

Barbara Balog  
Highlands Community Centres Inc

## **Establishment of an ARAFMI Group – Wingecarribee Shire**

### **Background**

Wingecarribee Shire – 2700sq kms, semi-rural, four towns, seven villages, scattered settlement throughout, cool climate, dense bushland, agriculture – potatoes, dairy now giving way to viticulture, olives, native flowers.

Population 41,000 and increasing - double the state average. Myth, we are a wealthy community, in fact our income is *significantly below* state average. Distance across the shire impinges on the ability of services to provide adequately. Public transport is very inadequate (eg. most villages and outlying areas rely on school bus for transport, some areas have access to a rail service) Unemployment rates are high. Homelessness in our community is of growing concern.

Highlands Community Centres Inc is a multi-purpose neighbourhood centre based in Bowral. During 2000, we assisted over 9,000 people across our various services, which puts us in touch with an enormous cross section of the communities disparate needs. The main services we provide include information and referral, advocacy, emergency relief, domestic violence crisis help, court support, youth service and community development. This is my role - is working with people in our community by undertaking projects and activities to improve services and increase equity across the Wingecarribee Shire.

Local Mental Health services have been far from satisfactory. For some time the local Mental Health service has been considerably understaffed. They find it difficult to employ and keep qualified staff - large turnover and subsequent impact on continuity of care. This is further exacerbated as inpatient care for consumers necessitates travelling to Goulburn, an adjoining Health Area. This further complicates service delivery due to communication issues and lack of follow-up services available to consumers in our area.

Highlands Community Centres' workers continually heard of difficulties encountered from consumers and carers regarding the local Mental Health service. We were particularly concerned for carers as it appeared that they had no voice or support so we decided to do something about it. Setting up a support group for carers was well within our Mission and Goals Statement and we believed that there was a huge need in our area. This need was heightened when Cate, who has a son with schizophrenia, was completing her Welfare Diploma Student Placement with us. During her placement, Cate had some difficulties relating to her son to contend with as well as placement responsibilities. Our organisation was flexible, but not all employers are or can be. Who is there to care for the Carer?

This workshop will follow the process we took.

Late in 1999, a funding opportunity arose through SWSAHS NGO and Mental Health Partnership Program Seeding Grants, for which we were successful with our application.

From the inception of this project, planning was paramount and has continued to be ongoing. Media publicity has also been part of this process. Considerable time was spent researching relevant information and I was in contact with key people from

ARAFMI and mental health organisations in Sydney, Wollongong, Newcastle, Canberra and Melbourne to gain extra knowledge and expertise. It was decided to hold a public forum in order to launch a local support group.

Apart from organising speakers and venue, I also embarked on an intensive media publicity, prior to the event. Flyers were distributed to all parts of the Shire and included Psychiatrists, Psychologists, GPs, counsellors and Chisholm Ross, Goulburn as well as selected stores. The Wingecarribee Mental Health Team were also asked to forward information to families with which they were in contact. Local media, including newspapers, radio and TV were all notified, I spoke on different radio stations five times both prior and after the event.

### **Public Forum**

Thirty people discovered that they were 'not alone' when they attended the public meeting, at Mittagong on Monday, 31<sup>st</sup> July, at 5.30pm. The speakers all seemed to be well received.

Sarah Kelly-Moore, the Director of NSW ARAFMI, travelled from Sydney and began the evening by discussing the history and activities of the association. Jack Kelly, a Carer, President of Hunter ARAFMI and Committee Member of NSW ARAFMI was our main speaker. He had travelled from Maitland. Jack shared his story of caring for his son who has schizophrenia. He also spoke of the benefits of being a member of ARAFMI from a personal perspective.

Local services were also represented. GP, Ann Parker, encouraged those present to speak with their GPs about the issues that they experience and to join the ARAFMI group as it was an excellent way to seek some resolution to the dilemmas facing them.

Showing support for ARAFMI and how services could link and work together, Rose Mason, Director of Wingecarribee Mental Health Services, gave an update on current services and the direction Mental Health Services are taking.

Anita Hilliard, Mental Health Consumer Advocate, gave a powerful and poignant account stressing the importance of support for carers.

Peter Lach-Newinsky also spoke briefly and introduced himself as the co-facilitator, with Barbara Balog, of the proposed support group.

Many of those present stayed on after to mingle and speak with the presenters. Seventeen people left their details wishing to be part of a support group.

The first support meeting took place two weeks later and we have met fortnightly ever since.

### **Activity**

*Divide into small groups/pairs and discuss how you would address these situations:*

Jane – her husband suffers from bi-polar. Was retrenched six months ago. Currently, refuses to take his medication or see his doctor. Doesn't believe that he has a problem but that Jane has the problem. Jane is working full time, trying to make ends meet while husband is out spending. They have three teenagers who are embarrassed by their father's behaviour and prefer to visit friends as much as possible.

Margaret and Jim – have two adult sons, both have schizophrenia. One adheres to medical regime and lives at home, the other refuses all care and is currently “on the streets”. They don’t always agree on best care for their sons.

Simone – has daughter with schizophrenia. Numerous suicide attempts. Does not live at home. Simone is divorced, her two sons live some distance away and are supportive where possible.

Megan – her son has schizophrenia. Diagnosed two months ago, following a psychotic episode and hospitalisation for several weeks. She knows very little about her son’s illness and is confused and frightened.

Leanne – her son suffers from depression. He was an “A” student, studying at University, before his illness. Now spends most of his time in bed. Her husband believes that she should stop fussing over him and that its time the son snapped out of it and went back to Uni. She finds it difficult to relate to the doctor and doesn’t know what she should do

Julie – her husband is exhibiting paranoid behaviour. Has put locks on all the doors in the house and lock himself in certain rooms for hours at a time. He refuses to see a doctor. Their teenage daughter is afraid.

Susan – her daughter has had different diagnosis over the last five years. Not always compliant with medication and self medicates with various illicit substances. Daughter has had a history of ‘disappearing’ when she is experiencing psychosis and it is then that her behaviour is often life threatening. Lives at beachside suburbs. Husband does not cope with the illness.

Karen & Michael – their daughter has bi-polar. She is a single mother with a 7-year-old son. He often misses school to “take care of Mummy” They are very concerned about their grandson’s wellbeing and often are unable to visit because of their daughter’ wishes.

Julie – her son was diagnosed with schizophrenia following a severe psychotic episode after he drove off a cliff. He has had several life threatening episode since and she is aware that his condition is deteriorating once more.

*These are examples of issues that families were dealing with. Many felt that they had no support from local services and were having difficulty coping. We addressed these issues by the following action.*

### **Action**

Linking families and other carers. *Networking and support.* Members no longer feel ‘alone’. Many are in regular contact with each other. A comment often said is that they don’t have to explain or excuse. They are able to say how it feels for them at the time.

*Group ownership.* From the outset, the two facilitators worked with that in mind. The group decided the frequency of meetings (fortnightly) and the venue (was changed after two months to a more central location).

The initial plan was to run an Eight-Step Program. It was apparent from the first few meetings that participants needed to off load freely; for most this was the first time that they had ever been able to do so. The facilitators felt strongly that this was more

important and decided not to pursue the set program. It is interesting to note that now, after twenty meetings, that some members are now looking to participate in an Eight-Step Program.

The group facilitators believe that it is important to be flexible and allow the group to steer its own course.

*Sharing of information.* Members of the group gained information from a range of sources, literature, internet, and organisations such as Mental Health Information Service, Sane, Schizophrenia Association and the National Mental Health Strategy. They have considered available training – those who have undertaken the Advocacy training have found it very helpful. In order to ensure the group's sustainability, Highlands Community Centres offered training to all members so that the onerous task of leading the group would be shared. This would also enable members, who may have been the designated leader, to be substituted and deal with their own issues if necessary. A qualified presenter conducted the training over two evenings, with ten people participating.

Members also have investigated other projects such as Compeer and Casa Venegas and will continue to explore possible options to improve lifestyle for those with a mental illness

Issues around *advocacy* have been paramount. Advocacy continues to be a major part of the support group's work, with ARAFMI members looking at ways of gaining service for their family member who suffer a mental illness. Support for each other in approaching the Health Department, in particular, and other government bodies to improve services, has been ongoing. Our Local State Member, Peta Seaton, has also been very active and supportive on our behalf.

The group also have "The Kit, a Guide to the Advocacy We Choose To Do, A Resource Kit for Consumers and Carers". This 300-page kit was provided with Federal Funding as part of the National Mental Health Strategy. Highlands Community Centres is now classed as an Access Centre and is listed on a national data base as a source of assistance for those needing help in the Wingecarribee district. Services for families can only improve as members continue to advocate.

Three of the group participated in advocacy training during 2000 and six others have registered for the three-day training that is being held September, 2001; so their skills will be a real asset.

*Promotional activities* have also been an important part of the process. It provides a path to educate the community and information for those looking for support. The first major event was Mental Health Week, 2000.

To celebrate "Stress Less Day" on the Wednesday, 11<sup>th</sup> October, members manned a table in Springetts Arcade from 11am to 3pm. There was a range of mental wellness information for the general public. The staff from Pathfinders Massage Therapy Clinic provided free neck and shoulder massages. The information was well received from the general public and resulted in new members joining the local support group.

The other major function on that day was a Prayer Service held at 6.30pm at the Uniting Church in Albert Street, Mittagong. The short service was followed by a shared supper. The outline for this service originated from the NSW Mental Health Information Service. This service is adapted from public worship services arranged

by the pastoral staff of Parramatta Mission of the Uniting Church of Australia, in partnership with Western Sydney Area Mental Health Services on behalf of NSW Association for Mental Health. This service had been specifically designed for people living with mental illness and encouraged participation by the congregation. Members gave the Readings and one particular section, the Colours of Hope was particularly uplifting. Crepe paper, representing the colours of the rainbow were attached to string, members of the congregation were asked to come forward, raise a colour and say what that colour signified to them. The result was: red – *from the heart*, orange – *communication*, yellow – *freedom*, green – *new growth, spring*, turquoise – *clear thinking*, purple – *royal, God*, indigo – *deep love*. It was a very powerful symbolic ceremony. The group was also fortunate to have Peter Kearney, singer/songwriter who led the congregation with one of his songs. About 40 people attended the evening.

Feedback from those who attended was very positive. Participants felt that it was very healing and would like it to become an annual event. Planning is well underway for a similar event for 2001. Now that the Branch has been established a need for fundraising is evident. Arrangements have been made to sell Flannel Flowers, the emblem of Mental Health, at this year's promotions.

Our most resounding success has been in *forging links with the Wingecarribee Mental Health Service*. As a result of the Public meeting held June 2001, instigated by Peta Seaton, between the mental health team and ARAFMI, a Working Party was established. This small group has been able to influence the direction of the Service and allow Carers a voice. We also had a strong influence in establishing the Wingecarribee Mental Health Community Consultative Committee; an open committee, made up of carers, consumers, community members, non-government organisations and the sector director of Mental Health.

At a recent meeting, the significant input from ARAFMI - Wingecarribee Branch was acknowledged by the Health service.

I believe that this we are leading the change for an improvement in services and will continue to work towards that end. Inclusion is part of the solution whether you are carer, consumer, worker or friend. Establishing a vibrant working support group has had an enormous and widespread impact on all those who have shared the journey.

### **A Creed To Live By**

Don't undermine your worth by comparing yourself with others,  
It is because we are different that each of us is special.

Don't set your goals by what other people deem important,  
Only you know what is best for you.

Don't take for granted the things closest to your heart,  
Cling to them as you would your life for without them life is meaningless.

Don't let life slip through your fingers by living in the past or the future,  
By living one day at a time you live all the days of your life.

Don't give up when you still have something to give,  
Nothing is really over until the moment you stop trying.

Don't be afraid to admit that you are less than perfect,  
It is this fragile thread that binds us to each other.

Don't be afraid to encounter risks,  
It is by taking chances that we learn how to be brave.

Don't shut love out of your life by saying it's impossible to find,  
The quickest way to receive love is to give love.

The fastest way to lose love is to hold too tightly,  
And the best way to keep love is to give it wings.

Don't dismiss your dreams - to be without dreams is to be without hope,  
To be without hope is to be without purpose.

Don't run through life so fast that you forget where you've been but also where you're going,  
Life is not a race but a journey to be savoured each step of the way.

Writer unknown

Source: National Mental Health Week, 2000 - A Resource for Churches

#### **ARAFMI - Wingecarribee: Summary of Achievements**

- Public Meeting 31<sup>st</sup> July 2000.
- First meeting, 14<sup>th</sup> August (met fortnightly since).
- Mental Health Week. "Stress Less Day" on the Wednesday, 11<sup>th</sup> October.
  - Stall promotion, From 11am-3pm, in Springetts Arcade, Bowral
  - Prayer Service held at 6.30pm at the Uniting Church in Albert Street, Mittagong, followed by a shared supper.
- Several members completed three-day Advocacy Training in November, 2000.
- Several members completed three day Presentation Skills Training in December, 2000.
- Federal Funding, as part of the National Mental Health Strategy, supplies us with the 300 page, "The Kit, a Guide to the Advocacy We Choose To Do".
- As a result, Highlands Community Centres becomes an Access Centre (listed on a national data base as a source of assistance for those needing help on mental health issues in this district).
- Leadership/ Group Skills Training held on the 30<sup>th</sup> April and 1<sup>st</sup> May, 2001.
- Peta Seaton, MP, instigates a meeting between Ian Southwell, CEO of South Western Sydney Area Health Service and several ARAFMI members.
- Public Meeting was held between Area Health Managers, the local mental health team and ARAFMI, on Wednesday, 13<sup>th</sup> June, 2001.
- Working Party established, consisting of three members from ARAFMI and three from the Mental Health Service to look at the Key Priorities for Action and Appropriate Strategies that were raised at Public Meeting.
- Several members attend "Understanding and Coping with Schizophrenia and Bi-Polar" in Liverpool.
- Establishment of the Wingecarribee Mental Health Community Consultative Committee; an open committee, made up of carers, consumers, community members, non-government organisations and the sector director of Mental Health.
- Successful Submission for \$950, from Wingecarribee Shire Council, for Mental Health Resources to be donated to Library.
- Several members attend "Eight Step Healing" Program in Liverpool.

- Inaugural Annual General Meeting; held on 17<sup>th</sup> September, at the Mittagong RSL, at 6pm. Local Branch established.
- Expression of Interest for funding from NSW Caring for Carers Mental Health Program; submitted by 21<sup>st</sup> September.
- Six members registered for Advocacy Training at Institute of Psychiatry, Parramatta on September, 26-28<sup>th</sup>.

**Planning commenced for:**

- Management Committee Training, October 2<sup>nd</sup> and 3<sup>rd</sup>.
- Mental Health Week, "Stress Less Day", October 10<sup>th</sup>: Promotion in Springetts Arcade.
- Prayer Service at Mittagong in the evening.
- Presentation of Resources to Wingecarribee Library.
- Possible facilitation of an "Eight Step Healing" Program in the Wingecarribee.