



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

Stage 1 Research Summary

December, 2012

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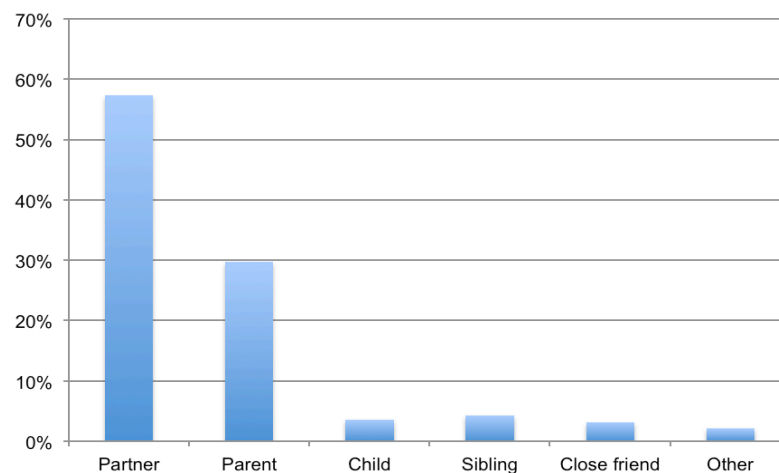


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Families4Families is an 18 month pilot peer support network for families living with acquired brain injury (ABI) in South Australia. Prior to its launch in January 2013, preliminary research has been conducted to identify the experiences and needs of families following ABI, in order to inform the design of the network. This summary provides an overview of findings from Stage 1. To read the full report, please visit the website: www.families4families.org.au/research-project/

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 (see Figure 1).

Figure 1 – What is your relationship to your family member with ABI? (n=194)



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 (see Table 1). Audio recordings were transcribed for analysis.

Table 1 – Focus group locations and participants

Location	Participants	
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

One survey question invited families to identify the health and support needs of the person with ABI, (Figure 2), in addition to the supports family members provide (Figure 3). The most frequent support needs involved cognitive and executive functioning difficulties including memory, planning and self-monitoring, with behavioural and mental health support identified by a combined 54% of respondents (n=122).

Figure 2 Health and support needs of person with ABI (n=226)

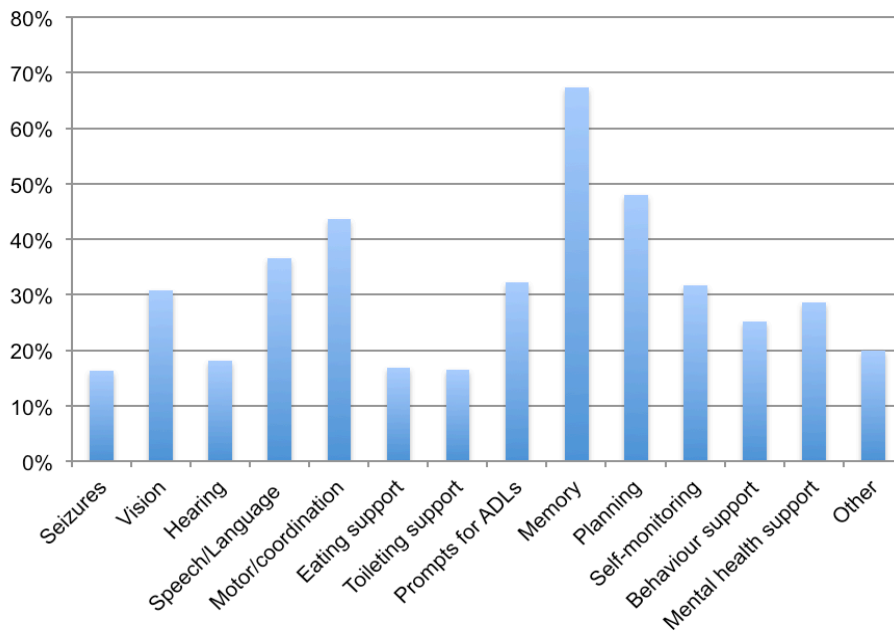
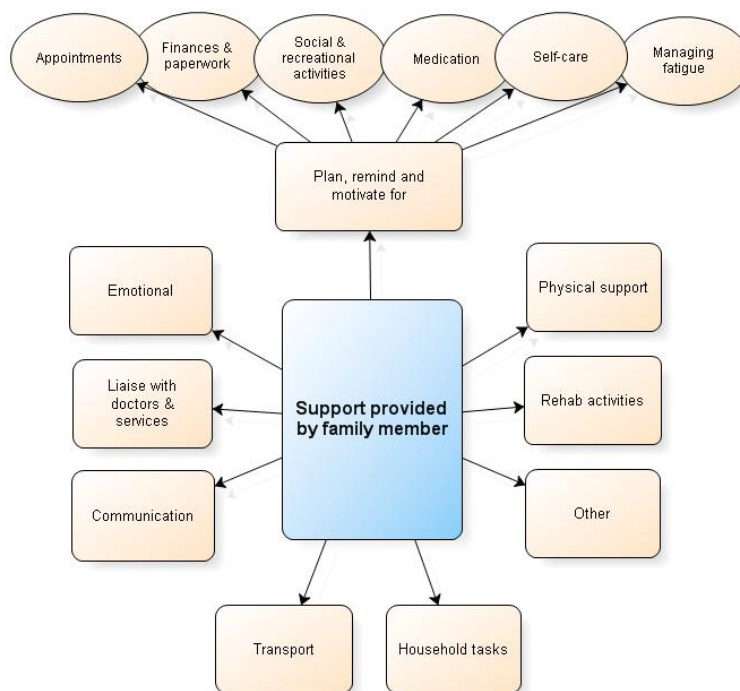
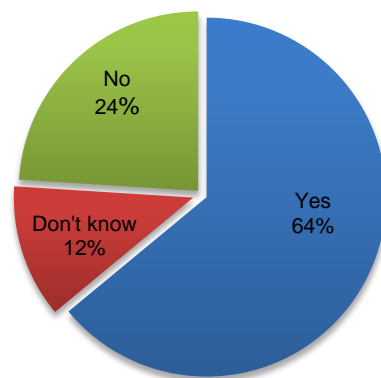


Figure 3 Supports provided by family member to person with ABI



Of 130 survey respondents, 83 (64%) indicated there are support services that their family need that they are currently not receiving. 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 4). 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 4 Are there support services that your family need that you are not currently receiving? (n=130)



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

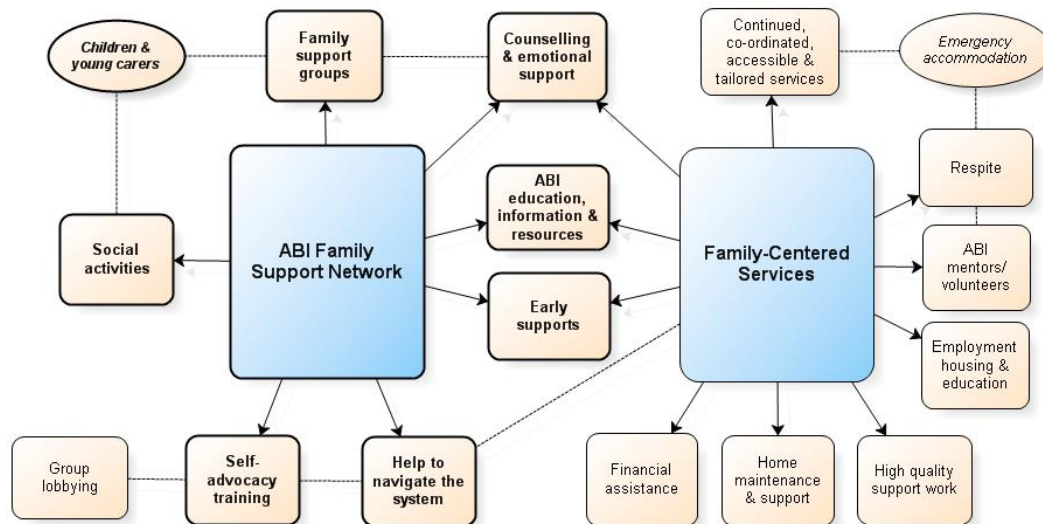
- **peer supports** which could be provided by a family support network and
- professional health and disability services with a **family-centered philosophy**.

A total of 349 survey comments were coded to emerging themes presented in Figure 5. 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 to help achieve recognition of family needs.

Figure 5 illustrates the themes from combined survey and focus group analysis. Themes which are in **bold** represent supports which could be provided by a Family Support Network, with others provided by services operating under a family-centered approach.

Figure 5 – Supports identified as most helpful from survey and focus group analysis



Results from this study and other recent South Australian reports (including the ABI Model of Rehabilitation for SA) reveal a disability system which is chronically under-funded, crisis-driven, and often struggles 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.

This research highlights the critical 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.

This research project was funded by Julia Farr MS McLeod Benevolent Fund with the support of the Community Re-entry Program, Flinders University.

Ethics approval 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).

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