Benefits and Barriers of participation

1. Evidence for participation

There has been significant research highlighting the value of consumer participation. This includes an emerging body of consumer-led and focused research drawing on ‘the lived experience’ and first-person perspectives that inform the evidence on consumer participation. People with mental illness have unique expertise and understanding due to their firsthand experience of mental illness. Consumers are directly impacted by the quality and effectiveness of mental health care and are key stakeholders in the mental health system. The evidential support for consumer participation highlights:

- **Improvements in health outcomes**
  
  Research studies indicate that consumers who understand their health conditions and who are actively involved in decisions about their own care are more likely to value treatment programs and have better health outcomes.5 It is especially important for mental health consumers to develop a sense of control over their illness and recognize trigger factors and early warning signs of relapse.

- **Improvements to quality of healthcare**
  
  The involvement of consumers in service planning, delivery, monitoring and evaluation is more likely to result in services that are more accessible and appropriate to service users.

  The involvement of consumers in the training of psychiatric nursing students illustrates increased awareness of the students’ actions and highlights how these actions may impact on consumers.

  The evidence for consumer participation in improving the quality and safety of health care is supported by the inclusion of consumer participation within accreditation and quality frameworks.8 In the mental health context, this is reflected in accreditation requirements for both clinical and psychiatric disability rehabilitation support (PDRS) services against the National standards for mental health services 1996 and the Standards for psychiatric disability rehabilitation and support services 2004.

- **Accountability**
  
  The participation of consumers is a key mechanism for ensuring and improving accountability. This is exemplified by legislation on consumer participation on health service boards and in reporting on safety and quality.

- **Active consumer and carer participation in health services**
  
  It is a fundamental right for consumers and families/carers to be involved in decision-making that affects them and this is supported by Australian legislation promoting participation across all levels of government. Consumers and families/carers have a right to nominate for health boards of public health services where there is opportunity to participate in the governance and influence of health services.

  Overall, five key themes are apparent in the evolution of consumer participation in mental health services. These themes are:
• the communication of human rights and specific consumer rights in legislation
• increased attention on empowerment, where consumers are viewed as of equal status with staff delivering services
• expectation of a ‘customer focus’ in service delivery and quality outcomes
• increased emphasis on service monitoring and quality processes
• greater collaboration between consumers and service providers
• increased consumer leadership through consumer delivered services.

Recovery framework

For over 20 years, Victoria has seen the vital contribution of the PDRSS sector to consumer participation. PDRSS provide day programs, mutual support and self-help, home-based outreach, residential rehabilitation and planned respite to people with mental illness and their carers. These rehabilitative programs promote empowerment, skill development and re-learning, personal growth, coping and resilience skills. With consumers, these services have actively promoted the notion of ‘recovery’ and ‘recovery-focused’ to respectively describe positive rehabilitative experiences and services with an individualised approach to rehabilitation and support. The PDRSS sector subscribes to principles of psychosocial rehabilitation and has a strong service culture and commitment to consumer-led recovery through participation and leadership.

Importantly, a recovery approach contributes to contemporary thinking and practices in mental health treatment, rehabilitation, and support. A recovery orientation provides a framework of evidential support for consumer participation in individual treatment and support, as well as broader service and policy planning, analysis and evaluation.

Recovery is understood as a deeply personal, unique process of moving towards a satisfying and meaningful life. Recovery is viewed as both a process and outcome towards which the consumer and all those involved in the consumer’s treatment, care and support can work.

*Recovery in severe psychiatric disability involves a process of restoring or developing a meaningful sense of belonging and positive sense of identity apart from one’s disability and then rebuilding a life in the broader community despite or within the limitations imposed by that disability.*

Recovery is a complex process and experience, and occurs over some time. It is also recognised that there are phases within the recovery journey.

Hope of recovery and optimism about the future are important factors that aid recovery from illness. Within all public mental health services, a recovery focus embodied in practice and attitudes is essential to promoting hope, wellbeing and a sense of self-determination for consumers.

A recovery orientation allows for and creates new meaning and purpose, and encourages consumers to pursue personal goals and interests. Consumer participation, including consumer employment within mental health services, can assist with personal development and broaden career opportunities. Consumer participation also promotes a positive image to others on the capabilities of consumers and reflections of recovery.
Recovery models make the distinction between the experience of consumers and the programs and support provided by a service. Services offer treatment and rehabilitation interventions, but consumers experience the recovery journey. Services can facilitate recovery, but cannot create recovery.16 A collaborative recovery model is one that uses evidence based practices and recovery principles as a partnership between consumers and people assisting the recovery process - ‘…while a recovery process is personal, it need not be done alone.’

Notions of recovery include personal self-knowledge, but also extend to an individual’s perception of value and social meaning in the broader social context.18 A recovery orientation is a practical and positive way of challenging myths about the inevitable and enduring course of mental illness, and helps reduce stigma and marginalisation of consumers through social inclusion.

Active participation of consumers in their treatment, care and rehabilitation as this is likely to be conducive to their wellbeing and recovery. Services can ensure a range of one-to-one interventions and mechanisms are available to enable consumer participation in service planning and delivery.

2. Barriers to participation

There are a number of challenges and barriers to the implementation of effective consumer participation. The identification of these barriers to consumer participation and the development of strategies to reduce and counter them are critical.

<table>
<thead>
<tr>
<th>Some barriers to effective participation may include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• lack of clarity on the type and purpose of participation, e.g. where members of a process are not sure about their roles and functions, role strain can occur</td>
</tr>
<tr>
<td>• insufficient resources available or allocated for participation, e.g. for ongoing support, education and training</td>
</tr>
<tr>
<td>• attitudes, understanding and competency among staff on consumer participation</td>
</tr>
<tr>
<td>• lack of integration of consumer participation mechanisms within the formal service planning, delivery and evaluation processes</td>
</tr>
<tr>
<td>• adequacy of consumer representation is likely to impact on effective participation and the achievement of anticipated goals</td>
</tr>
<tr>
<td>• poor communication and non-collegial approaches between staff and consumers, including unequal power relationships, e.g. lack of shared decision-making power</td>
</tr>
<tr>
<td>• consumers may have support requirements that, if not supported, may prevent participation, e.g. young people or culturally and linguistically diverse people.</td>
</tr>
</tbody>
</table>

Some more barriers

Barriers exist that discourage people from participating in the mental health system – some are systemic and others personal. Systemic barriers for consumers and carers include lack of opportunities; lack of education and training; and lack of processes and mechanisms to support participation. Systemic barriers for service providers include inadequate supporting processes and mechanisms, including training.

At the personal level, constraints for consumers include:

- lack of experience and confidence in this area
- work or other competing responsibilities or interests
- reluctance to be public about their situation, especially in smaller communities
- wanting to keep mental illness a small part of their life.

Also at the personal level, a major constraint for carers is the difficulty in being able to take time away from their already busy roles as employees and carers, not just of the consumer they may be supporting, but often other family members too.

Handout 1. Case stories

Story 1: From a Tasmanian consumer involved with a consumer advisory group

From the first group meetings I attended a few years ago, I was inspired and could see hope for us in the future. Mainly as I had known for some time that the previous system had not very much idea how we felt and what we needed to do to express, resolve and heal. Basically the overpowering authorities gave us not much of a good future, little advice and no participation in our own destiny: basically no hope. We were usually chemically suppressed and made to stay out of sight and ‘out of mind’. We were expected to just survive, and not live and achieve as others could. This was very distressing as we all know and remember.

To start with, this new process and its approach is logical, creates new hope, courage, inspiration and (finally after the pain and suffering), a community and self help organisation that I feel is blessed by God in spirit and flesh.

We have lost too many confused consumers in the past, due to the clinical attitude and misunderstanding by professional advisors, who often lack real knowledge or life experience.

There is no going backward, in future it’s all onward and forward for a contented and happy life for all involved.

Thanks for your hard work and confidence in us all – good luck relates to good management.

Postscript
My children and most of my other family members support me and love me unconditionally, 100%. They have been there in the hard and difficult times and have had to bear the burden almost as much as I did. They deserve a lot of respectful admiration.

Story 2: From a Tasmanian consumer involved with a consumer advisory group

When I was approached to become a member of Tasmanian Community Advisor Group (TasCAG) as a Consumer Representative I had no idea this was to involve me in participation! I hoped I was doing the organisation the favour. Now, as I end my time on the Executive, I feel sad.

Participating in the consumers’ groups has given me the opportunity to be involved with other consumers and carers who have the main goal of improving mental health services to my community. To do this, I have had to stay motivated and interested in the welfare of others. I have had goals, which in turn helped me to ‘keep well’ and motivated. There are times when on the road to recovery I feel alone as a mental health consumer.

To give, rather than always receive and to serve rather than be served, has always given me a boost to my morale. I have always had a need to help others. To be able to participate has enabled me to see I have a positive future and I am able to continue to function and take my part in the life of my community. This, in spite of being a ‘Mental Health Consumer’!

I have learnt to ignore adverse response to my condition. I try to alert others that I may be too sensitive and raise my voice unexpectedly, however sometimes it is hard to remain confident in social situations. The more I participate, the more I learn about myself and my condition.
A final comment, perhaps my participation in TasCAG may have benefited by more formal training if that were available.

**Story 3: Between a consumer and a general practitioner**

A General Practitioner (GP) was reviewing the care of Tim, a 38 year old man. The GP used a clinical perspective to identify his problems as being bipolar disorder and high blood pressure. He was also overweight, his alcohol intake was high and he had not been taking his various medications regularly. The GP asked Tim what he saw as ‘his problems’ and his answer was simply and sadly, “I don’t want to lose contact with my son.” He had recently separated from his partner and the custody of his 10-year-old boy was being considered. The GP worked with Tim to develop an Individual Program Plan that was based on an overall goal of Tim maintaining a relationship with his son. All his medical problems were managed with that goal constantly in sight and Tim took a real interest in his own treatment and care.