

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](mailto: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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## Survivor Survey

Please note that in this survey, "brain injury" is used to describe all acquired brain injuries, including strokes and tumors.

### About You

Before we start asking you questions about your service needs and experiences, we would like to know more about you, and your brain injury.

#### 1.Are you:

- a)Male
- b)Female

#### 2.In what year did your brain injury occur?: \_\_\_\_\_

#### 3.How did your injury occur?

- a)Motor Vehicle Incident
- b)All Terrain Vehicle Incident
- c)Snowmobile Incident
- d)Motorcycle Incident
- e)Pedestrian Incident
- f)Stroke
- g)Assault
- h)Blunt Trauma
- i)Fall
- j)Tumor
- k)Near Drowning
- l)Other (Please Specify):\_\_\_\_\_

#### 4.Your injury was diagnosed as:

- a)Mild
- b)Moderate
- c)Severe
- d)I don't know

#### 5.How old were you at the time of your injury?

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

#### 6.How old are you now?

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

## Rehabilitation and Care-Related Services

Rehabilitation is what follows your care in hospital. The questions below will ask you about your rehabilitation.

### 7. Where did you go for rehabilitation? (Please select all that apply.)

- ☐ Hospital-based setting
- ☐ I received rehabilitation services in my community
- ☐ I did not receive rehabilitation services (Go to # 11.)
- ☐ I don't remember (Go to # 11.)
- ☐ I received services in another province/country
- ☐ Other(Please Specify): \_\_\_\_\_

### 8. Which of the following rehabilitation care-related services have you (and your family) received for your injury? (Please select all that apply.)

- Counseling:
  - ☐ Mental health counseling
  - ☐ Substance abuse counseling
  - ☐ Family counseling
- Rehabilitation Services:
  - ☐ Speech therapy
  - ☐ Occupational therapy
  - ☐ Physical therapy
  - ☐ Employment/Vocational counseling
- Support Services:
  - ☐ Nursing/Medical services
  - ☐ Respite care
  - ☐ Support groups
- Independent Living Assistance:
  - ☐ Recreational opportunities
  - ☐ Money management/financial counseling
  - ☐ Supported housing (i.e., Aiseirigh House, Peter's Place, Supervised Apt., etc.)
  - ☐ Personal care assistance
  - ☐ Household assistance
  - ☐ Transportation assistance
- Information:
  - ☐ Access to information about programs and services available
  - ☐ Information about your injury
- ☐ None of these
- ☐ Others (Please Specify): \_\_\_\_\_

### 9. What obstacles did you face in receiving your rehabilitation services? (Please select all that apply.)

- ☐ Transportation to and from my appointments was an issue
- ☐ Services were not available to me in my home/community
- ☐ The financial cost of rehabilitation was an issue
- ☐ I did not face any obstacles
- ☐ I don't know
- ☐ Not applicable
- ☐ Other (Please specify): \_\_\_\_\_

**10. Why did you not receive rehabilitation services? (Please select all that apply.)**

- ☐ Rehabilitation was not suggested for my injury
- ☐ I did not need rehabilitation
- ☐ I could not afford rehabilitation services
- ☐ Services were not available in my community and I could not travel for them
- ☐ I didn't know they were available
- ☐ I don't know
- ☐ Other (Please Specify): \_\_\_\_\_

**Housing/Independent Living**

The following questions will ask you about housing and independent living issues both before and after your injury.

**11. What were your living arrangements at the time your injury? (Please select all that apply.)**

- ☐ With Spouse/Common Law Partner
- ☐ With Parents
- ☐ With Siblings
- ☐ With Children
- ☐ With Caregiver
- ☐ With Roommates/Friends
- ☐ Lived Alone
- ☐ Lived in a Group Home/Small Options
- ☐ Lived in a Supported Apartment
- ☐ Lived in Transitional Housing
- ☐ Nursing Home
- ☐ No Permanent Address
- ☐ Other (Please Specify): \_\_\_\_\_

**12. In what community did you live before your injury? (If you live in a city listed, please select it as your answer, if you live in a rural area, please select the county.)**

- a) Annapolis County
  - ☐ Bridgetown      ☐ Middleton
- 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) Guysborough County
  - ☐ Canso      ☐ Guysborough
- h) Halifax County
  - ☐ Bedford      ☐ Dartmouth      ☐ Halifax      ☐ Sackville
- 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

**13. What is your current living situation? (Please select all that apply.)**

- \_\_\_ With Spouse/Common Law Partner  
 \_\_\_ With Parents  
 \_\_\_ With Siblings  
 \_\_\_ With Children  
 \_\_\_ With Caregiver  
 \_\_\_ With Roommates/Friends  
 \_\_\_ Live Alone  
 \_\_\_ Live in Group Home/Small Options  
 \_\_\_ Live in a Supervised Apartment  
 \_\_\_ Live in Transitional Housing  
 \_\_\_ Nursing Home  
 \_\_\_ No Permanent Address  
 \_\_\_ Other (Please Specify): \_\_\_\_\_

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

- a) Annapolis County  
     \_\_\_ Bridgetown    \_\_\_ Middleton
- 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)Guysborough County  
     \_\_\_Canso                      \_\_\_Guysborough
- h)Halifax County  
     \_\_\_Bedford                  \_\_\_Dartmouth                  \_\_\_Halifax                  \_\_\_Sackville
- 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

**15. With respect to your current housing needs and living arrangements, how much do you agree 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

- \_\_\_\_\_ Some responsibilities for independent living have been a problem for me (for example: budgeting, meal preparation, home repairs, scheduling appointments, transportation, decision making, taking initiative).
- \_\_\_\_\_ I have needed help with my personal care routine (for example, grooming, dressing, eating, etc.).
- \_\_\_\_\_ My role in the household has changed.
- \_\_\_\_\_ The Health Care Professionals I worked with have helped me understand my brain injury.
- \_\_\_\_\_ People I live with have been educated about my brain injury and understand how to help me with independent living.
- \_\_\_\_\_ Living in an environment where professionals help me develop independent living skills, would have been/has been helpful.
- \_\_\_\_\_ I am confident in my ability to live independently now and in the future.

## Financial Impact

We understand the impact a brain injury can have on an individual's, and his/her family's finances. This section will ask you a few questions about the financial impact of your brain injury.

**16. You currently receive financial support/benefits from: (Please select all that apply):**

- ☐ Full Time Employment (20 hours or more a week)
- ☐ Part Time Employment (Less than 20 hours a week)
- ☐ Seasonal Employment
- ☐ Occasional Employment (for example, short term contract work, temporary positions)
- ☐ Self Employment
- ☐ Insurance Settlement
- ☐ Legal Settlement
- ☐ Income Assistance
- ☐ Long Term Disability
- ☐ Worker's Compensation
- ☐ Canadian Pension Plan (CPP)
- ☐ Family Support/Benefactors
- ☐ I don't know
- ☐ Other (Please Specify): \_\_\_\_\_

**17. Please select the option that best reflects your opinion about the following statements about the effects of your injury on your finances: (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

- \_\_\_\_\_ My income has been negatively impacted as a result of my brain injury.
- \_\_\_\_\_ My income is enough to meet my basic needs.
- \_\_\_\_\_ I am uncertain about my financial situation in the future.
- \_\_\_\_\_ My injury has negatively impacted the finances of my family members.

## Education

These questions will ask you about your education. The term, “educational program” refers to any type of education – full time/part time, formal institutions, single courses, upgrading, etc.

### 18. Before your injury, what was your highest level of education?

- a) Did not attend school
- b) Completed Some or All Elementary School
- c) Completed Some or All Junior High School
- d) Completed Some High School
- e) High School Graduate/GED
- f) Some College (for example, Community College, Private business/career colleges, and trade schools)
- g) Some University
- h) College Completed
- i) University Completed
- j) Some Graduate School
- k) Graduate School Completed (Master's/PhD)
- l) Other (Please Specify): \_\_\_\_\_

### 19. Which of the following best describes you?

- a) I have been enrolled in an educational program since my brain injury.
- b) I would like to enroll in an educational program, but have not done so since my brain injury (Please go to #21).
- c) I do not want/need to enroll in an educational program (Please go to Employment section).

### 20. Which of the following best describes your current highest level of education?

- a) Did not attend school
- b) Completed Some or All Elementary School
- c) Completed Some or All Junior High School
- d) Some High School
- e) High School Graduate/GED
- f) Some College (for example, Community College, Private business/career colleges, and trade schools)
- g) Some University
- h) College Completed
- i) University Completed
- j) Some Graduate School
- k) Graduate School Completed (Master's/PhD)
- l) Other (Please Specify): \_\_\_\_\_



**21. Please tell us how much you agree or disagree with 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

\_\_\_\_\_ I am aware of potential educational programs that might be appropriate for me.

\_\_\_\_\_ I am aware of services that can assist me in learning if I choose to enroll in a program/course (for example: Student Accessibility Centres/Centres for Students with Disabilities, Canada Study Grants for Students with Disabilities, Labour Market Agree for Persons With Disabilities Program).

\_\_\_\_\_ I am aware that if I choose to enroll in a program/course, I may be able to access accommodations such as extra time to complete assignments/exams, tutoring, notetaker, and alternate means of completing course work.

**22. What obstacles did (or would) you face in enrolling in an educational program? (Please select all that apply.)**

\_\_\_ Financial reasons

\_\_\_ Transportation issues

\_\_\_ Medical issues

\_\_\_ Memory issues

\_\_\_ I don't know how to fine out about my options

\_\_\_ Not sure what I would like to study

\_\_\_ I need disability related supports (for example, special technology, a notetaker, a tutor, etc)

\_\_\_ I don't think I can do it

\_\_\_ Other(Please Specify): \_\_\_\_\_

## Employment

We appreciate the impact a brain injury can have on an individual's employment. We would like to know more about the impact your injury has had on your employment.

### 23. Before your brain injury you were:

- a) I was a child/teenager at the time of my injury
- b) Employed Full Time (20 hours or more a week)
- c) Employed Part Time (Less than 20 hours a week)
- d) Seasonally Employed
- e) Occasionally Employed (for example, short term contract work, temporary positions)
- f) Self-Employed
- g) In a Sheltered Workshop
- h) Unemployed and looking for work
- i) Unemployed and not looking for work
- j) Retired due to age
- k) Retired due to disability
- l) Family Caregiver
- m) Student
- n) Volunteer

### 24. Have you, at any time, been employed since your injury?

- a) Yes
- b) No (Go to # 26.)

### 25. You are currently:

- a) Employed Full Time (20 hours or more a week)
- b) Employed Part Time (Less than 20 hours a week)
- c) Employed Seasonally
- d) Employed Occasionally (for example, short term contract work, temporary positions)
- e) In a Sheltered Workshop
- f) Self-Employed
- g) Unemployed and looking for work
- h) Unemployed and not looking for work
- i) Retired due to age
- j) Retired due to disability
- k) Family Caregiver
- l) A Student
- m) Volunteer

### 26. What obstacles have (or would) you faced in returning to work?

- \_\_\_ Transportation
- \_\_\_ Memory problems
- \_\_\_ Concentration problems
- \_\_\_ Medical issues
- \_\_\_ Stigma/lack of understanding about brain injury
- \_\_\_ Others (Please Specify): \_\_\_\_\_

**27. Complete the following statement by selecting ALL the options listed below that apply to you  
I am not working because:**

- ☐ My injury prevents me from working (for example, you are often in pain, you have physical limitations, have problems with your memory)
- ☐ I am not interested in working
- ☐ I am unable to return to the job I had prior to my injury
- ☐ Working would interfere with receiving benefits
- ☐ I do not know what I can do
- ☐ I need help with job search skills (searching for jobs, resume writing, interview skills)
- ☐ I do not have the right training
- ☐ There are no jobs available in my areas of interest
- ☐ Other (Please Specify): \_\_\_\_\_

**Life since ABI: Your Relationships, Social Supports and Adjustment**

The following questions will ask you about your relationships and social supports.

**28. What was your relationship status at the time of your injury?**

- a) Married/Common Law
- b) Separated
- c) Divorced
- d) Widowed
- e) Single
- f) I was a child at the time of my injury

**29. What is your current relationship status?**

- a) Married/Common Law
- b) Separated
- c) Divorced
- d) Widowed
- e) Single

30. Please tell us how much you agree 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

- \_\_\_\_\_ Relationships with my family have, at times, been strained.
- \_\_\_\_\_ Changes in my emotions have created problems in my relationships.
- \_\_\_\_\_ I have lost contact with many of those I was close to before my brain injury.
- \_\_\_\_\_ Lack of support and encouragement from my community (friends, neighbours, employers, coworkers, family, etc) is a problem for me.
- \_\_\_\_\_ I feel disconnected/isolated from my community.
- \_\_\_\_\_ I often feel that I am a burden to those around me.
- \_\_\_\_\_ I have goals that are personally meaningful to me.
- \_\_\_\_\_ I have had support from health care professionals, my family, and community in accomplishing things that are important to me.
- \_\_\_\_\_ I have sought out support from others who have had a brain injury
- \_\_\_\_\_ I have been involved in services in the community for survivors of brain injury (for example; BIANs InRoads Program)

31. Thinking about the obstacles or barriers you have faced in accessing services such as educational, employment, housing, rehabilitation programs, please tell us how much you agree or disagree that the following were issues for you: (Place the number that corresponds to your answer in the space provided.)

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

- |       |  |
|-------|--|
| _____ | Living in a rural area.  |
| _____ | I cannot afford the services I need (for example, insurance does not cover them, lack of financial resources). |
| _____ | Poor communication among service providers (with each other and with me and my family/caregivers).             |
| _____ | I do not meet program eligibility criteria.  |
| _____ | Available services do not meet my individual needs.  |
| _____ | It is hard to find helpful information about services available to me.   |
| _____ | It is difficult to access services.  |

**32. Thinking about your experiences and needs as a brain injury survivor, please tell us how much you agree or disagree that each of the following are important issues to you. (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
	_____	Medical/Medication Issues						
	_____	Memory/Cognitive Issues						
	_____	Attention/Focusing Skills						
	_____	Anger Management Issues						
	_____	Isolation/Disconnected from those close to me						
	_____	Financial Issues						
	_____	Housing Issues						
	_____	Transportation Issues						
	_____	Employment Issues						
	_____	Education/Training Opportunities/Issues						
	_____	Public Awareness & Understanding of Brain Injury						
	_____	Continued support from health care professionals when I returned to my community						

**33. If you wanted more information about programs or services available to you, where would be the first place you would look?**

- \_\_\_ Department of Health
- \_\_\_ Department of Community Services
- \_\_\_ Friends
- \_\_\_ Family
- \_\_\_ Internet
- \_\_\_ Physician
- \_\_\_ Caregiver
- \_\_\_ Other Health Care Professional
- \_\_\_ The Brain Injury Association of Nova Scotia
- \_\_\_ Other (please specify)

**34.Overall, 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

**35. 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 on the next page and submit with your survey, or you can contact Nancy Green at (902) 473-5199 or email [bianssurvey@gmail.com](mailto:bianssurvey@gmail.com). Results of the survey will be available online at <http://bianssurvey.50webs.com>.

**THANK YOU!**

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

-----

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

I am interested in taking part in a focus group about these issues [\_\_\_\_].