The Brain Crew: An Evolving Support Programme For Children Who Have Parents Or Siblings With An Acquired Brain Injury

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As Lezak (1988) noted, brain injury is a family affair, it happens not only to the injured person but also to those around them. Family members (and younger children in particular) experience multiple negative consequences when a parent or sibling sustains a brain injury (Gan & Schuller, 2002). The effects of the brain injury, hospital treatment and subsequent rehabilitation result in substantial disruption to family lifestyle, negatively impacting on family functioning and dislocating family roles (Tyerman & Booth, 2001). Resultant dispositional changes can have a devastating effect on family relationships and specifically, relationships with and between children (Ducharme, Davidson & Rushford, 2002).

During and after inpatient rehabilitation, it has been reported that parents who have sustained brain injuries often show less effective parenting skills, less nurturing and less involvement with their children (Uysal, Hibbard, Robillard, Pappadopoulos & Jaffe, 1998). Conversely, family and child distress compromises the quality and sustainability of rehabilitation gains, with enduring outcomes more likely to ensue when families are incorporated into and assisted with appropriate rehabilitation services (Oddy & Herbert, 2003). Families in which a parent is undergoing rehabilitation for brain injury have alarmingly high levels of stress and distress (Tyerman & Booth, 2001). Many children report symptoms of depression (Uysal et al, 1998), have a poor relationship with the injured parent (Pessar, Coad, Linn & Willer, 1993) during and after rehabilitation and are considered an ‘at risk’ group, vulnerable to subsequent emotional and behavioural difficulties (Urbich & Culbert, 1991).

Pessar et al (1993) interviewed 24 families, in which the uninjured parent frequently identified that their children had experienced some degree of negative behavioural change, with 10 families identifying these behavioural changes as significant. They found that this negative behaviour change was often manifested through ‘acting out’ behaviours and emotional problems. In some instances, children take on additional care-giving responsibilities impacting on their developing sense of independence and autonomy (Sachs, 1991). Furthermore, Moore, Stambrook and Peters (1993) found that families with young children may face unique challenges when a parent sustains a TBI, particularly if financial strain exists.

The importance of the ICF in developing appropriate programmes for children

As recognised in the World Health Organisation’s (2001) International Classification of Functioning, Disability and Health (ICF), families should be seen not only as a primarily affected unit in the instance of injury and rehabilitation, but also a crucial target for rehabilitation intervention. In the treatment and care of people with brain injuries, individual rehabilitation interventions have only limited effect without accompanying environmental change in the family unit. Increasingly, clinical units are recognising that sustainable outcomes are more likely to ensue when families are incorporated into and assisted with appropriate rehabilitation service. Comprehensive rehabilitation interventions increasingly recognise that in the new health care environment, family support is integral to ensuring outcomes with enduring positive benefit to all affected parties (Holland & Shigaki, 1998, Sander, Caroselli, High, Becker, Neese & Scheibel, 2002).

International research indicates that there is substantial unrecognised need for proactive rehabilitation interventions that will maximise family adjustment and minimise child and family distress (Uysal et al, 1998). Structured child and family support programmes have been proposed as key elements of quality service delivery (Kreutzer, Kolakowsky-Hayner, Demm & Meade, 2002), particularly in response to emerging trends in health service delivery. In light of these needs, researchers are beginning to develop an evidence base for intervention with spouses, children and siblings of brain injured people (Oddy & Herbert, 2003).

There have been few initiatives targeted specifically at children (Visser-Meilly, Post, Meijer, Maas, Ketelaar & Lindeman, 2005), largely due to the cost associated with setting up such services. Due to cost constraints such services may be better placed within existing systems of care. Consequently, there is a need for these systems of care to expand their focus to also provide more family-based and systemic interventions. Without such a change, children will continue to receive ad hoc and fragmented services. Likewise, research projects and evaluations of stand alone pilots will be of limited benefit, since the resources required to develop such stand alone children’s programmes would be prohibitive.

Interventions that actively involve children rather than isolating and shielding them appear to be the most promising avenue for future development. Bursnall (2002) suggested the following key recommendations for provision of services to siblings of brain injured children: (1) encouraging ongoing

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communication to inform and validate feelings at home and school; (2) providing age-appropriate information, preparation and inclusion with choice as to the degree of involvement; (3) normalising and validating feelings through verbal or written discussion of feelings; (4) acknowledging contributions made in the rehabilitation process; (5) organising time out with parents and respite; and (6) forming groups to encourage learning from others in similar situations. These recommendations could equally apply to children who have a parent, older sibling or relative with brain injury.

Service-based developments that undergo continuous quality improvement and are integrated into standard practice would appear to be the most appropriate means by which to implement recommendations such as those outlined above. This paper describes the development of such a programme, its evaluation, and the way in which it has been integrated into standard practice, across both inpatient and outpatient settings.

Programme development: Identifying the problem

The setting for the programme development is the Acquired Brain Injury Outreach Service (ABIOS), a specialist community based rehabilitation service located in Brisbane, Australia and funded by the state health department, Queensland Health. The service aims to facilitate successful community integration for adults with an ABI, provide training and consultancy to service providers and carers and conduct research projects to improve outcomes for people with ABI and their families. Client programmes are based in the community and include a range of services and supports to assist people in establishing themselves back into their own community following ABI. As such, support of families is identified as a major component of ABIOS work. Prior to this project, this largely meant working with the person and their partner or the parents of an injured individual. Thus, while a lot of ABIOS work involves working with people who have young and teenage children, previous work was frequently limited to providing resources for the parent to give to the children, as visits were often conducted during school hours. ABIOS staff recognised the limitations with this approach, and some clients requested more direct ABIOS involvement with their children. This prompted a small group of rehabilitation case managers within ABIOS to work on a project in this area for the benefit of the entire ABIOS team, facilitating the development of an appropriate service model for assisting the children or siblings of those injured.

An analysis of goals set in the course of community-based rehabilitation provided by ABIOS (Kuipers, Foster, Carlson & Moy, 2003) had previously indicated that family needs, close relationships and related emotional issues constitute a key area of concern and difficulty for clients in rehabilitation. The need to establish a programme for children with an injured parent or sibling in an inpatient rehabilitation setting was identified as a strategic priority for several reasons. Firstly, within a sampling period in 2001-2002 of 160 patients, records held by the inpatient Brain Injury Rehabilitation Unit at the Princess Alexandra Hospital indicated that at least 40% of patients fell into 'family' demographic categories (married, defacto or divorced). During a similar timeframe, ABIOS database records showed that 62% of the ABIOS patient population fell into 'family' demographic categories, highlighting the need for family members to also obtain ongoing assistance with post-discharge rehabilitation and community integration.

Aims and objectives of the programme

The aim of this programme was to develop and implement a quality intervention to assist children with brain-injured parents, adult siblings or relatives by maximising short and long term family adjustment, increasing children's understanding of brain injury, expanding coping strategies and peer networks and reducing children's anxiety, social isolation and emotional/behavioural difficulties. In developing the intervention, the following objectives were identified.

1. To conduct a comprehensive review of evidence and research regarding interventions with children who have a brain injured parent or sibling.
2. To conduct a survey of previous patients, spouses, children and key hospital staff to determine crucial elements of a quality programme to assist children of a brain injured patient.
3. To develop an intervention programme based on (a) identified evidence, (b) clinical reasoning and experience, (c) expressed need and (d) principles of best practice.
4. To trial the developed intervention, following up with families to investigate benefits and identify aspects for improvement.
5. To implement the revised intervention within standard practice.
6. To develop a 'quality' protocol for the intervention to ensure ongoing refinement and relevance of the programme and to foster potential transfer of the programme to other clinical populations.

Objective 1: Identification of key evidence, quality and practice indicators

Initially, a Children's Group Working Party was formed consisting of six ABIOS staff members. To address the first objective, the working party undertook a literature review and agency search to ascertain the different models available for working with children who have a parent or sibling with ABI. From this process a realisation emerged that the literature offered little formal or structured guidance in this area. While some psychological interventions were reported for children with behavioural difficulties (Ducharme et al, 2002; Ducharme, 2003), only one programme that more generally addressed the needs of children whose parent had sustained an ABI was identified (McLaughlin, 1992). Other national agencies and services were contacted but none reported using a coordinated approach to the inclusion of children in the rehabilitation process. Contact with services providing support and education to children who have a parent with some other condition such as cancer, mental health issues or physical disability (e.g. Visser, Huizinga, van der Graaf, Hoekstra & Hoekstra-Weebers, 2004) identified some structured programmes being offered to children. In general these programmes lacked relevance to the ABI population because they were tailored towards children whose parents did not have cognitive impairments or focussed on the specific circumstances of those who were receiving palliative care. In conclusion, the review of evidence and service models provided insufficient information within the Australian context of brain injury rehabilitation for benchmarking.

Objective 2: Survey of needs

Given the inability to effectively benchmark against existing services, it became necessary to conduct a needs assessment, thereby addressing the second objective for the project. Brief interview format questions were drawn from 'general themes' identified in the literature and intended to elicit perspectives of previous patients, spouses and children. From existing ABIOS clients, 13 parents/spouses and 20 children were interviewed using a semi-structured interview format to investigate extent of need and identify potential strategies to assist children. A copy of the interview protocol is provided as an appendix.

The need for intervention was strongly indicated by the results of this survey. Children mostly described their feelings when their family member was injured as 'shocked', 'scared', and 'sad'. They reported getting very little information about the injury – mostly from family (some of which was vague or frightening). When describing the things that assisted them at this time, the children did not mention any formal hospital-related people or services. Current assistance was perceived only in the form of support and information from family, talking to friends and teachers, and their family member's gradual recovery. Children identified that if they had more information it could be easier to understand and help their parent or sibling once they returned from hospital. As found by Butera-Prinzi & Perlesz (2004), children also identified wanting to be included earlier (in the hospital environment).

Parents described the effect of the injury on their children noting that they were 'worried', 'scared', 'had difficulty sleeping' and were 'upset and frightened'. Parents perceived that the best way they could assist their children was to give them family support and maintain as much normal structure to their lives as possible. Parents noted their children's fear at seeing their family member in hospital and rehabilitation and an associated reduction in fear when the family member returned home. Other parents noted that their children expressed concern that their family member 'will be a vegetable'.

Together, these findings suggested the need for an integrated approach that addressed the concerns and expectations of both children and their parents. The need for information, delivered in age appropriate formats was highlighted as was the need for a group experience that allowed sharing between children and normalised their experience.

Objective 3: Development of the initial intervention

Interviews indicated that the primary intervention should commence within inpatient rehabilitation rather than later in the community setting. McLaughlin's (1992) suggested interventions such as psycho-education, participation and individual and group therapy were incorporated with the themes identified in the needs assessment to develop a unique support programme entitled the 'Brain Crew'. Other alternatives for the programme were explored including a more comprehensive one on one service with children at the family home, but this was identified as being too labour-intensive and would not advance the peer support and normalisation goals of the programme. The programme was innovative within a rehabilitation service context, given that it was developed using principles of family systems rather than a medical model, and sought a broad adjustment focus rather than targeting behavioural issues. The inclusive nature of the programme ensured that it addressed the needs of the majority of children, not merely those experiencing extreme reactions to their parent's injury. The 'hands-on' approach resulted in a programme that was experiential and participatory rather than merely educational.

In the development of the programme, the content of each session was written by a different member of the working party. Close liaison between all members of the working group ensured consistency in methodology, materials and group facilitation and the contribution of a diverse range of talents, skills and knowledge to the entire programme, as expertise from different allied health professionals was drawn on.

Consumer involvement in the programme development and delivery was facilitated by the inclusion of an ABIOS client in the artwork design and as a co-presenter in the session dealing with 'Physical Changes Following an ABI' so that he could demonstrate physical changes following an ABI and discuss practical implications of this with the children.

The programme was designed to be developmental in nature with flexibility and capacity for individual tailoring (e.g. children involved in the group would be consulted regarding activities they enjoyed so that these could be incorporated into future sessions). The final session was also developed as a revision of the major learning that took place throughout the previous sessions, based on activities that the children particularly enjoyed. This aimed to continue the experiential basis of learning which the group employed. Parents were to be provided with an Information Sheet at each session which outlined the content and activities covered in the session and parents (both injured and non-injured) attended the final session where each child would be presented with a Certificate of Attendance and their own activity and information book.

The 'Brain Crew' programme was first implemented in October, 2003. It was conducted for 2 hours, once every week for 6 weeks at the same time as the existing Brain Injury Rehabilitation Unit (BIRU) Family Support Programme. It was facilitated by ABIOS staff but conducted within the inpatient setting of the BIRU. Children invited to participate were those who were related to an adult with an ABI who was an inpatient at the time, thereby requiring high levels of collaboration between staff within BIRU and ABIOS. Table 1 provides a description of the process and content for the programme. Five children participated in the initial programme, four of whom had a parent with an ABI and one who had a sibling with ABI.

Objective 4: Initial pilot evaluation framework

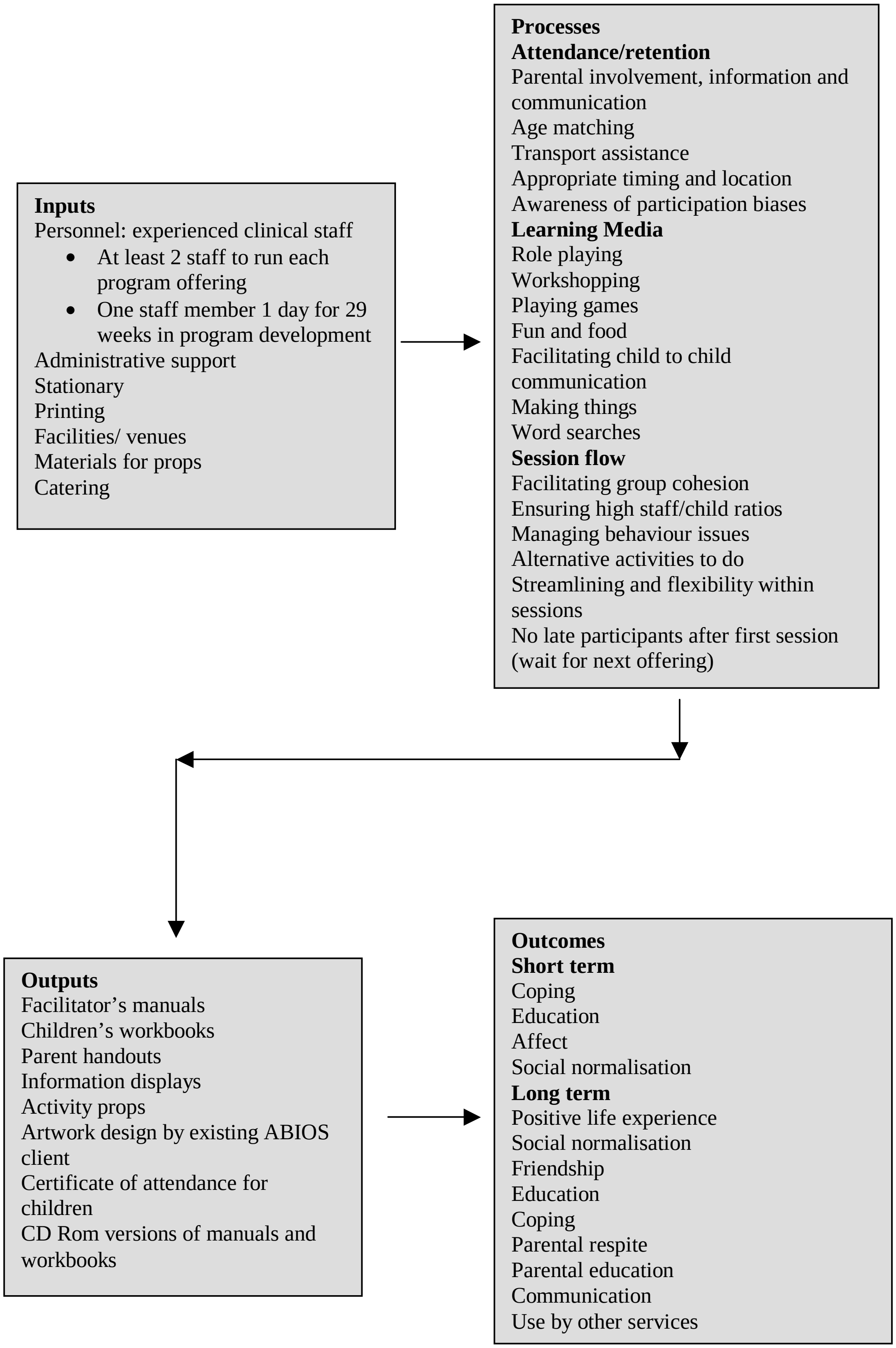
A programme logic model of evaluation similar to that proposed by Schalock and Bonham (2003) was used to determine programme inputs, processes, outputs and outcomes. This approach was considered most appropriate for the development of a new programme, particularly where the intention was to integrate the programme into standard clinical practice within a continuous quality improvement (CQI) cycle. Figure 1 illustrates the key findings from the inputs, process and output evaluation. Inputs included personnel, facilities, stationery and printing resources. This evaluation of process was considered important within the CQI cycle to inform the continued development and integration of the programme within standard practice. From this process, staff and participants identified a range of benefits and challenges in the delivery of the programme. These related to the generalisation of the content to a broader audience, use of resources, media through which the programme was delivered, age grouping of children, group recruitment, retention and attendance, use of content, programme timing, format and context. The identified inputs were significant for the development and production of the outputs, and the process of programme development and implementation. The main finding from this aspect of the evaluation was the need for flexibility to individualise components of the programme (at an input and process level) to ensure the needs of the children were being met.

Pilot Outcomes

The pilot evaluation protocol consisted of individual semi-structured interviews with children and parents within two weeks following the completion of the programme and three month follow-up evaluation in the form of focus groups. Qualitative evaluation of the programme's impact was considered most appropriate given the fact that participants were children and many standardised scales have limited utility in child populations. It was also considered that a qualitative evaluation would more clearly capture the intended 'consumer focus' and more effectively inform the CQI process. The resulting qualitative data was coded with the qualitative software, N.Vivo (QSR International, 2002) using basic thematic analysis (open, axial and selective coding process). Qualitative analysis sought to explore ways in which the programme helped both parents and children, and identify the most and least beneficial activities/

Table 1: Initial programme content and process

Content	Topics Covered	Brain and brain injury Physical changes Cognitive changes Behavior and emotional changes Problem-solving and coping strategies Review session
Process	Programme structure	2 hours per week 6 week duration Held in the Brain Injury Rehabilitation Unit Participants recruited through social workers Facilitated by 3 ABIOS staff Run parallel with the existing Family Support Programme
	Delivery modes	Content in workbooks Group discussions Question/answer and memory games Make your own brain Experiential role plays Visual imagery and relaxation
	Coping strategies facilitated	Exploration of support circles Safe supported learning Sharing stories Normalisation of experiences Validation of feelings



Inputs
Personnel: experienced clinical staff
- At least 2 staff to run each program offering
- One staff member 1 day for 29 weeks in program development

Administrative support
Stationary
Printing
Facilities/ venues
Materials for props
Catering

Processes
Attendance/retention
Parental involvement, information and communication
Age matching
Transport assistance
Appropriate timing and location
Awareness of participation biases
Learning Media
Role playing
Workshopping
Playing games
Fun and food
Facilitating child to child communication
Making things
Word searches
Session flow
Facilitating group cohesion
Ensuring high staff/child ratios
Managing behaviour issues
Alternative activities to do
Streamlining and flexibility within sessions
No late participants after first session (wait for next offering)

Outputs
Facilitator's manuals
Children's workbooks
Parent handouts
Information displays
Activity props
Artwork design by existing ABIOS client
Certificate of attendance for children
CD Rom versions of manuals and workbooks

Outcomes
Short term
Coping
Education
Affect
Social normalisation
Long term
Positive life experience
Social normalisation
Friendship
Education
Coping
Parental respite
Parental education
Communication
Use by other services

Figure 1: Inputs, processes, outputs and outcomes identified during the initial evaluation

aspects of the programme. Initial coding occurred at the level of the word or phrase. Words or phrases were coded if they represented one of three conceptual categories, namely an ‘expression of emotion’, an ‘action or service received’ or a ‘need/problem/issue’. For each word or phrase coded, care was taken to retain any links to other concepts (i.e., causal words used by participants to link two or more concepts or linkages created by the proximity of concepts). If two or more concepts co-occurred within a single unit of text (i.e., within a single phrase or group of sentences), attention was focussed on identifying if and how they were related. Words or phrases could represent positive, negative or neutral examples of the category and every instance of the concept was coded.

Five children initially completed the programme and interviews by independent staff were conducted with 4 parents and 5 children, 2 weeks after completion of the programme. Children and parents reported positive and substantial gains from the intervention including increased understanding of ABI, reduced behavioural difficulties and emotional distress in children and improved coping strategies. The children consistently described three major positive outcomes of the programme

- general educative information (eg learning “*things about the brain*”)
- practical coping information (eg “*what to do if Mum gets angry*”)
- having fun (normalising)

Parental interviews identified the positives of education (understanding of brain injury) and affect (anxiety, stress). Specifically parents reported that children understood ABI better, were less afraid of other patients in BIRU, showed increased confidence, were better able to cope with peers at school, enjoyed activities in supervised environment, were more content and relaxed about things, felt involved again, and benefited from positive interactions with staff.

Combined, this analysis suggested that the benefits of the programme translated into the following key areas:

a) COPING - coping with family change
b) EDUCATION - learning more about ABI and how family member had changed
c) AFFECT- feeling less anxious and worried about their family member and less sad because they understood more
d) SOCIAL NORMALISATION - participants were able to meet other children who also had family members with ABI

Focus groups conducted three months following the completion of the programme supported the sustainability of the benefits that children had gained. Brain crew remained a positive experience of which children continued to hold quite clear memories. The themes identified at follow-up included positive life experience, communication, social normalisation and friendship, education, coping, parental education and respite. The children reported that it was “*really good fun*” and “*gave us a chance to meet other kids in the same boat*”. The programme made them “*feel special and listened to*”. They gained more understanding about brain injuries which enabled them to understand what the parent was going through. “*It helped me learn more about brain injuries which means I can understand what Mum was going through*” and often mentioned that they would “*tell other kids that it is really good fun and you learn lots of things about brain injuries*”. They had learnt strategies to help deal with the challenges once their parent returned home. “*It made it easier for me to go to school*” and “*I’ve learnt stuff to help deal with Dad’s behaviour once he came home*”.

From the perspective of the parents, the 3 month focus group data identified that the programme had an unexpected but important function in providing respite and allowed time for parents to concentrate on their relationship whilst the Brain Crew was running. As one parent mentioned, “*It was the first time we had been out to dinner in 24 years together… we actually spoke to each other through dinner*”. Parents reported that the children still talked to each other about the brain, demonstrating that it was useful to providing education to the children about how the brain works, *“they can name all the parts still”*. Furthermore, the children often helped to educate their parents about changes following brain injury. As one parent mentioned *“I actually learnt things that I didn’t know”*.

One clearly articulated benefit mentioned by parents was that it gave children an opportunity to meet peers who were going through a similar experience, normalising the situation and allowing them to *“all talk about it”* and ask *“how’s your parent?”* Parents felt that the programme has increased their children’s ‘openness’ and confidence to talk with peers, teachers and school counsellors. It *“amazed me because she doesn’t normally talk to anyone”*. In addition, it assisted the parent and children to more effectively manage behavioural changes by assisting the children to modify their own behaviour and assisting the parent to manage the children’s behaviour, *“The kids have realised through Brain Crew not to push me too far”*.

Objective 5: Implement devised programme within standard practice

The ‘Brain Crew’ intervention was developed with the intention of continued delivery within standard ABIOS practice. For this to occur, the project required support at service management level. Initially, ABIOS committed ongoing material resources in the revision and maintenance of the outputs including the facilitators manual, children workbooks and parent handouts, ongoing staff involvement in the running of the programme, its evaluation and continuous improvement as well as ongoing management commitment to review service delivery policy in respect of the programme and monitor effectiveness. BIRU committed the physical space for the running of the programme.

With this support, the programme was implemented within standard practice, initially being offered up to four times per year for children who are related to an adult with an ABI who is an inpatient at the time. Following the initial implementation of the programme, it has been delivered 3 more times in conjunction with Family Support Programme by ABIOS staff as an integrated service delivery model and completely funded within the existing budgets of ABIOS and BIRU. The developed resource package (facilitator’s manual, children’s workbooks, parents handouts) became a permanent resource for the ABIOS team and a new support person booklet was developed to assist other people close to the child such as grandparents and teachers, by providing basic brain injury information for them.

The programme was then made more widely available due to the perceived need of consumers. In August 2005, ABIOS handed the normal programme package back to BIRU for them to integrate within the inpatient setting while ABIOS has expanded the programme into the community setting for those children whose parents were not inpatients at BIRU or whose parents sustained their injuries prior to the development of this programme. Therefore the programme now has two arms to ensure that the maximum number of children can be supported and that the programme can be utilised in the long term. Indeed, in order to enhance access, the programme is now offered within school holiday periods, condensed into a 2 week programme run in 3 hour sessions. This has allowed children who found it difficult to attend after school the opportunity to participate and also facilitates the availability of the programme in providing some respite for families during the school holiday period. The other change to occur in offering the programme in the community setting is that the venues then become community-based and therefore provide a more 'child-friendly' environment. Flexibility has emerged has the key to successful programme implementation. Since its inception, the programme has now been offered a total of 8 times with 56 enrolled children, 49 of those commencing the programme and 44 completing the programme.

During this time, repeated requests from school counsellors, indigenous schools and other rehabilitation programmes locally and interstate for its use as a resource prompted redevelopment of the programme into an individual format. The individual format was completed during 2006 and aimed to facilitate use of the programme among children who are unable to or have difficulty participating in a group setting. As part of this process, the entire programme was redeveloped to include administration, manuals and evaluation resources in CD format for wider distribution. During 2007, the CD package has been enhanced through the development of printed covers and PDF formatting.

Additionally, in implementing the programme as part of standard practice, other opportunities and activities have also emerged. For example, a new and ongoing consultation was established as a direct result of this project with the Commonwealth Carer Respite Service and eventuated with the provision of a 'Cool Camp for Kids' where children were able to participate in camp-based recreational activities during the school holiday period. While the activity has not been incorporated within standard practice at this point in time, it is hoped that additional offerings of the camp can be established in the future.

Objective 6: Develop a 'quality' protocol for ongoing refinement, review and expansion to foster transference

As part of the implementation of the Brain Crew Programme into standard practice, a formal quality and review process was established consisting of:

- Ongoing annual review of client (BIRU and ABIOS) demographics to establish changing needs of the population
- Ongoing questionnaire administration completed by the children themselves at the final session and distributed to parents for completion within two weeks following each programme aimed at gathering feedback about the programme structure, appropriateness and effectiveness
- Ongoing review (quarterly) and refinement of the programme and quality protocol (including resources) based on consumer feedback
- The keeping of facilitator records to identify procedural improvements

The programme has developed a number of future plans utilising the ongoing information obtained through the quality protocol to inform development. These include the intention to apply for funding to enhance the relevance of the training allowing expansion to other Queensland Health zones and community organisations as well as training community co-facilitators in services supporting children in rural areas. Plans have been made to take 'Brain Crew' online and to market its use to other services providing support to people with ABI at both a national and international level. Finally, a parallel interest has developed within the team, identifying the need for parenting programmes that are relevant to parents with ABI and their partners.

Conclusions

This paper has described the ongoing development, implementation and evaluation of a support programme to assist children whose parent older sibling or relative has a brain injury. The aim of the programme was to maximise short and long term family adjustment, increase children's understanding of brain injury, expand children's coping strategies and peer networks and reduce children's anxiety, social isolation and emotional and behavioural difficulties. The six week programme was conducted once per week for 2 hours, run at the same time as an existing family support programme. Initially evaluated by child and parent interviews and focus groups conducted 3 months post intervention, children and parents reported positive, substantial and enduring gains from the intervention including increased understanding of ABI, reduced emotional distress and improved coping strategies for children. The value of the programme lies in its implementation as a continuous quality improvement (CQI) initiative, both dynamic and reactive to consumer need and feedback and providing exciting opportunities for expansion.

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Appendix

Child Interview Protocol

1. What age were you when your mother/father had their injury?
2.
    a) What was it like when you first heard about your mum/dad's injury/stroke/illness?
    b) Did you have anyone to talk to about this? (Hospital, family, friends, school)
    c) What was your reaction when your mum/dad came home from hospital?
    d) Did anyone help you or talk to you about what was happening?
    e) What is your reaction now to having a parent with an acquired brain injury?
    f) Does anyone help you or talk to you about what was happening?
3. What did/do you want to know about?
4. Would you like to talk to someone now about brain injury and what has happened to your family? Who would that person be?
5. Where is the best place to talk to you about brain injury and what has happened to your family?
6. What resources have been used to help you understand brain injury and what has happened to your family? How helpful do you think these resources have been?
7. What resources would you like to have access to as a way to understand brain injury and what has happened to your family?
8. What services have you used for information to assist you in understanding brain injury and what has happened to your family? How helpful were they?
9. What do you think is the best way we could help children like you who have a parent who has had a brain injury?

Parent Interview Protocol

1. What ages were your children when you/your partner had the ABI?
2.
    (a) What were the children's reactions at first when you/your partner had the brain injury?
    (b) How concerned were you about these reactions?
    (c) What information and/or support were you offered?
    (d) What were the children/s reactions when you/your partner came home from hospital?
    (e) How concerned were you about these reactions?
    (f) What information and/or support were you offered?
    (g) What are the children's reactions now?
    (h) How concerned are you about these reactions?
    (i) What information and/or support were you offered?
3. What were/are the children asking about? What did/do they want to know?
4. Who do you believe is the best person/people to talk with your children about brain injury, at the stage that they are now?
5. What setting is the best place to talk with your children about brain injury?
6. What resources have you or others used to talk about brain injury with your children? How helpful were these resources?
7. What resources do you think you would like your children to have access to as a way to understand brain injury?
8. Have you or your children ever used services for information to assist your children in understanding brain injury? How helpful were they?
9. What do you think is the best way we could help children who have a parent with a brain injury?