

A Socio-Economic Evaluation of the Families 4Families ABI Support Network **Pilot Program** 

### Report prepared by Jennifer L Farnden, PhD

Families4Families Inc

Supported by Michelle Bellon, PhD\*, Ruth Crocker\* and Jaime Gardner<sup>‡</sup> \*Disability and Community Inclusion, School of Health Sciences, Flinders University; <sup>‡</sup>Community Re-entry Program, South Australia

## 29 September 2014

## Submission for: Julia Farr MS McLeod Benevolent Fund

(Grant funders of Pilot Program & Chapter Two Program)







## **Table of Contents**

A Socio-Economic Evaluation of the Families4Families ABI Support Network Pilot Program	1
Table of Contents	2
Executive Summary	3
Introduction	4
Literature Review	6
Families4Families Pilot Program	9
Program Outcomes	12
Costs	19
Conclusions and Recommendations	22
References	25
Appendix A	27
Appendix B	29
Appendix C	36
Appendix D	38
Appendix E	40

## **Executive Summary**

In 2012 Julia Farr MS McLeod Benevolent Fund provided a grant to Flinders University and its Community Re-entry Program to conduct a multi stage research project encompassing the delivery of the Families4Families Pilot Program for people with acquired brain injury (ABI) and their families.

Stage One of the research encompassed a needs assessment of people with ABI and their family members with data collected using survey and focus group methods. The data was analysed and utilized in designing the delivery model for the Families4Families Pilot Program. Commencing in January 2013, the program targeted people with ABI, at least 18 years of age, and their family members. The Pilot Program ran until 30 June 2014 during which time 2705 people with ABI and their family members attended 178 social events, information and educational sessions.

The Families4Families Peer Based Support Model introduced, and further developed throughout the Pilot Program, was been found to be successful for most members. The longitudinal outcomes of the program are the focus of a concurrent report being provided to the Julia Farr MS McLeod Benevolent Fund trustees. Whilst benefits have been gained, the corresponding financial costs of the project have yet to be clearly documented to enable accurate cost benefit analysis to be undertaken. Complicating this analysis is the fact that a large portion of the resources utilized within the peer based support model developed have been inkind and volunteer contributions from supporting individuals and organisations.

Cost benefit analysis utilizing cost and attendance figures illustrate that Families4Families has delivered 155 Local Support Group sessions attended by a total of 1839 people at a grant funded cost of \$85,171.06. In addition, 18 Early Support Program sessions were attended by 468 people at an estimated cost of \$14,766.83 while 5 Special Events were delivered to 398 attendees at a cost of \$1,453.13. In total the Families4Families Pilot Program provided 178 sessions with a total of 2705 attendances. The average cost data for Local Support Groups illustrated that each hour of face to face service cost an average of \$239.58 while the average cost per participation hour was \$12.40. Full cost analysis illustrates that the underlying low delivery cost is largely due to the high levels of in-kind contributions and volunteerism utilized within the peer based support model. Clear benefits were evidenced via the attendance and other feedback data including comments, evaluation outcomes and feedback from ABI professionals.

This report provides Trustees with a thorough socio-economic evaluation including estimates of the full cost of program delivery. The report concludes that Families4Families is a relatively low cost program delivering clear benefits to members across a challenging and geographically diverse target group. This is largely due to its utilization of volunteerism and a peer based model of support. It is hoped that this report will enable future decision makers to understand the true costs of delivering the meaningful and long-term changes derived from well managed peer support models. It is recommended that further research is undertaken to assess the overall economic benefits from the program as it is anticipated that lower need for paid supports, lower levels of Medicare funded mental health care plans and disability funding is needed due to the benefits members derive from the programs.

It is anticipated that this report will serve the basis of future funding allocations by groups such as the NDIA who are moving toward a new disability system model where individuals with disability and their family members are adequately supported, educated and empowered to life their best lives possible.

## Introduction

### **Background**

In 2012 Julia Farr MS McLeod Benevolent Fund provided a grant to Flinders University and its Community Re-entry Program to conduct a multi stage research project encompassing the delivery of the Families4Families Pilot Program for people with acquired brain injury (ABI)<sup>1</sup> and their families.

Stage One of the research was an assessment of the needs and experiences of people with ABI and their families undertaken using survey and focus group data collection techniques. Findings relating to needs that could be addressed via a peer based support network model were utilized by Families4Families management to design the Pilot Program then delivered for a period of 18 months.

During the Pilot Program (January 2013- June 2014) peer supports were provided for people with ABI, at least 18 years of age, and their family members across South Australia. The Families 4Families Peer Based Support Model introduced, and further developed throughout the Pilot Program, has been found to be successful for most members. During this time 2705 people with ABI and their family members and supporters attended 178 social and educational sessions. Overall, the impressions and experiences of the program from people with ABI, their families and Carers, along with professionals working in the ABI field, were very positive. The formal findings of the Longitudinal Outcomes Stage Two Research project are being documented by the Flinders University research team in a related report due 30 September 2014. However, it is already clear that the Families4Families peer based support network is delivering key benefits to our target audience. These benefits include providing members with a peer support network and giving them more information about how to life their best lives post brain injury. Consistent with its objectives, the program is also being successfully implemented in regional areas and for all sectors of the community.

Whilst benefits have been gained, the corresponding financial costs of the project have yet to be clearly documented to enable accurate cost benefit analyses to be undertaken. This report provides an analysis of the financial aspects of the delivery model including program allocations of actual expenditures and a range of average cost figures. Complicating this analysis is the fact that a large portion of the resources utilized within the peer based support model developed have been volunteers and in-kind contributions from supporting individuals and organisations. It is hoped that this report will enable future decision makers to understand the true full costs of delivering the meaningful and long-term changes derived from well managed peer support models. It is further anticipated that this report will serve the basis of future funding allocations by groups such as the NDIA who are moving toward a new disability system model where individuals with disability and their family members are adequately supported, educated and empowered to life their best lives possible.

### **Families 4 Families Mission and Objectives**

Families4Families builds capacity in people impacted by brain injury and their families via its innovative peer support model. Families4Families was designed, developed, is managed and delivered by people with ABI and their families based on the principles of self-help, information, education and mutual support. The

Acquired Brain Injury may occur due to motor vehicle accident, sports injury, fall, stroke, assault, hypoxia, brain cancer, brain surgery, aneurism, foetal alcohol syndrome and a range of other events.

Network has built a leading edge peer support model thanks to the previously untapped passion, skills and deep knowledge of people with ABI and their family members and their desire to support other families impacted by this challenging, and often unexpected, disability. Outcomes are assessed via leading-edge research projects underpinning our program model thanks to the strong support we receive from Flinders University. Without the financial support of the Julia Farr MS McLeod Benevolent Fund, this model would not have been able to be delivered within the Pilot Program.

Families4Families' mission is building resilience in our families and we are passionate about ensuring our members are fully educated about their disability and the systems that are available to support them. Programs focus on ensuring members with ABI and their families, including Carers, are able to fully embrace the incredible possibilities that Australia's new world-leading disability system will offer. Programs enable our members to build relationships within their own families, within our Network and within their communities.

Families4Families ensures its members are supported to become more self-sufficient, empowered and more active agents in their own lives. Members have the opportunity to access a range of Local Support Groups within their local communities where they exchange ideas, information and gain mutually beneficial support. Groups are founded on the concepts of peer support, sharing of experiences and knowledge, and leading edge, research proven, innovative program delivery. A strong focus on building resilience is resulting in emotionally supported member families with strengthened relationships with their local communities, and their fellow members, and with reduced need for paid supports.

Building social networks and referrals, expanding learning opportunities and greater community participation is already resulting in people having a greater sense of worth and meaning in the life they are designing post-disability acquisition. Feedback from Network members and brain injury clinicians throughout our pilot illustrates the strong support to maintain and expand Families4Families programs and events.

Pilot Program and ongoing Association objectives to be achieved are:

- Maximise the resilience, wellbeing and quality of life of families following ABI including a greater focus on supporting children with ABI and their families;
- Provide sustainable, volunteer based peer-support programs that can be replicated across regions and across disability target groups; and,
- Achieve greater community awareness and inclusion of families impacted by ABI.

Families4Families offers participants the opportunity to change their lives by changing themselves. Brain injury is permanent - but living without personally determined meaning and without social, educational and community support does not need to be. A focus on what individuals and their families CAN do, rather than what they CANNOT do post-injury, is crucial. Bringing about a fundamental change in how people with disability, and their family, dream and hope is essential, yet beyond a small group of 'self-starters', this fundamental shift has yet to occur. Inspiring people with disability and their family members to create lives beyond survival and receipt of service to those in which they can shift toward self-actualization and living

A preliminary evaluation undertaken during September 2013 found 82% of members agreed they were emotionally supported due to their participation with Families4Families. This is particularly important given 'emotional support' was the primary need expressed as being unmet during Stage One needs assessment survey and focus group data collection.

with meaning is essential in order to reap Productivity Commission (2011) outcomes. In Families4Families members this fundamental shift is starting to occur.

Families4Families Incorporated aims to continue to develop its sustainable model of people with disability and their families supporting others with disability and their families with our model encouraging positive adaptation, lives full of choice and control and ensuring an educated, empowered membership working with real and deep knowledge to advance and better our local communities.

### **Literature Review**

#### **Prevalence of ABI**

The number of people impacted by ABI across SA is significant. Approximately 33,600 or 2.2% of the SA population live with ABI. South Australia is second only to Queensland in terms of prevalence of ABI across our population, as shown in Figure 1 (AIHW, 2007). Nationally 1 in 45 (or 432,700) people have ABI with activity limitations or participation restrictions across Australia (AIHW, 2007). Evidence illustrates that more men than women are impacted by ABI, that nearly 2 out of 3 are injured before the age of 25<sup>3</sup> and there disproportionately higher rates of ABI for people living outside major cities (2.2%) than for people living in major cities (1.6%) (AIHW, 2007).

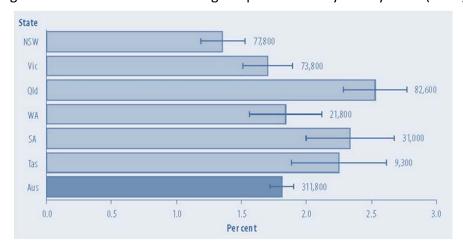


Figure 1: Prevalence of ABI Among People Under 65 years by State (2003)

## Impact of ABI on the Family<sup>4</sup>

The influence of physical, cognitive, behavioural and social functioning following brain injury have been well documented (Sohlberg & Mateer, 2001; Ylvisaker & Feeney, 1998). Cognitive and emotional changes impact on social relationships, employment and daily functioning of people with ABI (Kushner, 1998; Rees,

Children in particular do not recover well from brain injury. Anderson & Catroppa (2006) note 'Residual functional impairments are commonly documented in physical, cognitive, educational, behavioural, and social domains and result in a significant, ongoing social and economic burden for the child's family and for the broader community'. Families play a central role in the lives of many children with ABI and evidence suggests that the wellbeing of caregivers is inextricably linked to the wellbeing of the children for whom they care (Schor, 2003). Evidence suggests that when parents of children with a disability experience poor health, they may be less able to care for their children, setting up a continuous cycle of negative outcomes (Lacavalier, Leone, & Wiltz, 2006; Bromley, Hare, Davison, & Emerson, 2004).

This section draws from prior research undertaken by the Families4Families research team and these literature review findings were provided in a similar format within the initial grant submission from late 2012.

2005; Tyerman, 1997). These difficulties place stress on the family unit as well as creating reliance on the family for social and recreational opportunities (Tyerman, 1997; Kneafsey & Gawthorpe, 2004).

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, Perlesz, Kinsella & Crowe, 2000, Ponsford, Olver, Ponsford & Nelms, 2003). There are high levels of depression, anxiety, reduced quality of life, burn-out, decreased family functioning and relationship breakdown which placed pressure on the family unit and its ability to continue to support the person with ABI (Turner, Fleming & Parry et al, 2010). Unsupported family members are frequently unable to cope with family breakdown very high with at least 63% of marriages breaking down 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 impact of ABI on its many facets and roles of its members, family members struggle with managing the diverse loads as Carer, supporter, advocate and therapist (particularly in cases of rural and remote geographic circumstances).

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 (Sheija & Manigandan, 2005; Winstanley, Simpson, Tate & Myles, 2006). Families play a pivotal role in the rehabilitation and reintegration of people with ABI, thus it is essential their wellbeing is considered, and ongoing family-centric supports provided (Chan, Parmenter & Stancliffe, 2009).

The effects of ABI influence not only the individual with brain injury and their primary caregiver, but also the extended family network and community within which they are situated. Families are most commonly the major of 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 many are often poorly prepared (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. Family systems theory shifts the focus from an individual to the family. 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." (Parmenter & Stancliffe, 2009, p.6)

The literature is filled with studies documenting areas of unmet need for families living with ABI. These areas include respite, emotional support, caregiver training, health information, information about ABI, and community support networks. In particular, support groups are recommended as an important tool in helping cope with a family member's brain injury (Gan et al 2006; Acorn, 1993; Campbell, 1988, & Willer, Allen, Liss & Zicht, 1991)

Unfortunately, few resources exist to support family caregivers cope with the short and long term challenges associated with brain injury (Boschen, Gargaro, Gan, Gerber & Brandys, 2007). This lack of social support in SA specifically was identified by Singh (2008), with data indicating the negative impact on caregiver burden. Gan et al (2006) strongly advocate for the need for a family systems approach to family intervention after ABI. The impact of this lack of support was identified and confirmed by Stage One research undertaken by the Families4Families research team (Bellon et al, 2012). The provision of family-centric supports, provided without reducing the focus of the person impacted directly by the ABI, is the underlying principle of the Families4Families peer based support network model.

### **Peer Based Support and ABI**

In other sectors, peer based supports have been utilized and evaluated for many years. In the mental health sector, peer support is used to describe a range of different contexts, activities and ways of working. The history and development of peer support in this field includes self-help groups, mutual support groups, the user/survivor movement and broadly 'self-management' (Chronic Conditions Alliance, 2011). Repper and Carter (2010) have brought together international peer support literature and review the various approached in the mental health. In Australia, qualitative support for group-based family-to-family education programs in the related mental health sector can be found in the evaluation of the Well Ways program. This program is an initiative of the Mental Illness Fellowship Australia, delivered via MIFSA in SA, and aims to provide information and increase carers' capacity to care effectively for themselves, their families and the mental health consumers. Foster's (2011) study evaluated the impact of the Well Ways Program and support service piloted in rural Queensland<sup>5</sup>. An important finding from this study is the suggestion that 'an additional therapeutic factor for the family carer is the shared experiential understanding and empathy between them and a worker who is also a family carer. This has implications for the provision of future support services by carer and other organisations, as the participants in this study indicated they were much less likely to access or accept support from a health professional than a fellow family carer.' (Foster, 2011, p61). Family driven support services are seen to have value, and can be offered as complementary support services in an effort to address unmet need. In addition, the national MyTime program for parents with children with a disability has also been recently evaluated (Orima, 2013).

While there is a growing body of knowledge on the long-term impact of ABI for the survivor and their family network, the breadth and depth of peer support programs and their evaluation is distinctly less in this field than for those developed and delivered within the mental health field. It is clear that further research is required to measure the outcomes of family-based community support programs following ABI. Trialling programs which aim to meet unmet need and foster strong social networks is a priority to help develop resilience and positive adjustment following a brain injury. The focus of the Families4Families Pilot Program and its costs and benefits are broadly evaluated in this report.

į

The pilot involved 8 weeks of group education and discussion sessions with four follow-up sessions over a period of 12 months. 8 family carers attended the weekly Well Ways group education program, delivered by trained family carers. The program was delivered in a Manual, providing information on mental illness using a bio-psycho-social theoretical and practical framework. Emotional support offered to participants during the program ranged from one-off sessions to intermittent or regular support, and was delivered face to face or by phone and/or email. Support also aimed to include advocacy and liaison with health professionals and health-care services. Themes from post-program interviews identified the benefits of receiving emotional support in dealing with difficult times, connecting through shared experience and exploring different options. Family carers valued the emotional support, reporting it enhanced their ability to manage their own well-being and their care giving roles.

## **Families 4 Families Pilot Program**

### Families 4Families Peer Based Support Model

Families4Families Incorporated has provided people with disability (ABI) and their families<sup>6</sup> the opportunity to design, create and establish their own model of support and then to use this model to share with and support other families impacted by ABI<sup>7</sup>. Families4Families successfully up-skills people with ABI and their family, increasing their ability to be active participants in the changing disability system. This is achieved within a framework based on the philosophy that 'nobody gets left behind' with multiple access points, ways of connecting and methods of information delivery reflective of the complex nature of ABI due to members' varying memory, planning and problem solving challenges. Core components of the support model, illustrated in Table 1, are eNewsletters<sup>8</sup>, posted Newsletters, emails, mailed printed Bi-Annual Calendars, individual session flyers, Facebook flyer posts, volunteer phoning system<sup>9</sup> and local support groups (10 running regularly throughout the Pilot Program).

Families4Families is built on volunteerism and self-help foundations. Undertaking our scope of programs and support groups has only been possible thanks to our passionate group of management committee members, all drawn from membership 10. While volunteers are essential in the Families 4Families consumer led model of support, staff are essential for core administration, coordination, strategic management and financial management aspects of the Network along with its leading-edge research program. 11 Without such in-kind contributions the cost of the model would have been far greater and not affordable within the grant funding provided.

Families4Families benefits from the skills and knowledge of a part-time Coordinator and Flinders University staff who provide immeasurable expertise in disability, social inclusive practises and independent research expertise<sup>12.</sup> As Manager<sup>13</sup>, Dr Jennifer Farnden brings an unusual combination of passion with expertise, professionalism with lived experience and ability to connect and network with professionals as well as support vulnerable people and their families. She is also a member with lived experience of ABI as Carer to her husband who sustained a severe TBI in a road trauma in 2008.

Individuals who are living with ARI but have no or minimal, family support are also welcome as members of the Network, and their participation is encouraged and facilitated. Throughout Families4Families the term 'family' refers to the network of people affected by ABI. This includes centrally the person with ABI, together with their parents, his or her partner, children, siblings, extended family and close friends who provide support.

Educational opportunities, counselling supports, information sharing, peer support and recreational events currently enable people with ABI and their families to support each other. Opportunities for members to share and benefit from each other's experiences, knowledge, coping strategies, understanding of bureaucracies, resilience and adaptation skills have been embraced by members and have been shown in the short to medium term to be highly effective.

<sup>80%</sup> of members have email addresses and receive our email Newsletters monthly electronically, while for the remaining 20% printed copies are delivered via post. Email newsletters contain file links to all sessions' flyers which can then be printed off and these always provide maps, parking and transportation information along with the offer of assistance to get to events via our office and support staff.

Volunteers, either with ABI or as a family member of a person with ABI, have been trained in phoning other members and checking on them, reminding them of upcoming events in their area and confirming they have received all available and wanted information. Support is provided ensuring our volunteers are geared for success in these tasks, often working in pairs and with flexible time frames to reduce any potential stress. This is incredibly successful, and with regular checking members are now building relationships with the office volunteers adding another element to the important sense of connection being targeted. Obviously another key outcome is the sense of accomplishment and achievement derived by the volunteers who gain self-esteem and confidence, skills, training and this is likely to reduce their need for alternative supports or day programs.

Our management committee comprises 15 members (7 of whom have ABI, the remainder family members. Profiles are provided publicly on our website (http://families4families.org.au).

<sup>11</sup> Dr Farnden is due to complete a Master of Disability Studies in late 2014.

In particular Dr Michelle Bellon, Research Team Leader, and Ruth Crocker.

Dr Farnden works currently full-time as a volunteer, whilst throughout the Pilot program received limited salary with 3 hours weekly paid from Julia Farr Research Grant funds.

Table 1: Families4Families Peer Based Model of Support

	Program Brief Description	Numbers/Frequency
LOCAL SUPPORT GROUPS	Peer based group information and educational programs running at any locations that have enough families, delivered by trained Volunteers & (only when required) topic experts/professionals. Best practise development undertaken by Manager and research team.  Local Support Groups provide emotional support, social interaction, information sharing and up skilling for ALL families, assist in mental health management, develop coping strategies, peer role modelling of community involvement and living lives with meaning and control.	10 Local Support Groups have been running – most since January 2013. Currently 7 regular information session support groups are held in various metropolitan and rural/remote locations across SA. Two social clubs are held, one in South East Metro Adelaide, the other in Mount Gambier. One shed group ('Brainy Blokes') is also held in the Fleurieu Peninsula (rural).
SPECIAL EVENTS	Regular special social events at various city, rural and regional locations with the help of community groups and volunteers. On average 100 attendees, with at least 4 events annually. Family focussed events are held ensuring all children are catered for and mixing with peers groups possible.  Provides social interaction (including within child and youth peer groups), builds empathy, assists in management of mental health issues, community interaction, opportunity for sharing, emotional support, peer role modelling of community involvement and living lives with meaning and control.	Four special events have been held since the commencement of the program with attendance ranging from 53 to 147.  Network Launch event, International Day of Families BBQ, Movies Day, Farm Day and Welcome Back Luncheon were all highly successful events held during 2013/14.
TELEPHONE SUP- PORT PROGRAM	Trained in referral options and in basic counselling skills, volunteers receive calls on a roster system with support provided and systems developed for follow ups and additional volunteer supports. Clear system of new member entry, updates and keeping members informed.  Provides social interaction, point of referral to F4F programs and other agencies & resources, increased utilisation of available supports, increased community involvement, increased attendance at all Network events, emotional support (for some it is the only option for communication).	Phone calls are taken across business hours on weekdays by a trained volunteer and a weekend roster is also in place for volunteers to manage calls over the weekend. On average 5-25 calls are taken weekly, and any missed calls are returned promptly.  Eight trained phone volunteers are currently trained in this program, while additional staff would allow greatly local phone support.
ONLINE SUPPORT PROGRAM	Trained Volunteers upload new pre-approved content ensuring ongoing provision of all relevant brain injury and disability information via the regularly (at least weekly) updated website; University placement students, members & volunteers provide members with IT issues and limited knowledge with training and support enabling them to access Network Facebook forums. For some members online communication is their only tool for communication with other members (eg those in Locked In State). Manager undertakes eNewsletters, content approvals and ensures links are maintained with University Practicum coordinator enabling placement students.  Provides social interaction, information delivery, mental health support, referrals to agencies and resources, provides roles for members who may not be able to verbally communicate (due to Aphasia), gives opportunity for young people to help older members in gaining key knowledge, assists mental health issues.	The Families4Families website is accessible to the general public as is our Facebook page. Our Facebook groups are secured, closed groups (i.e., those wishing to join first request to join a group and then are approved). Facebook group activities are actively monitored by member volunteers and Management Committee Members.  eNewsletters are distributed monthly.  The number of members receiving monthly eNewsletters has grown from 326 (March 2013) to 482 (April 2014).
EARLY SUPPORT PROGRAM	Program to provide introductory Families4Families support program information and connection to all families recently impacted by ABI. Regular staff and/or volunteer information sessions within BIRS and acute care facilities (RAH, FMC). Flyer distribution by volunteers to all locations including all Country Health SA sites. Morning teas within BIRS provided by catering volunteers and Network committee members.  Provides social interaction for new ABI families, builds connections, assists in management of transition phases within at risk families, assists in early connections/support and resources/referrals information.	Presentations by Families4Families are given regularly to new families and staff (whom become referring agents). Families4Families have presented seminars at Brain Injury Rehabilitation Service (BIRS) and Brain Injury Rehabilitation Community and Home (BIRCH). Families4Families also co-presents part of the Brain Injury Rehabilitation Unit's (BIRU) Family Education program session 'Life After Brain Injury' every 7 weeks. Families4Families also hosts monthly morning teas held at BIRU.
ABI AWARENESS PROGRAM	In community via guest presentations & lectures in schools (a key focus for young volunteers), therapist training facilities, service clubs, CWAs, churches and other community locations and groups. Research outcomes and program development findings are shared Internationally. A school speech program with members telling their stories is currently being developed and delivered with potential to significantly impact on teacher and peer ABI awareness for our young members with ABI.  Improves long term support & Network growth opportunities, assists in management of mental health issues, increases community interaction, provides volunteer speakers the opportunity for sharing, peer role modelling of community involvement and living lives with meaning and control, builds community tolerance, recognition and knowledge.	Between July 2012 and March 2014 over 33 presentations have been delivered regarding the Network, the majority presented by Network Manager, Dr Jennifer Farnden.  Guest presentations have been made at a number of locations and to a number of groups including students Flinders University and the University of South Australia, BIRU families and BIRCH (& BIRS) therapists, The Corner Uniting Church Ladies Fellowship to name a few.
RESEARCH PROGRAM	Dissemination of prior research reports to a wider ABI audience. New child and youth needs assessments and feedback on all project(s) proposed to be reported on and disseminated nationally. Development of broader ABI & Health Economics study to establish evidence of ABI rehabilitation benefits for children, and adults, impacted by ABI. Ongoing Longitudinal assessment of participation is to be undertaken by Flinders University Research Team members. Stage Two Final Interviews will be undertaken in July 2014 with the final reports due in September 2014 (including participation outcome measures and assessments).  Provides evidence of family needs and experiences, allows young person programs to be designed and evaluated by same target groups.	Major papers published:              Experiences and Needs of Families Living with Acquired Brain Injury in South Australia, Julia Farr, December 2012.             Involvement and Benefits of a Family-Focused Inclusive Model of Support for People with ABI, Julia Farr, August 2013.             Family perspectives on supports considered most helpful following brain injury in metropolitan and regional/remote South Australia: under development for submission to 'Brain Injury'.  Conferences/Presentations:

Table 2: Families4Families' Existing and Planned Local Support Groups with Attendances and Existing Membership

LOCAL SUPPOR	T GROUPS & DETAILS (shaded groups do not currently exist)	REGION	MEMBERS IN RE- GION	SESSIONS, PROJECTIONS	SERVICES				
Metro Group	Existing group (being held in Warradale Uniting Church) to be held monthly in new Families4Families Location, Glandore Community Centre.	Metropolitan	57	11 sessions with 25 attendees	275				
Evening Group	Existing group (being held at DIRC, Adelaide) to be held monthly in new Families4Families Location, Glandore Community Centre.	Metropolitan	29	11 sessions with 25 attendees	275				
Enfield Group	Existing group held monthly in Northern Metropolitan location at the Enfield Community Centre, Enfield.	Metropolitan	44	11 sessions with 25 attendees	275				
Barossa Group	Existing group held monthly in the Barossa at Carers Link Nurioopta.	Rural/regional	22	11 sessions with 25 attendees	275				
Southern/ Fleurieu Group	Existing Southern Rural group held monthly at Myponga or in Sellicks Beach Community Centre (locations varied according to session topic).	Rural/regional	32	11 sessions with 25 attendees	275				
Mount Gambier Group	Existing group held in Mount Gambier at the Main Corner Complex.	Remote	19	11 sessions with 25 attendees	275				
Eyre Peninsula Group	Existing Eyre Peninsula group held every two months currently, expanded to monthly sessions, some likely to be social gatherings, in Port Lincoln.	Remote	30	11 sessions with 25 attendees	275				
Mount Barker Group	New group for members living in the Stirling, Crafters, Upper Sturt, Heathfield, Nairne, Tailem Bend, Strathalbyn, Piccadilly, and Murray Bridge, held in Mount Barker.	Outer Metropolitan	12 (will expand as awareness in area grows)	11 sessions with 25 attendees	275				
Yorke Peninsula	New group for members living in Kadina, Thrington, Moonta, Bute, Wallaroo, Tickera, and Alford, held in Kadina.	Rural/Remote	9 (will expand as awareness in area grows)	11 sessions with 25 attendees	275				
Western Group	New group for members living in Henley beach, Grange, Tennyson, Semaphore, Seaton, Woodville and Findon, held in a community lo- cation at Woodville/Grange.	Metropolitan	70	11 sessions with 25 attendees	275				
Family Group	New group held on weekends at Glandore Community Centre aimed at families with children. Group to include social activities and picnics utilising park/playgroup space	Metropolitan	96	11 sessions with 25 attendees	275				
oung Carers	Regular groups run by those with lived experience of a parent, sibling or other family member with ABIproviding coping strategies, opportunities to share and informal social networks to children and youth supporting someone with ABI. Some pilot sessions have been held but to expand this program funding is needed.					Viability of potential locations and number of attendees will be assessed when funds are secured. However, Stage Two interview sug-			110
oung Carer (YC) Camps	Young Carers (12-25): Two camps annually for YCs attended by at least 10 YCs, 2 Young Volunteers plus at least 2 staff and Network members.	families with children v lings usually become Yo	with ABI (as their sib-	2 events with approxi- mately 10 attendees	20				
outh with ABI ages 13-25)	Regular groups run by those with lived experience of ABI providing coping strategies, opportunities to share, referrals and information provision and informal social networks to young people with ABI.	attendees will be asses	cations and number of sed when funds are	22 sessions with up to 20 attendees each	440				
Children with ABI ages 0-12)	New group for children with ABI. The group will also feature a com- ponent for siblings of children with ABI and other family members.	secured.							
Brainy Blokes'	Eight 'Brainy Blokes' sessions have been held with the number of attendees ranging from 2 to 13.	Rural & Southern Metropolitan	32	11 sessions with 10 attendees	110				
yre Shed Group	Men's shed group for those living in the Eyre Peninsula area.	Remote	30	11 sessions with 10	110				
inner Club South/East Met- o)	Eight Carer/Caree Dinners have been held with the number of attendees ranging from 20 to 28.	Southern Metropolitan	57	11 dinners with 20 attendees	220				
ocial Group Mount Gambier )	Eight Mount Gambier Group meals have been held with the number of attendees ranging between 11 and 15.	Remote	19	11 dinners with 20 attendees	220				
ocial Club North/West Metro)	Social dinner/lunch group held for members living in North-West Metropolitan suburbs.	North-West Metropolitan	44	11 dinners with 20 attendees	220				
	across all Local Support Groups Annually upon commencement of DSO f	unding (ie. by January 20	15):		4475				

### **Local Support Groups**

Local Support Groups are core to Families4Families and enable important topics to be delivered within member families' local communities. Topics delivered are selected based on members' needs assessments<sup>14</sup> and ongoing feedback. Topics, including disability funding, concepts of choice and control,

Stage One Research Report provides a full overview of the needs and experiences of people with ABI and their families and can be downloaded at: http://families4families.org.au/research-project/stage-one-research-outcomes-report/. Information needed included ABI education and information, knowledge of resources, help navigating the service system, disability funding and concepts of choice and control possible within Individualised Funding and family advocacy support and training.

memory and cognitive challenges. Information booklets provided to take away enable recall and deep learning for all. Groups are successfully building capacity for the individual with ABI and their family members resulting in personal authority and social inclusion.

Families4Families is a young, vibrant organisation meeting previously unmet needs in a challenging sector. Our innovative approach and philosophy has given a voice to previously silent ABI families and our support groups bring together previously unconnected community members. Families4Families is considered essential as we move toward an Australia benefitting from a leading-edge disability support system<sup>15</sup>. Therefore, it is important to analyse the cost effectiveness of the peer support model developed and to reflect upon the benefits derived from this expenditure.

## **Program Outcomes**

The Families4Families Pilot Program ran for a period of 18 months during which time the program established itself as a separate organisation, Families4Families Incorporated, and gained DGR and Charitable status from the ACNC and ATO at the end of the Pilot period 16. The Association has leased its own premises at community rates from the City Council of Marion at Glandore Community Centre and has established its own insurance covers and indemnities for all volunteers, officers, members and property at the end of the Pilot period. The Association has gained its first government support via an Office for Youth youthConnect grant (\$50,000), to establish additional Youth with ABI and Young Carer programs. The Julia Farr MS McLeod Benevolent Fund have contributed further seed funding (\$100,000) to allow the Families4Families model to be further developed, for consumers to be provided an even greater voice, and for more team members to come on board within program operations.

The new Association, built during the Pilot Program, now has a membership of 286 families. Undertaking our scope of programs and support groups has only been possible thanks to our passionate group of management committee members, all drawn from membership<sup>17</sup>. In addition, an Advisory Panel of professionals provided oversight and advice to the committee and the Families4Families team, ensuring best practice and leading-edge information being delivered in all sessions.

#### **Attendances**

Attendance figures for Local Support Groups are provided in Table 3. Attendance figures have been collected for all sessions and events delivered throughout the Pilot Program. This is undertaken based on our philosophy that 'nobody gets left behind' with multiple access points, ways of connecting and methods of information delivery reflective of the complex nature of ABI. Our members' attendances are recorded in

Comments collected during the Stage 2 pre-program interviews (January 2013) demonstrated a strong level of interest in helping other families following ABI, with over half (51%, n=54) specifically indicating they wanted to help support others' journeys. Additional feedback collated after 9 months of the pilot indicated a third (34%) of members would like to volunteer within the Network. 62% of respondents were eager to 'share your personal journey of experience of ABI as part of an information session of shared lived experience of the acquisition, impact, challenges and adaption strategies of living with an ABI'. Opportunities within school speaking programs, community talks as well as Families4Families group sessions are planned to be provided for these members, which will afford crucial opportunities to participate, have a positive impact on other's lives following brain injury and help raise ABI and disability awareness

<sup>16</sup> The Incorporation Certificate and ATO Endorsement Certificate are provided in Appendix A.

Our management committee comprises 15 members (7 of whom have ABI, the remainder family members. Profiles are provided publicly on our website (http://families4families.org.au).

individual files kept on each member family. This ensures that we immediately are aware if a regular doesn't attend, or if someone attends who is not yet in our database, and also enables our database to be kept up to date with each Local Support Group's membership. This then leads into another aspect of the program, our volunteer phoning system<sup>18</sup>. The team is also able to record other events which the whole team needs to be aware - for instance, has a member received some bad news, has there been a loss, separation or other issue – in an unobtrusive manner.

Table 3: Families4Families' Existing Local Support Groups Attendances

EXISTING LOCAL SUPPORT GROUPS (1 January 2013 - 30 June 2014)		Region	Members @ Group Location	Number of Sessions	Total Attendances
Metro Group	Southern Metropolitan, held at the Corner Uniting Church, Warradale.	Metropolitan	57	14	209
Evening Group	City location at the Disability Information and Resources Centre (DIRC), Adelaide.	Metropolitan	29	18	178
Enfield Group	Northern Metropolitan location at the Enfield Community Centre, Enfield.	Metropolitan	44	17	230
Barossa Group	Held at CarersLink Nurioopta.	Rural/regional	22	16	157
Southern/Fleurieu Group)	Southern Rural group held in Myponga or Sellicks Beach Community Centre.	Rural/regional	32	16	207
Mount Gambier Group	Held in Mount Gambier at the Main Corner Complex.	Remote	19	12	153
Eyre Peninsula Group	Eyre Peninsula group held in Port Lincoln.	Remote	30	11	131
Young Carers	Two preliminary groups have been held. Five Young Carers attended the first session and 7 Young Carers attended the second session.	Remote & Metropolitan	Evaluation showed approximately 44 (20%) had Young Carers.	2	12
'Brainy Blokes'	Brainy Blokes sessions commenced in mid-2013 and now have many regular attendees.	Rural & Southern Metropolitan	12 regular attendees	10	101
Carer/Caree Dinners	Carer/Caree Dinners are two linked dinners with members having independent (with support workers) and also shared social time.	Southern Metropolitan	32 regular attendees	27	308
Mount Gambier Social Group	Mount Gambier Group meals have been held regularly, with attendees ranging between 11 and 21.	Remote	19	12	153
Total Attendances a	155	1839			
Total Attendances a	18	468			
Total Attendances a	5	398			
Total Attendances a	cross ALL Families4Families Pilot Program	for members:		178	2705

Summary attendance figures are provided in Table 4 showing that in each group, attendances are solid and, overall, are increasing over time. These summary figures show that most of the Local Support Groups are running with consistently high attendances. Our smallest group is the Barossa group, anecdotally due to the large number of members attending sporadically due to challenging life circumstances. Large groups are

Volunteers, either with ABI or as a family member of a person with ABI, have been trained in phoning other members and checking on them, reminding them of upcoming events in their area and confirming they have received all available and wanted information. Support is provided ensuring our volunteers are geared for success in these tasks, often working in pairs and with flexible time frames to reduce any potential stress. This is successful, with regular checking members now building relationships with the office volunteers adding another element to the important sense of connection being targeted. Obviously another key outcome is the sense of accomplishment and achievement derived by the volunteers who gain self-esteem and confidence, skills, training and this reduces their need for alternative supports or day programs.

spread between the inner metropolitan and rural areas – illustrating success across geographical spread.

Table 4: Families4Families' Local Support Groups Average Attendances

Local Support Group	Ave Attendance Jan-Jun 2013	Ave Attendance Jul-Dec 2013	Ave Attendance Jan-Jun 2014
Barossa Group	8	12	12
Brainy Blokes	5	10	13
Dinner Clubs	11	12	13
Enfield Group	14	17	16
Evening Group	10	10	11
Eyre Peninsula Group	13	10	15
Metro Group	16	14	18
Mount Gambier Groups (2)	11	12	17
Southern Group	15 <sup>19</sup>	13	14
Overall F4F Pilot Average	11.935	12.696	14.429
(LLocal Support Groups Ionely)			

The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) funds the Parenting Research Centre (PRC) to deliver the MyTime Peer Support Groups for Parents and Carers of Children with Disability or Chronic Medical Condition Program (MyTime). This is another peer support program operating at a similar time in Australia, and a recent evaluation of this program showed average attendance figures as shown in Table 5. The average attendance figures for the Families4Families program operating on such a minimal budget is considered outstanding when the overall average attendances are compared (14.4 compared to 4).

Table 5: Average number of registered Participants per MyTime Peer Support Groups

Period	Member	Attendanc
Jul-Sep 2010	8	4
Oct-Dec 2010	9	5
Jan-Mar 2011	11	3
Apr-Jun 2011	12	3
Year Average	10	4

In addition to the relatively high levels of attendance of Families4Families Local Support Group sessions, an informal evaluation undertaken during October 2013 found that 59% of available members were regularly accessing Local Support Groups. A membership level for the overall Association as well as for those designated to each Local Support Groups has also been calculated and this is increasing. From a membership at Launch of 115 member families, over the 18 month Pilot Program membership rose to 265 families. Given that no funds were allocated to marketing or publicity, this 130% increase is large and certainly has meant higher levels of administration and group load than anticipated.

An initial concern for Julia Farr MS McLeod Benevolent Fund Trustees was the risk that the person with disability, in this case ABI, would be somehow displaced by the broad family-centric focus taken in the program's model and approach. A preliminary report was provided in August 2013 illustrating the involvement and participation levels of people with ABI within the Pilot Program and Table 6 further

Southern group is higher in first 6 months due to two social/educational sessions held on public holidays in a farm environment, leading to higher attendances in two sessions from members travelling from outside the usual group location.

illustrates that taking a family-centric approach does not displace those members impacted directly by ABI.

Attendance levels for Local Support Groups are solid and growing over time. In addition, people with ABI are attending these groups in high numbers and there does not appear to be any displacement or reduced involvement due to the family centric approach taken within Families4Families.

Table 6: Families4Families' Local Support Groups Average Attendances by Participant

Local Support Group	Ave Attendance People with ABI	Ave Attendance Family Members	Ave Attendance All Members
Barossa Group	4.125	4.875	9.812500
Brainy Blokes	5.500	4.100	10.100000
Dinner Clubs	4.308	6.539	11.846154
Enfield Group	7.063	8.625	14.375000
Evening Group	3.824	5.294	10.470588
Eyre Peninsula Group	5.500	6.600	13.100000
Metro Group	5.308	9.154	16.076923
Mount Gambier Group	5.957	6.435	13.304348
Southern Group	5.667	7.200	13.800000
Overall F4F Average (LSGs)	5.273	6.818	13.070707

The other major program for which attendance figures are kept is within the Families4Families Early Support Program. In preliminary research assessing target group needs, the Families4Families Stage One Research Report found one common theme was the request for supports in the early stages following the ABI. Such support was to provide both insight from others with lived experience and also knowledge of how to access specific health services before, or soon after, hospital discharge. Comments provided included:

"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)

"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)

The Stage One research found that 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. For these reasons, Families4Families has worked to establish their Early Supports Program and have, since late 2012, worked to spread news of the Network and its supports across various early support domains and, specifically, within any acute care and rehabilitation services that will allow our entry. Table 7 provides a listing of these events showing 18 sessions providing information to 468 attendees including 80 people with ABI being successfully delivered.

Social outings were also considered crucial from respondants within the Stage One needs assessment research. Various social events have been planned and delivered throughout the Pilot Program, with the management committee committed to providing 3-4 special events annually. Attendances at these events are solid, with 398 attendances across the 5 events held from January 2013 to June 2014.

Attendance alone is an insufficient measure of program success. It is important to also evaluate the outcomes from sessions – are members less socially isolated, for instance, and are they learning about their own situation and limitations within a safe, caring and encouraging environment? Going to events and

sessions is one thing, gaining benefit from this involvement is crucial and this will now be briefly assessed<sup>20</sup>.

Table 7: Early Support Program Sessions

Presentation or Event Held	Date	PWABI	Attendance	Location
Carers SA Counselling presentation	15/11/2012	0	30	Carers SA
DIRC Presentation	5/12/2012	1	30	BIRU
Birch Session	13/02/2013	18	40	BIRCH
BIRU Family Education Session	5/03/2013	6	12	BIRU
HRC Day Rehab presentation	11/03/2013	0	16	HRC
CWA Presentation	13/03/2013	5	150	Victor Harbor
BIRU F4F Staff Education Session	10/04/2013	0	25	BIRU
Northern Carers Session Speech	12/04/2013	0	7	BIRU
CRP Early Supports Presentation	3/05/2013	15	30	Flinders University
Onkaparinga Council ABI Awareness	14/08/2013	3	30	Onkaparinga
Week Session				Council
Carers Week Carers SA Session	15/10/2013	0	15	Carers SA
BIRU Family Education Session	10/12/2013	1	6	BIRU
BIRU Family Education Session	3/03/2014	2	9	BIRU
BIRU Family Afternoon tea	17/03/2014	4	12	BIRU
BIRU Family Education Session	28/04/2014	2	8	BIRU
Birch Session	7/05/2014	16	20	Birch
Birch Session	7/05/2014	3	18	Birch
BIRU Family Education Session	23/07/2014	4	10	BIRU
TOTAL ATTENDANCES ACROSS SESSION	S:	80	468	

#### **Feedback and Benefits**

The effectiveness of peer support groups has been directly examined in only a limited number of methodologically robust, comprehensive studies. For this reason the report being undertaken concurrently on the longitudinal outcomes of the Pilot Program are eagerly awaited. Nevertheless, available evidence consistently suggests that participation in Families4Families' peer support model is associated with the following positive outcomes:

- acquisition of relevant knowledge and skills by members receiving support;
- improved physical and psychological health reported by members receiving support; and
- increased coping and decreased isolation in members giving and receiving support.

These positive outcomes of peer support groups appear to be driven both by the level of social support provided in the Local Support Groups, and the quality of the organisational structure and overall Families4Families model. Participant feedback gained via the internal evaluation undertaken during October 2013 included a request for 'Any other suggestions/comments?' and those received included:

'I don't know how we managed before attending F4F sessions. I just wish we had you in our beginning of our journey in 2011. I am now on management committee as I want to help give back to help other people. Keep your immeasurable work guys. Much gratitude and love.'

'Keep up the great work Thanks!!!'

<sup>20</sup> There is only a brief, preliminary discussion of feedback and benefits due to this being the focus of the concurrent report being undertaken by the Flinders University external evaluation team on the Longitudinal outcomes of the program.

'Thank God for F4F and the people I have met through the network. They are lifesavers! I don't know how I would have managed without the support & info, particularly from Jen!!!'

'We very much appreciate what F4F do. (Name given) has a very mild form, so is very functional hence our needs are very small - but we have gained much information from your group and are very thankful for that.'

'The sharing of knowledge and coping skills from the group is always helpful. We all share the hardship and frustration of brain injury and its just a comfort to be amongst people who understand. I don't want it to consume my life but adjust to living with it. I would love the broader community to be more educated.'

Thank you to all of you who have put so much time and effort into creating and developing what F4F is today. I cannot tell you what a relief it is to discuss the life changing impacts of ABI with people who truly understand. What is more, we can find out much more efficiently and effectively how we can improve our lives.'

In addition, comment sheets are provided at most sessions and responses received during the Pilot Program have included:

'hi everry one had good day at our meeting lotts to think of lunch was a blast mikhel helped me with my computer was looking in the wrong place for this syght it was her all the time hard to beleve its friday all ready hoping for good weather to go flying this weekend was good to see amanda again she has a great smile am stufed now' (Online members forum for people with ABI only).

'I went to the group and I realised this is about me' - The Corner group

'I have a brain injury - I didn't realise that having a stroke was a brain injury' - Southern Fleurieu

'I'm meeting people the same 'ilk' as me, people having a second crack at life' - Southern Fleurieu group

'My family aren't supportive, so its good to be around other people who 'get' me'.

Being with other people that have been through experiences the same as me, they understand where I am at' - Enfield group

'Hearing other peoples stories inspires me and that I'm not the only one going through this' - Enfield

'It would have been good to have this straight away when I left Hampstead'.

'I was 15 when my dad had a stroke - I wish there was something like this around [then]'.

'She [Jen] talks about what I've experienced' - Mt Gambier group

In addition, evaluation has been sought throughout the project, as the aim is the development of an efficient and effective leading edge, peer based, self-help model that can be replicated nationally. External evaluation undertaken (by Flinders University Final Year Placement student) on the first 9 months of the Pilot Program, ending 15 October 2013, found (with 74 responses providing a 50% response rate) that:

- 82% of respondents agree that Families4Families is currently meeting their need for emotional support (this is with removal of members that self-identified personal reasons for not agreeing – including all respondents it is still an impressive 68%).
- For people with ABI, this percentage is 81% (or 65% including all), and for family members and/or Carers this is 75%.
- 49% of all respondents regularly attend group sessions, and this figure increases to 59% when people with spontaneously provided personal reasons are excluded (eg. 'I just need to stay out of hospital and organise myself', and '...am visually impaired and on oxygen so' [cannot leave home]).

Key findings were from the evaluation question "What have you found most helpful from the Families4Families Peer Support Network"? Table 8 supports the Families4Families team belief that 'connection with others' and 'understanding from peers where I am at' along with information tailored to the ABI experience has been the missing element in programs offered to target families to date.

Table 8: Most Helpful Aspects of Families4Families Programs

What have you found most helpful from the Families4Families Peer Support Network?	All	People with ABI	Family Members
Connection with others who have been through similar things to myself	68%	77%	69%
Understanding from others/peers where I am at	45%	55%	46%
Information about ABI	64%	71%	67%
Emotional Support	39%	48%	40%
Information and referrals on how to access supports and resources	57%	61%	65%
Increased social interaction/feel less socially isolated	31%	39%	31%
Sharing of my personal experience with peers to help others	50%	52%	54%
Social dinners/outings	41%	42%	42%

Feedback from participants is crucial but long-term success is also impacted by how professionals in the field view the peer based support network and its programs. Thus feedback from professionals who work with our target group is also highly valued. Several key ABI professionals have provided letters of support to Families4Families<sup>21</sup> and their comments include:

"I have kept myself informed of this Association's work and believe that their programs are providing much needed support for our target audience of people impacted by ABI...I would strongly support and advocate for this type of group as a valuable addition to the support offered to families impacted by ABI nationally." (Nick Rushworth, Executive Officer, Brain Injury Australia)

"I am very pleased to furnish a letter in support of the F4F ABI Support Network highlighting the importance, and vital role, of this family support group for people faced with emotional distress and ongoing dysfunction in the head-injured individuals, under these very difficult and life-changing circumstances...I commend Families4Families as a remarkable and effective model of support services which has proven valuable to many of SA BIRS patients and their families". (Dr Miranda Jalbart, Medical Director, SA Brain Injury Rehabilitation Service)

"The Department for Communities and Social Inclusion (DCSI) is supportive of Families4Families as a consumer led organisation; specifically set up to provide invaluable support and information for people with Acquired Brain Injury (ABI) and their families." (Dr David Caudrey, Executive Director, DCSI)

"Families4Families is a fantastic peer support service initiative. Its model offers the 'insider knowledge' and expertise of those who have experienced ABI and who have a working knowledge of what to ask, what resources to seek, how to problem solve practical issues, and how to best support oneself and one's loved ones through the enormous life shift and ongoing challenges after a brain injury...Families4Families uses an impressive, coordinated range of approaches... community groups, facebook pages, website, phone supports, follow up efforts, training services...demonstrate an incredible commitment and resourcefulness to meet the needs of their ever growing membership group, all within a very tight budget, augmented by a sizeable volunteer base." (Liz Williams, Speech Pathologist, BIRCH)

Overall, the impressions and reported experiences of the program of members including both people with ABI and their family members are very positive. The attendance figures and feedback received from both participants and professionals who support the same target group members illustrates that Families4Families' Pilot Program delivered key benefits to member families impacted by ABI. These benefits

Several letters of support, provided to support various grant and other applications, are provided in Appendix B.

include providing families with a peer support network and giving them more information about how to live their best life possible with ABI. Consistent with its objectives, the program is also being successfully implemented in regional areas and for many sectors of the community.

### Costs

### **Grant Funding**

The funding provided by Julia Farr MS McLeod Benevolent Fund to Flinders University, as auspicing agency, to deliver the Pilot Program was \$162,502 of which planned research expenditure was \$34,258.09. However, this budget excluded a range of in-kind supports being provided by various other individuals and organisations. In addition, an enormous amount of support was provided by a range of individual volunteers and research team members. Therefore, further analysis of the actual expenditures is required to fully understand the cost of the Pilot Program. In addition, it would be most useful for the cost/benefit analysis for the Pilot Program model to allocate the actual expenditures to the various program categories being delivered. That is, to apportion costs, where possible, to the types of supports provided including the key Local Support Groups but also phone support, website, Facebook groups, and eNewsletters. Therefore the cost analysis here must include determining:

- Expenditure analysis of cost versus budget, to illustrate the actual use of funds to deliver the Pilot Program for the 18 month delivery period;
- Estimated Full cost analysis, to illustrate the overall actual use of funds and the value of the in-kind contributions provided by various volunteers and organisations during the Pilot Program;
- Allocated costs (Actual and Full) to various aspects of the full Pilot Program delivery model; and,
- Costs analysed according to levels of activity (including attendance and hours of program delivery).

Table 9 presents the total funding (exclusive of GST) provided by JF to F4F to deliver the Pilot Program in the first 18 month grant agreement. These costs have been apportioned to the various program types delivered within the Pilot Program. In many cases this involved the analysis of the transaction details to determine the purpose of the expenditure and, when this was not possible or appropriate, allocations based on estimated usage and relevance to each program has been utilized.

The Association's ABI Awareness Program, Early Support Program, Online Support Program, Special Events encompassing various social outings such as Movie Days and Family BBQs along with the important Telephone Support Program which includes our informal member advice and advocacy all ensure members are supported in a variety of ways. In addition, the Research Program was undertaken with costs less than estimated in the initial grant submission due to the reduced total staff costs and a lower rate of allocation to research. However, the majority of the grant funds have been expended on the provision of the Local Support groups in a range of communities. Local Support Groups are a core component of the program model and the high level of funding directed toward them, particularly in rural and remote locations, illustrate the obvious focus of the Association on grass root programs and support opportunities for all.

Table 9: Pilot Program Financial Statements by Program Type

Program Type	Expenditure Details	Amount		Total of Programs & Grant	
ABI Awareness Program	Staff Costs (20%)	\$	6,664.18		
ABI Awareness Program	Travel Costs - mileage reimbursements (20%)	\$	14,360.30		
	Marketing and Promotional Items	\$	3,403.23	ć	24,427.72
	Marketing and Promotional Items	\$	3,403.23	Ş.	24,427.7.
arly Support Program	Travel Costs - mileage reimbursements (20%)	\$	14,360.30		
any support roop and	Parking Costs (50% for these events)	\$	406.53	\$	14,766.83
ocal Support Groups	Staff Costs (50%)	\$	16,660.45		
	Travel Costs - mileage reimbursements (60%)	\$	43,080.91		
	Support Group Costs (Non-group specific)	\$	7,702.00		
	Operational Costs (Non-group specific)	\$	4,251.42		
	LSG Metro Group	\$	384.68		
	LSG Evening Group	\$	950.00		
	LSG Enfield Group	\$	558.73		
	LSG Barossa Group	\$	214.40		
	LSG Southern/Fleurieu Group	\$	-		
	LSG Mount Gambier Groups (Social and Normal)	\$	2,360.36		
	LSG Eyre Peninsula Group	\$	2,971.58		
	LSG Brainy Blokes Group	\$	-		
	LSG Dinner Club Group	\$	6,036.53	\$	85,171.0
Online Support Program	Staff Costs (10%)	\$	3,332.09		
	Organisational Registrations	\$	2,113.95		
	Website Hosting and other IT Costs	\$	3,570.00	\$	9,016.04
Research Program	Staff Costs (10%)	\$	3,332.09		
-	Research Specific Staff Costs (data collection)	\$	6,480.00		
	Postage and Printing	\$	3,427.28		
	Telephone and Focus Group costs	\$	3,411.25		
	Parking Costs (50% for these events)	\$	406.53	\$	17,057.1
Special Events	Hiring Costs for Venues	\$	480.00		
	Other Special Event Costs (eg Films, materials)	\$	973.13	\$	1,453.13
Telephone Support Program	Staff Costs (10%)	\$	3,332.09		
Including informal advocacy)	Telephone and internet costs	\$	4,853.56		
	Postage and Printing (Office - mainly to members)	\$	2,424.44	\$	10,610.09

#### **Average Cost Estimates**

Table 10 analyses the Local Support Group cost of \$85,171.06 and estimates these costs on an average basis per group, per face to face contact hour, per participant and per attendance hour. The average cost per group is estimated to be \$8,517 based on the 10 established Local Support Groups running across South Australia. The average cost per hour of face to face Local Support Group delivery is also calculated, estimated to be \$239.58. This estimate is based on calculating the hours of delivery for each session, in most cases the Local Support Groups run for 2 hours of face to face service delivery however some sessions run for slightly different times, such as the Dinner Club which run for 3 (Carers) and 3.5 hours (Careers) per session. The average cost per registered member family was then calculated at an average cost of \$297.80 per member family. The contact hours for all 145 sessions were all tallied in a spreadsheet. The contact hours were then multiplied with the attendance figures for each of the sessions providing a total number of 6867 participant attendance hours for the Pilot Program period for all Local Support Groups. This then enabled the calculation of the cost per participation hour of \$12.40 for the Pilot Program.

Table 10: Costs of Families4Families Local Support Groups

Cost Estimates	Pilot Program Average
Total Local Support Group Costs	\$85,171.06
Cost per group	\$8,517.11
Cost per hour of face to face Service (based on 355.5 hours of Local Support Group contact hours)	\$239.581
Cost per registered member family (based on 286 member families currently registered)	\$297.80
Cost per participation hour (based on 6867 participation hours, calculated by multiplying all sessions attendances by hours of session, tallied for every Local Support Group session and summed for the whole period).	\$12.40

This cost effectiveness data can be compared to some of the average cost data presented within a similar MyTime evaluation. In Table 11 the average cost per hour of participation by parents in face-to-face group support activity of My Time, the cost per group, cost per hour of service and cost per participant is provided along with the relevant Families4Families average costs. Despite the MyTime being a larger program, with related economies of scale, and having some security of funding and government support and related publicity, the cost per participation hour of \$45.00 illustrates a far more expensive model than the \$12.40 for the Pilot Program under analysis. Both figures can also be compared with a relevant cost benchmark. The Australian Psychological Society 2012–13 recommended fees per client for group counselling by a registered psychologist of \$41.50 per hour (exclusive of GST) for a group of 5 or more clients of 2 hours duration. Comparisons against this cost benchmark should be made with caution given the different nature of the services delivered. However, the figures do further support the exceptional affordability of the average cost per participation hour for the Families4Families Pilot Program's Local Support Groups.

Table 11: Costs of MyTime and Families4Families Peer Support Groups

(\$)	MyTime Cost Averages 2011–12	Families4Families Cost Averages 2012-14
Total cost	\$3,520,000.0	\$85,171.06
Cost per group	\$14,080.00	\$8,517.11
Cost per hour of service	\$220.00	\$239.581
Cost per participant	\$1,161.00	\$297.80
Cost per participation hour	\$45.00	\$12.40

#### **Full Cost Estimates**

While the figures above illustrate the cost effectiveness of the Pilot Program, the grant funding received would not have enabled the full program delivery if not for significant in-kind and volunteer contributions to Families4Families. Actual costs relative to Budgeted (forecast) figures, shown in Appendix E, give an indication of the expenditure for the program and planned and delivered. However, the question 'what is

the full cost of delivering a peer support program for people living with disability and their families?' cannot be fully answered without including accurate estimates of in-kind and volunteer contributions. A full cost accounting system is designed to measure the complete, true costs of services and incorporates a wider range of costs than what is provided by a standard costing system (Gresham, 2010). Full cost accounting's advantage, when compared to standard accounting, is that it provides more cost factors to be considered for planning and decision-making purpose. Therefore, an overall estimate of the in-kind contributions along with volunteer hours must be considered in this evaluation.

Table 12 shows actual and estimated in-kind contributions and volunteered hours utilized throughout the Pilot Program. The key in-kind contributions included are the items most easily estimated to ensure robust figures, such as the infrastructure fee that was waivered for the Program, and total \$59,235.50<sup>22</sup>.

Table 12: In-Kind and Volunteerism Contributions for Full Cost Analysis

			,	
In-Kind or Volunteerism Item	Amount / Rate	Number / Activity Level	Total Cost (18 Months)	Total Full Costs
In-Kind Contributions:				
Flinders University: Infrastructure provided by University		total grant		
including office space, printing, accounting, HR/Legal IT	•	based on this	\$40,625.50	
and other systems. Fee waivered by the University.	usual le	y charged)		
Carers Support: Annual funding enable to delivery of the Carer Dinner Club for Carers and Carees.	\$8,640.00	Annually	\$12,960.00	
Rosey Batt and Associates: Provided legal advice re				
Incorporation and DGR submissions, assisted with Rules of Association (\$1000 pa) and provided ongoing printing	Estimated \$2,500.00 pa	Annually	\$3,750.00	
support (\$1500 pa).  Andersons Solicitors: Provided catering funds.	\$1900.00	Nogotiated	\$1,900.00	
TOTAL IN-KIND CONTRIBUTIONS:	\$1900.00	Negotiated	\$1,900.00	\$59235.50
Volunteered Hours <sup>23</sup> :				\$59255.50
Manager Volunteerism: During Pilot, Manager recorded all hours and was paid 3 hours weekly, other hours	\$63.66	5445 Hours	\$346,628.70	
provided here (HEO8 Hourly rate 52.18 + 22% on costs).  Coordinator Volunteers: During the Pilot a volunteer				
coordinator volunteers. During the Pilot a volunteer	\$45.91	474 Hours	\$21,761.34	
been paid at the HEO5 Hourly rate (37.63 + 22% on costs).	7		,,··	
Office Volunteers: During the Pilot various volunteers				
provided office support, including University placement students and members. Using lowest estimated rate, HEO3 Hourly rate of 30.40 + 22% on costs.	\$37.09	1171.85 Hours	\$43,463.92	
Event Coordination and Other Volunteers: During the				
Pilot various volunteers provided other hours of service, such as with Catering and event coordination. HEO4 used	\$41.18	1807 Hours	\$74,412.26	
with casual rate of 30.40 + 22% on costs.				
TOTAL VOLUNTEERED HOURS WITHIN PILOT:		8,897.85 Hours		
TOTAL ESTIMATED VALUE OF VOLUNTEERED HOURS WITHIN P	ILOT:			\$486,266.20
TOTAL IN-KIND AND VOLUNTEER CONTRIBUTIONS WITHIN PILE	ОТ:			\$545,501.70
Total Grant Funds Provided to cover Costs of Pilot Program:				\$162,502.00
TOTAL ESTIMATED FULL COST OF PILOT PROGRAM:				\$708,003.70

Volunteer estimates have been calculated using the Flinders University HEO (Higher Education Officer) general staff casual rates to determine a value for the various types of hours provided. The actual hours have been recorded diligently throughout the Pilot via a 'Volunteers Book' in which all volunteers have

<sup>22</sup> Additional organisations contributions and ongoing organizational relationships developed are discussed further in Appendix C.

As Flinders University was the employer during the Pilot Program, their HEO Rate tables have been used for these estimates. Tables available online at http://www.flinders.edu.au or upon request.

recorded office hours and via diary entries of the other main volunteers (such as Manager, Dr Jennifer Farnden). The total value of the significant volunteer contributions is \$486,266.20. Thus the full cost of the Pilot Program, including in-kind, volunteer and grant funding provided is estimated to be \$708,003.70. It is clear that part of the reason that the average cost estimated are very low is due to the volunteerism and inkind contributions negotiated for inclusion in the program delivery.

It should be noted that in this study the full cost estimates presented do not include any allowance for costs incurred by Julia Farr MS McLeod Benevolent Fund in their ongoing evaluation and assessment of various submitted reports documenting the program delivery other than the funding provided to Flinders University under the grant agreement. It is anticipated that there has been significant staff costs associated with Trustee program management and Advisory Panel membership of Research Officer as well as other various meetings and appointments with CEO, Robbi Williams. In addition, the research team members at Flinders University have not included any estimates of time spent on the Families4Families projects and these would also total many hours of research expertise.

### **Conclusions and Recommendations**

This report provides Trustees with a thorough socio-economic evaluation of the Families4Families peer based support network. The Association has, during the 18 month Pilot Program, delivered a model of support encompassing an ABI Awareness Program, Early Support Program, Online Support Program, Special Events encompassing various social outings such as Movie Days and Family BBQs along with the important Telephone Support Program which includes our informal member advice and advocacy ensuring members are supported in a variety of ways. Over the Pilot Program period, membership rose from 115 member families at the Launch, to 265 at the end of June 2014 to a current level of 286 families (September 2014). Families4Families aims to build capacity in its members, comprising people impacted by brain injury and their families, via its innovative peer support model.

Families4Families members have the opportunity to access a range of Local Support Groups within their local communities where they exchange ideas, information and gain mutually beneficial support. Local Support Groups are core to Families4Families and enable important topics to be delivered within member families' local communities within the geographically diverse membership. Attendance levels for Local Support Groups are solid and growing over time, with 155 such sessions with 1839 attendances. People with ABI are attending these groups in high numbers and there does not appear to be any displacement or reduced involvement due to the family centric approach taken within Families4Families. Early Supports Program has spread news of the Network and its supports across various early support domains and acute care and rehabilitation services with 18 sessions providing information to 468 attendees including 80 people with ABI being successfully delivered. Social events were requested within initial needs assessment research and attendances at these events are also solid, with 398 attendances across the 5 events held from January 2013 to June 2014. A total of 2705 attendances across a total of 178 sessions were delivered.

In addition to strong attendance, feedback from Network members and brain injury clinicians provided illustrates strong support to maintain and expand Families4Families supports. Attendance figures and reported experiences of the program of members including both people with ABI and their family members are very positive. Feedback received from key professionals who support the same target group members

illustrates that Families4Families' Pilot Program has delivered key benefits to member families impacted by ABI. These benefits include providing families with information about how to live their best life possible with ABI and such benefits are being provided in geographical diverse areas in many communities.

The funding of \$162,502 provided by Julia Farr MS McLeod Benevolent Fund to deliver the Pilot Program was analysed to determine expenditure allocations to each program type. This data was then used to determine program delivery costs on an average basis – per member family, per delivery hour, per participant attendance hour. These costs figures compared favourably with a comparison peer support program, My Time, and also when compared to the cost of therapy delivery. It is clear that Families4Families is a relatively low cost program delivering clear benefits to members across a challenging and geographically diverse target group.

Families4Families has built a leading edge peer support model thanks to the previously untapped passion, skills and deep knowledge of people with ABI and their family members and their desire to support other families impacted by this challenging, and often unexpected, disability. The high level of volunteerism within Families4Families is the reason why the average costs of delivery are affordable as without volunteers and other in -kind contributions the cost of the model would have been far greater at \$708,003.70 and therefore not affordable within the grant provided. The \$545,501.70 value calculated in this report illustrates that the average cost estimated are very low is due to the volunteerism and in-kind contributions negotiated for inclusion in the program delivery. It is clear that the peer based model of support and its high utilisation of volunteerism enables a less costly delivery than would otherwise be possible. It is hoped that this report will enable future decision makers to understand the true costs of delivering the meaningful and long-term changes derived from well managed peer support models.

It is anticipated that this report will serve to contribute toward the calculations basis of future funding allocations. Groups such as the NDIA need to know the cost of peer support given their goal of moving toward a new disability system model where individuals with disability and their family members are adequately supported, educated and empowered to life their best lives possible. This report provides the cost, actual and full, data required to enable such planning and for funding decisions.

It is recommended that further research is undertaken to assess the overall economic benefits from the provision of peer based supports to disability and ABI target groups. It is expected that, if fully modelled, the overall cost of program provision would be significantly less than the currently provided model, which is not working effectively (as evidenced by the Stage One report). Such a study would weigh up the costs and benefits of alternatives - in this case we would compare the costs and benefits of 'usual care' versus 'usual care and Families4Families'. This health economics study would be to model the various economic savings derived more broadly from the Families4Families model and how this changes the burden on other aspects of government systems. A simple example may be based on the benefits derived if Families4Families reduces family breakdown<sup>24</sup>. If a family breaks down, then the costs of the person needing supported accommodation is mainly borne by the government disability system as a significant cost (for example, up to \$300,000 pa). The cost of this higher level accommodation is a saving due that is avoided by operating the effective Families4Families program. Another example is if it is found that the network reduces the

<sup>24</sup> The network has received ongoing feedback from several families that, without the network, they would not have been able to stay together leading to their loved one with ABI being placed in supported accommodation or a care facility such as Highgate House.

health system burden of mental health costs<sup>25</sup>. The health system would make potential cost savings associated with lower levels of depression and anxiety as well as improved QOL. In addition, the benefits derived by members living with heightened levels of choice and control due to the many sessions delivered on self-managed and Individualised funding is another potential benefit to members yet to be effectively measured. It is recommended that such a health economics study be commissioned and undertaken to illustrate the community wide benefits anticipated benefits members derive from the programs delivered.

### References

- Acorn, S. (1993). An education/support program for families of survivors of head injury. Canadian Journal of Rehabilitation, 7, 149-151.
- Acorn, S. (1995). Assisting families of head-injured survivors through a family support programme. Journal of Advanced Nursing, 21, 872-877.
- AIHW (2007), Australia's health 2004. Australia's health no. 9. Cat. no. AUS 44. Canberra: AIHW.
- Boschen, K., Gargaro, J., Gan, C., Gerber, G., & Brandys, C. (2007). Family interventions after acquired brain injury and other chronic conditions: a critical appraisal of the quality of the evidence. NeuroRehabilitation, 22, 19-41.
- Bromley, J., Hare D.J., Davison K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. Autism, 8 (4), 409-423.
- Campbell, C.H. (1988). Needs of relatives and helpfulness of support groups in severe head injury. Rehabitation Nursing, 13, 320-325.
- Chan, J., Parmenter, T., & Stancliffe, R. (2009). The impact of traumatic brain injury on the mental health outcomes of individuals and their family carers. Australian e-Journal for the advancement of Mental Health, 8(2), 1-10.
- Erch, T., Rapport, L., Coleman, R., & Hanks, R. (2002). Redictors of caregiver and family functioning following traumatic brain injury: social support moderates caregiver distress. Journal of Head Trauma Rehabilitation, 17, 155-174.
- Foster, K. (2011). 'I wanted to learn how to heal my heart': Family carer experiences of receiving an emotional support service in the Well Ways programme. International Journal of Mental Health Nursing, 20, 56-62.
- Gan, C., Campbell, K., Gemeinhardt, M., & McFadden, G. (2006). Predictors of family system functioning after brain injury. Brain Injury, 20(6), 587-600.
- Gan, C., Gargaro, J., Brandys, C., Gerber, G., & Boschen, K. (2010). Family caregivers' support needs after brain injury: a synthesis of perspectives from caregivers, programs, and researchers. NeuroRehabilitation, 27, 5-18.
- Gresham, T. (2010). The Characteristics of a Full Cost Accounting System, published by Demand Medi, http://smallbusiness.chron.com/characteristics-full-cost-accounting-system-41699.html.
- Hillier, S., Hillier, J., & Metzer, J. (1997). Epidemiology of traumatic brain injury in South Australia. Brain Injury, 11(9), 649-659.
- Jacobs, H.E. (1988). The Los Angeles Head Injury Survey: Procedures and preliminary findings. Archives of Physical Medicine and Rehabilitation, 69, 425-431.
- Kneafsey, R., & Gawthorpe, D. (2004). Head injury: long-term consequences for patient and families and

<sup>25</sup> The network has received ongoing feedback from many members that they no longer need to see their Neuropsychologist due to the support received via their Families4Families sessions and events.

- implications for nurses. Journal of Clinical Nursing, 13, 601-608.
- Kushner, D. (1998). Mild traumatic brain injury: towards understanding manifestations and treatment. Archives of Internal Medicine, 158(15), 1617-1624.
- Man, D. (2002). Family caregivers' reactions and coping for persons with brain injury. Brain Injury, 16, 1025-1037.
- ORIMA Research (2013), Evaluation of the MyTime Peer Support Groups for Parents and Carers of Children with a Disability or Chronic Medical Condition, 15 February 2013, see www.orima.com.
- Perlesz, A., Kinsella, G., & Crowe, S. (2000). Psychological distress and family satisfaction following traumatic brain injury: injured individuals and their primary, secondary and tertiary carers. Journal of Head Trauma Rehabilitation, 15, 909-929.
- Ponsford, J., Olver, J., Ponsford, M., & Nelms, R. (2003). Long-term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. Brain Injury, 17, 453-468.
- Rees, R. (2005). Interrupted lives: rehabilitation and learning following brain injury. Melbourne: IP Communications.
- Schor E.L. (2003). American Academy of Pediatrics Task Force on the Family. Pediatrics, 111(6), 1541-1571.
- Singh, P. (2008). Care-giving after traumatic brain injury: the impact on the caregivers' quality of life. Unpublished Masters Thesis, School of Medicine, Flinders University.
- Sohlberg, M. M., & Mateer, C. A. (2001). Cognitive Rehabilitation: an integrative neuropsychological approach. New York: The Guilford Press.
- Tate, R., Lulham, J., Broe, G., Strettles, B., & Pfaff, A. (1989). Psychosocial outcome for the survivors of severe blunt head injury: The results from a consecutive series of 100 patients. Journal of Neurology, Neurosurgery, and Psychiatry, 52, 117-126.
- Turner, B., Fleming, J., Parry, J., Vromans, M., Cornwell, P., Gordon, C., & Ownsworth, T. (2010). Caregiver's of adults with traumatic brain injury: the emotional impact of transition from hospital to home. *Brain Impairment, 11(3), 281-292.*
- Tyerman, A. (1997). Social bases of community rehabilitation: a review. Community Rehabilitation following Acquired Brain Injury, 1(1), 29-46.
- Willer, B.S., Allen, K.M., Liss, M., & Zicht, M.S. (1991). Problems and coping strategies of individuals with traumatic brain injury and their spouses. Archives of Physical Medicine and Rehabilitaiton, 72, 460-
- Winstanley, J., Simpson, G., Tate, R., & Myles, B. (2006). Early indicators and contributors to psychological distress in relatives during rehabilitation following severe traumatic brain injury. Journal of Head Trauma Rehabilitation, 21(6), 453-466.
- Ylvisaker, M., & Feeney, T. (1998). Collaborative brain injury intervention: positive everyday routines. College of Saint Rose: Albany.

## **Appendix A**

### **Incorporation Certificate**



### **SOUTH AUSTRALIA**

Associations Incorporation Act 1985 Section 20(1)

Incorporation Number: A41816

## **Certificate of Incorporation**

This is to certify that

#### FAMILIES4FAMILIES INCORPORATED

is, on and from the third day of July 2013 incorporated under the Associations Incorporation Act 1985.

Given under the seal of the Corporate Affairs Commission at Adelaide on this third day of July 2013







27 June 2014

#### Endorsement as a deductible gift recipient

Endorsement as a deductible gift recipient under Subdivision 30-BA of the *Income Tax Assessment Act* 1997 is provided as detailed below.

**FAMILIES 4 FAMILIES INCORPORATED** Name

31 836 219 114 Australian business number

Endorsement date of effect 6 May 2014

item 1 of the table in section 30-15 of the Income Tax Provision for gift deductibility

Assessment Act 1997

Item(s) in Subdivision 30-B of the Income Tax Assessment Act 1997

www.abn.business.gov.au

4.1.1 registered public benevolent institution

Your organisation's endorsement as a deductible gift recipient, together with the date or period of effect, is entered in the public register maintained by the Australian Business Registrar at

Your organisation must notify the Tax Office in writing if it ceases to be entitled to endorsement.

Chris Jordan Commissioner of Taxation and Registrar of the Australian Business Register

CHARITY\_ADVICES\_645-GDG-0000079-0000237

## **Appendix B**

### **Letters in Support of Pilot Program**



4 August 2014

To Whom It May Concern,

I write to support the work of Families4Families Incorporated. Since 2012, this organisation has been offering peer-based supports for people with acquired brain injury (ABI) and their families in South Australia. I have kept myself informed of this Association's work and believe that their programs are providing much needed support for our target audience of people impacted by ABI. I have known Dr. Jennifer Famden since early 2012 and have been impressed with her commitment to the betterment of the lives of people impacted by ABI and their families in SA during that time.

My role with Brain Injury Australia has assisted me to develop awareness and appreciation for the importance of psychosocial support during the multiple phases of hospitalisation, rehabilitation and the transition back to the community for people who have sustained an ABI. In particular with ABI, which is often known as the "hidden disability" (as it often does not have any physical features) it is sometimes presumed that someone has made a complete recovery. However, the long term and often challenging nature of their disability is usually unrecognised. Families caring for the person who has sustained an ABI are often dealing with multiple issues such as the loss of emotional support, sharing and companionship and also their loved one's changes in personality, cognition and insight and reduced financial resources.

Given the crucial long term role that family members are often thrust into as carers, primary decisionmakers and providers for those who sustain ABI, families deserve to be involved supported and assisted throughout the phases of acute care, rehabilitation and beyond. Families4Families and their focus on the whole family post-injury takes into account these challenges and offer programs for the whole family. Research evidence on their programs illustrate that this doesn't reduce their focus on the person with ABI at the centre of their member families.

I would strongly support and advocate for this type of group as a valuable addition to the support offered to families impacted by ABI nationally. I hope that this information supports Families4Families' submission. I commend their application to your serious attention. Please feel free to request additional clarification if required, via my contact details below.

Sincerely,

Nick Rushworth **Executive Officer** Brain Injury Australia PO Box 220

Marrickville NSW 1475 Weemala Flat

Royal Rehabilitation Centre Sydney 257 Morrison Road

Ryde NSW 2112 Phone: (02) 9808 9390 Mobile: (0417) 373 622

Email: nick.rushworth@braininjuryaustralia.org.au



### **Government of South Australia**

SA Health

Letter of Support

Re: Families4Families ABI Support Network: "F4F" Ongoing Funding recommendation in view of Need

Represented by Dr Jennifer Farnden

This letter of endorsement and recommendation is based on the findings from indepth family/carer survey, conducted by "F4F", endorsed by SA Brain Injury Rehabilitation Service. There are well-known trends reported in the published literature in this field, that families with a member who has an acquired brain injury have a higher risk of family breakdown, mental health impairment, loss of employment, and adverse impact on wellbeing and academic performance of children.

As a direct result of the work of "F4F" and its volunteers - launched in November 2012 - robust outreach activities and groups of support people have developed across metropolitan, regional and rural areas, many of whom live far from health or counselling services.

Dr Jennifer Farnden has just won won the Rural Doctors Workforce Agency "Community Rural Health & Wellbeing" Community Achievement Award for "F4F".

I am very pleased to furnish a letter in support of the F4F ABI Support Network highlighting the importance, and vital role, of this family support program for people faced with emotional distress and ongoing dysfunction in the head-injured individual, under very difficult and life-changing circumstances. . I can confirm this by my own observations over the past 2 years of dealings with Dr Farnden and "F4F" volunteer staff members, and on clinical contact with clients and families who use and value "F4F"

SA Brain Injury Rehabilitation Service gave use of our client database (in accordance with SA Privacy laws) to assist "F4F" to conduct their initial survey. SA BIRS welcomes "F4F" staff and volunteers to our education forums and promotes the "F4F" Network by displaying brochures and membership information in our ward and clinics. It is planned to start regular monthly "family morning tea" groups at HRC to further nurture these positive ties and begin building links early for such families.

I sincerely hope that the "F4F" ABI Support Network will gain your support to financially enable "F4F" to build sustainable programs aligned with their vision, and to promote:

Increased resilience in families Improved wellbeing and mental health Improved access to community services (via "F4F" referrals / information sharing) Improved family functioning (via "F4F" education on ABI, strategies for behavioural management) Prevention of carer burnout Improved community integration(via social networks through "F4F")in turn promoting self esteem

CENTRAL ADELAIDE LOCAL HEALTH NET-

WORK

Royal Adelaide Hospital

The Queen Elizabeth Hospital St Margaret's Rehabilitation Hospital

HAMPSTEAD REHABILITATION CENTRE

207-255 Hampstead Road Northfield, SA 5085 Tel: +61 8 8222 1600 Fax: +61 8 8222 1608 ABN 21 783 680 287 www.rah.sa.gov.au

SOUTH AUSTRALIAN BRAIN INJURY REHABILITATION

SERVICE (SA BIRS) Tel: +61 8 8222 1851 Fax: +61 8 8222 1926

Brain Injury Rehabilitation Unit (BIRU)

Brain Injury Rehabilitation Community & Home (BIRCH)

**Brain Injury Outpatient Clinics** Concussion, Medical, Neurop Spasticity Manageme

Rehabilitation Physicians Dr Miranda Jelbart, Medical Director Dr M-L Sipski

Traumatic and acquired brain injury has a high incidence and prevalence in SA. It is estimated that only around 20 % of those with traumatic head injuries are seen in health services, and that up to 25% of offenders have had at least one head trauma affecting cognition, behaviour and social integration.

This unmet need is beyond the resources of health services and SABIRS to manage; hence availability of an excellent peer support network is an essential component that should be assisted by the State.

Lommend Families 4Families as a remarkable and effective model of support services which has proven valuable to many of SA BIRS patients and their families (who are also carers in a majority of cases.)

Yours sincerely

and self worth.

Dr Miranda Jelbart, Rehabilitation Physician

Mianda feldant

Medical Director, SA Brain Injury Rehabilitation Service



Adelaide Health Service

Hampstead Rehabilitation Centre

SOUTH AUSTRALIAN BRAIN INJURY REHABILITATION SERVICES (SA BIRS)

> Brain Injury Rehabilitation Community and Home (BIRCH)

> > 8 Briar Road FELIXSTOW SA 5070

08 8360 9600 08 8360 9640

25 November 2013

To whom it may concern

#### Re: Letter of support for Families 4 Families Inc

I provide the following as a letter of support for the work of Families4Families and while they are relatively new, I feel confident to recommend them as a group worthy of any consideration you may provide in regard to funding or other modes of support.

I work as one of the therapists with BIRCH (Brain Injury Rehabilitation Community and Home), the community team of the SA Brain Injury Rehabilitation Service (SABIRS) and have done so for over 20 years. My main areas of work relate to supporting people to begin to re-build a sense of who they are/how they see themselves and supporting them to participate in life roles and activities that hold meaning and value for them (eg work, study, family and recreational roles). As a speech pathologist, I particularly have input around communication, thinking and behavioural changes that may be affecting their aims (eg. changes to memory, concentration, organisation, mental endurance, social communication, comprehension, frustration tolerance, etc). I work with individuals, and where possible, their partners, children, friends and colleagues. I have had the privilege of working along side many individuals and their families as they make every effort to navigate the unknown and generally rough 'seas' of life after an acquired brain injury (ABI). While I am only a clinician and have no concept of what it must be like to live the day to day life challenges after brain injury, I do bear witness to what families and individuals demonstrate and tell me. So many issues arise after an ABI, including significant concerns around access to information, support and services, increased levels of care requirements and associated burden for families, reduced financial capacity, social isolation, stress and distress - all compounded by a persistent lack of general understanding of ABI in the community and services.

Although government and non government services attempt to serve as many people affected by ABI as best they can (and still, many people miss out), an area of service need that has remained an issue over time is that of supporting families and personal networks after an injury. ABI introduces life-long changes and most services have limited capacity for long term service provision, and very few extend input to families. Families4Families is a fantastic peer support service initiative. Its model offers the 'insider knowledge' and expertise of those who have experienced ABI and who have a working knowledge of what to ask, what resources to seek, how to problem solve practical issues, and how to best support oneself and one's loved ones through the enormous life shift and ongoing challenges after a brain injury. Only those who have 'been through it before' can offer this perspective, plus the benefit of lessons learnt along the way. Families4Families uses an impressive, coordinated range of approaches in an effort to facilitate access to people who may find their network helpful. Their community groups, facebook pages, website, phone supports, follow up efforts, training services, fund raising and other activities demonstrate an incredible commitment and resourcefulness to meet the needs of their ever growing membership group, all within a very tight budget, augmented by a sizeable volunteer base.

The BIRCH team values the unique resource that Families4Families offers and we regularly make referrals and ensure information about them is accessible to all those we serve. I regularly hear reports of how helpful and valuable Families4Families has been for people with ABI and their families, and feel this is a very important component to helping families 'stay afloat'. Families4Families' peer support for parents and partners is impressive as are their efforts to attend to the needs of children (younger and older) whose parents are affected by ABI. Children are able to have their feelings normalised by meeting with others who have similar experiences. They can share a sense of belonging and understanding (especially

important in the context of a wider community that tends not to understand), and over time, their confidence and capacity can develop via opportunities to mentor and support others in meaningful ways.

The other feature that gives me confidence to recommend of Families4Families, is their research component and link with the Disability and Community Inclusion Unit at Flinders University. Families4Families demonstrate an active approach to their planning, evaluation and reporting to ensure they understand the needs of their key stakeholders, that they are providing what their consumers require, and that they are doing so in an accountable, thoughtful manner that provides positive outcomes. They have released interim reports outlining a thorough review of the relevant literature and clear descriptions of need from focus groups, and they continue to gather data for analysis to ensure they are actively evaluating what they do. Future reports will be forthcoming as their project progresses. Under the professional, skilful, tireless and resourceful leadership of Dr Jen Farnden and the F4F Management Committee, Families4Families are providing essential peer support services to individuals and families affected by ABI, and are helping to:

- maintain people's personal, social and support networks (- and given the well established evidence around outcomes being better for those who have family and personal supports, the value of maintaining networks cannot be ignored, let along the economic value of this support being provided by those who do not draw a salary to do so)
- nurture and support direct caregivers, encourage their wellbeing, and prevent carer burnout as much
- attend to the needs of families, support them as a unit, and build their capacity and resilience including the very important and often missed needs of young and older children of those who may have parents affected by ABI
- link people to other relevant supports, opportunities, information and services
- build a sense of belonging and community for all members thus contributing to positive mental health and wellbeing
- provide people affected by ABI with meaningful and important roles with which to contribute their time, skills and experience, and help them to construct a positive sense of self and meaning after the onslaught of ABI – and with this, they are more able to feel good about themselves, which helps the functioning of the family unit/personal networks.

Families4Families' model of peer support and involvement of volunteers also holds a promising future for sustainability, provided they have access to a relatively small amount of ongoing core funding. Their service is cheap when you consider the benefits to the individuals and the community as a whole!

I strongly encourage you to consider providing financial support if it is at all possible, and am confident to commend them as a unique and effective peer-support service option for the many individuals and families affected by ABI in this state. I view them as a very important part of the ABI service network in South Australia.

Yours sincerely

Liz Williams Speech Pathologist

Brain Injury Rehabilitation Community and Home (BIRCH)



Disability and Community Inclusion Flinders Clinical Effectiveness School of Medicine Faculty of Health Sciences Sturt Buildings, South Wing GPO Box 2100 Adelaide SA 5001

Tel: 08 8201 3423 Fax: 08 8201 3646 Ruth.Crocker@flinders.edu.au ABN 65 542 596 200

CRICOS Provider No. 00114A

Dear Sir/Madam,

#### Re: Families4Families

I am writing with respect to endorsement of the attached funding application. As a member of the Families 4Families research team, I have been involved in exploring the experiences and needs of families living with acquired brain injury in South Australia. During the initial stages of the research project and development of the Families4Families ABI Support Network, I have been involved in providing direct support in the following ways:

- Facilitating focus groups in metropolitan and country locations
- Developing and running information sessions based on assessed needs and interests of members of the Network; to date these have included:
  - o Loss and Grief Following ABI, and
  - o Mental Health and ABI
- Attending other country sessions to provide additional support
- Supervising a senior student of the Bachelor of Disability and Developmental Education (BDDE) who has undertaken a practicum with Families4Families
- Initiating and further developing links with community-based mental health services to facilitate exchange of knowledge and skills in ABI and mental health, with a goal of improving access to and sustainability of mental health support for people living with ABI.

The areas in which I have been involved to date have enabled application of my knowledge and skills as a Rehabilitation Counsellor (RC), and a commitment to future in-kind participation to support the above application is based on my interest in and willingness to facilitate further development in related areas. These include:

- Supervision of future student placements, which will include specific placements for students undertaking a proposed major in rehabilitation counselling within the BDDE
- Attendance at and presentation to groups in country and metropolitan locations
- Further development of links between ABI and mental health organisations and support services to more effectively meet the expressed and assessed needs of families living with ABI
- Participation in future research projects in rehabilitation and mental health for individuals and family members living with ABI in South Australia.



As outlined in the application to which this letter is attached, and based on my involvement in the Families4Families project to date, the unmet needs of all members of families living with ABI are significant, and range across the lifespan. There is an urgent need to expand and improve supports available to this group of people in order to maintain family networks and enhance the quality of life of the members of each family, individually and collectively.

Feedback in relation to activities in which members of the Families4Families ABI Support Network are involved provides evidence of the value of the network in facilitating and encouraging volunteer participation, thus enhancing capacity for sustainability on a longer term basis.

If any further information about my commitment to and ongoing community service contribution towards enabling potential outcomes of the Families4Families Grant Application would be helpful, please do not hesitate to contact me for further details.

Yours faithfully

Ruth Crocker AssocDipRC, GradDipHlthSc (ComHlth), MA Lecturer, Coordinator Graduate Certificate in Disability Studies

## **Appendix C**

### **Organisations Providing Support to Families 4Families**

Entities Approached and Details	Outcomes
Flinders University will provide significant resources to this project. This includes providing insurance cover for the project's activities, sophisticated and strong internal controls, equipment including office space and IT resources, vehicles for transportation (including minibuses for support outings and alike), printing facilities and a broad range of other systems. Perhaps even more valuable are the benefits received from the valuable contributions of many senior and experienced academics within the research team. <sup>26</sup>	Support confirmed
Julia Farr MS McLeod Benevolent Fund has funded in full the Stage One and Stage Two research encompassing the Pilot Program being delivered from January 2013 – June 2014. The final stages of this project, the Stage Two final data collection and analysis and final report writing, are also funded with all deadlines concluding 30 September 2014.  In addition, in November 2013 a Second Phase 'Building Sustainable Capacity' Project application was submitted by Flinders University to Trustees upon request by Dr David Caudrey. Trustees have now assessed this application and it has been successful.  The 'Building Sustainable Capacity in Families4Families' project will run July 2014 – June 2015 based on a number of conditions. Julia Farr management have offered additional in-kind support including a member for our research team and additional external evaluation.	\$162,502 Provided 2012-14. \$100,000 Support confirmed for 2014/15 from Second Stage Grant Accepted.
Families4Families has obtained an Office for Youth, SA, <u>YouthConnect Grant</u> for a \$50,000 one-off project. Ted Evans, Chief Policy Officer, Department for Communities and Social Inclusion: Policy and Community Development, Office of Youth Policy and Dr David Caudrey were referees on the project application. This submission requested funding to cover the cost of a Volunteer Coordinator up to a total cost of \$50,000 to enable Families4Families to offer programs specifically aimed at children/young people with ABI, Young Carers and Young Volunteers.	Application confirmed June 2014 for 2014/15 period, \$50,000.
Carers Support SA (respite funding for the South East Metro segment of SA) has agreed, and contracted, to provide funding ongoing for the Families4Families Carers Dinner Club program. Members attend a dinner with the support of carefully selected support workers and their Carers attend a dinner nearby on a monthly basis within the South East Metro Respite Area. These dinners go extremely well, and we are pleased to have secured \$8640 pa recurrent for this (copy of contract available if required). Feedback from these events is favourable – while all our other programs offer joint activities, this opportunity to both Carers and Carees to be independently sharing their stories and experiences in a social setting has led to very high levels of satisfaction. However, it is felt that this is due to the fact that usually our programs are family-centric and hence this is considered a positive opportunity rather than being reflective of members wanting more separate activities.	Ongoing Funding for Carers Dinner Club Program, \$8640 pa.
The Head of Disability Services for South Australia, Dr David Caudrey, has had several meetings with the Families4Families Manager and is supportive of the program developed so far and its need to continue and evolve. The Network has the opportunity to approach the Department with a view to gaining some financial assistance but the Department is currently experiencing a	Ongoing Support.

<sup>26</sup> Flinders University has agreed to a full waiver of their usual 25% infrastructure levy as was provided for the Pilot Program project. Families4Families will benefit from the provision of School of Disability and Community Inclusion, Faculty of Health Sciences Infrastructure (as documented in the attached letter of support from Departmental Head Dr Caroline Ellison). The network will utilise all established HR, payroll, personnel, legal and finance systems provided by the University and will gain significant savings from placing programs, personnel, events, staff and assets under the established insurance and indemnity policies. In operating the network, full use of available facilities provided by this Levy will also be utilised, including office space (an individual office is provided to the Network), IT resources will be provided (to support the use of equipment purchased by the Network), and travel and transportation will also be accessed (including use of University mini buses and cars for staff and family transportation).

period of strong budgetary cuts and this has not been possible. Families 4Families Manager has provided training to Disability Services staff (fee based) and this has been received very positively. It is likely there will be additional scope for such training within DS and privately. Feedback from this training included:

"Everyone thought the day was fantastic, the feedback from the team has been amazing. I have never had feedback about training like I did that day. I thought the fact you added humour and really personalised the stories made it real and people got to understand the families perspective which is so important in our field. The explanation on what an ABI was and examples gave some insight into why people do what they do and this is very beneficial for staff to understand. I will be spreading the word about your organisation throughout Disability Services and recommending your training package to others. Thankyou so much, we had a great time. I would like to stay in contact - do you have a mailing list that I could join?

The Office for Volunteers to the South Australian volunteer community: Volunteer Support Fund (grants of up to \$3,000) and Federal grants are available. It is envisaged that Families 4Families will obtain at least \$5,000 from grant applications undertaken for the project period.

Application(s) to be Submitted, \$5,000 pa.

Each year the SACWA (South Australian Country Women's Association) selects a single community group and then directs all their fundraising efforts and outcomes toward this 'State Objective'. Families 4Families was nominated and came runner up to another charity for its State Objective for 2014/15. The SACWA has now requested we again apply for its State Objective for 2015/16 which we have undertaken. Announcement expected in January 2015.

Nomination Accepted, Outcome announced Jan 2014

The Friendship Foundation has selected Families 4Families as one of their Community Partners for their upcoming International Gratitude Day. As the only South Australian community group selected, the opportunities for future fund raising once this day is established is significant. Families4Families is hoping to raise approximately \$60,000 per annum from this event once it is running well, and are hopeful this would also raise our profile nationally.

Selection as **Community Partner** 

Other organisations and departments have committed ongoing support to Families4Families:

- Edwardstown Lions Club have committed to undertake various supporting roles in SA.
- City of Marion: Office and meeting room space at Glandore Community Centre for \$764 pa (including all outgoings) due to our community rate status being accepted.
- The Brain Injury Rehabilitation Services (BIRS)<sup>27</sup> have provided a letter of support for this proposal, continue to provide referrals and Families4Families information distribution and provide members on our Advisory Panel.
- Links with Brain Injury Australia (BIA) have been developed as documented in the Letter of Support enclosed in Appendix B.
- Carers SA have selected Families 4Families as a referring organisation for its Counselling Services, regularly support the Network via media and other coverage including the successful nomination of F4F Manager for a recently held Community Achievement Award<sup>28</sup>.

<sup>27</sup> The statewide rehabilitation ABI services encompassing the inpatient Brain Injury Rehabilitation Unit (BIRU) at the Hampstead Rehabilitation Centre and the outpatient Brain Injury Rehabilitation Community and Home (BIRCH).

<sup>28</sup> Information on the recently awarded Community Achievement Award for Dr Jennifer Farnden is provided in the end of Appendix E.

## **Appendix D**

### **Initial Budget Submitted with Grant Application**

Indicative Budget and Cash Flow What resources, eg staffing, equipment, IT, infrastructure and expenditure will be required for the project?<sup>29</sup> (costs exclusive of GST)

BUDGETARY CATEGORIES AND ITEMS	Total \$s	Research \$s	Support \$s
STAFF BUDGET	Total Project	Research Staff	Network Staff <sup>30</sup>
Project Coordinator (HEO4) 0.1 (20%) Research <sup>31</sup> + 0.4 (80%) Network for 18 months.	37,344.00	7,468.80	29,875.20
<ul> <li>Project Manager and Research Coordinator (HEO6) 0.1 (25%) Research<sup>32</sup> + 0.5 Network (0.2 of this paid) (75%) for 23 months.</li> </ul>	55,293.26	13,823.32	41,469.94
• Clerical Assistance: transcription of 20 individual interviews and 3 focus groups (3 hours transcription have been allowed per one hour interview @ \$30/hour, 4 hours transcription have been allowed per hour focus group @ \$34/hour plus on-costs).	2,208.00	2,208.00	0.00
RAH Administrative Assistance.	1,000.00	1,000.00	0.00
On-costs for all relevant positions	18,485.01	3,957.97	14,526.91
TOTAL STAFF BUDGET:	114,330.27	28,458.09	85,872.05
SUPPORT/OPERATIONS BUDGET			
Total Social and Recreational Support Event Budget	10,550.00	0.00	10,550.00
Total Peer Support Budget (incl transportation/travel)	15,371.00	0.00	15,371.00
Total Volunteer Management, Training and Reimbursements Budget	3,880.00	0.00	3,880.00
TOTAL SUPPORT/OPERATIONS BUDGET:	29,801.00	0.00	29,801.00
ORGANISING BUDGET			
Overhead and Variable Expenses	10,620.00	5,800.00	4,820.00
Fixed expenses (including investment in network owned IT)	2,700.00	0.00	2,700.00
TOTAL ORGANISING BUDGET:	13,320.00	5,800.00	7,520.00
MARKETING BUDGET			
Marketing Materials and Website	5,050.00	0.00	5,050.00
TOTAL MARKETING BUDGET:	5,050.00	0.00	5,050.00
TOTAL CTAFF DUDGET		20.450.00	05 072 05
TOTAL SUPPORT/OPERATIONS PURCET		28,458.09	85,872.05 29,801.00
TOTAL SUPPORT/OPERATIONS BUDGET		0.00	29,801.00

TOTAL STAFF BUDGET	28,458.09	85,872.05
TOTAL SUPPORT/OPERATIONS BUDGET	0.00	29,801.00
TOTAL ORGANISING BUDGET	5,800.00	7,520.70
TOTAL MARKETING BUDGET	0.00	5,050.00

<sup>29</sup> Additional detail for the budgetary plan based on the Appendix B proposed model is provided in Appendix D.

<sup>30</sup> Staff time is required in all aspects of managing the Network: Project management, strategic planning, financial management, government and organisational liaison, oversee support programs manage volunteers, project coordination, liaising with families, point of contact for enquiries, coordinate volunteers, meet with families, attend and support at events, marketing information provision and dissemination. Individuals will need to be highly motivated, organised and skilled in a range of professional fields to fulfil these needs, thus it is proposed that two staff members are recruited to enable an efficient and effective team: Project Manager and Project Coordinator.

Administratively, the Project Coordinator will assist in liaising with research project families, be a point of contact for research enquiries, provide research information to families and attend and support at any required research events.

<sup>32</sup> Staff time in the research project will be limited to the Project Manager's involvement with: data collection, data analysis along with the principal researcher, generating research reports including assisting with writing reports and other publications, and coordinating with departments and organisations for access.

BUDGETARY CATEGORIES AND ITEMS	Total \$s	Research \$s	Support \$s
IN KIND CONTRIBUTIONS & VOLUNTARY WORK:			
Project Development, preliminary research, collaborations & meetings and grant application work, estimated value provided.	47,105.00	23,552.50	23,552.50
Project Manager and Research Coordinator (HEO6) 0.2 voluntary position estimated value of 23 months including on-costs.	27,646.63	6,911.66	20,734.97
Flinders University infrastructure provision, based on 25% levy usually placed on all new projects undertaken. Includes savings for all insurances, organisational systems, facilities, etc.	40,625.00	8,564.52	32,060.48
TOTAL IN-KIND CONTRIBUTIONS INCLUDED33:	115,376.63	39,028.68	76,347.95

Total Cost of Research & F4F ABI Support Network including in-kind voluntary contributions utilised:	277,878.47	73,286.77	204,591.7
Research & Families4Families Funds Requested for Project:	162,501.84	34,258.09	128,243.75

#### **Total Funds Requested for Project:**

\$162,501.55

Ongoing costs for operating the network beyond September 2013 are likely to be approximately \$60,000.00 pa and the funding to allow this group to continue may include membership fees (\$5-10,000 pa); volunteer training grants (\$5,000 pa); fundraising efforts (anticipated to be \$20,000 pa); organisational contributions; funding from DSA upon proof of outcomes; training, consulting and presentations to ABI professionals and medical/educational facilities (already being undertaken by members); one-off community grants such as Commonwealth Bank and alike (\$10,000 pa) and other potential sources such as State government, and Federal government grants based on the mental health evidence that will be collected and available subsequent to the research project being successfully undertaken. That said, due to a clear project outcome being the establishment of ongoing and informal networks of families, even if the project is not successful in continuing beyond the end of this pilot it is believed significant gains will have been made for those individuals living with ABI. The informal networks will continue to give support to those with an ABI and their extended family 'teams' of support.

### **Project Cost/Benefit Analysis** | How much will it cost and how many people will benefit?

The total cost of Stages 1 to 4 is \$162,501.55 and this amount is sought from the Julia Farr MS McLeod Benevolent Fund. Research funding of \$34,258.09 will facilitate the inclusion of over 100 families in collecting and analysing data on the experiences, quality of life, mental health and support needs of families with ABI throughout South Australia. Findings from this research will be used to develop and implement a framework of effective social support, information provision, peer support and recreational supports for these family units. Ongoing assessment during support provision will be undertaken and will conclude with a final assessment of the wellbeing, mental health and unmet needs of additional family members allowing comparisons to be drawn from the initial measures taken prior to the establishment of the network. Over one hundred family members will be involved in the research project and, it is hoped, several hundred family members, including those members with an ABI, will benefit from the social supports provided over a period of 18 months. The project has the potential to benefit all families living with ABI in South Australia. Further, the research findings on the impact of providing social support to those with an ABI as well as their family members and carers has the potential to influence national and international ABI support practices.

Flinders University academic staff involvement in this project (Dr Michelle Bellon, Ruth Crocker and Prof Richard Bruggemann) will be undertaken pro bono. In addition, postgraduate students involved in the research project will allow further savings for the research budget. These large contributions are difficult to undertake accurately hence have not been included in these in-kind contribution calculations.

# **Appendix E**

## **Budget versus Actual Expenditures Pilot Program**

CATEGORY BUDGETARY TOTALS		Jun-12	Jul-12		Aug-12		Sep-12		Oct-12		Nov-12		Dec-12		Jan-13
TOTAL STAFF COSTS	\$	2,749.67	\$ 3,784.10	\$	2,774.10	\$	2,774.10	\$	3,291.54	\$	2,867.34	\$	2,867.34	\$	4,591.
TOTAL SUPPORT EVENT COSTS	\$	- (	\$ 200.00	\$	-	\$	90.00	\$	135.00	\$	180.00	\$	180.00	\$	2,450.0
TOTAL PEER SUPPORT COSTS	\$	192.00	\$ 297.00	\$	524.00	\$	552.00	\$	597.00	\$	642.00	\$	642.00	\$	642.0
TOTAL VOLUNTEER COSTS	\$	- (	\$ 10.00	\$	200.00	\$	210.00	\$	210.00	\$	30.00	\$	30.00	\$	210.0
TOTAL SOCIAL & PEER SUPPORT C	OSTS \$	192.00	\$ 507.00	\$	724.00	\$	852.00	\$	942.00	\$	1,372.00	\$	672.00	\$	3,302.0
TOTAL ORGANISING BUDGET:	\$	30.00	\$ 85.00	\$	3,485.00	\$	1,305.00	\$	1,857.50	\$	705.00	\$	105.00	\$	1,605.0
TOTAL MARKETING COSTS	\$	- (	\$ 184.00	\$	-	\$	2,056.00	\$	-	\$	640.00	\$	1,750.00	\$	200.0
MONTHLY TOTALS	\$	2,971.67	\$ 4,560.10	\$	6,983.10	\$	6,987.10	\$	6,091.04	\$	5,584.34	\$	5,394.34	\$	9,698.5
CATEGORY ACTUAL TOTALS	•		<b>1</b> 505 44		1,000,11	•	1 101 00	•	5.050.00	•	1 107 05	•	0.404.00	•	1.101
TOTAL STAFF COSTS TOTAL SUPPORT EVENT COSTS	\$	- 3	\$ 1,565.44		1,089.41	\$	1,424.92		5,352.00	\$	4,407.25		-,	\$	4,181.
TOTAL PEER SUPPORT COSTS	\$	510.00	\$ 200.00 \$ 885.00	_	1,136.25	\$	503.62 643.10		19.00	\$	120.00 15.00			\$	1,509. 536.
TOTAL VOLUNTEER COSTS	\$	- 9		\$	1,136.23	\$	043.10	\$	17.00		76.00	_	-	\$	216.
TOTAL VOLUNTEER COSTS	T	510.00	*		1.136.25		1.146.72	-	36.00	\$	211.00	_		Φ	2,262.
TOTAL ORGANISING BUDGET:	¢ 2100	178.33	, , , , , , , , , , , , , , , , , , , ,		2,868.23	_	192.92		461.77	\$			2,609.74	φ	828.
TOTAL MARKETING COSTS	\$	- 9	\$ 33.24	_	2,000.25	\$	1,916.00		-	\$	-	\$	-	\$	-
MONTHLY TOTALS	\$	688.33		_	5,093.89	\$	4,680.56	_	5,849.77	\$	7,091.29	\$	6,101.36	\$	7,272.
VARIANCE ANALYSIS:	\$	2,283.34	\$ 1,334.23	\$	1,889.21	\$	2,306.54	\$	241.27	\$	(1,506.95)	\$	(707.02)	\$	1,532.

Feb-13		Mar-13	Apr-13	May-13	Jun-13	Jul-13		Aug-13	Sep-13	Oc	ct-13	Nov-13	Dec-13
\$ 4,591.58	\$	4,591.58	\$ 5,349.02	\$ 5,349.02	\$ 5,349.02	\$ 5,349.02	\$	5,349.02	\$ 4,553.29	\$ .	4,553.29 \$	4,553.29	\$ 5,349.02
\$ 1,220.00	\$	740.00	\$ 970.00	\$ 1,220.00	\$ 540.00	\$ 540.00	\$	1,950.00	\$ 400.00	\$	1,100.00 \$	1,350.00	\$ 900.00
\$ 642.00	\$	642.00	\$ 670.00	\$ 670.00	\$ 670.00	\$ 642.00	\$	642.00	\$ 670.00	\$	670.00 \$	670.00	\$ 670.00
\$ 30.00	\$	30.00	\$ 220.00	\$ 40.00	\$ 40.00	\$ 1,230.00	\$	30.00	\$ 40.00	\$	40.00 \$	40.00	\$ 40.00
\$ 1,892.00	\$	1,412.00	\$ 1,860.00	\$ 1,930.00	\$ 1,250.00	\$ 2,412.00	\$	2,622.00	\$ 1,110.00	\$	1,810.00 \$	2,060.00	\$ 1,610.00
\$ 105.00	\$	105.00	\$ 1,005.00	\$ 105.00	\$ 105.00	\$ 105.00	\$	105.00	\$ 105.00	\$	105.00 \$	605.00	\$ 157.50
\$ -	\$	-	\$ -	\$ 40.00	\$ -	\$ 100.00	\$	-	\$ 40.00	\$	- \$	-	\$ -
\$ 6,588.58	\$	6,108.58	\$ 8,214.02	\$ 7,424.02	\$ 6,704.02	\$ 7,966.02	\$	8,076.02	\$ 5,808.29	\$	6,468.29 \$	7,218.29	\$ 7,116.52
\$ 6,493.64	\$	2,453.55	\$ 3,307.00	\$ 3,878.50	\$ 4,054.85	\$ 3,461.08	\$	4,689.83	\$ 4,732.33	\$ .	4,731.08 \$	5,588.58	\$ 4,386.08
\$ 1,665.46	\$	70.68	\$ 1,116.66	\$ 490.29	\$ 349.95	\$ 1,139.97	\$	4,521.94	\$ 1,212.38	\$	1,858.28 \$	561.77	\$ 433.64
\$ 485.84	\$	-	\$ 535.36	\$ 627.07	\$ 252.34	\$ 2,365.04	\$	349.59	\$ 627.56	\$	1,346.34 \$	372.00	\$ 464.65
\$ 48.55	\$	30.64	\$ 123.14	\$ 58.27	\$ 128.17	\$ 625.85	\$	316.17	\$ 152.84	\$	- \$	32.13	\$ -
\$ 2,199.85	\$	101.32	\$ 1,775.16	\$ 1,175.63	\$ 730.46	\$ 4,130.86	\$	5,187.70	\$ 1,992.78	\$ :	3,204.62 \$	965.90	\$ 898.29
\$ 328.00	\$	259.08	\$ 1,475.44	\$ 579.71	\$ 486.65	\$ 1,325.06	\$	679.54	\$ 1,425.93	\$	451.17 \$	246.94	\$ 229.83
\$ 1,805.95	\$	-	\$ 124.13	\$ 612.66	\$ -	\$ 260.31	\$	76.50	\$ 1,366.50	\$	47.27 \$	-	\$ -
\$ 10,827.44	\$	2,813.95	\$ 6,681.73	\$ 6,246.50	\$ 5,271.96	\$ 9,177.31	\$	10,633.57	\$ 9,517.54	\$	8,434.14 \$	6,801.42	\$ 5,514.20
	L						L					_	
\$ 1.177.52	\$	1.432.06	\$ 1.532.29	\$ 1.177.52	\$ 1,432.06	\$ (1,211.29)	\$	(2,557.55)	\$ (3.709.25)	\$ (	1.965.85) \$	416.87	\$ 1,602,32

Jan-14	Feb-14	Mar-14	Apr-14	May-14	Jun-14	TOTAL
\$ 5,349.02	\$ 5,349.02	\$ 4,326.18	\$ 5,008.28	\$ 3,322.47	\$ 7,121.12	\$ 113,974.00
\$ 1,000.00	\$ 1,250.00	\$ 400.00	\$ 900.00	\$ 1,950.00	\$ 1,400.00	\$ 11,300.00
\$ 520.00	\$ 625.00	\$ 625.00	\$ 580.00	\$ 342.00	\$ 167.00	\$ 14,205.00
\$ 30.00	\$ 40.00	\$ 40.00	\$ 40.00	\$ 10.00	\$ -	\$ 2,660.00
\$ 1,550.00	\$ 1,915.00	\$ 1,065.00	\$ 1,520.00	\$ 2,302.00	\$ 1,567.00	\$ 28,808.00
\$ 105.00	\$ 105.00	\$ 105.00	\$ 190.00	\$ 190.00	\$ 2,190.00	\$ 14,670.00
\$ 40.00	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 5,050.00
\$ 7,044.02	\$ 7,369.02	\$ 5,496.18	\$ 6,718.28	\$ 5,814.47	\$ 10,878.12	\$ 162,502.00
\$ 4,297.23	\$ 4,865.11	\$ 4,866.36	\$ 3,384.10	\$ 5,390.83	\$ 6,136.14	\$ 99,057.24
\$ 1,593.29	\$ 493.63	\$ -	\$ 1,099.40	\$ 1,902.86	\$ 1,265.35	\$ 22,108.86
\$ 1,196.08	\$ 44.45	\$ -	\$ 614.11	\$ 999.87	\$ 585.00	\$ 14,609.90
\$ 1,273.25	\$ 556.90	\$ 390.30	\$ -	\$ 35.77	\$ 81.15	\$ 4,162.49
\$ 4,062.62	\$ 1,094.98	\$ 390.30	\$ 1,713.51	\$ 2,938.50	\$ 1,931.50	\$ 40,881.25
\$ 1,386.76	\$ 1,275.26	\$ 415.16	\$ 633.86	\$ 2,476.70	\$ 1,971.31	\$ 25,801.19
\$ 77.27	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 6,319.83
\$ 9,823.88	\$ 7,235.35	\$ 5,671.82	\$ 5,731.47	\$ 10,806.03	\$ 10,038.95	\$ 172,059.51
\$ (2,779.86)	\$ 133.67	\$ (175.64)	\$ 986.81	\$ (4,991.56)	\$ 839.17	\$ (9,557.51)

# **Appendix F**

## **Volunteer Hours Table and Calculations**

										14,669.34															34346392		5 21,761.34	346,628.70	\$ 486,513.30
	Г									1813															1171.85		474	5445	8903.85
Total hours	00'6E	49,00	920.50	157.50	2.50	426.50	10.50	110.00	300	94.50	224.05	221.15	165.00	195.65	15.50	93.50	16.00	24.00	66.50	100.50	15.00	8,00	15.00	3.00	00.6	371.00	10300	5.445.00	\$903.85
Jun-14	0	0	99	125	0	Ю	2	10	m	60	α	0	10	235	1.5	0	ю	51	36	4.5	0	00	SĮ.	m	0	16	0	277	564
May-14	0	0	8	125	25	ы	0	۵۱	0	7	365	0	۵	235	0	25	30	6	15.5	15	ß	0	0	0	0	16	0	202	955
Apr-14	0	0	59.5	125	0	25.5	55	9	0	12.5	12	0	9	2315	0	0	0	0	0	51	0	0	0	0	0	87	0	253	472.65
Mar-14	0	e	18	12	0	ผ	e	00	0	15	30.1	0	12	18	0	0	0	0	0	5	0	0	0	0	0	15	0	283	1.689.1
Feb 14	0	0	6	12	0	R	0	9	0	11	21.2	0	00	31.5	53	2	0	0	0	35	0	0	0	0	0	02	0	22	463.7
Jan 14	0	0	52	п	0	æ	0	9	0	15	55	o	0	m	0	0	0	0	15	9.5	o	0	o	0	0	60	0	001	21
Dec 13	D	0	6	12	0	8	0	ę	0	2	12	183	15	<b>с</b> л	0	16	0	0	b	33	0	ь	0	ь	D	12	0	408	661.5
Nov-13	0	0	ফ	6	0	8	0	9	0	4	145	13	10	175	7.5	16	0	0	0	14	0	0	0	0	0	22	0	382	603.5
0ct-13	0	0	2	m	0	Я	0	S	0	14	7	27.75	S	m	0	0	0	0	0	æ	0	0	0	0	0	16	0	335	510.75
Sep-13	0	0	ঠ	10	o	ล	0	9	0	4	15	3815	10	o	o	o	o	o	o	63	o	0	0	o	0	47	0	556	516.65
Aug. 13	0	o	ខ	on	О	8	o	ę	o	0	20.75	30.75	'n	o	U	w	o	o	o	ę	o	U	o	o	0	.5	o	322	514.5
Jul-13	7	7	73	12	0	28	0	φ	0	0	145	365	8	0	0	0	0	0	0	9	0	0	0	0	0	83	2	238	526
Jun 13	305	193	Ы	4	0	R	0	9	0	0	0	0	12	0	0	0	0	0	0	0	0	0	0	0	0	15	ın	330	464.5
May13	11.5	13	ю	4	0	8	0	9	0	0	12	0	9	00	0	6	0	0	٥	0	o	0	0	0	6	œ	80	\$Z\$	4795
Apr-13	0	0	ы	7	0	ล	0	9	0	0	0	0	00	0	0	-1	0	0	0	0	0	0	0	0	0	16	2	408	496
Mar-13	0	0	кз	7	0	8	0	g	0	0	0	0	9	11.5	0	10	0	0	0	0	0	0	0	0	0	16	10	329	4385
Feb-13	0	0	Ю	4	0	8	0	9	0	0	0	0	12	17	0	16	0	0	0	0	0	0	0	0	0	16	æ	287	438
Jan-13	0	0	Ю	4	0	St.	0	9	0	0	0	0	9	0	0	9	0	0	0	0	0	0	0	0	0	0	ĸ	287	218
HEDLevel	(Ŧ)	(1)	(Ŧ)	(*)	(17)	(1)	(v)	(1)	(4)	(7)	7	4	4	ব	4	ব	ব	ব	ব	ব	ব	4	4	4	4	S	S	00	
Name H	Karlia Brown	racey Mesing	8arb Bishop	Barry Bishop	Emily Bennett	Pam Bennett	June Menties	Geoff McConnel	Pamela Amold	MarieKnight	Sandra McCung	Kathryn Shepphard	Ruth Crocker	Di Cameron	SamMcKentie	Michele Bellan	Danielaštaři	Jules Nunn	Menyn Hackett	AnnetteRae	PaulneShinkfield	KenSleerran	Sharon Clark	Lynette Harnan	ani Ebbs	Victoria Allen	Sandi Sando	Jennifer Famcien	