Dr Jennifer Farnden OAM

Resilience, Participation & Belonging Post ABI –
Lived Experience Based Peer Support Programs & their Applicability in an NDIS World

National Acquired Brain Injury Conference
Royal Ryde 8-9 November 2016

Wednesday 9 November 2.50 pm

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The Impact of Acquired Brain Injury

The brain injured family …

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My Lived Experience of ABI

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ABI Research re Support Needs

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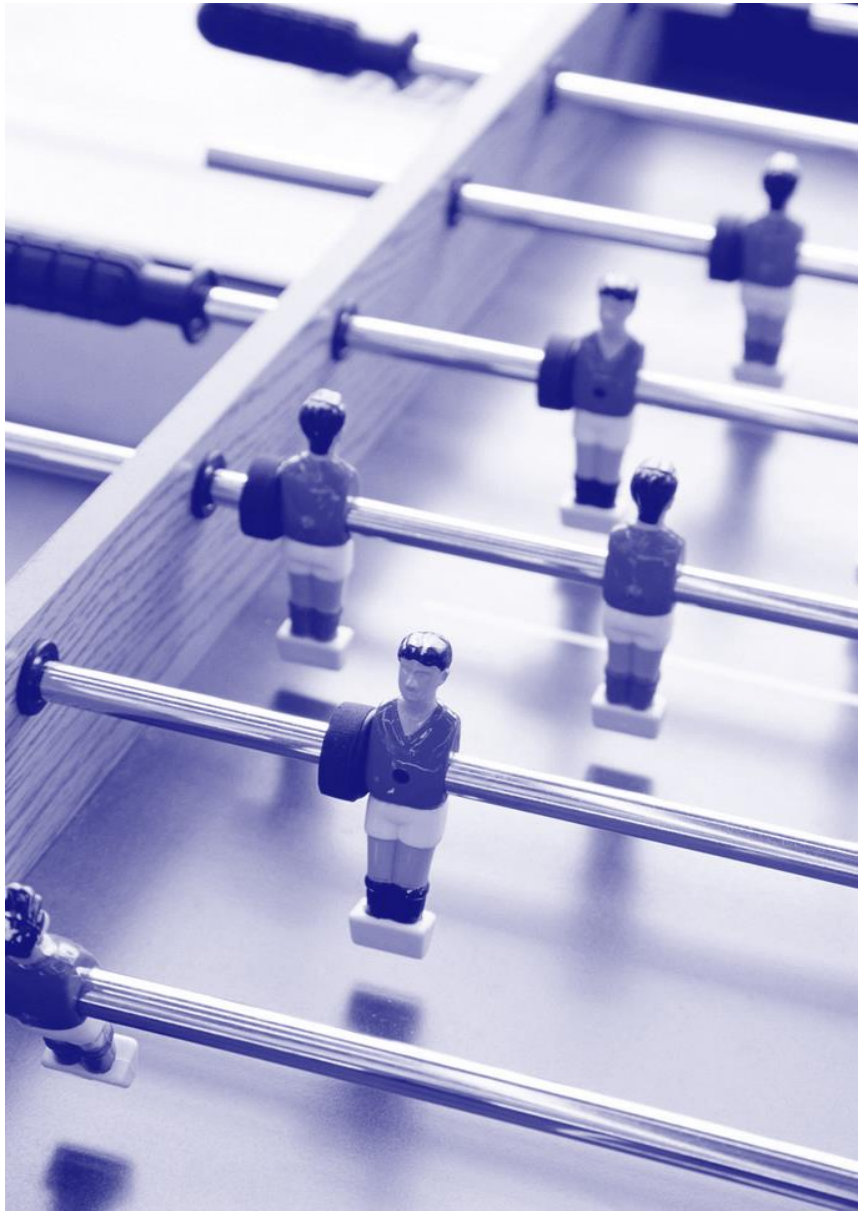

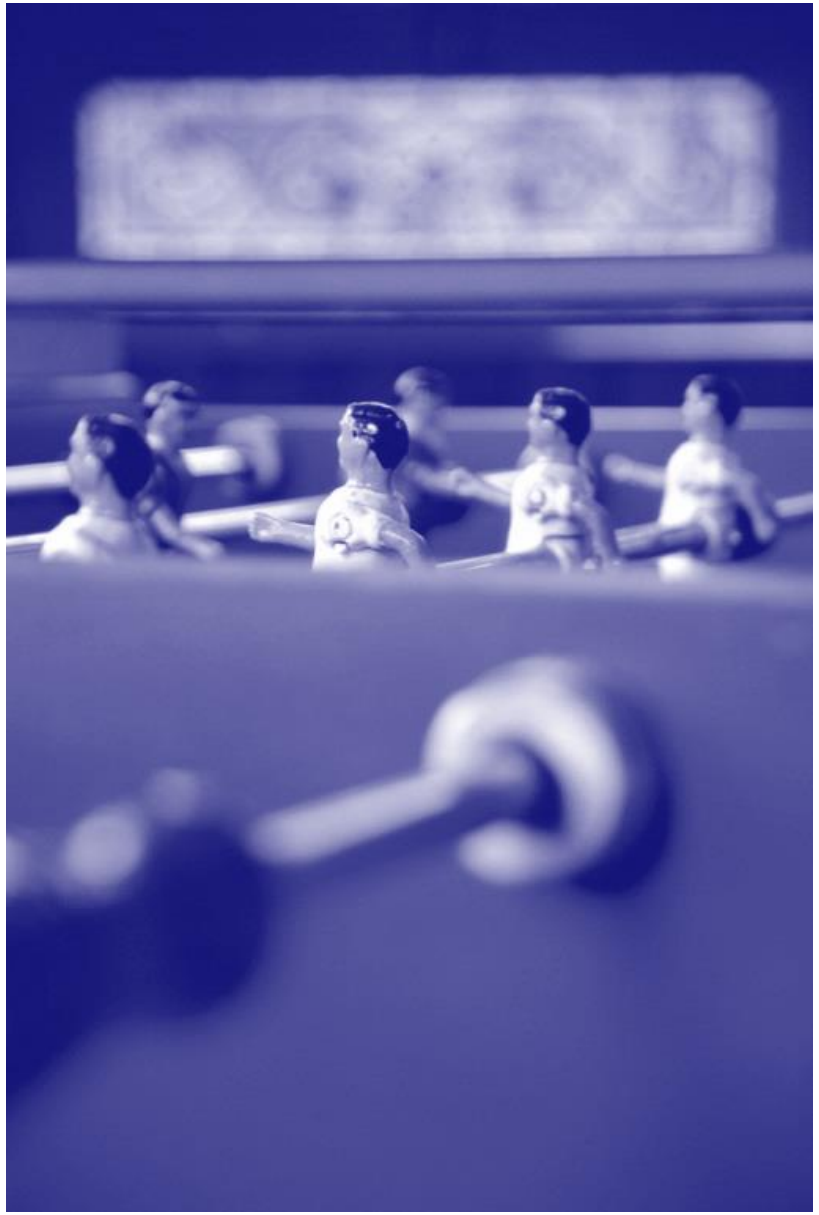

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Network Conception

Concern for remote/rural families

Concern for those isolated, without Information

Meeting Others

Information & Education

Peer Support Network Idea

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Network Conception

THANK YOU

CRP

Community Re-entry Program

for supporting our grant application, being our auspicing agent, and believing in the project.

Julia Farr

MS McLeod Benevolent Fund

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Positive Psychology Foundations

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Positive Psychology ➔ Peer Support Model

Information/ Education

Connection with others *(combined with inability to travel due to fatigue)*

Focus Groups & Surveys

(Stage 1 Research Findings)

Critical member input to design

Local (Peer) Support Groups
(providing developed content = Information Topics)
Website
Facebook Page
Facebook Groups
Phone support/referrals
Email support
Relationship Management Approach

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Stage 1 Research

Survey

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Focus Groups

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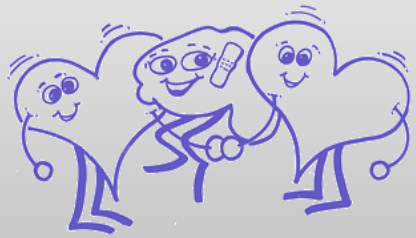
Families4Families
ABI Peer Support Network



July 2012

Stage 1

Stage 1 Research

Survey

22 questions:

- Demographic & diagnostic data
- Areas of unmet need

Total 2622 surveys sent:

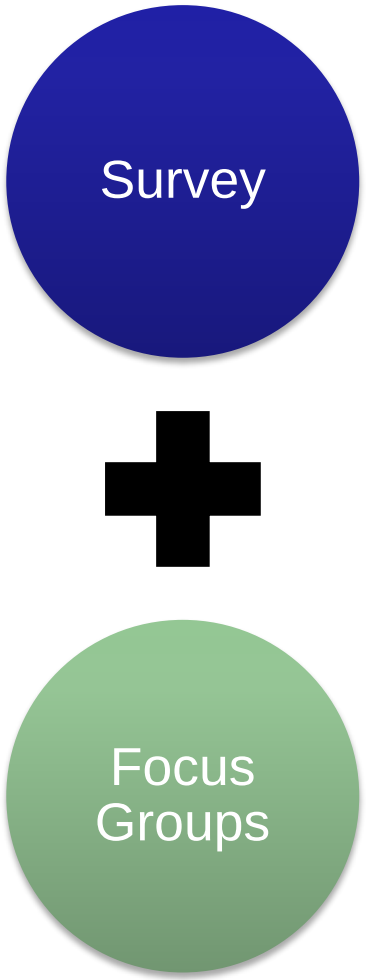
- Posted by SA BIRS to client database who received services between 2002-2012 (n=2512)
- Distributed by disability & carer groups (n=110)

228 completed surveys were returned:

- 194 by family members
- 34 self-completed by people with ABI*
- 207 RTS

Total survey response rate = 10.6%

Stage 1 Research



To explore identified needs & feedback on how an ABI Family Support Network could be designed to meet these needs.

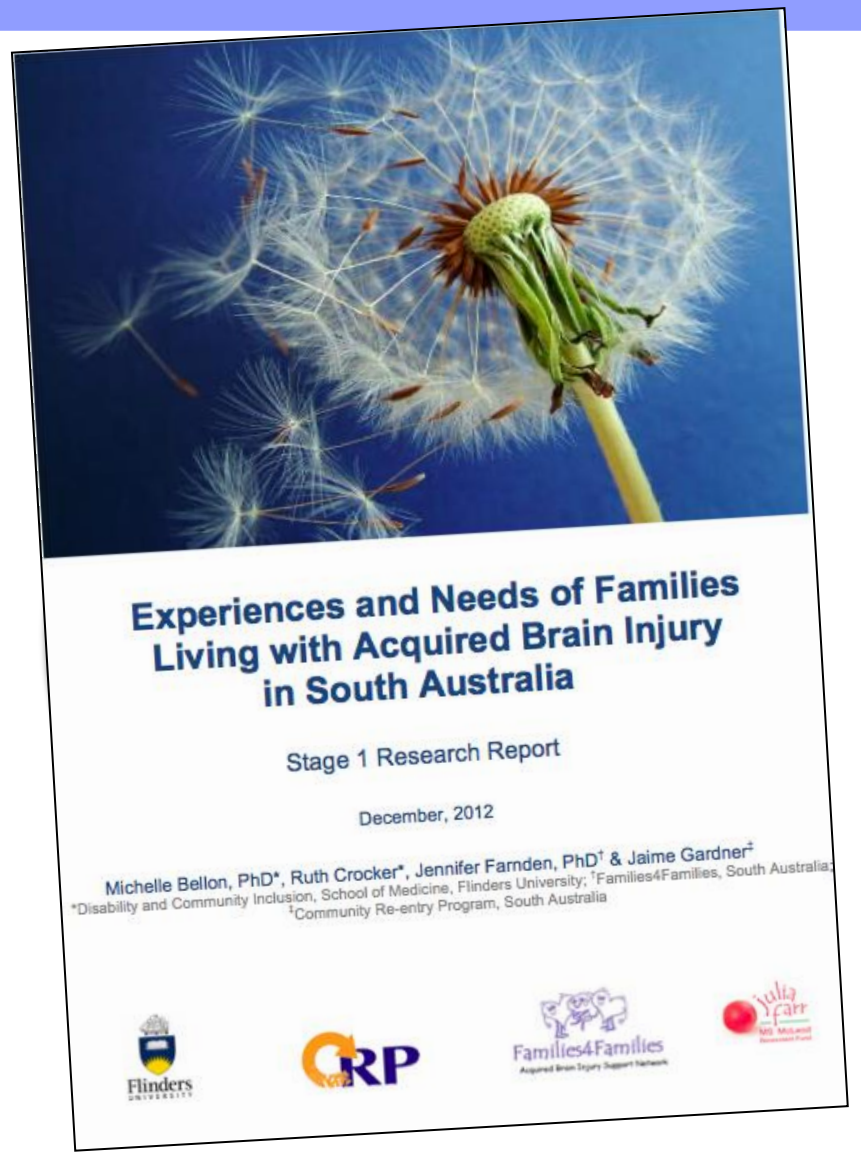
- 97 survey respondents indicated interest in participating in a focus group
- 90 minute focus groups audio recorded, transcribed, thematic content analysed using NVivo10, 2 independent raters

Stage 1 & 2 Research

Survey

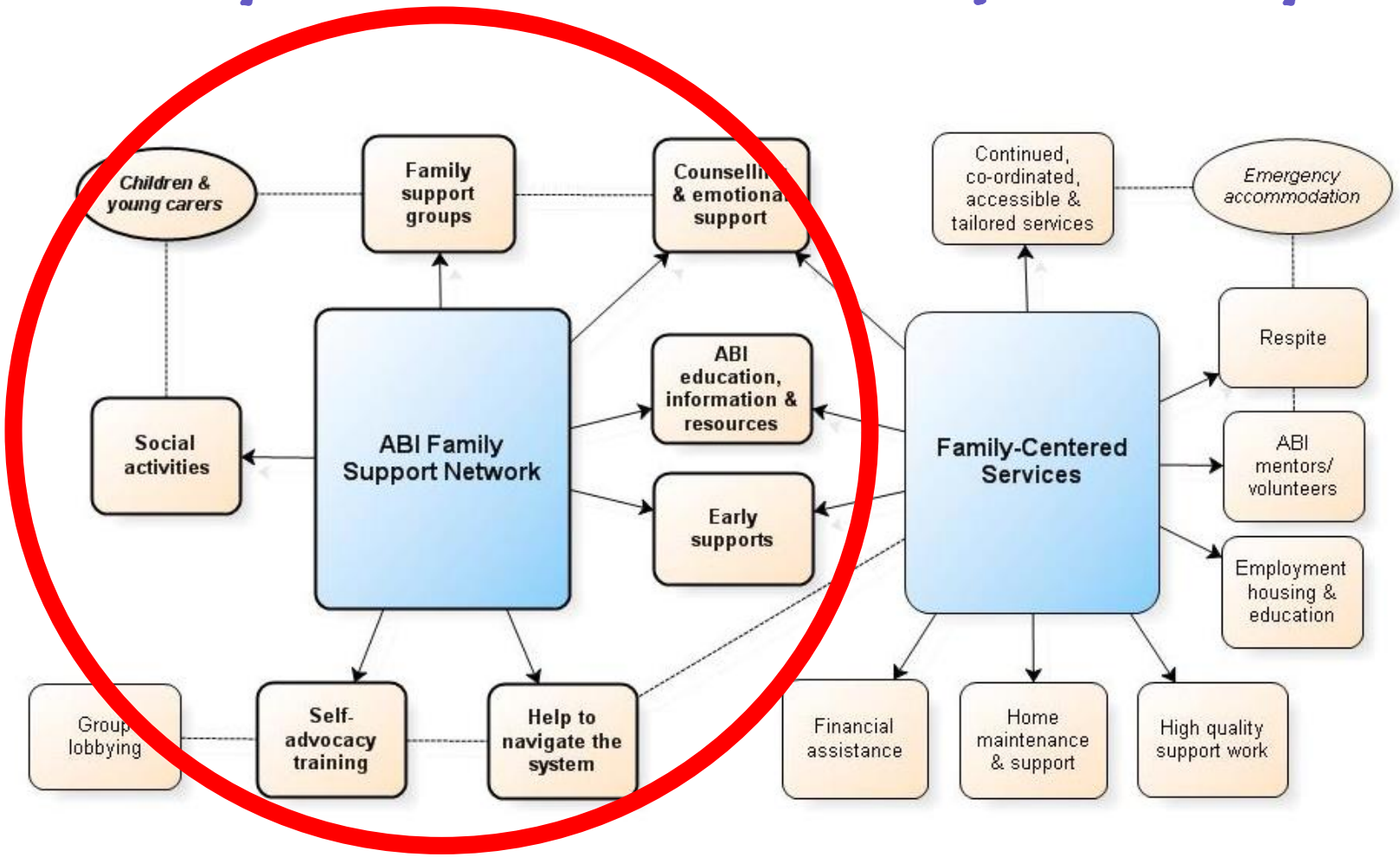
+

Focus Groups



July 2012 — **Stage 1** — Jan 2013 — **18 month pilot** — July 2014

Survey & Focus Group Analysis



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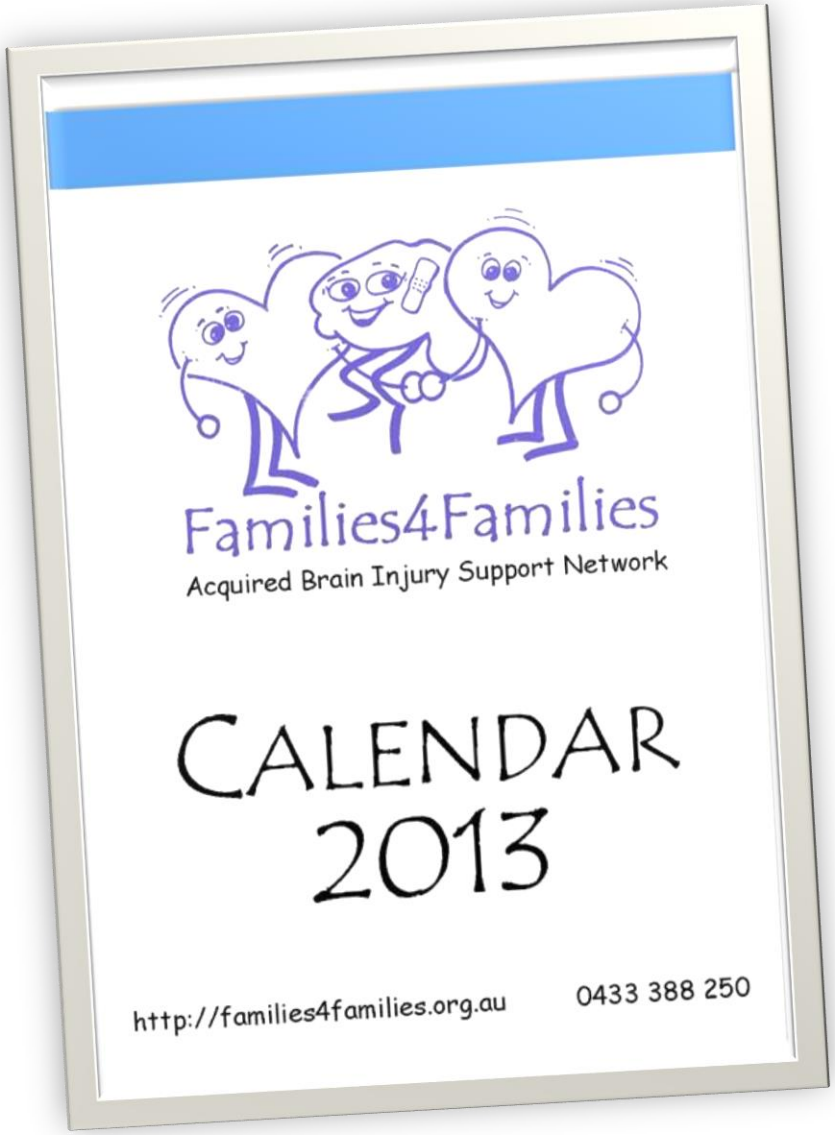
Stage 2 Research



Families4Families
ABI Peer Support Network

Jan 2013 — **18 month pilot** — July 2014

Initial Model of Supports

- Support Group Locations
  - 4 groups in metropolitan/outer metropolitan
  - 3 in remote/rural regions
  - Meetings monthly, six weekly or 4 times/ year, depending on location
- Social, Recreational & Sharing Events: All family members involved *(some for specific member groups)*
- ABI Education & Training, Information sharing
  - Via website, Facebook, phone, email, face to face at meeting & groups

Positive Psychology ➔ Peer Support Model

Information/ Education

Connection with others *(combined with inability to travel due to fatigue)*

Focus Groups & Surveys

(Stage 1 Research Findings)

Critical member input to design

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(providing developed content = Information Topics)
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Facebook Groups
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Email support
Relationship Management Approach

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What supports would be most helpful?

Family Support Groups

Opportunities to share experiences, gain a new perspective, and 'give back'. (I will read related quotes)

> *"Whilst we were in that hospital situation and the Hampstead situation we always felt we had someone to talk to. Once we left there we felt incredibly isolated." (Partner, FG)*

> *"…sometimes you feel so alone and then to hear other people talking about stories that are the same, you think 'Oh, it's not just me.' So we all understand." (Partner, Metro FG)*

What supports would be most helpful?

ABI education, information & resources

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

> *"Strategies on how to deal with the mood swings, anger and depression i.e. language to use that supports."* (170 Partner)

What supports would be most helpful?

Help to navigate the system

What services/supports are available & how to access them:

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

Key Research Outcomes

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

Julia Farr
MS McLeod
Benevolent Fund

Families4Families Launch

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Stage 2 Research

Measuring Participation Outcomes

Families4Families

18 month Pilot Program: January 2013 – June 2014

December, 2012

Phone interview & questionnaires:

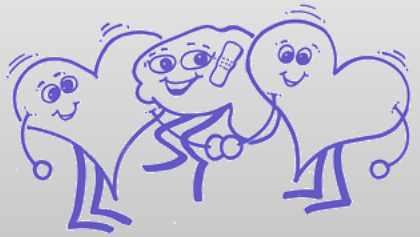
- Basic demographic information
- Quality of Life (WHOQoL-Brief)
- Depression, anxiety & stress levels (DASS-21)
- Positive caregiving experiences (CAS-modified)

July, 2014

Phone interview & questionnaires:

- Evaluation of F4F Participation
- Quality of Life (WHOQoL-Brief)
- Depression, anxiety & stress levels (DASS-21)
- Positive caregiving experiences (CAS-modified)

Families4Families
ABI Peer Support Network



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Evaluating outcomes of a peer support network for families following acquired brain injury

Bellon M, Sando S, Crocker R, Farnden J
Disability & Community Inclusion, School of Health Sciences, Flinders University, SA, Australia
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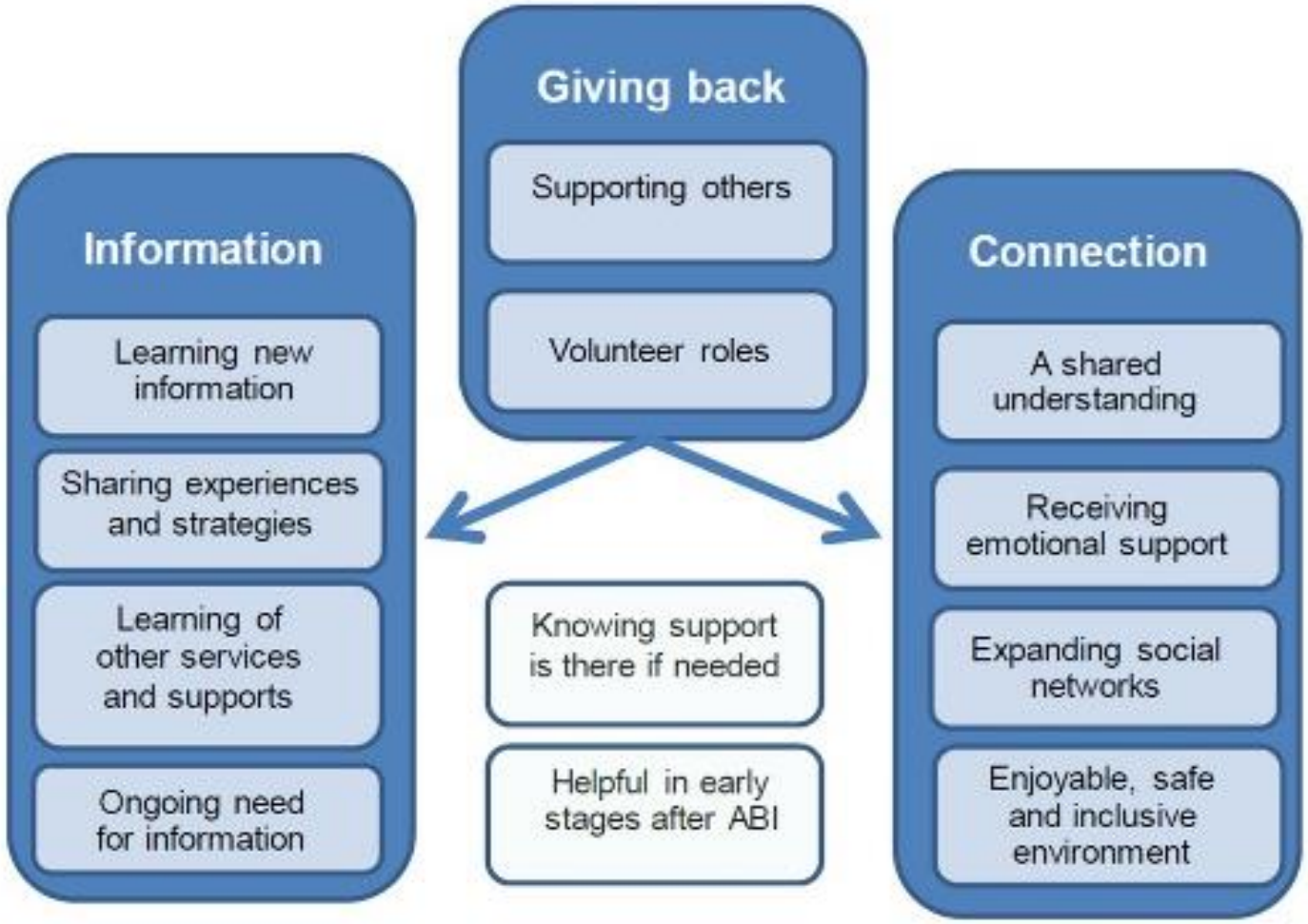
inspiring achievement

Figure 1: Benefits of the Families4Families Program



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"I've been in the system for 17 years and it's only since F4F have been established that I have learnt more about ABI."
(#15, Active attender)

"I go with my husband. We attend for both of us. It's very helpful just because you can talk about the different things associated with brain injury to other people who understand."
(#9, Active attender)

"We have got a better understanding of the disability support system and have gained knowledge about resources and agencies that we can contact."
(55, Occasional attender)

"It's reassuring to have contact with others from the facebook page who acknowledge and like the postings my daughter has put up about me. We have developed friendships through this."
(#37, Active attender)

Acknowledgements

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

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Stage 2 Research
Measuring Participation Outcomes

Stage 3 Research
Measuring Longitudinal Outcomes

Families4Families

18 month Pilot Program: January 2013 – June 2014

Families4Families

12 month Chapter Two: June 2014 – July 2015

December, 2012

Phone interview & questionnaires:

- Basic demographic information
- Quality of Life (WHOQoL-Brief)
- Depression, anxiety & stress levels (DASS-21)
- Positive caregiving experiences (CAS-modified)

July, 2014

Phone interview & questionnaires:

- Evaluation of F4F Participation
- Quality of Life (WHOQoL-Brief)
- Depression, anxiety & stress levels (DASS-21)
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July, 2015

Phone interview & questionnaires:

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- Positive caregiving experiences (CAS-modified)

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Families4Families: Longitudinal outcomes of participation in a South Australian peer support network for families following acquired brain injury

(Stage 3 Research Report, October, 2015)

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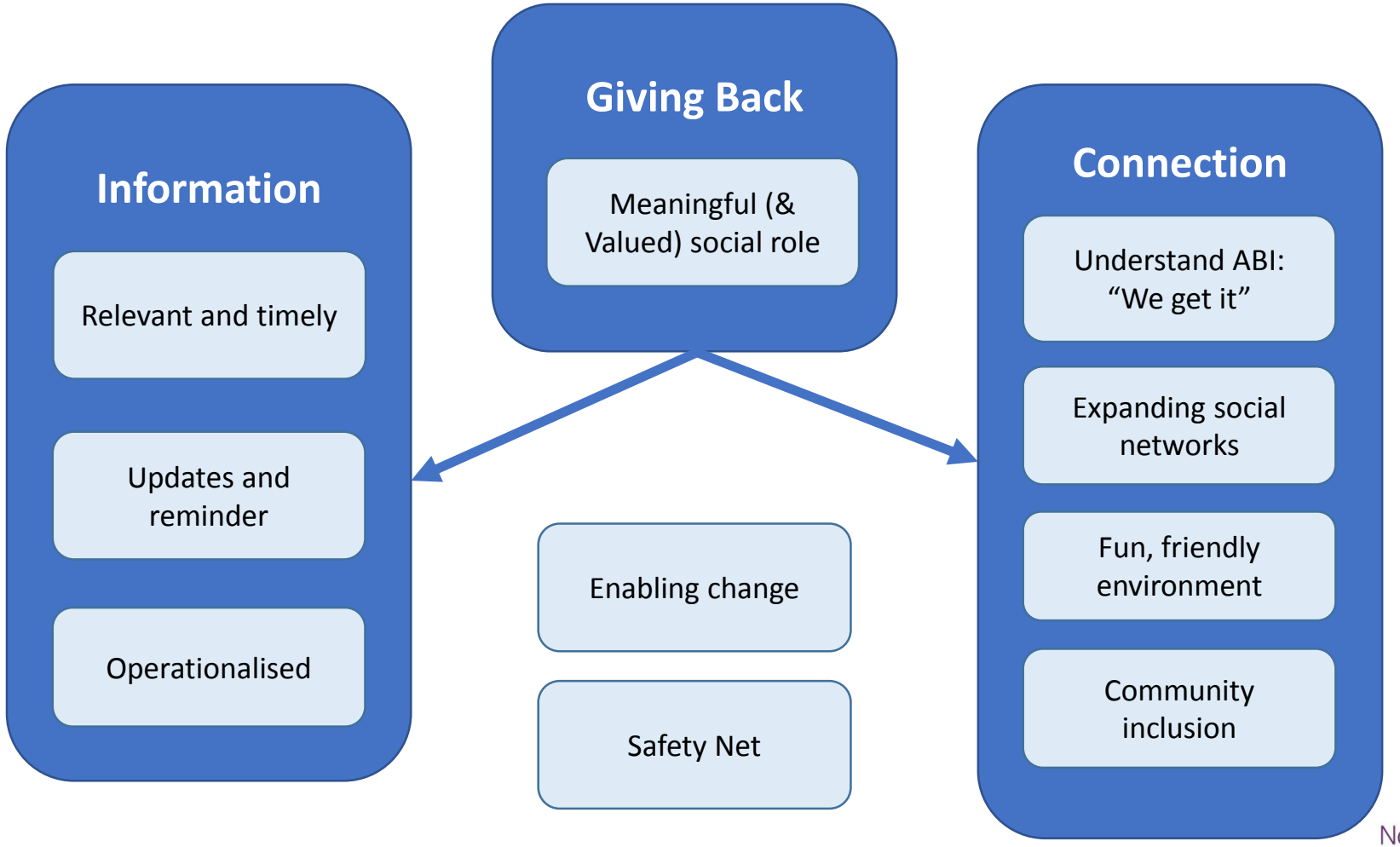
Longitudinal (Wave 3) Benefits of the Families4Families Program



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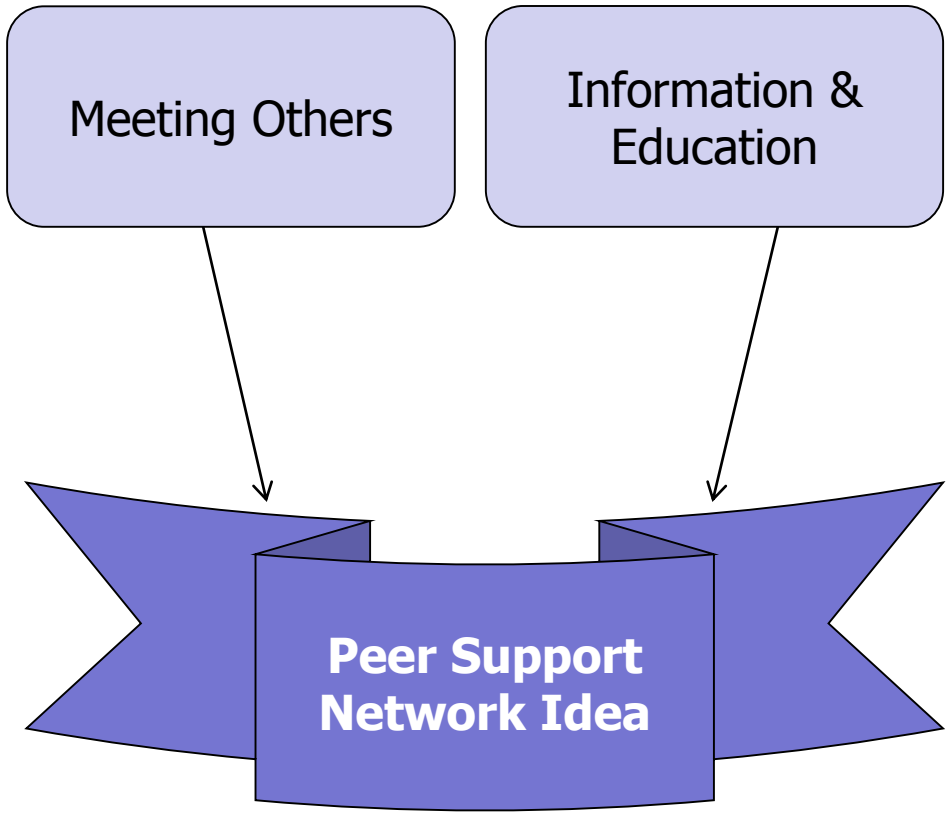
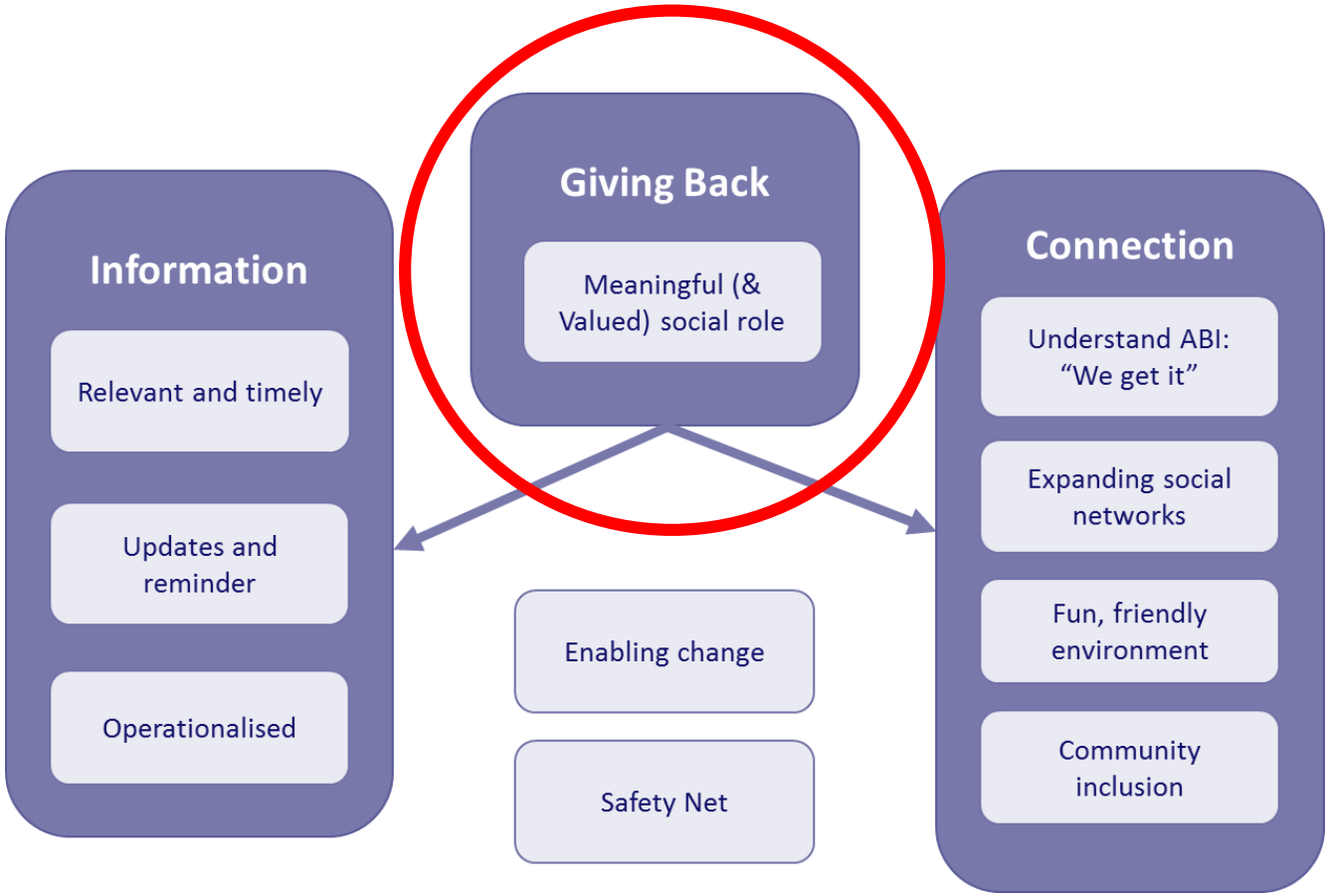
Families4Families: Longitudinal outcomes of participation in a South Australian peer support network for families following acquired brain injury

(Stage 3 Research Report, October, 2015)

Themes	Sub-themes	Example of Responses
Information	Relevant & timely	*"I learn everything every time I go to a session. I always learn something." (F9, Active)*
	Updates & reminder	*"We have learnt things that are available to us which we had either forgotten about or weren't aware of." (A14, Active)*
	Operationalized	*"They offer the knowledge and tell you how to go about it." (F9, Active)*
Social Connection	Understand ABI: "We get it"	*"I really like going to have a meeting with people in the same situation. It's like having a family and they understand what you're going through" (A22, Occasional)*
	Expanding social networks	*"We have made a lot of new contacts" (F24, Occasional)*
	Fun, friendly environment	*"It's been great now that we have hired the bus - that has produced a real community spirit and we compare notes and have lots of fun on the bus on the way to and home." (A37, Active)*
	Community inclusion	*"Getting out into the public" (A50, Occasional)*
Giving back	Meaningful social role	*"[I am the] Group leader as well administration assistance with telephone calls and mailing out programs and other admin duties. I am on the Management Committee and the Advisory Panel. I find it rewarding personally and it makes me feel like I'm a useful person in society, giving back to the community." (F18, Active)*
Other	Enabling change	*"In the past 12 months, I have gone off my antidepressants and I've enjoyed being part of Families4Families which has had a huge impact on my well-being. F4F has made me feel welcome. It has all helped so I've gained a lot. I've thought about my mental health issues and have been smart enough to do something about it now that I feel that I have good support through Families4Families." (A37, Active)*
	Safety net	*"You know that [Families4Families] are there should I need in the future or to refer a friend." (F7, Occasional)*
Longitudinal Benefits of the Families4Families Program (published in Research Report)		

Network Concept vs Model Outcomes





Powerful benefits from reciprocal nature of peer support

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Families4Families

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Mission Statement

Our Mission is to assist people with acquired brain injury and their families to build resilience and live a good life via our innovative, volunteer, peer based model of support.

Our tailored, family focussed programmes centre on Local Support Groups which facilitate capacity building and a sense of belonging through sharing of information, lived experiences and positive coping strategies.

Research and formative evaluations underpin our model.

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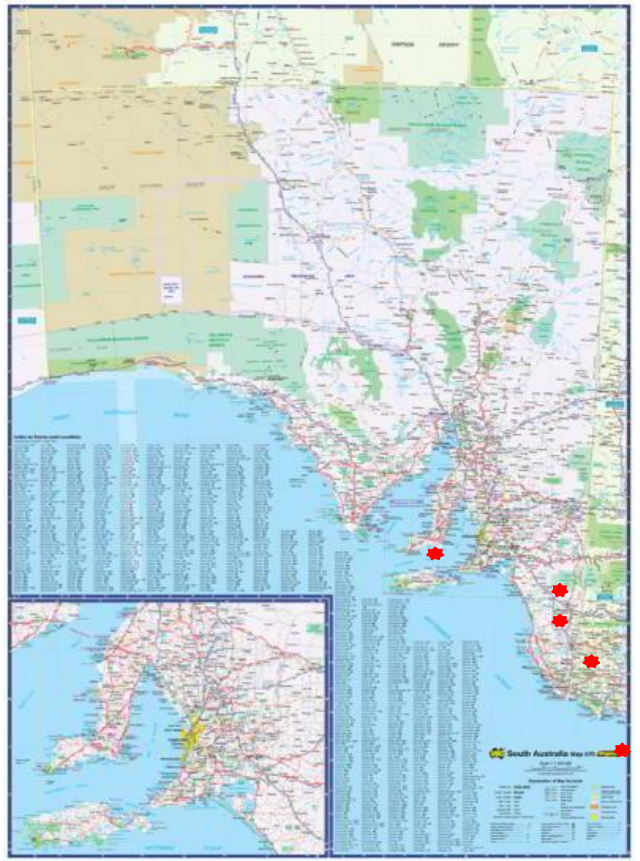
Local Support Groups

- 20 Local Support Groups running 2016
- Most are very successful – some we want to adjust
- Much need in the rural areas – and if we build it, people come!
- We surround the sessions with ‘wrap around’ supports
- Our model is most successful DSO nationally
- We run sessions that provide REAL and ACCURATE information about how things work on the ground
- Our topics include: ABI and Mental Health, Advocacy, Anger and ABI, Behavioural Coping Strategies, CBT, Crisis support, Cyberspace after ABI, Employment after ABI, Financial Management and Budgeting: Surviving the Long Term (and Short Term), Introduction to ABI, Loss and Grief following ABI, Reflections on Living with ABI, Role Changes after ABI, Sexual Changes after ABI, Supporting Someone with ABI, Volunteering, Wellness



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Families4Families: ABI Support Network | Jennifer | Home 20+ | Find Friends

Page | Messages | Notifications | Insights | Publishing Tools | Settings | Help

Families4Families
Acquired Brain Injury
Support Network

Families4Families: ABI Support Network
@Families4FamiliesNetwork

Facebook page/groups

Families4Families: ABI Support Network
Published by Simple Share by Constant Contact [?] · July 31 at 2:03pm · TV & Movies

Check out our Families4Families eNewsletter August 2016. We have also just had a film on us released - go to http://www.peerconnect.org.au to view.

Families4Families eNewsletter August 2016
Check out our Families4Families eNewsletter August 2016. We have also just had a film on us released - go to http://www.peerconnect.org.au to view.
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535 people reached | Boost Post

Like | Comment | Share

Families4Families: ABI Support Network shared a link.
Published by Marie Knight [?] · August 6 at 9:28am · Health & Fitness

Recovery from Brain Injury Occurs for the Rest of a Person's Life
The human brain is a wonderful organ with amazing flexibility. Learn more about recovery.
YOUTUBE.COM

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This post is performing better than 90% of other posts on your Page. Boost it to get more great results.

309 people reached | Boost Post

Like | Comment | Share

Marie Knight, Amanda Ferguson and 9 others | Top Comments

3 shares

Write a comment...

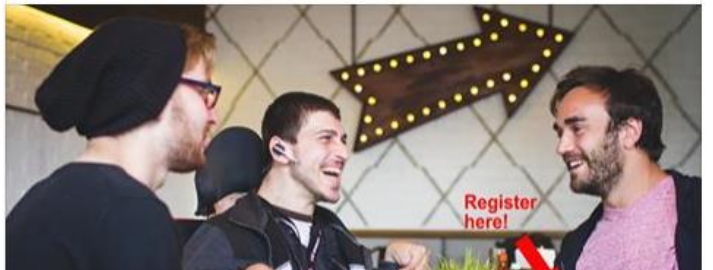
Amanda Ferguson Very positive interview.Hope for future recovery.
Like · Reply · 1 · August 6 at 2:26pm

Jennifer Farnden shared Families4Families: ABI Support Network's post.
Just now · Work & Money

Families4Families: ABI Support Network
Published by Eventbrite [?] · 13 mins · Work & Money

I am going to HireUp introduction next week - how about you? For anyone interested in recruiting their own workers while still having someone else do the tough ...

See More



Management Committee Members 2016

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F4F Model of Supports

- Local Support Groups
- Special Events
- Early Support Program
- Phone Support & Advocacy
- eNewsletters
- Research Program/Projects
- Website & Facebook Groups
- Our Hub

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Current Network Scope:

- 535 members across South Australia;
- 20 Local Support Groups – meeting usually monthly;
- 236 sessions delivered in 2016;
- Fully volunteer designed, managed and evaluated;
- National leaders in peer support model development and delivery;
- Founded & developed based on academic research;
- Attendances – tracking for more than 3,000 in 2016; and,
- More than 1,000 volunteer hours monthly contributed by people living with ABI and their Carers/Family members currently.

National experts in peer support (DSO)

Developed model to take Nationally

Expanded target groups likely

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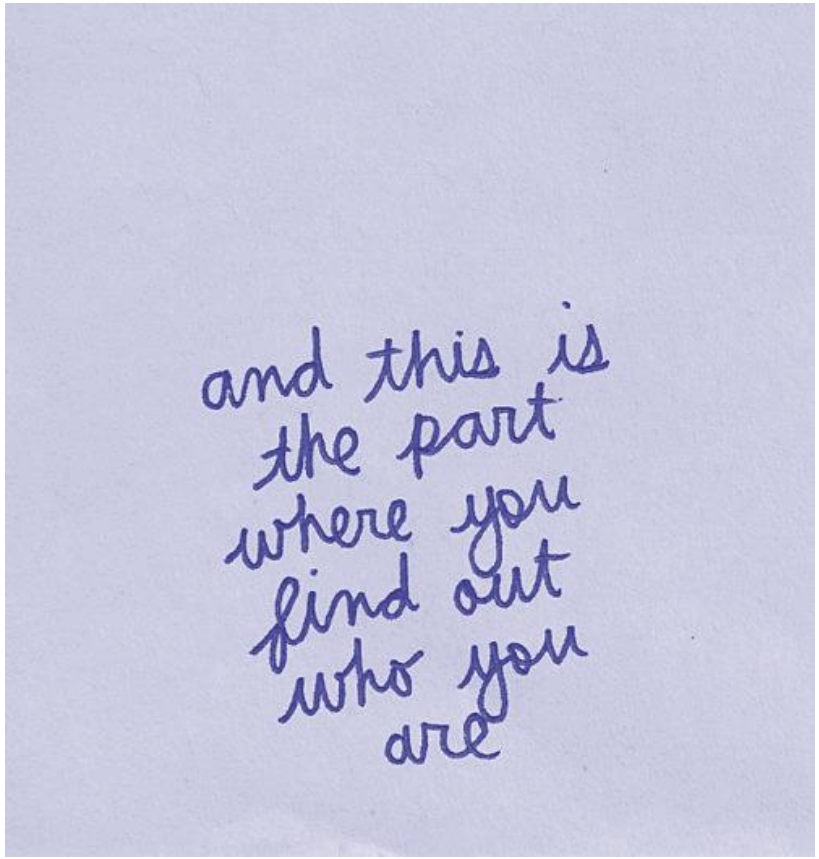
Families4Families Today



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Peer Support & NDIS ILC Outcomes

How can F4F continue?

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April 2014: Applied for DSO Selection (huge submission)
Announced November 2014 – only 1 in SA!
Funding Jan 2015 – Dec 2016
NOW – submitted huge reports, work plans & an external evaluator is deciding if we get more funding to continue!
(Decision due – November 2016…)

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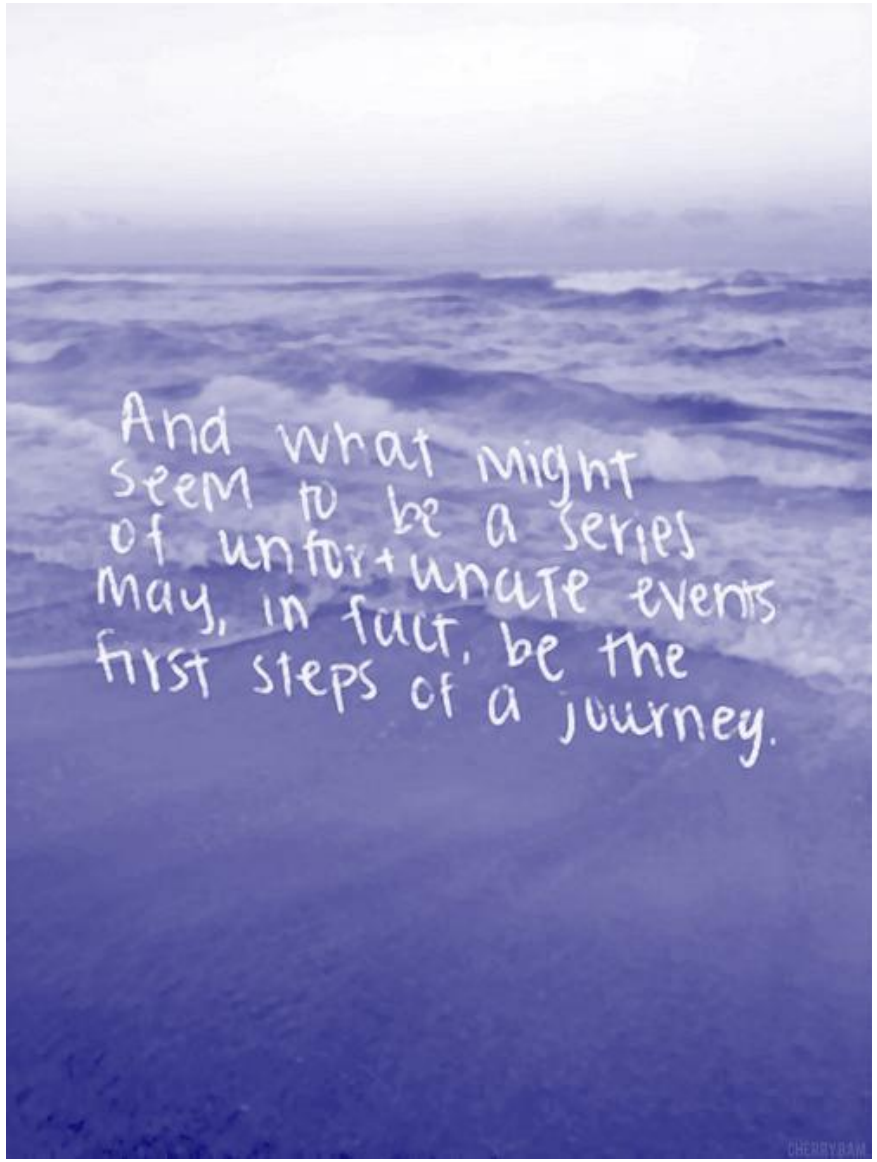
Challenges Ahead

- So much need: 530+ member families, yet 30000+ people impacted by across SA…and national interest.
- Still no core funding – NDIA DSO funds end in December 2016.
- Master of Disability Studies & developmental educator qualification being utilised – but so much need!
- Need for more fundraising
- Health system changes in SA (less beds)
- Government support currently N/A
- Succession management and…continuing without founder….



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Families4Families Member

" …The truth is we have crossed a bridge to another land; a land not inhabited by many, a land we did not wish to inhabit or explore. In finding ourselves in this land, however, we do not feel poor or dispitied or diminished. We feel strong, open and more knowing. This land is not full of gloom or bereft of meaning. Rather it is filled with keys to what is real and important."

Sage (2013)

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Question Time

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