | | | |
| ___ Berwick | ___ Kentville | ___ Wolfville | |
| l) Lunenburg County | | | |
| ___ Bridgewater | ___ Chester | ___ Lunenburg | ___ Mahone Bay |
| m) Pictou County | | | |
| ___ New Glasgow | ___ Pictou | | |
| n) Queens County | | | |
| ___ Liverpool | | | |
| o) Richmond County | | | |
| ___ Arichat | | | |
| p) Shelburne County | | | |
| ___ Shelburne | | | |
| q) Victoria County | | | |
| ___ Baddeck | | | |
| r) Yarmouth County | | | |
| ___ Yarmouth | | | |
| s) Out of Province/Country | | | |

4.What is your relationship to the survivor? (Please select all that apply.)

- ☐ Parent
- ☐ Current Spouse/Partner
- ☐ Former Spouse/Partner
- ☐ Sibling
- ☐ Child
- ☐ Extended Family Member (Aunt, Uncle, Cousin, Grandparent)
- ☐ Caregiver
- ☐ Other (Please Specify):_____

5.Thinking about your experiences at the time of your family member's brain injury, please tell us how much you agree or disagree with each of the following statements: (Place the number that corresponds to your answer in the space provided.)

1	2	3	4	5	6	7	8	9
Strongly Disagree	Disagree	Slightly Disagree	Neither Agree or Disagree	Slightly Agree	Agree	Strongly Agree	I Don't Know	Not Applicable

- _____ The Health Care Professionals working with our family member communicated effectively to us about our family member's brain injury.
- _____ We were able to easily access information about what services/programs were available to us.
- _____ We were able to easily access information about what services/programs were available to our family member.
- _____ Support was made available to our family to help us cope with our family member's brain injury (for example, counseling, education).

6.Thinking about life since your family member's brain injury please tell us how much you agree or disagree with each of the following statements: (Place the number that corresponds to your answer in the space provided.)

1	2	3	4	5	6	7	8	9
Strongly Disagree	Disagree	Slightly Disagree	Neither Agree or Disagree	Slightly Agree	Agree	Strongly Agree	I Don't Know	Not Applicable

- _____ We received information that was easy for us to understand about our family member's brain injury and how to help him/her live independently.
- _____ We received sufficient support from health care professionals to help us better learn how to care for our family member.
- _____ We are aware of the respite care options available to us.
- _____ Relationships among family members have at times been strained.
- _____ We have received support from other families/individuals who have a family member living with a brain injury.
- _____ Caring for my family member has, at times, been a challenge for our family.

7.As a family member/caregiver to a survivor, how much do agree or disagree that each of the following are important issues in meeting the needs of survivors and their families/caregivers:

1	2	3	4	5	6	7	8	9
Strongly Disagree	Disagree	Slightly Disagree	Neither Agree or Disagree	Slightly Agree	Agree	Strongly Agree	I Don't Know	Not Applicable

- _____ Respite care
- _____ Family counseling
- _____ Education about brain injury
- _____ Support from professionals
- _____ Comprehensive information about services/programs available
- _____ Support from other's who have family members living with brain injury
- _____ Improved availability and access to services (such as in-home supports, long term care, extended rehabilitation services, transitional care services etc.)
- _____ Financial Assistance/Funding of necessary services
- _____ Improved community support/outreach programs (for example, day rehabilitation programs, support, etc.)

8.Are there other issues that you believe are important to survivors and their families/caregivers that we have not considered?

9.Overall, as a family member/caregiver, how would you rate your satisfaction with the care, programs, and services available for persons with brain injury in this province?

- a)I am very satisfied
- b)I am satisfied
- c)I am somewhat satisfied
- d)I am neither satisfied or dissatisfied
- e)I am somewhat dissatisfied
- f)I am dissatisfied
- g)I am very dissatisfied

10. Other questions, comments, concerns?

If you are interested in learning more about this project or would like to take part in a focus group fill out the form below or contact Nancy Green, Service Development Coordinator at (902)473-5199 or bianssurvey@gmail.com. Results of the survey will be available online at <http://bianssurvey.50webs.com>.

THANK YOU!

If you would like to enter your name into the prize draw or are interested in participating in a focus group, fill out the form below and submit separately from your responses.

Name: _____

Address: _____

Telephone: _____ Email: _____

I am interested in participating in a focus group about services and unmet needs for brain injury in Nova Scotia [____]