# The Case for Peer-run Groups

Liz Carr

This is one section reproduced from the book “Doing it Together.
A collection of approaches, experiences and purposes of an in Groups,
Committees, Organisations, Networks and Movements”. A resource of
**www.ourconsumerplace.com.au**

# The Case for Peer-run Groups

## The journey so far...

Attitudes and beliefs about "mental illness" and appropriate forms of treatment for people with lived experience of mental health issues or emotional distress have been evolving since records have been kept. The advent in the 1950s of medications as a form of treatment for people experiencing mental or emotional distress marked a major breakthrough leading to other developments.

Following the 1986 introduction of the Mental Health Act protecting the rights of involuntary patients, the Victorian government started to fund community mental health support services, often incorporating consumer groups that had emerged through consumer and carer activism. In the early 1990s, the Burdekin Report provided evidence of the poor treatment and abuse of people receiving institutional care, adding to the impetus for de-institutionalisation. People were demanding to be listened to, complaining loudly about the numerous breaches of their human rights, perpetuated as part of their clinical treatment and many became active in the consumer movement.

The development of a "*recovery*" paradigm in the 2000s and subsequent evidence of the relationship between trauma and mental ill-health has led to a deeper understanding of the causes of mental or emotional distress, paving the way for more appropriate responses to people experiencing mental health issues. This has sharpened our understanding of the importance of people being self-determining about their lives to the greatest possible extent.

### *Clinical mental health services*

While acknowledging the benefits accruing from drug treatments, the past six decades were still dominated by a mechanistic, biomedical view of mental illness, whereby it is said to derive from some "*chemical imbalance*" or genetically-determined issue within affected individuals. The more recent understanding that the overwhelming majority of people experiencing mental or emotional distress have had a history of trauma or abuse is finally questioning this paradigm, as more sophisticated understandings are finally starting to gain traction, often led by consumers themselves.

Whilst pharmacology will continue to play an important role in the treatment of symptoms of mental or emotional distress along with psychiatry more generally, it's never been a popular approach for a very large number of consumers. It is now clear that these medications carry the risk of leading to serious health issues as people with lived experience have a life expectancy 15-20 years less than average. New ways of providing support and treatment to people living with symptoms of mental ill-health or emotional distress need to be explored.

The 2014 Mental Health Act introduced profound changes to clinical service delivery; nominated persons, advance directives, obligatory inclusion of clients in treatment and planning decisions will all enable consumers and their networks to play a significantly more active role in making decisions about and maintaining their mental and physical health.

## Non-clinical mental health services

For its entire history, the Psychiatric Disability Rehabilitation and Support Service (PDRSS) sector established comprehensive mechanisms for people with lived experience to join and become part of a consumer group or, a consumer community facilitated by the services. Despite its popularity with consumers, we have witnessed a gradual reduction of this aspect of service delivery over a decade or more and the current recommissioning of services to become Mental Health Community Support Services (MHCSSs) will obviously radically curtail consumers' ability to access opportunities to join with others with lived experience.

Many consumers are distressed about this change, fearing that it will also cut-off their social connections, opportunities and friendships. In its *Pathways to Social Inclusion* series (2008), VicServ provided robust data, demonstrating the vast number of people with lived experience who are disconnected from family, friends or any social network. Why wouldn't people be distressed?

The community mental health sector is now starting to consider the National Disability Insurance Scheme (NDIS) and what it is likely to mean for the future of community mental health support and service delivery in Victoria. We are a long way from being able to predict the new landscape under the NDIS, but even from this distance, it is apparent that a large number of people currently eligible to receive community mental health support won't be any more under the NDIS. Just how their needs will be responded to is yet to be considered.

Consumers' right and need to be included in the social and economic fabric of society, on an equal basis with others, must be addressed by the MHCSS and other community support organisations; their need to access appropriate housing, health services and employment opportunities must be front-and-centre of the work of the community sector and much needs to be done to address the multiple systemic disadvantages faced by people with lived experience, given the ongoing discrimination they suffer on a personal and institutional level. Whilst this may be improving in Victoria, people with lived experience today face numerous barriers to being a part of their community as enjoyed by everyone else.

Literature on social inclusion emphasises that alongside other critical human needs, everyone has a need to be connected to community; there is evidence about the direct correlation between the number of a person's community connections and their wellbeing (measured as physical and mental health, longevity, reported happiness, etc.). Mental health services have responded to this by promoting community inclusion for people living with mental health issues. The problem is that this has largely been addressed from the point of the person with the lived experience and not the community s-he is supposed to be included in.

At this stage in the evolution of the mental health sector, the community support sector in particular, has embraced and encouraged the consumer-developed concept of *recovery*. Working within this paradigm, many new MHCSSs and a few clinical services are supporting the development of new, innovative ways to promote consumer leadership, developing new consumer roles and initiatives, including peer support initiatives and embedding service co-design into their organisations. These are all critically important and without the commitment of services to enable this body of consumer work, little would be achieved. These opportunities, however, are only open to members of the consumer workforce or consumers who meet the criteria for admission into the service. In addition, service culture and attitudes about the capacity of consumers, the limitations imposed by funding criteria and the need to satisfy outcome measurement requirements necessarily result in restrictions being placed on the type and extent of work undertaken.

We need to remember too, that the recovery paradigm is a very recent evolution in mental health service delivery and it would be naïve to believe that our understanding won't continue to evolve. The work undertaken by people with lived experience will play a key role in this evolutionary process and the learning, emanating from the work of peer-led groups will form a critical part of developing approaches to supporting and treating people living with mental health issues.

## *Consumer activity*

VMIAC is the Victorian peak body for people with lived experience of mental or emotional distress. Since its inception in 1982, its small staff group has established, facilitated, met with, promoted, championed and otherwise provided support, to a vast number of different types and configurations of groups of consumers. Some of these have been established within mental health services and some have existed independently of the funded clinical and community mental health sector. Consumer advisory groups, consumer workforce groups, research, project, education or training, therapeutic, skills-based, diagnosis-based, issues-based or interest-based, self-help, peer support and advocacy groups have all been forming, talking, developing ideas, sometimes failing and sometimes succeeding, for as long as VMIAC has existed.

VMIAC has been only a part of a much larger volume of consumer activity over this time; the collective wisdom of the consumer movement, the disjointed network of consumer activity and consumer communities, existing across the state, has grown out of the vast experience we have amassed in starting, supporting and facilitating a myriad of different types of consumer groups and other consumer-focused activities.

People with lived experience have always expressed their desire and preference to be part of a consumer community; since starting to be listened to, consistent and persistent voices confirmed the value of 'drop-ins,' or the importance of group-based activities, or that the most therapeutic aspect of a hospital admission is the support, solace and companionship by other inpatients. The very few Victorian consumers, who have had the opportunity to be part of a peer-run group or community, tend to become strong advocates for its benefits and the value it provides, in enabling them to create lives of quality. In short, consumers will talk about their need for connection with others who have lived experience in whatever language fits their knowledge and experience of peer support. The fundamental request is common: open up opportunities that feel safe and enable people to find and take on valued roles; provide an environment that is conducive to healing and recovery and which emphasises the value to people of being able to give to others.

Yet, while the rhetoric of "*consumer choice and control*" is increasingly being heard in mental health services, the fact that there is no service response to this loud, articulate consumer voice demonstrates that a paternalistic attitude of "*we value your opinion but we know, better than you, what you need*" continues to drive service development.

## *Peer-led consumer groups*

Whilst drop-in and similar PDRSS attempts to meet the social needs of persons with lived experience run the risk of further marginalisation, years of consumer work and experience has taught us that peer-led consumer groups can provide enabling, inclusive, recovery-focused environments. We are able to make this differentiation because of a range of reasons, some of which we discuss below. The range and complexity of existing lived experience groups make it difficult to talk about a particular "form" of group; all consumer groups have multiple as well as common purposes, a mutual or peer support element always present, simply because that's part of what happens when groups of people with lived experience meet.

The concept of "*consumer work*" is a broad one in the movement, recognising that all consumer-led activity is underpinned by a motivation to develop new and better approaches to addressing the needs of people with lived experience. Of course, many service providers are aiming to do this as well, but the unique capacity of people with lived experience to know what is helpful and what is not and the unique knowledge we have as individuals, about our own needs and preferences, means that consumers will always be key drivers of positive change in mental health service delivery – especially now that we can be heard. Approaches to treatment and support that reduce our need to use expensive, debilitating clinical treatments currently offered, will drive innovation more effectively than any other motivation.

In terms of measurable outcomes for consumers, evidence of the value of peer-run groups is limited and mostly emanates from outside Australia. Such activities are barely funded by government and many operate at subsistence level, using volunteer labour with no capacity to evaluate or measure the outcomes they achieve. The evidence that does exist suggests that peer-run groups are effective in many ways, including reducing people's need to access clinical services, improving people's reported quality of life, reducing social isolation and enhancing access to resources to be able to live well in the community. We need to gather evidence from our Victorian experience, including evidence about different "models" of peer-run groups.

In examining and developing research about the efficacy of peer-run groups, it is important to be mindful of the era in which this research has been and will continue to be undertaken; deinstitutionalisation is still a recent occurrence; in numerous areas of their lives, people with lived experience continue to be discriminated against and paternalism about their capabilities continues to pervade services. Consumer work, including peer support work, promotes a greater sense of autonomy, control of our own destiny and confidence in our abilities. But this evolution takes time and, in the meantime, we must realise that we are frequently working with a profoundly disenfranchised, misunderstood and damaged group of people.

Based on evidence and our experiences, VMIAC's view is that inclusive, unstructured, independent, peer-run consumer groups, such as that provided by the Maine Connection, are the missing link in a complete public mental health services system in Victoria. A three-pronged structure - in-patient and community clinical services, community support services and independent mutual support and self-help organisations - already exists (the latter, being a small component only, receiving a very small allocation of the overall amount spent on mental health services). Providing broad access to inclusive peer-run groups would ensure a form of support accessible to anyone. Not all people with lived experience want or need to access mental health-specific support, but those who feel the need for a peer-support group should be able to access one as a multitude of other special interest groups do. Some people living with mental health issues would only need access to a peer-led group to support them in maintaining good mental health, while other people may access two or more alternative service types.

In VMIAC's preferred model, peer-led groups are developed according to principles of group ownership and individual choice; decisions about the group are made by the group and decision-making is often consensual, reached after inclusive discussion. Most decisions don't need consensus; if only eight people want to organise a camp or only five want to access Pilates, only those interested will work on this.

The Maine Connection's lack of a service 'model' means that no groups would develop in the same way, each group responding to its unique membership and culture and its members' expressed wishes. Inclusive, unstructured peer-run groups can deliver a multitude of functions and the remainder of this chapter will explore some of those.

### An alternative, more consumer-friendly way to promote social inclusion

In many ways, independent peer-run groups are better placed than MHCSSs to meet people's need for community connection. "*Inclusiveness*" is a major strength of an independent approach to peer support, whereby anyone identifying with the need to be part of a supportive group is welcome to attend, thus adding strength through diversity. Funded MHCSSs, in contrast, can only provide a service to people who meet their narrow criteria, skewing their membership, as only people with specific, defined characteristics or needs can be included.

We have learned that peer-run groups generate their own level of interaction with communities and, hence, safe and empowering opportunities for broader community inclusion beyond the group. For example, a local provider may ask to consult the group about the development of a community mental health plan, or a Local Council may seek a representative to sit on their community access committee. Group members might organise a Mental Health Week event or partner with another organisation to start a choir or other activity. A few group members might find a shared interest resulting in their participation in joint community activities.

### Opportunities for education, training and information sharing to group members

We see a developing need for people with lived experience to have a point of contact, enabling them to access information about the changing service system, to gain training and support to navigate the new NDIS and advocate for their interests or exercise their rights under the Mental Health Act. VMIAC's experience is that many organisations wish to deliver information to people living with mental health issues and consumer groups are an efficient and effective way to communicate directly with consumers.

As well, members share information with each other in peer-run groups; a subtle but important difference exists between a support worker, telling a client about a doctor open for new referrals and the person learning about that doctor from a friend, at their local peer support group!

## *Flexibility*

People with lived experience use peer groups in different ways, according to their own needs and preferences; some people become committed members for long periods of time; others stay for months or years, before they move on to take up other life opportunities; yet others come along on a casual basis or, they “revisit” the group from time to time. Not being bound by funding criteria, independent peer-run groups allow people to use the group flexibly, according to individual choice, changing circumstances and needs. People can participate, to the extent they choose, at any stage of their engagement, without needing to provide evidence of eligibility or having to commit to a specific program or period of involvement; some people need this level of flexibility to enable them to maintain the connection.

For many years, VMIAC has heard the call for access to peer communities, many people talking about the value of having this “*touchstone*” relationship with a peer group to support them in maintaining connections within the broader community. Even when they develop strong community connections outside the consumer community, many say that their capacity to do so is enhanced by being in groups where their lived experience is accepted and they can talk openly about their experiences.

## *Peer groupwork*

In a broad sense, the focus of this chapter has been on unstructured, inclusive, independent, peer-run groups, where at least one of the core purposes is to provide peer support and community to people with lived experience of mental health issues or emotional distress. In the broad family of peer-run groups, classifications can be made that could be useful in shedding light on the complexity of the need for peer group work. One way to describe peer groups, for example, is to differentiate between those that are established within a service provider organisation and those that are independent from such organisations.

A second point of differentiation is that between groups whose purpose is to provide mutual support and self-help, information or education opportunities to a well-defined subgroup of people with lived experience and groups with more inclusive membership criteria. In the first category, groups such as those facilitated by PANDA (Post and Antenatal Depression Association) and Compassionate Friends, Hearing Voices Network groups and numerous depression and bipolar support groups provide peer support, information, advocacy and education opportunities to members; others, such as GROW groups and the Maine Connection (featured elsewhere in this book) have very open membership criteria.

A third axis of differentiation is those groups that have a structure or framework within which activities take place and members interact and those that are specifically non-structured. An example of this is the difference between the GROW groups, adopting a form of 12-step program to support their members towards recovery, and the Maine Connection, which has consciously chosen to provide an unstructured space.

All these types of groups provide valuable functions and directly respond to a need expressed, by a group of people with lived experience; importantly, whether paid or not, everyone is a peer worker in a peer-run group.

Compared to other developed economies, governments across Australia have been conservative about providing funding to support the development of the consumer workforce, including the development of independent, peer-run consumer organisations; however, future developments in our understanding of and responses to mental health issues will arise from the work done by people with lived experience.

Locally and around the world, consumers have been developing concepts like *recovery* and increasing understanding of trauma-informed care; exciting and innovative approaches to working with people who hear voices and the benefits of alternative therapies which are becoming mainstream are being driven by the work of consumers, either independently or in collaboration with other providers. Only with government investing in this work, including in the valuable work occurring in peer-run groups, will future, more rights- and recovery-focused services and treatments emerge. As healthcare costs continue to rise and demand for mental health services continues to expand, this must be seen as a win-win approach.

We want a future, where people with lived experience of mental health issues, have the same capacity to access the resources needed to maintain a quality life, and to be included in social and economic activities on an equal basis with others. As long as people with lived experience are discriminated against in a range of ways we need to ensure that they can still enjoy community connection, meaningful activities and a quality of life within their own communities of choice before reaching out, in friendship and respect, to the very society that has discriminated against them.