

NGO Conference 2004
ILLAWARRA ARAFMI
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Surfing the tide of change: Collaborative Caring
SURFING THE TIDE OF CHANGE.

Collaborative Caring is becoming increasingly important as we move forward in the delivery of NGO services, effectively collaborative caring enhances an organisations ability to provide ongoing, quality services to its clients. In the Illawarra region we have seen sweeping changes to the mental health service once seen as the poor cousin of Sydney based services. Similarly Illawarra ARAFMI has grown from being a small information service to include a broader membership, increased staffing, and a changed role in collaboration with mental health and other health and community based services.

When a family is confronted with the mental illness of someone they love and care for they are naturally shocked, fearful and often unsure what to do. The family may also feel, angry, resentful, ashamed, and a sense of grief, loss and sadness. They may have a sense of “Why Our Family?”

The Illawarra ARAFMI. Family Support Program recognises that families and carers may be confronted with a broad range of difficulties and challenges when caring for a person with a mental illness. The isolation experienced by families seems overwhelming and the view into the future seems fraught with pain, exhaustion and stigma. The Illawarra ARAFMI program is implemented in a non-judgemental, caring environment enriched by the personal experiences and expertise of ARAFMI. members.

The special value in a self-help organisation such as Illawarra ARAFMI is its collaboration in the broad range of services for people with a mental illness. It is well recognised by carer organisations that families/carers are too often the forgotten stakeholders and, as such, their needs are frequently overlooked when planning and implementing mental health services. Illawarra ARAFMI seeks to overcome some of these difficulties in access and equity; to become a partner in mental health care.

When we use phrases like Quality consumer and carer participation in mental health care what do we really mean? For many carers this was the rhetoric of an earlier era where participation often meant deciding the colours of the bedspreads in the inpatient units or being invited to comment on a document or plan or protocol already set in concrete. As carers we saw many examples of plans already in operation prior to us being asked to comment, at times this was demoralising for carers who were genuinely interested in participating in mental health services. It was a denial of the expertise of carers, a denial of the role of partnership.

HISTORY

Historically Illawarra ARAFMI has always had a collaborative role, we had no choice. In 1982 there was barely the skeleton of a mental health service. We formed our first partnerships at this time with the scarce staff of Mental Health Services and began to lobby politically for increased services for this region, the Richmond program provided a small ground staff that formed the nucleus of the Illawarra Mental Health Service. Gradually over the years we have seen changes to the culture of mental health services and importantly in recent years there have been increased opportunities for consumers and carers to participate in mental health services. Illawarra Mental Health Strategic Plan 2003-2008 which states that the service **“involves and actively encourages the participation of consumers, carers and families in the planning of care and treatment as well as the planning of services.”** The strategic plan goes further and suggests that carers be included as partners in care and treatment, effectively this means that carers and mental health services share a closer relationship where communication is more transparent.

TODAY

Illawarra ARAFMI has also changed since those early beginnings, from our origin as a small NGO partly funded to an NGO currently with full time funding. The significant changes to Illawarra ARAFMI services were made possible in 2001 when we successfully applied to participate in the Mental Health Integration Project. These changes have allowed us to have a much higher profile in the community, we have expanded our programs and are seeing more carers than has ever been possible prior to MHIP.

Some of the service enhancements include.....

- ❖ Caring and Sharing
- ❖ Advocacy
- ❖ Groupwork
- ❖ Coping Skills
- ❖ Community Education
- ❖ Referral and Information
- ❖ Staff Education
- ❖ Inpatient Carers Group
- ❖ Counselling
- ❖ Partnerships
- ❖ Networks
- ❖ ARAFMI Staff Training
- ❖ Conferences
- ❖ Increased funding
- ❖ Resources for Families
- ❖ Formal and Informal Partnerships

All of the services above of course come under the broad heading of **Family Support** which was the foundation function of Illawarra ARAFMI and remains as the cornerstone of service delivery, family support is offered in a number of ways including....

- ❖ Face to face counselling/support
- ❖ Family groups
- ❖ Social activities
- ❖ Referral and information
- ❖ Telephone Support
 - Crisis
 - Ongoing
 - Isolated Families
 - One off referral, information
- ❖ Caring and Sharing
- ❖ Inpatient carer group

CARERS

When a loved one is diagnosed with a mental illness carers often feel marooned, with no point of reference, removed from what is happening around them, one carer expressed it as feeling like “the family is being eroded from the inside out”, this sense of One of the most comforting experiences the families of a person with a mental illness can have is to discover a safe space in the whirlwind of mental health care they have found themselves amidst. To discover that as disjointed as mental health care can seem there is a bridge and that as carers they are in fact part of that care. This does not happen automatically, it takes the dedication and determination of other carers, organizations like ARAFMI, and caring staff who may not have all the answers but who can empathise with the desperate sense of helplessness the family is experiencing at the time.

Given Illawarra ARAFMI’s long history of service collaboration it is perhaps not a surprise to see that the tradition has grown in strength. What began as an informal partnership with Illawarra Mental Health Services has become a much more formalized arrangement, referrals come through the service and ARAFMI’s role as a consulting partner is testimony to the expertise we have developed as an NGO. These partnerships have also extended to other sections of Illawarra Area Health Service, Community Based Services and private services representing a broad referral base for carers, consumers and others.

GROUPS

Group-work forms the backbone of Illawarra A.R.A.F.M.I service, group-work has a number of advantages for carers, groups are educational, supportive and allow carers to form networks which effectively helps to de-isolate carers.

The following represents the range of groups facilitated by Illawarra A.R.A.F.M.I

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- ❖ Coping Skills Groups occur on demand but fill up very quickly.

- ❖ Advocacy.
- ❖ Multiple Family Groups, currently a group has started which will run for the next 2 years.
- ❖ Carers Group WMH Unit.
- ❖ Caring and Sharing group has moved to Atchison St and will include guest speakers to provide ARAFMI carers with specific information.
- ❖ Special Interest Groups.
- ❖ Specific Education Groups.

VOLUNTEERS AND STUDENTS

As with most Community Services Organisations Illawarra A.R.A.F.M.I relies often on the expertise and assistance of volunteers and students. The Illawarra A.R.A.F.M.I management committee is comprised of volunteers who are carers, these volunteers take on many roles including representing Illawarra A.R.A.F.M.I in a number of forums, management committees and working parties, attending conferences, support and telephone support. We have 1 permanent volunteer who arranges social gatherings and heads our Mental Health Week Team and at any given time have 2 community services students on placement.

CARING AND SHARING

Caring and Sharing remains as a core function of Illawarra A.R.A.F.M.I. In 2003 these meetings became the forum for guest speakers from mental health services, the caring and sharing meeting recently moved from IMRC to Atchison St where the ARAFMI office is located.

ADVOCACY

Advocacy is an important role for Illawarra A.R.A.F.M.I as we are often the link between carers and Mental Health services and other health and community services. When carers experience crisis or feel overwhelmed by their day to day responsibilities they may feel they are least capable of self advocacy, confusion about mental health services and follow up care only add to the feelings of helplessness many carers feel. At these times carers may need an advocate to represent their needs either individually or as a group.

Individual advocacy may include.....

- ❖ Facilitating advocacy groups to empower carers as self advocates
- ❖ Supporting carers in case conferences
- ❖ Advocacy in court
- ❖ Advocacy in case management
- ❖ Advocacy with other agencies

Group Advocacy may include.....

- ❖ Representing the needs of carers on a broad scale in areas of:
 - Housing
 - Health
 - Legal/Courts
 - Education

EDUCATION

We know from research that families, carers, communities and staff who understand mental illness, who are familiar with mental health services and who are able to communicate with professional carers fare much better than families who do not. Education is empowering, helps to remove stigma, increases awareness of current issues, and provides opportunities for participation by carers, professionals and the broader community. For these reasons Illawarra A.R.A.F.M.I offers education in 4 ways.

Family Education- Family education includes individual or family psycho-education, coping skills groups, narrative groups, special interest groups and specific education groups, Multiple Family Groups.

Community Education – Community education includes participation in stigma reduction activities such as Mental Health Week, University and TAFE open days, Community based forums, IWD and other community events.

Service Education – Service education means literally educating other services, NGO's, Local Government, Health, Housing etc about mental health and carer issues.

Staff Education – Staff Education has in the past involved short guest speaking stints with staff of mental health services, it has also meant being available as a carers resource for mental health services staff, however as part of Illawarra A.R.A.F.M.I's service agreement for this 12 months is the development of a staff education package which it is hoped will become part of orientation for mental health services staff.

INFORMATION

As with education, information empowers. Illawarra A.R.A.F.M.I provides information in the following ways.....

❖ Illawarra A.R.A.F.M.I Carers Handbook distributed to:

- 350 carers
- 100 professionals

❖ Working with GP's Pamphlet sent to:

- 227 GP's across Illawarra region

❖ Specific information packages for carers/families

❖ Student information packages

❖ General A.R.A.F.M.I information packages for community organizations

INFORMATION PACKAGES

Part of the focus of the last 2 years of Illawarra A.R.A.F.M.I service delivery has been the development of information packages for various purposes, these packages include.....

❖ General AR.A.F.M.I information packages for community organisations

- ❖ Student information packages with information about mental illness, carer information, service information.
- ❖ Family Information Packages available from ARAFMI and in all Mental Health Units, these packages include information about specific mental illnesses, carer information, Handbook, mental health service information and information about seeking help.
- ❖ Monthly Newsletter, approx 100 each month.
- ❖ Mail Outs.

COLLABORATION WITH INPATIENT UNITS

One of the latest functions of Illawarra is support for carers visiting the inpatient units. This includes representation in the carers group at Eloura. As well as a facilitated Carers Group in the Wollongong Mental Health Unit every second Wednesday of the month.

COLLABORATION IN THE COMMUNITY

Illawarra A.R.A.F.M.I was founded on partnerships with Mental Health services and other community based services, these partnerships or networks until very recently were informal. In the past 12 months we have formalized a number of these partnerships including

- ❖ Specialist Psychological
- ❖ Youth Drug and Alcohol Service
- ❖ POPPY
- ❖ DVCAS/ATSI
- ❖ Lifeline South Coast
- ❖ Illawarra Mental Health Service
- ❖ Illawarra Institute of Mental Health – MFG's

FUTURE

- ❖ Greater co-operation between GP's and Illawarra A.R.A.F.M.I.
- ❖ Expand Illawarra A.R.A.F.M.I service agreements.
- ❖ Develop service agreements with Adult and Youth Drug and Alcohol services.
- ❖ Maintain and develop partnerships both formally and informally within mental health services and the general health and community sector to continue to ensure that carers have a voice and carer issues are articulated across planning, service and policy development.
- ❖ With future and ongoing funding, assume responsibility (in partnership with the Illawarra Institute for Mental Health) for the Multiple Family Group Programs.
- ❖ Implement training package for staff specifically focused on dealing with carers in many caring settings and situations.
- ❖ Development of social-interaction groups to help de-isolate carers
- ❖ Implement the 8 stage healing program.
- ❖ Increase staff training
- ❖ Update information packages targeted at community sector groups

- ❖ Update student packages by August 2003.
- ❖ Raise the Illawarra A.R.A.F.M.I profile by community based training and information/public relations packages. Reprinting and updating of Illawarra A.R.A.F.M.I information pamphlets, cards and handbook. Ongoing at 3 monthly intervals (pamphlets and cards) annually (handbook)
- ❖ Waiting lists for coping skills and other group programs ongoing.

RECOMMENDATIONS

- ❖ That Illawarra A.R.A.F.M.I is funded up to the level of MHIP in the Illawarra A.R.A.F.M.I 2004 triennial funding submission.
- ❖ That Illawarra A.R.A.F.M.I is granted funding to employ a part-time worker to develop and maintain an A.R.A.F.M.I service for Shoalhaven carers.
- ❖ That all Illawarra A.R.A.F.M.I staff receives training in line with service development.
- ❖ That Illawarra A.R.A.F.M.I assume responsibility for the MFG's in conjunction with Illawarra Institute of Mental Health.
- ❖ That Illawarra A.R.A.F.M.I maintains its autonomy from Illawarra Mental health Services while maintaining its partnership.
- ❖ That referral processes be revisited and perhaps prioritized and formalized.
- ❖ That Illawarra A.R.A.F.M.I informs all stakeholders (to encourage lobbying) if funding is not available to maintain programs at current level.

CONCLUSIONS

In closing today it is important to say that while the role of Illawarra ARAFMI has changed significantly since our beginnings 20 years ago, we retain carer support in all its context as our primary function. After all it is carers who provide the majority of ongoing care for people with mental illness. Carers may be any age, from any socio-economic background. A carer may or may not live with the person they care for and there are often many carers in one family. Carers are everyday people who give up their time, often their income and resources to look after a relative or friend in need. However mental illness can take its toll on caregivers.

Carers are a diverse group of people who need care for themselves. Many carers feel cut off and isolated - the pressures of caring can mean that they lose contact with their family and friends and often they cannot take part in family or social life as they may wish. This is why collaboration is important, this is why we work across the health, welfare and housing sectors, this is why carers involved with self-help groups such as ARAFMI feel less isolated.