Section Seven: Consumers supporting each other

Many people who are diagnosed with 'mental illness' in our culture end up as targets for cultural ignorance and mistrust. It's easy to become isolated under these circumstances. Coming together to meet, tell stories (including comparing notes of services past and present) and to share food can be an enlightening and empowering experience. Regaining a sense that we are entitled as much as anyone else in the community to a fulfilling life is an important message we can reinforce with each other.

Groups of consumers meet for different reasons. Some want to absorb as much professional knowledge as they can and part of the group experience is to bring clinicians into the group to talk about issues that concern the group. Other groups form around a dissatisfaction with services (or the lack of them). There are many other reasons why groups form and this section is an introduction to this important issue.

✷ Benefits of consumer developed and run groups

What people who have been part of developing consumer-run groups have learnt

> *Although there is nothing happy about being ill*
> *I have no right to complain because*
> *it appears to me that, thanks to nature,*
> *illness is a means to give us new life and hope,*
> *to heal us, rather than constituting an absolute evil.*
>
> Vincent van Gough, Dutch artist (1853-1890)

This section of the booklet has been written collaboratively by the current active members of The Maine Connection, a consumer-run group in Castlemaine, Victoria.

Below the group has identified some of the many benefits of being a member of a consumer-run group, and what they have learned in the process of setting up such a group:

- **Knowing Yourself:** Getting diagnosed with a mental illness changes your life. A self-run support group provides a regular opportunity to think and talk about how you've changed and how your world has changed. Other people's stories and reflections help you understand your own place in the world.

- **Knowledge of 'Mental Illness', 'Mental Health' & 'Recovery':** 'Mental illness', 'mental health' and 'recovery' are all very loosely defined and there is plenty of argument about the definitions. There are no physical tests to determine 'mental illness' or 'mental health', and 'recovery' mean different things to each of us. Informal discussion groups help people understand and define their own levels of distress and wellbeing, and enable us to make decisions about our own recovery journey.

- **Knowledge of the system – improving mental health services:** Discussions about our own circumstances and those of others, plus stories of our experiences with the mental health system, invariably raise ideas about ways in which the system could be improved. They also help people form ideas about ways of minimising their own risk of relapse into unwellness.

- **Normalising your condition:** Stigma, prejudice and discrimination stem from a fear and mistrust of difference. Increasingly it is clear that 'mental illness' is more the rule than the exception in society, and that it is the *extent of distress* experienced by people rather than the existence of *symptoms* which determine whether or not an individual receives a diagnosis. Freely discussing symptoms, medications, side-effects and the *experience* of 'mental illness' can work wonders in removing that sense of difference.

- **Regaining control of our lives:** One of the most distressing effects of a diagnosis of 'mental illness' can be a loss of trust in ourselves. In many cases, other people lose trust in us too, and as a result we may lose some control over our lives. Mental health services can add to this sense of not being in control of our lives by using involuntary 'treatment' and insisting that we follow *their* programs if we wish to receive a service. Finding the support of others that we can relate to helps us to regain a sense of ourselves, our strengths and our human value.

- **Building self-confidence and esteem:** Self-confidence and self-esteem are based on our perceptions of ourselves. If we have lost those through the diagnosis of 'mental illness' and all the consequences of that, we need to develop new ways of 'seeing' ourselves, and new ways of understanding who we have become.

- **Moving on:** We believe that a consumer run service is the fastest and most effective way of finding ourselves again – not who we were, but who we have become.

- **Developing a community:** Communities take time to develop. Despite members' insistence on inclusiveness, it took more than 12 months before we were confident that we wouldn't be 'taken over' by new members. Only after that did we distribute flyers advertising our existence and welcoming new people. Early days were spent determining what we wanted to be.

- **Rebuilding social networks:** Consumer communities may often be necessary as a part of re-establishing yourself in the world, but they are rarely enough. Many of us have experienced rejection by the wider community and until our social networks branch out into that wider society, we can't realise our potential. For many, stepping outside the consumer community is best done with friends. We have found that bringing the community into the Maine Connection whenever we can has also worked for us.

- **Creating a safe place for ourselves:** Creating a feeling of safety for people is essential. Sharing food initiates contact and is familiar and welcoming. Confidentiality ("What's said in the group stays in the group") is essential for people to feel safe. A friendly environment, casual and informal talk, including everyone in conversation, tolerating different points of view, and respectful behaviour by and to everyone are simple but effective ingredients in developing a feeling of safety.

- **Exercising your sense of humour:** Laughter is therapeutic, and consumer support groups ought, above all, be fun.

✷ Choosing the group that's right for you

Understanding the difference between self-help, advocacy and activist groups

> *"We're all mad here!"*
>
> From *Alice in Wonderland* by Lewis Carroll

Self help, advocacy and activist groups, in the context of mental health, are not all the same but sometimes one group might fulfil a number of roles or change through time.

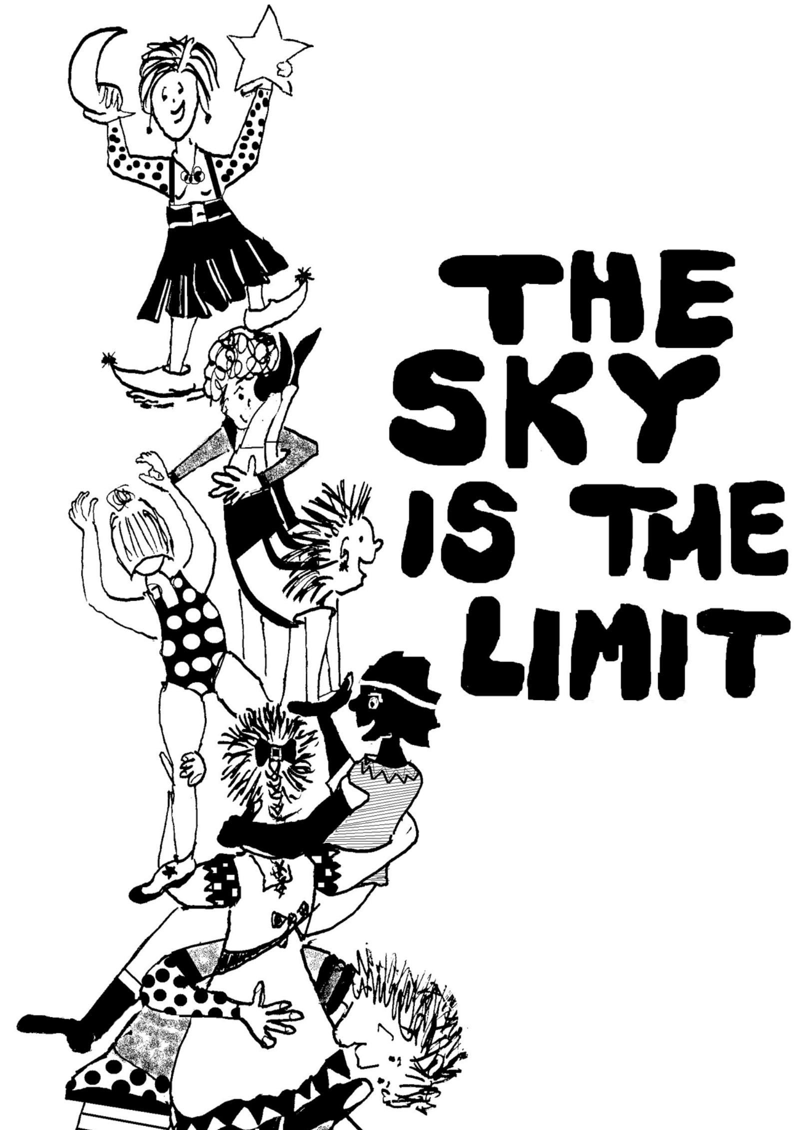
It is important to understand some of the differences because much of the angst that emerges in groups stems from the differing expectations of members and how they see the role of the group.

Self help groups emerge when people recognise what can be gained from coming together with other people who have had similar experiences. In an Australian context they:

- might be 'illness specific,' bringing together different people with a similar diagnosis, with many having a majority of members who use private mental health services;

- might concentrate on the individual person within the group, personal growth, helping each other overcome adversity and supporting members, especially through difficult times.

- tend to be less publicly critical of the medical establishment than other types of consumer groups. Rather, they might see their public role as fighting 'stigma' in the community and educating the public about their


THE SKY IS THE LIMIT

particular illness, often calling on medical experts to speak at meetings and offer 'professional advice'.

- tend to be interested in medical research and new treatments rather than issues like psychiatry as a means of social control or the role of drug companies in medical research.

Advocacy groups sometimes materialise from self-help groups as people become more and more frustrated with 'the system', poor communication and the prejudice they face in the community.

Sometimes it is easy to see this move from self-help to advocacy as a progression. This is not necessarily true. Many groups achieve both. Sometimes people simply don't want to get any more involved than just having friends to talk to who have 'been there, done that'.

Advocacy groups recognise the importance of effects like social exclusion, prejudice in the community, bad clinical practice, and systemic lack of communication skills.

These groups want to make a political difference, i.e. to change the power relationships within services and the community. They are reformers rather than survivors of 'the system'.

Activist Groups are rare in Australia, although they are common around the world. The most influential activist group is the World Network of Users and Survivors of Psychiatry (WNUSP). Rather than being reforming in nature they tend to be revolutionary. They;

- are a progression from the 'anti-psychiatry movement' in the 1970s (see page 11);
- often take a strongly political stance that psychiatry perpetrates atrocities and damages people;
- tend not to take part in many of the bureaucratic opportunities offered to consumers because they find these not only tokenistic and a waste of time but also just nibbling around the edges of a huge problem of social control and State abuse of power which they believe lies at the base of all psychiatry.

Activist groups tend to have an interest in psychiatry and the law, major institutions like the United Nations, international political debates, radical discourse and disrupting both clinical and consumer events that they find unacceptable.

✷ Consumer networking in rural Victoria

Special things to consider when communities are small and rural

> *"Perhaps the best time for networking is Mental Health Week with everyone holding an activity, but then again, isn't every week Mental Health Week?"*
>
> Kenneth Holt, consumer

For many consumers there are important differences between living in a country town or regional centre and living in a city. For one thing, one country area can stretch for hundreds of kilometres and mental health services are severely stretched. When these country distances are taken into account, coupled with lack of mobility and poor public transport and communications between towns, real networking problems becomes apparent.

Often consumers meet each other in hospitals and clinical services in the city or a regional centre; the nature of this setting can in fact inhibit the development of consumer run initiatives. Interaction is occurring in a space that is not 'owned' by consumers and we know that this 'ownership' is fundamental to successful group cohesion and autonomy to make decisions which are empowering. Furthermore, services might be in the same geographical area as defined by the Victorian Mental Health Branch but if one person lives in Wonthaggi and another in Cann River it can be hard to maintain contact. This is accentuated by the costs of keeping in contact from home, where all the calls are charged at high rates.

The result is that consumers who live on farms or in very small communities are largely isolated from other consumers. This remoteness and lack of connection is exacerbated by transport and communication difficulties.

Large regional centres and medium towns often support their own Psychiatric Disability Rehabilitation Support Service (PDRSS), which provides drop-in community based activities. As part of their charter, many PDRSS encourage community participation – people moving on from relying heavily on PDRSS services for friendships and community to form their own groups. Not all consumers want to branch out on their own but some do.

Help from PDRSS in forming a consumer run group can sometimes also be a curse. Some non-government institutions have trouble letting people experiment, fail, experiment again, get bigger, have a slump and then grow again. These are all attributes of any group anywhere; however, when we are talking about consumers being allowed to fail and rebound this is fraught with problems of judgements over "who's responsible". People working in the mental health sector often talk about the concept of 'Duty of Care' whilst many consumers are now talking about 'Dignity of Risk'. Balancing these two ideals and ideas is incumbent on regional and rural support services and the consumers who rely on them.

Despite the challenges, there are many exciting initiatives run by and for consumers in rural areas. However, there are few opportunities to learn from each other. In part this is because PDRSS services are often run by different non-government providers. It's worth noting that for a relatively small amount of money consumers wanting to start support and/or advocacy groups could travel to and see successful groups working, bring in key consumer expertise to talk about what they do, and engage Our Consumer Place.

Email is an excellent way to bridge some of the barriers created by distance in rural areas (though it must be acknowledged that not all consumers are computer literate). The Victorian Mental Illness Awareness Council (VMIAC) runs a mental health chat room site (see the Consumer Resources section for details). Leaving chat rooms aside, there are also excellent ways to acquire friends from your living room through such programs as Facebook and Twitter. These are mainstream, non-mental health sector sites.

Many PDRSS hold programs for consumers – for example, community lunches, men's groups, women's groups and outings – providing a friendly environment for people to socialise as an aim. Transport difficulties are usually solved by the PDRSS staff. These activities may be great for some consumers but they can also create the potential for *"small town syndrome"*. Consumers socialise within a small base of people whom they know extremely well but are not exposed to other groups of consumers in other towns and in other PDRSS areas. These internal activities can also contribute to the ghettoisation of 'the mentally ill'. We might get to know local consumers very well but our horizons can be limited by prejudice in our own communities.

This ghettoisation can, unfortunately, also contribute to us becoming outcasts and sticking together even more. The Victorian Mental Illness Awareness Council (VMIAC) plays a major role in bringing people diagnosed with 'mental illness' to Melbourne. Sharing meals brings people together, allows us to meet consumers from all over Victoria and have an experience of city life.

To find out more about these events find the Victorian Mental Illness Awareness Council in the Consumer Resources section.