WARNING

THIS BOOKLET CONTAINS CONSUMER EXPLICIT LANGUAGE AND INFORMATION WHICH MAY INADVERTENTLY CAUSE OFFENCE TO SOME PEOPLE.

THIS BOOKLET IS NOT SUITABLE FOR PEOPLE WHO WILL NOT LISTEN TO A CONSUMER PERSPECTIVE.
Mad Meetings

Consumers and Committees
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**Introduction to Committees**

Many consumers have struggled with committees. Some of us have felt bullied, not listened to with the same sincerity as others, not adequately informed by chairs, ignored by people co-opted from business, treated as stupid, or scrutinised in ways no other committee member has to endure.

We hear story after story of bad practice. People have silenced us and shamed us in equal measure. Committee members are often rude to us or purposefully dismissive because, underneath it all, they think we have been appointed above our station. Sometimes it is just unthinking or unintentional. But too many consumers have been damaged by these processes.

At the heart of this is a fundamental contradiction. How can consumers be ‘central’ players in the decision-making of the state and its institutions when the consumer body of knowledge is disrespected and often not acknowledged at all?

See the information sheet *Committees and Power* for more on the topic of power.

**Representation**

Decision-making and advisory bodies need to abandon the idea that a consumer can possibly be ‘representative’ on a committee, or that a consumer ‘representative’ somehow comes with ‘unscientific’ passion rather than a knowledge base.


**Consumer Perspective**

Consumer perspective and consumer views are two concepts that must deeply inform all consumers who sit on committees as consumers. We are not there primarily as ‘clever orators’, ‘political manipulators’, ‘lobbying experts’ or ‘power carriers’, although skills and knowledge of various kinds can help. We are there as consumers. The section on *Consumer Perspective* probes this idea further.

**Consumer expertise**

As consumers we are, or should be, experts in our own right, backed up by competence, facility and sound judgement. We have our own practically tested empiricism, research interests and research methods. Collectively we have years of experience, totalling many hundreds of hours of supervision from a consumer perspective, and an extensive knowledge base in the theory, politics and practice of social rights policy and community development. (See, for example, the work of consumer academic Cath Roper of the University of Melbourne: [http://www.cpn.unimelb.edu.au/trash_local/cath2.](http://www.cpn.unimelb.edu.au/trash_local/cath2.)

Consumers might not use this language, but we know all too well when people’s social rights, sovereignty and humanity are under threat, and this can occur even, or perhaps especially, when we are sitting on a committee.

Many consumers don’t know or trust the knowledge they have. Powerlessness and shame rob many of us of the ability to truly recognise our own achievements and potential. Well-structured peer support, such as that described
within the field of Intentional Peer Support, can help here (see www.intentionalpeersupport.org and www.brookred.org.au).

The key to having our expertise recognised lies not just in providing genuinely useful committee training to consumers, but in educating committees themselves to recognise and honour consumer expertise. The information sheet Committee Training explores this issue.

The language of committees

Part of the jostling that happens on committees is about language: what is acceptable and what is not. Too often the language of academic elites, bureaucrats, economists, medical scientists and clinicians is granted privileges or a status on committees that consumers’ language, particularly narrative or story, is not. This is a big challenge, but we know it can be overcome, as shown by examples of successful negotiations between, say, indigenous and non-indigenous peoples.

Respecting points made through narrative and, at the same time, respecting that consumers bring much more than just a narrative is hard. Committee chairs need to be well educated and diligent in ensuring that this respect is granted. Otherwise, discussion will tend to default to the much more powerful discourse of, for example, bureaucracy or the medical model. The information sheet Using Story on Committees looks at this issue in greater depth.

Beyond the standard committee

We’ve outlined a couple of models and resources that can be used to help ensure that alternatives to the standard committee model can flourish. See the information sheets Collaborative Committee Model and Committee Agreement Template. Both of these models are fundamental to understanding the importance of the second aspect of all committees’ responsibility: to be generative of new ideas and shared visions. Many committees are equipped only to make decisions.

Traditional committee structures have proven to be bad places for generating growth and testing new ways of groups interrelating. Collaborative Committees, on the other hand, are an exciting new way of understanding how committees can fulfil the breadth of their responsibility more creatively. The Agreement Template is a first for Australia. It gives consumers and others a structure to test the commitment of the organisation to consumers. The fact that it is ‘loaded’ is intentional, providing opportunities that will only come when all members of the committee are pushed.

Alternatives to committee participation

There are now many different ways of ‘getting inside’ the mental health system, as employees, researchers, outside commentators, consumers running peer services or academic appointments. One of the benefits of all this activity is that consumers whose ‘thing’ is not really sitting on (possibly) stuffy old committees can find other ways to influence the mental health agenda.

There is a wonderful and diverse population of consumers doing just this, whether they are nibbling at the edges of the medical model or pursuing a revolution; whether they are saying "Could you possibly please...?" or stamping their feet and saying "No!" Making a worthwhile contribution doesn’t come from being important; it comes from trying really hard.

The information sheet So You’ve Been Asked to Sit on a Committee poses some questions we can ask ourselves when trying to decide whether committee work is really for us.
Consumer ‘Representation’

"When the committee agrees with you, that’s representation; when it doesn’t, then you’re 'not being representative'."
(Anonymous)

When consumers are invited to sit on committees it is usually as ‘consumer representatives’. The notion of ‘representation’ is hotly disputed. For an overview, see the discussion paper by Wanda Bennett at www.ourcommunity.com.au/files/OCP/Dec2012.pdf.

This information sheet highlights some of the problems associated with ‘representation’.

Decision-making and advisory bodies need to abandon the idea that a consumer can possibly be ‘representative’ on a committee, or that a consumer ‘representative’ somehow comes with ‘unscientific’ passion rather than a knowledge base.

Even consumers who do have a pool of available consumer opinion to draw on still often run it through a screen of unacknowledged personal interest, often wielding power over other consumers’ ideas and attitudes as they do so. Traditionally the idea of ‘representation’ has left consumers failing to convince anyone, including some other consumers, that they are the experts in a particular area.

Clinicians are rarely asked to represent a constituency. It is more likely that they will be invited onto committees for their expertise in the area that is central to the committee’s charter. It should be the same for us. Many consumers are experts in areas ranging from the education of the mental health workforce to public education campaigns and research. If we start to recognise our own knowledge bases and those of our peers, we can handball work to those who can most knowledgeably contribute.

At the state and federal level, some consumers are conspicuous by their presence as ‘representatives’, particularly those consumers (and ‘carers’) who regard themselves as representing ‘the most vulnerable’. Governments encourage this, yet simultaneously there is an assumption that if you are able to speak for yourself then you are not among the most vulnerable group of consumers. However, if you ‘represent’ the ‘most vulnerable’, no matter whether this perception is cultivated or real, you become a voice that the government must hear. This is not acceptable to many anymore.

Often these consumers won’t or can’t speak from the first person or from consumer perspective and have very little exposure to the consumer body of knowledge or the high-level thinking that is happening in consumer academic think tanks, in consumer training, or in much of the consumer input into mental health journals internationally. Many are not aware of the issues surrounding the notion of ‘representation’.

What many of these people bring to these committees is a belief in themselves and the cause as they perceive it. They may convey a sense that they are expert because they ‘represent so many’ when in fact they are not.

Indeed, a small group of consumers are constantly being asked to ‘represent’ us when we have no guarantee that these people understand the fundamentals of prejudice, oppression critical theory, or what it means to play an influential social role.
Even when consumers are appointed to particular bodies, it is sometimes made very clear to us that the committee, once formed, is not a committee of parts, with different people representing different categories. Rather, it is ‘a whole’, making sound decisions for multiple purposes, such as governance, steering projects or developing guidelines.

There is a fundamental problem at the heart of this for many consumers because consumers are still often seen as representatives when everybody else is seen as an expert. This is problematic for everyone. The whole will not be the sum of its parts. The whole will be the most powerful, and therefore convincing, discourse.

In fact, the very notion of representation is invalid. The most that consumers can ever can do is bring our expertise – born of private experience, grounded in theory – and a keen knowledge of consumer perspective.

Unless consumers have opportunities to educate the people sitting on these committees, our expertise is not seen as expertise, even on committees where we are co-opted precisely because we have the knowledge and skills needed.

Once we start to internalise the thought that we are (and should be) leaders in all forms of systemic advocacy related to mental health, the importance of representation starts to lack relevance.

As Brenda Happell and Cath Roper wrote in a 2006 article in the Australian e-Journal for the Advancement of Mental Health, "Within this model of consumer leadership, the issue of ensuring that the voice of all consumers is heard by mental health services becomes the responsibility of all leaders, not merely that of those consumers who choose to participate."
Consumer Perspective

‘Consumer perspective’ is a way of looking at mental health that values the lived experience of those who have been diagnosed with a ‘mental illness’ as a crucially important source of insight. It means looking through the prism of emotional distress, ‘mental illness’, craziness, or whatever other way we choose to describe ourselves.

Consumer perspective, by its very nature, is pro-consumers, wary about the world, wary about medicine and other discourses, and framed by a deep respect for people who have been labelled in these ways. For more information on consumer perspective, see www.ourconsumerplace.com.au/helpsheet?id=4755.

Consumer perspective is singular, unlike consumer views, which are plural. It is singular and it is imperative. Consumer perspective defines who we are if we choose to sit on committees in the mental health sector, in government or in policy-making bodies. Consumer perspective informs and guides our contributions to decision-making, points of argument, service delivery review – indeed, anything that a committee or other body might examine.

Consumer perspective holds our integrity, our ethical judgement and our values. Consumer perspective is a rare and valuable resource. We need to develop aids and rehearsed ways of describing it that we can bring to any committee we sit on. We need to develop resources to help us do that.

Bringing consumer perspective to a committee

Bringing consumer perspective to a committee or other body is different from being a consumer ‘representative’. Consumer perspective requires us to stay in our consumer self for the duration of the meeting and when we are responding to papers and reading reports. The force or influence of this perspective may be stronger if we are closely allied with other consumers, but this is still totally different from ‘representation’.

This is not always easy. Paradoxically, those with the most status, the highest qualifications or the most impressive employment record tend to have the most problems with it. If we agree to sit on a committee as a consumer, then we are ethically committed to staying as a consumer. For consumers with greater social capital, this means staying in our least powerful persona for these meetings.

But it’s all we can do. Consumer perspective demands this of us. It’s a necessity and a gift of power back to all who do not have the privilege of sitting on the committee. Consumer perspective expects us to minimise the times we use terms such as ‘they’, ‘consumers’, ‘them’, ‘the people I teach’, ‘the people I work with’, and ‘the most vulnerable’. (This ‘I’ is a personal ‘I’ and not a professional ‘I’ except in unusual circumstances. This is an important understanding for consumers working in the mental health sector.)

Consumer perspective expects us to comprehend a whole world of consumers with major differences, but we need to deliver that perspective with grace, and we need to own our own powerlessness.

It’s important that people talk from a position of their own experience, because it is the least empowered voice in the sector. (This doesn’t necessary mean telling ‘I was…’ or ‘I am…’ stories, although it might.) This can be very difficult, because often people’s experiences are very raw. For many reasons some consumers decide they can’t talk from this ethical place, while others wander in and out of it.

Some consumers who are co-opted onto committees – even those who work regularly on committees – don’t understand the fundamentals of consumer perspective. Their contribution to the committee might not be
underpinned by a basic consumer ‘way of knowing’, even though their views are prominent in their contribution. Views, by their nature, are not enough.

**Perspective versus views**

There is some confusion among consumers about what constitutes ‘perspective’ and what constitutes ‘views’. Perhaps the easiest way to differentiate between them is to see perspective as a singular, a particular way of looking at the world (especially at committee deliberations) through the lens of practical experience as a consumer. Views, on the other hand, are always plural. For every committee-sitting consumer in Australia, there are 100 times as many views.

Consumer perspective dictates a way of seeing (and doing and behaving) that is wholly consumer-present and consumer-responsive. Views, on the other hand, stamp our own personal territory. Our views are important, as are the issues we pursue and the minority groups we come from, but they are not central to all consumers.

Views range politically to all extremes, and they are influenced by our individual psychology, our family of origin, where we went to school, whether we got bullied or praised as little kids – all the stuff psychologists tend to be interested in. Our views are also influenced by factors that have nothing whatsoever to do with our experience of being labelled ‘mentally ill’. Very often our views drive us, and this is fine provided we understand where our ideas are coming from.

Understandably, experiences that have hurt us or hurt someone we love will influence our contributions to any committee on which we sit. Problems occur when consumers on committees behave in ways that endorse one of the other influential discourses that already drive psychiatry, rather than in ways that question from a consumer perspective.

The consumer movement is trying very hard to encourage the sector and the community to recognise us as experts in specific areas within the field and as experts in our own discipline rather than as representatives who, by definition, can’t represent. And it is even trickier than this: often, unfortunately, consumers are directly discriminated against because of their expertise.

**Staying true to your consumer perspective**

When we have been selected to do something because of our consumer experience, we are trading two things: our experience of managing a health condition, and our experience of using health services. (And any other expertise we might have to offer, such as common sense.)

This experience is the basis of our expertise, of why we are there. This is what people want to know about. But one of the realities of speaking from a consumer perspective, whether you are working in a service, or sitting on a committee, is that it can feel very powerless, for several reasons.

Consumers of mental health services may have long histories of being discredited. Residual societal attitudes define us as weak, unreliable, untrustworthy or unable to give truthful testimony. It is no wonder we might sometimes feel powerless.

What’s more, we often find ourselves in situations full of people with more power than ourselves: doctors, professionals, people who have spent years studying at university. It is not uncommon for us to be working alongside people who have quite literally held legal power over our lives.

Power can be coded in language too. Without meaning to, people in meetings can seem to be talking another language, complete with its own shorthand and vocabulary. (A tip: asking what things mean reminds others of their
tendency to use jargon. They will be embarrassed, not you. Remember: often, we have nothing much to lose. Those with least power have least to lose. So it means we can tell the truth. It is refreshing to be around people who can tell the truth.)

When someone is exerting power over you – which happens routinely across all areas of our lives – recognise how it makes you feel, what brings it about. It’s useful knowledge. Ask yourself: "Why would that person need to put me in my place?" When someone exercises power over you, it’s usually about them.

Be mindful that a person’s experience cannot be queried as right or wrong. Because it is deeply felt, personal and individual, it is truthful. Sometimes you may have to remind people of this simple fact.

Ultimately, nothing feels good if it is at the expense of our integrity, our ‘truth’. In fact, our truthfulness and our analyses, borne out of our deeply felt personal experience, are our strengths, the source of our power, and the reason we are asked to provide consumer perspective in the first place.

But don’t give yourself a hard time if you think you just fell into an “I’m powerful too!” moment. By noticing it rather than denying it, you’ll be much better equipped to resist it next time.

It’s helpful to mix with other consumers rather than working as a lone ranger. Lone rangers are more likely to be tricked into co-option. It’s also good to join up with people who are thinking and theorising about ideas rather than fighting your committee battles on your own. Isolation amplifies everything.

**Ask yourself**

1. Am I talking to other consumers about this (if I am allowed to)? Where else is my consumer perspective coming from?

2. In meetings, do I usually come across as someone with strong views about certain issues or am I regarded as ‘easy pickings’? Think about the pros and cons of each position.

3. What enabled me to make that decision? What knowledge was I calling on? Was it my consumer perspective persona?

4. At what point do I let an idea go in negotiations within the group?

5. Do I really have expertise in consumer perspective? If so, do I push it sufficiently? If not, what am I going to do about it?

6. What does it take for me to feel safe?

7. Do I need to be liked or to feel powerful more than I need to fight for consumer perspective? What can I do about it?
Committees and Power

Once we have been appointed or elected to a committee, the interactions we have on and about the committee are political. This is because the decisions made by that committee and the relationships within that committee are about power, and power is always about politics.

Every place where important decisions are made is a setting for power-based interactions as people jockey for ascendency and fight for their point of view, claiming the best qualifications, superior standing in the community or professional arena, superior experience in their field, or affiliation with a powerful group in society.

Consumers are not always without power in this situation. Sometimes well-connected consumers join the more powerful groups. And sometimes this is to the disadvantage or disenfranchisement of other consumers.

Those who have power frequently deny it exists, and those who don’t have it often feel its absence acutely but might not know what this feeling is, or might be bamboozled into thinking it has something to do with their own competency or, to use the parlance of psychiatry, 'capacity'.

Sometimes, consumer members of committees have enormous problems locating the source of their feeling of powerless, which they might experience as anger or shame. Anger and shame are the product of poorly thought out committees, of inadequate processes in recruiting consumers, of ignorance about the role of consumers on committees, and of ignorance of the impact all these problems can have on consumers.

For many of us, these power arrangements trigger memories of trauma and shame at another time when we were powerless. The combination of anger, shame and memory drives many consumers into silence or loudness, depending on their temperament. Thus prejudice is reinforced, and particular consumers, or consumers in general, are then seen to bring nothing to the committee except angst, over-persistence, too much space, a lack of commitment, irrelevance, or just plain incompetence.

Many committees fail to take responsibility for the havoc they create in the minds of consumers who are trying to improve the world for their peers. This in itself is deplorable, but blaming the consumer for it is unforgivable.

Institutional power

Institutional power has nothing to do with bricks and mortar, or with deinstitutionalisation. Rather, it refers to the fact that certain roles are valued, honoured, deemed knowledgeable and prized not because of the particular individual in the role, or their attitudes or knowledge, but because of the social standing that comes with their social class, professional status, political preference or education.

Institutional power influences all discourses. Some ways of speaking and some categories of voices are privileged by definition, and there is prejudice against others. Institutional power operates regardless of how nice or gentle or obliging the representative of the powerful elite might be. Indeed, those who are the most obliging can actually cause greater confusion and potentially more harm than those non-consumers who are ratbags, as the following case study shows.
**Institutional power: a case study**

Nina taught grade three children. Her class loved her. She was gentle and kind and she gave unconditional regard to all the children.

In her grade was a little boy who was very different from his peers. Some said he had Asperger’s. No one was sure. He loved Nina.

Next door, Alexandra had a grade three class too. She wasn’t liked by staff or children. She constantly yelled, changed her mind, picked on the wrong kid and punished with verbal assaults. There was a young boy in her class who was also different. He was scared of her and hated coming to school.

One day, the principal cancelled a grade three excursion at short notice. Neither teacher was involved in the decision.

Both children were devastated. The child from Alexandra’s classroom bounced back quickly. He was used to disappointment and illogical decision making. The child from Nina’s class, however, did not forgive her. The letdown from such a high standard of care was devastating for the child. Eventually he was lured back to school, but Nina had a hard task getting his trust again.

This case study illustrates the idiosyncrasies of power. Non-consumer committee members who show sensitivity towards consumers and seem to like and welcome us cannot always protect us from those who have power over us, and possibly over them too.

Furthermore, the ‘nice’ people on committees can hurt consumers more than the difficult ones because we are more likely to trust them, only to find out later that they don’t have the power to deliver on what we might believe they have promised.

These sorts of realities should be talked about in a consumer-led education session for all committee members before the committee starts meeting.

**Using power**

Power doesn’t always manifest in the form of a yelling chairperson. Those who wield a lot of institutional power can say little and do so very quietly, but we will still all listen attentively.

Most consumers on most committees do not have the opportunity to win people over in this way because it relies so heavily on status. If we say something softly-softly, the chair may well wriggle in her chair, look towards someone else as if to demonstrate tolerance, and move on to the next agenda item.

There are ways of presenting arguments that can help consumers to get their points home. For example, we can ‘play the game’ by lobbying other delegates, those we perceive as having the ear of the chair, to help us to get our argument up. Often, power has to be fought with power.

The use of power is a game some consumers (and other committee members) enjoy and others hate. Those who hate it might choose not to sit on committees.

What the consumer movement must do, however, is share in the power. As a movement, we must create places where the greatest mix of consumers can be heard by the most important decision-makers in Australia. Committee-sitters need to be instrumental in making this happen.
The solution lies in educating committees. Most influential committees know nothing about issues of power or see them as unimportant. At the same time, many consumers have learnt to play the game and have found ways to be heard. This might win them friends among powerful elites, but it can come at a cost to consumer integrity.

Educating committees about power is essential to committees becoming useful mechanisms for the healthy regeneration of a sometimes destructive mental health sector.
Committee Training

The consumer movement is presently under-resourced to provide all the training that is needed. The psychiatric disability support sector is creating organisation-specific training teams, some of which are consumer specific (such as Voices Vic), and VMIAC provides some basic training, as well as some peer support training.

The training that is described here is brand new – essential, but new.

Educating consumers

One phenomenon we find intriguing is the seemingly unending need to train consumers to sit on committees. The training that tends to be provided is not ‘bad’ knowledge to have; it’s just not the most important learning that needs to take place. Knowing what meeting minutes are might be mildly useful, but knowing who actually controls them is much more important!

Most consumers can read. We encourage committees to publish the concrete, uncomplicated, not-about-power, nitty-gritty information (such as how to keep minutes) in booklet form. The booklet can be handed out to consumers who are interested.

People who don’t speak English as a first language and people with limited literacy also have a right to have a say on committees they believe can benefit from their expertise. Responsibility for enabling this lies with the secretariat.

Many organisations and bureaucracies believe it is consumers themselves who are asking for training in the pragmatic – taking minutes and the like. They believe they are responding to demand. Certainly some consumers will want to practise role-playing or to have their confidence bolstered in some other way to complement the written information in the booklet.

But we should be asking ourselves why consumers are asking for this sort of training. An almost universal legacy of ‘mental illness’ is a loss of confidence, self denigration and, worst of all, profound shame. Many of us don’t believe we can do anything. Of course, if we are uneducated, we are going to freak out at the visible structures and strictures of official meeting protocols. At this stage we ask for training about the mores that frighten us.

We don’t ask for training about the invisible issues of power, institutions, agency and consumer perspective because at that point we often don’t know that this body of knowledge exists, or that these things might be an issue. Training in these invisible aspects of committee work often takes an empathetic outsider, a competent consumer educator, who will help us take the first steps towards empowered membership on ‘other people’s committees' (a term coined by Flick Grey to describe the familiar bureaucratic committee model). This person needs to be someone who will not default to the easy training agenda of meeting procedures and rules of play.

After undertaking training in the issues of power, institutions, agency and consumer perspective, some would-be committee members will decide not to join the committee after all. It’s better not to join a committee than to join one that may cause harm.

Educating Committees

Many consumers who have been offered training to sit on committees believe that in fact it is the committees themselves that should be trained in understanding how committees work from a consumer’s point of view.

Many people don’t understand why consumers should be included on committees. Many secretly think it’s a waste of time, effort or both. Many are confused and often defensive.
Often organisations want to believe they are looking after ‘the most vulnerable people in the community’, and when these vulnerable people start sounding quite smart and challenging them in meetings they are either dismissive or convinced we are intruders of some sort.

There is a vital but rarely met need for consumer-delivered education. We need to teach lay people (non-consumers) about consumer perspective, the use of consumer voice, the role of consumer views, and especially sociological contexts that privilege certain discourses and disadvantage others.

In many cases, lay committee members have no idea what they don’t know in relation to consumer perspective and consumer expertise, and how this lack of knowledge is exhibited on committees. And if laypeople from within the sector need orientation and training in understanding the role of consumers on committees, then people co-opted from business, law, accountancy, social security and other non-aligned areas have an even greater need. The effects of their lack of knowledge are accentuated because they have been invited onto the committee specifically for their skills. Power has this effect.

If we can’t convince the CEO of the need for training, this is another example of institutional power at work. Without proper training, there is a risk that committees will continue to perceive consumers as walking, talking storybooks, with the risk of abuse that this entails.

Secretariats, too, need training from consumers. Without it, it’s only natural that they too will operate in a way that privileges the privileged and silences those with less social capital, particularly when they are bamboozled by the institutional power of other people on the committee.

The educators

Among consumers there are many qualified educators. There are consumers with TAFE qualifications, degrees, higher degrees and many years of practical experience in education.

Educators who have a first-hand understanding of consumer perspective and a strong understanding of the consumer body of knowledge are best placed to help committee members to acquire the skills and insights they need to work effectively with consumers on committees. They are also best placed to provide training to other consumers.

We desperately need to develop a Directory of Consumer Educators in Victoria. Until that happens, here are two important networks that may be able to assist:

- PAT (Psych. Action and Training). This network is convened by Cath Roper, Nurse Educator Academic at the University of Melbourne: http://www.cpn.unimelb.edu.au/trash_local/cath2
- VMIAC (http://www.vmiac.org.au/) lists other consumer educators. Contact Bill Moon.

Resource 1: workshops

Following is an outline of two workshops that can be used to train committees in the material outlined above. These workshops are underpinned by the design and findings of the 1999 report Learning Together: Education and Partnerships in Mental Health by Deakin Human Services Australia (www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-l-learn), and also by the board game Lemon Looming, a learning tool designed by Sara Clarke (www.ourcommunity.com.au/files/OCP/LemonLooning.pdf).
The success of the Learning Together Project taught us a great deal about how the different groups in mental health relate to each other, wield power and attempt to sabotage learning and meeting opportunities if their power base feels threatened. It is on the web and the introduction, at least, should be compulsory reading for these workshops.

This Learning Together Project taught us about the education of mental health clinicians and about deficiencies in their training. It taught us about the competitive relationships different groups of clinicians have with one another. It taught us that some clinical groups were very uncomfortable with group decision-making. Most of all, it taught us about deliberately setting up situations in which consumers can remain in control and deliberately challenge taken-for-granted assumptions about power without having to do or say anything.

The Lemon Looning board game is yet another example of a well-designed teaching tool being timeless. Like Learning Together, the board game is designed to set up situations where people experience powerlessness rather than listen to us talking about it.

They are hard workshops to run but when we pull them off the learning potential is huge. The board games are available at VMIAC but can’t be used without training. Our Consumer Place has staff with expertise in running these workshops effectively.

The workshops are designed to be run by consumer educators and offered to consumers and all other committee members before the committee begins to meet. They are designed to enable consumers to take part in educating committee members about consumer perspective in a way that is honourable, informed, empowered, non-angry (except when necessary), comfortable, non-silenced, non-compliant and non-stereotyped.

The workshops are not meant as ‘education for consumers’. They are designed for consumer educators to educate all sorts of people who sit on ‘other people’s committees’.

Nevertheless, some consumers will resist the offer of this training because they are, they say, already experienced in committee work. Getting through this opposition is important. What many, although not all, consumers in this position mean is that they are experienced at sitting on committees as they are presently understood. The existing model works for some consumers but marginalises, stigmatises and harms others. The risks of the existing model include:

- Painless but ineffective consumer participation;
- Consumers feeling backed into a corner and operating in a way that might be effective but may also cause further prejudice against consumer participation;
- Harm being caused to consumers;
- Fighting between consumers.

The workshops are run by consumers, which in itself conveys the important message that consumers are authorities. In order for the workshops to be successful, the participation of so-called ‘important people’ – the chair, the lawyer, the psychiatrist, and so on – is crucial. Without their participation, there is a risk that the workshops will be preaching mainly to the converted.

**Workshop one (2 hours)**

The purpose of this two-hour workshop is to bring all committee members – including consumers, the secretariat, lawyers, carers, accountants and the chair – together to learn about consumer perspective, consumer research and the consumer body of knowledge.
The workshop is tailored to the particular organisation and the particular committee, but it is not about fitting the consumer into the committee. The purpose is to bring all committee members together to learn all about consumer perspective, consumer research, and the consumer body of knowledge.

Regardless of whether members of the potential committee are consumers, carers, accountants or whoever, we expect them to come. It is imperative that they understand the basics of consumer expertise and consumer body of knowledge and all that this entails.

Content

“Always start where the student is at”

- For senior staff, co-opted members from ‘business’ or ‘other services’, it’s important to start with a style of processing knowledge with which they are familiar. There is an old education adage: start from where people are at.

- Experimental group work may lead to an exodus. The introductory workshop should therefore include a PowerPoint presentation and then questions. We have available from Our Consumer Place some material that can be adapted for a PowerPoint presentation about consumer perspective and the institutions of power.

- The PowerPoint does not have to be too complicated. Most people won’t have a clue about the consumer body of knowledge. Indeed, most won’t have a clue about the key sociological concepts that fit most tightly with our way of organising our knowledge, theory and research.

Workshop two (2 hours)

This interactive workshop must be tailored to the organisation and the particular committee but it will NOT be about fitting the consumer into the committee. Hopefully it will allow all participants to work towards an interactive way that people can speak respectfully to each other and also give people opportunities to feel uncomfortable and work through it, provided consumers are protected.

Opportunities to push the professionals to speak from the personal and consumers to speak from a professional narrative will be explored.

For non-consumers who miss this education session pressure may later be applied. It’s very important to create a safe committee for everyone. It’s also important that there is an expectation that this is important information. Consumers will rarely be able to do this promotion on their own.

Content

In the first stage of the workshop, the aim is to metaphorically ‘undress’ each member of the committee. That is, everyone, including consumers, takes off their shells of armour. This doesn’t mean in any way delving into people’s private lives. It means, for example, “I will get rid of my identity as a ‘nutcase’ – just for the moment – and put it aside.” Or, “I will get rid of my degree just for now.” Or, “I’ll get rid of my status as a CEO.” Or, “I’ll stop thinking of myself as a can-do person.” Or, “I’ll get rid of my characterisation of myself as a can’t-do person.”

The aim is to remove the social barriers we create to protect ourselves, understanding that this often occurs at the expense of others whose status in society is lower.
The process makes everyone potentially vulnerable, and that’s the point. It’s important because we need to find a point of equality. For some people, this will be their first insight into being vulnerable. This can lead to a better understanding of the powerlessness, the dignity and sometimes the sheer emotional strength of active consumers. It’s fine for people to think they are helping the ‘most vulnerable’. It’s a very different thing to feel vulnerable.

Some people will hate this. Who likes going to a workshop that involves role play? But it is only through metaphoric nakedness that we can build the sort of committee we need: a committee that is not characterised by elitism, power, control, privilege, and a consumer tacked on to the end as a token.

In the second stage of this workshop, committee members metaphorically re-dress themselves in different clothing. People get a chance to redefine themselves in front of the rest of the committee. People also get a chance to replace a piece of their original clothing, but only if they have a strong rationale in the context of the committee. Consumers can highlight the many attributes they bring to committees that go unheard, vilified or abandoned.

Participants are encouraged to ask themselves: What does this committee need from me? What unintended consequences does my membership of this committee have for the consumer? Who are we when we take off the garlands of class, privilege, health, education, profession and so on? This is a question that often troubles people with a psychiatric diagnosis. The aim of the workshop is to enable laypeople to gain insights into the same question.

Resource 2: MBTI

The Myers-Briggs Type Indicator (MBTI), a tool designed to help people to make use of the theory of psychological types described by Carl Jung, can be useful in committee education as an aid to understanding our own temperament, and the temperament of others on the committee.

MBTI gives committee members a way of understanding each other that is not based on power, status, occupation or qualifications. Even if a committee is working well, it is useful for members to see each other as people aiming, in different ways, for similar goals. Suddenly someone we think of as disorganised and sloppy is recognised as the person who really did save the committee and keep it on track after the big fight over the distribution of discretionary funds. Suddenly the painful accountant who delves into petty details is understood to be all that the committee has to protect itself from major fiscal mistakes. The consumer too may be seen in another light completely.

More information on MBTI is easily found online. The MBTI tool itself is also available online, for a fee (see www.myersbriggs.org/my-mbti-personality-type/take-the-mbti-instrument/).

Many other useful instruments for understanding ourselves and working better with people of different temperaments in a meeting context are available online too. They all serve as reminders that while social and political influences are at play on committees, psychological factors are at work too.
The Collaborative Committee Model

Introduction

The idea of a non-decision-making committee came out of the “Understanding & Involvement” Project, which was a consumer evaluation of acute hospital practice. The committee’s creation was organic, that is, it came out of the process of responding to a need identified by committee members.

The most interesting and educative part of this is that if the project team had not been so assertive in demanding Royal Park Hospital consent to a consumer perspective steering mechanism, this committee could easily have turned out just like any other committee.

The Steering Committee

As a consumer-run project, the team put in place mechanisms to try to make sure the consumer voice was loud. Most of these mechanisms worked well. They included:

• **Divining for those with energy.** An argument was made that efforts to artificially construct a committee mostly don’t work. Hand picking one indigenous person, one person with schizophrenia, one person from a culturally and linguistically diverse background, etc. would flop. It would be an artificial construct and its very artificiality may be its downfall.

• This was crucial because there was (and is) a timidity about saying that we don’t want one of each minority we can find. For this committee, and for many successful committees after, we knew we were not looking for multiple affiliations but rather for enough of a pulse to make a substantial difference. Sometimes this pulse is a flame put out by an over-preoccupation with diversity. Instead we used a metaphorical divining rod to feel where the energy was amongst consumers. Who was vitally interested in what we were trying to do?

• **Hand picking supportive staff:** This was a similar principle as divining. Consumers involved with the project argued that there was no point in using up precious energy arguing the case for the project with staff who were not committed. The project had been funded and it had the agreement of senior staff – the proving of its worth phase was over. Rather, the committee wanted to engage with the most supportive clinicians available and their role would be different. The team need allies.

• **Critical Mass:** The project team made sure that there was a ‘critical mass’ of consumers. This meant that there needed to be the same (or more) consumers on the committee than all the other members of the committee who weren’t consumers. For consumers to be heard, critical mass is imperative.

It was good but not good enough: Why the Steering Committee didn’t Work

Although the Steering Committee was carefully constructed and led by consumer expertise, it was limited by its structure. These limitations were retarding the capacity of the committee to generate much-needed new thinking.

Committees need to be both a maker of decisions and a crucible for new ideas and thinking. Steering Committee structures, by their very nature, enhance the decision-making function but often at the expense of lateral thought and vision.
The problem with this dual responsibility is that the two tasks often pull the committee in different directions, particularly when consumers who have been starved of opportunities to speak their mind are involved.

Below are the specific problems we found with our steering committee, but they are typical:

1. Just as the committee finds time for its secondary role as a think tank the chair would find the need to press on to conclude the meeting on time. This was unsatisfactory for everyone.
2. Note taking took a person out of important discussions for little return. Minutes felt both insufficient and too much.
3. Members said they didn’t find this way of making decisions very useful. This went back to the concept of ‘divining for energy’. Members unanimously believed that the energy was leaching and leaking. There were much more important things to do than sit on committees that made little sense to anyone. Everyone wanted to engage the crucible part and damn the decision-making!

“We’d just get to the part where the most important subjects, the most important ideas, were starting to shyly come to the fore when the chair felt impelled to bring the committee to order and readress the agenda. Everything was lost.”
paraphrased from Yoland Wadsworth U&I 1999

The Collaborative Committee

Surprisingly the U&I Project team solved the problem of the Steering Committee by making it a major part of the evaluation. This was clever:

- It was called a non-decision-making committee, thus taking the emphasis off debating and decision-making and on to talking and listening;
- The time dedicated to the committee increased from one hour to two hours once a month;
- The role of the chair was rotated and shared equally by consumers and lay people;
- The discussion was taped and transcribed;
- Notes went back to all committee members who now had a vested interest in checking what they had said and making sure that what they uttered on the day truly reflected what they wanted to say.
- The transcripts then gave the consumer researchers a good idea of what committee members wanted for the future;
- What was created was a vital, inquiring, inter-subjective conversation where members were truly listening rather than switching off and just practicing what they personally wanted to say next, which is the way of most people in standard Steering Committees behave.

Deep Dialogue

As the project developed, the idea of the Collaborative Committee grew in strength and favour. People wanted more. The Deep Dialogue component grew out of the Collaborative Committee.
Deep Dialogue became a major initiative of the U&I project. This was a way of structuring talking and listening, not plotting and talking over people or jockeying for power. It was necessary to control the environment to allow consumers and clinicians to speak without fear. It also allowed and encouraged emotion, recognising that to try and remove emotion would shut people down and yet again silence them. It was about asking questions rather than knowing answers. It was about talking about things that interested one person and then listening with great care to another point of view. Deep Dialogue committees have grown out of the original project at Royal Park Hospital.

It is hard. Really listening is hard. Nonetheless it is one of the most interesting and progressive ideas to have developed around the challenge of bringing people with very different amounts of institutional power, very different agendas, very different ways of speaking their truth, and very different levels of tolerance of difference together to respectfully exchange ideas and new ways of being together. It also puts forward the idea that as much effort needs to go into the crucible role of any committee as is put into its decision-making agenda.

Some Questions

1. Have you ever sat on a committee where you were frustrated by a lack of opportunity to really talk about the issue under discussion? What did you do?

2. Have you ever felt sidelined on a committee or been offhandedly told the committee is not the right place to bring up the issue that is important to you? What feelings do you have associated with this?

3. Sometimes consumers say that even though there are many people on a committee they feel alone. What is the dynamic behind this? Is it better to fight or to leave?

4. Do you find yourself tuning out during a committee and just waiting for the item number where you have lined up something you want to say? What happens if everyone is doing this?

5. Do you feel your expertise is truly respected? How do you know?

6. Do you sometimes feel committees are shallow and decisions are being made on the run? How do you slow them down?

7. Do you think you have ever experienced true ‘deep dialogue’ on a committee you have sat on as a consumer?

8. What is the ‘Tyranny of Agenda’? What can we do about it?

9. Would you describe most/any committees you presently sit on truly collaborative?

10. It is said ordinary committees suit some sort of consumers and collaborative committees suit another sort altogether. What do you reckon?

Conclusion

The following resources may be useful to help people understand the concepts behind collaborative committees:

1. Yoland Wadsworth and Merinda Epstein 1998 Building in Dialogue Between Consumers and Staff in Acute mental Health Services, Systemic Practice and Action Research, Vol. 11, No.4, 1998
   http://www.rmit.edu.au/browse;ID=fbk82b5yv4s;STATUS=A;SECTION=2;PAGE_AUTHOR=Yee%20Man%20Loie

3. See Fran Peavey, ‘Strategic Questioning’
The Role of the Secretariat

Most committees in the mental health sector have a secretariat: an administrative arm responsible for tasks such as preparing agendas and correspondence, and providing background briefing notes and advice to committee members.

To many of us, the job description of a secretariat staff member might appear pretty boring: photocopying, preparing sets of reading material, booking flights and rooms, making sure taxi vouchers are sent on time, and keeping minutes. The secretariat staff may also have the task of liaising with committee members, especially the chair, between meetings.

Small committees might have just one person responsible for all these tasks; a large national committee might have a staff of dozens of people.

The secretariat’s job is partly invisible to committee members, and this is how it is supposed to be, but some committees abuse the secretariat by imposing tasks that go beyond their role. Problems can arise when there is disunity on a committee and its members are trying, for example, to ‘out-science’ each other or produce more material to support their arguments than anyone else. In this case, the secretariat can spend a huge amount of time reproducing material that has more to do with the politics of the committee and the egos of particular members than it does with making good decisions.

The secretariat consists of people with jobs to do; they are not servants to those who make the loudest demands. To prevent this problem, sometimes committee members will be asked to channel their requests to the secretariat through the chair.

Often, some people on the committee have better access to the secretariat than others, even if this is simply a product of some consumers having neither the confidence nor the knowledge and belief in the consumer body of knowledge to be as pushy as clinicians or academics. Differences in personal style can also contribute to inequality of access.

Many of us believe that often there is significantly more dialogue between the secretariat and powerful committee members (this includes some consumers) than there is between the secretariat and those who are ‘sector nobodies’. Sector nobodies might include grassroots ‘carers’ or staff from the non-government sector, as well as consumers. However, this might just be a result of clever engagement by those with good skills – not everything is a vendetta against consumers! It rings true that the chair would make contact more regularly with people who are perceived to have ‘influence’.

It also makes sense, even if it’s unfair, that the secretariat would follow the chair’s lead. And of course let’s not forget that some of the bigwigs with large amounts of power are consumers.

Neutral or partisan?

Most secretariat staff strive for neutrality, but they are as caught up in the institutions of power in our culture as committee members are. Usually, secretariat staff are better able to understand and metaphorically hear a familiar discourse than an unfamiliar discourse. This is not neutrality.

For example, the way a bureaucrat hears the proceedings of a committee meeting is inevitably informed by the inter-subjectivity in his or her head about how the committee works.
Therefore we need to scrutinise the minutes with care. Sometimes the damage is done before we have an opportunity to correct a major exclusion or mistaken interpretation. When consumers, correctly, try to right the wrong out of context at the next meeting, non-consumer members might be niggly. They are niggly because we are taking up time, and, to them, our important issues may seem petty. Their power and influence is being tested even though this was not our intention at all.

A secretariat, like any bureaucracy, is made up of different people with different backgrounds, qualifications, political beliefs, attitudes towards power and powerlessness, more or less seniority within the bureaucracy, and more or less support for the idea of consumers as major players in the committee the secretariat services.

Bureaucracies in the health sector tend to be home to many people who have backgrounds as clinicians. This is a major problem for some because they can set themselves up as experts in all things mental health when they often have no, or little, understanding of consumer practice. A little knowledge can certainly be a bad thing.

All secretariat staff who serve consumers need training from consumers for the same reasons committee members need training (see the information sheet Committee Training for more on this).

**Committee rules and mores**

All sorts of mores accompany committees. These can be seen to protect those with pre-ordained power, because they maintain the conventional power base.

Mores can be brought to bear when a consumer starts to rock the boat in committee negotiations, or when a consumer fails to understand a committee regulation. In this situation the consumer can be made to feel they’ve made a fool of themselves, an attitude which is unfair but nonetheless painful.

The role of the secretariat in these matters is crucial. Nothing is neutral or impartial if the committee members have different understandings of the rules and mores of the committee. Secretariats need to develop written guidelines rather than make assumptions about shared knowledge. The guidelines should be short, illustrative, written in plain English and never patronising.

For example, guidelines might cover how committee material is distributed to members. For a consumer member who doesn’t own a computer or a printer, or can’t afford paper, this is important. Many senior academics and clinicians have a personal assistant as well as time at work to read, while many consumers have neither. Without written guidelines, complaining is more difficult and more risky: we are likely to be accused of being picky, or we might feel a need to ask for special favours. Both scenarios reinforce values we are trying to eradicate.

**Confidentiality**

Many consumers mistrust the term ‘confidential’. This mistrust comes from our dealings with services that regularly abuse this term. Many people have been hurt through believing our life stories were being held in trust when they were not.

It is therefore not surprising that many consumers distrust this term when it is used in relation to the secretariat. The secretariat needs to provide details of the committee’s policy on confidentiality in the terms of reference, which means outlining:

- Whether the committee is closed or open. Are proceedings confidential among committee members, or are they open to public scrutiny? The issue of ‘confidentiality or not’ can be vital to consumers but it tends to be unimportant to other members of the committee.
• What mechanisms are available to consumers on closed committees if they find themselves up against the wall, not being listened to, or having their knowledge sabotaged? The secretariat and the chair are responsible for ensuring that committee members are safe.

• The process to be followed if a consumer, or any other committee member, falls foul of the chair. This is not the role of the secretariat under normal circumstances, but what happens if the circumstances are abnormal?
Using Story on Committees

Using story – also referred to as narrative, or story-telling; in other words, stories based on lived experience – is one of the main features of the discourse of many oppressed groups, including people diagnosed with a mental illness.

Consumer discourse differs from medical discourse, bureaucratic discourse, research discourse, clinical discourse, management discourse and even carer discourse. These differences are fundamental to the ways different groups communicate, both inside their own group and outside.


On committees, various discourses confront each other and often vie for space, prominence and authority. Some discourses have more institutional power than others, consumer discourse tends to have the least power of all, and most committees have disproportionately few consumers. This combination of factors means that using narrative is not only an art but a minority art. We have to learn to use this tool exceptionally well if our message is going to stick.

Nevertheless, many consumers believe we have an ethical obligation to use story in committee deliberations, especially the more important ones. And some of us believe committees would benefit if other (non-consumer) committee members used story too. Overseas studies have shown that it changes the way decisions are made, and it changes the level of comfort for everyone on the committee. It means narrative is seen as more acceptable, even essential, by many on the committee who would otherwise not ‘get it’.

Narrative discourse plays a very important role in highlighting the effect that committees’ decisions have on real people. It doesn’t mean the story needs to be about a real person using services provided by the organisation that engages and funds the committee; far from it. Narrative holds a different way of thinking, a different philosophy about what counts as knowledge.

Unfortunately, many consumers have experienced working on committees that are ignorant about the use of story. For example, other members have a tendency to use ‘story time’ to read something else very overtly, or they take over and patronise consumers. Chairs have a big responsibility here, and they do not always live up to it. They might prefix consumer stories with comments such as "make it short now" or "not too long". (They never say this to other committee members.)

Attitudes such as this also underpin the idea that consumers need to be educated in meeting procedures and meeting etiquette, when we would argue that it is the committee that needs to be educated. Most committee members will be unaware that there is a problem; that consumer discourse is being inhibited by competing discourses.

There are ways we can learn to use story wisely – and not all the time and not too long and... There is a need for training here. (In fact, we'd argue that training in using story well is much more useful than training in how to take minutes or how a committee is structured.) Story envelops messages that privileged groups might otherwise misinterpret, redraft, overlook or just fail to understand.
When to use story

We all have a variety of ways of communicating with other committee members: story is just one of them. Different subject matter offers opportunities to communicate in different ways. Story, however, attracts attention because:

- Narrative is unusual in a committee context, and some committee members experience a wave of fear because they don’t ‘get it’. These people are often important or powerful, and they are accustomed to ‘getting it’. Not understanding sometimes causes powerful people to transfer their fear back onto the story-telling consumer. In doing so, they might describe our chosen discourse as ‘inappropriate’ rather than examining why they are feeling uncomfortable. (The term ‘inappropriate’ is used often in psychiatry, and it pushes our buttons because it begs the question of who decides what is and isn’t ‘appropriate’ – very rarely us!)

- Story is about emotions. There is debate within the mental health sector about whether emotions should or should not be part of meeting protocol.

Whether you choose to use story in your committee work may depend on the type of committee you are sitting on. Generally, story is tolerated better on local committees than on state or national committees. However, paradoxically, it might be these high-level committees that most need to learn from it.

We do, however, need to be judicious in how many stories we tell, and very tight in the telling.

Using story effectively

We must take responsibility for the way we use narrative. If a consumer yells a narrative account at other committee members, all this shows is that the consumer involved is rude and that using narrative is unattractive.

How can we use story effectively when we are outnumbered by people representing alternative (but not better or more important) discourses? It’s hard. In order to be confident and competent about using narrative on a particular committee, first consider asking for some time, perhaps 20 minutes at one meeting, to educate committee members about its use. Explain why using narrative is important, tell a short story (don’t let anyone call it an anecdote, because this belies the importance of the narrative), and then join the story to social or educational theory. This demonstrates that you are passionate and can put forward an intelligible argument to explain your story.

Most committee members will need step-by-step help in understanding. Take nothing for granted. Make absolutely sure the chair knows exactly what you are going to do before the meeting. If people feel they have been misled more trouble will arise.

Using narrative doesn’t come naturally to all of us. Some of us can be very long-winded. Some of us use narrative that goes nowhere; i.e. that doesn’t envelop a message. Following are some key skills that we can learn to help us become better users of narrative.

- Use a story only if it enhances your argument.

- Keep it short; practise this skill with other consumers if you get a chance. As a general rule, telling a story on a state or national committee shouldn’t take much longer than five minutes.

- Try to keep your passion controlled. Passion is inevitable when we believe strongly in something, but uncontrolled passion can camouflage your message. Some committee members will just switch off. Try not to feed their need for you to react to their stereotyping of you as your diagnosis. Stay calm even if you are infuriated by this. People rarely take responsibility for their own part in how all this gets played out in a meeting, but all we can do is stay strong inside ourselves.
• Consider what is useful and what is less useful in using narrative. This is best done in a training exercise with an experienced consumer team.

• A story needn’t be about your own experiences of using particular services. Sometimes, a story comes from an experience as an observer (see the case study following for an example).

• Your narrative must be short but it still needs structure: a beginning, substance, and a conclusion, including ideas for change.

• Don’t use props, such as PowerPoint, just for the sake of it. You might use them if you believe they’ll make you look more professional, but it’s an individual call. Sometimes narrative just arises in the meeting and you will have nothing written down, no PowerPoint, just you and your story.

• If your story relates to an item held over from the last meeting, have it placed on the agenda and be firm about it. The very worst time to try to make narrative work is during ‘other business’, when people are itching to leave or to share food and drinks. If the chair is resistant, enlist someone else to help you lobby. If this doesn’t work, you might have to introduce the item during the meeting.

• Think about what you are going to do if a chair cuts you off before you have started to speak. Consider whether you would want to complain to whomever the chair reports to.

• If there are committee members participating in the meeting by phone link-up, they won’t be able to see your hands or body language. In this case, be especially mindful of your voice: your tone, volume, modulation, and all the other ways you can tell a story when you can’t be seen.

• Sum up your story. What do you want the committee to do? How do you suggest they should do it? Who would you like to see execute this if the rest of the committee agrees to your suggestion?

**Dealing with resistance**

You might have to tell your story while people lean back on their chairs, fold their hands, read another document, look away from you, or even get up and leave the room. This is rude. It’s also what people do if they are unconvinced of the value of something, believe something is a waste of time by virtue of the fact that you are a consumer, or feel embarrassed for you. When this happens, try one of the following strategies:

• Stop. Don’t say anything, and wait for people to be embarrassed.

• Pose a question.

• Say something like, "We’ll do this next meeting when people are ready." You have to be brave to do this. They’ll probably blame your diagnosis. They probably won’t see themselves as the problem that they are.

• Continue on regardless, and try not to let others’ cynicism interrupt the cadence of your narrative. Perhaps ask some searching questions later that will make the rest of the committee think a bit.

• Comment on the lack of respect being shown towards you. Maybe pull individual members up. Then go on. (Before you choose this option, reflect on whether you have ever been guilty of showing this sort of dismissive body language to others.)
Problems and Politics
Within the Consumer Movement

Within the consumer community, many regard the process of committee appointments as idiosyncratic, undemocratic, pretend-democratic, highly insular, conservative, single-issue-focused or otherwise problematic.

This is not to say that people appointed to committees aren’t worthy or don’t do a good job or don’t get exhausted or aren’t furious with the rest of us sometimes when we don’t support the hard work they are doing on our behalf. The work is not always easy, and the people who do it need our support and encouragement and thanks. Nonetheless, the work needs to be scrutinised too.

Committee-sitting consumers

One characteristic of the consumer movement over the past 20 years has been our inability to recognise when another person’s expertise, ability or knowledge is greater than our own in a particular field. When this is the case, we need to handball committee work to the best person for the job, knowing that this will benefit all consumers.

This is one of the consumer movement’s challenges. We need to avoid a situation where some consumers seem to collect committees like trophies, regardless of their skills or knowledge in one field or another.

Interestingly, the phenomenon of committee-sitting consumers has characterised other social reform movements as well: indigenous groups, culturally and linguistically diverse communities and the women’s movement, to name a few. In the 1960s, for example, the women’s movement split over accusations that everything was being organised by white, middle-class, well-educated, professional women. A new politics arose to enable disempowered women to be heard.

It can be disconcerting when a small group of consumers are constantly asked to ‘represent’ us when we have no guarantee that these people understand the fundamentals of prejudice, oppression or critical theory, or what it means to be playing particular influential social roles. Do committee-sitting consumers care that ‘representation’ and even ‘consultation’ are concepts consumers are starting to mistrust and discredit? Do they understand the difference between ‘consumer perspective’ and ‘consumer views’? Certainly some have not experienced poverty, powerlessness or the power of the state.

Grassroots versus elites

We identify as a grassroots movement, but we have long been, and continue to be, haunted by accusations of elitism.

Too often, we yell at each other in frustration rather than yelling at the system. When we have limited institutional power, it sometimes feels too hard to critique the professor or the chair of a committee, so we tend to let rip at our peers instead. This is understandable but not helpful. The problem is made worse by lay people’s interference in our debate.

Of course there are many things we disagree about. It would be very strange if we didn’t. But when people accuse others of elitism, defining ‘elitist’ as anyone with an intellect or education, and ‘grassroots’ as anyone with schizophrenia, we undermine ourselves. This sort of debate negates our own ambition to stop the government, the sector and services of all kinds from dividing people up in these ways.
Then there are influential consumers who don’t come anywhere near ‘the movement’. (For an overview of this issue, see Neami’s Consumer Participation and Leadership Report at www.ourcommunity.com.au/files/OCP/ConsumerParticipationAndLeadershipReport2010.pdf.) What do we do about them? This is one of the big issues the consumer movement faces.

Abjection

Abjection refers to the real nitty-gritty of being marginalised by our diagnosis, to the part of us that is disgusting to others (and maybe to ourselves): overt ‘madness’, drooling, shakiness, smelliness, farting. By its very nature, abjection disturbs order, rejects neat and tidy, rejects systems, borders, positions and rules. In contrast, committees are most often all about order, decorum, rules (both known and unknown), systems and systemic knowledge.

Consumers on committees may have abject parts, but we tie these up with a ‘madness chastity belt’ when we perform on committees. Those of us who deny our abject selves deny the abject in all consumers. We subscribe to the hidden code within the consumer movement that the abject belong 'over there' and 'we' belong on committees. This is both understandable and undesirable.

Stigmaphobia

Consumer academic Flick Grey uses the term ‘stigmaphobia’ to describe the reason why marginalised groups scramble for acceptance by casting others as even more marginalised; or the way people with a marginalised diagnosis cut off their ties with an even more marginalised diagnosis to climb the acceptability ladder. (See www.ourcommunity.com.au/files/OCP/PositiveThinkingAboutConsumers.docx.)

The case study below is a good example of one group of people with a disability trying to fight for acceptance and social justice by disallowing the integrity of another oppressed group. We must fight together to rid mental health, and especially consumer interest groups, of infighting for legitimacy through committee structures.

Stigmaphobia: a case study

I was lecturing students in a first-year course in community development. I wanted the course to be practical, so I invited a procession of grassroots social change organisations to come and talk to the students.

In week three, two men came from a group working with people with an intellectual disability. They started their talk by saying to the students, "We just want to make sure you know we have intellectual disabilities. We’re not psychos or anything like that."

The following week, two men from an organisation for people with psychiatric disabilities came along, and they started their talk by saying, "Don’t think we’re dumb. Dumb is stupid. We’re not stupid; we have challenges with our brain chemistry. Most of us are very bright."
Other moral and ethical issues

Consumers everywhere want acknowledgement, and this has several major implications for committees.

First, it makes some experienced consumers unwilling to leave a dysfunctional committee to make a point about bad process, because they would be leaving behind the recognition that committee membership provides. Furthermore, they know that leaving the committee might only pathologise them further in the eyes of the establishment. Sometimes, however, there is no other way to make the point that a committee is not as it needs to be.

The unfortunate reality at this time is that if an experienced consumer leaves a committee because of real and substantial problems with governance or bullying, for example, it typically takes less than a week for another consumer to jump into the void.

This leads to inexperienced consumers being thrown in at the deep end where there is little likelihood that they will support an ethical position taken by their predecessor. Their first experience of power may affect them in such a way that they forget they are a consumer.

Consumers as employees

Historically, few consumers worked within ‘the system’. Indeed, few worked, full stop. Most activists were on disability pensions and many still are.

Over the past decade, however, and particularly the past five years, more and more consumers have been employed in the psychiatric disability rehabilitation and support (PDRS) sector and in clinical services. At first glance, this is wonderful. However, it has led to some changes in the way consumers on committees are conceived.

Some employed consumers sit on many committees linked to their employment. As a result, some find that committee work fills up their time and isn’t productive, and they become jolly sick of it. At the same time, these consumers are bringing the same views to committees over and over again. Of course, the organisation is saving money because they already pay the consumers as staff.

There is a political imperative to have consumers looking and sounding as though they need the service being provided. If this is not the case, the service provider has a public image problem. So local and ‘less important’ committees spend a great deal of energy trying to interest consumers (who are often not interested) in sitting on them. These consumers may spend an inordinate amount of time with the organisation’s PR people creating illusions of inclusiveness, not only through committee structures but also through public storytelling. Consumers need to challenge this.

A way forward: deep dialogue

‘Deep dialogue’ refers to a particular way of structuring talking and listening. It is intended to enable deep conversations between consumers and service providers. For an outline and examples, see www.ourcommunity.com.au/files/OCP/DeepDialogue.pdf, and also the information sheet The Collaborative Committee Model.

What is needed within the consumer movement, perhaps, is deep dialogue about how we do our work, how we appreciate others, how we critique, how we manage the workload and how we manage the power.

The problem with deep dialogue is that the process of deep listening and theorising entails allowing decisions and debate to hang in the air. It’s hard. In contrast, most committees are defined by the imperatives of debate and decision-making.
The consumers who are committed to, intrigued by or adept at deep dialogue are a different group of consumers from those who get pleasure from the rough-and-tumble of standard committees, with different politics, skills and temperaments. Bringing these two different groups of consumers together respectfully using deep dialogue would be helpful in building our understanding of our place in committees.

The risks of undertaking this process include the possibility that that some might not see it as important enough to attend, and that it might trigger another period of mud-slinging between consumers locked into their opposing positions.

**Self-examining questions**

**For consumers:**

- How would you know if you were sitting on too many local, state or national committees? What feedback would convince you? What would you do about it?

- What does ‘representation’ mean to you? What are the problems with the concept, and what can you do about it in your committee work?

- You are a consumer on a committee. You are worried about the lay committee members’ tolerance of another consumer member, one who is emotional and uses story, and who is uncommitted to ‘science’, ‘professional authority’ and ‘professionalism’ (as defined by the committee). What will you do? What does this say about you and your role?

- You are on a committee with several consumers who are famous or have social status, obvious wealth or a high-flying career. You know they are paternalistic and even find the word ‘peer’ uncomfortable. They feel proud to help ‘poor other’ consumers. What do you do?

- The organisation where you are employed as a consumer wants to co-opt a famous singer to sit on an influential committee as a consumer. They refuse to use the term ‘consumer’, and you know they know nothing about consumer politics, other consumers’ views or the consumer movement. What will you do?

**For organisations with consumers on committees:**

- What might your organisation do if the consumer you interview for a position on an important committee is bright, intelligent, amenable and ‘not political’ and has a good track record but can’t answer questions about consumer perspective, power, the consumer movement or the consumer body of knowledge?

- Your organisation has a committee that needs consumer advice in the field of culturally and linguistically diverse mental health. The only consumers available to work on the committee appear to have a very limited understanding of concepts such as social power, personal agency, institutional practice, consumer perspective and consumer values. How do you balance your need to understand the voice of the minority group with your need to understand the voice of the consumer movement?

- You are under pressure to second a consumer employed in your organisations onto several committees. Is this person in a privileged position? Is the person in a compromised position? What are the effects of this?

- What is the difference between a ‘collaborative committee’ and a mainstream decision-making committee? What are the benefits and drawbacks of each type? How would you set up a collaborative committee?
• What are the advantages and disadvantages of going to a consumer organisation to ask for a delegate to a committee within your organisation?

**Interesting Reading**: *Positive Thinking about Consumers* by Flick Grey:
http://www.ourconsumerplace.com.au/resources#recent
Template: Committee Agreement

This document is designed for use by chairs and members (including consumer members) of decision-making committees in mental health. It can be used as-is or adapted to suit the needs of a particular committee.

Underlying this document is the assumption that members of committees that seek to involve consumers must learn how to do so with knowledge, humility and respect.

Ideally, the use of this document should be approved before any committee members are recruited. Selling it to a committee that has already been established can be difficult. Ideally it will be accompanied by consumer-run training designed to educate committees in working with consumers.

As a member of this committee:

I welcome the presence of consumers on this committee. I will demonstrate this in my support for the important role they play, and in my respect for the soundness of their judgement, their skills and their right to be decision-makers.

I understand and will promote the fact that no consumer can be the ‘right consumer’ for every issue. I will support the consumers on the committee in areas in which I have specialist expertise.

I acknowledge that consumer committee members are the experts in the consumer body of knowledge, a body of knowledge which must influence all deliberations of this committee.

I understand and respect the sociological concepts of agency, powerlessness, class, gender and race and the effect these have on all committee interactions. I acknowledge the power that may have been bestowed on me by privilege, class and education.

I understand that institutional power is often invisible, and that silencing consumers can be done in the nicest and most congenial of ways. If consumers display anger at being silenced, I will try not to see this anger as part of their ‘mental illness’ or as a result of their lack of committee skills, or as ‘just behavioural’. I will not use the language of the ‘medical model’ to describe or judge any committee member.

I respect the imperative to listen to consumers. I respect their use of narrative when it’s the best way to communicate essential intelligence to committee members. This is the way of oppressed groups and should be respected. I will listen with attention, respect and an assumption that something important is being shared.

I understand the need for consumer members to hold some meetings in consumer-friendly places rather than places that reinforce the power of the already powerful.

I accept that the nearest to best-practice model we have in health is the model of inclusion of indigenous people in health decision-making. I undertake to recognise that consumers wish to receive the same respect for their knowledge, heritage, and multigenerational pain, suffering and shame as many indigenous people.

I accept that no matter what my background is, and no matter who I do or do not represent, all committees have hierarchies of power and insiders and outsiders. I understand that consumers are more likely than other committee members to inhabit a place in the committee which leaves them sounding shrill or silences them. I recognise that it is incumbent on committee members to examine what they themselves are doing that may be causing this to happen.
I understand that consumers vary in their politics, their emotional commitment, the areas that are most important to them, the amount of time they have available, the resources they have and the degree to which they can or can’t abandon consumer ethical codes as part of a bargaining plea with other committee members. I respect these differences and will try not to stand as arbiter of any consumer’s passion, style or authority of diagnosis.

I acknowledge that the consumer movement is developing its own body of knowledge and its own code of ethics. I am familiar with the work that is going into these². I support the consumer members of this committee as experts in their field. I expect consumers on the committee to be moral and ethical but not necessarily professional.

I recognise that consumers and carers are not the same group. I understand that treating them as one is unacceptable to many consumers. I recognise that both perspectives need a presence on most committees. I understand that there are many people who are both carers and consumers but that the vital issue is perspective. I understand that people identifying only as carers are not able to talk as consumers and vice versa. I understand that it is not okay to use the collective phrase ‘consumers and their carers’ in documents produced by the committee or in deliberations.

If I am a consumer or carer, I agree to identify myself as such, even if I am appointed to the committee as a lawyer, an accountant, an academic, a retired businessperson, a community member or anything else. I understand that this information will be kept confidential within the committee if needed. I understand that I have a responsibility to other committee members and to the decision-making process to acknowledge my multiple ‘hats’.

Signature: ______________________________
Date: ______________________________

² For information about development in the consumer body of knowledge contact PAT (Psych. Action and Training) through Cath Roper, Centre for Psychiatric Nursing, University of Melbourne
So you’ve been asked to sit on a committee

So you’ve been asked to sit on a committee as a consumer. Don’t be grateful – be informed!

‘Representation’ is one of the lowest rungs on the participation ladder. If all you ever did on a committee was to repeatedly make this point and advocate for additional mechanisms and genuine power-sharing partnerships with consumers, this would be a great deal.

Nevertheless, here are some questions you should ask yourself and others before you agree to take on committee work.

• It can be flattering being asked to be on a committee. Before it goes to your head, do some background checking. Are there others who went before you? What do they say about their involvement? Are there other consumers in the organisation or service whom you should get to know, so that the left hand knows what the right hand is doing?

• What’s your expertise? Ask yourself: am I the right person for this role? For example, if the committee’s focus is homeless services, or youth, or education, do you have this expertise? If you don’t, who might? Handballing to the best person for the role is the right thing to do.

• Why is the committee seeking consumer representation? It’s useful to know what their expectations are, and whether these are reasonable. You may even want to get this down in writing. If you’re happy with the answer, make sure the whole committee is briefed. This may help to stop some of the ‘drift’ in what people might ask you to do and help remind others of what your role and boundaries are.

• What are your entitlements? You should be entitled to:
  o Sitting fees, reimbursement of expenses, and paid reading time;
  o Resources for connecting with other consumers (e.g. transport, administrative support, computer, printer and telephone access);
  o Other resources you identify as important for your participation (e.g. orientation, training, peer support, peer supervision).

• How else will the organisation support you in your role? Nobody can faithfully ‘represent’ all consumers of a service. However, it is reasonable to make the case for forming an advisory group of service users who are properly resourced, who will support you, and to whom the organisation is accountable. Watch out if you are told you are just one of many stakeholders. This is called the tyranny of equality. If the consumer’s point of view is not going to be privileged, there is a risk of wrong things being allowed to happen on your watch. This is not your fault, but it may mean being exposed to the frustrations of the people you are trying to ‘represent’.
Ebony and Georgina³: The story of two consumers on a committee

EBONY

Background

Ebony arrived late on the consumer scene. She came with a significant skill base that she had developed sitting on boards and committees in the private sector. Although only recently involved with other people diagnosed with ‘mental illness’ she had much to contribute from her successful business career.

Mission

Ebony is devoted to people who have been silenced because of the bad feelings associated with a particular diagnosis. She is determined to improve and increase the medical services available in both the public and private sectors. Her mission is to find ways to promote this diagnosis in the community and rebrand it so the community will understand it better and stop stigmatising people. She is driven to prove this diagnosis as a genuine mental illness.

Go-getter

Ebony has a can-do personality. She has well-developed skills in working with politicians and winning them over. She highly values these skills. It enables her to get things achieved without unnecessary bureaucratic delays. She knows she can match it with the most senior politicians, academics and some clinicians.

Consumer body of knowledge

She doesn’t think much of ‘talk fests’ and really thinks that talking is only valuable if it leads to a decisions and action. If asked, Ebony would not know anything about the history of the consumer movement, consumer perspective, consumer ethics and democracy. She doesn’t see the need to waste time on something that isn’t very helpful.

Background to the Committee

Ebony has been very active in this area over the past eight years. She is dedicated and driven, having recreated herself as the go-to consumer. Ebony is determined to get this group of patients into services in a respectful way. Her main interest is in creating services that people can use whether they have money or not. She knows she has a great deal of social capital and the skills to make ponderous political and bureaucratic wheels turn.

³ All names are pseudonyms
GEORGINA

Background

Georgina is a veteran in the consumer movement. She has been making herself unpopular by fighting for the human rights of one of the most maligned groups of consumers (those bearing the same diagnosis as the people Ebony is fighting for) for more than 25 years.

Mission

This diagnosis was certain to bring discredit even for Georgina. But against the tide of opinion within the sector she kept on fighting. Consumers with this diagnosis told their stories to her. They trusted no one else. She sometimes felt burdened by their pain. She did her own research and found patterns in the way people with this diagnosis were being treated. Her knowledge about the consumer experience of life with this label was second to none. She was determined that the medical world would hear about what they were doing to harm and marginalise people with this diagnosis. Better, non-oppressive healing was her mission.

Orator

Georgina’s greatest contribution was as an experienced, dynamic speaker. Over 20 years she gave major speeches around Australia demanding significant changes to the care that was missing for this group of people and the pain and harm being perpetrated by systems set up to ‘care for’ them. She had given major addresses overseas.

Reflective

Georgina’s manner was reflective and inquisitive. Sometimes she changed her mind between the start of the meeting and the end. She had a keen intellect and was known to be deliberate carefully. She was very conscious that she had changed her position on some crucial issues over time and she desperately wanted to share these new ideas with Ebony.

Consumer body of knowledge

Georgina was passionate about what was happening to people with this label. In her early days she wrote about the problems caused by lack of services but she was increasingly troubled about the capacity of the medical industry to provide experiences that would be healing. She leant heavily on her long-standing and proud heritage as part of a consumer movement that guides people with mental illness to make decisions that are consumer-ethical from a consumer discourse.
Ebony and Georgina: the story of a committee

Ebony’s Experience of the Committee

Appointments to the committee

After the committee was announced Ebony was elated. At last! She was personally satisfied – a lot of hard slog had gone on behind the scenes. She knew that she would be asked to sit on this committee because she had been so active. Even though she didn’t have the right diagnosis she thought this was less important than the many skills she could bring to the discussion. She knew she could use her social capital. Immediately she started lobbying for Georgina to also be appointed. She was frustrated that a few people were using Georgina’s diagnosis to exclude her. Ebony was cross but not prepared to tarnish her own reputation to save Georgina’s.

The Committee as a Challenge

Ebony faced the committee as a challenge. She didn’t have time for navel gazing. She worked out exactly what she wanted to achieve and how she could achieve it. She found money to provide the ‘evidence’ she believed she needed to support her argument. It didn’t matter where that money came from. She found volunteers and reconstructed them to be ‘neutral’ to help her produce a database.

Strategies

Strategically she did well. She cleverly steered clear of lobbying for anything that would evoke the ire of any of the clinical groups represented on the committee. She avoided their defensiveness and didn’t challenge territory. This fitted with her plan. She aimed at community intervention. This was a good move and didn’t involve directly challenging anything medical.

The Committee

Ebony had an advantage over Georgina in several ways:

1. She’d worked with many of the committee members on other projects over the previous few years;
2. She stuck to community intervention rather than clinical intervention;
3. Once she had won her target goal she had the right temperament to ignore the challenging attitudes of other committee members;
4. She fitted in with the committee in terms of social class and social capital;
5. She didn’t have any sort of obvious social justice agenda;
6. She was interested in individuals and not in systems;
7. She liked sitting on these sorts of committees;
8. She was content to lobby clinical committee members out of session;
9. She didn’t worry about consumer perspective or any moral requirement to speak from a consumer discourse; and
10. She was spot-on strategically. No energy was wasted on anything that wouldn’t pay back.
Georgina’s Experience of the Committee

This committee was devastating for Georgina. The disrespect was palpable. For Georgina, the poor processes of the committee made her continued presence tenuous. The members of this committee did not know how to listen to each other let alone her, she decided.

Chairing

Unfortunately the committee was chaired unsympathetically. Every time Georgina said anything she felt she was dismissed without adequate consideration of her point of view. She was unable to be the expert they wanted because she was ethically committed to being the expert consumers needed. The chair couldn’t hear her because the consumer discourse was out of her hearing range.

The working of the committee

Georgina was frustrated by the tone that was set at the committee. She experienced several of the clinicians as pompous. Only two members had any time at all for Georgina’s substantial body of work. It was humiliating for Georgina to have done so much and to constantly hear it negated or minimised. Despite evidence to the contrary the clinicians on the committee could not get past the idea that they were the expert (by definition) and she was not (also by definition). She was frustrated.

Process

For Georgina there were deficiencies in process. From a consumer perspective the committee should have been briefed about ethical inclusion of consumer expertise and the chair should have policed it. The process of people going away and drafting content and then recommendations was flawed. Georgina, an experienced drafter, continually shaped recommendations that were scuttled.

Recognition of expertise

Like Ebony, Georgina developed one major goal and this was consumer leadership in the education of clinicians around this diagnosis. It was much more contentious ground; however Georgina believed strongly that recognition of her empirical expertise (and Masters qualification) should have demanded respect.

Conclusion for Georgina

The end result was that nobody learnt anything from Georgina’s vast knowledge. There was not one recommendation that reflected Georgina’s work. The process left Georgina furious, lonely and even more disillusioned than she had been when it all started.

The developing gap between Ebony and Georgina

Style

Ebony intuitively moved towards power and influence and joined forces with clinicians often as she was hell bent on getting out of the process the one recommendation that she wanted. This was a good political strategy but Georgina was wary of Ebony moving away from consumer perspective that Georgina considered fundamental.
Ebony was driven and fought or beguiled everyone to achieve her objective, which was sincere and well intentioned. Her determination, uncluttered by the moral and ethical considerations of consumer principles and perspective, still meant lots of work but work with a very different flavour from Georgina’s.

For her part, Georgina was sad because of the increasing distance between the two consumers and the assumed superior knowledge creeping into Ebony’s practice. Ebony, reading Georgina’s growing troubles, tried to ‘help’ but it wasn’t appreciated. Georgina, on the other hand, experienced it, through the eyes of frustration, as disrespectful of her long career in this area. This was a pity. Ebony would not have known that her attitude towards ‘winning’ was putting Georgina in a difficult quandary.

Knowledge

Ebony did not know about, nor did she prioritise, the consumer body of knowledge or the important debates happening around ‘consumer perspective’, ‘consumer view’, empowerment, ‘consultation’, ‘representation’ or anything coming from the thinking arm of the consumer movement. Unlike Georgina, Ebony didn’t have a problem with the ‘medical model’ and the medical discourse. These were all fundamental to Georgina. A win without a consumer movement behind you was not a win.

Politics

Ebony believed that Georgina wasn’t political enough and was setting herself up for trouble by not being politically savvy. She was progressively frustrated by Georgina’s lack of pragmatic skills. Georgina was angry and upset that Ebony wasn’t listening to her political advice gained over two decades. When Ebony talked about politics she understood it as party politics, power through using whatever means one had available to score points. When Georgina talked politics she was talking about internal power elites within mental health.

Discussion Items:

• Do you think compulsory consumer perspective education would have made any difference to the attitudes of the people sitting on this committee? If not, what can we do?

• What could Ebony and Georgina have done to help each other?

• Some consumer organisations recommend that consumers should be co-opted on to committees in self-chosen pairs to increase their capacity to put forward cogent arguments that they know will be backed up by the other consumer and enable strategising between meetings. What do you think?

• At what point should we jump off a committee and go viral?

• How can the consumer movement support people sitting on committees, especially if the committee is a potentially volatile committee?

• Are there hidden rules for national and state committee-sitting? Are they pushing us away from our core values as consumers?

• When we are seen by a committee as our ‘illness’, what can we do about it? Does the chair have a role?

• What could Georgina have done that was consumer-ethical and consumer-moral but still enable her to complete the run of this committee without a bad impact on her health?
• Ebony is a good political operator and Georgina has skills and 20 years experiences of the consumer movement, including the important debates that are taking place amongst a broad range of consumers. How could they have got through this process and found more common ground?

• Was this committee a win or a loss for consumers?