

EDUCATION AND SUPPORT
MENTAL HEALTH CONSUMER PARTICIPATION
PROJECT
FINAL REPORT

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This report is written by Panayiota Romios, Vanessa Lynne and Charin Naksook of Health Issues Centre.

2. INTRODUCTION

Health Issues Centre, in conjunction with the Victorian Mental Illness Awareness Council (VMIAC), developed and conducted the Education and Support Mental Health Consumer Participation Project in 2006 and 2007.

2.1 Purpose of the Report

This report documents development and implementation of the project. It is intended to provide information for policy development around consumer participation in mental health services.

2.2 Background of the Project

Health Issues Centre conducts annual training sessions to support consumer involvement in the health care system. Over several years mental health consumers have been over-represented in these training sessions.

It is evident that the education and training needs of these consumers are very exact and they require specific attention to support them in their involvement with mental health services.

VMIAC has had contact with consumers through meetings with them on Acute Wards, at Community and/or Extended Care Units, and at Psychiatric Disability Rehabilitation and Support Services (PDRSS). The consumers supported by VMIAC range from people who are very unwell at the times of meeting, to people well on the road to recovery. Additionally, the education sessions conducted by VMIAC for consumers have attracted some consumers not involved with PDRSS who have heard about the sessions and requested the opportunity to attend.

The learning priorities of these consumers arise from their own personal needs and concerns highlighting a range of issues that come with living with a mental illness, including isolation from their broader community, uncertainty, and frustration with the mental health service system.

Feedback from consumers supported by VMIAC indicates that being able to understand their own mental health and then having the opportunity to understand the role of services and supports is an important prerequisite to meaningful participation.

3. AIMS

The project aims to facilitate active consumer involvement in mental health service planning, delivery, monitoring and evaluation.

More specifically, the project's aims are:

- To determine the skills, knowledge and awareness needs of the learning group (mental health consumers)
- To provide education and training that meet the orientation and information needs of the training participants
- To support the training participants to better negotiate the mental health system, exploring all available resources and options
- To increase the capacity of VMIAC to provide ongoing education and training opportunities to the mental health consumers it supports.

4. METHODS

4.1 Project Reference Group

A Project Reference Group was established to provide guidance and support concerning development of needs assessment, content of education and training and access to relevant information and resources for the training. The Reference Group also assisted with reviewing draft reports and project outcomes.

4.2 Needs Assessment

The needs assessment was based on consultations with mental health consumers supported by VMIAC. Three consumer groups were invited to take part in the focus groups, including:

- The VMIAC consumer consultant group supported by VMIAC
- The consumer group based at the Victorian Transcultural Psychiatry Unit
- The Maine Connection group in Castlemaine.

The focus group was designed to explore issues around: existing consumer participation involvement; understanding of consumer participation principles and strategies affecting their care and treatment; skill and information needs; learning style preferences; and resources and support required. Health Issues Centre staff facilitated the three focus groups.

The focus groups involved 27 participants. These comprised:

- Seven VMIAC consumer consultants
- Seven consumers at the Victorian Transcultural Psychiatric Unit group, St Vincent's Hospital, and a staff member from the Brotherhood of St Laurence
- Thirteen consumers at the Maine Connection, Castlemaine.

The participants were recruited through VMIAC. The focus group participants received printed information about the project. They were also given a verbal

explanation and time to ask questions about taking part in the focus group. The consumers had their consumer advocate/group coordinator present at the discussion.

The focus group lasted about one-and-a-half hours. Written consent for audio taping was provided by consumers prior to the focus group discussion commencing. The audio tapes were transcribed. Transcripts were read and analysed by Health Issues Centre researchers.

4.3 Draft Report

Following the focus groups, education and training needs of consumers were identified and plans for education and training implementation were developed. A draft report containing key findings from the consumer consultations was prepared for the Project Reference Group's consideration.

4.4 Education and Support Sessions

The Health Issues Centre Training Coordinator, in conjunction with VMIAC staff and with additional consultation with key mental health educators and workers,¹ developed content and format for the education and training for mental health consumers. Two sessions were piloted; one with the VMIAC Consumer Consultant group and the other with the Maine Connection—a self-help group based in Castlemaine.

Results of the piloted sessions were reported to the Reference Group to complement the findings of consultations with consumers.

With the Reference Group input, another education session was delivered to the consumer group at the Victorian Transcultural Psychiatric Unit. A further two education sessions were developed and conducted—a follow-up session with the Maine Connection on self-advocacy and a session on the mental health care system that was advertised broadly for anyone interested to attend.

¹ Thanks to Cath Roper, Melbourne University, Ben Isley, VICSERV, Michael O'Brien, VMIAC

5. FOCUS GROUP RESULTS

5.1 Questions and Issues

Participants of the focus groups were asked to discuss issues around barriers to participation, their existing knowledge and skills, needs for training and education, learning priorities and learning styles.

The opening question focused on consumers' perspectives of barriers and supports in mental health services for consumer participation.² Developing a focus on consumer participation to explore the development of a more participatory and consumer focused mental health system was difficult to establish as participants' focus was usually on their illness, whatever the question asked. The consumers usually made a reference to their illness when they introduced themselves and did again throughout the focus group discussion. They were at ease in sharing their experiences of illness, and considered this was necessary for educational development:

To support them to advocate for themselves, you have to understand what they get, how they feel. (Transcultural)

There was diversity in consumer participation within each focus group and differences in levels of participation experiences among the three focus groups. The VMIAC group comprised consumer consultants with existing skills in participation and consumer advocacy. The Transcultural Psychiatric group was culturally and linguistically diverse with relatively less experience in mental health service participation. The Maine Connection group comprised rural consumers with mixed experiences of participation. Nevertheless, perspectives across the three focus groups are similar. Consumer input was considered an important component to improving the quality of the mental health care system. Further, consumers shared the same views about the difficulties mental health consumers experience within the mental health care system and have had similar participation experiences in services. They also identified similar educational priorities and learning preferences.

5.2 Recurring Themes

5.2.1 The struggle

A sense of feeling under pressure and frustration was strongly felt across all groups and across most issues discussed. Consumers described episodes of power imbalance between service providers of mental health care and consumers. They struggled to deal with the attitudes of and treatment by mental health service providers. They reported having experienced lack of respect, not being listened to, not given enough information and not given a chance to exchange views by the mental health service providers. They said:

The wish of a patient is ignored. (VMIAC)

Your powers are at the discretion of the psychiatrist entirely, and that needs to be pointed out to people. (Maine)

² The question was asked in the first two groups and omitted in the third group as it tended to encourage consumers to describe their experiences of having mental illness.

Because we are sick they think we are incompetent.
(Transcultural)

Consumer consultants, who already had experience of and skills in participation, also struggled with obstacles relating to mental health service providers— mistrust, attitudes and lack of acceptance of consumer input. In their role as consumer consultants they also faced prejudice and inadequate support from mental health service providers:

I have a problem with senior management not seeing us as colleagues but seeing us as consumers, and the fact is we are their colleagues. (VMIAC)

The consumers are also struggling with lack of services, such as after care and support post discharge:

I can see the people with disabilities; they have people to take them to swimming pools. But those people (with mental illness) if they are a bit better and they can do something ... (the services) don't care. They think you are better now you can do it yourself. And it's very hard for them. They need somebody. (Transcultural)

5.2.2 The experience of being involved

Consumer participation across the three groups was considered valuable by focus group participants. They described their experiences of being involved in their respective groups as very positive, helping them regain self-confidence and sharing ideas with each other. Joining a mental health consumer group had helped with their recovery from mental illness:

When I come here I see and I feel that he understands me right away and I feel comfortable. ... When I come here I feel like they are my sister and brother. I feel happy.
(Transcultural)

The consumers identified the following factors as contributing to a good mental health consumer group. These include:

- Being accepted
- Being with people of similar experience
- Being able to share these experiences
- Being respected
- Being able to talk about taboo subjects such as suicide
- Not being judged
- Being equal
- Non-domineering
- Trust
- Feeling safe
- Relaxed and casual setting
- Consumer consultant was present but not interfering.

Having taken advantage of their involvement in these groups, the consumers consulted strongly recommended more groups of this type be available for mental health consumers. They pointed to the need for substantiating the benefits of such groups in providing support and ongoing information to consumers and suggested

the establishment of such groups become a standard of mental health service delivery.

5.2.3 The confidence in existing knowledge and skills

Asked about their existing knowledge and skills, the consumers quickly identified knowledge about their mental illness, how they respond to medication and what the best medication options were. All consumers expressed self-confidence in this respect:

Patients really are experts about their own care, about their needs, about when they are becoming unwell. Patients really know what's best about their mental health care. (VMIAC)

We have the knowledge of our bodies. (Transcultural)

Because we are taking it we understand the medication first-hand, and we know which medication works and which doesn't. (Maine)

The consumers believed they also had skills to support other mental health consumers. They stressed their skills in communication and listening and empathy. They also emphasised that as consumers they had knowledge of mental health programs. However, they were aware that this existing knowledge and experience of mental health has not been appreciated by the service providers:

One of the issues that's different for consumers in mental health service is forced treatment, which doesn't occur in any other field. ... If the psychiatrist says 'no, you're going to stay on this particular medication', then that's what happens. . (Maine)

They also acknowledged their individual skills; for example, music, creativity and analytical skills.

Consumers from the Transcultural group believed that diverse cultural backgrounds added strength to their skills:

We come from a collective culture where we are more inclusive of the community. ... So because we have that, we can be very productive in the mental health service. (Transcultural)

5.3 Needs for Education and Support

Consumers did not distinguish their educational needs for participation in mental health services from those for recovery and regaining employment. Training opportunities serve the same purpose for them— being well again and being able to function in the community. The VMIAC group, comprising consumers who are already on their career path as consumer advocates and consultants, were able to more precisely identify the areas they need to develop to become more effective in the mental health service system.

The consumers identified their needs for education and support in six areas:

5.3.1 The recovery journey

A fundamental need, and the first step for education, is to regain the self-confidence broken by mental illness:

We're told mental illness is wrong, we're told these negative facts about ourselves instead of positive stuff. If you're told negativity, it takes away your self-confidence. (Maine)

This self-confidence was seen as part of the recovery journey and ranged from being able to debrief to anger management to confidence building. Social skills, being assertive, handling discrimination and stigma, developing friendships were also raised:

We need to learn how to mix with other people...learn to cope when people aren't very nice to you. (Transcultural)

One skill is the confidence to do. With a mental illness comes a lack of confidence. ...she's gained a confidence to go out and do this, so how do you teach people confidence? (Maine)

5.3.2 Advocacy skills

"How to advocate for yourself", as the Maine group put it, comprises skills in communication, negotiating, networking and accessing resources. The list included:

- Support for resource sharing
- Negotiating with mental health service, especially senior management, decision-makers
- How to run meetings with mentally unwell people
- Problem solving
- Fund acquisition
- Organising public campaigns
- Leadership skills, character building skills
- How to set up a self-help group or support group
- Information technology, publishing.

5.3.3 Understanding the mental health system

The consumers wanted to learn more about the mental health system:

I've done training and work in the Mental Health Act, and I think we probably need to have a course that teaches the Mental Health Act from a consumer perspective and focuses on rights and things like that. I'm particularly interested in the experience of consumers in emergency departments, and I want to know when their rights kick in. (VMIAC)

They identified needs for knowledge in the following areas:

- Introduction to mental health care system
- Consumer and carer consultant counselling
- Understanding how things work in the mental health service
- Understanding decision-making processes in the service
- Knowing what services are available in the community
- Access to 'hidden clinical meetings'
- How the private mental health service is accountable.

5.3.4 Legal aspects

The consumers in all three groups indicated their need to learn about their rights as mental health consumers and other legal aspects. One consumer stated:

I think that part of the information that people need to be able to speak on their own behalf is the knowledge of their rights, and what the Mental Health Act actually says about that is that people have the right to participate as much as is possible in their own care and treatment. The reality as we know is that psychiatrists don't respect that right. But I don't think that the message is to tell people you've got no rights, I think the message is to tell people you've got the right to be heard, if you're not being heard in this way then you've got the right to make a complaint about that. (Maine)

Other issues raised included:

- Rights as consumers, citizens as well as employees in health
- Responsibilities that go with these rights
- How to make a complaint
- Industrial relations
- The Mental Health Act, for consumers and from consumers' perspective.

5.3.5 Need to 'train' or share experience with, other consumers

There was a willingness among consumers to share their experience and knowledge with other consumers or consumer groups. This sharing was seen as an effective educational strategy. The consumers were very confident in their knowledge and their ability to share it with other groups to work together as well as providing a means for feedback.

Consumers from the Transcultural Psychiatric Unit group specifically mentioned that being trained to become community educators would assist them in their efforts to realise adequate community understanding about mental illness. Several consumers thought this type of community involvement assists with their recovery. It can bring them out of temporary relapse.

Some participants themselves wanted to be trained as trainers. One said:

You should give us the opportunity to do some of the training. (Transcultural)

Training support is needed to enable focus group participants to share their experiences with formal or informal consumer networks:

- For individuals, training to become confident in 'telling stories' to others, ability to convert experience into words
- For consumer groups, transportation and funds to enable individual and group visits
- A forum to share the experience
- A place or system where resources and individual knowledge can be collected and accessed by other consumers.

5.3.6 Building a career path

Several consumers had experienced discrimination and stigma in previous jobs. They wanted to return to employment and were confident in their work credentials. They were interested in training support to achieve long-term employment. One stated:

There're studies that show people with mental illness can be more reliable and punctual in employment. It's just about giving a bit of understanding. (Transcultural)

Also being trained to effectively participate in a mental health service was considered an opportunity to be employed in health services. The consumers would like a certificate as evidence of this training so it is useful for their future employment. This is necessary because:

Working is empowering. (Maine)

5.4 Learning Styles

The most preferred learning style was 'hands on' for people with mental illness. Consumers in all three focus groups clearly identified learning from each other as their best way of learning. Such learning arrangements may assist in ensuring consumers are well informed about mental health services generally and have access to specify information from a consumer perspective. For example, mentoring has already happened among some consumers.

Consumer consultants suggested working in a buddy system for their role because, "working alone is dangerous" (VMIAC).

Consumers described they learn best through:

- 'Hands on' experience such as role play
- Discussions rather than lectures
- Variety of methods
- Specifically, no butcher paper, no PowerPoint presentation
- Small groups
- An informal setting
- Feeling relevant: *I just learn stuff that I take an interest in. Something that's forced on to me I don't do so well.* (Maine)
- Learning in one's own time, with time to reflect and come back to the next session in the following week
- Having reading materials to take home
- A mix of educational tools
- Big issues being broken into small segments over a few weeks so consumers can choose and go when they can and not miss out the whole lot, because, *"I don't know how I am going to wake up"*. (Maine)
- A program balanced by input from consumers as well as consumer organisations such as Health Issues Centre
- Morning sessions, followed by social activities such as lunch, with peers
- An incremental process, building in training as part of every meeting
- Being allowed time to absorb information, learning at one's own pace
- Honouring the experience of each individual consumer
- Acknowledging that everyone learns differently, recognising individual qualities. Some consumers said they learn best in conventional styles such as a lot of listening and reading. Some did not like to participate in role play.

Cultural aspects in learning styles were explored in the Transcultural Psychiatry Unit focus group. Language was found to be the most important issue. One consumer referred to her friend who had learnt English in Australia but has subsequently lost her English language proficiency due to illness:

Since she's been sick she says she can't remember anything at all, and I say "don't worry, just keep on, later on you will remember again". (Transcultural)

Another consumer said he needed:

- A glossary of terminology in medical and mental health system in plain language
- Sessions delivered in simple language
- Handouts, which must be in simple language
- Training for a particular linguistic group should be done by a bilingual trainer, otherwise using interpreters (Transcultural)

5.5 Barriers to Learning

From the consumers' perspective, the major problem that obstructs learning is their health: their illness and response to medication; the resulting lack of self-esteem. Also feeling isolated.

Further, learning opportunities that forces them to mix with other people creates discomfort for some consumers. There are feelings of shame and:

Embarrassment that other people will recognise you as being mentally ill. (Maine)

Other barriers to learning are:

- The environment in which the learning takes place
- Lack of trust
- A group situation where one feels unfriendliness and uncomfortable in a domineering environment
- Lack of financial support for consumer groups to go out to activities, to buy quality educational tools
- When a session is too long
- When the content is too jargonistic.

5.6 Conclusions

The consumers were very positive about their capacity to contribute to health service participation from their own experiences as well as to supporting other mental health consumers. Despite limitations of encountering negative attitudes from mental health service providers, and managing their health, involving consumers in their health care at an individual and service level can bring a range of benefits to consumers and mental health services.

A consistent theme throughout the needs analysis was the need to develop more confidence and be in situations that are affirming and confidence building. The importance of being acknowledged as a person and not just an illness was mentioned many times. Stigma is still a sizable issue for many mental health consumers. Many mentioned needing to have a purpose in life and for some this meant being gainfully employed and contributing to their community.

6. EDUCATION AND SUPPORT SESSIONS

Based on the findings from the needs analysis the group charged with designing the training session component decided to address the issue of self-esteem and how it relates to participation in the mental health system. Developing or regaining self-esteem is fundamental to recovery and it is also a factor that can impact positively on the ability and motivation of a person to acquire new knowledge and skills. This in turn can impact on participation. The corollary of this is that low self-esteem is likely to remove the motivation to learn and affect the ability to concentrate in learning situations, even if the information is important to the wellbeing of the person to whom it is being delivered. Thus, participating, even at the individual level, is affected.

The focus group findings also supported the decision to use an approach to delivery that involved the participants fully and placed them at the centre of the process. Implicit in this approach is the understanding that learning is effective and relevant when it emerges from the experiences of the participants and can at the same time be directed by them. To this end the three sessions were facilitated rather than presented, allowing the participants to engage to the extent they felt comfortable.

6.1 The Maine Connection – Castlemaine

The topic of the session was Rebuilding Self-Esteem. David Mithen (VMIAC Education Officer) and Vanessa Lynne (HIC Training Coordinator) prepared the session. David facilitated the majority of it with input from Vanessa. Fourteen members of the Maine Connection participated in the session.

The session focused on six main questions that arose from three modules formerly developed by David Mithen:

- What makes you feel good?
- What makes you feel bad?
- How permanent are these feelings?
- Does your self-esteem depend on what you think about yourself, or what others think about you?
- What effect has a diagnosis of mental illness had on the way you feel about yourself?
- What IS self-esteem?

The session explored these questions by allowing everyone who wanted to contribute to have a voice. The process was started by using a "Round Robin" technique (everyone speaks in turn). Everyone chose to contribute whatever they felt like saying:

Usually when we do that "round the room" thing I feel a sense of panic as it gets closer to my turn. I noticed that I didn't panic at all today and I think that shows how comfortable I am here.

From time to time David would ask a question of clarification or summarise the point the person was making. This was a clear indicator to the speaker that he was listening attentively. Some participants addressed issues not strictly related to the question, and, rather than re-direct them, David and the group continued to listen. Members were also free to stand up and walk around or make a hot drink if they wanted to. It was very rare for anyone to interrupt a person who was speaking.

The evaluation was verbal rather than written with positive comments indicating the group had gained a lot from the session:

I felt really good about being here. It gives you an insight into how others feel and think and everyone is individual. Everyone had a go today, and it was really interesting and great to be part of it.

We've been in a hot shed talking about an emotional issue and no-one left. It's a credit to David and everyone else. Everyone really wants to self-discover.

6.2 Consumer Consultants

The session's topic was 'Developing Self-Esteem in Others', facilitated by David Mithen. Eight consumer consultants joined the session. The content was informed by:

- Feedback from session with Maine Connection
- Input from group about importance of self-esteem as a first step
- Participant/observer – participating in the process
- Feedback about the process
- Implications for the role of consumer consultant.

The second session differed because of the group involved. This group has more experience as advocates and many of those who attended are in the paid workforce as a consumer consultant.

The session started describing the rationale for working on self-esteem as a first step in any educational/training process that involves mental health consumers. They were asked to participate as if they were consumers to experience the process and to provide their perspective.

Similar questions were asked of this group though the one on how a diagnosis of mental illness impacted on self-esteem was left out. The facilitators decided to do this to concentrate the session more on their role in supporting other consumers in the health system rather than on their individual mental health issues. Overall, in spite of their different experiences, the answers to the questions tended to be the same and the engagement with the group was very similar.

Some of the issues that arose in the group centred on experiences the consultants had in their roles both with consumers and with health professionals. More than one participant expressed frustration with being seen as a service provider by some consumers and as a consumer by some services providers. Others spoke of how they believed they really made a difference because their perspective is not clinical, so it gave them the freedom to sit and do nothing with the consumer if that is what was needed at the time.

The session addressed self-esteem but the facilitated nature allowed the group to explore their role and how their self-esteem ebbs and flows within it. Discussing situations that made them feel bad allowed them to explore how to address this rather than just complain about it. In this way, the session worked well as a vehicle for exploring workplace challenges. It also raised the issue about their need and desire for ongoing education and support in their role to address their personal and professional development.

6.3 Transcultural Psychiatry Unit

Self-Esteem and recovery was the topic of the session, facilitated by Vanessa Lynne, with assistance from Michael Fleming (VMIAC metropolitan advocate). Five consumers from the Victorian Transcultural Psychiatry Unit attended the session. The content focused on self-esteem, with the following questions being discussed:

- What makes you feel good?
- What makes you feel bad?
- How permanent are these feelings?
- Does your self-esteem depend on what you think about yourself, or what others think about you?
- What effect has a diagnosis of mental illness had on the way you feel about yourself?
- What IS self-esteem?

This small group of culturally and linguistically diverse (CALD) consumers provided the most inspiring outcomes of all three sessions.

The same questions were asked but the second question stimulated a conversation that indicated clear cultural differences from the other two groups. The participants were all from collectivist cultures (those that put the needs of the group above their own individual needs):

When I feel good about myself I can help others.

As a group, their response to the question of what makes them feel bad was the same—when they couldn't help others. Each participant saw him/herself in the context of their family and community and their recovery as a necessary part of being a functional member of these groups.

Some of their distress at having a mental illness also came from being rejected by the group. They discussed their shame and the shame of others in their community around the issue of mental illness:

In my community it's bad to have a mental illness. They told me that I wasn't mad and didn't need to go to the doctor.

This experience has led some of the group to advocate on behalf of mental illness in their communities:

When my community talks about mental (illness) I tell them – that is me! That is my son!

6.4 The Victorian Mental Health System – A Consumer Perspective

The Project Reference Group recommended a session to be conducted with mental health consumers who, unlike the consumer consultants and the consumer groups taking part in the project, have not had experience of participation. Eight people registered and attended the session facilitated by Michael Fleming and David Mithen.

The session aimed to explore consumers' perspective on the Victorian mental health system, asking:

- How Victoria's public mental health services works

- The Mental Health Act – why we have one and what it means
- Consumer participation – how you can become involved with services and the system
- Consumer delivered services
- Questions.

While it wasn't a high priority for consumers (as summarised in the focus groups), a session on the mental health system was offered generally in a central location (Ross House). The session was advertised widely through the extensive VMIAC network and through Infoxchange. Personal networks were also activated.

The three-hour session provoked some spirited discussions among the participants, who comprised three main groups: rural consumers (3); consumer consultants (2); and carers (2). A worker also attended. Participants were interested and engaged in the discussion about the impact and implications of the Mental Health Act. As is often the case, a few participants took the lead in sharing their experiences. This "domination" of the process created challenges for the facilitators—should they attempt to curtail the discussion and risk silencing the participants (thereby reinforcing their existing perceptions that their opinions are not valued)? Or should they allow the participants to continue sharing but risk alienating those who want the session to progress onto other areas? The facilitators attempted to balance both of these by allowing some sharing to go past the point where many other facilitators would have stepped in, but intervening eventually to acknowledge the needs of the rest of the group. Mixed groups of this nature will almost invariably face the same issues; further consideration needs to be given as to whether this is the best way to present the information.

Most of the people who attended the session were already quite well informed about the mental health system, having been involved in it at various times and in various ways. The value of the session was in having the time to discuss the issues around navigating the system, especially when unwell. The participants used the time to share their experiences but also to make suggestions about how the system could become more "user-friendly" by taking more notice of the consumer voice.

Those who attended indicated that they found it useful; there is scope to develop the session to be part of more structured training for consumers working in the mental health system. The diversity of participants in the small group was unexpected and demonstrated that there is also interest among carers and workers as well in exploring the consumer perspective. With further promotion this session is likely to attract greater attendances.

6.5 Maine Connection – Advocacy

The topic focused on 'Beyond self-esteem and into self-advocacy'. Fourteen people in the Castlemaine group attended the session. With David Mithen as the facilitator, the consumers discussed:

- Experiences of using an advocate
 - What it is, how it helped, why it works when self-advocacy doesn't
- The importance of knowing/understanding the system
 - How this knowledge can be gained
 - How does illness affect our ability to absorb/use information?
 - Whose role is it to provide information?
 - When is the best time to get information?
 - Having the knowledge yourself versus knowing how to get it

- Ideas for providing/sharing information.

This was the second session with the Maine Connection and followed on from the first session that explored the role of self-esteem in recovery.

Once again each person was invited to participate through a Round Robin process, but people were free to contribute as they wished once the discussions were under way. David made sure that everyone was included by inviting the quieter members to participate if they hadn't contributed for a while.

The group spent some time discussing the type of information they need about the mental health system and the importance of timing in receiving it. Most agreed that information is hard to absorb when they are ill and many conceded that they may have received information during that time that they subsequently forgot.

A long discussion ensued about who had responsibility for making sure they received the information they received. Some had only found out about supports such as the Maine Connection by accident or through a friend:

It would be good to have some sort of a central directory of services and what they do, because often if you're trying to advocate for yourself it can take a long time to find out who's the right person to talk to.

I sought out counsellors, family support workers, etc. who then referred me to other support services. Word of mouth, just talking to people, has also helped me to find out what was around.

Some suggestions for addressing their information needs were the case manager, information kits, a directory of services for each region, information nights and consumers working as volunteers delivering information to consumers on discharge:

Maybe it's more important for psych services to help people to identify what they need, and for them to do their job in helping them achieve this, rather than for us to understand how the system works.

7. EDUCATION AND SUPPORT FOR CONSUMERS

7.1 Content

After the three sessions on self-esteem, one thing is very clear—a single session outline would not have worked. Each group used the topic to explore their own issues in their own way. The discussion focused on self-esteem so the topic was addressed, but it was addressed in a way that had meaning to the different groups of participants. No matter what the topic, any session would have to be tailored to meet the specific needs of the group and for this reason targeting education and support to a homogenous group of consumers is less desirable than strategically targeting groups. In this way, mental health consumers are really no different to any group of adults in a learning situation—learning is more relevant and more accepted when it addresses the specific needs and experiences of the participants.

The session presented to the consumer consultant group demonstrated how workplace issues can be addressed through a topic that on the surface looks to be just about the person and his/her feelings about his/herself. The issues that emerged from the session for the consumer consultants were often common and the group shared their reactions and strategies. In this way members of the group were able to learn from each other—a mode of learning that was affirmed in all three focus groups.

7.1.1 Role of Presenter

The role of the presenter is also important in maximising the learning potential of the session. A facilitator with personal experience as well as subject expertise is more likely to succeed in guiding and focusing the session than a presenter with just subject knowledge. Feedback during the sessions affirmed that having David Mithen and Michael Fleming as the main facilitators gave the sessions credibility.

7.1.2 Processes of Support

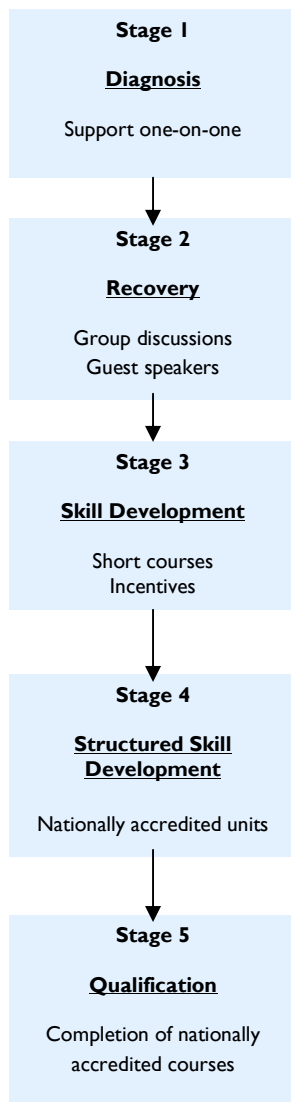
Conducting the needs analysis and preparing and delivering the sessions provided a clear indication that a continuum of education and development activities would address the education and support needs of a wide variety of mental health consumers far better than an ad hoc, content-based response to training needs.

Another issue that was constant throughout the various groups, and in discussions, was entering or re-entering the workforce following recovery. This in turn addresses the bigger issue of the possibility of creating participation and even career paths for mental health consumers featuring a number of different options with multiple entry and exit points. The latter stages of the pathway could lead to careers for consumers in various aspects of the mental health system.

To be effective this path would have to start right at the beginning at diagnosis, with sufficient supports in place that enable the consumer to hold onto as much self-esteem as possible. The second stage in the participation process occurs during recovery. At this stage people can participate in education and support that is unstructured to a large extent but one in which the focus is on self-esteem building and reinforcing. For some this stage in the continuum may be one that they participate in for a while but may choose to take no further. Others may decide to progress to greater levels of participation with or without various career options being an end point, but with the first stage always available for them to return to (see figure 1).

The self-esteem sessions detailed above and trialled during this project could be seen as part of the second stage, while developing skills that enhance the self-esteem in others (the focus of the session to the consumer consultants) could be seen as part of the third stage. If a person decides to complete a course in group work, that would be the fourth stage. Adding this completed unit to a collection of others to gain a qualification completes the fifth and final stage.

Figure 1



Each of these stages stands alone and the second stage is always available for people to participate in during recovery.

In each of these stages there are also possibilities for inserting information or skills development in consumer participation. In the first stage the information and support is practical. In the latter stages it becomes more theoretical or can be applied in different contexts; for example by becoming a part of a consumer advisory committee or being part of a planning or evaluation process.

Consumer consultants fit neatly into the model (above) and a more structured approach to their education and development could address some of the concerns they expressed during the course of this project. One of these is the lack of clearly

defined competencies for consumer consultants. Each one is employed by a hospital or PDRSS and the job is defined accordingly. This makes any training support difficult to tailor. If consumer consultants had competency-based role descriptions flexible enough to be adapted into the various settings where they worked, training to the competencies would be much easier. It would also provide standards that the consultants could achieve and be measured against. Some consultants stated that they have difficulties finding their place in the system—some consumers see them as professionals and many professionals see them as consumers creating ambiguities both in their roles and in their relationships with each group. Many are employed as staff but don't believe they have the same status as staff. With a clearer role description and structured training to fit into this, some of these issues could be resolved. If, in time, the structured training was developed into a nationally accredited course, credibility may no longer be the same issue.

7.1.3 Continuum of Education

From being a small project that looked at training in consumer participation, the project has broadened out to consider a full continuum of education and support. At different times consumers will want and need different things from systems, courses and people. A training pathway starting with recovery and progressing to employment allows a full range of options to be considered. With the latest interest in consumer delivered services, even more possibilities open themselves up.

More work needs to be done to explore both the possibility of designing a career pathway (in the long-term) and in the shorter term, looking at ways of supporting the existing structures by offering support in ways that are appropriate to the person in whatever stage they have reached or role they are in.

8. CONCLUSIONS AND RECOMMENDATIONS

Consumer participation in mental health has been well recognised within services; however, from the consultation discussions and the education and support sessions conducted, it is evident that mental health consumer participation cannot be described in a uniform way. What emerged are two distinct groupings, one of which comprises consumer consultants and consumers already involved and seeking to achieve change (e.g. Consumer Advisory Committee members). This group requires very specific support to enable them to carry out their role and responsibilities. The other group comprises consumers who require support to assist them with issues associated with self-esteem and stigma. As clearly communicated throughout the project, the debilitating effects of illness and medication will impact on the ability of this group of consumers to effectively participate, even at the individual level at times. Development of consumer participation for this group therefore relies on ongoing support of effective and empowering consumer participation strategies within the services and in the community.

While the project was reconceptualised to an extent, the original aims were still achieved.

- ▶ to determine the skills, knowledge and awareness needs of the learning group (mental health consumers);

The focus groups yielded some very important information both about how mental health consumers experience their journeys, and how they wish to receive the education and support they need to assist them on that journey. This information supplemented and complimented the information that VMIAC had also acquired during their consultations with consumers. It reinforced the need to work closely with consumers in the development and delivery of education programs targeted at them.

- ▶ to provide education and training which meets the orientation and information needs of the training participants;

While the focus of the project was consumer participation, the clear link between recovery and participation was made over and over again. The sessions delivered as part of the project addressed the concerns and needs outlined during the discovery stage and formed the basis for many of the recommendations contained in this report.

- ▶ to support the training participants to better negotiate the mental health system, exploring all available resources and options available;

Discovering the barriers to negotiating the system is helpful in putting together appropriate education and support for doing so. The pilot session on the mental health system provides a template for future sessions of a general nature. More specifically though, the knowledge that negotiating the system is affected by multiple factors will inform the design of any future programs so that consumers with different needs and on different stages of their journey can be catered for.

- ▶ to increase the capacity of the VMIAC to provide ongoing education and training opportunities to the mental health consumers it supports.

If any increase in capacity was achieved, it was mainly through the formation of a good working relationship with HIC throughout the project. The partnership brought together the existing education expertise of VMIAC with the resources at the

disposal of HIC—mainly in consumer engagement and adult education. There is a clear desire to work together in the future to develop some of the ideas outlined in the recommendations as well as developing and delivering education and support in ways that were informed by this project.

In addition there are two very practical and achievable recommendations to make as a result of this project. Both of these are at the far end of the educational continuum model (above). The broad recommendation (below) addresses the more far-reaching consequences of this project:

1. Education and support to consumers who wish to become more involved in their mental health service. This can include members of Community Advisory Committees of mental health services or consumers wishing to take on an advocacy role in their own community. For CAC members, the kind of support that could be developed might include the provision of information or the delivery of relevant education and training to both consumers and the health professionals who work on the committees with them.
2. Educational and resource support for consumer consultants. A clear set of competencies that are common for all consumer consultants, no matter what their setting, supported by education and resources that address them, will go part of the way to addressing their expressed concerns. This in no way limits their ability to respond to the unique needs of the services they work in; instead it allows them to develop their professional capacity with knowledge and skills that can be transferred from setting to setting.

In addressing the needs of these two groups, ways of overcoming the stated barriers to participation and learning need to be taken into consideration. Foremost is the desire by consumers to work with and learn from other consumers. A consumer delivered education and support service would meet this need.

Any education of support offered also needs to take into account the clearly expressed preference for facilitated sessions in language that is clear and concise rather than presentations that talk "at" rather than "to" people. This points to a clear preference for consumer-centred learning approaches.

In a broader sense, there is a clear desire among consumers to develop a structured and supported pathway that builds on and develops skills and strategies with the potential to lead to careers in the mental health system. Further potential exists to develop this pathway as a consumer delivered training service with nationally accredited courses developed and delivered by consumers to consumers.

9.1 Focus Group Questions

The following questions were used as a guideline in consultation with VMIAC consumers:

- To be effectively involved in the mental health system, what knowledge and skills do you think you need?
- If you were to design a course for mental health consumers to become more involved in the mental health system, what knowledge and skills would you include in the training?
- What knowledge and skills do you believe you have already?
- What knowledge and skills do you believe you still need to develop?
- How do you learn best? Describe a positive learning experience you have had that worked well for you.
- What gets in the way of you learning easily? Describe a learning experience where this has happened.
- Besides training, what else do you need to support you in your consumer participation activities?

9.2 Participant Information



PARTICIPANT INFORMATION THE EDUCATION AND TRAINING MENTAL HEALTH CONSUMER PARTICIPATION PROJECT

You are invited to take part in the **Education and Training Mental Health Consumer Participation Project**. Health Issues Centre in conjunction with the Victorian Mental Illness Awareness Council (VMIAC) is conducting this project. This project is funded by the Reichstein Foundation.

Health Issues Centre is an independent, not for profit organisation that promotes consumer perspectives in research and health services. You can read more about Health Issues Centre at www.healthissuescentre.org.au

Project aims

The project aims are:

- To determine the skills, knowledge and awareness needs of the learning group (mental health consumers);
- To provide education and training which meet the orientation and information needs of the training participants;
- To support the training participants to better negotiate the mental health system, exploring all available resources and options available; and,
- To increase the capacity of the VMIAC to provide ongoing education and training opportunities to the mental health consumers it supports.

What is it involved?

You take part in this project by joining a focus group facilitated by Health Issues Centre's researchers. The focus group aims to identify skill and information needs in order to develop the education and training. This focus group will take one to one and a half hours.

Possible Benefits

Your participation will help us develop appropriate education and training for mental health consumers. VMIAC and Health Issues Centre hope that this training will support mental health consumers:

- To acquire the knowledge and skills needed to participate and make informed choices about care and treatment;
- To have an awareness of basic consumer rights and responsibilities and mental health system issues; and,
- To increase their understanding of the strategies of participation.

Possible Risks

There are no physical risks of being involved. There is a small possibility that you may find discussing some issues reminding you of upsetting experiences. If you find taking part in the focus group uncomfortable, you do not have to continue it, and you may withdraw from the project anytime.

Privacy, Confidentiality and Disclosure of Information

The focus group will be tape-recorded. All tapes will be transcribed. Transcripts and notes will be coded for the purpose of need analysis, and your name will not be identified.

Participation is voluntary

Taking part in any research project is voluntary. If you do not wish to take part you are not obliged to, and there will no impact on your relationship with any health professional involved in your recruitment, or the researchers. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Reimbursement

You will be remunerated for taking part in the project focus group. This will be arranged through VMIAC.

Further Information or Any Problems

If you require further information or if you have any problems concerning this project, you can contact:

Panayiota Romios, Deputy CEO, Health Issues Centre, 9479 5827