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REPORT TO THE AUSTRALIAN FEDERATION OF DISABILITY ORGANISATIONS' INFORMATION LINKAGES AND CAPACITY BUILDING'S (ILC) NATIONAL READINESS PROJECT

– SURVEY RESULTS

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Executive Summary

With funding from the National Disability Insurance Agency's (NDIA)'s Community Inclusion Capacity Development (CICD) grants programme, the Australian Federation of Disability Organisations (AFDO) invited the AFDO Full Member organisations that comprise the Disability Australia consortium (DAC) to undertake a survey of people with a disability's unmet needs for National Disability Insurance Scheme (NDIS) Information, Linkages and Capacity Building (ILC) services and supports – to assess and inform "national readiness". Brain Injury Australia (BIA), as a member of DAC, undertook the survey, beginning with the 2,400 subscribers to its monthly newsletter. The survey was prepared and sent in early July, 2017 with a 21st July deadline for responses.

There were a total of 538 responses to the survey, which comprised 29 questions. There were 227 total BIA subscriber responses to the survey (42.5% of total responses). Nearly half of all respondents (266, 49%) were "Someone that works with people with a brain injury", aged 50-59 (157 [29%]), female (304 [58%]), and lived in a capital city or suburb in New South Wales.

Most respondents reported BIA is in "in touch" with them, mainly via the monthly newsletter or visits to BIA's website, and that they preferred these online communications. Further, there was a clear preference to receive information from BIA primarily in written form - by email, on its website, and on its Facebook and Twitter pages. The quality of information about ABI provided by BIA was generally judged to be "good".

To improve on its role in the ABI sector, BIA should deliver, in ranked order, more "learning and development events" for families and carers, "events" (e.g., workshops, forums, or conferences), peer-support groups, and more information about ABI and ABI services (e.g., NDIS) on its website. These responses are in general agreement with several ILC streams and activities and are relevant to BIA and other ABI organizations in their own ILC or ILC-type activities.

Respondents expressed an unmet need for information about acquired brain injury (ABI) and the NDIS. Nearly half of respondents request further help from BIA to access and understand the NDIS in relation to ABI. One action that BIA should consider is to develop a dedicated information page on its website, as well as learning and development activities – such as the two days of workshops planned for November, 2017 – in relation to eligibility and access to the NDIS for people with an ABI.

439 (81%) respondents reported encountering barriers to participating in their communities. Lack of money or sufficient personal income was the main barrier, followed by "poor attitudes of people in the community" towards people with ABI, lack of employment opportunities, or limited access to transport to access community events. Of those who responded to problem using government ("mainstream") services, most solved the problem themselves or, with the help of a family member or advocate.

Most respondents reported having, or cared for someone who has, Severe Traumatic Brain Injury", followed by "Moderate Traumatic Brain Injury", then "Concussion", "Mild Traumatic Brain Injury", "Stroke", and "Alcohol or Other Drug-Related Brain Injury". Problems with memory was the most commonly reported ongoing symptom, followed by difficulties with concentration, fatigue, and decision-making.

Several respondent groups felt their needs were not adequately represented by BIA and its ongoing activities. These groups include people in rural, regional or remote communities, General Practitioners (GPs), allied health professionals, people with an ABI, their carers or families experiencing inequity, people with an ABI who have specific visual or auditory disabilities, people with an ABI or their families or carers aged 65 or over, and those with severe ABI. The results suggest that BIA's communications and events need to target a broader range of groups affected by ABI.

Background

With funding from the National Disability Insurance Agency's (NDIA)'s Community Inclusion Capacity Development (CICD) grants programme, the Australian Federation of Disability Organisations (AFDO) invited the AFDO Full Member organisations that comprise the Disability Australia consortium (DAC) to undertake a survey of people with a disability's unmet needs for National Disability Insurance Scheme (NDIS) Information, Linkages and Capacity Building (ILC) services and supports – to assess and inform "national readiness". Brain Injury Australia (BIA), as a member of DAC, undertook the survey, beginning with the 2,400 subscribers to its monthly newsletter.

The focus of the ILC is on community inclusion for people with disabilities. The NDIS aims to achieve this goal in two ways:

- **Personal capacity building: ensuring people with disability, their families and carers have the skills, resources and confidence they need to participate in the community or access the same kind of opportunities or services as other people**
- **Community capacity building: ensuring that mainstream services or community organisations, such as BIA, will be more inclusive of people with disability.**

BIA, founded in 1986, is the central clearinghouse of information and gateway to nationwide referral for optimising the social and economic participation of all Australians living with brain injury (ABI).

ABI in Australia is common. According to the Australian Bureau of Statistics' 2012 Survey of Disability, Ageing and Carers, over 700,000 Australians have a brain injury, with daily "activity limitations" and "participation restrictions".

- Three in every four of these people are aged 65 or under
- As many as two out of every three acquired their ABI before the age of 25
- Three-quarters of people with a ABI are men
- People with ABI have more disabilities and health conditions than the average person with disability
- People aged 65 years or over are more likely as those aged less than 65 years to have ABI with activity limitations or participation restrictions.

The survey responses BIA received will improve its efforts to meet the needs of all people living with a ABI in Australia, and to prepare for the ILC.

Report

Survey Responses

There was a total of 538 responses to the survey, which consisted of 29 questions.

The survey was delivered to the 2,400 individual and organisational subscribers to BIA's monthly e-newsletter, comprising those with ABI, their families and carers ("Consumers", 626 email invitations sent), those working in government (368 email invitations), education (161 email invitations), disability or non-disability organisations (306 email invitations), or private companies (458 email invitations). Organisational subscribers - those who work with, provide services to, or research people with an ABI – were asked to either distribute to the link to the survey to people with an ABI or respond on their "behalf".

The survey was also shared via a weblink from AFDO's Facebook page.

Total BIA subscriber responses to the survey: 227 (42.5% of total responses) (Table 1).

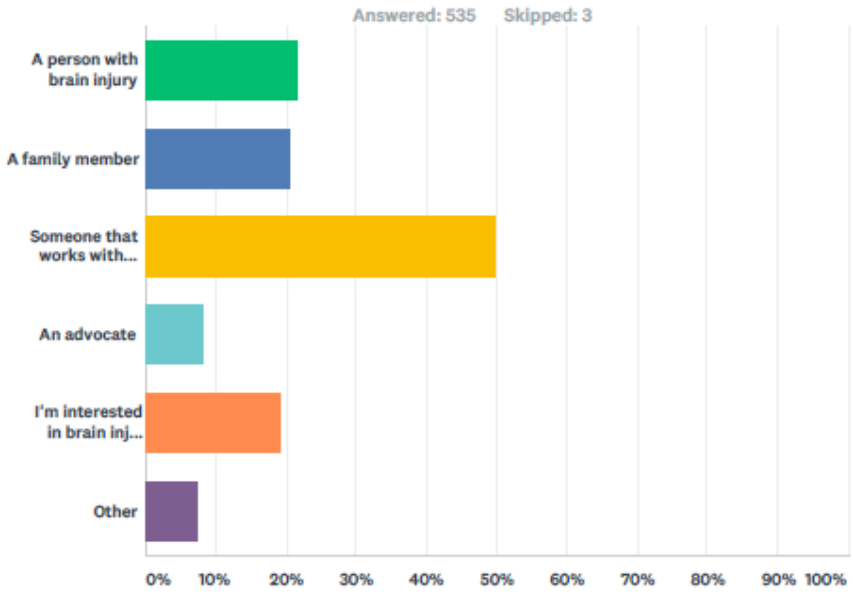
Table 1: Total BIA Supporter Responses to the Survey

Respondent BIA Group	Completed Survey (n)	Partial Completion (n)	Opted Out (n)	Total Responses (n)
BIA Consumers	78	10	10	88
BIA Government	43	6	1	49
BIA Education	17	3	0	20
BIA Organizations	20	7	1	27
BIA Companies	39	4	12	43
Totals	**197**	**30**	**24**	**227**

Respondent Demographics

Nearly half of all respondents (266, 49%) were “Someone that works with people with a brain injury” (Figure 1). A quarter of respondents were people with a brain injury (116, 21.6%), and a quarter were family members of someone with a brain injury (110, 21%) (Figure 1). Nearly a quarter were “Interested in brain injury issues” (103, 19%) (Figure 1).

Figure 1: Are you...?



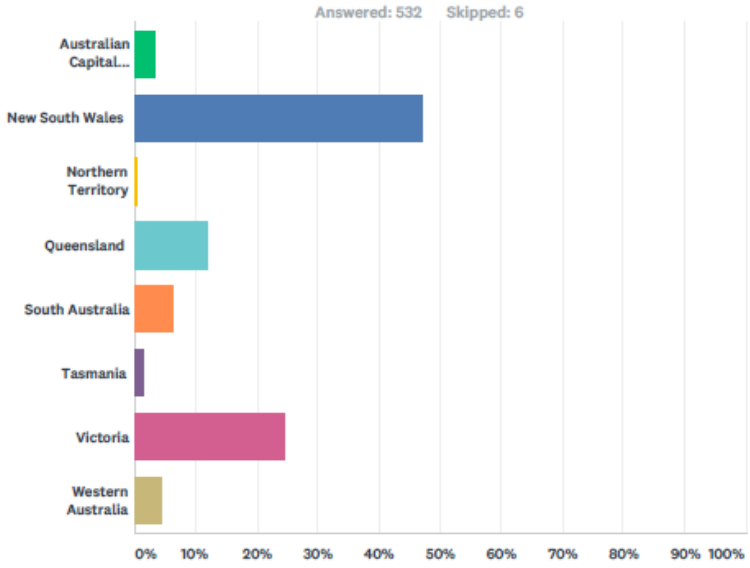
Answer Choices	Responses	
A person with brain injury	21.68%	116
A family member	20.56%	110
Someone that works with people with a brain injury	49.72%	266
An advocate	8.22%	44
I'm interested in brain injury issues	19.25%	103
Other	7.29%	39
Total Respondents: 535		

Of the respondents who were “Someone that works with people with a brain injury”, 38 (7%) were government employees, 14 (2%) were employed within the education sector.

157 (29%) of respondents were aged between 50-59, 304 (58%) were female, New South Wales was the most prevalent State respondents resided in (251, 47%), followed by Victoria (131, 24%) and Queensland (63, 11%) (Figure 2). Only 20 (4%) respondents lived in Australian territories (Figure 2).

The higher proportion of female respondents to the survey is partly explained by the high proportion of respondents (266, 49%) were “someone that works with people with a brain injury”, given the over-representation of females in, for example, the allied health professions.

Figure 2: What state or territory do you live in?



Answer Choices	Responses	
Australian Capital Territory	3.38%	18
New South Wales	47.18%	251
Northern Territory	0.38%	2
Queensland	11.84%	63
South Australia	6.58%	35
Tasmania	1.50%	8
Victoria	24.62%	131
Western Australia	4.51%	24
Total		532

Over two-thirds (65%, 351) lived in a capital city or the suburbs, one-third (178, 33%) in rural or regional Australia.

English is the “most widely spoken language at home” (518, 97%).

16 (3%) respondents are Aboriginal or a Torres Strait Islander.

Support from Brain Injury Australia

362 of 502 respondents (72%) replied that Brain Injury Australia is "in touch" with them. 361 (73%) said this contact was through BIA's monthly newsletter, or regular visits to BIA's website (105, 21%), Facebook or Twitter pages (89, 18%). Only 23 (4%) replied this contact was through telephone contact. Of the responses recorded under "Other", roughly 3% (14) were "in touch" with BIA through email. These data make clear that most respondents interacted with BIA through online activity.

More than two-thirds obtain information about ABI from BIA (313, 65%), and 340 (73%) of respondents rated the information BIA provides as "good". Other sources of information about ABI were disability websites or newsletters (200, 41%), workshops or forums (182, 38%), books (151, 31%), Google (138, 28%), or doctors (114, 23%). Only 31 (6%) respondents reported family as an information source about ABI. Over one-quarter (23%, 113) obtained ABI information from their service provider(s).

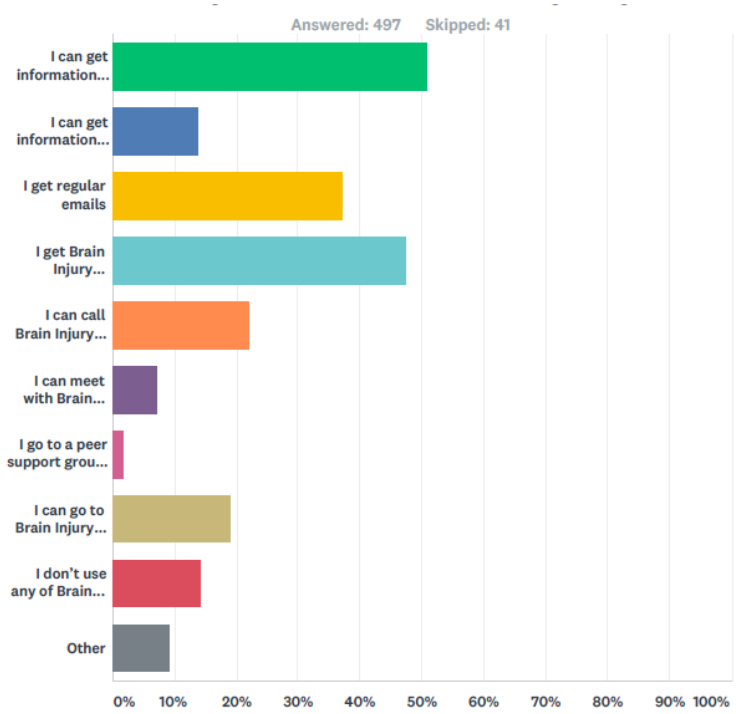
Concerning workshops or forums, one respondent suggested: "I wonder if it would be worthwhile to have a series of 1-2 workshop/information events where you [BIA] invite those that you feel you want to engage with in the broader community, in the first instance. From there you gain insights and set your strategy."

Of the responses recorded under "Other", less than 2% obtained information about ABI from research publications. Less than 1% obtain information about ABI from their professional colleagues.

After BIA, "good information" sources about ABI were disability websites or newsletters (224, 48%), workshops or forums (222, 47%), books (204, 44%), government websites or newsletter (183, 39%), "my doctor(s)" (178, 38%), or Google (156, 33%).

What respondents stated they liked about BIA is information on BIA's website (253, 50%), BIA's monthly newsletter (236, 47%), regular emails (185, 37%) (e.g., email notification of the newsletter), attendance at BIA's events (e.g., conferences or workshops) (95, 19%), or obtaining information on BIA's Facebook or Twitter pages (69, 13%) (Figure 3).

Figure 3: What do you like most about being with Brain Injury Australia?



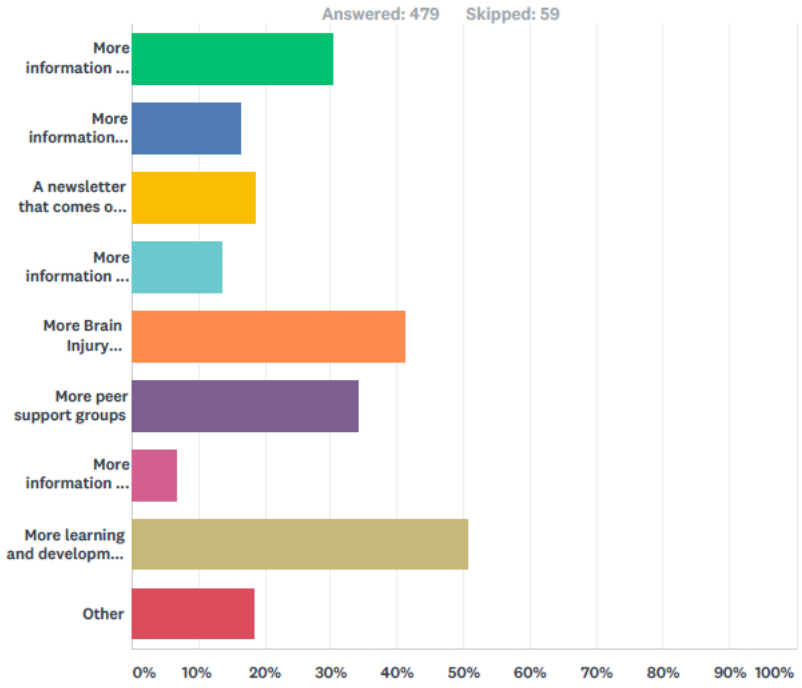
Answer Choices	Responses	
I can get information from the website	50.91%	253
I can get information from Facebook or Twitter	13.88%	69
I get regular emails	37.22%	185
I get Brain Injury Australia's monthly newsletter	47.48%	236
I can call Brain Injury Australia for help or support	22.13%	110
I can meet with Brain Injury Australia staff	7.04%	35
I go to a peer support group (face-to-face or online)	1.61%	8
I can go to Brain Injury Australia's events	19.11%	95
I don't use any of Brain Injury Australia's services or supports	14.29%	71
Other	9.26%	46
Total Respondents: 497		

Two-fifths (201, 41%) of respondents found BIA "Somewhat helpful", (156, 32%) "Very Helpful", 21 (4%) said "Not very helpful".

To improve on the helpfulness BIA delivers to its constituents, the 4 commonest responses were that BIA should conduct more "learning and development events" (243, 50%) for families and carers, more "events" (197, 41%), more peer-support groups (163, 34%), or publish more information on its website (145, 30%) (Figure 4).

These responses align with several ILC streams and activities and are relevant to BIA and other ABI organizations in their own ILC or ILC-type activities. Specifically, there is a broad unmet need for "Individual Capacity Building" (ILC Stream 4), especially for professional development, peer-support groups, and information or programs for families and carers. Further, there persists a strong unmet need in the ABI community for accurate and clear information on ABI (ILC Stream 1: Information, Linkages and Referrals).

Figure 4: What kinds of help do you think Brain Injury Australia should offer in the future?



Answer Choices	Responses
More information on the website	30.27% 145
More information given face-to-face or over the phone	16.49% 79
A newsletter that comes out more often	18.58% 89
More information via Facebook or Twitter	13.57% 65
More Brain Injury Australia events	41.13% 197
More peer support groups	34.03% 163
More information in different formats – Auslan, Braille, Easy English (please tell us your preferred format in the 'other' text box below)	6.68% 32
More learning and development activities	50.73% 243
Other	18.37% 88
Total Respondents: 479	

Helping people with ABI access the National Disability Insurance Scheme (NDIS) to receive government supports was the most requested additional service BIA should provide (219, 55%), followed by

- Helping people with ABI join social activities (211, 53%)
- Up-to-date advice on recovery and adaptation to ABI (203, 51%)

- Up-to-date advice on health and disability services (198, 49%)
- Regular communication with other people living with a ABI on information, available services and supports, and opportunities to participate in the community (193, 48%)
- Make it easier for people living with brain injury to participate in social activities, including sport and the arts (164, 41%)
- Help education services to better meet the needs of students with a brain injury (148, 37%)

It seems that many people with ABI, their families and carers, still do not have sufficient information about their eligibility for, or how to access, the NDIS, and how to access its disability services for ABI. Thus, one clear action that BIA should consider is to develop an information page on its website about the NDIS.

(Brain Injury Australia is holding two days of workshops on the NDIS for people with an ABI, at Royal Rehab in Sydney's Ryde on Monday 21st and Tuesday 22nd November. The Monday 20th November workshop is aimed at clinicians, allied health professionals, service providers and the broader disability sector – to give them an overview of the Scheme's architecture and mechanics, to optimise the fit between the lived experience of their clients' brain injury, the Agency's processes and their clients' plans which are the lifeblood of the Scheme.

The Tuesday 21st November workshop will be for people with a brain injury, family members, carers and advocates. It will be a "nuts and bolts" introduction to accessing the Scheme, to working with the Agency to ensure all "reasonable and necessary supports" are included in plans, plan reviews etc. This workshop will be facilitated by the experts involved in the Monday workshop, above, and run for half a day.)

The following respondent groups felt their needs were not adequately represented by BIA and its ongoing activities (see "other" responses):

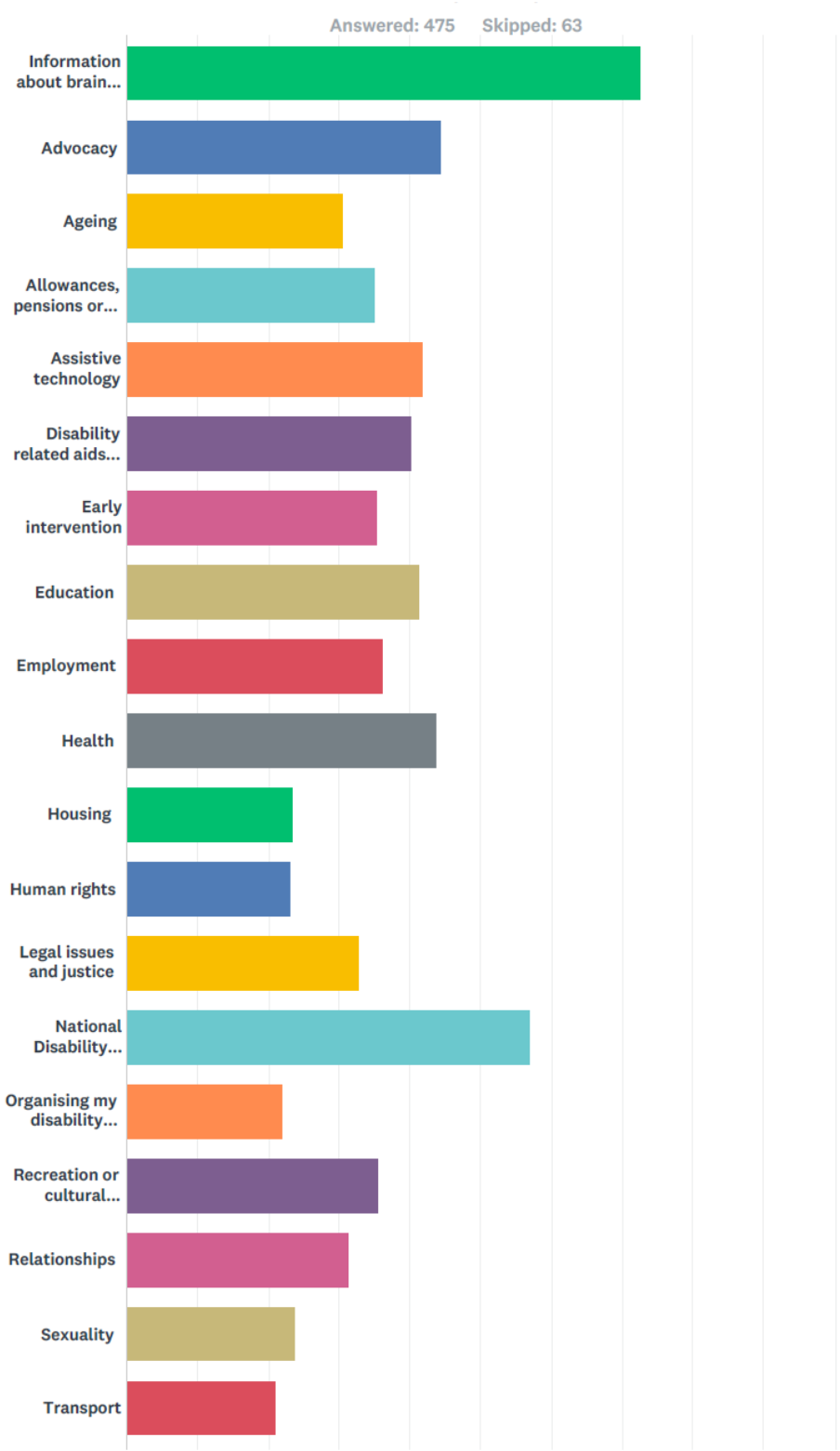
- People in rural, regional or remote communities
- Wheelchair users
- GPs, Allied Health Professionals
- People with ABI, their carers or families experiencing inequity
- People with ABI who have specific visual or auditory disabilities
- Those without means of transport to access services or community activities
- People with ABI or their families or carers aged 65+

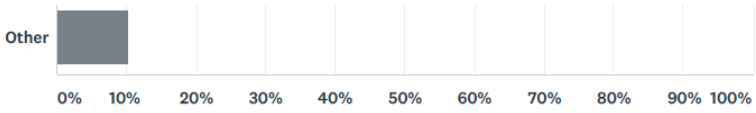
Respondents prefer BIA to provide information primarily in written form - by email (323, 68%), on its website (284, 60%), and on its Facebook and Twitter pages (133, 28%).

Roughly, 5% of respondents ("Other" responses) asked for the following means to communicate information: workshops, webinars, clinician forums, public information sessions, and in Auslan.

Respondents strongly prefer to receive information about ABI specifically (345, 72%), the National Disability Insurance Scheme (NDIS) (270, 56%), Advocacy (211, 44%), Health (208, 43%), Assistive Technology (199, 41%), and Education (197, 41%) (Figure 5).

Figure 5: What topics would you like information about?





Answer Choices	Responses	
Information about brain injury	72.63%	345
Advocacy	44.42%	211
Ageing	30.53%	145
Allowances, pensions or payments	35.16%	167
Assistive technology	41.89%	199
Disability related aids and equipment	40.21%	191
Early intervention	35.37%	168
Education	41.47%	197
Employment	36.21%	172
Health	43.79%	208
Housing	23.37%	111
Human rights	23.16%	110
Legal issues and justice	32.84%	156
National Disability Insurance Scheme (NDIS)	56.84%	270
Organising my disability supports	21.89%	104
Recreation or cultural activities	35.58%	169
Relationships	31.37%	149
Sexuality	23.79%	113
Transport	21.05%	100
Other	10.32%	49
Total Respondents: 475		

One respondent wrote: “1; 'How to navigate' the insurance nightmare, with a newly acquired ABI and 2; ABI basic information/awareness kits that a person with an ABI, particularly ‘mild’ traumatic brain injury/post-concussion syndrome (mTBI/PCS) can pass onto their employer and the insurer and their health care practitioners, a consistent, up to date, evidence based information kit particularly where high paying specialists are still writing reports to the effect that: - "I do not believe there is significant evidence that there is a distinctive post-concussion syndrome, and in any case if there were these symptoms, in the absence of neuro-imaging findings, usually settle within a matter of months. If they failed to settle then this is almost certainly diagnostic that the causation is not related to the blow to the head but rather to psychological factors"- This is what people who have sustained concussion/ mTBI/PCS are dealing with in 2017. There is sufficient evidence indicating that 'imaging' is not a determinant of PCS - yet leading specialist (psychiatrists whom insurers rely on to write such reports) - are churning out at the detriment to those suffering from PCS, 3; neuropsychological testing - expose (Types of testing - generalised or custom - how certain tests are used for litigation, as opposed to assisting with diagnosis for treatment and recovery, 4; a national preferred list of BIA medical practitioners who are up to date on ABI research. Practitioners who participate in ABI awareness workshops, exposed to recent research, best practice in diagnosing and treating mTBI/PCS”.

Barriers to Participating in the Community

439 respondents reported encountering barriers to participating or joining in the community. Lack of money or sufficient personal income was the main barrier (204, 46%), followed by "poor attitudes of people in the community" towards people with ABI, lack of employment opportunities (145, 33%), limited access to transport (131, 29%), or safety concerns (129, 29%).

Of the responses recorded under "Other", less than 1.5% reported "access to community groups or services".

Nearly half (44%, 192) had, on some occasion, difficulty using "mainstream services" - for example, health/ mental health services, education, justice, housing, child protection and employment. Most people interact with a range of services throughout their lives. However, 201 (46%) reported no difficulty using mainstream services.

The most frequently reported problem using mainstream services was "being misunderstood by others" in the community (29, 11%), poor understanding of ABI by services providers and healthcare professionals, including GPs (24, 9%). 22 (8%) reported access to services/groups/recreation or entertainment sources was the most significant barrier to using services (Figure 6).

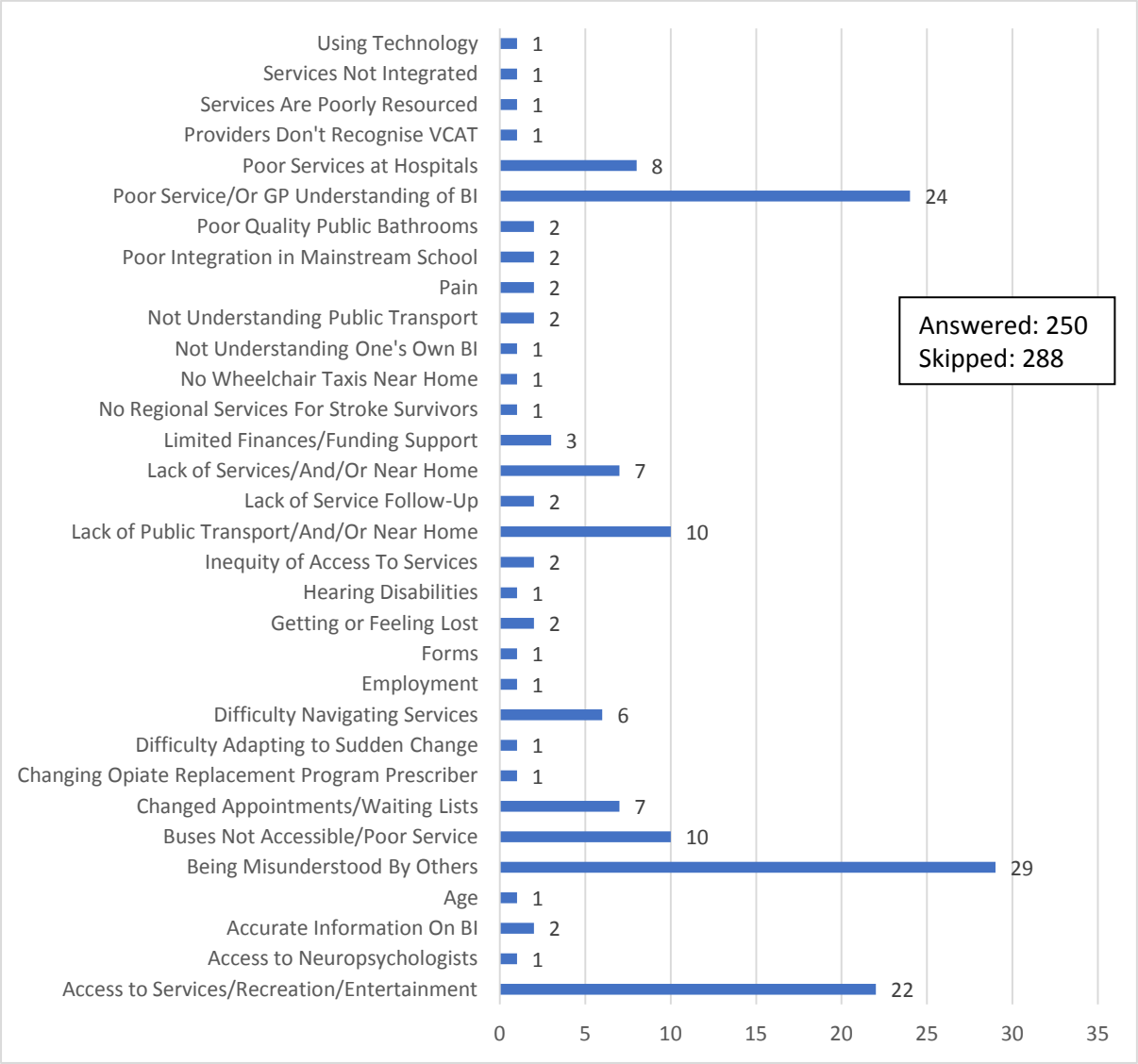
Reported trends in the international research literature lend support to these reports (e.g., Kreutzer et al. 1994; Mazaux & Richer, 1998; Paterson & Scott-Findlay, 2002; Holm et al. 2009; Degeneffe et al. 2014; Acquired Brain Injury: The Facts, 2016; Curvis et al. 2016; Grigorakos et al. 2016; Kreutzer et al. 2016).

In the survey's "other" responses, people living in rural, regional or remote areas in Australia consistently reported a treatment or service "gap" in their experiences of ABI. Management of ABI can be challenging in sparsely populated areas of Australia where limited medical resources delay early diagnosis and urgent surgical intervention (e.g., Gilligan et al. 2017; Townsend et al. 2017). Following hospital discharge, technology may be a useful means for service providers to communicate with rural or remote residents recovering from ABI (e.g. Acquired Brain Injury: The Facts, 2016; Brunner et al. 2017).

Taken together, these data strongly suggest that ensuring mainstream services meet the needs of people with ABI more effectively is an important, ongoing task. Specifically, these survey data demonstrated the following unmet need for ILC-type supports and services:

- More campaigns to improve the community's general ABI awareness and understanding
- Training to individuals; e.g., healthcare professionals to enable them to better relate to, or work with, people with ABI
- Creating personal networks that connect people with ABI to opportunities (for example, learning or up-skilling opportunities)
- More community activities in which people with ABI can participate
- Consulting with/incorporating the views of, people with ABI and their families/carers in the provision of community activities and other services
- Improving the capacity of other community/mainstream services to respond to the needs of people with ABI

Figure 6: Examples of Problems Encountered Using Mainstream Services



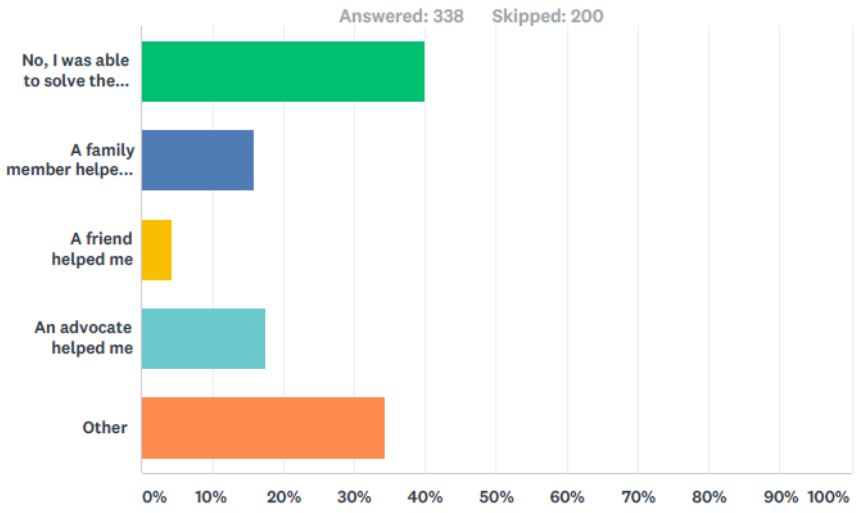
Of 353 respondents, 119 (33%) did "nothing" in response to the problem using mainstream services, 79 (22%) met directly with services to discuss the problem at issue, 76 (21%) "just went somewhere else", 33 (9%) "made a formal complaint". Crucially, 49 (13%) "didn't know what to do". This latter group may not have had sufficient understanding of services to make an informed response, and reinforces the function of BIA as a reliable source of information about ABI services.

15 (8% of 183 respondents (32%); 355 (66%) skipped this question) people wished that, to solve the problem using mainstream services, providers had "understood me or my needs", or 13 (7%) wished that the community at large had "understood me or my needs".

Two respondents noted: "It would have changed my life outcomes remarkably if I could have accessed the right medical assistance. Lost 20+ wasted years of my life due to this failing unfortunately"; and "I wish that information on research on brain injuries was better known by the medical profession. I am very fortunate in that I had a few very good medical practitioners on my team batting for me".

Of those who responded to the problem, most solved the problem themselves or, with the help of a family member or advocate (Figure 7).

Figure 7: Sources of Assistance Facing a Problem Using Mainstream Services



Answer Choices	Responses	
No, I was able to solve the problem myself	39.94%	135
A family member helped me	15.98%	54
A friend helped me	4.14%	14
An advocate helped me	17.46%	59
Other	34.32%	116
Total Respondents: 338		

Brain Injury Type and Ongoing Symptoms

102 (27%) of 375 respondents reported “Severe Traumatic Brain Injury”, 39 (10%) “Moderate Traumatic Brain Injury”, 34 (9%) “Concussion”, 32 (8%) “Mild Traumatic Brain Injury”, 20 (5%) “Stroke”, and 10 (2%) reported “Alcohol or Other Drug-Related Brain Injury”.

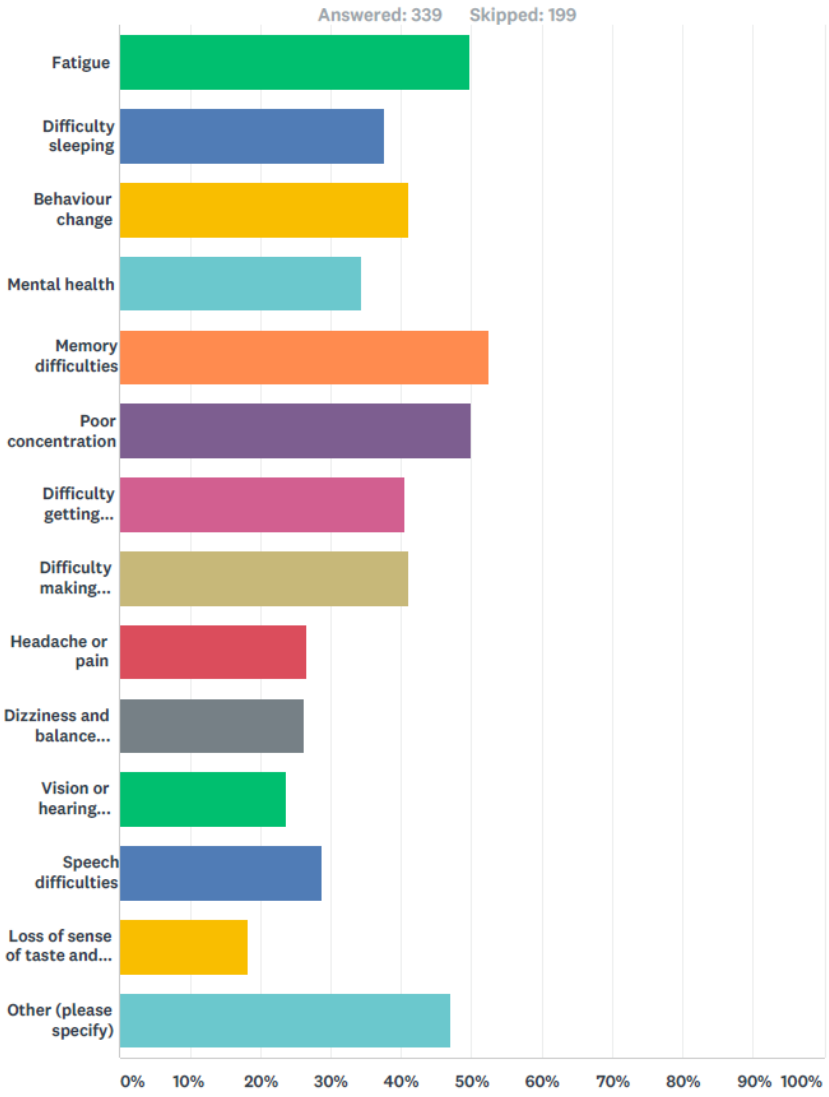
Given the lack of activities BIA undertakes targeting severe ABI, people with severe ABI may be an under-represented group in BIA’s activities and communications.

59 of 390 respondents (15%) reported personal experience of “Mild Traumatic Brain Injury/Post-Concussion Syndrome” (Question 26 only).

Disabled memory (177, 52%) was the most commonly reported ongoing symptom, followed by disabled concentration (169, 49%), fatigue (168, 49%), decision-making (139, 41%), change in personal behaviours (139, 41%), or “getting organised” for upcoming tasks (137, 40%) (Figure 8).

Numerous international research studies and guides in the ABI literature support the prevalence of these reported symptoms (e.g., Heinemann et al. 2002; Pickelsimer et al. 2007; Selassie et al. 2008; Coronado et al. 2012; Scholten et al. 2014; Acquired Brain Injury: The Facts, 2016).

Figure 8: Ongoing Symptoms



Answer Choices	Responses	
Fatigue	49.56%	168
Difficulty sleeping	37.46%	127
Behaviour change	41.00%	139
Mental health	34.22%	116
Memory difficulties	52.21%	177

Poor concentration	49.85%	169
Difficulty getting organised	40.41%	137
Difficulty making decisions	41.00%	139
Headache or pain	26.55%	90
Dizziness and balance difficulties	26.25%	89
Vision or hearing difficulties	23.60%	80
Speech difficulties	28.61%	97
Loss of sense of taste and/or smell	18.29%	62
Other (please specify)	46.90%	159
Total Respondents: 339		

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Appendix: Links to the Survey and Graphed Data

Download the full survey here

Download graphed data from the survey here.

Download graphed data for “other” responses in the survey here.