Annual Report 2009

The Brain Injury Network of SA Inc.

THE BRAIN INJURY NETWORK OF SA INC

PATRON

Professor Richard Clark
Director, Cognitive Neuroscience Laboratory at Flinders University
Member of Steering Committee, South Australian Neuroscience Institute and Chair of its Education Committee
Member, International Scientific Board, Brain Resource Company Ltd

EXECUTIVE

CHAIRPERSON:	**Mr Karl Mortimer**
VICE CHAIRPERSON:	**Mrs Pam Kirkham**
TREASURER:	**Mr Geoffrey Pritchard**

COMMITTEE MEMBERS 2008/09

Mr Christopher Farrand

Ms Erica Farrant

Ms Alison Lamshed

Ms Judy Barton [resigned May 2009]

Ms Melissa Merritt [resigned May 2009]

Dr Colin Winsor

OFFICE ADDRESS:
Torrens Building
220 Victoria Square
ADELAIDE SA 5000
Now located at 70 Light Square, Adelaide.
Telephone: (08) 8217 7600
Facsimile: (08) 8211 8164
Email: info@binsa.org
Website: www.binsa.org
Country Callers: 1300 733 049

STAFF July 2008- July 2009

Executive Officer	Ms Dawn Brooks [retired Jan. 2009] Mr Ralph Kogler [January - July]
Service Manager	Ms Kaye Murn
Counsellor (part-time)	Ms Terri Finn
Advocate (part-time)	Ms April Vanderaa [till March 2009 – Parenting Leave till March 2010] Julia Dolling [May 2009 – March 2010]
Springboard Program Assistants (part-time)	Ms Judy Gray Mr Chris Matthews
Community Service Officer (part time)	Ms Karen Marsh [Jan – July 2009]
Reconnect Transition Program Facilitator	Ms Ann Madigan
Administration Officer (part-time)	Ms Toni Paxton

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The Brain Injury Network of SA Inc. is pleased to present the eighteenth Annual Report and Financial Statement for the period 1 July 2008 to the 30 June 2009.

The activities of the Network as recorded in this Report have been undertaken according to

- the objectives as stated in the Constitution
- National Disability Standards
- The Pre qualified Provider Panel requirements
- BINSA Strategic Plan
- Funding and Service Agreements

The organisation is involved in the Service Excellence updating requirements for external accreditation.

We trust the Report will provide a comprehensive overview of the achievements and ongoing vision, role and function of the Network.

Disability as a Result of Brain Injury

People who have had a brain injury may have ongoing difficulties in any one or combinations of the following areas:

- Physical
- Sensory
- Cognitive
- Behavioural/Psychological
- Health

These may present challenges in the areas of

- Social/interpersonal relationships
- Communication
- Personality
- Ongoing health issues e.g. epilepsy
- Concentration
- Planning
- Executive function
- Moods
- Mobility
- Memory function
- Anger management
- Information processing

The often "hidden" cognitive effects and the very complex combinations which manifest with significant impact on the psychological, emotional, social and vocational outcomes for the individual indicate that acquired brain injury is one of the most challenging areas of disability.

In many instances psychiatric conditions emerge which present a further major hurdle for the individual, relatives and the system.

In addition this hidden disability is not well understood by the community or the service system and very often by those affected.

The following factors distinguish people who have had a brain injury from people with other disabilities:

- Self identity and expectations of life after the brain injury are still strongly shaped by social and intellectual development before the brain injury.
- Typically there is a store of memories and experience from before brain injury.
- Sometimes there is little or no change to IQ scores on standardised tests. Neuropsychological tests, however, may reveal areas of difficulty.
- The ability to use that intelligence, knowledge and abilities in everyday life may be significantly compromised.

What are the Aims and Objectives of the Network

(a) To provide support, information and assistance to people who have experienced brain injury and their relatives.
(b) To provide advocacy and where appropriate preparation and training for self-advocacy.
(c) To promote public and professional awareness of brain injury and the needs of people who have experienced brain injury and their associates.

(d) To promote and contribute to research into the management of brain injury and the factors which optimize recovery.

(e) To affiliate and network with other relevant organizations.
(f) Represent people with brain injury and their families on National and International bodies.

Achieving the Aims and Objectives

To achieve these aims and objectives BINSA has:

- Elected a management committee, which includes consumers, family caregiver, community and professional members.
- Represented abi needs, concerns and interests to both State and Commonwealth governments.
- Represented consumers needs and issues to politicians, government officers and service providers, when invited
- Expressed BINSA's interest in involvement in policy development.
- Responded to requests to support families with relatives in the acute care hospitals, rehabilitation, long-term care settings and the family home.
- Stood alongside individuals as requested in legal matters or in negotiating appropriate services, both by correspondence or in attendance.
- Facilitated the provision of information, education and informal support
- Produced a quarterly newsletter.
- Developed networks with relevant disability and community groups and agencies to increase awareness and support.
- Worked with Commonwealth funded employment programs and FACHSIA to facilitate better access to employment support.
- Brain Injury Awareness Week 2008 activities.
- Advocated on behalf of individuals as requested.
- Conducted residential workshops for people with abi to develop self-advocacy skills.

- Managed the Springboard program, (an education and therapy rehabilitation program for young adults with severe cognitive and physical disability as a result of acquired brain injury).
- Conducted seminars and workshops to provide access to professionals who are able to assist those seeking to learn strategies to manage living with abi.
- Liaised and worked cooperatively with other disability organisations on issues of mutual concern.
- Responded to relevant Government proposals and policy papers.
- Provided opportunities for members to be informed about changes to Government policy and service delivery.
- Represented the interests of the brain injury sector to enquiries and reviews of Government
- Participated in Australian Government consultations.

Funding

BINSA Inc operates on recurrent funding provided through the Office of Disability and Client Services (Department for Families and Communities) for the Springboard Program, the Learning and Lifeskills program, the Counselling services and the Peak Body function. The advocacy function is supported by the Australian Department of Families, Housing, Community Services and Indigenous Affairs. National Advocacy Program
Subscriptions and donations from the BINSA membership and concerned citizens also support the operation of BINSA Inc.

Sponsorship

The Motor Accident Commission generously sponsored the pilot Reconnect Transition Program for a further 12 months.

The Network is most appreciative for the financial support from all these sources and is dependent on ongoing funding and generous donations.

Compliments/Complaints

The Brain Injury Network welcomes comments, compliments and complaints, which enable us to continually improve the quality of our service.
One complaint was made in the 12 months to the 30th June 2009. The matter was thoroughly investigated both internally and independently and appropriate disciplinary action was taken.

Occupational Health Safety and Welfare

In 2008/09 there were no WorkCover claims.

During the reporting period 5 incident reports were lodged by paid and volunteer staff. As a result of the reports changes have been made to policy and practice to improve the safety of BINSA clients, Springboard participants and staff.

SECTION 1

CHAIRMAN'S REPORT 2008/09

CHAIRMAN'S REPORT 2008/2009

This is my ninth report as Chairperson of the Committee of Management of the Brain Injury Network of South Australia (BINSA). Over the years the reports have detailed changes in the organisation. There have been reports on staffing changes and on changes in funding. This last financial year of 2008-09 has once again seen some significant changes.

In January 2009, Dawn Brooks retired. Dawn has been the Executive Officer of BINSA almost since its inception. She has been the Chairperson of the Head Injury Council of Australia (HICOA), the chairperson of the Disability Advisory Committee to the State Government, and on numerous other advisory committees over her 16 years with BINSA. She has been (and still is) a strong advocate for people with acquired brain injury and for their families and carers. Dawn also was awarded a Churchill Fellowship to study community based rehabilitation in Scandinavian countries and Switzerland in 1995 and the National Disability Inclusion Award in December 2007

Upon her retirement, the BINSA Committee of Management gave Dawn life membership to BINSA in recognition of her outstanding contribution to BINSA and its members. Dawn's formal contribution to BINSA will be missed.

After a recruitment process to replace Dawn as Executive Officer the Committee of Management selected Mr Ralph Kogler. Ralph had impressive experience in the health sector. He resigned from the position in July after securing new premises for BINSA.

In 2008, BINSA was informed by the Department for Premier and Cabinet that it would assist our organisation to find new accommodation. A site was located at 70 Light Square, Adelaide - close to the University of South Australia campus and the location of the proposed RAH. The Department for Premier and Cabinet has funded the fit out and moving costs and has provided funding for subsidising rent for 10 years. This is a significant additional financial contribution from the State Government. The new premises are more spacious than our previous accommodation. I thank Mr Mark Horwood and Mr Bronte Treloar of the Department for Premier and Cabinet for their support.

Unfortunately the timing of fit out for the new tenants in the Torrens Building in Victoria Square meant an interim move from our old "digs" to less than ideal accommodation for a few weeks. My great thanks to the staff of BINSA for their patience and hard work to move the organisation twice and for maintaining quality services.

Since the end of July I have acted as Executive Officer in an unpaid capacity and assisted by Dawn, who has been contracted part time to undertake the day-to-day tasks of the Executive Officer.

There have been other changes in staff too. In March April Vanderaa went on maternity leave. In January Ms Karen Marsh was employed as the Community Services Officer. She resigned in July, for family reasons.

Ms Kylie Smith provided excellent support for the final sessions of the Assuming Control Course as well as facilitating the City and Northern Groups.This helped BINSA out of a difficult situation and maintained high quality support to clients.

Ms Judy Gray from Springboard retired on 18 September 2009. Judy has been the backbone of Springboard for 11 years. She has made an outstanding contribution to the achievements of Springboard participants, supported the volunteer team as well as maintaining supplies and cleanliness in the BINSA kitchen areas. Thank you Judy, you will be greatly missed.

Sadly, Ms Anne Madigan, who was employed for the Reconnect program, could not be retained, due to the completion of the project and the uncertainty of acquiring future funds for it.

Ms Emma Riggs has now joined BINSA to support the Springboard Community Access and Learning and Lifeskills programs until the end of November.
Board members Ms Judy Barton and Ms Melissa Merritt resigned their positions due to other commitments. My thanks to Judy and Melissa for giving their valuable time, perspectives and expertise on the Committee of Management, in support of BINSA.

A sincere thank you to all our staff, both old and new, and to my colleagues on the Committee of Management. It has been an interesting and challenging year in many ways, but also the opportunity for new beginnings.

As the State member organisation of Brain Injury Australia (BIA), South Australia hosted a BIA board meeting and planning workshop in July.
As always, on behalf of the Committee of Management and members of BINSA, I thank the State Minister for Disability, the Hon Jennifer Rankine, and the staff of Department for Families and Communities and the Federal Minister, the Hon Jenny Macklin, the Hon Bill Shorten Parliamentary Secretary with responsibility for Disability Services and the staff of Department of Families, Housing, Community Services and Indigenous Affairs for their continued financial support. The Australian Government provided additional funding to BINSA for 2009/10. I also thank Mr Andrew Daniels, Chief Executive Officer, and staff of the Motor Accident Commission for funding for the Reconnect program.
I look forward to 2009-10 as a year of consolidation and progress. There are still some issues that will need addressing, such as the ongoing deficit but I am confident that the newly elected Committee of Management, and staff of BINSA will resolve these and continue to be dedicated to supporting our members; people with acquired brain injury, their families and carers.

Karl Mortimer

SECTION 2

EXECUTIVE OFFICER'S REPORT 2008/09

EXECUTIVE OFFICER'S REPORT 2008/09

This report covers the period from 1st July 2008 to 31st January 2009. There is no reporting of the period from 1st February 2009 to 30th June 2009 due to a change of staffing arrangements.
The organization has experienced significant challenges again this year as it has sought to recruit and retain qualified and experienced staff.
Clients and participants as well as staff have had to weather the challenges, uncertainty and changes as well as maintain the quality and standards of BINSA's services and programs.
Your patience and tolerance is sincerely appreciated.
The organization also is very appreciative of the generous donations received and for the ongoing funding support received from the State Government's Office of Disability and Client Services, the Australian Governments, Department of Families, Housing, Community Services and Indigenous Affairs [FAHCSIA], and the Motor Accident Commission.
As always we are reliant on these funding sources to be able to advocate for children and adults with acquired brain injury and their support networks.

Brain Injury Australia
The Brain Injury Network of SA Inc has maintained its membership with the National Body – Brain Injury Australia.
Karl Mortimer and Dawn Brooks have represented BINSA as the SA State Peak Body on the National Board.
Mr Nick Rushworth, BIA Executive Officer was the guest speaker at the 2008 BINSA AGM.
Where possible BINSA has had input into policy responses and BIA's development of policy papers.

National Disability Strategic Plan
BINSA made a late submission to the consultation process for the development of the National Disability Strategy.
It is important that the needs of those living with ongoing impact of brain injury are considered. A generic, "one size fits all" plan may mean that the disabling hidden long term effects of cognitive impairment are overlooked. This may result in funding allocations or policy and service development priorities ignoring the needs of those BINSA supports.
A submission was also made to a FAHCSIA consultancy conducted by Jenny Pearson and Associates to provide information about the nature and activity of organizations funded under the National Disability Advocacy program.
It is important to note that some consider advocacy for specific disabilities [eg: acquired brain injury] should not be funded so it was imperative that BINSA provide a robust argument to put the need for those with abi to have access to advocates who understand the hidden disabling effects of acquired brain injury.
Whilst the 31,000 in SA living with the ongoing disabling impact of an acquired brain injury continue to be denied the support required to access affordable

housing, home support services, ongoing therapy, equipment and support to participate in the community it is important that there continues to be strong representation and access to individual advocacy support to ensure civil, human and legal rights are recognised.
The lack of community understanding about the nature of the disabilities associated with abi and the support needed to ameliorate the challenges in daily living strengthen the case for abi specific advocacy.

Information
Individuals, family members, professionals, students, community service providers continue to contact BINSA seeking information to assist them to both understand the nature of abi and for individuals to make informed decisions and choices as they rebuild their lives and futures.
In 2008/09 318 contacted BINSA seeking such support.
The notion that an over stretched government, generic agency can provide this specialist and specific information has proven unsatisfactory for most who contact BINSA.
Requests for the following information have been received:

- The Brain Injury Network and its services.
- Brain injury and the ongoing impact.
- Rehabilitation services or private practitioners
- Insurance and compensation processes or services
- Human rights and discrimination issues
- Employment support
- Complaints processes
- Accommodation options
- Legal support and representation

We have continued to distribute the two brochures developed by BINSA to assist individuals to know what the Disability Services Act requires of Service providers (including the Brain Injury Network) and what an individual can do when the standards are not met.
We have also provided information about self advocacy and BINSA's advocacy role.
In 2008/09 BINSA provided information on 4084 occasions. This included 318 phone calls, posted information (as requested), drop-ins, attendees of forums and workshops, Newsletters and other mail outs to BINSA's membership.
It has been BINSA's practice to refer enquires about abi to Disability SA (DSA) as directed after our funding was removed in 2007. Many have called back because they were not given the information required or because they were referred back to BINSA by DSA staff. Many of the requests for information have been from DSA staff and other State Government agencies including Families SA, Corrections and Domiciliary Care SA. Requests have also come from hospital staff, solicitors, carer organisations, Members of Parliament, electoral officers, Police Department, Office of Public Advocate, Public Trustee officers, employment agencies in South Australia as well as Interstate agencies with clients relocating to South Australia or requesting resources from BINSA.

Review of Brain Injury Rehabilitation in South Australia
I have provided a consumer perspective on the review working group over the past year. Many BINSA members and staff have also contributed in the consultation forums.
It is hoped that a comprehensive Statewide service system will emerge to ensure that those with minor brain injury as well as those with moderate and severe injuries will have access to an adequately resourced range of assessment, rehabilitation, behaviour support and community support services across the State.
Linkages and integration with other systems such as drug and alcohol, mental health and behavioural support services are expected to be part of the plan.

We would urge the relevant Ministers and Departments to do whatever is required to make this significant development a reality.

Brain Injury Awareness Week
In Brain Injury Awareness Week BINSA hosted the 2008 Achievement and Service Excellence Awards. The celebration event was held at Henry's Brassiere at Ayres House. We thank the Honourable Stephen Wade for presenting the Awards. Students from St Mary's College provided an excellent musical contribution.

Other organisations provided details of their activities, which were included in a calendar of events circulated to the sector.
Once again we have appreciated the involvement of the University of South Australia by including an assignment about brain injury and its impact on the life of an individual.

Relocation
An additional challenge this year for the organization has been the uncertainty of tenure in the Torrens Building.
The Premiers plan to make the Torrens Building the hub for establishing overseas universities in Adelaide meant that BINSA and all the other non-government organization have had to re locate.
Several options were suggested and considered however the needs of BINSA's programs and membership did not match the capacity of most of the facilities presented.
The negotiations for relocation to 70 Light Square were completed in 2008/09 under Mr Ralph Kogler's time as Executive Officer and the organization moved in on 19th September 2009 after the fit-out was completed.

Advocacy Staff News.
Our congratulations to April and David Vanderaa on the arrival of little Lukas.
We welcome Julia Dolling as she has taken on the Individual Advocacy role whilst April is on parenting leave.
Thank you also to those who have provided in kind support and service to BINSA over the year.

Thank you

Sincere thanks to the staff for their commitment and contribution to the organization and its clients, participants and members during this challenging year.

Thank you to Professor Richard Clark for his ongoing interest and support as BINSA's patron and to Angela Gregory who has again provided effective and competent management of BINSA"S financial and payroll matters.

Thankyou to Dr Tim Anstey for the careful and independent research and evaluation of the Reconnect program.

We are also most appreciative of all who have provided support and services to BINSA and its members over the year.

We have once again had excellent support from out two regular volunteers Geraldine Jones [until January 2009] and Keryl Beesley and we thank them most sincerely for their generous contributions, Keryl for her administration assistance and Geraldine for organising our library resources.

The generous contribution of other volunteer effort is detailed in other reports.

The organization also has had the voluntary leadership support and professional expertise of Karl Mortimer and the members of the Management Committee.

Thank you for your leadership and guidance of the organization over the past challenging 12 months.

Future Challenges

Once again the challenges for the year ahead relate to providing quality services with limited resources and recruiting and retaining quality staff.

Dawn Brooks
Executive Officer – 1st July 2008- 31st January 2009

SECTION 3

LEARNING & LIFESKILLS PROGRAM & COUNSELLING 2008/09

LEARNING & LIFESKILLS PROGRAM
July 2008 – June 2009

The **Community Learning and Lifeskills Program** has been operational at The Brain Injury Network of South Australia Inc. (BINSA) since 2003. This program is *a different type of rehabilitation*.

This report provides the following information on the Learning and Lifeskills Development Program:
- Broad Aim/Key Features/Program Components/Goals of the program
- A Review incorporating a brief statistical overview of the program from July 2008-June 2009

BROAD AIM

The Learning and Lifeskills Development (L&L) Program provides psycho-social rehabilitation and support to individuals with an ABI to develop/increase the individual's potential, skills/abilities, knowledge of brain injury and services/resources available to them and increase individual choices through a comprehensive range of social, recreational and educational activities for those with ABI. Some sessions have also been open to family members.

Program Goals

- Build self-esteem, self-confidence and motivation.
- Reduce social isolation.
- Increase community participation.
- Develop skills- such as self-advocacy & determination, public speaking, social relational, planning and organisational skills, also skills in dealing with service providers and government departments.
- Promote positive achievements to the community.
- Provide opportunities to regain/gain skills to assist in the self-management of individuals' lives
- Assist people to adjust to changes imposed by his/her brain injury- these may be physical, cognitive, psychological, emotional, financial and/or social.
- Increase the independence of people with acquired brain injury in order to rebuild and enhance their lives.
- Increase the social networks of individuals involved in the program

Key Features

- Increasing community awareness of acquired brain injury through Brain Injury Awareness Week (BIAW) activities and provision of information.
- Providing education, skill development opportunities/workshops and/or information about different aspects of brain injury

- Providing opportunities for people with an ABI to regain, learn or develop life skills in a supportive and respectful environment and in response to the expressed needs of members.
- Provision of supportive groups where people are able to meet, share concerns/stories and receive information/support.

Program components

- Monthly information and/or education sessions/workshops for people with acquired brain injury
- Provision of individual self-advocacy and self determination opportunities for people with ABI
- Brain Injury Awareness Week activities
- Limited one to one counselling is also provided & referrals are made to appropriate services and agencies as required.

Review & Statistical overview 2008-09

The following is a review of all the components and involvement of the Learning and Lifeskills Development program for the past year of July 2008 – June 2009.

Community Learning and Lifeskills

During the latter half of 2008, Community Learning and Lifeskills activities were implemented by a combination of BINSA staff in the absence of a Co-ordinator. In the first half of 2009, the program was co-ordinated and presented by newly appointed Co-ordinator Mrs Karen Marsh.

Pancake Day

Regular Groups

The long-running City Group and Northern Group continued to bring information, guidance and fellowship to participants while enabling BINSA to identify areas/issues requiring further attention.

Monthly Seminars
A series of seminars for people with abi and/or their supporters was held. The topics covered included Strategies for living with Visual Changes after ABI (attended by 8 people with abi and a family member) and Problem Solving Strategies (attended by 22 people with abi and 7 family members/supporters.).

Additional functions that were held under the banner of Community Living and Lifeskills were a Women's Health Afternoon Tea for Pap Smear Awareness Week attended by 23 women (people with abi, friends and family members, staff and women from other organisations in the Torrens Building) and a gathering of 32 BINSA members, staff and supporters for Pancake Day on Shrove Tuesday.

COUNSELLING

The counselling position has been offered 1 day a week this year.
The number of hours funded in no way reflects the need for service. Over 40 clients have received a service this year with over half receiving 4 or more sessions.

There has been an increase from 2008 in the number of clients requesting sessions who have a family member in acute care. These people have needed assistance to understand what is happening with their family member and to work through the range of emotions they were experiencing. Additionally there has also been a significant number of people contacting for support who have a family member under 16 years of age.

Families and clients who no longer have formal connections with other brain injury services continued to require assistance, indicating that brain injury is a life long experience for all involved.

Issues have centred on adjustment to changes following brain injury both from a family members and client perspective, strategies to manage behaviour, grief and loss and relationships.

Terri Finn
Counsellor

SECTION 4

SPRINGBOARD PROGRAM 2008/09

The Springboard Program continues to offer carefully targeted rehabilitation to eligible adults with abi. The people whom the program serves are those who have been profoundly affected by their injury, with multiple challenges, and all are supported to achieve rehabilitation goals which reflect their values and aspirations. The program ran for 227 days during the reporting period.

Participants
During the reporting period, four participants left the program. Two of these came to the end of their 3 year program, one new participant on probation found that she could not commit to attending regularly and another opted to seek services closer to home because of insurmountable transport difficulties.

Five new participants commenced their programs, four of these proceeding to the therapy phase of their involvement.

The natural turnover of participants brings a constant air achievement, as volunteers and staff meet new people with abi, support them through this long stage of their rehabilitation journey, and farewell them as they take their new or relearned abilities to the next phase of their lives.

Examples of the goals achieved by individual participants in the reporting period are successful saliva management to the extent of eliminating the need for carers to wipe, improving mobility to enable full participation as father of the bride in a garden wedding, walking without an aid indoors and in selected outdoor areas, engaging in conversation which is succinct and appropriate to the situation, using public transport safely without an attendant, using verbal expression clearly enough to teach others a new skill, writing legibly with the non-dominant hand.

Farewelling Springboard participant

Volunteers
A complement of 33 Volunteers were involved in the Springboard Program during the reporting period. Of these, 12 attended for the whole 12 months. Nine volunteers left – one moved interstate, 4 took up paid employment, 2 began studying, one retired and one moved on to other interests. Twelve new volunteers began working with the Program. Of these, seven were third and fourth year Speech Pathology students who came in not as students on placement, but to participate in all elements of the program to broaden their experience. These particular volunteers need to fit their commitment to Springboard around their study requirements, but all attend as frequently as they can.

A quarterly snapshot of volunteer hours (July, October, June and April) shows that on each Springboard day, volunteers contribute an average of 14.4 hours a day to the Springboard Program. The majority of volunteers come in once a week for the full five hours. Several come in twice a week, and a small number come in irregularly when other commitments allow. The current age range of volunteers is from early twenties to mid sixties.

The value of the contribution made by volunteers is immeasurable; their generosity is outstanding, even though they invariably maintain that through their involvement they receive far more than they give.

Volunteer week, stall in Rundle Mall

Staff
Springboard is staffed by a full time Service Manager and 2 part time Program Assistants, one of whom comes through an agency, from where coverage for sick leave etc. is also sourced. One of the Program Assistants attends only for the hours that participants are present, and the other is engaged for an additional 1.5 hours each day to undertake some administration and program support tasks. These staff hours, in combination with the volunteer hours, enable each participant to have a minimum of 1:1 support available at all times if needed.

During the second half of the reporting period, the BINSA Community Services Co-ordinator had 8 hours a week allocated to co-ordinating and presenting the Learning and Lifeskills component of the Springboard Program. For 3 months of the first half of the reporting period, some Learning and Lifeskills activities were presented by a locum OT in the absence of a BINSA Co-ordinator.

Also during the 2009 months of the reporting period, the service offered by Springboard was enriched through the involvement of final year Occupational Therapy students on clinical placement. Successive students were based full time at BINSA for eight weeks, each working with both individual participants and with groups of participants. In 2009, a second year student from the Disability and Community Rehabilitation degree course at Flinders University was also on placement at Springboard 2 days a week for 10 weeks. His commitment to the program is such that he signed up as a volunteer while waiting for his formal placement to begin.

The eclectic mix of staff, volunteers, students and participants at Springboard brings with it an energy and breadth of experience that is highly valued.

Springboard Therapy Programs
Each Springboard participant is a person who has been assessed as being likely to benefit from Speech Therapy and Physiotherapy. During each day at Springboard, every participant has at least an hour of these therapies implemented by staff and volunteers who have been trained by the consultant therapists. Speech therapy services are provided by Disability SA's Speech Pathology Student Unit, where final year students are supervised by clinician Ms Anne Walter. Physiotherapy services are provided by Dr Susan Hillier from UniSA. Both therapists bring to Springboard a passion for improving the abilities and lives of people who have experienced abi, and both demonstrate a strong commitment to the program.

During the reporting period, all ongoing participants had their individual programs reviewed and revised to reflect their changing abilities and to further challenge them. New participants had their initial programs put into place, and reviewed if needed. Staff and volunteers were trained to implement each participant's therapy program. Records show that a total of 802 individual therapy sessions were provided, along with 10 group therapy sessions.

When therapy sessions are in progress, there exists an intense atmosphere of endeavour and enterprise as participants, with the support of staff and volunteers, seek to extract every possible success out of every task. Achievements large and small are celebrated spontaneously and with pride by all.

Springboard Learning and Lifeskills Program
The Learning and Lifeskills component of the Springboard program has 3 elements. The morning greeting and orientation session starts the day, the lunch break is an important social and communication time, and the structured afternoon activities reflect the rehabilitation goals of individuals as they engage in group or solo activities.

Early in the reporting period, documentation was developed to record the activity being undertaken during afternoon sessions, in such a way that individual and group goals are clarified prior to the activity, and progress in achieving the goals is documented after the session.

Learning and Lifeskills activities have included presentations by participants (eg. My Sporting History/Achievements), by volunteers (eg. My Scuba Diving), by staff (eg. My Michigan Home) and by visitors (eg. SAPol Dog squad). A variety of craft activities were enjoyed by participants, as well as outings (eg. Adelaide Zoo), quizzes and cognitive activities, and competitive modified sporting activities. A highlight for one group was a series of Friday Afternoon Dance Classes, in which one participant who had learned ballroom dancing earlier in life taught staff, volunteers and participants some of the basics.

While all afternoon activities are purposeful and goal orientated, for most the sense of enjoyment and achievement is tangible.

Thankyou
The BINSA Springboard team is grateful to:

- The Springboard participants for their wisdom and optimism.
- The Springboard volunteers for their energy and generosity.
- The BINSA Management, Chair and Management Committee for their support.
- The family members for their commitment to the requirements of the program.
- The taxi drivers and volunteer drivers for their reliability and good cheer
- Our BINSA colleagues for sharing our successes and our concerns
- The Department of Families and Communities for their commitment to what we are achieving at Springboard.
- UniSA and Flinders University for their interest in the program
- Dr Susan Hillier for physiotherapy services
- Disability SA Speech Pathology Student Unit, and particularly therapist Anne Walter, for Speech Pathology services.
- The visitors and presenters who have brought knowledge, fun and new experiences to us all.

My personal thanks go to the Program Assistants – Judy Gray, Chris Matthews and Victoria Zelipski – and to Community Services Co-ordinator Karen Marsh. Each of you contributes much that is unique and of immeasurable value, always maintaining your focus and professionalism. Be proud.

Kaye Murn OT
Service Manager
BINSA

SECTION 5

ADVOCACY
2008/09

Individual Advocacy

JULY 2008 - March 2009

The Brain Injury Network of South Australia Inc. (BINSA) is funded under the National Disability Advocacy Program (NDAP) of the Department of Families, Housing, Community Services and Indigenous Affairs to provide individual, systemic, self and legal advocacy.

In 2008-2009 BINSA continued to provide advocacy services to those with ABI, at different stages of the journey on the road to independence following the advent of a brain injury in their lives.

Definitions:

Individual Advocacy

- A focus on individuals in crisis or high need.
- A focus primarily on the protection of the rights of people with disability, particularly through:
  - the prevention of abuse, discrimination or negligent treatment of people with disability
  - encouraging people with disability to make informed choices.

Self Advocacy

- A focus on supporting and empowering people with disability to represent or advocate for their own interests in the community, through:
  - the development of personal skills and self-confidence
  - advice, information and encouragement.

Systemic Advocacy

- A focus on introducing, influencing or producing broad and / or long term change in the community to ensure the rights of people with disability are attained and upheld, through:
  - the pursuit of changes in legislation, policies and practices of organisations providing services to people with a disability
  - influencing community development
  - community education
  - working together with other groups, particularly with individual advocacy services.

(quoted from NDAP consultation paper entitled "Working Towards a Common Understanding of Advocacy")

BINSA recognises and affirms the following underpinning values through their advocacy involvement:

- Individuals have the right to have an advocate and /or representation so that their voice is heard when they are unable to speak on their own behalf
- Individuals have the right to choice and participation in their community, employment, education and training and the support they require to do so
- Family members also have the right to have their views and needs heard and considered

- Individual's rights to an adequate service within the standards and principles of the Disability Services Act and encourage their right to make a complaint using BINSA's complaints procedure
- BINSA also seeks to promote a positive image of people with disability as a result of brain injury and promotes their right to participate in and contribute to the community.

Review & Statistical overview 2008-09

The following is an overview of advocacy July 2008-March 2009. [April Vanderaa]

BINSA in Collaboration
In July 2008 we were approached by Disability SA to facilitate focus groups to obtain feedback on service coordination. 4 focus groups were organised (1) Kadina, (2) Adelaide, (3) Aberfoyle Park and (4) BINSA staff and Management Committee members. Feedback was collated and provided to Disability SA.

BINSA approached the Office of the Public Advocate to provide information about the advocacy role of BINSA and as a result of the discussion a forum for all disability advocacy organisations in South Australia to meet, discuss and create a common agenda of issues was planned and implemented. The Public Advocate was also present at this meeting.

Residential Workshop
BINSA held another Residential workshop entitled *Pathways for Effective Self-Advocacy* on September 24th and 25th 2008 at the Clare Country Club. This was an opportunity for both people with acquired brain injury who are living in the mid-north region and those from the metropolitan area to participate in workshops to gain skills in self advocacy. Speakers providing sessions included: Con Polychronis (BIRU), John May (Sevenhills Winery), Pauline Wood (Central Northern Legal Services), Shirley Callaghan (Relationships Australia), Emma Scamps (RAH and BIRU) and BINSA staff. 16 people attended the two day residential workshop.

Individual Advocacy
Some issues requiring appropriate advocacy included: emergency and priority housing from Housing SA, transport, letter writing, sourcing legal representation, assistance with DSP applications, job capacity assessment, gaining access to equipment and/or services, and human rights/discrimination issues relating to employment.

Self referrals have been quite common. Often this is when people have received advocacy in the past and have new issues arising requiring advocacy support. Organisations that have referred to us over the past year include: Housing SA, Disability SA, Raine and Horne Real estate, Brain Injury Outpatients and Victim Support Services.

Several possible advocacy referrals from Disability SA were redirected to the South Australian Government direction to have Disability SA provide these services to registered clients.

Most issues were fully resolved; however (1) matter was referred internally on commencement of my maternity leave.

Information

Information was provided to 55 people between December 2008 and March 2009.

May 2009 – June 30th 2009. Julia Dolling

The position of individual advocate was vacant for three months from April Vanderaa beginning her 12 months maternity leave and Julia's commencement in late May 09. Julia was pleased to join the team at BINSA having worked with BINSA previously as a project worker in the past. Julia has 18 years of experience in the brain injury field in both Victoria and South Australia.

Self advocacy During this period there has been:

- the development of personal skills and self-confidence through the provision of information and encouragement. i.e. writing letters of complaint, letters requesting flexibility in service provision in relation to person's impairments.
- clarification and discussion about needs that are not being met or not considered adequately at service review meetings.

BINSA also provides a **systemic advocacy**, whereby we advocate for changes to the system. BINSA continues to seek changes in current services or for funding for new services that will improve the quality of life for people with an acquired brain injury, their family and carers. A focus on introducing, influencing or producing broad and / or long term change in the community to ensure the rights of people with disability are attained and upheld, through:

- participation in state-wide workshops run by SA Health to determine requirements for improving rehabilitation service provision to people with ABI. The State-wide Rehabilitation Clinical Network identified that rehabilitation, accommodation and support services currently provided to people with brain injury in South Australia are fragmented, do not reflect best practice or evidence based standards. Concerns and information gained form the workshops is informing the development of a Statewide Acquired Brain Injury (ABI) Rehabilitation Service Plan.

There has been a continuous demand for **Individual Advocacy** from BINSA throughout the year with an average of six new cases each month as well as information requests. Referrals have come from family members and friends (significant others), and other organisations including: Mental health service providers, Housing SA, Disability SA, Disability Employment agencies, Carer Respite services, BIRU, Community health services, Royal Society for the Blind, Nursing home, carer support agency as well as self-referrals from individuals.

Issues raised in individual advocacy.

1. **Greater access to neuro-psychological assessments**. Requests for NPA continue to be required given that evidence of cognitive impairments is required for access to DSA services and disability employment services. These requests have come from mental health service providers Disability service providers, other advocacy services and family members. There are limited services in the public health system, and long waits. Many are unable to afford private practitioners even if they have private health cover.

2. **Disconnection and poor access to services due to the impacts of social isolation.** The impact on family and community is also profound. Commonly, people with ABI experience deterioration in their family, social and community networks. Issues faced by people with ABI include unemployment, loss of family and social networks, homelessness, alcohol and non prescription substance over-use, entering the criminal justice system and feeling disengaged from the community. These changes can precipitate feelings of isolation and hopelessness and places people living with an ABI at a greater risk of suicide. Requests for advocacy support has often come from isolated persons with ABI who have no one they can turn to help them problem solve and self advocate. They often have no sounding boards able to be objective while also being aware of the impacts of their ABI. Isolation clearly impairs ongoing skill development in negotiation and communication skills especially when there is a loss of self confidence. This only further disadvantages those trying to self advocate. Many individual referrals coming from those with an ABI were related to challenges they were experiencing in managing daily living while living alone. These included coping with constant fears of being broken into and abused, inability to relate to difficult neighbours, home management including cleaning, repairs, keeping warm, getting to medical appointments and paying bills whilst experiencing anxiety depression, and struggling because planning initiation and memory capacities are impaired.

3. **Financial Vulnerability.** Several concerns have been raised by clients with ABI who required advocacy to gain better transparency about management of their finances and fears that they were being taken advantage of. Several requests for help involved liaison with Centrelink to clarify changes to their review processes of the DSP. Having someone else to talk to about these fears and to clarify their rights and responsibilities regarding Centrelink has been useful. Some people with ABI contacted BINSA for help in self advocacy to guide them through the process of not losing control when dealing with different levels of officialdom especially when they were fearful around financial vulnerabilities.

4. **Maintaining Family relationships**. One of the most distressing effects of acquired brain injury involves families coping with personality and behavioural changes due to the ABI. In particular family members and other service providers have been seeking consultative support, information and training around how to manage family relationships when there is challenging behaviour.

5. **Difficulties accessing Disability SA Services.** Many clients either didn't remember they were registered with DSA either because they had not had contact from DSA for a long time, or were unaware they needed to trigger becoming active again. No contact had been interpreted that they were no longer a client of DSA. BINSA helped clients to recontact DSA to organise a review of their service support. Difficulties still exist where progress from rehabilitation into community living is being significantly delayed due to the lack of more appropriate accommodation options. Also BINSA received concerns from ageing carers who were exhausted from caring for their relatives due to their inability to access adequate levels of personal support funding through DSA.

6. **Mild ABI no DSA case management. Several requests for support came from people with a mild or undiagnosed ABI who did not meet DSA eligibility** and were unaware of where to get help or information to manage their impairments or what community support services were available to assist.

7. **Understanding Service system.** Family members continue to contact BINSA wanting to understand the acute and rehabilitation systems better so that they can advocate on their relatives behalf. BINSA's information packages have been very useful as a back up to advocacy around specific concerns raised.

8. **Difficulties related to the criminal justice system.** BINSA continues to receive requests for help from individuals with an ABI who are trying to understand their rights and obligations in the justice system as well as express the implications of their ABI on their capacity for just sentencing. We have greatly appreciated the support and advice provided by David Fabbro from Andersons solicitors in these matters.

9. **Challenging behaviour**
   There have been several requests from people who are experiencing difficulty due to the 'invisible' or 'hidden' nature of cognitive impairment and the impact on the areas of thinking and behaviour. As a consequence, the difficulties people with ABI face in the community are often misunderstood. In particular problems with impulsivity, anger management, and inappropriate communication have caused problems with the criminal justice system i.e. with police, courts, correctional facilities and institutions. At its core, the criminal justice system has an assumption of responsibility for one's actions. This assumption may not be correct where an individual with a brain injury is concerned and a well informed advocate has been able to support individuals to access legal representation or assist with explaining the impact of cognitive impairment.

A person with acquired brain injury may have lost the skills to provide a calm and logical response to a situation that they perceive to be unjust or threatening, yet that same person may show no evidence of having a disability when attending court with the support of a duty solicitor, or when being interviewed by a

psychiatrist. Impulsivity, impaired anger management skills, short-term memory loss, susceptibility to suggestion, and impaired social skills, can result in a person being charged, convicted and sentenced, instead of treated, rehabilitated and supported in the community. BINSA will continue to work with these clients in one to one and group self advocacy skills as well as exploring how best to work with the sector in reducing stigma and discrimination due to their hidden impairments.

Country issues include;

- No support for family members coping with behaviour issues related to ABI.
- Poor continuity between specialist city and generalist local health services.
- Social isolation.

Additional funding

In July this year the position was able to be expanded from 15hours to 22hrs a week, following BINSA's successful application for "top up" funding from the National Disability Advocacy Program (NDAP) of the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). The focus of this annual ongoing Commonwealth funding is to provide individual, systemic, self and legal advocacy, with the greatest percentage of this funding directed to individual advocacy. This funding has enabled BINSA to expand the individual advocacy service and plan the delivery of a self advocacy workshop in 2010.

As the Individual advocate I have appreciated...

- our BINSA staff team and management committee who have been committed to ensuring the continuity of our services even during significant turmoil this year with staff changes and two office moves.

- significant others and those with ABI who keep advocating for themselves and their peers. Keep informing the sector of your needs never give up. Your support and belief in BINSA's advocacy will help us continue our efforts to improve service access for themselves and others! Your support and commitment is greatly appreciated!

- the Australian Government for the ongoing advocacy funding to people with ABI, it is a privilege to be able to work with individuals with ABI to work with them to access their human and civil rights!

April Vanderaa
Individual Advocate
July 2008-March 2009

Julia Dolling
Individual Advocate
May – June 2009

SECTION 6

RECONNECT
2008/09

Reconnect Transition Program

July 08- June 09

The Reconnect Transition Program (RTP) completed its second full year in 2009. The RTP was an initiative of the Brain Injury Network of South Australia in collaboration with the Brain Injury Rehabilitation Service. It was a two year pilot program fully funded by the Motor Accident Commission.

The program is aimed at people with an acquired brain injury who typically have completed the intensive phase of their rehabilitation program and are interested in assistance with continuing the transition from rehabilitation to day-to-day life. This transition period after intensive rehabilitation is a challenging time for participants and their families as the long term disabling impact of their injury can become more evident as individuals attempt to resume the 'normal fabric of their pre injury lives'.

The program continued to offer participants in a group work setting the opportunity to discuss experiences, obtain information, continue to work through the everyday challenges of living with an acquired brain injury, and develop skills in a welcoming atmosphere in which everyone's experience is respected. The program is run across 10 weeks and each session is a minimum of 2 hours duration.

The program is directly responsive to the expressed needs and interests of participants and has covered a wide variety of areas including topics such as 'Living with ABI', 'Stress Management & Relaxation', 'Mood & Feelings', 'Self Talk', 'Communication' and 'Interpersonal Relationships'.

There is a consistent format with each weekly session which includes: revision of discussion and outcomes from earlier sessions; group or pair work on the newly introduced topic: a relaxation exercise; identifying 'Take Home Messages' from the current session including identification of any strategies for home practice and an end of session summary. Participants are given their own RTP Manual which includes resource material relevant to the topic and is developed in direct response to the weekly outcomes of group discussion and exploration. A written summary of each session is forwarded to participants between sessions.

In 2008/09 participants & Mentors alike have travelled from rural Sth Australia; the Adelaide Hills, Fluerieu Peninsula and all directions of metropolitan Adelaide.

Each group includes a number of trained mentors, people who have themselves made a successful transition from intensive rehabilitation to day-to-day life. These mentors attend each session and are available to share their perspectives and insights with the rest of the group. The ongoing generosity and contribution of Mentors has been a defining feature of the RTP.

End of program participant feedback strongly endorses the unique and irreplaceable role Mentors play in the Reconnect program. The current Mentors continue to exemplify a strong commitment and respect for their role as coach, counsellor and companion to participants within the group work setting. In 2009 a second Training program for new Mentors was hosted at the BINSA offices. Seven individuals completed this Training Program, three of whom immediately took up the invitation to Mentor in the subsequent RTP group. In total, Mentors have collectively voluntarily contributed in excess of 750 direct contact hours to the program, <u>400 of which have been in the last reportable year</u>. An amazing contribution, by anyone's estimation and an indication that volunteering at BINSA is alive and well!

Participants have reported a strong sense of both relief and gratitude to know that they are not alone and that their experiences of brain injury are not isolated but shared by others. The unprecedented sense of legitimacy and validation this gives to participants cannot be overstated and has typically enabled participants to give further voice to their challenges and struggles within the group context.

The Reconnect group is experienced as a safe environment and potentially one which is more 'hope filled' and positively directed than what participants may be familiar with. That is, the Reconnect group can be a place where a belief about the possibilities for change and the capacity to cope or be successful can be considered and progressed, as the Mentors can attest to and are an authentic witness of this.

Three Reconnect groups have been run across the twelve month reportable period. These three groups had 15 enrolled participants (9 male and 6 female) and were assisted by the active contribution of 7 different Mentors (5 males and 2 females). A carer also participated in one of these groups. Age of participants has ranged between 20 and 56 years. The time between when a person has acquired their brain injury and participated in the Reconnect Transition Program has ranged between 3months and 14years. Nine enrolled participants have acquired their brain injury as a result of a road related trauma, (including motor vehicle, motor bike, cycle and pedestrian related injury). Venues for the Reconnect group have either been in the city at BINSA offices or at the Fullarton Park Community Centre.

The benefit of the RTP to participants is perhaps best captured in their own words. A snapshot of participants' comments follows:

> *"….I now understand that 'differences in the way I feel and think are because of having a brain injury and not because I am stupid or useless.'*
>
> *"Perhaps the greatest benefit that I have experienced is in finding out that I am not alone; I don't have to feel isolated; others have walked my path. No longer do I have to feel scared about feeling different. What I feel is real, … there is a medical basis for it".*
>
> *"In fact for the first time in a while the RTP has enabled me to consider with a greater sense of optimism and enthusiasm my own capacity and how I can be an active participant in the world and not a bystander, alone and isolated."*
>
> "It is only now, being apart of this group, 18months post injury that I realise having a brain injury is not the same as mental illness or intellectual disability. There is specific pathology for my difficulties with forgetfulness and decision making. I don't have to keep on loathing

myself, nor judge myself by the fears I have of how other people perceive me."

"There is great public misconception about brain injury. There is so much stigma attached to it. If I wasn't part of this group I wouldn't have the insight and that is really scary! It would have had lifelong implications for how I … felt about myself."

" This group has helped me to trust myself….after an ABI you feel nervous…you are often misunderstood and persecuted. You can feel like everything is, not just an effort, but a real struggle… even just having a conversation you can feel all the things that aren't working are on show. It doesn't feel like that here."

"There has been … learning from others who have managed having an ABI… they've done OK... it has given me confidence that I can manage too… I can be OK too."

"This has helped me have a sense of who I am as a person and what I can achieve even though I do have a head injury."

"Having an ABI made me go through a massive priority reappraisal / re evaluation. I had to rediscover who I was and what was important to me. It is like meeting your self again and sorting through the process of liking myself. Having a group is a kind way of helping it happen."

"This group reminds me that there is no formula for having a brain injury or how to cope with it……but that you don't have to do it alone.'

"I've learnt to trust myself. To be prepared to try new things. Be prepared to fail. Be prepared to learn from that experience".

"I didn't think I needed help… I try to keep a brave face…. Working with the Mentors has increased my self awareness and my ability to cope. It's hard to 'cope' if you try to pretend you don't need to".

"I'm a 'walking on egg shells' type person……….but after a few weeks at Reconnect I didn't feel I had to be that person here. Very few of us really come to terms with our injury but Reconnect is an opportunity to do that."

"It's two years since my accident. This is the first time I really feel I've been able to meet with people who truly understand what it's been like……..to be bone tired, and it is still morning … to not understand what some one has said even though they've repeated it to me… The

opportunity to be able to talk about how it feels and not be judged or feel like someone thinks I'm a slacker……it's is worth the journey."

As the RTP was a pilot project it is being independently and externally evaluated by Dr Tim Anstey. Feedback about the program has been sought from participants, mentors and program staff, along with other key stakeholders. The main focus of the evaluation is to assess outcomes for individual participants, specifically including changes in emotional well being, social well being and the acquisition of coping skills. A final report has been prepared for the consideration of the Motor Accident Commission

Acknowledgements

In addition to the acknowledgements as outlined in last years AGM report I would like to recognise the contribution of the following:

- the generous sponsorship of the Motor Accident Commission
- the collaborative partnership of staff from the Brain Injury Rehabilitation Services and Motor Accident Commission
- the entire BINSA staff who have supported both the conceptual and operational implementation of the program
- the generous contribution of time, skills and person of the individual mentors
- and not least of all, the individual participants who have actively and openly engaged with the program, often having to 'take a risk' in doing so.

It goes without saying that it has been my absolute privilege to have had the opportunity to act in partnership with each of the above to facilitate the development of this innovative program.

Ann Madigan
Facilitator
Reconnect Transition Program

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