

## Empowerment

### **Project 26003: Anxiety Disorders Consumer Education, Support and Prevention Program**

**Aims:** This project was undertaken by the Panic Anxiety Disorder Association Incorporated (\$47,554). The aim of the Anxiety Disorders Consumer Education, Support and Prevention Program was to encourage consumers with an anxiety disorder; and their carers, to take an active part in their individual recovery. The Program also aimed to prevent disabilities associated with anxiety disorder; such as agoraphobia, drug and/or alcohol abuse, major depression and suicide.

**Description:** The target group for the Program was people with anxiety disorders and their carers in the Northern Territory, Queensland and Western Australia.

The main objectives of the Program were:

- providing Panic Anxiety Management Workshops to people with anxiety disorders and their carers in the target areas;
- training of interested, appropriate consumers to facilitate the Workshops in the target areas;
- providing assistance in the establishment of local support agencies in the target areas;
- researching and evaluating the effectiveness of the Panic Anxiety Management Workshops; and
- conducting a public awareness and education campaign.

### **Outcomes:** *Panic Anxiety Management Workshops*

Panic Anxiety Management Workshops were held in Perth, Darwin and several locations throughout Queensland. The evaluation of the Workshops found that they were effective in terms of reducing the

severity of anxiety disorder symptoms. Further, a three month follow-up with participants by self completed questionnaire showed a significant decrease in the severity of the major symptoms and fears associated with anxiety disorders. The Workshops encouraged carers and other family members to interact and to establish support networks.

### ***Training of Consumers to run Workshops***

Training was completed and Workshops were held by consumers in Queensland, Western Australia and the Northern Territory. Formal training consisted of attending presentations, preparing training material and researching other issues of relevance. Training was available to any consumer nominated by the Panic Anxiety Disorder Association. Over the period of the Program, six consumers were provided training to undertake workshops and other presentations.

### ***Assistance in the Establishment of an Association in the Targeted Areas***

Independent Panic Anxiety Disorder Associations have been established in Queensland, Western Australia and the Northern Territory.

### ***Public Awareness and Education Campaign***

Public awareness and education campaigns were conducted during the Program. This included a number of radio interviews, ongoing community awareness announcements on radio and in the print media, newspaper editorials, advertisements in major and community newspapers, and ongoing flier distribution. 'Today Tonight', a current affairs program on Channel 7, also ran a segment on anxiety disorders and the Panic Anxiety Disorder Association.

The public awareness and education campaign was found to be an effective strategy, reflected in the number of people attending Workshops and contacting the Panic Anxiety Disorder Association and the Anxiety Disorders Foundation. An aim of the campaign was to provide details of the major symptoms and fears associated with disorders to encourage people to seek assistance or advice early.

### ***A Working Model***

The working relationships developed during the Program between the Panic Anxiety Disorder Associations and individual State and Territory government departments, other non-government organisations and individuals contributed to the overall success of the Program. The



- **Peer Support Function and Volunteers:** Peer Support workers undertook to offer regular support services of between 4 and 12 hours a week, which included responding to telephone enquiries and speaking with people in-person. Others offered their time to provide reception and switchboard functions as well as general administrative assistance. A manual was developed to outline the responsibilities and duties of volunteers.
- **Support groups:** Several support groups were organised and met weekly during the project. The groups were established to discuss practical solutions to the issues faced by the participants and were well attended.
- **Newsletter:** A bimonthly newsletter was prepared and sent to over 200 individuals and organisations. The content of the newsletter included information about the Peer Initiative and Resource Centre for Mental Health, community support issues, and activities of interest to consumers.
- **Outreach Service:** The project developed an outreach service to a number of psychiatric inpatient facilities. The outreach units were highly valued by professional staff working in the facilities.
- **Community Development and Networking:** Throughout the life of the project, considerable work was undertaken to distribute information about the project widely within the community.
- **Conferences:** Representatives of the project presented talks to three national conferences of mental health service workers and consumers.
- **Library and Resources:** A resource box of books and other material was established on topics related to mental health, self-motivation, alternative therapies, and relationships. Much of the material was received as donations.

**Outcomes:** The project clearly demonstrated the value of training peer support volunteers. The evaluation of the project recommended the establishment of a statewide training centre based on the training model established by the project.

The project provides a thorough demonstration of how consumers can actively contribute within the network of established mental health services. The project also offers many lessons about establishing a self-help-based organisation and developing a shared vision and culture to enable an organisation to administer as an independent body. The project also offers some lessons about the importance of specifically focussing the role of an organisation to ensure that core activities receive sufficient attention.

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**Project 11014: Arts on Fire: Integrating people with a mental illness into the community through community based arts activity.**

**Aims:** This project was undertaken by Access Arts Incorporated (\$120,840). The aim of the project was to develop a national model for empowering people with psychiatric disabilities to be involved in their communities through integration in community based arts projects.

**Description:** This project endeavoured to develop a model utilising community-based arts projects to assist in the integration of people with mental disorders and serious mental illness into the wider community.

The project was organised and managed by Access Arts in Brisbane which is a non profit professional arts organisation that supports people experiencing disabilities to pursue their ambitions in the arts. The project team comprised representation from Access Arts, the artist in residence from the Prince Charles Hospital, a university researcher and a senior psychologist.

People with psychiatric disabilities were involved in the planning, and design of the project and determined the services and support they required. Essential to the project was the recognition of consumer’s rights through participation and skill development in arts-activities as part of their rehabilitation process.

Two different community settings were selected to develop the project model, one in the inner city and the other in the country. In each setting public meetings and community surveys were held initially to:

- share information and to gather community input into the proposed design and outcomes of the project;

## Outcomes:

- involve the local Shire Council in community decoration of the landscape; and
  - inform the community of the goals of the participants.
- The Access Arts project resulted in the creation of an innovative model of artistic development. In Stage 1 of the project, the participant's artistic works were exhibited publicly and outdoor works were installed in a local park. Participants reported that during their creative stage:

- self esteem and friendship networks increased;
- access to community networks expanded;
- dependence on Day Care facilities decreased; and
- expectations of community arts were fulfilled with the pleasure of "leaving something behind in the park".

In stage 2 of the project a group of participants created works of art and were involved in story telling, movement and dance workshops. The outcome of the workshops culminated in a "Fire Event" presentation and an installation of the works of art in a local parkland.

Participants found that the project gave them a "chance of somewhere to go" and "most of us were gifted but we knew nothing about how to make it happen."

A clinical evaluation of the effectiveness of the project found that at the end of the project the participants displayed a significant reduction in psychiatric symptomatology, and improved in living and social skills.

It is expected that this model could be implemented at a national level by other arts, local government and health agencies to enable people with psychiatric disabilities the following benefits:

- increased quality of life;
- increased community living skills;
- reduced dependency on health services; and
- empowerment and confidence so that they could inform health professionals on the type and level of support required.

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## **Project 22004: The Community and Consumer Service Project**

**Aims:** This project was undertaken by the South Eastern Area Health Service, University of New South Wales, Prince Henry and St Vincent's Hospitals (\$310,000). The aim of the Community and Consumer Service Project was to empower clients by establishing parity between clients and staff and to involve clients in their rehabilitation process in a consensual manner that promoted their dignity, self-respect and self-determination.

**Description:** Clients with schizophrenia and bipolar disorders were invited to participate in a randomised controlled trial over a 12 month period in the Eastern and Inner City Sectors of the South Eastern Sydney Area Health Service.

Strategies employed to assist clients to participate as partners in the management of their illness were:

- developing a client focused or partnership approach to case management;
- developing customised recovery plans based on clients' goals;
- organising recovery agreement meetings between clients, families, mental health staff and consumer advocates; and
- assigning consumer advocates to the client group in the trial.

The trial evaluated the impact of these strategies on client functioning, disability, quality of life, service satisfaction, family burden of care, re-hospitalisation and the use of psychiatric services and treatments.

One hundred and nineteen clients consented to participate in the trial after meeting pre-determined diagnostic and selection criteria.

Subsequently each client was allocated to one of the following groups:

- Standard Case Management Group (control group, 35 participants);
- Client-Focused Case Management (research group 1, 39 participants); and
- Client-Focused Case Management with Consumer Advocate (research group 2, 45 participants).

Initially there were no significant differences detected between the three groups on sociodemographic variables, illness factors, medication factors or compliance with service variables or in the baseline assessment of clients. Baseline assessments were made on all clients entering the trial using a range of measures which included the Global Assessment of

Functioning, the Life Skills Profile, the Health of the Nation Outcomes Scale, the Quality of Life Scale, and a global measure of Service Satisfaction and Family Burden of Care.

Clients were followed up at 6 months and 12 months before referral back to the standard community case management teams.

**Outcomes:** On completion of the trial the following objectives had been achieved:

- case managers delivered a client-focussed approach to case management which was satisfying to clients;
- consumer advocates participated in service delivery and reported increased client satisfaction;
- client functioning, disability and quality of life improved over time for the whole group; and
- family burden was reduced especially in the client focussed case management groups.

Although clients expressed increased satisfaction with a client-focussed approach to case management, significant differences between the groups on the measures of functioning, disability, quality of life and family burden of care were not apparent during the trial. At the follow-ups all clients in the research groups reported that participation in the trial had made their lives “better”, whereas clients in the control groups reported that “things remained the same”.

The clients in the consumer-focused case management with advocacy group expressed that having an advocate was “supportive” and “helped me reach my goals”. Data for this group was compared with clients who experienced client-focussed case management only together with clients who only saw advocates occasionally. The report states that although the sample size was small and the outcomes were difficult to evaluate in this group, the clients benefited from the experience. The trial provided a worthwhile learning experience for the advocates which indicated that an advocacy program should be developed and implemented.

At the 12 month follow-up the control group had significantly higher contact with crisis intervention over the period of the trial than the research groups but no variances were obvious in the number of hospital admissions or number of days spent in hospital between the groups.

Implementation of recovery agreement meetings was not progressed as originally intended at the beginning of the trial. Inhibiting factors included: the clients difficulty in completing paperwork; family and

professional involvement was seen to be threatening to the client; and the clients illness frequently delayed completion of paperwork.

The timeframe for the project was dictated by the period of the funding and the need to follow-up each client at 12 months. It was felt that a longer trial would reveal more significant outcomes. Some recommendations emerging from the trial were:

- a partnership/client focused model of practice be integrated into community practice;
- a consumer network is established to enable training and support for consumers working as advocates; and
- case manager and client ratio for delivery of case management services should be approximately 25:1.

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**Project 23010: The Welcome Back Project**

**Aims:** This project was undertaken by the Rotary Club of Canberra (\$64,400). Final amount funded: \$46,219.16. The aim of the project was to assess community willingness to actively participate in the process of re-integrating people with a mental disability into the mainstream community following an episode of acute disability.

**Description:** The Welcome Back Project (previously named the Links Program) was a pilot project sponsored by the Rotary Club of Canberra. The Rotary Club invited members to volunteer as mentors to assist people with a mental disability to integrate back into the community. It also identified the need to provide continuing education on issues relating to mental health to the community.

Educational aids such as information phamplets and a training manual for mentors were developed to increase awareness and understanding of mental illness. Mental health professionals assisted in the education of mentors and participated in group discussions with possible participants in the project.

Unfortunately, while there was considerable general interest in and commendation of the project by Rotary Club members only a small number of people volunteered to become mentors. In these circumstances the project was discontinued.

**Outcomes:** The program established that there is a willingness of some members of the community to participate in programs which involve mental health sufferers with the resources and support of mental health professionals, but barriers need to be broken down so that there is a better understanding and acceptance of mental illness in the community.

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**Project 24029: Developing Effective Consumer Participation in Mental Health Services: The Lemon Learning Tree Project**

**Aims:** This project was undertaken by the Victorian Mental Health Council (\$207,140). The project aimed to increase the level and effectiveness of consumer participation in the mental health system by developing and conducting training programs for service providers and consumers.

**Description:** The Lemon Tree Learning Project was established in 1995. The "lemon tree" became a symbol for a number of ideas because the lemon tree stood for "an explicit, almost defiant, acceptance of the stigma of mental illness in the general community where it is regarded as something shameful". The metaphor continues that, by learning to appreciate "the taste of the lemon juice (the experience of mental illness as communicated by the consumers)" there comes an awareness of "the zest and unique qualities of the juice of the lemon (consumer experience)". The report on the project states that there is an unequal

power relationship between service providers and consumers and that service providers do not have the same agendas as consumers.

The principal work of the project was the development of resources and training packages for consumer-only groups and service providers. The report describes consumer efforts to influence decision making in mental health services and develop programs and opportunities for reflection and dialogue among consumers and service providers.

Two full-time consumer workers with teaching and research experience were appointed to manage the project.

## Outcomes:

In the Lemon Tree Learning Model, training for consumer participation was divided into the following programs:

- “Root Learning.” A training program which gradually built an infrastructure to support consumer participation. This form of training was considered very valuable as it encouraged trust and learning and the development of strong relationships which endured. Training included participation in regular monthly meetings with the Child and Adolescent Mental Health Service (CAMHS), which was attended by service providers, consumers, parents and project officers. The success of this program led to further funding for staff-consumer consultants for CAMHS.
- “Branch Learning.” This training program was developed around existing knowledge and depended on consumer participation. There were five different training courses designed in the category of “branch learning”. All courses were consumer driven and in some cases were prepared in collaboration with service providers. These encompassed education and training of consumers as staff-consumer consultants; workshops to enhance consumer participation in mental health service delivery; courses in consumer facilitation to enhance participation in consumer networks; and “deep dialogue” between consumers and service providers over an extended period of time.
- “Leaf Learning.” This referred to single training sessions about consumer participation when requested by a service for practicing providers. These single sessions did not guarantee an ongoing commitment to the project. This training was considered the least effective for meeting the long-term needs of consumers as it was not consumer driven and did not influence any cultural change in the attitude toward consumers. “Leaf learning” was resource intensive and it was found that a “one-off” training session was ineffectual to service providers who had difficulty with the concept of consumers as participants in their service.

