



Experiences and Needs of Families Living with Acquired Brain Injury in South Australia

Stage 1 Research Report

December, 2012

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Executive Summary

Families4Families is an 18 month pilot peer support network for families living with acquired brain injury (ABI) in South Australia. Prior to its launch in January 2013, preliminary research has been conducted to identify the experiences and needs of families following ABI, in order to inform the design of the network. This research report presents findings from Stage 1.

This first phase of research involved data collection through surveys and focus groups. 2502 surveys were posted to families who had received services from SA Brain Injury Rehabilitation Services (SA BIRS) between 2002 and 2012, with an additional 110 surveys distributed to SA disability and carer groups. 228 completed surveys were returned (10.6% response rate). 194 family members (110 partners, 56 parents, 8 siblings, 7 children, 6 friends and 4 'others') in addition to 34 people with ABI completed the 22-question survey, providing a range of demographic and diagnostic data and identifying areas of unmet need. All survey respondents were invited to participate in focus groups to further explore experiences and needs, and provide feedback on how the *Families4Families ABI Support Network* could best be designed to meet these needs. Five focus groups were held across metropolitan and regional South Australia, gathering data from a total of 43 participants with ABI and their family members. Audio recordings were transcribed for analysis.

Survey and focus group participants identified a range of 'supports most needed', with themes falling under two main categories:

- Supports which could be provided by a family peer support network
 - counselling & emotional support
 - family support groups (including children, young carer and partner groups)
 - ABI education, information and resources
 - family social activities
 - help navigating the service system
 - early supports (within first year of ABI)
 - family advocacy support and training
- Family-centered health and disability services
 - continued, coordinated, accessible and tailored services
 - respite
 - financial assistance
 - high quality support work
 - home maintenance and support
 - employment, housing and education
 - ABI mentors/volunteers.

Results highlight a need for ongoing supports for the entire family following ABI, a number of which could be delivered through a family peer support model. These findings will inform the development and implementation of the *Families4Families ABI Support Network*, with Stage 2 of the research measuring the effects of participation over 18 months.

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Contents

Chapter 1: Introduction and Aim	4
Background	4
Aim	5
Project outline	5
Chapter 2: Method	7
Survey	7
Focus groups	8
Data analysis.....	9
Ethical approval.....	9
Chapter 3: Results	10
Survey: Demographic data on families who provide support	10
Relationship to family member with ABI	10
Age of respondents	11
Primary support	12
Geographical location	13
Highest level of study	14
Survey: Demographic and diagnostic data on adults with ABI.....	17
Gender.....	17
Current age.....	17
Cause and age at time of ABI.....	18
Compensation received.....	19
Living situation	20
Activities of the person with ABI	22
Health & support needs of person with ABI	23
Supports provided by family member	24
Survey: Areas of unmet need.....	26
Survey & focus groups: What supports would be most helpful?	29
Counselling & emotional support.....	31
Family support groups	32
ABI education, info & resources	34
Social activities	35
Help to navigate the system	36
Early supports.....	37
Self-advocacy support & training.....	37
Service quality: Accessible	38
Service quality: Coordination & follow-up	39

Service quality: ABI educated.....	39
Continued rehabilitation services.....	39
Financial assistance	40
Respite	41
Employment, housing and education	41
High quality support work	42
Home maintenance and support	42
ABI mentors/volunteers	43
Not applicable.....	43
Chapter 4: Discussion & Conclusion.....	44
Family peer supports.....	45
Family-centred services	47
Recommendations	49
Conclusion	50
References	51
Appendix	55

1. Introduction and Aim

Background

Acquired Brain Injury (ABI) is a significant cause of disability, with prevalence in South Australia estimated to be approximately 31,000 or 2.2% of the population (AIHW, 2007). The Australian Institute of Health and Welfare defines ABI as “*multiple disabilities arising from damage to the brain acquired after birth. It results in deterioration in cognitive, physical, emotional or independent functioning. It can be as a result of accidents, stroke, brain tumours, infection, poisoning, lack of oxygen, degenerative neurological diseases etc.*” (AIHW, 2006). Severity can range from mild to profound, with a broad range of effects reflecting the heterogeneity of this condition. Long term effects can include altered physical, cognitive, behavioural and psychosocial functioning, which often influence independence, daily activities, relationships, employment and quality of life (Ashley, Leal & Mehta et al, 2010; Bryan, Harrington & Elliott, 2010; Rees, 2005; Sohlberg & Mateer, 2001; Ylvisaker & Feeney, 1998). It is also important to acknowledge the effects this experience has on the wider family network.

A growing body of literature consistently reports families affected by ABI experience strain, emotional distress, caregiver burden, and social isolation (Erch, Rapport, Coleman & Hanks, 2002; Gan, Gargaro & Grandys et al, 2010; Kneafsey & Gawthorpe, 2004; Perlesz, Kinsella & Crowe, 2000; Phelan, Griffin & Hellerstedt et al, 2011; Ponsford, Olver, Ponsford & Nelms, 2003). The risk of clinical depression, anxiety, reduced quality of life, burn-out, decreased family functioning and relationship breakdown is ever present, affecting family cohesion and carers’ ability to support the person with ABI (Turner, Fleming & Parry et al, 2010). Unsupported family members are frequently unable to cope, with high rates of family breakdown. This is particularly so when a partner becomes the primary carer, with 63% of marriages reported to end by six years post-injury (Tate et al, 1989). In addition, the majority of people with ABI live with their parents in the long-term (Jacobs, 1988) despite the fact many were living independently pre-injury. In cases where family units do survive the trauma of ABI, family members take on roles of carer, supporter, advocate and therapist, particularly in cases of rural and remote geographic circumstances (Brain Injury Australia, 2011; Griffin, Friedemann-Sanchez & Jensen et al, 2012).

Research indicates that the provision of social support for families following ABI assists in coping with the neurobehavioural effects of brain injury and lowering family levels of stress and burden of care (Shejia & Manigandan, 2005; Winstanley, Simpson, Tate & Myles, 2006). As families play a pivotal role in the rehabilitation and reintegration of people with ABI, it is essential that the wellbeing of family caregivers is considered, and ongoing supports provided (Chan, Parmenter & Stancliffe, 2009).

Unfortunately, few resources exist to support families to cope with the short and long term challenges associated with brain injury (Boschen, Gargaro, Gan, Gerber & Brandys, 2007). This lack of social support in South Australia has again been identified by Singh (2008), with data indicating the negative impact on care-giver burden. This research clearly identifies the need for greater supports for family members of those with ABI.

The effects of ABI influence not only the individuals with brain injury and their primary caregivers, but also the extended family network and community within which they are situated. Families are most commonly the major source of support for individuals, and play a central role in promoting healthy adjustment through rehabilitation and community living (Gan & Campbell et al, 2006). It is the families that often take on the responsibility of lifelong care and support, well after formal

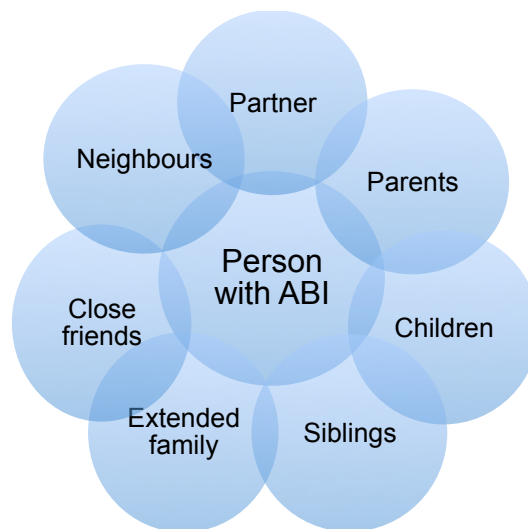
rehabilitation has ended, a role for which there is no preparation and little (if any) available training (Man, 2002). It is therefore essential that closer attention is paid to the mental health and wellbeing of the family unit after brain injury. Gan et al (2006) strongly advocate for the need for a family systems approach to family intervention after ABI. This is the underlying principle of the *Families4Families ABI Support Network*.

Aim

The *Families4Families ABI Support Network*, funded by the Julia Farr MS McLeod Benevolent Fund, aims to identify the experiences and needs of families living with ABI in South Australia (Stage 1), and then design, establish and evaluate an 18 month family peer support network for this population (Stage 2).

Within this study, the term ‘family’ refers to the network of people affected by ABI. This includes centrally the person with ABI, together with his or her partner, parents, children, siblings, extended family and close friends who provide support (Figure 1). Family members are invited to participate in all stages of this research.

Figure 1.1 – Family network



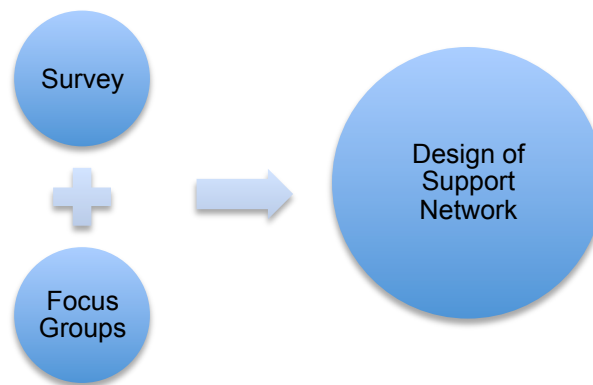
Project outline

The project is divided into 2 stages to be completed within a two-year period (2012 - 2014).

Stage 1: Preliminary data collection & analysis (see Figure 1.2):

- Survey sent to families living with ABI across South Australia, collecting demographic and diagnostic information from families, areas of unmet need and further support which is required.
- Respondents invited to participate in a focus group to further explore identified needs, and provide feedback on how an ABI Family Support Network could be best designed to meet these needs.
- Findings analysed to develop and implement the *Families4Families ABI Support Network*, a pilot program which will deliver peer supports for families with ABI by families with ABI.

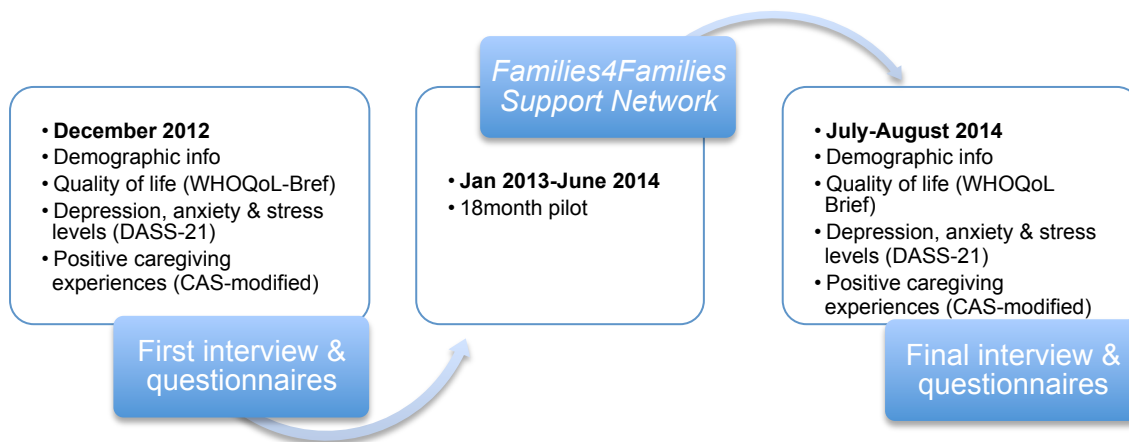
Figure 1.2 – Stage 1 Outline



Stage 2: Evaluation of outcomes (see Figure 1.3):

- New members of the *Families4Families ABI Support Network* will be invited to participate in the evaluation of the service by participating in a phone interview and completing a series of questionnaires. These questionnaires will be repeated at the end of the pilot program, and interviews conducted to evaluate the outcome of participation on quality of life, care giving experiences, mental health and support needs and the development of sustainable informal community networks.

Figure 1.3 – Stage 2 Outline



This study gathers important data on areas of need identified by families living with ABI in South Australia. The development of the *Families4Families ABI Support Network* provides participants the opportunity to design, create and establish their own model of peer support, and use this model to help other families experiencing a newly acquired brain injury. The network will seek to provide families affected by ABI the opportunity to share and benefit from each other's experiences, knowledge, positive coping strategies, understanding of systems, resilience and adaptation skills, and expand or develop new social networks which last beyond the program. The evaluation of this program will provide important data on outcomes and effectiveness, and present recommendations to inform the development of family peer support networks, which may be applied to other areas of disability and community support.

2. Method

Survey

The first phase of the project involved collecting survey data from family members who provide support to adults with ABI in South Australia. A letter of introduction, information sheet and 22 question survey were distributed to families affected by ABI (see appendix). This included partners, parents, children, siblings, extended family and/or close friends who are involved in providing support.

Criteria for participating in the survey required that respondents:

- were a family member providing support to an adult (<18yrs) with ABI
- were over 18 years of age
- lived in South Australia
- had adequate English communication skills to complete a survey

The survey package was sent to 2622 families from the following sources:

- The SA Brain Injury Rehabilitation Service (BIRS) is the largest provider of inpatient and outpatient services to people with ABI in SA. 2512 survey packages were sent to families on their client database who had accessed BIRS services over the previous 10 years (2002-2012).
- The study was also advertised by various disability and carer organisations in South Australia, with an additional 110 survey packages distributed.

A cover letter requested that the survey be completed by a family member and returned using the reply paid envelope included. The survey requested a range of demographic information with respect to the family member completing the survey and the person with ABI, including details of services and supports they need but are not currently receiving (and why), and what supports would be most helpful. The survey also invited respondents to indicate if they would like to participate in a focus group to further explore identified needs, and provide feedback on how an ABI Family Support Network could be best designed to meet these needs.

A total of 228 completed surveys were returned by the cut-off date (31.8.12):

- 194 by family members
- 34 self-completed by people with ABI

207 were 'returned to sender' (reported by Hampstead Rehabilitation Centre mailroom, and probably indicative of the 10 year timeframe from which potential respondents were selected), with the total survey response rate 10.6%.

Although self-completed responses by people with ABI were not originally sought in the survey design, this data was included in analysis as it provided additional valid information, which contributes to our understanding of experiences and needs following ABI in South Australia.

Focus groups

Survey respondents were invited to participate in a focus group, and indicated their interest by returning the completed Consent Form and Contact Details form (included in the survey package).

Criteria for participating in focus groups required that they:

- were a family member providing support to an adult (<18yrs) with ABI, or were an individual with an ABI
- were over 18 years of age
- lived in South Australia
- had capacity to provide informed consent (or have a legal guardian who can provide consent).

97 respondents indicated their interest in participating in a focus group. These individuals were separated according to geographical locations, and five focus group locations booked across metro and regional South Australia (see Table 2.1)

Table 2.1 – Focus group locations and participants

Location	Attendees	
Campbeltown (Metro)	13	8 Family; 5 people with ABI
Adelaide (Metro)	9	7 Family; 2 people with ABI
Barossa (Northern Regional)	5	4 Family; 1 person with ABI
Noarlunga (Southern Regional)	9	4 Family; 5 people with ABI
Mount Gambier (Outer Regional)	7	6 Family; 1 person with ABI

Sampling of respondents occurred using maximum variation sampling technique (Patton, 2002). This involved inviting a wide selection of people so their responses reflect the diversity of experiences of the population. Respondents from each geographical region were systematically invited via telephone by the researchers to attend their closest or most convenient focus group, ensuring there was a mix of genders, ages, people with ABI and family members. Attendance ranged from 5 to 14 participants per group, and consisted of a combination of family members that provide support (partners, parents, siblings) and individuals with ABI. Participants were invited to arrive for a cup of coffee/tea 30mins prior to the session commencing, and encouraged to stay behind to debrief with fellow members and meet the Families4Families Manager. Reimbursement for travel and related expenses was offered to all participants.

Each focus group was facilitated by an experienced Rehabilitation Counsellor, and supported by a Bachelor degree research assistant. All focus groups began with broad open-ended questions, allowing participants to share their experiences of ABI. Participants were then supported to identify areas which they feel they would like support. For example, *“What have you found to be helpful and what would you like to see more of?”*

A total of 43 participants attended, including 29 family members, and 14 people with ABI. There were 30 females and 13 males, with 27 from metro regions, six from inner regional and eight from outer regional areas.

Data analysis

Each 90 minute focus group was audio recorded and transcribed verbatim, with identifiers removed to maintain confidentiality. Each audio recording and transcript was compared to ensure accuracy of transcription. Members of the research team read all transcripts, with data imported into NVivo 10 for analysis.

Transcripts were reviewed by the research team, and major themes identified, with multiple reviews and revisions made. Two independent raters coded all transcripts (raters were a PhD-level researcher and Bachelor-level research assistant) by allocating text to themes as they emerged. Raters used iterative constant comparison to identify new themes as they emerged. If the raters did not achieve a minimum 80% agreement on the first transcript, themes were revised and expanded, and the process repeated until agreement reached satisfactory levels.

Ethical approval

Ethical Approval was granted by the Flinders University Social and Behavioural Research Ethics Committee (Project No 5457) and the Royal Adelaide Hospital Research Ethics Committee (Protocol No 120619) prior to commencement of the project.

3. Results

Survey: Demographic data on families who provide support

Relationship to family member with ABI

The survey was completed by 194 family members (141 females and 50 males, 3 not indicated), with relationships and genders presented in Figure and Table 3.1. Just over half of the survey respondents were partners of a person with ABI (n=110, 57%) including spouses, fiancés and defacto relationships (73 females and 37 males). The second highest response group was parents (n=57, 30%), 50 of whom were mothers. Respondents also included 8 siblings, 7 children and 6 close friends. Relationships identified as 'other' (n=4) included ex-partners.

Figure 3.1 – What is your relationship to your family member with ABI? (n=194)

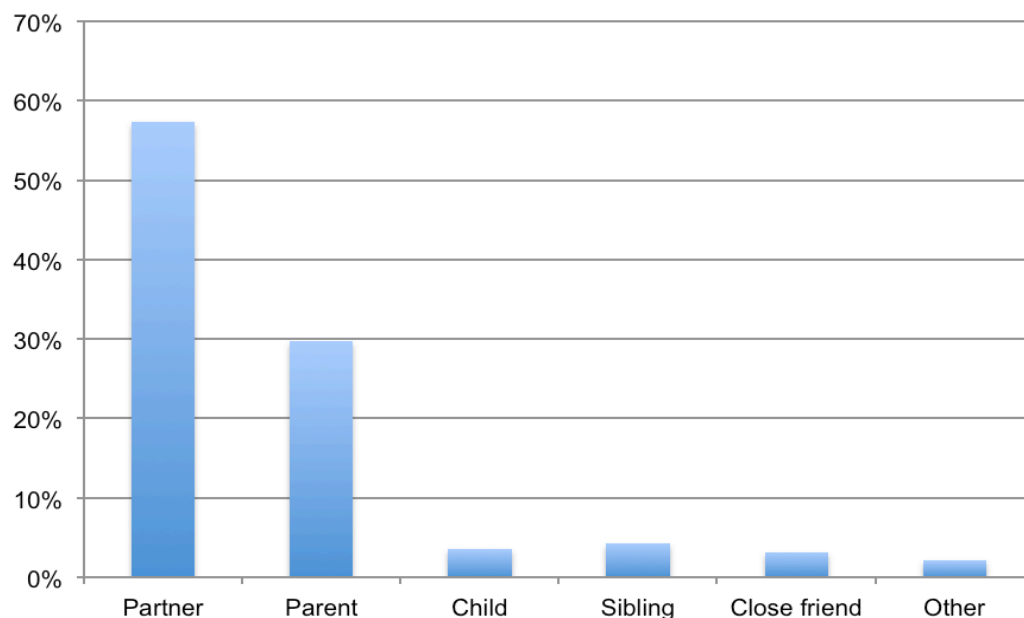


Table 3.1 – Gender of family respondents by relationship

Relationship	Male	Female	Total
Partner	37	73	110 (58%)
Parent	6	50	56 (29%)
Child	2	5	7 (4%)
Sibling	2	6	8 (4%)
Close friend	3	3	6 (3%)
Other	0	4	4 (2%)
Total	50	141	191

* 1 parent did not indicate their gender, 2 respondents did not indicate their relationship

Age of respondents

The majority of respondents represent an older sample, with just over half aged in the 51-65 year age bracket (n=104, 54%). This may not be surprising given that almost 30% were parents of adults with ABI. Thirty seven respondents (19%) were over 66, 11 respondents (6%) between 18-35, and 40 respondents (21%) were between 36-50 (see Figure and Table 3.2).

Figure 3.2 – Age of family member providing support (n=192)

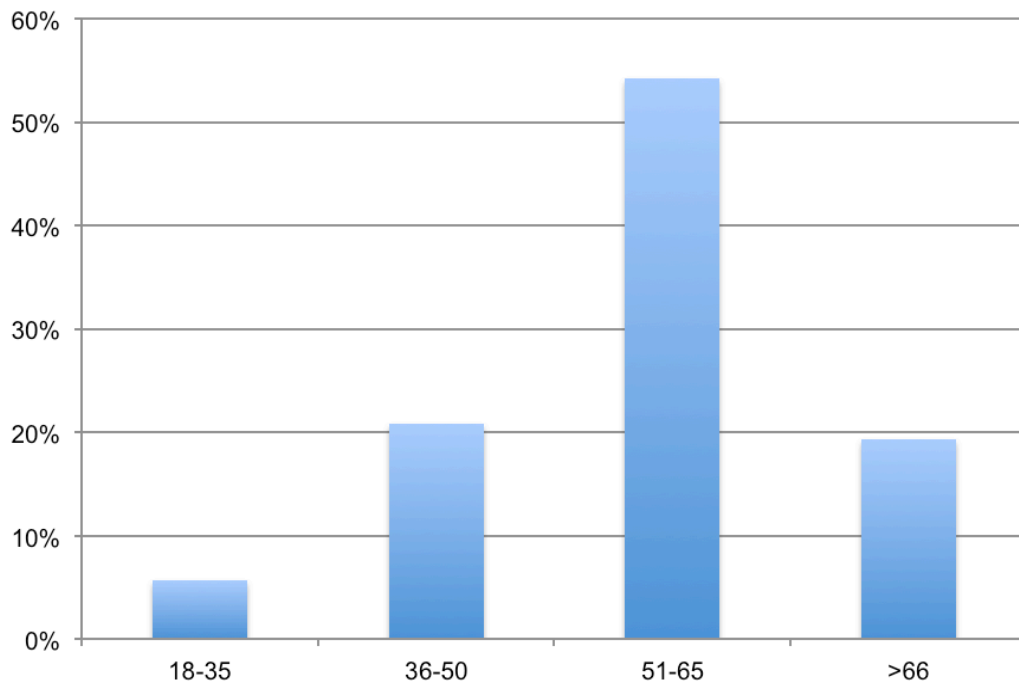


Table 3.2 – Age respondents by relationship

Age range	Partner	Parent	Child	Sibling	Close Friend	Other	Total
18-35	8	0	1	1	1	0	11 (6%)
36-50	30	4	3	0	1	1	39 (21%)
51-65	53	34	3	7	4	3	104 (54%)
>66	19	17	0	0	0	0	36 (19%)
Total	110	55	7	8	6	4	

** 2 different missing cases from each variable have resulted in slight total differences than reported above*

Primary support

The vast majority of respondents (n=162, 84%) indicated they consider themselves the primary support person for their family member with ABI, with 95% of partners and 79% of parents identifying with this role (see Figure 3.3).

Some provided further comments, including:

"I am [his] frontal lobe!"

"I am constantly attending to her although she lives in another house owned by me"

"Also have assistance from our daughter"

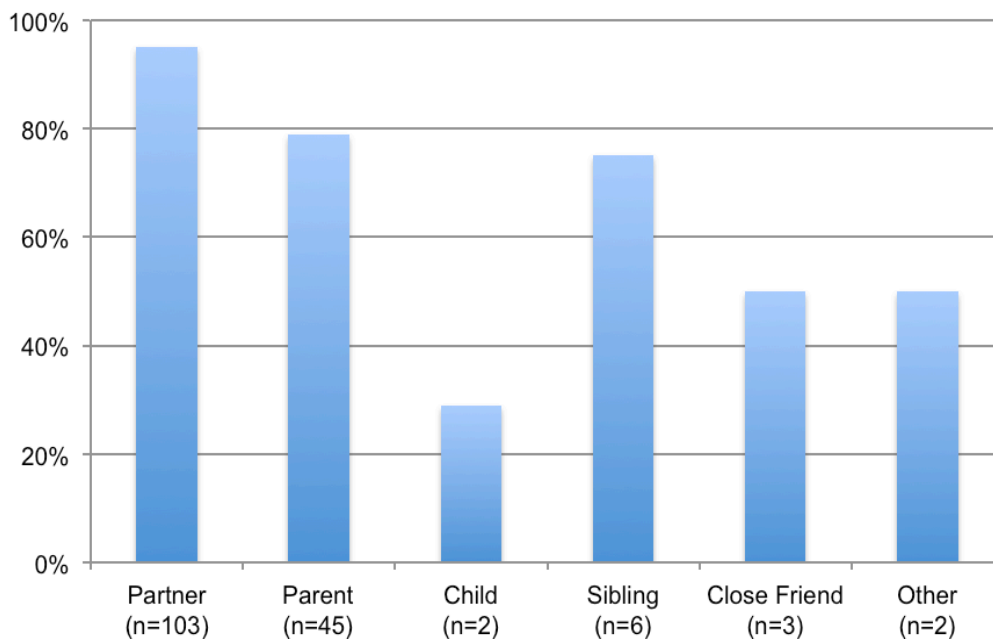
Comments from those who were not the primary support included:

"Not now as he is married"

"Doesn't need support"

"At the time of ABI"

Figure 3.3 Family members who identify as the primary support person (n=162)



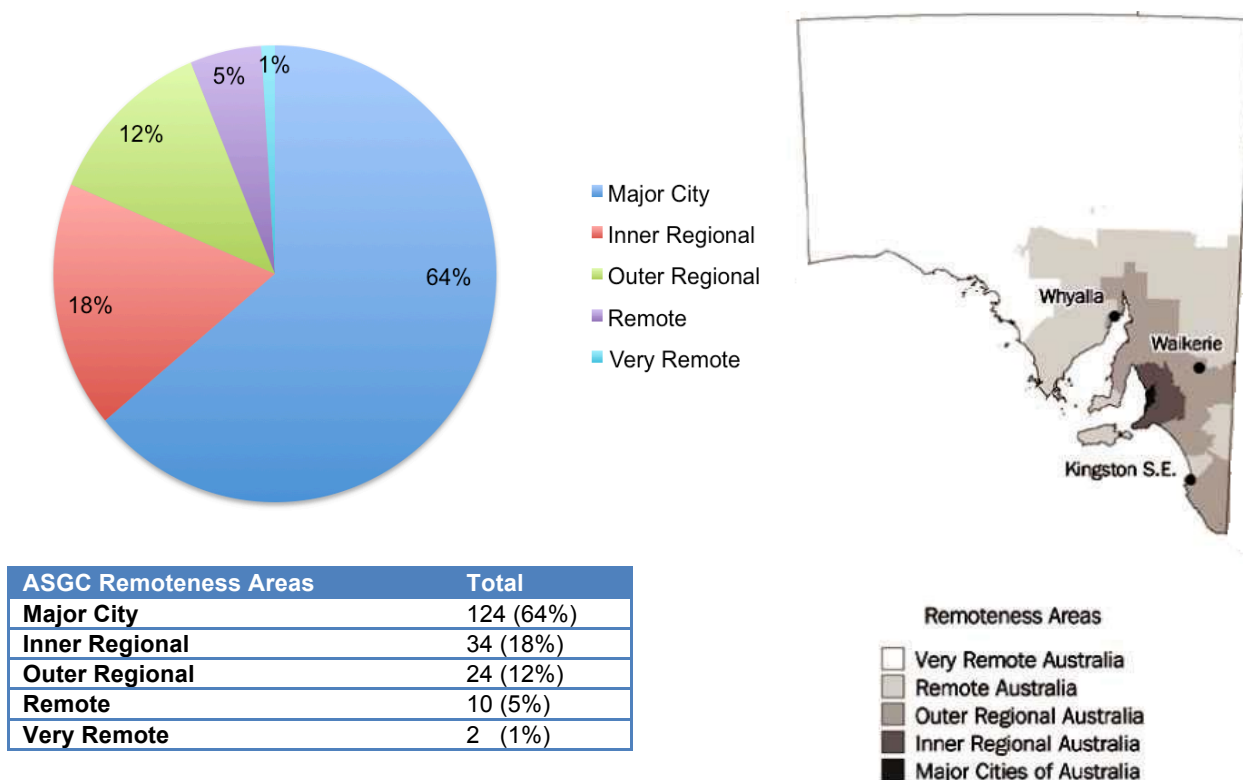
* 1 respondent did not indicate their gender and is not represented in the figure above

Geographical location

Areas in which respondents currently live are classified using the Australian Standard Geographical Remoteness Areas (ASGC RA). The classification includes 5 categories: Major Cities, Inner Regional, Outer Regional, Remote & Very Remote. ASGC RA was selected in preference to Accessibility/Remoteness Index of Australia (ARIA) and Rural, Remote and Metropolitan Areas classification, as it defines the least remote areas more tightly than ARIA classification (AIHW, 2004).

Although most respondents currently live in 'Major City' regions (metro) (n=124, 64%), 30% were from regional areas, with another 5% from Remote and 1% Very Remote regions (see Figure 3.4). This sample has enabled the collection of important regional perspectives on access to services and supports which may differ from metro-centric experiences. It is important to note that in 2004-05, "people living in Inner Regional areas were 1.42 times more likely to have an ABI, and those living in Outer Regional and Remote areas were 1.42 times more likely to have an ABI than those in Major cities. So while 32% of the population lives outside Major cities, 38% of people with an ABI live outside Major cities." (National Rural Health Alliance, 2012, p6). This has critical implications for ensuring services and supports are available in regional and remote areas.

Figure 3.4 ASGC Remoteness Areas (n=194)



Australian Bureau of Statistics
ASGC Remoteness areas of Australia

Highest level of study

One hundred and ninety one respondents provided details on their highest level of study since school. Forty-seven respondents (25%) indicated they had no further study since school, 69 (36%) attained TAFE/Trade qualifications, 37 (19%) held undergraduate and 31 (16%) postgraduate degrees. Six respondents provided details of 'other' studies which included a range of work-related courses (Figure 3.5).

This group represents an educated population, with 71% holding qualifications, 35% of which are at University level. These figures are only slightly higher than the 2011 Australia average, with the Australian Bureau of Statistics reporting 27.9% of Australians hold a Higher Education qualification at undergraduate level of higher and 34.6% hold a vocational qualification only (ABS, 2012).

Table 3.5 presents a breakdown of education for each relationship, revealing similar patterns among partners and parents.

Figure 3.5 Highest level of study since school (n=191)

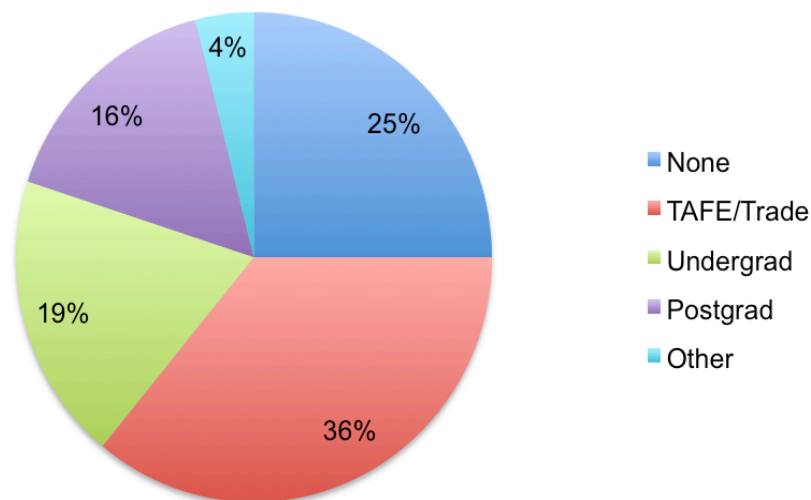


Table 3.5 Highest level of study since school by relationship

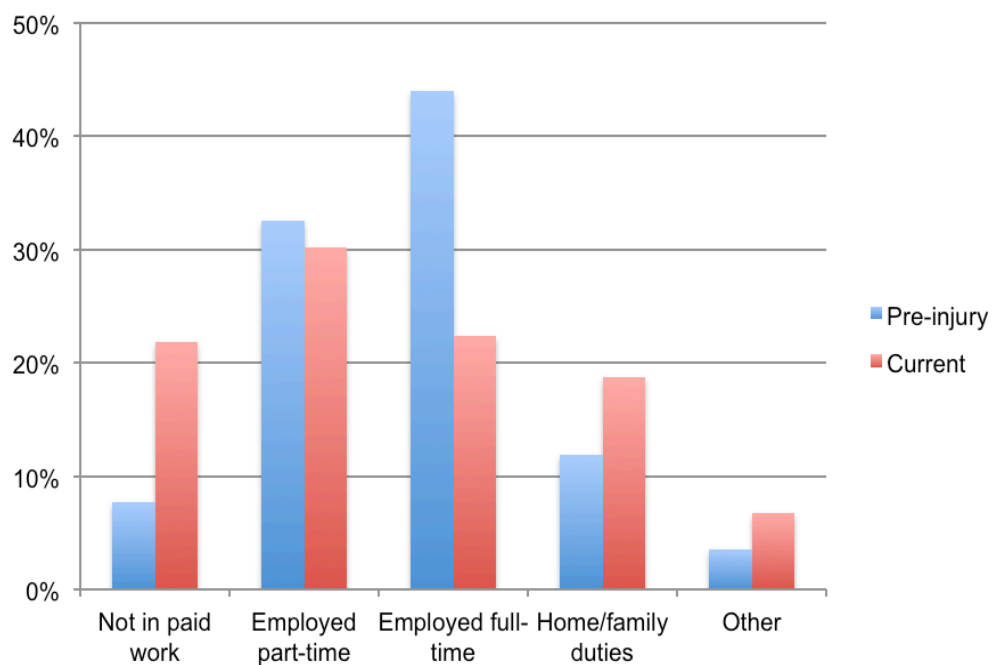
Study	Partner	Parent	Child	Sibling	Close Friend	Other	Total
None	27	16	1	1	0	2	47 (25%)
TAFE/Trade	44	18	2	1	2	1	68 (36%)
Undergrad	19	11	2	2	2	1	37 (19%)
Postgrad	16	8	1	4	2	0	31 (16%)
Other	2	3	1	0	0	0	6 (4%)
Total	108	56	7	8	6	4	

* 1 respondent did not indicate their relationship, resulting in the difference in totals

Employment status

One hundred and ninety two family members indicated their pre-injury and current employment levels. Figure 3.6 illustrates the almost three-fold post-injury increase in the number of respondents not in paid work from 15 (8%) to 42 (22%). Although part-time employment only reduced slightly from 63 (33%) to 58 (33%), there was a dramatic decrease by half in the number of those in full-time employment from 85 (44%) to 43 (22%). This is of note, considering the number of respondents reporting post-school education and training. Home/family duties increased from 23 (12%) to 36 (19%). 'Other' comments included a range of volunteer roles, which increased slightly over time.

Figure 3.6 Pre-injury and current employment levels (n=192)



Employment levels	Not in paid work	Part-time	Full-time	Home/ family duties	Other	Total
Pre-injury	15	63	85	23	7	193
Current	42	58	43	36	13	192

If we compare changes in employment levels between partners and parents, we see more dramatic changes in parents following their child's ABI in all areas (except home/family duties which remain at similar levels) (Figure 3.7 & 3.8).

Figure 3.7 Partner's employment levels (n=109)

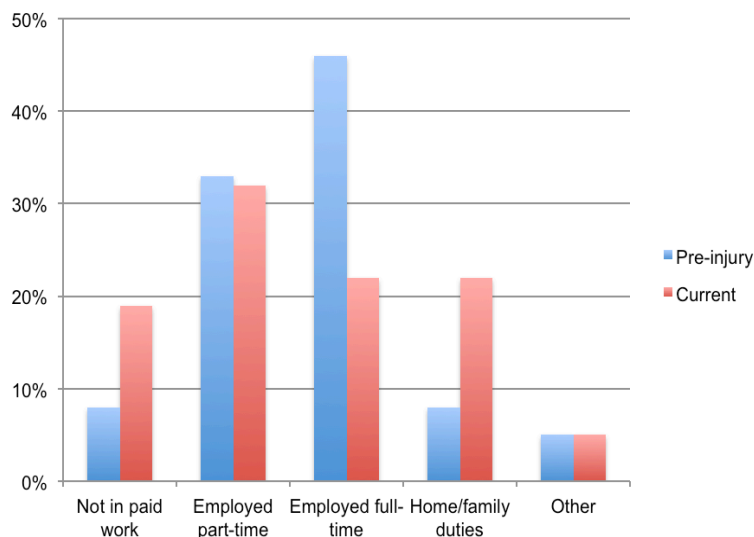
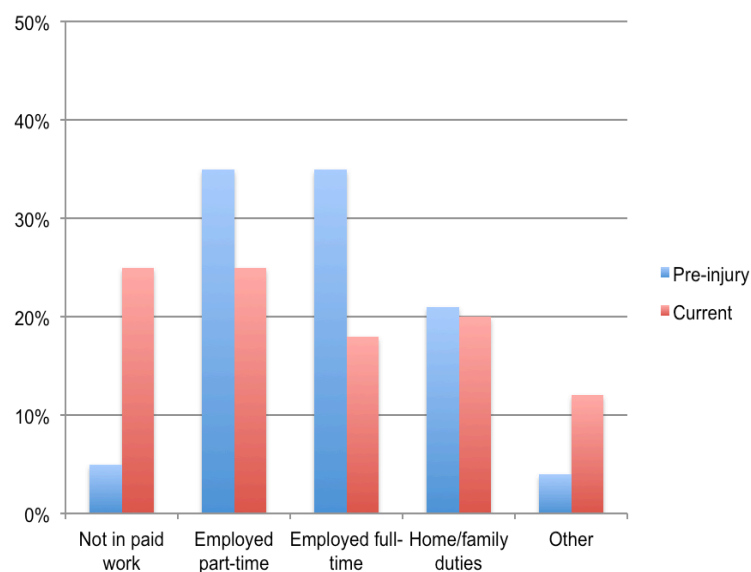


Figure 3.8 Parent's employment levels (n=56)



Employment Level	Not in paid work	Part-time	Full-time	Home/ family duties	Other	Total
Partners:						
<i>Pre-injury</i>	9	36	50	9	5	109
<i>Current</i>	21	35	24	24	5	109
Parents:						
<i>Pre-injury</i>	3	20	20	12	2	57
<i>Current</i>	14	14	10	11	7	56

* Pre-injury employment 3 missing cases, current employment 4 missing cases

Survey: Demographic and diagnostic data on adults with ABI

Demographic and diagnostic information on the person with ABI was provided by a total of 228 respondents: 194 family members and 33 self-completed surveys by adults with ABI.

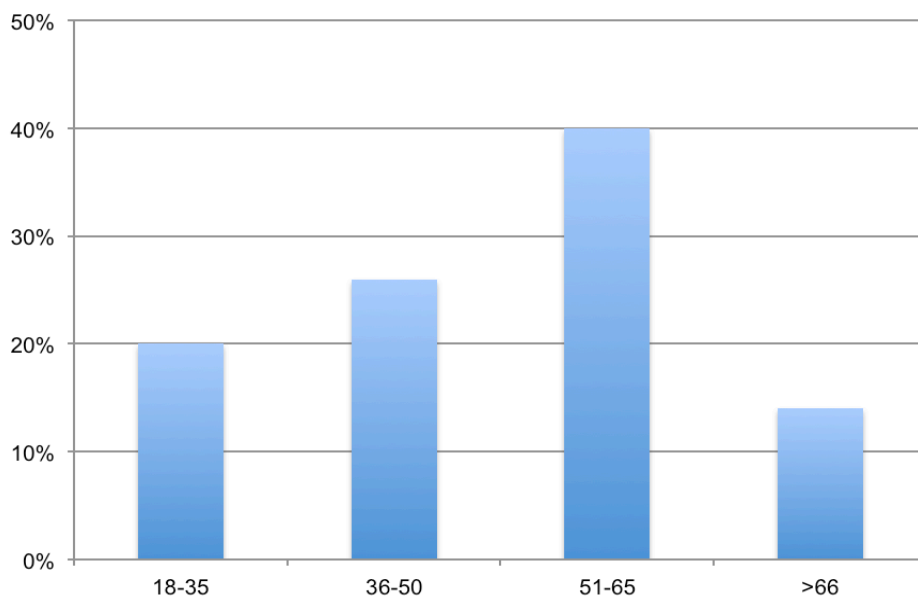
Gender

One hundred and forty four males (63%) and 84 females (37%) with ABI are represented in this survey. Similar gender distribution is reported in wider national statistics of ABI, with males representing more than two-thirds (68%) of people with ABI under 65 years with some activity limitations or participation restrictions (AIHW, 2007).

Current age

The average current age of the person with ABI was 50 years (SD 14.68, range 28-90), representing an older sample. Fifty four per cent were aged 51 and over, with the remaining 46% aged 50 or below (see Figure 3.9).

Figure 3.9 Current age of person with ABI (n=226)



Age range	Frequency	
18-35	46	20%
36-50	59	26%
51-65	90	40%
>66	31	14%

Cause and age at time of ABI

Two hundred and twenty six surveys indicated the cause of ABI, with frequencies presented below (Figure 3.10). The most common cause of brain injury was stroke (30%), closely followed by motor vehicle accidents (29%). Fifty percent were traumatic brain injuries (MVAs, falls, assault, sport and suicide attempts), with 45% non-traumatic injuries (stroke, tumor, hypoxia and drug/alcohol related). ‘Other’ causes of ABI accounted for 5% and included comments such as “*found unconscious, cannot remember what happened*”, “*not sure exactly – overdose of medication maybe*” and two reports of “*work-place accidents*”.

Mean time since injury was 8 years (SD 7.26, range 6months-40 years), with a mean age at ABI of 42.2 years (SD 15.89 range 9-86 years). Table 3.6 and Figure 3.11 below illustrate the average age and range at the time of various causes of ABI. The two largest groups contain noticeably different average ages at the time of ABI, with those involved in a motor vehicle accident an average age of 32.4 years, compared with an older average of 51.5 years at time of stroke. This is not surprising, as although stroke is a cause of disability in all ages, it is most common in older populations (Fortune & Wen, 1999).

Figure 3.10 Cause of ABI (n=226)

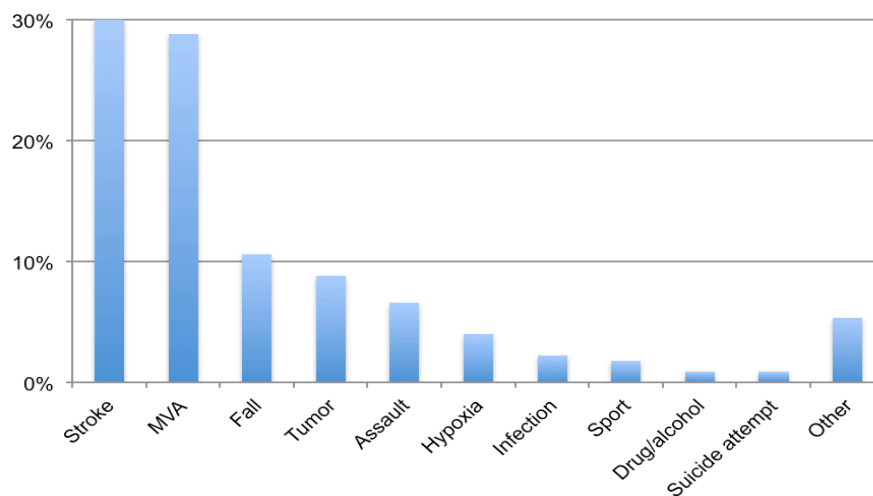
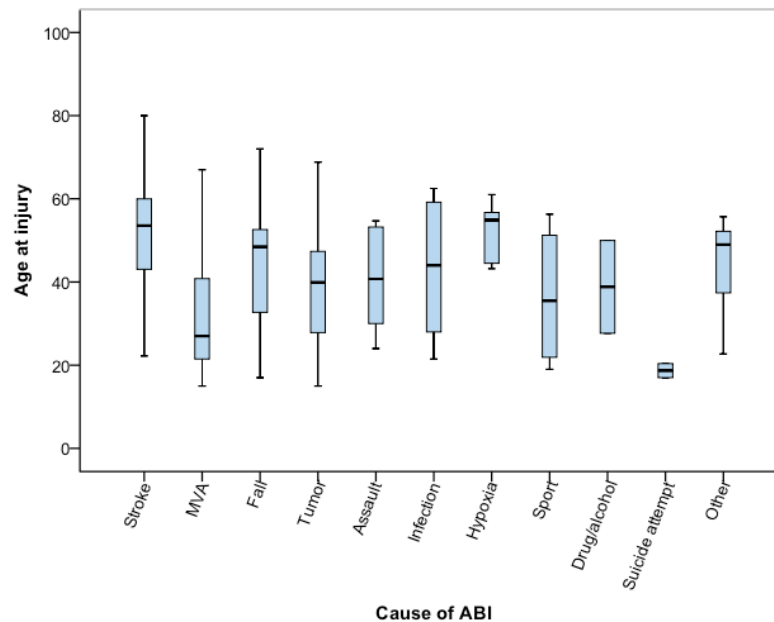


Table 3.6 Cause and Age at time of ABI

Cause	Frequency	Mean age at injury (yrs)	SD	Range
Stroke	68 30%	51.5	13.5	9-80
MVA	65 29%	32.4	15.1	15-86
Fall	24 11%	44.3	13.7	17-72
Tumor	20 9%	40.5	14.7	15-69
Assault	15 7%	40.2	11	24-55
Hypoxia	9 4%	48.4	14.7	13-61
Infection	5 2%	43	18.2	22-63
Sport	4 2%	36.6	17.6	19-56
Drug/alcohol	2 1%	38.9	15.8	28-50
Suicide attempt	2 1%	18.7	2.4	17-20
Other	12 5%	43.8	11.4	23-56

Figure 3.11 Age at injury by cause of ABI

Compensation received

Two hundred and twenty three respondents indicated whether their family received financial compensation following the ABI. The vast majority did not receive compensation (n=157, 70%), with only 21 (9%) still waiting for an outcome, and 45 (20%) reporting a payout (Figure 3.12). Some provided further comments, presented in Table 3.7. There are limitations to interpretation of this data, as some confusion seemed to exist as to whether compensation included insurance only or other types of pay-outs as well. It is noted that 57% and 46% of Victorians with severe and moderate traumatic brain injury (respectively) were reported as compensable under either 'no fault' or common law transportation accident schemes (Access Economics, 2009). As our study has included non-traumatic injuries (eg stroke), little comparison can be made, however differences between road accident schemes are apparent, with SA a 'fault-based' common law scheme.

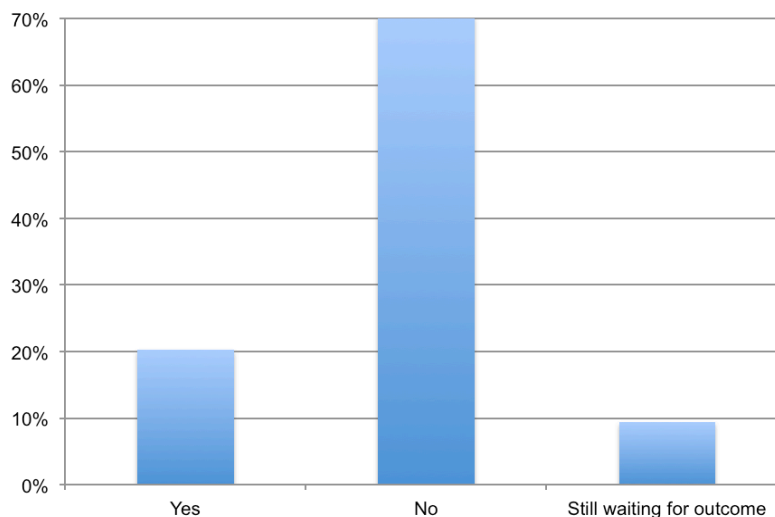
Figure 3.12 Did your family receive financial compensation (n=223)

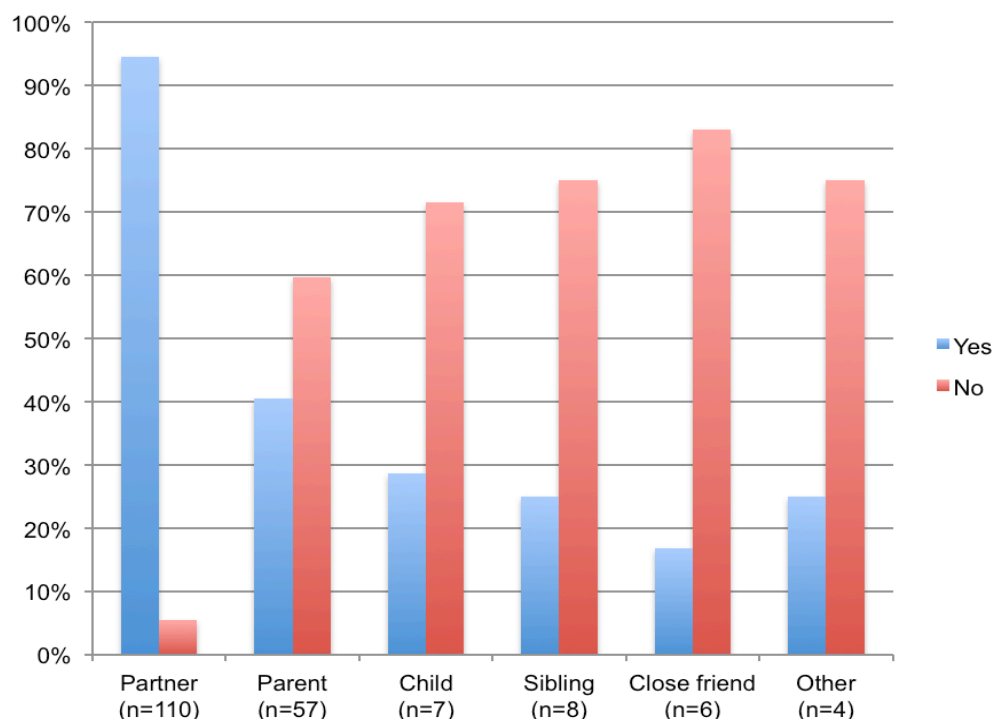
Table 3.7 Examples of comments relating to compensation

Examples of 'Yes'	Examples of 'No'
<i>4 years after the accident</i>	<i>Self-inflicted</i>
<i>But not what he should have got</i>	<i>Still waiting for explanation as to why it happened.</i>
<i>Financial compensation from insurance policies</i>	<i>Thanks to a kangaroo!</i>
<i>Income protection and TPD</i>	<i>Was purely an accident</i>
<i>Insurance from Employment for travelling to and from work</i>	<i>Accident overseas – travel insurance paid medical costs overseas and carer flights</i>
<i>Workcover out of court settlement after lengthy legal proceedings</i>	<i>Assailant not identified due to police incompetence</i>
<i>Small amount from insurance</i>	<i>He did not even receive his sick pay</i>
<i>We pulled out of the case for people's safety and accepted what given. Bad management by Administrators appointed by Court/d Board with excessive fees/charges has limited his monies to only last him between 2-4 years</i>	<i>He was at fault</i>

Living situation

The majority of respondents indicated their family member with ABI currently lives with them (n=135, 70%), with 95% of partners currently living with their spouse with ABI (n=104), in comparison with only 40% of parents (n=23) (Figure 3.13).

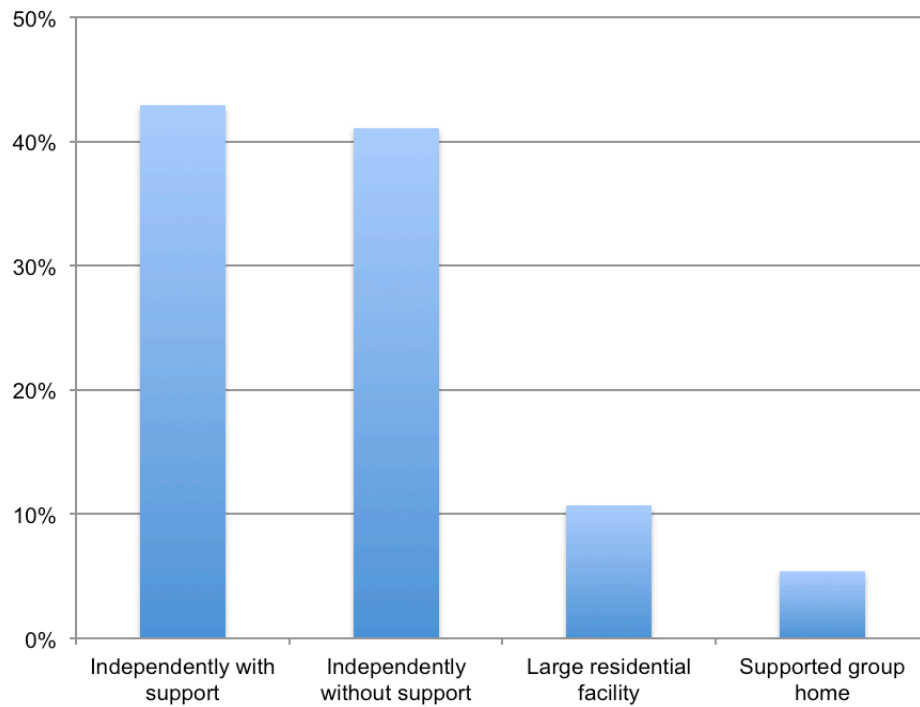
Figure 3.13 Family members currently living with person with ABI (n=192)



Does your family member with ABI currently live with you?	Partner	Parent	Child	Sibling	Close Friend	Other	Total
Yes	104	23	2	2	1	1	133 (70%)
No	6	34	5	6	5	3	59 (30%)
Total	110	57	7	8	6	4	

Of 56 respondents who indicated their family member with ABI does not currently live with them, the vast majority (84% n=47) indicated they lived independently in the community either with or without support, with 11% (n=6) in a large institutional facility, and the remaining 5% (n=3) in a supported group home (Figure 3.14).

Figure 3.14 If not with you, where does your family member with ABI currently live? (n=56)

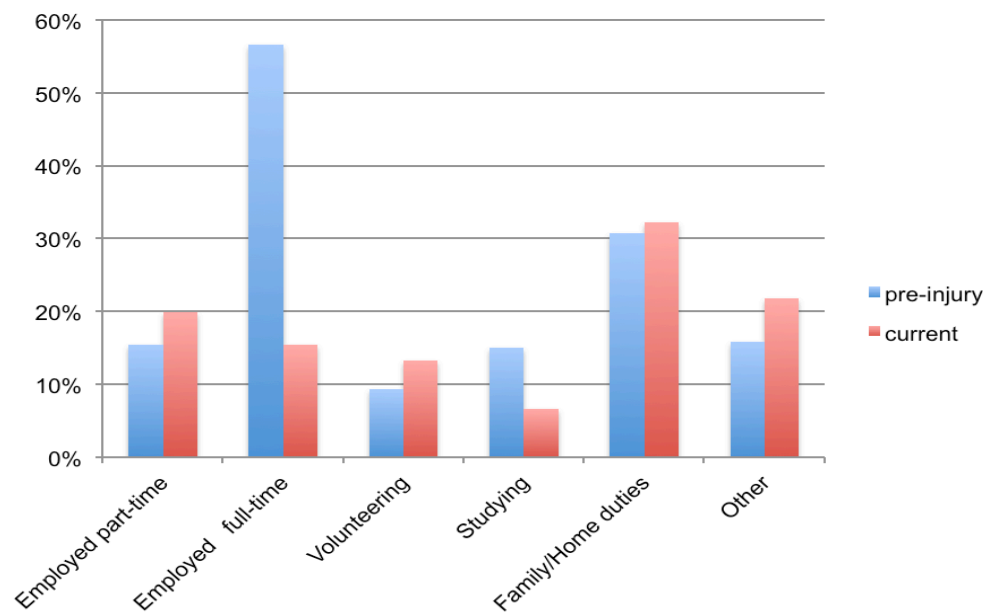


Residence of person with ABI	Frequency	
Independently with support	24	43%
Independently without support	23	41%
Large residential facility	6	11%
Supported group home	3	5%

Activities of the person with ABI

Two hundred and twenty five respondents indicated a range of vocational, educational, and other activities which the person with ABI was engaged in both before the injury and currently. Respondents were invited to select all categories which apply. Figure 3.15 illustrates the dramatic decrease in full-time employment from 56% to 15%, and drop in studying from 15% to 7%. All other categories saw slight increases post-injury, including part-time employment, volunteering, family/home duties, and 'other' activities. Examples of 'other' comments are provided in Table 3.8.

Figure 3.15 Activities of person with ABI (n=225)



Activities of person with ABI	Pre-injury	Current
Employed part-time	35 (15%)	43 (20%)
Employed full-time	128 (56%)	35 (15%)
Volunteering	21 (9%)	30 (13%)
Studying	34 (15%)	15 (7%)
Family/Home duties	69 (31%)	73 (32%)
Other	36 (16%)	49 (22%)

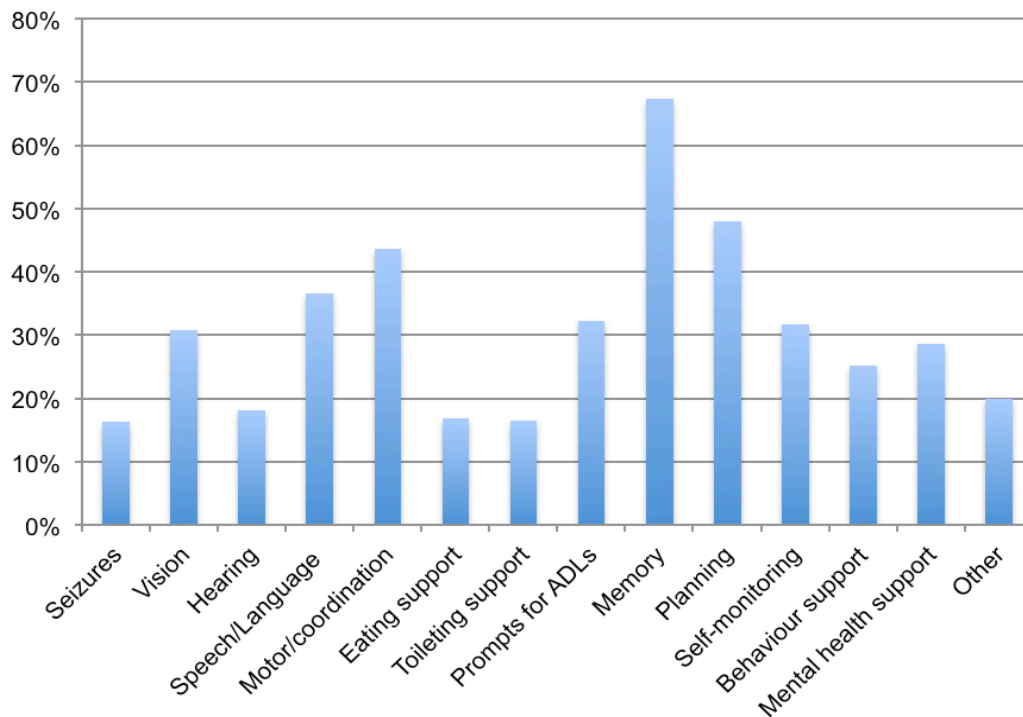
Table 3.8 'Other' activities of person with ABI

'Other' pre-trauma activities	'Other' current activities
Social & Recreational: Club involvement Road motor cross Cycling, swimming, adventure holidays Horse showing Girl guides, choral society	Social & Recreational: Community Re-entry Program Riding for Disabled Day center Social tennis Outings with a carer
Caregiving duties: Carer for frail aged mum Full-time carer of husband and daughter	Caregiving duties: Supporting mother with breast cancer Carer for daughter and husband with mental illnesses
	Ongoing rehabilitation: Springboard Speech therapy Mental health support group

Health & support needs of person with ABI

Survey respondents were invited to identify all health and support needs which applied to the person with ABI (Figure 3.16). The most frequent concerns involved cognitive and executive functioning difficulties including memory (n=153, 67%), planning (n=109, 48%) and self-monitoring (n=72, 32%). Behavioural and mental health support needs were identified by a combined 54% of respondents (n=122).

Figure 3.16 Health and support needs of person with ABI (n=226)



Health & support needs	Frequency	
Seizures	37	16%
Vision difficulties	70	31%
Hearing difficulties	41	18%
Speech/Language difficulties	83	37%
Motor/coordination difficulties	99	44%
Eating support needs	38	17%
Toileting support needs	37	16%
Prompts for ADLs	73	32%
Memory difficulties	153	67%
Planning difficulties	109	48%
Self-monitoring difficulties	72	32%
Behaviour support needs	57	25%
Mental health support needs	65	29%
Other	45	20%

Supports provided by family member

One hundred and ninety respondents provided details to an open-ended question seeking information on the supports they provide to their family member with ABI. Table 3.16 presents the themes, number of comments, and examples of responses (also illustrated in Figure 3.17).

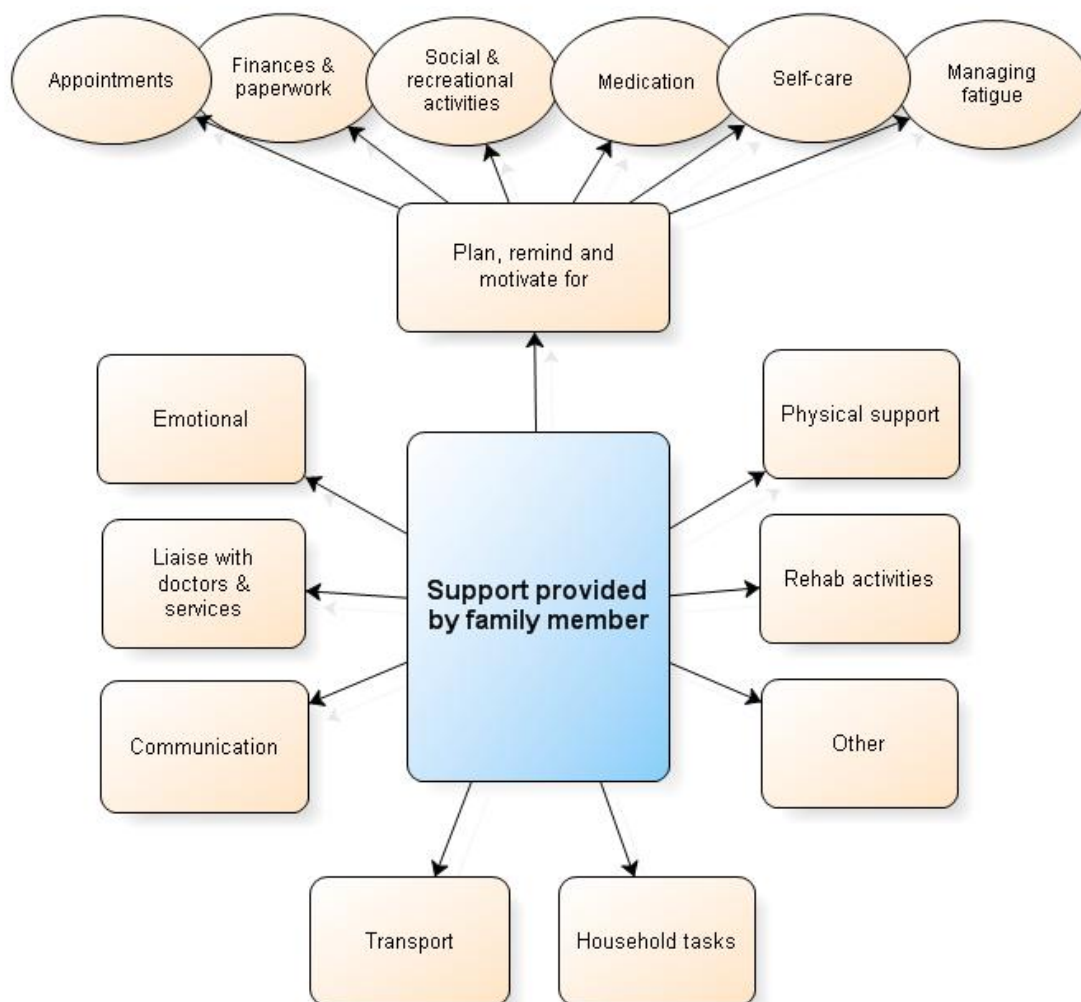
Table 3.16 Supports provided by family member to person with ABI

Supports	# of Comments	Example of Response
	190 respondents answered this question	
Plan, remind & motivate for:	256	
<i>appointments</i>	72	<i>"I feel that I do all the thinking. To get him to work on time I have to set everything up. Any change in routine and he can't cope. All appointments are made & carried out by me. I do his medication."</i> (001 Mother)
<i>medication</i>	29	
<i>finances & paperwork</i>	45	<i>"I need to be aware of things that [he] organises because he doesn't always think them through and he is impulsive e.g. taking on phone contracts without thinking them through properly. Also needs to monitor his money as he is inclined to spend all his available money."</i> (106 Mother)
<i>managing fatigue</i>	2	<i>"Ensuring she has adequate rest to cope with mental fatigue."</i> (013 Husband)
<i>self-care</i>	27	<i>"Hygiene prompts (change clothes, deodorant, shaving etc)."</i> (009 Wife)
<i>social & rec activities</i>	30	<i>"Social (eating out), shopping, visiting friends, recreation - swimming, walking, leisure - art group involvement."</i> (083 Friend)
Transport	82	<i>"Her father transports her in a specially designed van."</i> (145 Mother)
Household tasks	74	<i>"On call 24 hours to son; Dry his sheets daily, sweats heavily. Maintain his home, washing/drying/meals, washing dishes, vacuuming, dusting, washing floors, all the gardening, empty bins."</i> (223 Mother)
Emotional support	51	<i>"He needs help to work on his mental health each day, to know within himself that he is OK and he has support. Depression, for who he used to be, he can and does know that his ABI has changed him and the way he does things and how his brain works. He has difficulties understanding that the ABI has and will affect him for life. Understanding himself and why he does certain things".</i> (025 Partner)
Physical support	28	<i>"Transferring (partially - assistance only), dressing, toileting, washing and cleaning after, showering assistance."</i> (042 Wife)
Liaise with doctors & services	12	<i>"I am her advocate and liaise with care agencies and Disability SA."</i> (145 Mother)

(cont)

Communication	7	<i>"Some interactions with others are difficult due to aphasia and additional explanation/clarification sometimes required to ensure that he fully understands." (117 Partner)</i>
Rehab activities	3	<i>"helping with daily exercised set by physiotherapy." (056 Wife)</i>
Other	15	<i>"1:1 support 24/7...I would describe it as much, much more than 'support'. I would describe it as being crucial to the person's very survival, sanity, sense of identity and cohesion and happiness." (028 Mother)</i>
None	15	<i>"No longer required." (054 Husband)</i>

Figure 3.17 Supports provided by family member to person with ABI



Survey: Areas of unmet need

One hundred and thirty respondents answered the open-ended question “*Are there support services that your family need that you are not currently receiving? Why?*” Sixty-four percent (n=83) indicated ‘yes’, providing comments describing one or more supports needed. An additional 31 respondents (24%) indicated that they didn’t require any other services, however 16 (12%) indicated they ‘didn’t know’ and weren’t aware of what is available (Figure 3.18, Table 3.17). This highlights the importance of a family support network which could provide direction on a peer basis to identify and assist access to services for which the family may be eligible, and develop the skills to advocate for services they need. It is also acknowledged that while this indicates significant unmet need, those family members who are more strained may not have participated in this survey, resulting in a biased sample.

Figure 3.18 Are there support services that your family need that you are not currently receiving? (n=130)

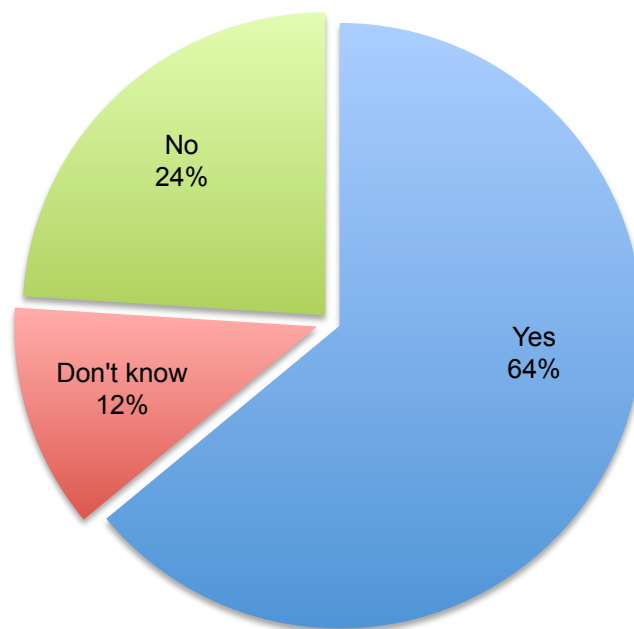


Table 3.17 Are there supports that your family need that you are not currently receiving?

Themes	# of Comments	Example of Responses
	130 respondents answered this question	
No	31	<i>"After 17 months, I think we are finally seeing all the people that my partner needs to see. This has been a slow and disjointed process, and in hindsight seems to be a reactive rather than proactive process. I do believe that we were never made aware of what services were available to us, particularly upon discharge of rehab. For example, it was about 15 months before he saw a pain specialist, which had been a major issue since day 1. If we knew that this was available, then it would have happened much sooner."</i> (103 Wife)
Medical & rehab services & equipment	25	<i>"Things are pretty good now that family member has been diagnosed with ABI and ACAT assessment and now receives carer support through Anglicare. Before this happened, it was terrible - there seemed to be no services available to help her and I was very frightened about what would happen to her. We tried all sorts of avenues to try to obtain assistance. It took a 6 week stay at RAH followed by several months at Hampstead before the ABI diagnosis was given, ACAT assessment done and a proper care plan put in place. Thankfully this was not too late."</i> (219 Sister)
Don't know	16	<i>"Not sure what else is available that I don't know about."</i> (018 Wife)
Financial assistance	16	<i>"Financial support: my income puts us above the income threshold (just). Consequently we have used up nearly all our savings within one year of the ABI. Many of our carer support meetings are during the day and as I work I cannot attend."</i> (190 Wife)
Access to services	11	<i>"This postcode lies in the centre of a triangle of support services but remote to each of them. That in itself is a problem accessing a number of these services."</i> (067 Husband)
Counselling & debriefing	9	<i>"Any one that has an ABI and any one associated with that person should have ongoing counselling to cope with everyday things and for support, because the mental pain never goes away. We do not have any now as it is too expensive."</i> (180 Sister)
Respite	9	<i>"More respite to take some pressure off me and after 13.5 years of caring, travelling to him, I am burnt out and need a holiday, but no-one in family will support me to have one...They explain (to my son) "Mum needs time out", he only wants me and there is no system in force to make him comply - as he has rights to have his own way. My young son & daughter used to visit son, but after many years of his challenging behaviour, they now pulled away and have very little contact, which is sad."</i> (223 Mother)
Activities for person with ABI	7	<i>"[Our son] in his words, is "bored shitless". He needs appropriate intellectual stimulation and this is not available."</i> (114 Father)

(cont)

Family peer support & social events	6	<i>"I would like to be in touch with someone in similar circumstances as it is very isolating. If there was a support group where we could meet socially it would help us both. I have tried to reach out but nothing seems to be available. I go to carers that's the extent of my respite. If anything becomes available in our area we would be interested. I feel ABI is totally neglected. I don't know where to turn" (024 Wife).</i>
Home maintenance & support	3	<i>"Cleaning! I work full time and care full time! Having access to cleaning support for my daughter would give me support to enable me to do my work and care for her." (164 Mother)</i>
ABI education & information	2	<i>"We'd like ABI education, information and social events for the whole family." (004 Wife)</i>
<u>WHY?</u>		
Don't know what is available or where to enquire	12	<i>"Have no real idea even now what supports are available" (160 Mother)</i>
Too expensive	9	<i>"Physiotherapy – not affordable on DS pension. Speech therapy – not affordable. Disability aids (not within scope provided by DSA)." (072 Wife)</i>
Service doesn't meet our needs	9	<i>"Respite for Mum is exceptionally difficult to find/access. Mum has high physical needs but has limited impairment intellectually (despite slow short term memory problems). So when she has gone into respite she has been in an environment with much older, frail people getting close to their final years. She has found this very distressing emotionally and the "damage" done has outweighed any benefits of respite to dad/me. In addition, respite care has never been able to provide the level of specialist understanding of her leg brace/walking requirements, so she has often gone backwards whilst in respite - which was the case after suffering a 2 (mini) stroke in 2010. We had to be very assertive in getting her out of respite and home where the level of care was significantly higher." (119 Daughter)</i>
Service is not available	7	<i>"Not enough respite - have to book respite over a year ahead. People with ABI are not suitable to be placed with mental patients in respite. They already placed my partner with this and it is terrifying plus other reasons. Needs at least 4 respites per year funded." (Wife 129)</i>
Not contacted or offered services	6	<i>"I receive no support and have never been offered any support." (127 Husband)</i>
Not eligible	5	<i>"Not eligible due to compensation." (130 Father)</i>
Person with ABI reluctant	4	<i>"Don't receive support services. My husband is extremely reluctant to do anything independently. Expects me to be available 24/7." (144 Wife)</i>
Lack of support workers	3	<i>"We have had discontinuous support service for past 6 weeks due to lack of employees." (028 Mother)</i>
Service is too far away	3 (2 Inner & 1 Outer Regional)	<i>"Don't receive support services. Very few available in regional country." (144 Wife)</i>
Haven't sought services	3	<i>"None. Have not sought." (012 Partner)</i>

Survey & focus groups: What supports would be most helpful?

One hundred and fifty six survey respondents provided details to the final open-ended question “What type of supports would be most helpful to assist your family in coping with the challenges of living with ABI?” Themes emerged under the following two major categories:

- peer supports which could be provided by a family support network and
- professional health and disability services with a family-centered philosophy.

A total of 349 survey comments were coded to emerging themes presented in Table 3.18. The majority of comments relate to a desire for increased supports from services (n=213, 61%), with 29% (n=100) identifying ways in which they would find peer-based community supports of benefit. Only 19 (5%) indicated no supports were currently needed.

This question was also asked in each focus group. Analysis of transcripts revealed themes which mirrored those from the survey. Three hundred and forty comments were coded with equal emphasis placed on peer-based community supports (n=166, 49%) and family-centered services (n=165, 49%). The most frequently occurring theme within focus group discussions was the need for family support groups (n=84, 25%), with emphasis also placed on the need for group lobbying and emergency accommodation.

Figure 3.19 illustrates the themes from combined survey and focus group analysis. Themes in bold represent supports which could be provided by a Family Support Network, with others provided by services operating under a family-centered approach. Each is explored in further detail below.

Figure 3.19 Supports identified as most helpful from survey and focus group analysis

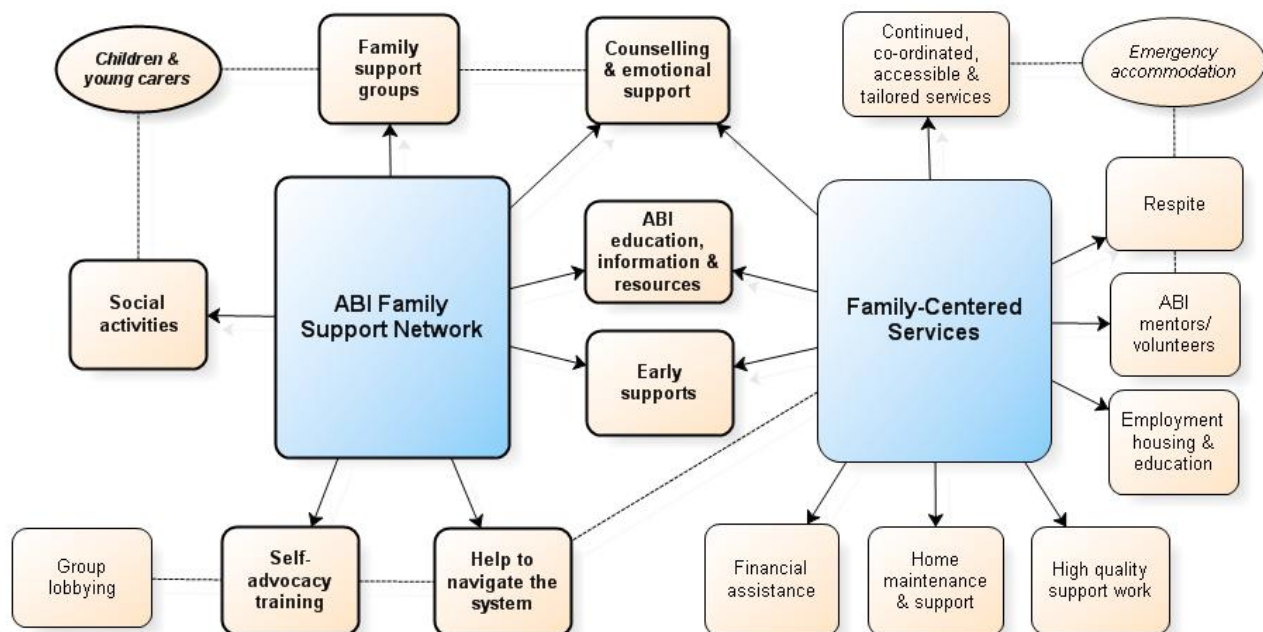


Table 3.18 Supports that would be most helpful to assist your family following ABI (Survey analysis)

Survey themes	# of Comments	Example of Participant Responses
156 respondents answered this question		
ABI FAMILY SUPPORT NETWORK		
Counselling & emotional support	45	"Continuing access for counselling and advice when necessary." (029 Mother)
Family support groups	33	"A support group with people living with ABI is needed as you are isolated dealing with challenging behaviour daily and a group to connect with others would be supportive as these people would identify with you, where others not living or understanding brain injury don't. It's hard to know how to fit in when you go to events, after living in 'carer world' so long, I feel out of place, don't identify with them." (223 Mother)
Children	3	"Kids of people with ABI group to talk to other kids that have the same problems." (165 Husband)
ABI education, info & resources	29	"Maybe workshops with others in similar situations, outlining the process that lay ahead." (091 Daughter)
Social activities	19	"More socialising to help gain social skills. It would be great if there were events where families could get-together. I get frustrated that there is very little if anything for people recovering from brain injuries and their families." (007 Wife)
Help to navigate the system	17	"Help knowing what is available." (177 Wife)
Early Supports	14	"Early support in hospital from those who have first-hand experience of what happened, to show there is 'light at the end of the tunnel.'" (084 Husband)
Self-advocacy support & training	2	"I needed to get a local MP to support me." (131 Wife)
FAMILY-CENTERED SERVICES		
Service Quality	37	"Better rehab – CLOSER and ongoing with opt in/out options" (004 Wife)
Accessible	14	"I have rung council, disability & carers all to no avail. I personally do not have time to pursue all these services so we manage alone." (024 Wife)
Coordination/ follow-up	12	"A person visiting us even years after the accident. It has been 4 years now and we probably all thought we were coasting along but I think we all (5 of us) should have kept talking to someone about our life and the different ups and downs we have." (167 Wife)
ABI educated	8	"Access to help with professional who understand the complexity of the needs of the carer in this situation e.g. change of role from wife to carer and having to maintain the running of household when the person of ABI feels inadequate." (031 Wife)
Continued rehab services	30	Creative speech therapist to assist both [son] and I with communication challenges. (174 Mother)

(cont)

Financial assistance	28	<i>All fulltime carers need remuneration for the services they provide to highly vulnerable and courageous young adults. (028 Mother)</i>
Respite	22	<i>"Respite suited to younger people (not nursing home type)." (072 Wife)</i>
Employment, housing & education	18	<i>"Assisting with finding employment, re-education (to help him cope when he cannot do the work he was trained to do)" (077 Wife)</i> <i>"A nursing home for people under 65 YO with rehab facilities e.g. physio, counselling with activities to suit a younger person and the support to encourage participation." (107 Mother)</i>
High quality support work	16	<i>"Access to workers who are well trained and who show motivation and ingenuity, who care, respectful, innovative, energetic and suitably educated and who are prepared to work with families in a committed and continuous fashion." (028 Mother)</i>
Home maintenance and support	12	<i>"Home assistance (cleaning weekly or fortnightly) due to carer's shortage of time." (030 Mother)</i>
ABI mentors/ volunteers	3	<i>"Mentoring programme - someone [son] can get to know and trust and accompany [him] to appointments, therapy, recreation, social activities - someone more [son's] age, not mine." (174 Mother)</i>
Not applicable	19	<i>"None needed at this stage" (085 Husband)</i>

Counselling & emotional support

'Counselling' was the most frequently cited term within survey responses, and in combination with emotional support, was the highest requested support. There were frequent requests for ongoing access to counselling services (beyond those available from psychologists under the Medicare-funded schemes), more affordable counselling, with a focus on loss and grief, mental health support (depression and anxiety), and an opportunity to receive emotional support regarding fears and anxieties for family members in addition to the person with ABI:

"Counselling for family members to understand better: what to expect with moods, capability etc. Mother is still quite unaccepting of sons ABI and tends to introduce him as "this is my son, he has a disability" and then his name! I guess she is somewhat ashamed about it and confused/upset that it happened to one her family members." (083 Friend)

"In the beginning, knowing more about what was going on, someone we could talk to and encourage positive outlook/thinking. You feel so scared seeing what your child is facing-wondering if you will cope with taking on children etc" (160 Mother)

"Please think about providing support and advice for counselling for families at the time to prepare them for the loneliness and difficulties. The shockwaves from an injury like this don't stop. It's worse than a bad marriage as there is no escape and nowhere to go. Living with such grief for my husband and what he is going through has been difficult to deal with as a result, I've just become very cold just to cope. So please, think about the families as much as you think about the patient." (040 Wife)

The role of Creative Arts Therapy was mentioned within one focus group, highlighting this as a positive medium to support all family members in adjustment and fostering resilience.

In addition, participants identified that counselling and emotional supports should also be available through phone support:

“24 hour phone line for emotional support when all else fails.” (025 Female partner)

“As an independent person myself, I struggle to ask for help, but an understanding ear at the other end of the phone would be nice. I don't do group therapy very well, it just seems to accentuate the difficulties. Resilience is the key word.” (031 Wife)

“Phone help. Sometimes my husband gets verbally and physically violent with no memory of it ten minutes later. However I am left in a traumatised state with no-one to talk to.” (009 Wife)

“A call line where you can ask questions or clarify when you are dealing with ABI behaviour.” (169 Wife)

Family support groups

Survey and focus group participants voiced a strong desire for social connection, opportunities to share experiences and gain new perspectives in family support groups:

“Opportunities to meet other people with, and carers for ABI.” (004 Wife)

“It would be great if there were events where families could get-together. I get frustrated that there is very little if anything for people recovering from brain injuries and their families.” (007 Wife)

“Being able to talk to people [dealing] with similar cognitive issues to know what support is out there.” (039 Husband)

“For me, ability to contact carers in similar circumstances who have been through similar experiences and can share insights and strategies. Hearing stories of recovery.” (190 Wife)

“A person visiting us even years after the accident. It has been 4 years now and we probably all thought we were coasting along but I think we all (5 of us) should have kept talking to someone about our life and the different ups and downs we have.” (167 Wife)

The desire for support groups was the most common theme identified within focus groups, with family groups described as a means of reducing experiences of isolation:

“I'm a single parent; I've got lots of friends now who are single parents but there isn't one person in my circle of friends that I've made over those five years that has been through what I've been through. It's either divorced from adultery or for whatever reason they've separated but nobody can quite understand, can they, what we go through in our families? Also I know how frustrating it can be when you are the spouse and how you go – well for myself I can only say that I went through times of just this incredible love and compassion and other times when I just was at my wit's end in how to cope. Just again that ongoing support, some sort of a network where there is a space as families we could share and support each other I think would make a tremendous difference.” (Wife, Metro Focus Group)

“...sometimes you feel so alone and then to hear other people talking about stories that are the same, you think ‘oh, it's not just me’. So we all understand.” (Partner, Metro Focus Group)

"The impact [the accident] had on [husband] has been dramatic but I also felt like the impact it's had on the rest of the family has been significant. I couldn't get my head around the fact that there was no-one to talk to. Like, you had professionals, but some of the professionals too did not seem to really get what you were going through. They went home at night. They kind of had their normal lives when they left and I felt like there was no 'after hours', you know?" (Wife, Metro Focus Group)

Others sought opportunities to 'give back' and support other families:

"The opportunity to help others in the same situation." (051 Fiancé)

"My sons accident was so long ago (40 years) that services were not available when we really needed them and we have worked through them but would be happy to help others in need." (192 Mother)

"Informal networks with other families experiencing ABI. She does not want to let her experiences go to waste, but rather utilise them to support others in similar situations. Early support in hospital from those who have first-hand experience of what had happened, to show there is "light at the end of the tunnel". She became very depressed in hospital surrounded by elderly people who were past the stages of starting a family." (084 Husband)

One focus group participant articulated the following benefits of a family support group:

"One of the things that really, really helped me was the doctor there put me in touch with somebody else who's husband had an acquired brain injury because of the same viral infection and meeting her and talking to her and going through her experiences, and the same choice that she had to make, really, really helped me and also gave me some of that relativity. Since then I've still only really met one other person that is a carer of somebody with an acquired brain injury but again sharing those experiences and sharing that knowledge – and when you're talking about information, information about services, I've always learnt from those interactions. That's a thing that's been really positive and really helped me and one of the things that I think like a network could really help deliver." (Wife, Metro Focus Group)

A number of comments directly requested groups for children and young carers whose parents have an ABI, in addition to a support group for partners:

"Kids of people with ABI group to talk to other kids that have the same problems." (165 Husband)

"Support for the children. Maybe chance for children to meet others who have had a similar family experience." (169 Wife)

"Our youngest son (aged 13 at time of stroke), has struggled to accept the change to his father. He has lost respect somewhat due to his short temper and lack of motivation. My husband took a huge part in the older boys lives, sport wise. He still attends their sport and will stand in the rain to watch them but he sleeps too much and is so hard to motivate to do anything, even walk around the block or to take dogs to the park. I feel our youngest son should have had support." (070 Wife)

"Partner of ABI support group." (165 Husband)

A children's workshop on ABI available in Queensland was described as a model example, which should be replicated in South Australia:

"They came and picked my children up and took them to a workshop for other children who had a parent who had some sort of acquired brain injury, or lack of oxygen, however it's affected the brain, and that was fantastic. They showed them pictures of the brain and they talked about the changes in their mummy or their daddy. I remember them coming home and saying to me 'oh, mum, there's other people. We met this child and we met this child and this person's daddy, he tried to hang himself and they've gone through this and they've gone through that'. So somehow they felt we'd actually done really well and for the first time they found a place to put what they were feeling and I think – so when we moved down from Brisbane to here there was nothing and it was very difficult. Unfortunately a year later because my children were teenagers and just coping with teenagers, my ex-husband didn't cope very well and he ended up leaving. If that support had been in place for him and for us I really believe that we probably would have still been together in that would have been helpful to help us all cope." (Wife, Metro Focus Group)

The serious risks to unsupported children following an ABI in the family are highlighted in the following quote:

"I'm here to advocate for other families because for us unfortunately, you know, it has torn our family apart to a point also I would like support for teenagers. Unfortunately my son turned to drugs when his father [with ABI] left and I had to put him in rehab and he's come through the other side but there needs to be support for teenagers because when they hurt drugs are one of the first things that they'll turn to because it's everywhere; it's huge in Adelaide. When you were saying about the learning curve for acquired brain injury I went through that but I also went through the huge learning curve of what it was to have a child who turns to drugs and how prolific it is here in Adelaide. My heart goes out to the kids because these kids are just hurting inside and it's drugs or alcohol that as teenagers they will often turn to because their world has been turned upside down. You know, in our case they lost their dad really. He was never quite who he'd been before and so there needs to be some sort of support to help kids navigate this really isolated world." (Mother, Metro Focus Group)

ABI education, info & resources

Participants identified the need for further information about acquired brain injury, both generally, and in relation to specific situations:

"Maybe workshops with others in similar situations, outlining the process that lay ahead." (091 Daughter)

"Someone to translate medical mumbo jumbo into layman's terms." (091 Daughter)

"More information and education opportunities to meet health professionals, service providers, in social events and educational events." (163 Close friend)

"It would be fantastic if any new information that is learnt to be passed onto family members to help with the daily challenges. It could help to be assessed every 2-3 years and tested because we all know there is new data and information coming out monthly, yearly, with all the research that's being done." (226 Partner)

One focus group participant described the discrepancy in level of education and resources provided across different conditions:

"I felt that when my stepfather got diagnosed with diabetes they got all these resources, all these booklets and courses and programs and equipment and I thought okay, diabetes is a challenge but that's nothing compared to living with brain injury." (Wife, Regional Focus Group)

Requested information covered a range of themes, including inviting rehabilitation specialists for question and answer sessions:

“Understanding behavioural/personality changes after ABI and memory difficulties.” (199 Person with ABI)

“Access to info re medical/mental health.” (168 Close friend)

“Strategies on how to deal with the mood swings anger and depression i.e. language to use that support.” (170 Partner)

“When someone has what would be regarded as a minor brain injury (concussion) they are sent home as concussion usually heals in 7-12 days. But when symptoms do not go away there is no information (pamphlet) to advise what to do.” (173 Husband)

Two focus group participants provided the following examples:

“So one of the nurses down there said to me ‘I think the problem is that you think that [husband] thinks the same way you do and he doesn’t and you’ve got to learn to handle him differently’. I looked at her and I said ‘well, who’s going to teach me that? This has been going on since 2003 and nobody has offered any help. They could not send me anywhere. They did not know who to send me to. I thought ‘this is just ridiculous’.” (Wife, Metro Focus Group)

“The lack of information I just think is so wrong. Everyone should be given the same information and it should be so easy because the last thing you feel like doing when you’re rushing around in hospitals and those hours sitting next to the bed and that is to start trying to find information and that’s what I find so frustrating. You mentioned that [your husband] was able to go to a couple of sessions for counselling at BINSa but there’s no counselling for family members, like you can’t get counselling.” (Mother, Metro Focus Group)

Without private health cover, other families have been unable to have follow-up neurological scans and access specialist services to review and understand changes over time.

“It’s also for me too, to actually understand what is happening and what things I can do to maybe not infuriate a situation, to work through a situation. And that’s really quite difficult when there’s nothing there... I don’t know how the brain works. And I need to know so I can help a situation instead of making it worse.” (Wife, Outer Regional Focus Group).

In relation to sharing information on resources, one focus group engaged in considerable discussion on technologies such as iPads and smart pens, sparking ideas for their use as learning, rehabilitation and community inclusion resources. Such an exchange of ideas occurs when people come together and can stimulate new social, learning and engagement activities.

Social activities

Respondents described the need for social activities as a family, and also individually:

“More socialising to help gain social skills. It would be great if there were events where families could get-together. I get frustrated that there is very little if anything for people recovering from brain injuries and their families.” (007 Wife)

“Outings, companionship, friends, bridge (cards).” (023 Person with ABI)

"Social support - others in my social circle generally don't understand the limitations that an ABI person/partner face - we no longer go places with more than a couple of steps (for example) but others just don't get this. It would be good for us to feel like we are 'normal' and have normal needs not viewed as a 'problem' or burden." (117 Wife)

"We currently participate in attending Dinners that are arranged by North East Network, through Uniting Wesley, and the CRP Northern Group, through Flinders University. Whilst both of these groups are an outlet for me, my spouse finds them emotionally draining. If there was some type of support for him, such as Bus Trips or Activity groups, where only ABI people are involved and he could be picked up and taken to these events, that could give me a break." (112 Wife)

The timing and availability of social activities was identified by one respondent:

"More 'ABI' social activities on weekends and holidays." (001 Mother)

Help to navigate the system

Comments under this theme described difficulties knowing what services and supports were available, and requested assistance in learning how to navigate the health and disability system.

"A 'show bag' of services available and who to contact eg Centrelink, stroke foundation, support group." (059 Mother)

"Resource book, what's available in one document." (043 Husband).

"A person to sit down and tell us about all the services and payment we are able to access without us finding out years later." (165 Husband)

"Help knowing what is available." (177 Wife)

"Most of these issues we have sorted out but they are things which many of us probably struggle with but we do not know who to go to for the relevant assistance. Having someone to contact who could advise as to where to go if we need support." (191 Sister)

"I've got no family. I was floundering. My doctor was really good but she could only go a certain way. She wasn't holding my hand. I didn't know where to go; I still don't know where to go after 15 years." (Person with ABI, Metro Focus Group)

"Having a plan: Where do you go, what do you do, who do you ask?" (Wife, Outer Regional Focus Group)

Other more specific comments described frustrations in trying to complete forms, assistance with Victims of Crime:

"First and foremost, understanding the legalities with activating POA and guardianship, liquidating assets, financial investments etc (a minefield)." (091 Daughter)

An excellent illustration of information sharing in practice occurred during the outer regional focus group. When one family described their difficulty in finding affordable accommodation during their son's hospital stay, three other members exploded with shared suggestions of alternative options and resources:

"I thought you had to be a 'cancer family' to stay there? I didn't know that!"

"Oh no, we stayed there!"

"Everyone can stay there."

"If you've got a doctor's appointment, you can stay there. I stayed there 3 times with my son."

"And also they have a bus that will take you from your hotel to the hospital and it doesn't cost you anything."

"And the Red Cross will do the same; they'll pick you up and they're cheaper than a taxi. That's what I do when I'm in Adelaide."

Peer support in sharing knowledge of services and supports that are available is a crucial element of a family support network, and can help fill a need in the absence of a coordinated brain injury sector.

Early supports

One common theme was the request for supports in the early stages following the ABI:

"Early support in hospital from those who have first-hand experience of what happened, to show there is 'light at the end of the tunnel.'" (084 Husband)

Other comments related to access to specific health services before hospital discharge:

"Psychological/Neuropsychological assessment and support as routine care at Recovery Unit level." (012 Wife)

"Neuropsychological support came way too late for my partner (about 9 months), and again hindsight shows that it should have been months earlier. Some form of family counselling in the early days would have been helpful for our whole family, in order to understand and cope with the changes and problems." (103 Wife)

Another critical element is receiving a diagnosis of ABI and information that enables families to access supports in a timely manner. Determining eligibility for specific services and supports is essential and entry to the service system is facilitated by an early understanding of what may be needed and for what purposes. One focus group participant shared the following experience following her husband's recovery after a heart attack:

"My husband wasn't tested for [ABI] and for the next 4yrs I struggled to find out why, once the surgeons had told him he had 10% damage to his heart and that he was now fine and could go back to work, why he was struggling with his memory, struggling with many of the things that you've spoken about and could not support our family and was a different man to the man that I had married. I cannot understand why there is not anything in place in hospitals to test anybody who's been resuscitated." (Wife, Metro Focus Group)

Self-advocacy support & training

A number of comments illustrated the need for support and training in self-advocacy:

"I needed to get a local MP to support me." (131 Wife)

"Changes need to happen with bureaucrats to make system work better to get the answers you need when advocating for son, instead of going around in circles dealing with them, causing lots of frustration. They need to treat carers better and show them respect." (190 Mother)

The desire to develop a lobby group for families affected by ABI was raised numerous times within focus group discussions. In particular, issues included lobbying for carer wages, time off, holidays and superannuation, and well-staffed community accommodation. One recurrent issue was the need for ABI to be acknowledged within Centrelink Disability Support Pension and Carer Payment application and review forms, in addition to the need for family care-givers to receive recognition for the executive functioning support provided following ABI in order to access Carer Payment:

"Centrelink 'No Box' to tick for ABI. Very difficult to negotiate that system." (222 Mother)

Families experiencing exhaustion found this extremely challenging and were frustrated that this time consuming and ongoing role fell to them:

"You've got to have the energy to access it." (Mother, Metro Focus Group)

Service quality: Accessible

A number of respondents from Remote, Inner and Outer Regional areas cited the difficulties of living at a distance to needed services:

"We live in remote SA. We would have more help if we lived in a city area but we choose to remain here." (010 Wife)

"People to help with transition back into normal living in country SA is non-existent." (019 Wife)

"SA Disabled in Whyalla Hospital are very under-equipped and hard to get to top floor of the hospital. Support groups are very hard to find. You have to go to them when they should come to us. Facilities on the way to and from Adelaide for disabled are more difficult to get to than for non-disabled." (061 Male friend)

"Once you go through that tunnel (from Adelaide) you are forgotten. The country is a forgotten place. It's the same once you go north of Gawler. You're forgotten. It's only city based. We don't know what happens in the city, but obviously it doesn't happen in the city either!" (Mother, Outer Regional Focus Group)

Others referred to difficulties accessing services which were either unavailable, available at the wrong times of the day (no after-hours services), or inflexible:

"Being able to access respite. Seems to be a terrible shortage of places. they are heavily booked up. The place we use is getting booked up for 2014 already." (018 Wife)

"While [he] was a full time patient at Hampstead Rehab Centre, Centrelink made me take him out of the center to go to the Centrelink office so the doctor there could assess his disability. The doctor would not visit [him] at Hampstead and I was told he had to go. Centrelink is not a very helpful service in the least!" (171 Partner)

Service quality: Coordination & follow-up

Participants referred to a need for increased coordination of health and disability services and follow-up:

"Better coordination of communication between doctors, Hampstead, Disability SA, Paraquad etc and perhaps one central person/s (group) to oversee person with ABI. [Husband] is reluctant to seek help unless drastic/emergency. Follow up by some of these services to check if family/carer are getting info and care needed by any appropriate services." (042 Wife)

"I have rung council, disability & carers all to no avail. I personally do not have time to pursue all these services so we manage alone." (024 Wife)

"As this can be such a long term challenge there is a need for follow-up after the immediate injury treatment phase e.g. follow-up once returned home (not 2 weeks later when full realisation is not yet established). While inpatient excellent family conference with all health prof, no contact from any health professionals after this for family member. No involvement or support or discussion of how our 3 children would/were coping with impact of ABI on/for their father and challenges for our family e.g. how many places can mum be at once never mentioned." (099 Wife)

"Follow up treatment/assessments locally by a team and include family members advising what to expect." (108 Husband)

"I haven't seen a lot of support for him at all in 3 years. I sort of thought he would see someone maybe every year, but I haven't seen anything at all." (Wife, Outer Regional Focus Group)

Service quality: ABI educated

The need for people working in the sector who have a good understanding of the effects of ABI on the individual and family was cited in a number of comments:

"Access to help with professional who understand the complexity of the needs of the carer in this situation e.g. change of role from wife to carer and having to maintain the running of household when the person of ABI feels inadequate." (031 Wife)

"Accessible family therapy (with ABI specialists)." (004 Wife)

"Access Taxi Drivers trained to understand ABI people." (126 Mother)

"More help and understanding from hospital staff all the way up to GPs and even some so called professionals." (019 Wife)

Continued rehabilitation services

Ongoing access to a range of allied health services was identified, including ongoing Physiotherapy, Occupational and Speech Therapy, Psychology, Neuropsychology and Social Work:

"Being able to access Hampstead facilities such as physio and aqua therapy." (104 Husband)

"Neuropsychologist - available after hours when [son] is distressed, usually after 10pm-1am. Creative speech therapist to assist both [son] and I with communication challenges. Dietician

and fitness therapist to advise and support [son] so I don't get caught up in constant arguments.” (174 Mother)

“Continuing access to services - eg social workers & counselling would be a tremendous help, even though he is currently in a residential care facility.” (149 Wife)

“Guide-dogs to do more training as he has lost a lot more vision.” (078 Partner)

The need for flexible rehabilitation arrangements was also expressed, in addition to services tailored to specific populations:

“Better rehab – CLOSER and ongoing with opt in/out options” (004 Wife)

“A local Hampstead gym/Physio/Hydro/OT community centre for the younger age group.” (151 Wife)

Financial assistance

The majority of families in this study reported no financial compensation following the ABI (70%), with comments revealing high levels of financial stress. Support for a no-fault insurance scheme was strong. Comments under this theme ranged from the need for carer remuneration to fund supports, ongoing rehabilitation and aids, travel to and from Adelaide, more access cab vouchers and access financial advice.

“The NDIS would be a great help if we could access funds to provide my wife rehab facilities such as more physio, massage, exercise machine (cost prohibitive).” (053 Husband)

“Paid help with airfare and accommodation but not full cost. They do not cover cost of transport in Adelaide to travel from airport/motel/doctors etc [from Pt Lincoln, Remote]. Huge expense and an ongoing expense!” (059 Mother)

“Being in a country area financial help to and from Adelaide would of helped.” (061 Male friend)

“Aids for disability [are] not provided by DSA.” (072 Wife)

“Taxi coupons are vital as [son] cannot get on public transport.” (146 Mother)

“Financially draining - just some petrol money, help with additional phone and power costs and so forth would have lightened the burden. Perhaps such help is out there, again, I was too silly to look.” (150 Mother)

“Who to go to for financial assistance when you are on work cover. For things like Electricity, gas, water, we get no assistance in paying for our bills at all which is wrong, especially in my case where I am nearly bankrupt. We are just lost in the system.” (115 Partner)

A number of focus group discussions identified a range of local/community sources of funding which could be applied for. Sharing such information, including tips on how to source these funds, was an area in which participants considered peer support could be a vital element to help with ‘navigating the system’.

On a different level, other comments included the need for financial support and fair conditions for full-time carers:

"All fulltime carers need remuneration for the services they provide to highly vulnerable and courageous young adults. [They should receive] 2 hours off every day. All fulltime carers (who are WORKERS after all) need 2 days off a week as do all other workers." (028 Mother)

Respite

Respondents identified the need for formal respite options in addition to some 'spare time' and time spent apart. Appropriate, age appropriate respite was commonly identified:

"More respite in adequate places - not nursing homes." (022 Wife)

"Of more concern is the availability of emergency respite if dad gets sick. This has happened twice when dad has been hospitalised - and caused me great distress as I literally had to cancel all work commitments (difficult for a sole practitioner) and move in to look after mum 24/7 while still trying to get into hospital to support dad. I am always concerned about if/when this will happen again. The last time I was writing a paper for my PHD for a conference and was getting up at 3am to write 4 hours before taking on caring role for the day (not fun)." (119 Daughter)

"Respite in home for short periods - eg 2-3 days, so [daughter] does not have to leave home while carers are away (a lot of planning, time and effort and money is required for longer respite stays in a respite centre away from home)." (145 Mother)

"More respite to take some pressure off me and after 13.5 years of caring, travelling to him, I am burnt out and need a holiday, but no-one in family will support me to have one...They explain (to my son) "Mum needs time out", he only wants me and there is no system in force to make him comply - as he has rights to have his own way. My young son & daughter used to visit son, but after many years of his challenging behaviour, they now pulled away and have very little contact, which is sad." (223 Mother)

Another respondent voiced a critical concern which is faced by many. This is a challenging scenario where the needs of the family member are overshadowed by the needs of the person with ABI. Clearly additional respite options are required:

"I would like to see Legislation that when a person with a brain injury refuses to go into respite for carer to have a holiday, that their rights can be revoked for that to happen, just for respite time needed. With no insight or reasoning, person with brain injury does not see the needs of carer at all and appreciate if they get time out, they will both benefit." (223 Mother)

Employment, housing and education

Comments related to support and assistance to find work for the person with ABI were made:

"It would be very good if my son was able to do some work related activities. He reads the paper and does the crossword and target word." (015 Mother)

"Assisting with finding employment, re-education (to help him cope when he cannot do the work he was trained to do)." (077 Wife)

In addition, the provision of support in finding appropriate independent or supported housing for those impacted by ABI was noted by many:

"Small home (2 people) living situation" (109 Mother)

"A nursing home for people under 65 YO with rehab facilities e.g. physio, counselling with activities to suit a younger person and the support to encourage participation." (107 Mother)

"Son needs support in most things, would ideally be best in a support-type house where he can be supervised and has social contact with other like-minded people." (096 Mother)

Further comments related to the need for appropriate temporary housing during family stay at Hampstead:

"The support needed most was accommodation, near Hampstead Rehab. I was booked into accommodation owned by Hampstead, a 4 bedroom home and found I was to share with an Aboriginal male, only the two of us. The bedrooms were all locked. At the time I was in my late 60's and could not cope with this situation and also felt as though my self-esteem and trust in social workers was very low." (079 Wife)

The need for further appropriate and supported study opportunities for people with ABI were also identified:

"Opportunities for [husband] to study." (051 Wife)

High quality support work

Comments under this theme highlighted the need for continuous (permanent) disability support workers who know the client and family well, are motivated to facilitate positive change, are well trained with ABI specific skills and are well remunerated:

"People with more understanding. Support workers don't usually get enough information about clients." (001 Mother)

"Access to workers who are well trained and who show motivation and ingenuity, who care, respectful, innovative, energetic and suitably educated and who are prepared to work with families in a committed and continuous fashion." (028 Mother)

"More suitably trained carers. Recognition by Agency Managers of specialised needs of a client. Many services are "generic" and not tailored to suit high level disability clients." (145 Mother)

Home maintenance and support

A number of respondents requested assistance with house cleaning, garden and home maintenance. These are described as additional costs that budgets which are already stretched cannot include:

"Help at home/shopping, gardening, basic maintenance as have no support group." (205 Person with ABI)

"I would like a little help with home duties but am unsure what is available the cost factor may be too expensive for my budget." (212 Person with ABI)

"We want to stay in our family home but as we have been here for 43 years, it is in need of painting walls inside and out and carpets cleaned. But we are not prepared to move. ... A regular man to mow and clip plants and clean gutters (our pension does not stretch for this - I cannot climb a ladder or do this work)." (129 Wife)

One issue raised by some focus group participants was that of perceived gender inequity with respect to eligibility for this type support. For instance, one female caregiver highlighted the fact that although she was expected to fulfil all domestic duties herself, in addition to her multi-faceted caregiver role, she was unable to access assistance with many 'outside' jobs that her male partner had regularly undertaken prior to onset of his ABI. It was reported, however, that a male caregiver supporting a female partner had been considered eligible for regular help and was provided with funding for domestic duties that his partner had previously undertaken. Though beyond the scope of the peer support network, acknowledgement of gender equity within the service system is considered important in terms of adequately and appropriately supporting families living with ABI to achieve and maintain a positive quality of life.

ABI mentors/volunteers

Volunteers and mentors were identified as one avenue of increasing social opportunities for their family member with ABI. The following 2 comments focus on the need for similar ages of the mentor/volunteer and person with ABI:

Mentoring programme - someone [son] can get to know and trust and accompany [him] to appointments, therapy, recreation, social activities - someone more [son's] age, not mine. (174 Mother)

"Young volunteers to take younger patients to library and shopping." (030 Mother)

Volunteers can also play a role in transport and communication:

"Access to volunteers to take ABI family members to important meetings and report back to family on results etc." (091 Daughter)

Not applicable

In addition, a number of participants also reported that they were currently doing OK, and didn't at that time require further supports:

"At this stage I think we are managing ok. I have organised social support through NEN & CRP. I have a contact @ Disability SA if required. I have arranged all activities." (112 Wife)

"Doesn't need any support, he had 8 weeks rehab in Hampstead and apart from not being as confident as he used to be, he has made a wonderful recovery" (086 Wife)

"After 17 months, I think we are finally seeing all the people that my partner needs to see. This has been a slow and disjointed process, and in hindsight seems to be a reactive rather than proactive process. I do believe that we were never made aware of what services were available to us, particularly upon discharge of rehab. For example, it was about 15 months before he saw a pain specialist, which had been a major issue since day 1. If we knew that this was available, then it would have happened much sooner." (103 Wife)

4. Discussion & Conclusion

This research has identified a range of family experiences and needs following ABI in South Australia. The primary aim of collecting this data is to inform the development of the pilot *Families4Families: ABI Support Network*. A number of themes have emerged relating to supports requested, with implications for clinical practice and development of community supports.

Results from this study illustrate a range of family experiences following ABI. The multi-faceted and ongoing nature of family member's roles is apparent, with expressions of exhaustion and frustration even when various elements of the system are working relatively well. It is widely recognised that shifts in family roles and responsibilities occur, with adaptation required to significant physical, cognitive and emotional changes. This in turn influences the social, vocational and recreational participation of both the person with ABI and their family members. The experience of isolation was also commonly reported, not only from those providing 1:1 care around the clock, but also by families who felt disconnected from friends and the general community who have little understanding of the effects of ABI. The combination of decreased employment rates for both groups and reduced access to financial support (including compensation and pensions) places this population at increased risk of poverty, negatively impacting career prospects, social and community engagement, mental health and the broader elements of quality of life (Arango-Lasprilla, Nicholls & Cabrera et al, 2011).

Survey and focus group participants were asked to identify supports that would be most helpful to assist their family in coping with the challenges of living with ABI. Themes fell under two major categories: (a) community supports which could be provided by a family peer support network and (b) access to appropriate timely and family-centered health and disability services. Many comments from this study describe a range of service delivery issues, which mirror those identified by the Statewide Rehabilitation Clinical Network Acquired Brain Injury Model of Rehabilitation for South Australia (February, 2012). Key areas of overlap include:

- Lack of equitable service access for people living in outer metropolitan areas, the country, the aged and those from various socially marginalized groups
- Insufficient ABI vocational and educational support services, and lack of access to these services
- A lack of alternatives for intermediate and age-appropriate longer term residential care
- Poor availability of rehabilitation services across the post-injury lifespan
- Lack of formal pathways for periodic reviews and service re-entry
- Limited access to home based rehabilitation
- An absence of designated services for specialist counselling, advice and support to families, including specialized behavioural management services
- A need for comprehensive information and educational resources for carers and consumers
- Training and education to staff and care workers in community settings
- Limited access to well-trained ABI support workers
- Limited access and long delays in access to neuropsychology services across the continuum for ABI patients.

(Acquired Brain Injury Model of Rehabilitation for South Australia, February, 2012, p18)

Data from both this research and the ABI Model of Rehabilitation for SA reveal a disability system which is chronically under-funded, crisis-driven, and often fails to respond to the ongoing needs of

individuals with ABI and their families. Patchy or non-existent coordination services, limited access to professionals with ABI specialist knowledge, and poor knowledge of both the immediate and long-term effects of brain injury are just some of the challenges facing South Australian families. Many have battled for many years with scant resources, though have been regarded by an over-stretched system with extensive waiting-lists as coping well-enough. It is only when abandonment or family break-down occur do we see the immense strain placed on families requiring supports which are not available through the broader system. The role of a family peer support network within this environment will be to assist families to navigate what services are available, to access information and supports, and to provide social and educational opportunities which foster resilience and positive coping strategies.

Family peer supports

This study has identified the following supports that could be provided by a family peer network:

- elements of counselling and emotional support (also related to professional services),
- family support groups (for all extended family members, including groups for children, young carers and partners),
- social activities for the entire family,
- information and education on ABI,
- help to navigate the system,
- supports available within early phases of the brain injury, and
- self-advocacy training.

Many elements of these results have also been recommended by the NIH Consensus Report on rehabilitation for persons with traumatic brain injury (TBI), which identifies family members would benefit from skills training, support groups, family therapy, networking and other intervention methods (NIH, 1999). In their more recent review of the qualitative literature, Gan, Gargaro, Brandys, Gerber & Boschen (2010) identified the following four priority areas of caregiver support following ABI: (a) information and education in dealing with the effects of the brain injury, (b) emotional and practical support for family members, (c) continuous, comprehensive and long-term supports, and (d) social and community integration of the person with brain injury. Each of these findings are similarly represented in the current study.

These areas of support are further reiterated in Rotondi, Sinkule, Balzer, Harris & Moldovan's (2007) qualitative needs assessment of 80 people with TBI and 85 primary support people. Interviews revealed needs varied across the different phases of rehabilitation and community living. Strong themes during in-patient phases included provider quality, emotional support, and understanding of the injuries. Prominent themes during transition to home and living in the community included guidance, life planning, community integration and behavioural and emotional issues. Of particular note, the type of information needed by both those with ABI and their family members are on understanding brain injury, treatments and consequences over different phases as care settings, functioning and personal roles change. *'Services need to be responsive to changes in needs over time, accessible to consumers of services for as long as they are required, and designed to be directed and customized by users.'* (Rotondi et al, 2007, p14).

The importance of information and support at times of transition (often categorized under 'early supports') was identified as a key factor in the present study. This included acknowledgement that families may not have a clear understanding themselves of specific needs at such times, as the effects of changes in environment and level of day to day structure and support are such key factors in effectively managing life with ABI. Many spoke of how having someone with lived ABI experience would have helped at this early stage.

“Whilst we were in that hospital situation and the Hampstead [rehabilitation] situation we always felt we had someone to talk to. Once we left there we felt incredibly isolated”.

The potential for peer support to be of assistance in preparing for times of transition is highlighted, as some respondents considered professional opinions and associated information to at times dismiss families’ intimate knowledge of the person with ABI. Some families considered they were

only provided with ‘worst case scenarios’ and that expectations of recovery and future quality of life were then very low. Contact with peers who share information about similar experiences, in relation to rehabilitation and potential for recovery months or years into the future, had been found helpful and supportive for those who had access to it, and was recommended for other families.

Recent findings from one Australian study called for more specific caregiver support and preparation prior to discharge from hospital to home for people with ABI and their carers (Turner, Fleming, Parry, Vromans, Cornwell, Gordon & Ownsworth, 2010). Twenty-nine caregivers of adults with TBI completed a set of questionnaires relating to caregiver strain, depression anxiety and stress at 3 points; pre-discharge, 1 month post-discharge and 3 months post-discharge. Results indicated elevated levels of both stress and strain in caregivers during the transition phase from hospital to home (indeed higher than those found in caregivers of patients with brain tumours and cancer patients). These findings can be considered in light of role changes and the myriad of emotional, practical and financial difficulties the family is confronted with at this time.

Families who have encountered particular challenges in relation to ‘navigating the system’ at various stages have expressed an interest in and willingness to assist with developing clear information and providing this on a peer support basis at early and later phases of rehabilitation and community life. The difficulty of knowing what services and supports are available was a very strong theme, with a comprehensive ‘list’ of what others have accessed a viable resource.

One point raised by a number of participants was the high level of importance for their own and others’ well-being of finding and maintaining links with general practitioners and other medical and allied health and human service professionals who understand ABI. Where health and other human service professionals did not have this specific knowledge, a willingness to learn about ABI themselves or provide links to others who did was considered vital. This was mentioned as a factor in relation to both accurate diagnosis and potential for future change and development when links to appropriate services and supports were enabled. This is particularly important given the high need for GP reports and referrals in order to access disability, social security, psychology and other services in South Australia.

“There should be a way of finding out who the GPs are that know about brain injuries. I mean I’m already seen by a GP in Campbelltown and I live in Fairview Park. I will go anywhere if I will be treated by a doctor that knows what I’m going through.”

Another common experience was that of siblings and friends who did not appear to understand or appreciate the ongoing and evolving challenges of families following an ABI. This was generally attributed to lack of awareness of the effects of ABI, and assumptions that if the person ‘appeared’ as they had prior to onset, that the person with ABI and other family members were potentially exaggerating ongoing challenges and frustrations. Increasing awareness and education about ABI for family, friends, workers and the extended community must play a crucial role, with efforts needed to raise the profile of ABI. This may also be exacerbated due to the current disability

system and compensation rules requiring families to 'prove' need and 'illustrate' disability, leading to community views that people with ABI may be 'exaggerating' their disability and needs.

Family-centred services

Additional supports needed from health and disability services included:

- counselling and emotional support (also linked with family peer supports),
- continued, coordinated, accessible and tailored health and disability services,
- respite (including emergency accommodation),
- access to employment, housing and education,
- high quality support work (including well remunerated, educated and motivated workers),
- home maintenance and support,
- financial assistance, ABI education and information (overlapped with family peer supports), and
- ABI mentors/volunteers

The majority of comments under each theme illustrate the need for services to be inclusive of the entire family (family-centered) rather than solely patient/client-centered. The need for a family systems approach to family intervention after ABI is strongly advocated within the current literature (Gan et al., 2006; 2010). Family systems theory shifts the focus from an individual to the family (Corey, 2009). This approach considers the entire family as a unit rather than targeting only the person with ABI or their primary caregiver. In their review paper on the impact of TBI on mental health outcomes for individuals and their families, Chan, Parmenter & Stancliffe (2009) call for greater support and assistance for family carers of individuals with TBI. The 'client' in rehabilitation and community life is not just the person with TBI, but must include the family who support the person over their life.

"The shift in focus is important for appropriate planning, formulation of policy and allocation of adequate resources to ensure better re-integration into the community. Failure to do so will only be costly for the society and government, as when families break down, the 'burden' of caring will become the responsibility of government agencies." (Chan, Parmenter & Stancliffe, 2009, p6)

The following quote from one survey respondent illustrates the impact of not adopting a family-centred approach:

"As a family, we have never been offered any support. After his stroke, [husband] was given excellent medical care and rehab and seemed to make a good recovery, but that has all slipped backwards now. At 52 he still believes that there isn't much wrong with him and I suppose it could be a lot worse. I was 41 at the time of the stroke, with 2 young children and have struggled with the effects on our family for 10 years. It has been a horrendous nightmare. It would have been so good to have some support for me, even someone to talk to, but I've ended up a lonely middle-aged woman with a bleak future. The disability triumphant we see on TV are unfortunately not real life and I am still shocked at how the stroke defines us all these years later. I know a terrible thing has happened to [husband] but the effects on the rest of us are just as catastrophic." (040 Wife)

In another qualitative study exploring family caregivers' support needs after brain injury, Gan et al (2010) reiterated the need for ABI support services which are family systems-based. The individual with ABI is a part of a family system and the whole system needs to be supported: **"Brain injuries affect families, not just individuals."** (p16) Their following recommendations are supported by the current research findings:

- a. Access – any member of the family system, including children, will be able to access services for themselves, related to the family member with ABI.
- b. Long-term (life-long) – families will have continuous access to service: the service system will respond to changing needs of the family unit over the life span, particularly when the injury occurs during childhood.
- c. Individualised and flexible – family members will have access to information and/or services multiple times and as needed or as ready; the system will accommodate different points of entry.
- d. Efficiency – wherever possible, services and information for the family will be provided concurrently with services for the survivor (eg while attending therapy or follow-up appointments). This helps to eliminate the added burden to the family caregiver of attending separate appointments.

The current study appreciates the potential challenges of balancing person-centered and family-centered approaches to foster ongoing, flexible support. In recognising the importance of supporting each family as a dynamic unit, the need for effective case management to facilitate genuine response to the needs of each person within that unit is acknowledged. Effective support including partners and children has been highlighted, including age-appropriateness, gender and cultural considerations of all forms of support and services.

Recommendations

- ✓ A variety of family peer support groups to share experiences following ABI across metro, rural and remote regions
- ✓ Counselling and emotional support for families to share grief, anger, desperation, frustration, hope and celebration following ABI
- ✓ A central location to share information on services and supports available (and tips on how to access these) that is available to all families across South Australia
- ✓ Information and resources on ABI in easy to understand language on what to expect and strategies on how to respond for families
- ✓ Access to social and recreational activities for all family members including children, siblings and extended family
- ✓ Access to professionals with specialist expertise to ask questions by both the individual with ABI and family members
- ✓ Annual follow-up with rehabilitation specialists to explore changes and share information on new research findings long-term, not only within the first few years.
- ✓ Increased education on ABI for health and disability professionals including GPs, support workers, social workers and case managers
- ✓ Increased education for Centrelink and government agency employees on ABI and family outcomes following ABI
- ✓ Training available for families to develop skills in self advocacy
- ✓ Strategies to increase the availability of services to families living in rural areas
- ✓ Services/professionals responding to the needs of the family unit rather than just the person with ABI.
- ✓ Availability and training of technology such as iPads and smart pens (such as Livescribe) for rehabilitation and communication.
- ✓ Urgent need for well-staffed accommodation: lobbying required for support workers to be well paid, well trained with ABI skills and supported to be innovative.
- ✓ Affordable access to entertainment & social activities (eg theatre, music gigs, short stay holiday venues)

Conclusion

This study has described a range of experiences and needs of families following an acquired brain injury. Survey and focus group participants across geographical regions within SA have provided demographic and diagnostic information, and communicated the varying challenges and supports that are still needed. Results highlight a need for ongoing supports for the entire family following ABI in South Australia, a number of which could be delivered through a family peer support model.

Key areas of support identified have included counselling and emotional support, as an adjunct to professional counselling which is not necessarily available or accessible to all people living with ABI. Also of importance were opportunities to participate in social activities, and to become involved or regain a role in the community through personally-defined meaningful and mutually supportive interactions with others. The nature of support found to be helpful and recommended for others was flexible in nature and times of availability, provided by others with lived experience, and accessible in the geographical areas in which people reside. These are areas of support that can be developed and implemented through the *Families4Families* peer support network to complement an increased focus on family-centered health and disability services, and will be reported on following completion of the 18 month pilot project in 2014.

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Appendix



Government of South Australia

SA Health

CENTRAL ADELAIDE LOCAL
HEALTH NETWORK

HAMPSTEAD
REHABILITATION CENTRE

a campus of
Royal Adelaide Hospital
207-255 Hampstead Road
Northfield, SA 5085
ABN 21 783 680 287
www.rah.sa.gov.au

SOUTH AUSTRALIAN BRAIN
INJURY REHABILITATION SERVICE
(SA BIRS)

Manager SA BIRS

Tel: + 61 8 8222 1463
Fax: + 61 8 8222 1461

Dear Sir/Madam,

**RE: Families4Families: Exploring the experiences and needs
of families living with acquired brain injury in South Australia**

Please find enclosed details of a research study being conducted by Flinders University on the experiences and needs of family and carers of people with an acquired brain injury (ABI) in South Australia, funded by Julia Farr MS McLeod Benevolent Fund.

The South Australian Brain Injury Rehabilitation Service (SA BIRS) has agreed to assist this research, by inviting all families who have received services from SA BIRS over the past 10 years to participate in this important survey.

Please be assured that your details have not been and will not be passed to the researchers in accordance with SA Privacy Laws. Your confidentiality is assured - the survey can be completed and returned anonymously.

If you and your family would like to participate further or receive information about the Families4Families support network, you can complete and return the separate contact form provided, to the address on that form

If you have any questions or concerns, please contact the office on 8222 1456.

Yours sincerely,

Dr Miranda Jelbart
Rehabilitation Physician
Medical Director

Ms Bev Dodd
Manager

SA Brain Injury Rehabilitation Service
Hampstead Rehabilitation Centre

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 5457) and the Royal Adelaide Hospital Human Research Ethics Committee. For more information regarding ethical approval of the project the Executive Officer of the Flinders Committee can be contacted on 8201 3116, email: human.researchethics@flinders.edu.au or RAH HREC on 8222 4329.



Disability and Community Inclusion
School of Medicine
GPO Box 2100
Adelaide SA 5001
Tel: 08 8201 3645
Fax: 08 8201 3646
Michelle.Bellon@flinders.edu.au
CRICOS Provider No. 00114A

LETTER OF INTRODUCTION

Dear Sir/Madam,

I hold the position of Lecturer in the Disability and Community Inclusion Unit, School of Medicine at Flinders University.

I am undertaking research on the subject of family experiences and needs following an acquired brain injury (ABI) in South Australia, funded by Julia Farr MS McLeod Benevolent Fund.

I am asking for volunteers and would like to make contact with family members or carers who provide support to a person with ABI like yourself (eg your partner, parent, child, sibling, extended family member or close friend who is over 18 years of age). I would be most grateful if they would complete a short survey which relates to your family's experiences. No more than 15 minutes will be required to complete this survey.

Please give this survey package to your family member or carer to complete.

The survey can be returned in the reply paid addressed envelop provided by 31st August 2012.

If they would like to participate further, we will be holding focus groups in varying locations across SA in October 2012. Focus group participation will provide family members, including the person with ABI (yourself), the opportunity to describe the unmet support needs of your family, and discuss how an ABI Family Support Network could be best designed to meet these needs.

The Information Sheet included provides further details.

Please be assured that any information provided will be treated in the strictest confidence and no participant will be individually identifiable in the resulting report or other publications. Participants are, of course, free to discontinue at any time or to decline to answer particular questions. Please be assured that this will not result in any discrimination, reduction in the level of support, or any other penalty.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 8201 3645, by fax on 8201 3747 or by email to michelle.bellon@flinders.edu.au

Thank you for your attention and assistance.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Michelle Bellon'.

Dr Michelle Bellon
Principal Investigator
Disability and Community Inclusion
School of Medicine Flinders University

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 5457). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

INFORMATION SHEET

Title: *Families4Families: Exploring the experiences and needs of families living with acquired brain injury (ABI) in South Australia*

Principal Investigator:

Dr Michelle Bellon
Disability & Community Inclusion
School of Medicine
Flinders University
Ph: 8201 3645

Description of the study:

This study aims to explore the experiences and needs of families living with acquired brain injury (ABI) in South Australia. 'Family' is defined as the network of people affected by ABI. This includes the person with ABI at the centre, together with his or her partner, parents, children, siblings, extended family and close friends who provide support. Information on this study, together with a short survey, have been sent to families who support an adult with ABI to collect information on family support needs.

Information from this study will be used to develop and introduce the *Families4Families ABI Support Network*, a pilot program which will deliver social, recreational, educational and community support for families with ABI by families with ABI across South Australia. This project is funded by the Julia Farr MS McLeod Benevolent Fund, and supported by the Disability and Community Inclusion Department, Flinders University .

Purpose of the study:

This study will gather important information on areas of need by families living with ABI in South Australia. The development of the *Families4Families ABI Support Network* will provide participants the opportunity to design, create and establish their own model of peer support, and use this model to help other families experiencing a newly acquired brain injury. The Network will seek to provide families living with ABI the opportunity to participate and share their experiences, exchange positive coping strategies, access respite, and develop social networks.

What will I be asked to do?

If you are a family member supporting a person with ABI (eg partner, parent, child, sibling, extended family member or close friend), and are over 18 years old, you are invited to complete a short survey. The information you provide will help us to understand how your family has been affected by ABI, and identify areas of support which you would find most helpful. No more than 15 minutes should be required to complete this survey.

Focus Group

If you would like to participate further, we will be holding focus groups in October 2012. The 90 minute focus groups will provide family members, including the person with ABI, the opportunity to describe their unmet support needs, and discuss how an ABI Family Support Network could be best designed to meet these needs. Each group will contain no more than 12 participants.

If you would like to participate in a focus group, please indicate your interest on the survey and return it together with the Contact Details Form. Focus groups will be held in varying locations across SA and **travel costs will be subsidised**. We encourage both people with ABI and their family to participate if possible.

Consent for audio recording

Focus groups will be audio-recorded using a digital voice recorder. This will then be transcribed, to assist with analysis of results. I will seek your consent to record the session and to use the transcription in preparing the report on condition that your name or identity is not revealed, and to make the recording available to other researchers on the same conditions. It may be necessary to make the recording available to secretarial assistants for transcription, in which case you may be assured that such persons will be advised of the requirement that your name or identity not be revealed and that the confidentiality

of the material is respected and maintained. If you would like to indicate your interest in participating in a focus group, please **complete and return the attached Consent Form and Contact Form**.

Families4Families: ABI Support Network

Information from the survey and focus groups will be used to develop the *Families4Families ABI Support Network*. This is a pilot program providing families living with ABI the opportunity to share their experiences, exchange positive coping strategies, access any available resources and information and expand or develop new social networks. The Network will be run by families for families. Information on the Network will be sent to all interested participants and the broader community. **Involvement is not required** to participate in this research, however it may meet the needs of some respondents. Please indicate on the survey if you would like to receive information on the Network when it begins in early 2013.

What benefit will I gain from being involved in this study?

By sharing your experiences, you are contributing to our understanding of how families cope following an ABI and identifying what supports need to be provided. Your involvement directly assists the development of the *Families4Families ABI Support Network*. We are very keen to enhance the resources available to families living with ABI and anticipate this program will fill a significant gap.

Will I be identifiable by being involved in this study?

Please be assured that any information provided will be treated in the strictest confidence, and you will not be individually identifiable in the resulting report or any other publication. The survey can be completed and returned anonymously.

The researchers will maintain the anonymity and confidentiality of all participants in the focus group. However, we are unable to control other participants. As such, verbal agreement will be sought from all focus group members to maintain the anonymity of other participants and the confidentiality of discussions.

Are there any risks or discomforts if I am involved?

We anticipate few risks from your involvement in this study, however if any of the questions cause you to feel concerned, upset or needing further support, please contact:

Lifeline, Uniting Care Wesley Adelaide (24 hour counselling service) 13 11 14
This service will refer callers requiring more in-depth or ongoing support to a counsellor in the callers' local area.

If you have any questions or concerns regarding the survey, the research project, or anticipated or actual risks or discomforts, please do not hesitate to contact the Principle Investigator.

How do I agree to participate?

Participation is voluntary. You may refuse to answer any questions or simply not return the survey.

If you would like to participate in a focus group, a consent form accompanies this information sheet. If you agree to participate please read and sign the form. You are free to withdraw from the focus group at any time without effect or consequences.

How will I receive feedback?

Outcomes from each stage of the project will be summarised and provided to you if you would like to see them. Please indicate your interest on the Contact Form.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.



Flinders
UNIVERSITY

ABI Family Survey



Thank you for taking the time to complete this survey.

The confidentiality of any information you provide is guaranteed. You do not need to put your name on this Survey and there are no identifying marks on these forms.

Most questions only require you to **tick the appropriate box**.

If for you there is more than one appropriate answer, **tick all the boxes you feel are appropriate**.

Some questions ask you to write some additional information or comments.

The more information you can provide, the better we will be able to determine your experiences and needs as a family member or carer supporting a person with ABI.

It is important that you return the completed Survey before 31st August 2012.

A reply paid address envelope is provided for this purpose.

If you and/or your family member with ABI are interested in participating in a focus group, please include the completed volunteer **Consent and Contact Forms**. Please note that the survey will be processed anonymously.

The focus groups will explore what supports your family needs, and invite your ideas on how an ABI Family Support Network could be best designed to meet the needs of your family and others with ABI.

Once again, thank you for your help in completing this survey.

Dr Michelle Bellon
Principal Investigator
Flinders University

1. What is your postcode? _____

2. What is your relationship to your family member with an ABI?
(eg partner, parent, child, sister/brother, extended family, close friend etc)

3. Would you consider yourself their primary support person?
(You do not have to be the primary support person to complete this survey)

Yes ☐ No ☐

Other comments: _____

4. Are you:

Male ☐ Female ☐

5. How old are you?

18 – 25 ☐ 26-30 ☐ 31-35 ☐
 36-40 ☐ 41-45 ☐ 46-50 ☐
 51-55 ☐ 56-60 ☐ 61-65 ☐
 66-70 ☐ Over 70 ☐

6. What study have you done since school?

None ☐
 TAFE/Trade qualification ☐ _____
 Undergraduate qualification ☐ _____
 Postgraduate qualification ☐ _____
 Other (please indicate) ☐ _____

7. What was your employment status prior to your family member's ABI?

Not in paid work ☐ _____
 Employed part-time (hrs p/wk) ☐ _____
 Employed full-time (hrs p/wk) ☐ _____
 Home/family duties ☐ _____
 Other (eg volunteer work) ☐ _____

8. What is your employment status now?

Not in paid work ☐ _____
 Employed part-time (hrs p/wk) ☐ _____
 Employed full-time (hrs p/wk) ☐ _____
 Home/family duties ☐ _____
 Other (eg volunteer work) ☐ _____

9. Please indicate gender and current age of your family member with ABI

Male ☐ Female ☐

Age: _____ years

10. What was the cause of your family member's ABI?

(eg motor vehicle accident, fall, stroke etc)

11. How long ago was the injury?

Years _____ Months _____

Other comments: _____

12. Did your family member receive financial compensation following the ABI?

Yes ☐ No ☐ Still waiting for outcome ☐

Other comments: _____

13. Does your family member with ABI currently live with you?

Yes ☐ No ☐

If not, where do they live?

Independently without support ☐

Independently with support ☐

Supported group home ☐

Large residential facility ☐

Other comments: _____

14. What vocational and educational activities is your family member with ABI currently involved in?

Employed part-time (hrs p/week) ☐ _____

Employed full-time (hrs p/week) ☐ _____

Volunteering (hrs p/week) ☐ _____

Studying ☐ _____

Family/Home duties ☐ _____

Other (please indicate) ☐ _____

15. What vocational and educational activities was your family member involved in prior to their ABI?

Employed part-time (hrs p/week) ☐ _____

Employed full-time (hrs p/week) ☐ _____

Volunteering (hrs p/week) ☐ _____

Studying ☐ _____

Family/Home duties ☐ _____

Other (please indicate) ☐ _____

16. What health or support needs does your family member with ABI have?

(Please provide any details you feel are relevant)

- | | | |
|---|--------------------------|-------|
| Seizures | <input type="checkbox"/> | _____ |
| Vision difficulties | <input type="checkbox"/> | _____ |
| Hearing difficulties | <input type="checkbox"/> | _____ |
| Speech and/or language difficulties | <input type="checkbox"/> | _____ |
| Motor control/coordination difficulties | <input type="checkbox"/> | _____ |
| Eating support needs | <input type="checkbox"/> | _____ |
| Toileting support needs | <input type="checkbox"/> | _____ |
| Prompts to achieve daily living tasks | <input type="checkbox"/> | _____ |
| Memory difficulties | <input type="checkbox"/> | _____ |
| Planning difficulties | <input type="checkbox"/> | _____ |
| Self-monitoring difficulties | <input type="checkbox"/> | _____ |
| Behaviour support needs | <input type="checkbox"/> | _____ |
| Mental health support needs | <input type="checkbox"/> | _____ |
| Other (please specify) | <input type="checkbox"/> | _____ |

17. What type of support do you provide for your family member with ABI?

Eg transferring, dressing, transport, reminding about appointments etc

18. Which of these services are (a) available to you in your area (b) available for your family to currently access, and (c) do you use?

	Available in your area?	Can you access?	Do you use?
Inpatient rehabilitation services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Outpatient rehabilitation services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community-based rehab services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disability coordination (eg Disability SA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disability support worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respite (centre-based)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respite (in-home)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advocacy services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day program/activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please indicate) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other comments: _____

19. Are there any support services that your family need that you are not currently receiving? Why?

20. What type of supports would be most helpful to assist your family in coping with the challenges of living with ABI?

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There are no margins, text, or other markings on the paper.

21. Would you be interested in participating in a focus group to discuss areas of family need and support following ABI? This participation would enable you to provide valuable feedback on what you would like to see in the *Families4Families ABI Support Network*.

Yes ☐ No ☐

If yes, please complete and return the Consent form and Contact form, and we will contact you to make arrangements. Travel costs will be subsidised.

22. Would you be interested in receiving information from the *Families4Families ABI Support Network*?

Yes ☐ No ☐

If yes, please complete and return the Contact form, and we will send you information.