

SKILLS TO ENABLE PEOPLE & COMMUNITIES

DETAILED INFORMATION SHEET

Skills To Enable People and Communities (STEPS) is a Queensland-wide information and skills program for adults with Stroke or Acquired Brain Injury (ABI) and their families and friends. The effect of brain injury or stroke on a person's life can be extensive, and can also result in changes in their family, social and community networks.

- ◆ STEPS aims to develop networks of support for people with ABI or stroke, and their families.
- ◆ STEPS will help people understand the effects of acquired brain injury, how to look after themselves, and how to participate more in their communities.
- ◆ The STEPS Program Model aims to help establish sustainable, self-managed networks of support for people with ABI and their families in local communities around Queensland.

"I think as time goes on you face a whole lot of different challenges... it was good to talk to other people that had an injury like me... it doesn't make you feel...left out"

Stroke survivor, Gayndah, Qld



BACKGROUND

People who have sustained an Acquired Brain Injury and who are now living with Acquired Brain Injury (ABI) are a large and diverse group whose disability service needs are currently not well met in Queensland. ABI is a broad category encompassing a number of causes including traumatic brain injury (as a result of car accidents, falls, etc.), but also non-traumatic causes, such as strokes, tumours, poisoning, progressive diseases, and so on. Statistics drawn from such an indistinct category are typically difficult to interpret. Similarly, data on incidence from hospital admissions are often confusing given the broad spectrum of outcomes and severity of brain injury.

In 2003 the Australian Bureau of Statistics Survey of Disability, Ageing and Carers indicated that 432,700 people had an ABI and some activity limitations or participation restrictions. This equates to 2.2% of the total population of Australia. Stroke as a group was not included in these ABI results. According to The Australian Institute of Health and Welfare, the national prevalence of stroke in 2004-2005 was 225,800 which equates to approximately 1.2% of the total population. Of the population with ABI, approximately 110,000 live in Queensland, which represents a significantly higher percentage of the population (3.3%) than any other state (2.2%).

The effects of a brain injury on a person's life can be extensive.

- It is common for people with ABI to report multiple disabling impairments (physical, cognitive, sensory, emotional, communication and behavioural).
- Apart from the impact on the individual, the impact on family and community is also profound. It is common for people with ABI to experience deterioration in their family, social and community networks.

- Service and support opportunities in Queensland are limited and community attitudes restrictive. Subsequently, people with serious brain injuries face significant social and rehabilitation problems. These typically include unemployment, greater risk of alcohol and drug abuse, mental health problems and inappropriate accommodation (such as nursing homes and service models designed for people with psychiatric or intellectual disabilities).
- For adults and children with ABI who live in rural areas, these problems are further compounded by a paucity of community services and the geographical dispersion of available services across vast areas.
- The enormous task of family members in caring for a person with brain impairment is compounded by the lack of community awareness. Rehabilitation and community integration would be easier if the community within which they live was more able to understand and respond to their needs. The success of families to support members with ABI is often dependent on the ability of the local community to accept the person with a disability and support the family.

AIM

The statewide establishment of a sustainable Program Model of self-managed networks of support for people with ABI in Queensland. This will include:

- Engagement with local communities to gauge interest and develop partnerships
- Training of community facilitators to develop and sustain local networks of support
- A group intervention with a core curriculum to establish networks in Queensland
- Resources to establish and sustain individual and group self-management strategies locally

KEY PRINCIPLES: SELF MANAGEMENT AND SUPPORT

Self Management Program

The STEPS Skills Program is a free, 6-week information and skills-based program with the following features:

- It has been specifically developed for people with brain injury or stroke and their families
- It facilitates discussion of community themes
- It uses a self-management framework
- It promotes community networking beyond the life of the 6-week program

Use of Peer and Lay Leaders

The STEPS Skills Program is delivered by trained facilitators from a range of backgrounds, including health and disability service workers, lay and peer leaders. A lay leader can be relative or friend of a person with an ABI, or other interested community member. A peer leader is a person who has sustained an ABI. The engagement of lay and peer leaders is especially sought for a number of reasons:

- their commitment to their local community and likely ability to support on-going networking activities
- they have authentic, lived experience of an ABI or caring for a person with an ABI
- STEPS leadership may provide a valued participatory role for people with ABI, their families and friends

Network Groups

The STEPS Skills Program uses a self-management approach to foster the development of ongoing informal community networks of support, called STEPS Network Groups

PROGRAM PHASES

Community Engagement

Local communities are approached to gauge their interest in the program and to explore local solutions for people with brain injury, their families and carers.

Leader Training

Local people are provided with training to develop and deliver local group interventions and on-going network groups. STEPS Skills Program Leader Training Program is a 2-day training package, typically delivered in the local community. Leaders must be trained to deliver the STEPS Skills Program. Training is supported by facilitator manuals and resources. Training and support is provided to facilitators through all phases of the program.

Group Intervention

The STEPS Skills Program (Program Information) is a 6-week interactive group program offered throughout Queensland, in metropolitan, regional, rural, remote, and indigenous communities. It involves trained leaders delivering 6 x 2-hr sessions using a workbook to follow a structured Program Outline. The workbook facilitates group discussion and sharing of stories and experiences and focuses on ways for participants to look after themselves, enhance relationships with friends and family, plan and achieve goals and learn ways to get the support they need. There is also a strong focus on group self-management as a means of encouraging ongoing contact between members once the 6-week program has ended.

A STEPS Poster, provided for all group programs, summarises the program and gives the STEPS Program a statewide identity.

Network Groups

Many participants continue to meet after the 6-week program has ended and these ongoing self-managed networks, STEPS Network Groups, can be either formal or informal. Program facilitators are provided with additional support for ongoing network groups through support, manuals and resources.

PROGRAM GOVERNANCE

The Program is a service arm of the Acquired Brain Injury Outreach Service (ABIOS), Queensland Health, and is managed by the Program Manager.

EVALUATION

During the three year project phase (2006 –2008), data was collected both by project staff and externally by Griffith University Research Centre for Clinical Practice Innovation. It involved the examination of inputs (e.g., resources), processes (e.g. outputs, deliverables) and outcomes. Outcomes have been measured across a range of stakeholder groups including people with ABI, their family members and friends, rehabilitation service providers, community health providers and other community representatives. Outcome evaluation has utilised both quantitative and qualitative approaches. The following information represents results obtained for the period 2006 – 2008.

Clinical Outputs

STEPS Skills Program Sites

34 STEPS Skills Programs were offered across Queensland, as follows:

Greater Brisbane	Annerley, Bracken Ridge, Cleveland, Capalaba, Kingston Logan Central, Buranda, Wooloowin, Mitchelton, Carina, Chermside, New Farm, Maroochydore, Caloundra, Varsity Lakes
Regional Centres	Bundaberg, Rockhampton, Cairns and Mackay
Rural Centres	Roma, Charleville, Innisfail, Mt Isa, Cunnamulla, remote Far SW Qld

Participant Numbers

257 people participated in STEPS Skills Programs around Queensland. Of these, 140 reside within a 200km radius of Brisbane, 79 in regional centres (i.e. Bundaberg, Rockhampton, Cairns and Mackay) and 38 in rural centres (i.e. Roma, Charleville, Innisfail, Cunnamulla, Far SW Queensland).

STEPS Leader Partnerships

A total of 60 leaders were trained to deliver the STEPS Skills Program. Of these, 10 STEPS Skills Programs were delivered by sole service provider leaders, and there were 24 partnership arrangements. A large proportion of these involved partnerships between service providers and lay and/or peer leaders (11).

Post-Program Network Groups

A significant number of group participants were involved in ongoing network groups. 13 groups of participants either continued to meet or amalgamated with others to form 10 ongoing formal groups (i.e. groups who meet together on a regular basis). 6 groups of participants continue to maintain informal connections with their each other. 13 groups have chosen not to maintain connections.

STEPS Leader Network

In order to provide ongoing support and developmental opportunities for our trained leaders, a STEPS Leader Network has been formed. Its main activities are:

- Quarterly newsletter
- Leader Contact List
- Teleconferences for business planning, leader reflection and relevant educational topics
- Other training opportunities
- STEPS Leader Conference, Brisbane, March 2008

Clinical Research Outcomes

Leader Experience

The evaluation detailed reasons for people choosing to become a STEPS Skills Program Leader, their experience of STEPS Skills Program Leader Training, experience of STEPS Skills Program delivery and challenges involved. There were significant differences between health professional leaders and peer/lay leaders in terms of their reasons for becoming a leader. For peer and lay leaders, there was a strong altruistic focus as well as a desire for self education and to fill a service gap. Health professional leaders saw the STEPS Skills Program as a structured course to provide a post discharge service, an opportunity for professional development and a financially viable training option for organisations. The findings highlighted the central and crucial role of local community Leaders in leading STEPS Skills Programs including recognition that leaders see their role as part of a broader partnership between themselves, participants, local organisations and community.

Participant Outcomes

There were significant findings in the area of social resources. For example, younger participants were shown to rely more on friends than family, whereas older participants relied more on their families. Additionally, female participants were shown to rely more on significant others than males. There was a pattern of change on emotional scales (anxiety, depression and stress) but these were not statistically significant overall. Some significant differences ($p < .01$) in scores for depression, anxiety or stress were evident depending on occasion, age and gender. There were also correlations between scales (measuring autonomy, emotion, support,

information access, and ability to seek help). These demonstrated evidence of self-efficacy and coping, the notion of 'structural support', information access and ability to seek help correlating with empowerment. These were encouraged through shared group experience and purpose, resulting in the concept of "collective coping".

Supporter Outcomes

Overall, the results show a trend towards significance for increased perceived social support over time. More specific findings suggested significant relationships, as follows: poor health equates with negative impacts of caring; high scores on the social support scale equate with good health; high emotional stress coupled with high workload equates with low carer satisfaction; and that high scores on the satisfying aspects of caring coupled with poor emotional health equates with high scores on the stressful aspects of caring.

What next?

Please do not hesitate to contact us if you wish to discuss the STEPS Program further.

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