

# Section Eight: Consumer Perspective – the basics

Very few humans live a life totally segregated from other human beings. We live a communal existence pulled together by history, culture and social structures such as systems of government, families, and organised religions. Having been defined as having a 'mental illness' and experiencing the social institutions that this places in our path, including forced detention and 'treatment' we might not want, inevitably reshapes the way we see the world.

This combination of extreme events created by others' defining us as 'mentally ill' and our own personal history, leaves most of us seeing the world differently from others who have not had these experiences. This is the basis of consumer perspective.

It is also the fabric which knits us together in opposition to some of the ways we have been defined and treated and this, in turn, fashions our movement for social change.



## \* Some thoughts about the term ‘consumer’

This debate belongs to people diagnosed with ‘mental illness’ .

*“From antiquity, people have recognised the connection between naming and power.”*

Casey Miller and Kate Swift, authors

Consumer thinkers since the 1970s – when the word ‘consumer’ gained currency – have been discussing the pros and cons of this term. It is a very interesting discussion and a summary of it can be found on Our Consumer Place website ([www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au)). Some of the main issues include:

1. **The language is contested:** many consumers themselves dislike the term, often for radically different reasons. For example, some people regard it as a euphemism adopted by policymakers and services to appear inclusive. Others find the term too political, i.e. not representing their relationships with clinicians. Still others dislike the association with consumption.
2. **The language is contextual:** some people employ the word ‘consumer’ when they are engaged in advocacy or activism but choose to use the word ‘patient’ when in hospital because this more accurately describes their current context. Others use the term ‘consumer’ when working with policymakers, but prefer terms like ‘mad’ or ‘survivor’ in other contexts.
3. **The language varies internationally:** outside of Australia, other terms may be more common, e.g. ‘user’ or ‘survivor’.
4. **The language is our language:** it is up to us to ensure that we continue to discuss and debate its relevance and efficacy and we should have the right to self-definition.
5. **The language is useful politically:** it is useful to have a term to describe ourselves collectively. It is unrealistic to say we are all ‘just people’, as tempting as this may be.
6. **The language is consistent with consumer groups across all health sectors but not in other sectors.** For example, in the Psychiatric Disability Rehabilitation and Support Sector (PDRSS) the most



common terms are 'participant', 'client' or 'resident'. The movement for change in the disability sector also uses different language.

The discussion about language reflects contemporary debates about where mental health sits and where we can gain greatest traction in terms of power. This debate is gaining momentum as consultation continues into what we want of a new Australian-wide consumer body.

As Melbourne consumer Alan Pinches' work suggests, the word 'consumer' is far from perfect but it's the best we have available at the present time.



## \* What is ‘consumer perspective’?

### The lens through which we see the world

“We don’t see things as they are; we see them as we are.”

Anaïs Nin, French author (1903-1977)

**Consumer perspective** is a way of looking at life through eyes that have been categorised as ‘mad’ or distressed enough to require intervention from a mental health professional.

Such a perspective is acquired as a result of receiving, or being unable to receive when you wish to, services in the mental health system. It is based on a belief that as individual consumers we are **‘the experts’** about our own life and carry the wisdom to best articulate our own needs if we are accorded the time, space and means to do so.

Sometimes consumer perspective is called ‘the expertise of **lived experience**’ which is often under-recognised and even undermined by the social institutions that govern contemporary social life.

It’s an idea that developed out of a collective consciousness and political solidarity that grew from the consumer/survivor movement and provides a way of looking at the world from the point of view of a group that has been marginalised and discriminated against.

*Consumer perspective* is about ‘belonging’ and reclaiming citizenship using the language and terms defined by the group for itself.

#### **Consumer perspective is also:**

- that ‘hard to define’ camaraderie that draws people together in an acute unit and the recognition that any oppression we face is a shared oppression;
- an intangible recognition that happens in services which leads us not to ‘dob on’ each other;
- the allowance we give everyone to define what is happening for them in their own way;
- a healthy questioning of taken for granted definitions of ‘professionalism’;
- knowing and believing in the concept of consumer ‘common-sense’;
- a historically wary way of looking at the world.



## Consumer perspective is **not** about:

- interpreting others' behaviour using the tools supplied by the medical establishment;
- blindly accepting the language supplied by the medical model;
- assuming any one of us can speak for others;
- setting up our own groups and organisations which merely imitate the inequitable power relationships we have experienced in services;
- assuming that any of us is different and somehow better placed to mentor others whom we perceive and categorise as less able.

**Acknowledgement:** Some of the material in this section has been adapted from: Epstein, M., & Shaw, J. (1997), *Developing effective consumer participation in mental health services: The report of the Lemon Tree Learning Project*, VMIAC

## \* **How are 'consumer views' different from 'consumer perspective'?**

**We have an infinite number of different views within consumer perspective**

*I wonder if I've been changed in the night? Let me think: was I the same when I got up this morning? I almost think I can remember feeling a little different. But if I'm not the same, the next question is 'Who in the world am I?' Ah, that's the great puzzle!*

Lewis Carroll, *Alice in Wonderland*

While the idea of 'consumer perspective' can be understood as singular, consumer views can never be understood in this way. There are as many different views as there are individuals diagnosed with 'mental illness'!

This is important to keep in mind because people often confuse an individual consumer's experience with 'consumer perspective' (so, for example, if one consumer is happy with a service, they might say "consumers are happy with our service"). This has implications for consumers representing other consumers.

We can offer our consumer perspective – speaking from the lived experience, and stressing the importance of this lived experience being respected. Our views are shaped by:

- **Social Institutions:** We use this term to include governments, the family, the media, legal systems, etc. It is impossible to live in the social



world without being influenced by social institutions. Each of us is affected differently, depending on our position within these institutions.

- **Personal History:** Our own personal history affects our views too. This includes our childhood, whether we lived through child abuse or neglect, sexual abuse, absent parents or anything else that deeply affected our ability to operate within the institutions of our community. Personal history doesn't stop with childhood – we make it every day, and every day it continues to make us.
- **World View:** The modern world is fast changing, fragmented and stressful. To survive as individuals and as a culture we need a way to understand new information – sometimes called our “world view”. It helps us see the big picture, make decisions about what information is important and what can be discarded; what becomes a priority; what is worth fighting for; whether we are convinced by medical definitions of what is happening in our lives and whether we choose to become politicised as consumers or whether we put our energy somewhere else.

## \* Introduction to the consumer/survivor movement

### From personal experience to collective action

*The World Network of Users and Survivors of Psychiatry recognises and respects madness as part of human diversity and therefore respects the rights of those who experience reality differently to others.*

World Network of Users and Survivors of Psychiatry

The consumer/survivor movement is a social movement (like the environmental movement or the feminist movement) – a collective of people with a common desire for social change, e.g. to change society's treatment of us, or how the mental health system works.

Our desire to be part of a social movement tends to arise out of personal experiences of injustice. As with any movement, there are differences between people's views, interests and priorities.

### Who is part of the consumer movement?

It might be useful to think of the consumer movement as something



people choose to identify with. You can be part of the consumer movement without being an activist (someone whose work – paid or unpaid – is dedicated to changing social conditions), but there are many wonderful consumer activists out there!

You are part of the consumer movement if that is how you think of yourself.

### **What 'basic ideas' do we share?**

People who see themselves as part of a movement are usually committed to making the world a better, fairer place and recognising that success takes group effort. Our political development, particularly overseas, was influenced by civil rights movements and disability activists as they struggled for self determination; equal rights before the law; removing discrimination; and improving access to what we need in order to take up our citizenship rights.

Some of us have also been influenced by the writings of anti-psychiatrists (like RD Laing, Foucault or Thomas Szasz) or consumers/survivors who have reflected on their own experiences of injustice. See the list of consumer perspective writings in the Consumer Resources section for more references.

### **Why be part of a movement?**

On a practical level, more can be achieved through a group than on an individual basis. Also, the difference between feeling alone with our views or feeling part of something larger can be both liberating and empowering.

### **What does the consumer movement do?**

The slogan "Nothing about us without us" has been adopted by the disability movement (of which we are a part). This speaks to the range of things we do: community education, reconceptualising what 'mental illness' is, influencing policy, improving access to and quality of services, campaigning for human rights and against discrimination, providing peer support and alternative services, to name a few. We all have different priorities, but there's much work to be done.

### **What has the consumer movement achieved?**

In Australia, the consumer movement has championed the notion that people diagnosed with 'mental illness' can and do recover. We have raised issues about human rights and have fought for consumer participation



at all levels of service delivery and policy development, which is now reflected in all national and state mental health strategies. We have also added our knowledge to what is understood about mental health.

Internationally, the movement has been represented at the United Nations, including playing a key role in the development of the *UN Convention on the Rights of Persons with Disabilities (CRPD)*. Overseas, consumers/survivors have established peer-run services, fought involuntary “treatment”, raised awareness around pharmaceutical companies’ power, and campaigned for ‘madness’ to be respected as part of human diversity.

### **Where is our history?**

The Victorian consumer/survivor movement has a long and rich history of fighting for the rights of our fellows in this state. Very few people know about it. It has never been documented and this is tragic. Without our history we can’t know where we are going.

It also means that we are losing precious insight with each new generation of consumers, advocates and activists; we are losing the potential to build on what we already have. History is important for self-reliant groups and communities.

### **What is the future of the consumer movement?**

So long as we live in an imperfect world there will be social movements. Some major current issues include forced treatment under the *Mental Health Act 1986 (Vic)*, violations of consumers’ rights, tokenistic representation of consumer voices and fighting for our right to self-determination.

### **How can I get involved?**

There are many ways to get involved – you might want to start by checking out the Our Consumer Place website ([www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au)) and contacting the Victorian Mental Illness Awareness Council (see the Consumer Resources section for contact details).

You might be interested in other consumer/survivor groups – there are a huge variety, local, national and international – or you might be interested in starting something yourself. Our Consumer Place can help you find what you’re looking for, or (if you are interested) help you to start up something new!

