



Chapter, Support group and Online Needs Assessment – 2012/2013

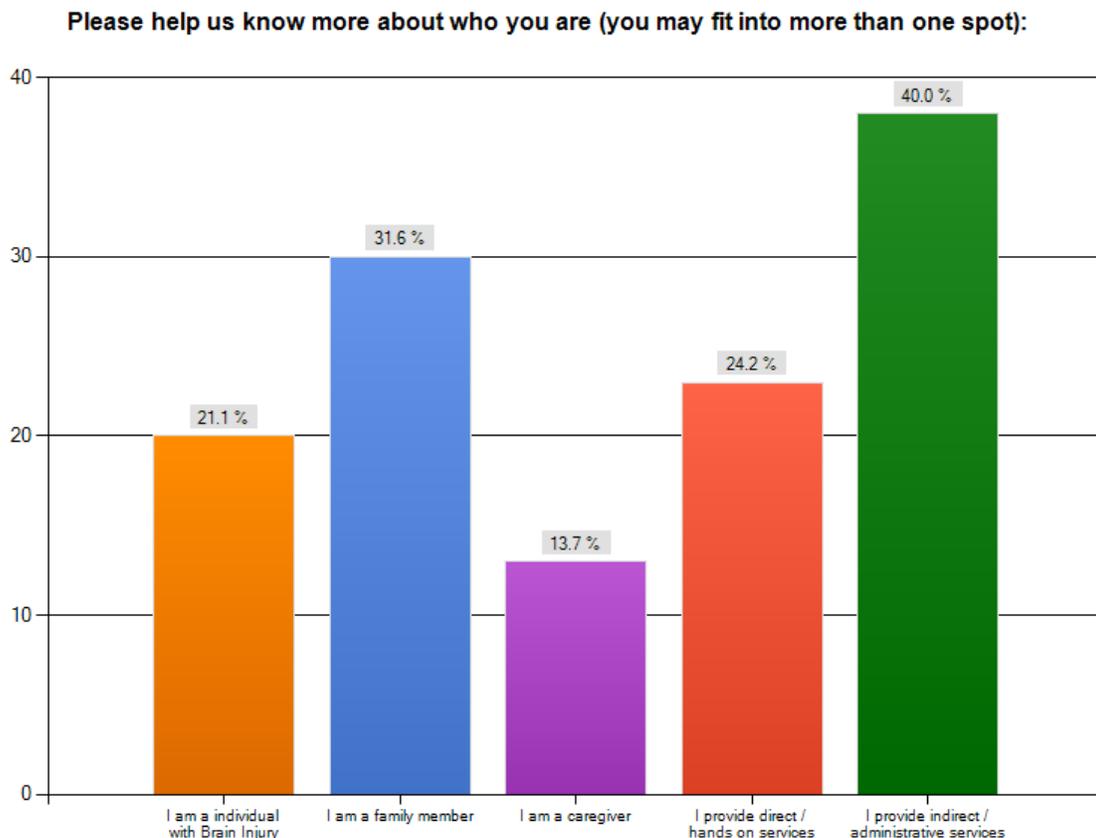
Background: From October – December of 2012 the Brain Injury Alliance of Iowa conducted a statewide needs assessment with its membership, Chapters, Support Groups (Mason City, Tri-State/Dubuque, Quad Cities, Central/Des Moines, East Central/Cedar Rapids/Iowa City, Lakes/Spirit Lake, Northeast/Waterloo) IBIRN sites (145) BISN peer support members, corporate members, past attendees of conferences, webinars and workshops, and many others via secondary contacts from collaborators such as IDPH and others.

Copies of the web based survey and the Chapter/Support group questionnaires may be found in Appendix A. While there were minor variations in questions there was substantial alignment in both efforts.

We received 97 responses to a Web based survey. With the exception of the Southwest portion of the state these online responses were from across the state.

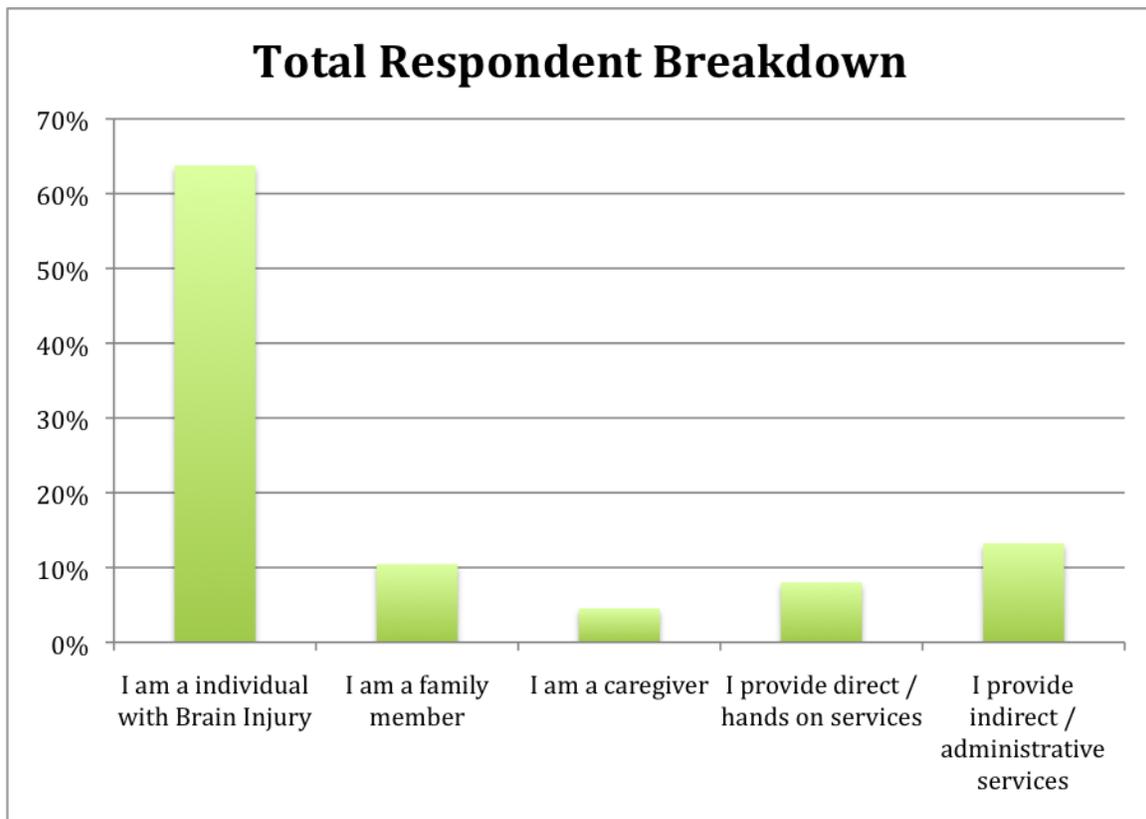
The breakdown of these responses is shown in Chart 1.

Chart 1 – Online Response Breakdown



There were 103 individuals and 60 group based responses from 8 separate Chapters and Support group locations (see above) either via individual paper based submissions or focus groups respectively. When added to the online responses this input significantly increased the response rate from individuals with lived experience of brain injury from 21.1% to 64% as seen in Chart 2.

Chart 2 – Combined Online and Support Group Response Breakdown



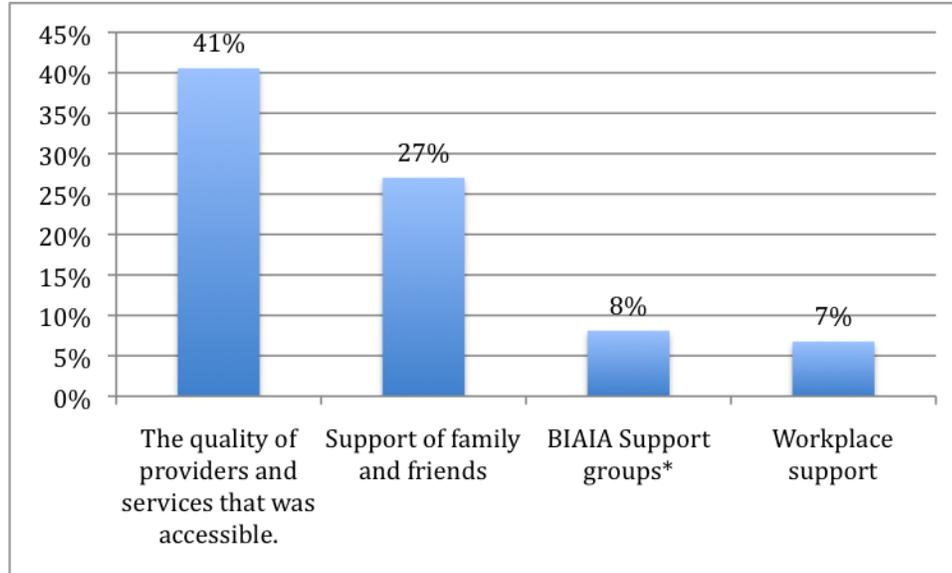
Below are the results from a qualitative analysis of the needs assessment responses for use in the Iowa State Plan Planning purposes. This analysis combined the responses from the online and the support group data. Response items, areas and themes were first identified. Items, areas and themes were combined in cases where they aligned under a more major heading (i.e., memory issues and balance issues as top concerns after leaving the hospital were grouped into a category labeled “Sequela”).

Overall impressions include a continued lack of access to post acute services and funding for them. In addition, and perhaps somewhat contradictorily, there was a clear theme of increased access, availability and quality of services over the past few years. Waiting list and lack of access to the BI waiver is a recurring theme, as an expressed need for enhanced brain injury knowledge in the professional community. Access to support in navigating the financial and disability landscape and linking to services post brain injury was a major theme. Also a major theme was the need for availability and access to an array of post acute community based services and supports.

1. What have been your best and worst experience post-brain injury?

Best: (70% online response rate)

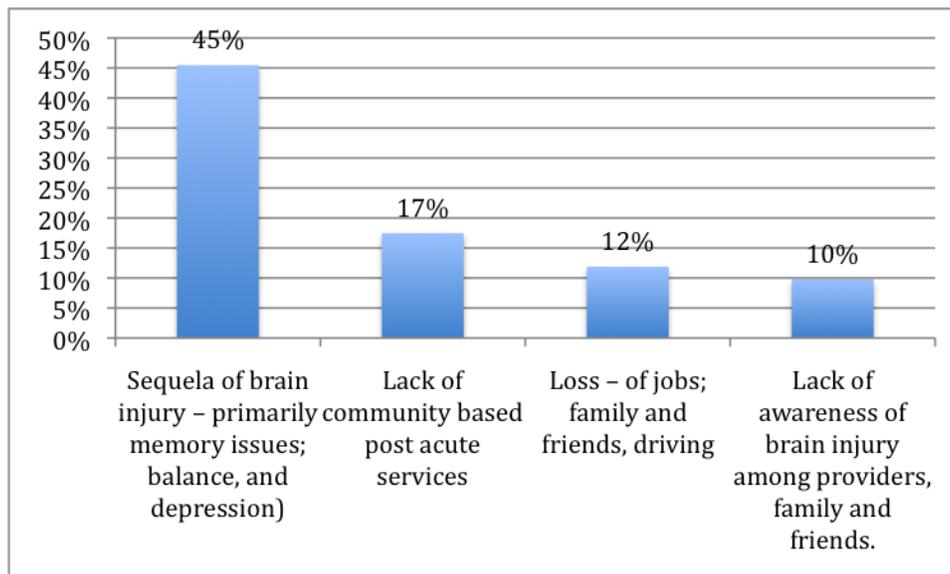
1. The quality of providers and services that was accessible.
2. Support of family and friends
3. BIAIA Support groups*
4. Workplace support



(* - Note that as a majority of responses to the BIAIA needs assessment were from Support group members / settings this may be a significant source of bias to this question.)

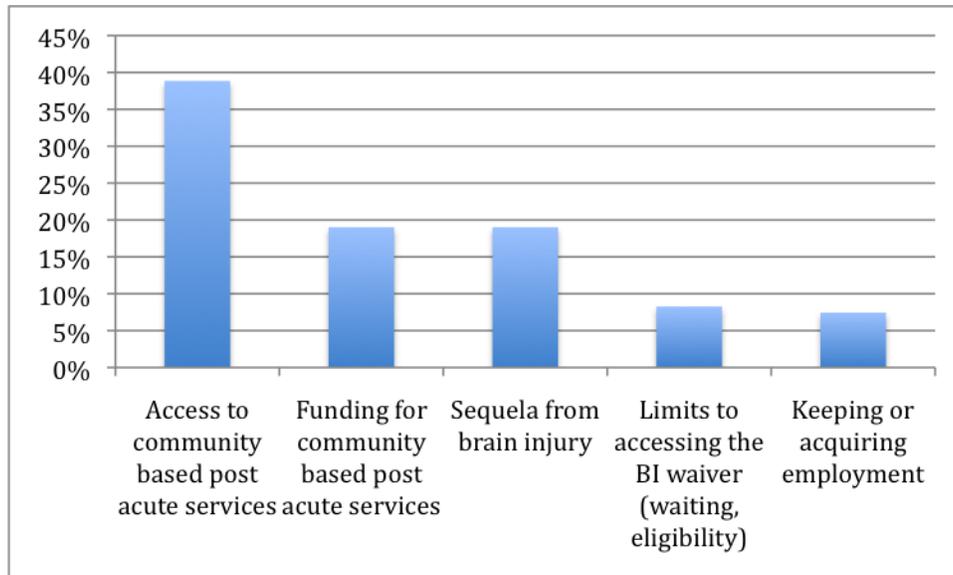
Worst: (68% online response rate)

1. Sequela of brain injury – primarily memory issues; balance, and depression)
2. Lack of community based post acute services
3. Loss – of jobs; family and friends, driving
4. Lack of awareness of brain injury among providers, family and friends.



2. Describe your three top concerns on leaving the hospital. (84% online response rate)

1. Access to community based post acute services
2. Funding for community based post acute services
3. Sequela from brain injury
4. Limits to accessing the BI waiver (waiting, eligibility)
5. Keeping or acquiring employment

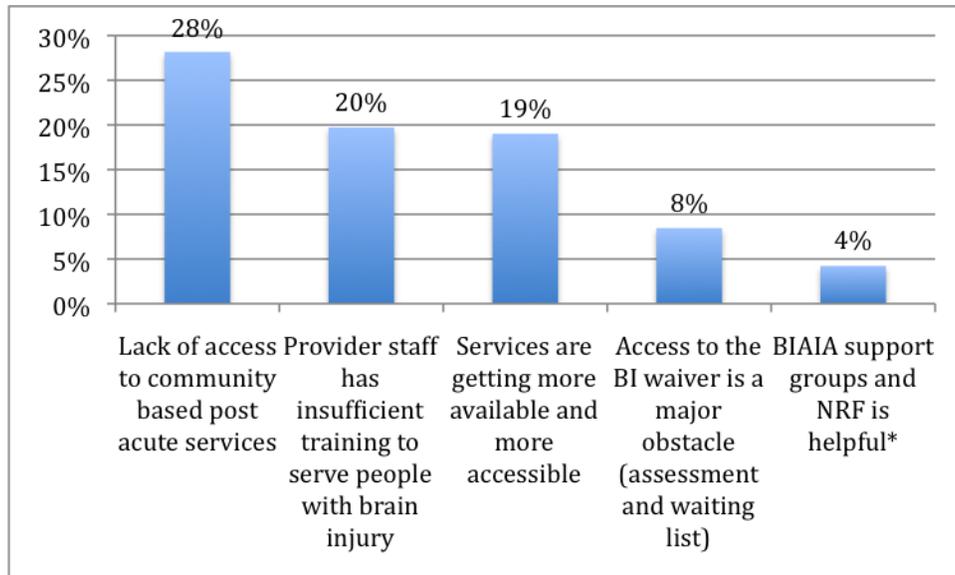


3. Are you currently in your preferred living setting? If not, can you tell us why? (85% online response rate)

1. 65% indicated that yes they were in preferred living situation
2. The remainder was not satisfied with current living situation with *accessibility and safety (unsafe neighborhoods)* issues being the primary concerns.

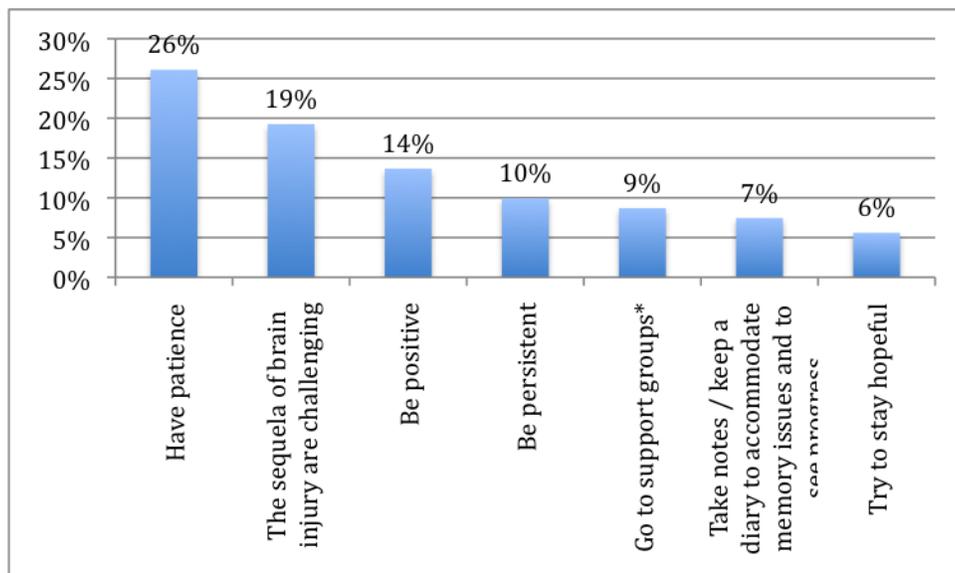
4. What is your experience with services for persons with brain injury? (64% online response rate)

1. Lack of access to community based post acute services
2. Provider staff has insufficient training to serve people with brain injury
3. Services are getting more available and more accessible
4. Access to the BI waiver is a major obstacle (assessment and waiting list)
5. BIAIA support groups and NRF is helpful*



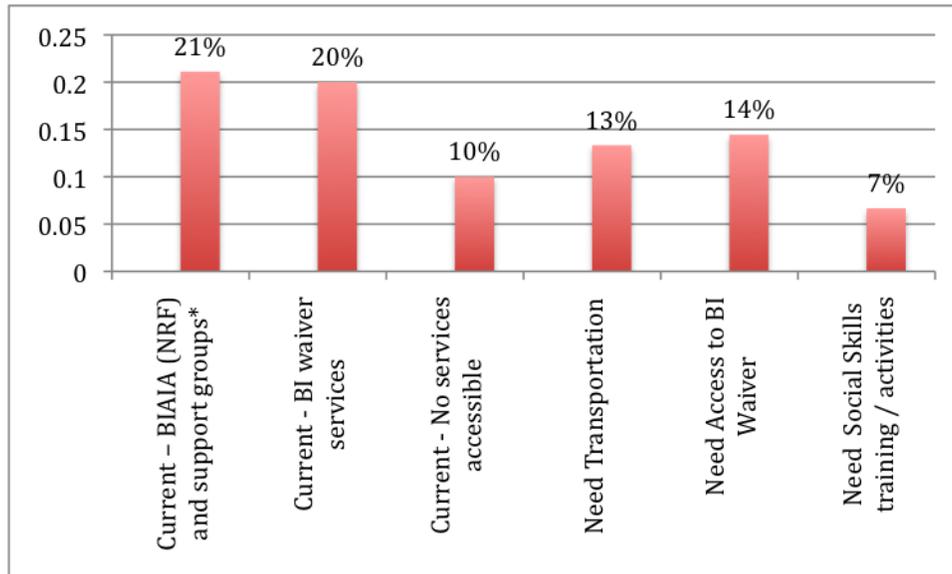
5. Imagine that a person you know has just sustained a brain injury: What advice would you give them about the changes they might be facing? (79% response rate)

1. Have patience
2. The sequela of brain injury are challenging
3. Be positive
4. Be persistent
5. Go to support groups*
6. Take notes / keep a diary to accommodate memory issues and to see progress
7. Try to stay hopeful



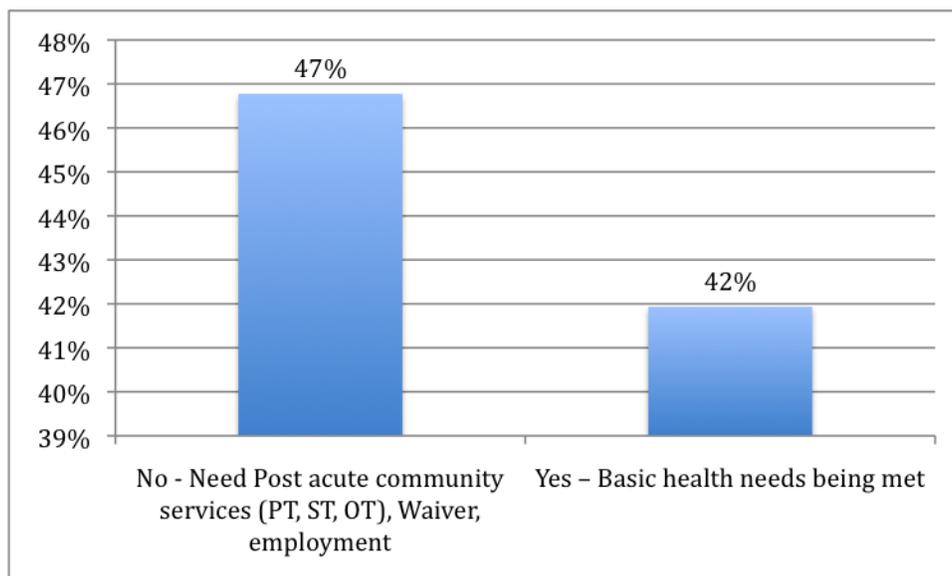
6. What type of community supports are you utilizing? If funding were not an issue, what type of supports would you like to have? (49% response rate)

1. Current – BIAIA (NRF) and support groups*
2. Current - BI waiver services
3. Current - No services accessible
4. Need Transportation
5. Need Access to BI Waiver
6. Need Social Skills training / activities



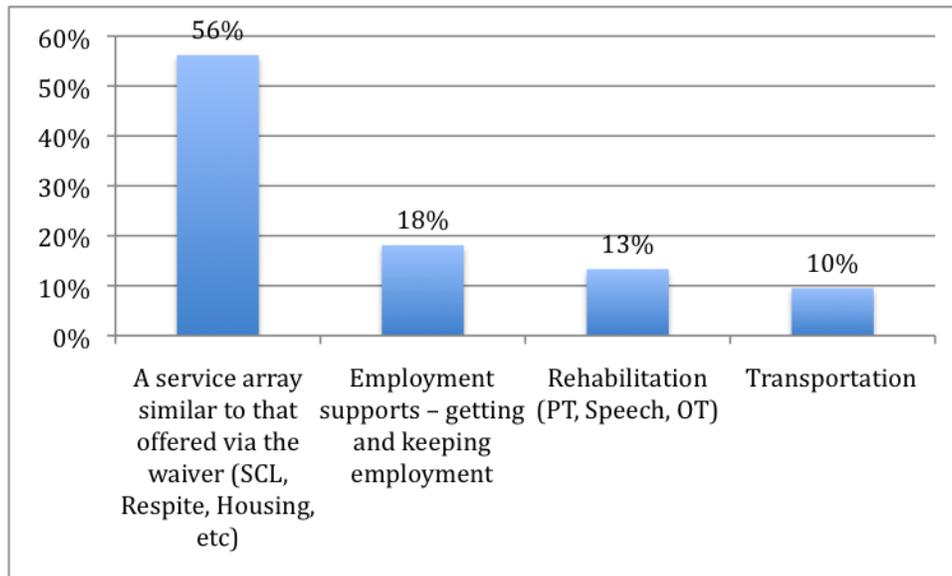
7. Do you feel that your healthcare needs have been addressed? i.e. therapies, employment, financial health? (29% response rate)

1. No - Need Post acute community services (PT, ST, OT), Waiver, employment
2. Yes – Basic health needs being met



8. If payment for services were not an issue, what type of services or supports do you , or other Iowans with brain injury, need to live well? (66% response rate – online survey question only)

1. A service array similar to that offered via the waiver (SCL, Respite, Housing, etc)
2. Employment supports – getting and keeping employment
3. Rehabilitation (PT, Speech, OT)
4. Transportation



9. Other comments

1. These comments were variable. Only “lack of access to post acute community based services” was a dominant theme