

SARC *briefs*



Experts by Experience: strengthening the mental health consumer voice in Tasmania



People who have experience of using the system and who have done some thinking about this and know other people using the system can offer sensible advice about how to make it better. It's about being experts by experience.

Consumer leader



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This study looked at the achievements and struggles of the mental health consumer movement across Australia in order to inform the development of consumer activities in Tasmania. It was undertaken by Anglicare Tasmania in partnership with the Tasmanian Mental Health Consumer Network.

The research draws together information from interviews with over 70 consumer leaders from across the world, and all Australian states and territories.

What is a Mental Health Consumer?

The most common term for someone who has used, is using or might use mental health services is a 'consumer'. It is a useful term because it can be aligned with the wider consumer rights movement, expectations around rights and protection and being treated with respect and dignity.

The Mental Health Consumer Movement – What Is It?

The movement developed during the 1970s and 1980s and internationally its catchphrase is 'nothing about us without us'. It is a diverse association of individuals and organisations, small local groups and national networks which campaigns for improved mental health services and consumer-led alternatives.

A large part of the movement seeks to influence the mental health system by getting inside it through consumer participation and involvement mechanisms and sitting on boards, advisory committees and other decision making bodies. There is also a push to be employed within the system as consumer consultants involved in systemic advocacy, as peer support workers, as consumer representatives and as consumer educators involved in training mental health staff. Other parts of the movement aim to create alternatives to the mental health service system and to advocate for mental health reform from independent consumer-run organisations.



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[Soon] they will be funding us to provide information or services, to produce goods or offer workers or take on contracts. That has been the pattern worldwide. We are getting far more professional than we were 20 years ago and governments won't be funding us just to sit round and have talk-fests about advocacy.

Consumer leader

In New Zealand we got a little bit tired of consumer participation. We felt that was about being invited to someone else's table according to their agenda and culture and roles. We felt if we talked about leadership then we would have our own table or at least a shared table.

Consumer leader

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Recovery – What Is It?

Until relatively recently it was a common belief that mental illness was irreversible and that people with a severe mental illness would never be well again. Today there is a much more positive view of mental health which sees the purpose of mental health services as promoting recovery, wellness and self determination.

Recovery does not necessarily mean a cure or clinical recovery but is about living well despite illness or symptoms. It is a process or journey which the individual undertakes and is underpinned by notions of hope and healing, a positive identity, taking responsibility and control and choice.

Key finding 1: Achievements of the Consumer Movement

Nationally the mental health consumer movement can claim a number of successes.

Its two key aims are to transform mental health provision into a recovery-orientated service and to ensure consumer participation is a routine part of service delivery and evaluation, policy and planning. These aims are now accepted goals for those making decisions about mental health services in Australia. A recovery focus has become a cornerstone of mental health policy. In addition mental health services are now required to promote the participation of consumers at all levels.

Twenty years ago consumers were excluded, their experiences of services were not valued and they were not involved in debate. Today the consumer movement is established, accepted and seen as being a good thing.



What next?

Many consumers now want to see:

- the further development of credibility and respect in working relationships with professionals;
- a professionalisation of the consumer role with formalised representative roles, standardised peer support services, consumer-run and controlled services and a growth of consumer businesses;
- an expansion of the consumer workforce with more specific roles in the education and training of clinicians and further inroads into consumer-controlled research;
- skills development so consumers can become more effective; and
- the establishment of technical assistance centres to assist in setting up and sustaining consumer groups and organisations.

Key finding 2: The Consumer Movement in Australia?

A complex jigsaw of consumer activities and participation mechanisms exist across Australia. At one end of the spectrum are a multitude of small consumer support and self-help groups providing mutual support and social and recreational activities to members. At the other end of the spectrum there are consumer driven and controlled advocacy services, a paid consumer workforce employed by mental health services to provide a consumer perspective and consumer-run services and organisations working outside the system, advocating for systemic change and role modelling alternative services.

Each jurisdiction is different but most have witnessed a burgeoning of consumer initiatives on the ground accompanied by a push to develop state wide consumer run peaks and a consumer workforce.

Key finding 3: Struggles

Despite the achievements, for many consumers and other stakeholders the consumer movement has not reached its full potential. In many places there has been a failure to translate support for consumer initiatives and participation mechanisms into the financial resources and the capacity building required to make them work effectively.

Some of the key issues for the movement are:

- how to best promote a recovery agenda so that it becomes a reality for mental health consumers;
- how to progress the cultural change necessary to remove the barriers to effective participation in clinical services;
- good practice in developing a consumer workforce;
- the advantages and disadvantages for consumers of working with the carers and families of people who are mentally ill;
- the meaning of consumer leadership and representation; and
- good practice in establishing and sustaining consumer-run organisations.

Key finding 4: The Consumer Movement in Tasmania

Despite having active and influential consumers, there have been low levels of consumer activity in Tasmania which in many regards lags behind other jurisdictions.

Key consumer initiatives in the state have been:

- a consumer consultancy project from 1996-2002 which offered support to in-patients and began to develop a consumer workforce;
- the Tasmanian Mental Health Consumer Network 2006-2009 which has performed an important role in advocating for system improvement and improved community attitudes and worked to strengthen the mental health consumer community; and
- a growth in small consumer support and self-help groups.

Despite these developments, Tasmania's small and dispersed population and a lack of financial and other resources have mitigated against state wide consumer activity and involvement and raised concerns about the sustainability of consumer-run initiatives. This has resulted in an on-going debate about how best to promote the consumer voice so that it informs policy, planning and service delivery.



The whole system needs to adjust to having well consumers involved in positions – representative or paid – when they might at any other time be using that system themselves as unwell consumers.

Consumer representation provides a mechanism for showing that people can be well enough to participate as a lot of clinicians only see people when they're crook. It's about undoing the fear and stigma.

Consumer advocate

Most of the consumer workforce don't last more than ten years. They are put in positions to advocate against the people who fund them and there are many conflicts between the expectations and role and ethics of the consumer.

Consumer leader





For more information

The full report, *Experts by Experience: strengthening the mental health consumer voice in Tasmania* by Teresa Hinton, is published by the Social Action and Research Centre at Anglicare Tasmania and the Tasmanian Mental Health Consumer Network.

It is available by calling **6213 3555**. It can be downloaded at www.anglicare-tas.org.au.

Key Finding 5: Future Options for Tasmania

The research demonstrates that the difficulties faced by Tasmanian consumers are not unique. Mental health consumers elsewhere, and indeed many community organisations and other social justice movements, have shared these struggles.

Although there is no 'road map', there are valuable lessons to be learnt from experiences in other jurisdictions and internationally.

Anglicare recommends:

- that the Department of Health and Human Services provide funding to establish a state wide mental health consumer run organisation which can provide a support base for mental health consumers, foster a sense of hope and inspiration and build a cadre of knowledgeable consumers and leaders who can press for change;
- that the Department of Health and Human Services support and facilitate the development of a consumer workforce in collaboration with mental health consumers; and
- that the Department of Health and Human Services support the creation of an appropriate supporting infrastructure to promote consumer activities and participation.



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Sometimes we are just there as tokens.

That's the feeling. Consumer reps are there and consumer consultants just so they can tick a box to say they've had consumer representation.

Consumer leader

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Social Action and Research Centre (SARC)

Anglicare's SARC team work with low income Tasmanians to identify the structural barriers that impact most severely on their lives. The Centre pursues policy change on these issues at a State and Federal level.

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