Section One: Introduction

✷ What does 'consumer' mean?

What is a 'consumer'? Who is a 'consumer' Am I a 'consumer'?

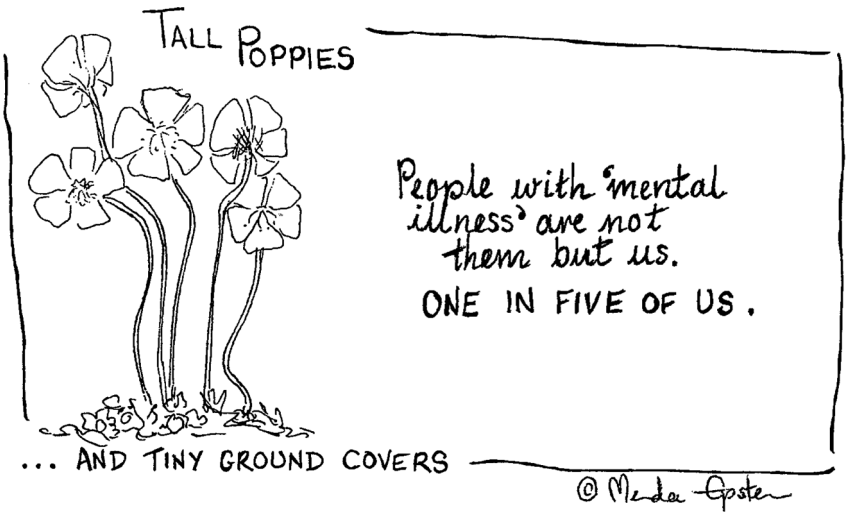
> *"The word consumer is far from perfect but it's the best we have available at the present time."*
>
> Our Consumer Place, drawing on the work of Alan Pinches, Victorian consumer consultant

In this booklet the word 'consumer' has been chosen to describe people who:

- self identify as users of mental health services, and/or
- have been diagnosed with 'mental illness' and/or
- have been active within a mental health consumer/survivor/service user movement that is aiming to bring change – both radical and incremental – to the way people labelled with 'mental illness' are treated by services and society, and/or
- describe ourselves as a 'patient', 'client', 'consumer', 'service user', 'survivor', 'psych. survivor', 'sufferer', 'person with a psychiatric disability', or use reclaimed language (language that is used against us) such as 'mad', 'crazy', 'loony', 'nutcase' or 'batty'.

Simply put, you are a consumer if that is how you identify.

More detailed information about consumer language, perspective and activities is in the final section of this booklet, *Consumer Perspective – the basics*.



✷ Some different ways to understand 'mental illness'

Welcome to the debate! No need to hurry; it is sure to go on for a few hundred years yet

> *"I am interested in madness. I believe it is the biggest thing in the human race, and the most constant. How do you take away from a man his madness without also taking away his identity?"*
>
> William Saroyan, American writer, 1908-1981

In order to understand our own relationships with 'mental illness' it's useful to understand the many different approaches in the community. It is also important to understand that we all choose different ideas and different concepts to describe our experiences of mental distress. There are no 'facts' here but many choices.

In the Middle Ages distressed people were seen as witches and persecuted and from 18th Century until the mid 20th Century people were locked away in huge psychiatric asylums which were visited by bored members of the public as a source of entertainment. These places did not offer asylum.

Even today debates rage about how society deals with difference and not everyone involved in receiving, avoiding, providing or writing about mental health services comes with the same ideas and beliefs about the nature of 'mental illness' or even whether it exists at all.

Some of the ways people understand 'mental illness' are outlined below:

1. **Medical Model**

   Since the 1950s the 'medical model' has become the dominant way of understanding emotional distress within mainstream thinking.

   This model sees 'mental illness' as a medical problem to be solved by specially trained doctors (psychiatrists), clinical psychologists, behavioural therapists and pharmaceutical companies.

2. **Social Models**

   There are also various ways of understanding mental distress as a social phenomenon. Dominant amongst these are approaches which concentrate on childhood trauma, neglect and abuse as fundamental

in understanding many forms of adult mental distress. Others see war, torture, social dislocation, sexual violence, bullying in the workplace, genocide and family violence as social determinants of many of the fears and 'behaviours' that are labelled 'mental illness'.

3. Psychosocial Models

This way of understanding 'mental illness' involves seeing it as a medical problem, but one that is linked with social and economic disadvantage. Issues such as homelessness, unemployment and isolation are seen as central to understanding the lives of people who have been diagnosed with 'mental illness'.

4. Anti-psychiatry

Anti-psychiatry refers to a number of different (and often conflicting) intellectual arguments against the 'medical model' and tends to be highly critical of diagnosis, pharmaceuticals and current mental health treatments such as electroconvulsive therapy (ECT) and involuntary 'treatment'.

The main thinkers within the anti-psychiatry movement, which emerged in the 1960s, were not consumers themselves but dissident psychiatrists, sociologists and social theorists. Anti-psychiatry is not as dominant as it was 30 years ago, but many of the key ideas have spread in various forms, and many have been taken up by consumers/survivors.

5. Alternative and Complementary Medicines

Many practitioners and consumers subscribe to models of healing which avoid conventional medications and therapies.

These alternative approaches include naturopathy, chiropractics, herbalism, traditional Chinese medicine, shiatsu, meditation and homeopathy. Some traditional doctors work in partnership with practitioners using alternative approaches.

6. Consumer Run Services, based on consumer expertise

This model is based on an assumption that the consumer body of knowledge is expert.

Consumer-run services take many forms, including peer-run crisis services, 'warm lines' (peer-run telephone counselling lines) and Intentional Peer Support. There are very few consumer-run services in Australia, but there are many different models around the world.

✷ Rethinking 'mental illness' as lived experience

If we look at madness differently, sometimes it makes sense, has value or is part of human variation

> *"Sometimes a breakdown can be the beginning of a kind of breakthrough, a way of living in advance through a trauma that prepares you for a future of radical transformation."*
>
> Cherrie Moraga, Chicana feminist writer

The most common way we are taught to understand 'mental illness' is as a 'biochemical imbalance in the brain.' Many consumers call this the medical model (see page 10).

Consumers in New Zealand have developed a wonderful website called 'Out of their Minds', which uses the insights of lived experience to explore other ways of thinking about 'mental illness'. They argue that the idea of 'mental illness' is "not just a phrase but a whole way of thinking," and suggest that it might be more useful to think about our *experience*, rather than 'symptoms.'

Whatever our beliefs about 'mental illness', it makes sense for us all to think of mental distress as an experience, at least as much as we think of it as a form of illness. This shift in thinking can make a big difference to our understanding of mental distress and people who experience it.

When we think of an illness, we tend to think of something:

- requiring hospital treatment
- that doctors know the most about
- that makes you dependent or weak
- that makes you broken, needing to be fixed
- with a prognosis, i.e. expectations of a return to wellness, ongoing disability, or death.

When we think of an 'experience', it can be something:

- good or bad, or both
- that can be learned from
- of value, e.g. when job-hunting, or helping others with something you have experienced
- that can be shared; that others can relate to

- unique, or universal, or somewhere in between
- that no-one else is the expert on if they haven't had that experience.

When thinking about mental distress as an experience, it's a lot easier to recognise the positive as well as the negative aspects of it.

Valuing the experience

While we don't want to minimise how tough our experiences may be, it may be possible to find some value in them. It's well recognised in our community that we often develop insight after life challenges such as marriage break-ups, close brushes with death or the death of a loved one. The same value is almost never ascribed to the learning that follows challenges to our mental health. It makes sense to value these experiences – we learn a lot about ourselves and about the world when things go wrong, forcing us to face challenges head on:

> *"This includes experiences of severe anxiety, extreme highs or lows, hearing voices that no one else hears, and whatever else of the many and varied experiences usually labelled 'mental illness'."*
>
> Out of their Minds website

Acknowledgement: Our thanks go to 'Out of their Minds' (www.outoftheirminds.co.nz/), a New Zealand website which describes itself as *"a new website exploring the value of mental distress, madness, 'mental illness', or whatever you want to call it"*. We have leant heavily on their material to write on this topic.

✷ Thinking about 'recovery'

There are many different roads

> *Here,*
> *Surrounded by the sterile relics of sanity,*
> *Lost in a labyrinth of refracted thought,*
> *I sit ...*
>
> Sandy Jeffs, Melbourne-based poet

The concept of 'recovery' from 'mental illness' deserves some reflection. At first glance, the path seems clear – similar to if we were recovering from an accident, physical illness or major surgery, we might need to rest, follow the advice of relevant medical professionals, take appropriate medications and gradually get our lives back to how they were before we "got sick". However, this image is simplistic even for recovery from physical problems, which may constitute a major transition, leading a person to rethink who they are and what they want in life.

For those of us who have experiences labelled as 'mental illness,' this is even more likely to involve some transition and rethinking of our lives. This is especially true when we have experienced catastrophic consequences – shattered self-esteem, difficulties functioning, social isolation, poverty, prejudice, loss of identity, hope and job opportunities, severed relationships with friends and family, and more.

We all have different ideas about what makes a good life, the meaning of our experiences of 'mental illness' and how we want to move forward from where we are. After many years of being consumers, listening to other consumers and reading many articles written by consumers, we've identified a continuum of responses, ranging from what could be called 'recovery through acceptance' at one pole, to 'recovery through resistance' at the other. Some of us tend towards one end or the other, while many others take a bit from both sides, developing our own understanding – accepting some things we have been told while rejecting others.

Recovery through acceptance

When we say "acceptance," we mean belief in the medical model of 'mental illness' or, perhaps, acceptance of past life events. This approach tends to lead to a fundamental respect for the assistance offered by the therapeutic professionals in our lives.

Consumers who follow this path tend to have found a diagnosis useful in understanding our experiences – it was more distressing not having a diagnosis! We tend to prefer behavioural approaches to psychiatry and psychology, recognising that learning new, practical skills is invaluable in our recovery. We also tend to respond to therapy that 'holds hope.'

Recovery through resistance

Recovery through resistance is obviously not encouraged by those who run the current systems in mental health. However, many of us have found strength and meaning in active (sometimes political) resistance to psychiatric labelling, psychiatric 'treatment' and psychiatric invasion of our lives.

For many people, psychiatric hospitals are iatrogenic (that is, they make us sick). Submitting to psychiatric power – often because we have been forced to – can be immensely disabling and disempowering. Many of us are still battling to recover our deep trust in ourselves.

Those who follow this path tend to prefer approaches that are politically-nuanced, collaborative, transparent, and transformative. We will often

reject traditional psychiatry and psychology. We may also reject the term 'consumer,' preferring to call ourselves 'survivors'; we might also reject the term 'recovery,' preferring to work towards transformation, either of ourselves or society. Trusting ourselves, rather than the systems that we critique, is central to our journey.

It's important to bear in mind that we won't all follow the same path. There is no 'right' or 'wrong' approach.

There are many roads

Another path that many consumers take is through creativity, exploring the richness of the inner world.

One consumer, Sandy Jeffs, says that "through creativity we can utter the unutterable, say the unsayable, speak the unspeakable and sense the insensible". Some examples of creativity in recovery are: the Penguin Artists (a Moonee Valley consumer-run group), the Splash Arts Studio (run through the North East Alliance for the Mentally Ill) and the Stables Studio (run through Prahran Mission) – all have websites you can find through a Google search.

Spirituality is also important to many consumers. For many of us, our 'recovery' involves seeking inner peace, greater wellbeing or a more direct experience of the sacred through religious or spiritual practices. For example, there are many 12-step programs (based on the model pioneered by Alcoholics Anonymous in the US in the mid 1930s) that take a spiritual approach to problems in life. This approach may be useful for mental health consumers.

✷ Stigma, labelling, discrimination, oppression

A consumer's view

"Many people think they are thinking when they are merely rearranging their prejudices."

William James, American philosopher and psychologist (1842-1910)

The challenges of having a 'mental illness' diagnosis are often exacerbated by the negative treatment we receive from the people around us. This is often described as 'stigma'. However, this might not be the most useful way to think about these issues – in fact, we believe that this way of thinking actually perpetuates problems!

What is "stigma"?

'Stigma' is a term that originally referred to a physical mark on a person, identifying them as disgraced; someone to be shunned from the community, typically because they had done something shameful (like commit a crime).

As it is used today, the concept of 'stigma' is quite confusing. 'Stigma' is a 'thing' rather than an action. 'Stigma' no longer refers to a visible mark, but is something to do with generalised negative attitudes towards a group of people. When we say (for example) that "there is stigma in the community against people with mental illness," we are being very unclear about what this 'thing' is – who these negative attitudes come from and how or why they are perpetuated. The word 'stigma' makes it seem as if these attitudes are "just out there," attaching themselves to the stigmatised group without anyone actually doing anything.

Does it matter what we call it?

We think it's important to think very carefully about these issues if we are to truly change the way people with 'mental illness' are treated. In the context of mental health, the most common approach to combating stigma is to "educate the community", teaching them to be better informed about the medical model of 'mental illness' – often along the lines of teaching people that "mental illness is an illness like any other," or imparting basic information about specific diagnoses (sometimes called 'Mental Health Literacy').

There are two major problems with this approach. Firstly, there is a great deal of evidence to suggest that this kind of 'education' actually makes people *more prejudiced* – for example, not wanting to have contact with people with a diagnosis of 'mental illness' or believing that people with 'mental illness' are dangerous or unpredictable. There are many different theories about why this dynamic occurs, but no one knows exactly why.

Secondly, many of us see this approach as misrepresenting the cause of "stigmatising" attitudes – these approaches presume that the cause of stigma is "ignorance" (of the medical model), whereas many consumers believe that being labelled (i.e. given a diagnosis) itself causes stigma.

How else can we talk about these issues?

Some of us prefer the term 'prejudice' as it is clearer about the fact that *other people in the community* are prejudiced and that these people are the problem, not us. Others prefer terms such as 'discrimination' or 'oppression'. Again, these terms make it very clear that other people (and

social institutions) are the ones at fault. They are also clear that there are acts involved, not just attitudes. The term 'oppression' is often specifically used to describe the use of forced 'treatment' – the term 'stigma' doesn't really work in this context! Talking in terms of 'oppression' makes it possible to talk about issues like forced 'treatment' in a context of human rights and self-determination. It also connects us politically with other forms of oppression, such as that experienced by indigenous groups or people with other disabilities.

Yet another approach draws on 'labelling' theory, and argues that psychiatric labels ('diagnoses') are themselves part of the problem. People who work in education, sociology and criminology have developed ideas about how labelling people is damaging, and part of the process of treating them as 'other'. Some consumers argue that a similar process happens in mental health – that the actual process of being labelled is itself discriminatory and oppressive.

Damaging language:
10 terms that are used against us

The way people use words can be damaging.
Here are 10 shockers but there are many more.

1. **'Manipulative':** This term is used often, particularly by clinicians in hospital settings. Many consumers would argue, however, that what appears to be 'manipulation' is usually in fact an *ineffective* attempt to get needs met. It's an important life skill to be able to manipulate effectively.
2. **'Attention Seeking':** Again, it seems that just about everyone who has been diagnosed with a 'mental illness' has been described as an 'attention seeker' at some point. It's meant to be a criticism but when you think about it, is there anyone in the world who doesn't need attention? Anyway, if you just turn the words around and say 'seeking attention', the meaning changes.
3. **'Non-compliant':** This tends to be used as shorthand for saying someone disagrees with his/her doctor's recommendations. As consumers, we suggest that it signals that more communication is needed, or that the person is becoming more empowered to make independent decisions.

Continued...

4. **'Lacking Insight':** This term is very like 'non-compliant'– a person is deemed to *have insight* when s/he seeks or accepts 'appropriate treatment.' Of course we all have our own insights but too often, in mental health contexts, the person with more power (the mental health professional) lays claim to the 'correct' insight.
5. **'Inappropriate':** What is or isn't 'appropriate' is largely about social norms; arguably, it has more to do with social control than mental wellbeing.
6. **'Passive Aggressive':** This seems to be a term of frustration when the skills of the clinician are being tested. In many consumers' experiences, it tends to be used in contexts where someone is struggling with expressing difficult emotions from the past (fear or anger, for example). Judgemental responses from professionals just add to the difficulty and make it harder to express these emotions.
7. **'Just behavioural':** This term is used to distinguish between people who are considered legitimately 'unwell' (with a 'mental illness') and those who are just plain recalcitrant (often displaying traits associated with 'personality disorders'). As consumers, we argue that this language is dismissive, blaming and unhelpful.
8. **'Venting':** Again, this term is often used in hospital settings. It describes a situation where a mental health professional has listened (or feigned listening), while a patient has shared something that is important to her/him (and possibly very intimate). The professional has then gone away and dismissed the communication as being unimportant or pathological.
9. **'Dependent':** As adults we are not supposed to be dependent, so this term can cut deeply. The reality we must remember is that this so-called 'dependency' is often a product of the industry of psychiatry, which demands compliance with medication and medical mores on the one hand, and 'appropriate insight' on the other.
10. **'Splitting':** is used in a derogatory way to describe consumers who the system, represented by 'The Treating Team', believes have the capacity to badly affect team unity; that is, to split the team. Apparently we do this by liking some members of the team and not others.

An exercise for a group of consumers might be to brainstorm all your most detested words, print a list and distribute it widely. It's even better when you can offer alternatives.