

THE CONSUMER MOVEMENT IN AUSTRALIA

A memoir of an old campaigner

By Merinda Epstein



Our Consumer Place is Australia's Mental Health Resource Centre run entirely by people diagnosed with 'mental illness'



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The Running Postman Project

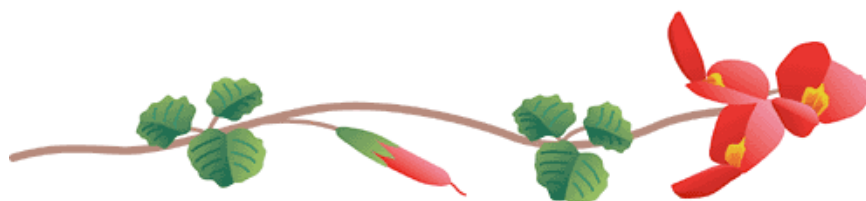
The Running Postman is a native Australian creeper that is a hardy groundcover that sends up small red flags along its route as it crosses the soil. We named this project the Running Postman Project as it describes what we hope will be a continually developing store of people's experiences across Australia and overseas. Like the red flags of the Postman we hope more people will add their memoirs to enhance this project and metaphorically hold their hands up for the long march ahead.

Merinda has set the ball rolling with her memories and ideas about local Victorian consumer-movement adventures and her National experiences from 1975 – 2013. It doesn't matter if you have not been around so long. Everyone's story is important. The more people who join in the deeper and richer the history becomes. People interpret what a memoir is very differently and this is fine provided that it is in some way about 'the movement' and rise and fall of consumer 'participation' in institutions, society and life.

Our requirements are that no piece be longer than 25 pages and that people who submit give permission for work to be posted for free public access on the Our Consumer Place website. That these pieces be perceived as a vine that has its own vitality that comes out of creativity and not debate. No pieces will be accepted that criticise another's memories or priorities. However there's plenty of room to describe an alternative way of seeing the world which comes straight from you.

Items will be published on the Our Consumer Place website and we'll have a wonderful resource for future generations.

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The Consumer Movement In Australia

A memoir of an old campaigner¹

By Merinda Epstein

June 2013

¹ My memoir includes consumer politics nationally and in the state of Victoria during the period 1975 - 2013


Introduction

I started my fight for the rights of people diagnosed with mental illness in 1975, the year Gough Whitlam was sacked and my sister was diagnosed.


The dismissal of the Whitlam Government, by what I believed were unethical forces, shocked and distressed many of us. Somehow, under Gough, Australia had felt like a place where we could all live without oppression, even people with 'mental illness'. The Whitlam Government galvanised us. We learnt that social justice was important and could be achieved with passion and courage.

These were inspirational times. Many of us joined marches to stop the Vietnam war, to fight for Aboriginal land rights and for the recognition of gay men and lesbians as well as radical approaches to closing down the asylums.

At the start we were small, isolated clusters of people supporting each other around the kitchen table, very similar to the early days of the Women's Liberation Movement. The consumer pioneers in the 1970s were like little creeks at the top of the mountain just starting to tumble down the mountainside. We were separated by geography, social class, diagnosis, organisational affiliations, politics, cultural attitudes, our parents and our own profound experiences. However, so many of us were determined to reform the mental health system.



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Consumer Movement?

Consumer Movement – *I thought I saw a movement. It was. It was. I've seen a movement being born. It is truly a marvellous experience of human ingenuity and passion.*
- MadQuarry Dictionary, 2013

Not everyone agrees that we have a 'consumer movement'. There are arguments in the grey literature (informal consumer newsletters, etc.) and the formal literature (largely sociology) to suggest we are indeed a movement, if a fledgling one.

One of the arguments is that *mentalism* (see Judi Chamberlain) is no different to any of the other 'isms': feminism, racism etc. Each group is trying to carve out a respectful place in the nation's consciousness.

Other consumers believe we have so many differences that we are nothing more than a varied mix of individuals who at some time have been diagnosed with 'mental illness'.

I tend to side with the former position and this will be evident here.

1970s

The 1960s and 1970s were heady years for those of us who were lucky enough to experience them as adults. Social justice, community development, people power, the proletariat... none of these were yet deemed dirty words.

Indeed, it was the opposite. The first consumer organisation in Australia of which I am aware, though it was not one that I was active in, was a group called **CAPIC** – the ‘Campaign Against Psychiatric Injustice and Coercion’.

CAPIC represented a very radical, anti-psychiatry position. Its members would turn up at all sorts of official events and demand change, demand psychiatrists be sued for harm caused by a variety of contemporary practices.

There were many other radical groups fighting for human rights at the time. It was the era that I wish could have stayed forever. But that is not how history works. CAPIC was the right movement for its time.

Many small consumer groups were supported by the non-government sector. In those days the psychiatric disability support sector was poor and radical. We could rely on impoverished small organisations to house us, support us and even help us charge the barricades of the service system. We had a common enemy out there, rather than an enemy within, which is all too common these days regardless of the employment of consumers within the sector. All these groups were also supported by a highly politicised university student sector.

The consumer movement in Australia started to change. This seemingly strange term ‘consumer’ was not a concept that CAPIC and other bodies would know or deem to be useful. The language of ‘consumer’ came to us via physical health consumer politics which has now morphed politically into the chronic illness alliance.

The logic for the language was a reaction to some of the elitism, lack of accountability and communication disasters experienced by patients. Patients started to fight back at first with a small voice and then gradually more a more supported one. The logic was: *Because you provide me with a service for which I duly pay I expect good service, good communication and active decision-making opportunities. We want a say.*

1980s

My sister was dead. We saw it coming but this didn’t help much. She’d been sexually assaulted by clinicians in places where she had sought refuge. This is not a new thing. Her death galvanised me into greater action and along a path that has now lasted 28 years.

At first I spoke as a ‘carer’. In those early days it felt safer to be a ‘carer’ than to be honest and talk about my own consumer experiences. Tentatively, 18 months later, I realised I could not do that anymore. It was ethically wrong. I was asking my sister to carry the responsibility for mental illness for the whole family and she was dead and unable to challenge these assumptions.

From that moment, despite my initial dislike of the word 'consumer', I became a consumer activist, a responsibility I took – and take – very seriously. I am grateful to my sister that even after her death she taught me the importance of taking responsibility for my own liability.

The social and economic conditions changed after 1980. University students were cut off from their radical and relatively selfless preoccupation with making the world a fairer place by the introduction of HECS fees and the privatisation and gradual and then almost total obliteration of active student unions. The time we had available as students to share opportunities for radical thinking and human rights action disappeared under a cleverly intentional user-pays scheme of ever-increasing fees that robbed students of opportunities to create new ideas that would continue to challenge the institutionally endorsed power hierarchies which often crippled emerging consumer collectives.

Students and trade unions had been supporters of consumers. Their loss of power, I think, contributed to the demise of CAPIC.

The fight for the human rights of people diagnosed with 'mental illness' also changed. It was a new epoch, where the emphasis was on charity and the rich graciously bestowing largesse upon us. We were expected to be grateful and humble.


It was during this period in the histories of First World economies and their attendant philosophies that Archbishop Helder Camera from Brazil famously said, "When I give food to the poor, they call me a saint. When I ask why they are poor, they call me a communist".

Many of the organisations that had acted together to support small unfunded groups were separated and privatised. The non-government sector was no longer funded for the systemic advocacy that had driven us and sustained our spirit. The psychiatric disability support sector was hobbled by progressive governments demanding that they provide services, rather than lobby for our rights.


CAPIC died amongst all this change. Many other good agencies did likewise. It was at this time that many of the concepts we had found so compelling became politically incorrect. Systemic advocacy, community development, collectives, consumer radicalism, etc. all but disappeared.

At the same time groups like CAPIC which traded on the political advantage of not being funded by anyone, and therefore not being beholden to any funders, lost ascendancy. Funded groups are, by their very nature, less self-determining. They shed autonomy for money. They found more power and influence. With the resources to play a much greater role in the politics of mental illness these organisation competed with each other, bureaucratised, politically organised and sold consumer participatory knowledge. Much changed.

This still happens today. This was a much tamer interpretation of activism but hard won nonetheless. The 'consumer' word looked more in place in this context. Interestingly the physical health consumer movement staggered and slowed down. We may be now achieving more in mental health than the chronic illness sector. As far as I know, but I could be wrong, the only mechanisms for consumers to be involved in most areas of physical health is to sit on committees or 'tell a story' of their experience living with an illness, or plough through incomprehensible bureaucratic research or public reports for 'consumer comment'.



It was a new epoch, where the emphasis was on charity and the rich graciously bestowing largesse upon us. We were expected to be grateful and humble.



After notorious events, they sometimes organise and occasionally have the financial capability to bring in lawyers. This doesn't happen so much in mental health because of the oppression we live under and our lack of funds. Nonetheless it is not unheard of.

Health Issues Forum and NCCPH

Some organisations were funded. Perhaps the two most influential ones were The Health Issues Centre, driven by Meredith Carter, in Melbourne and the Health Consumers Forum in the ACT. Both of these organisations have worked hard to provide a critique in a climate where they believed that they had to be seen as 'reasonable', not only to preserve funding but also because of a fundamental belief that incremental small changes would be the most effective way to go.

During the early 2000s the Health Issues Centre was funded to create a National Centre for Consumer Participation in Health (NCCPH). It was federal money. The centre was short lived. It's hard to be a consumer centre for a medical industry market and the centre was troubled by definition and the impossibility of the task. No organisation can be all things to all vested interests. In this case, no one was able to really define who a consumer was. The centre lacked a grounded, grassroots momentum and struggled with expectations of the funding body that were contradictory and, frankly, impossible.

I worked for the NCCPH for several years and was frustrated by its orientation. Housed at La Trobe University, it was inevitable that it would automatically tend towards academic analysis, non-grounded methods and positivist research. There was an urgency from NCCPH to look academic, to look cooperate, to make a mark in these sorts of consumer-excluding ways. There were problems with fitting the genuinely organic idea of community-generated change in health services into a centre that remained unapologetically wedded to the medical model and which wrote, thought and talked a privileged medical discourse.

Consumer Health Forum (CHF)

Located in the national's capital, the Consumer Health Forum of Australia is the other significant consumer body to work across all areas of health and wellbeing. Similar to the Health Issues Forum, there seems to be an inbuilt determination within the CHF to be seen to be as worthy by the most conservative groups within the health sector. This has not stopped the Forum speaking out on important matters and doing some good work. However, unlike some of what we are now doing in mental health, much of what CHF is forced to do is reactive to the agenda of governments, bureaucracies, research organisations, hospitals, doctors, clinical unions and other places where power is found.


CHF is a national organisation (made up of a membership of smaller groups). It works diligently to allocate all its requests for consumer participation to its members. These groups are sometimes consumed by this demand. It can tie up the small groups' capacity and make proactive work, especially when it involves bold alternative visions, very hard to prioritise. However, this is the nature of peaks. The National Mental Health Consumer and Carer Forum (NMHCCF) and The National Register of Mental Health Consumers and Carers (NRMHCC) have similar challenges.

CHF's history of working with mental health consumer groups is limited. The term Flick Grey popularised in her work in mental health is useful here. *Stigmaphobia* describes a process where one group of oppressed people improve their lot by vilifying another group who seem lower in the pecking order. This is a challenge for all peak bodies as they juggle their priorities.


The socially more acceptable ‘illnesses’ like, maybe, cancer (except lung cancer and throat cancer), childhood illnesses and degenerative diseases are terrible and people suffer enormously but they provoke a different community reaction, more research and project money than the chronic illnesses that bring major community sanctions such as obesity, fibromyalgia and chronic pain.

It is possible to see how illness-specific group members of CHF may want to distance themselves from this taint and promote themselves publicly as heroes, warriors, survivors and non-complainers. And it's not surprising, then, that the people with fibromyalgia and chronic pain may, in turn, want to distance themselves from people with mental illness, especially when such illness is represented in frightening ways. When an organisation has to represent all, mental illness is often to be found near the bottom, highly medicalised and sanitised to deflect potential glare.

CHF has a role as a peak to try and manage these competing needs and often psychiatric illness is lost in the process. There is also the question around where mental illness best fits – chronic illness or disability. This raises the real dilemma that we are badly listened to by both sectors and the peak lobby groups that represent us.



We probably had to push ahead faster because we were starting from such a low base of disrespect, forced ‘treatment’, deplorable judgmental language and the ominous presence of keys and other symbols of legal, as well as medical powerlessness. We couldn’t wait.



Consumer Leadership in Mental Health

Consumer leadership in mental health (rather than ‘participation’ or ‘representation’ – two terms we argue have lost their credibility) is, perhaps, ahead of its physical health counterparts. We are participating in many more sophisticated roles, particularly at the local level.

It is encouraging for us to remember what we have achieved, as well as recognising the enormity of the ongoing task. We probably had to push ahead faster because we were starting from such a low base of disrespect, forced ‘treatment’, deplorable judgmental language and the ominous presence of keys and other symbols of legal, as well as medical powerlessness. We couldn’t wait.

During this time of consecutive conservative governments and then socially conservative Labor ones, the political landscape changed and progressive groups were threatened.

Year of the Disabled – VMIAC

We pick up the scent again in 1981, the International Year of the Disabled. Two social workers were infuriated that Psycho-Social Disability was completely invisible from this year of support and celebration. It was from this year that Victorian Mental Illness Awareness Council (VMIAC – known colloquially as V.M. or vim-ee-ack) was born. It is because of this that the peak consumer

group in Victoria has such a funny name – it started out as a means to bring people with a diagnosis of ‘mental illness’ into the public consciousness.

Progressively VMIAC became more and more trusted by the establishment and that brought with it increasing funding for consumers to be actively involved in the sector. For most of the late 1980s and early to mid 1990s VMIAC was responsible for producing excellent consumer resources and high quality consumer-controlled research and teaching materials. This fine legacy included the *Lemon Tree Learning* book, the ‘Lemon Looing Game’, a tool to educate staff, and the two Deep Dialogue projects.

The most important work of VMIAC in this era was the Understanding & Involvement (U&I) Project. This work won several awards, including one for innovation in evaluation sponsored by the Australasian Evaluation Society. This three-year consumer enterprise remains in active use as a textbook for clinical and evaluation design students around the world.

1990s

Emerging Social Change Movements

Emerging social change movements bring with them many challenges. Amongst these is the all but inevitable development of schisms and breakaway groups. It divided the suffragettes, the gay and lesbian movement and the movement to bring asylum seekers to Australia with humility and grace.

We have not been spared from this. After all that we have been through individually and collectively it would be naïve to think that we could make the jump from powerless to power-holding without a degree of anomy. Our history, unfortunately, is full of wasted opportunities brought about by power struggles.

The Life of Two Brians

In the early 1990s The Hon. Brian Howe, the then Minister for Health in the Keating Government, was moved to commission a large scale investigation into the state of public mental health services throughout Australia. This Minister was committed to people with a diagnosis of ‘mental illness’ in Australia being heard.

Up until this point of time the Federal Government had had no direct influence in mental health policy or funding in Australia. Then, over the years from 1991 – 1993, two influential documents were published nationally.

The National Inquiry Concerning the Human Rights of People with a Mental illness

In October 1993 Brian Burdekin, who served as the Australian Human Rights Commissioner from 1986 to 1994, launched the National Inquiry Concerning the Human Rights of People with Mental Illness Report. It became an enormously influential document that, amongst other

things, sustained the radical changes that would follow in the first strategy. We came to know it as ‘The Burdekin Report’.

Not only was this report damning of mental health services in every state and territory but it also introduced for the first time national funding into mental health provision. It also introduced the idea that consumers and carers must be actively involved in all areas of decision making if the sins of the past were not to be repeated.

The First National Mental Health Strategy

The second document was the First National Mental Health Strategy. Minister Howe used federal money to push for radical change in state and territory policy by putting accountability clauses on all federal monies reaching the states and territories.

Fortunately for us the active role of consumers and carers was one of the non-negotiable conditions put on the states: *“If you want our money then prove to us that consumers and carers are strategically involved at all stages of decision-making in your state”*. This was effectively the start of a new, but not necessarily totally good, era as it was also the start of flagrant and often ill-disguised tokenism as committees, from Federal Government down, found unfortunate and non-collegiate ways to tick the boxes of first ‘involvement’ and then ‘participation’. They wanted the money more than they wanted us.

National Community Advisory Group (NCAG)

The initial major requirement of the First National Mental Health Strategy was to create the National Community Advisory Group (NCAG) in mental health. It consisted solely of consumers and carers and had an open door to Minister Howe. This degree of influence was unheard of at the time.

The early years of NCAG were fraught and some of the pertinent issues remain today. It surprised nobody at the time that the states and territories were asked to nominate a carer **or** a consumer to sit on this new influential body. It also surprised no one that most states and territories chose carers. The appointments meant consumers were hopelessly outnumbered and there was understandable fury. On this occasion the problem was solved by appointing Simon Champ and me as ‘independent consumers’ to balance the numbers. However, this was a local answer to a very complex Australia-wide and continuing problem.

Consumers are profoundly divided as to whether consumers and carers should be heard together or separately. Some consumers are furious that at both state and federal government level there remains an insistence on slashing the two groups together – ‘consumer/carer’, when there is no doubt in their minds that the ‘carer’ voice is far more powerful.

This issue also causes grief to some Australian consumers who work internationally. We are demeaned within the World Network of Users and Survivors of Psychiatry, our world lobby organisation, for example, because we haven’t been able to break the shackles of carer paternalism. Of course, there are other consumers who don’t agree.


NCAG started to play a role in 1993 and for its seven years of existence bureaucrats and expert clinicians went through three distinct stages.

At first there was incredulity that people diagnosed with ‘mental illness’ could possibly be there in the same room, offering opinions, winning important points in influential arguments in


elite meetings and on important committees. Thus far in history 'important people' has been defined only in contrast to 'needy people' so this was a huge change. Strange things happened as those with institutional power were publicly shocked. At first, many reacted with almost over-the-top politeness that enabled us to get our way perhaps more often than we should have!

The second stage involved professionals – researchers, clinicians, bureaucrats, and others from all sorts of powerful groups – realising that we were not a novelty that would go away. This frightened them on to the offensive and institutional power-over was evoked. We were here to stay and we had an interest in issues substantially important to us. We made it clear we would not be manipulated easily, although the professionals offered all sorts of power tokens to get us off the main agenda. It became increasingly difficult for all of us. Our heyday had come and gone. There was a discernible move from novelty to the beginning of disguised anger and pulling rank.

The third stage was predicated on many professionals getting defensive of their own hard-won qualifications, seniority, and (for one at least) the god-given right to rule. Parts of the consumer movement responded by playing the same power games: evoking important titles, becoming famous outside their consumer status, power dressing, even bowing and scraping. To some it was about pragmatism, to others, selling out.



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The Australian National Consumer Network (Mark I)

The other major innovation with the First National Mental Health Strategy was the development of the First Australian Mental Health Consumer Network, complete with a supporting secretariat. Everyone was excited about it. There were two consumer delegates from each state and territory.

Slowly and then rapidly during the next seven years this network disintegrated. This is a phenomenon of most social change movements. It is not just about the 'capacity' or lack of 'capacity' of people diagnosed with 'mental illness', or even the capacity of the ones who seem to get appointed rather regularly.

It's very hard to topple a powerbase of professional knowledge and bureaucratic assumptions or indeed the culture that has surrounded mental health provision for centuries. Unsupported, the task of the network was untenable. Many of us have been damaged in more or less obvious ways by psychiatric services. Many of us have been hurt in more or less serious ways by consumer politics. We know better than any group that the issues that drive us are found writ large in our individual histories.

Social change movements attempt to formalise our activities at some cost because our individual motivations and passions are as varied as we are. Not only was the network pulled in different directions but also those with their hands on the rope were operating from a kind of primal need that was totally authentic, but certainly not bureaucratic. Again, bureaucratic ambitions too often get smashed. The first network started with great hope but slipped, foundered and was eventually defunded.

The era of the 1990s brought with it change from the bottom up and from the top down which collided and sparked something important. The *Report from the Inquiry into Mental Health by the Human Rights Commission* (Burdekin Report) brought a massive response from the Keating Government that was accompanied by ultimatums to the state and territories, big increases in funding and, of course, the first policy recognition of the roles to be played by consumers and 'carers'.

In Victoria, the mental health bureaucracy, under Jennifer Williams, shot into action. There was a minor war to be won here and the Victorian Government wanted to be the first state to make the changes in consumer and carer participation initialled by the Federal Government. They were searching for ways to do this.

VMIAC and Consumer Consultants – the start

VMIAC had a key card here. The Understanding & Involvement (U&I) Project had created and tested over a number of years a mechanism the government needed – Consumer Consultants (originally called 'staff-consumer consultants' to recognise their proposed role of conduits between the culture of staff and the experiences of consumers) . The Mental Health Branch could see their political as well as their practical potential.

Unfortunately an unwise, though understandable, decision was made. Clinicians in public services in Victoria had just been through a major restructure. Area Mental Health Services were brand new, clumsy and difficult to manage. Clinicians were reeling from a lot of structural change in a very short amount of time. They were angry and leaving the public system. Many were being told they now had to be 'case managers' rather than practice the profession they had trained for. Any more 'radical' and central office-determined changes would have put the new Area Mental Health Services in jeopardy.

And so the decision was made to introduce Consumer Consultants without the tested conditions-of-practice developed by VMIAC that should have been there to support these new positions. This was a recipe for disaster. Consumers had for a long time lobbied for interventions from consumers to start in the acute units – what the U&I team called the 'deep end'. It was here that the major damage was perpetrated and here that clinicians were most stressed, desperate and recalcitrant. The U&I recommendations came with a 10-point support structure that, if implemented, would have kept consumer workers safe. This was, we thought, vital, because these positions were service-culture change-agent positions. Changing comfortable and highly protected cultural assumptions was a difficult job for anyone let alone relatively junior people going back into situations akin to places in which they had been harmed in the past.

The Mental Health Branch rationale was that the new Area Services needed to feel empowered to make their own decisions about policy and the allocation of decentralised funding, which was a new idea. The terrible mistake was that the policy was already made. It was the detail that was missing and this rendered the policy neither central nor local. No one wanted to own it. No one wanted to pay for it.

On one level the Victorian Mental Health Branch was chasing tick-boxes with the Federal Government for introducing a broad scale state-wide initiative for consumer participation in all Area Mental Health Services. However, despite the U&I Project, services were left to develop the Consumer Consultant positions on their own. It was frustrated Area Mental Health Services that let consumers know that Consumer Consultants had been introduced as a 'Budget Neutral Policy'!

The end result was that the first consumers employed as consumer consultants didn't know what they were supposed to be doing, services had no idea either, and clinicians working with these new employees also didn't understand. It took many years to undo the harm that happens when the rapid pursuit of product becomes disunited from good process even when that process was well known to the sector.

It didn't go smoothly but action was happening on the ground, in the clinical sector at least, for the first time.

VMIAC: Leading the Way in Advocacy in Victoria

The late 1990s heralded in a strong advocacy role for VMIAC. This was a new emphasis.

Like most big shifts in focus, there were those who were critics of this change of influence, believing that VMIAC, as the consumer peak in Victoria, was letting the Victorian Government off the hook because the government should (and 'must' was the term used by some) fund **both** a top class non-government advocacy agency **and** a peak consumer body.

There is still some dissention, but VMIAC has gained a reputation as having formidable advocates and many consumers were thrilled to see VMIAC continue to press for systemic advocacy against the political trend.

2000s

New Roles for VMIAC

Over the first decade of the 21st Century the emphasis moved again, although the core business of VMIAC remains one of advocacy. Several trends emerged. One was the growing consumer workforce in mental health services in both the clinical and psychiatric disability sectors. These positions, evolving originally from VMIAC's own 'Understanding and Involvement' research, had morphed uncontrollably and there was no structure, no consistency, no support, no job descriptions and lots of lost souls on their own trying to change the system.

Added to that, a new group of consumer workers emerged relatively recently. Called Personal Helpers and Mentors (PHaMs), this group of workers are funded nationally by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). For some of us this money was tarnished from the beginning. We believed the funding should have been used to support the growing, small, grounded consumer economy that was emerging. We lobbied but it wasn't good enough.

We didn't want a model of daily helping that may infantilise the receiver. Helping is one of those words that many of us want to disappear. Respect is better. However this new program was singularly about 'helping' and maybe 'empowering' (another idea that many believe should be used sparingly). With the goal of helping it was inevitable that in some cases relationships between consumer-provider and consumer-recipient would end up becoming exactly what we


have fought so hard to eradicate – enmeshed in the language of high functioning versus low functioning, recovered versus chronic, important versus non-important, giver versus receiver.

Unfortunately this is how it has worked in some settings and I still find it difficult to reconcile myself with it despite knowing some fantastic PHaMs workers. Like the consumer consultants before them they were often introduced as innocents into a politically charged and difficult work environment. They are primarily employed in the Psychiatric Disability Support Sector and are often equally at sea. In Victoria, VMIAC was well-positioned and well-equipped to provide education and moral support to these new workers, as well as institutional support for consumer workers everywhere in Victoria.


VMIAC continues to grow and now, with a big building complex, the organisation can offer lots more enterprises, including, but not restrained to, political lobbying, and systemic and individual advocacy.

Consumers as Experts

Once we start to think about ourselves as experts rather than ‘representatives’ things start to change. It is then obvious that consumers all emphasise different things and we won’t always agree. When our broken lives, our terror, our joblessness, our fears, and our abuse are so viscerally experienced, bringing people from very different backgrounds together to make imperative decisions for consumers will often result in angst – heartfelt angst. But this is angst with a different quality: one that is less likely to bounce back on us.



Once we start to think about ourselves as experts rather than ‘representatives’ things start to change.



A new national network has just been created to give voice to consumers and particularly to have greater say in the Mental Health Council of Australia. We have not yet seen the new network in action but we are all hoping it won’t self-combust. Certainly those responsible for setting it up are being careful but this includes it being auspiced by a non-consumer agency and that has many consumers suspicious.

We are a Broad Church

There are consumers today who strongly believe we have sold out to the forces that enslave us. There are others who believe that our ongoing health and longevity as a movement (given today’s historical context) comes from acceptance that we are a broad church.

At one end we have several radical groups which are generally identified by a refusal to use the word ‘consumer’ and a preference for the term ‘psych. survivor’ (as in ‘survived the psychiatric system’). They are affiliated with the more radical part of the international movement, the World Network of Users & Survivors of Psychiatry (WNUSP) and the more radical end of the disability sector. They are unequivocally against any sort of forced treatment, don’t recognise that ‘mental illness’ is anything other than a cultural construct by psychiatrists who want to make money, and are very critical of ‘Big Pharma’ (slang for pharmaceutical companies). These groups would never accept money that they see as tainted. Rather than sit on bureaucratic committees, they are more likely to be picketing at the front door.

At the other end of the continuum we have the far-right groups. These may be characterised as being politically conservative; pragmatic in nature rather than ideological. They are criticised

for not differentiating between consumers and carers. They are also criticised for a lack of connection to grassroots consumers, or even any understanding about what a consumer movement is, and what it is trying to achieve. 'Mass action' is a foreign concept for them. They like to be well funded because this buys them political authority and seats on important committees. Towards this end their preference is for individual action over collective thinking and they will accept sponsorship by commercial friends: drug companies, private health insurance companies and private hospitals, for example.

Consumers from the right are in demand by some elements of the industry as they are seen as 'like us' and therefore safer to sit with at the table. They are also criticised for being allowed to punch way above their weight.

The importance of this dynamic, and the importance of having a very broad range of views, is that, in theory at least, the extremes empower those of us who are working more or less in the middle.

Disability or Illness?

In terms of a 'movement', we have historically sat on the fence regarding whether we fit into disability politics or 'chronic illness' politics. This has disadvantaged us. Firstly it has divided us and secondly it has left us with a relatively feeble position within the disability sector.

It is particularly important to be thinking about this as the National Disability Insurance Scheme (NDIS) starts to happen. We are not organised sufficiently to make a significant play for resources under this scheme. This is an essential concern for the future.

Internationally the more radical end of the Australian psych. survivor movement has worked well in pursuit of human rights for people with psycho-social disability, particularly at the United Nations. The disability movement is no less challenged by the complexity and variety of political voices and scenarios than the consumer movement is.

Many consumers don't want us affiliated in any way with the disability agenda because of the hierarchies within that sector. Acquired brain injury, intellectual disability and psycho-social disability are often relegated to the bottom of their heap. That's not where many people with a 'mental illness' want to be.

There is also a huge debate within the mental health consumer community between those who are repelled by the thought that their experiences represent a disability and those who find such classification reassuring. This is an age-old debate and some consumers feel very strongly about it. There is a general sense by some that if we affiliate more fully with disability politics we will be able to reclaim some of the latent radicalism we have lost. The disability sector seems more determined to find ways to 'bomb' major repressive institutional structures and political impasses.

This debate feeds into internal consumer concerns about definitions of 'illness', the judgemental language of 'high functioning' and 'low functioning', the place of so called 'personality disorders', the language of exclusion, the language of risk, and the language of 'seriousness'.

In some consumers' minds the introduction of the NDIS will further split and splinter the consumer movement as it seems likely that those people who get access to this monetary support will achieve it primarily on the basis of their diagnosis. This might be the only way it can realistically happen but many consumers are wary anyway and sick and tired of the million-and-one euphemisms for psychotic illness: serious mental illness, Serious Mental Illness, SMI, Severe Mental Illness, Severe and Enduring Mental Illness and so on. This is 'answer pending'.

Local Groups or National?

Over the past 10 years there has been increasing financial support for consumer groups of various kinds. This comes amongst cuts to bureaucracy and services. Governments have recognised that some consumer groups are a good investment financially and in term of improving people's health ².

The nature of most consumer groups is that they are local. There are different sorts of groups: support groups, activist groups, advocacy groups and peers doing things together. Many have sprung up.

Support Groups

Many support groups represent a particular diagnosis and often see their role as bringing in 'experts from the field' – often psychiatrists – to tell people 'The Truth' about 'their' diagnosis and what 'they' should do.

Members of support groups are often people who do not, and perhaps never will, see themselves as 'consumers', let alone part of a 'consumer movement'. Often support groups are run by carers, or auspiced by private hospitals. Those who attend are often a bit better off financially. Many are, at that point in their lives, truly attached to the medical model as the most important way to deal with their experiences.

The other form of support group is very local, often with members carrying substantial burdens in terms of their health, experiences of hospital and involuntary 'treatment'³, managing poverty, their isolation and the requirements of Centrelink and job service networks. These support groups sometimes spin off from organised Psychiatric Disability Support Services (PDSS).

People offer themselves to support others around day-to-day existence and events like police encounters, Centrelink, the Crisis Team, or other horrors. Where there is strength and confidence in numbers, these experiences can be made easier.

People at this end of the human food chain are often the best in the world at understanding the importance of friends, advisers, protectors and 'people like us'. There is something heroic about it. People, through the group, very quickly learn who is good at what and who is not – without judgement. Interestingly, the research by Professor Segal in California in 2011 found that it was these sorts of groups that often provided the greatest benefits for members' mental health in the longer term. Where the core of the human spirit is threatened and survival is sometimes at stake, heroes emerge.

Advocacy Groups

Advocacy groups are primarily there to demand change and help consumer members stand up for themselves.

The term 'advocacy' is a complex concept within the consumer movement. Some consumers and groups use it interchangeably with activism, or use it to describe one friend helping and supporting another.

² See University of California Berkely, Steven Segal, Professor of Social Science and Social Policy, for an important discussion of the importance of consumer groups.

³ There are many consumers who argue, "if it's involuntary it's not 'treatment'."

Consumers working as professional advocates lay claim to a specific body of knowledge: experience, skills and morals learnt in order to provide advocacy ethically. Indeed, they often claim that untrained advocacy by consumers is dangerous.

The point here is simply that advocacy points to a group having identified a problem or problems that they jointly want to fix or get cranky about. Recognising the issue is systemic and not just individual is the kernel from which an advocacy grows. Advocacy groups combine collective knowledge, skills and experience to attempt to resolve systemic problems. They proactively work for change and this turns a group from support to advocacy, although the group might move back and forward between the two.

Activist Groups

Activist groups (see above) are typically radical groups whose fundamental aims are to overthrow psychiatry which they believe is corrupt, has far too much power, and is far too close to big business through drug companies, health insurance companies and private hospitals (often owned by psychiatrists who work in them). They organise to disrupt what they see as an unethical, amoral system in any way they can.

This can be in the form of picketing events, interrupting certain speakers at conferences, manoeuvring to get their point of view in the media, especially the new media, and writing for journals in a range of areas of public life. Revolution is the aim.

They often work with radical thinkers in other areas of public critique, including disability and indigenous activists, and people fighting asylum seeker policy. These groups often support each other effectively across sectors, across states and countries, and across issues.

Peer Groups

One of the joys of the past 10 years has been watching the growth of increasingly sophisticated peer groups that are proactively coming together to share their lives and looking forward to healthy futures together. These groups bring together people who want to get away from a preoccupation on psychological growth to understanding lives within their historical, socio-cultural and political context.

Some consumers report that this can be hard work but incredibly rewarding. Models include Hearing Voices Groups in Victoria and interstate, Peer Zone from New Zealand and Intentional Peer Support whose Australian base is in Brook Red in Brisbane.

Over the past few years, organisations in the psychiatric disability support sector have been developing and marketing peer training, which they intend to use imperialistically and profitably. Models will be registered, marketed and branded. For many consumers this feels dangerous. Ownership and blatant competition for power and money is an anathema to the idea of genuine peer interaction for many. But the jury is still out.

Power

Power is a tricky business. Powerlessness releases the little red devils in us and powerfulness releases our golden dragons. It is difficult for a group that has traditionally had little power to watch as some individuals get this new power and some do not. These clashes of self and

community interests are the forces that push the self-destruct buttons of many consumer groups and organisations.

We all need to take a deep breath and look to our personal and collective strengths without putting down others in the process. We must also resist the inevitable critics within the mental health sector who will watch our organisations and groups implode and will claim it is the disposition of those with 'mental illness' to be unable to perform at the level required.

Powerful groups almost never know they wield destructive power. Our survival depends in part on us reminding all of them that our tendency to combust owes much more to their power-over tactics than it does to our temperaments, skills or ability to function at 'their' level.

2000 -2010

A decade of Uncertainty

Social movements do not progress either evenly or fairly. This should have been the decade of enlightenment but for some of us it was not. During this decade of change many consumers were used and abused in the name of bedding consumer 'participation' into the fabric of psychiatry. The consumer body of knowledge was not yet established and many consumers, services, corporations and bureaucracies interpreted 'participation' in dramatically different ways. Some people were not 'out' and yet demanding power. Others resented this. Other people were dumped politically by new people rising to powerful positions within the sector. To some it felt that history was being whitewashed but to others this was all part of 'progress'.

Bullying

Away from home:

For me this decade was one of extremes. The first few years of this decade I worked in a very influential non-consumer organisation hundreds of kilometres away from my home. The CEO of this organisation was a hidden 'consumer' and a bully. This experience emphasised the precarious nature of consumers at the time. My presence as an 'out' consumer ignited his fear of being exposed and ridiculed. He took it out on me. I was accused of speaking from a consumer perspective, which was seen as offensive yet I had no choice. I was employed as a consumer.

I had never even seen bullying like this let alone experienced it. I was unprotected, vulnerable and scared that it might get physical. Screaming, shutting me out, ridicule, picking on my physical disability, making me do work 10 times to correct non-existent mistakes and threatening me were all common. Eventually I fled back to a job in Melbourne feeling like I was useless. Because I 'admitted' to having a 'mental illness' I was too scared to explain anything to anyone except the local consumer organisation, which was not strong enough to initiate anything on my behalf. I dreaded the probability that most would see my desperate state as 'just my illness talking'. I eventually spoke to the appropriate union but I didn't trust action being taken. This bully eventually received his comeuppance. A decade later staff did complain and he

was found guilty and lost his job. As much as I silently hoped this would help me feel better about myself, it didn't.

Back home:

I was lured back home to an organisation which was committed to consumer engagement in health. I was welcomed by reputation but everything went wrong. I was unable to use my skills and talents in ways which were useful. Once again I was bullied. This is the reason, I realised, that **we** need to support each other, see past our differences. This organisation managed to get rid of two mental health consumer workers within weeks of each other and nobody seriously questioned what was going wrong. I want this category of insider prejudice to stop. In my opinion knowledgeable, dedicated and outspoken consumers are a precious asset not a threat.

What I don't want is patronising consumers 'helping' me or other consumers in positions like mine. Sucking me into a 'being looked after' position is equally dehumanising and manufactures more powerlessness. This inherently assumes that those of us who are bullied are needy; an assumption I categorically reject. I felt I had no power to change the hideous situation I was in because I **did** have no power to change the situation.

Mental Health Legal Centre

Finally, I settled at the Mental Health Legal Centre where I was a bit out of place – I don't have a particularly legal mind- but where my history of active participation for nearly 20 years of work for consumers was acknowledged and appreciated and I felt safe for the first time that decade.

My experience with inhumane bullying had knocked me for a six however. The fear forced me to frame my life completely differently and in a way I didn't like. My confidence was shot. I found it hard to critique practice and other people. My emotions were raw and defensive. I constantly felt unheard – a legacy. Staff at the Mental Health Legal Centre were affirming, and proud of my contribution. I was appreciated.

With my experience of being bullied still foremost in my mind I watched the drafting of the 2006 Disability Discrimination Act by the Victorian Human Rights and Equal Opportunities Commission. Despite our lobbying, people with psycho-social disabilities were not covered - the only disability not covered, under this Act. I was consistently directed to the Mental Health Act, which is silly because this Act has a totally different purpose. The Mental Health Act, even the new one (2013) I suspect, does not cover people with psychiatric disabilities being bullied in the workforce.

My attitude to this unfairness remains profound. It's so sad the Mental Health Legal Centre has gone. It provided the first experience of sanity for me in this decade. I am very grateful and I want it to come back to life.

Legacy known, used and appreciated

This was not a decade of total loss everywhere. I know that. Indeed part of my experience was that other consumers were coming from nowhere to build a more substantial hold on the sector from a consumer perspective. This is fantastic but I struggled to reconcile my demise with others rapid recognition. I'm told this is typical of someone who has been traumatised through bullying. Like all human beings consumers need to be acknowledged for our contribution.

Arriving back in Melbourne I found my work had, in some places, been systematically destroyed, hidden or unacknowledged. This was bad timing.

2000 – 2010 Good things from this decade

Whilst I was trying to survive some other very important things were happening in Victoria:

1. The consumer academic position was established at Melbourne University and this has been influential. At last we had a focal point for our thinking. Before that we seemed to be constantly just 'doing' and reacting;
2. Psych. Action and Training (PAT) was formed and supported by Cath Roper, the incumbent consumer academic. It was a focus for theory and consumers providing clinical education;
3. The consumer workforce was growing and becoming more diverse supported by the Victorian Mental Illness Awareness Council (VMIAC);
4. More consumers were being employed in clinical and community sector services;
5. Real consumer debates and differences were being respected as an essential part of a fledgling movement rather than differences being personalised;
6. This was the decade where consumers started to be employed in much more senior and responsible positions.

No. It was not all bad.

2010s

Powerful Consumer Groups


These are loosely formed groups of those with significant power within the system. Included are people who are 'in the know', have Qantas Club membership, know all the important people by first name, write Consumer as their occupation and know a lot of classified information. They sit on boards, expert committees and seem always in the shadow of power.

Some consumers find these powerful consumers problematic, especially if they develop a sense of ownership about their role and authority. There are few mechanisms to review how well they perform as consumers, and whose views are being represented, especially by those who would claim legitimate representative status.


This is similar to the situation at the earlier National Community Advisory Group (NCAG) on which I sat during the 1990s. The important difference, from my point of view, is that in the 1990s I was in the in-group and in 2013 I am not. The world seems very different when you are on the outside of power and not the inside. Recognising this and accepting it is imperative.

Of course, these allegiances do matter. Every action acted and every idea thought changes our appreciation of our own and others' roles in bringing about social and institutional change.

There is always suspicion about who gets chosen for privileged positions and by what criteria. This is especially so now that the idea of 'representation' has been skittled. People who get 'over-the-top angry' are tolerated because others are scared of them. Failure to consult other consumers with expertise and/or experience in issues on the specific agenda creates further difficulties. This is very different from the old idea of 'representation'. There are accusations of 'elitism' on one side and 'tall poppy syndrome' at the other.



The world seems very different when you are on the outside of power and not the inside.



Powerful consumers have the power (and tendency) to destabilise, become corrupted, over-represent the far-right end of consumer politics, and support the status quo, precisely so as to maintain their own status and to reproduce themselves or others in their own likeness.

However, to be fair, these 'committees-of-status' can also be excruciatingly horrible, exhausting, fruitless and hard work. Many consumers don't understand how difficult it is to sit on committees where you have no power and little authority.

Mental Health Council of Australia (MHCA)

The Mental Health Council emerged out of the embers of the National Community Advisory Group in Mental Health in the late 1990s. As members of NCAG we knew that consumer access to the 'real' decision makers would fall dramatically. No one listened to us but this is exactly what happened. Many professional and other organisations were lobbying hard. They were annoyed by Minister Howe's foresight. The new minister was Michael Wooldridge and he killed off NCAG and created something altogether different and non comparable. We lost out.

The national body which was to represent all interested and 'national' groups bore no resemblance to NCAG, whose membership was only consumers and carers. I was asked to be the interim chair of this new organisation. At least that was something, but the offer was inconspicuously withdrawn less than a week after I was approached. Apparently Minister Wooldridge wasn't quite ready for a consumer chair. However, this was not the important thing. The important part was that consumer groups and organisations have rarely been 'national'. By our very nature we are local. Our groups are local. The criteria for this new body defeated us before it was even up and running. In our eyes it was silly and our demise was obvious. It was a great shame.

Interestingly, carers maintained tight control. They lost nothing. This was because every single Chair of the Mental Health Council of Australia has been an influential father of an adult child with a psychotic illness. This is wrong and undemocratic. Why is it that problems such as this don't get called for what they are? It's not fair to consumers and it's not fair to those of us who have the 'wrong' diagnosis. I expect and hope the MHCA will come out with a statement at some stage as to why this is continuing to haunt their legitimacy in the sector. Maybe there is a good answer.

As carers dropped in, consumers simply dropped out. We definitely did lose important territory we had gained through so much work by NCAG. This was felt acutely with the forced demise of

the first National Mental Health Consumer Network. As the only truly democratic consumer member of the MHCA, the network in all its raw machinations was, at least, founded in the grist of truly authentic experience. With our network gone the MHCA was left with the embarrassing and difficult problem of only having three specialist consumer organisations/networks in its membership. They were blue voices (beyondblue), GROW and the Australian Private Consumer and Carer Mental Health Network (APCCMHN). For many of us these three groups were insufficiently grounded to fulfil the space left by NCAG. Out of more than 40 member organisations, only three had a consumer presence – hardly good enough – but MHCA was slow to act decisively.

The tragedy of losing authority at a federal level is not total, however. The Mental Health Council of Australia was forced to create two mechanisms to try and right the wrong.

The National Mental Health Consumer and Carer Forum (NMHCCF) **(<http://www.nmhccf.org.au/>)**

This is a group of consumers and carers who meet regularly, discuss important issues, write position papers and generally try to keep tabs on the major issues of the day.

Unlike NCAG, which had an open door to the Minister, the NMHCCF reports to the Mental Health Council of Australia. The council seems to be very supportive to the needs of consumers to be heard and heeded.

The MHCA website has a lot of information about the NMHCCF.

The National Register of Mental Health Consumers and Carers (NRMHCC) **<http://www.mhca.org.au/index.php/consumerscarers/the-national-register-of-mental-health-consumers-and-carers>**

Much of the meeting attendance arm of NCAG's activity has been taken over by this group of consumers who nominated and were approved by the Mental Health Council.

This is an interesting process. There are good things about it, in that it divides the meeting-sitting part of national consumer work from the national deliberation, thinking and debating arm, which remains the endorsed function of the NMHCCF. Those of us on NCAG have memories of being 'committee-ed out' and also having to sit on committees where we did not profess to have expertise. With a larger number of consumers involved, the workload can be eased and people can stick to the areas in which they are particularly knowledgeable or know someone who is. This is a great move.

Consumer Businesses

Whenever opportunity knocks there will be someone who will take advantage of it. The past decade has seen the emergence of consumers, either on their own or in partnership, establishing their own businesses and selling something that is important to them (and us) in mental health sectors around Australia. Depending on one's politics, the product being sold and this type of enterprise can be seen as either a terrific new addition to the market, or something that represents a retrograde step.

Consumers running sophisticated educational courses and showing that they are absolutely capable of doing so profitably will continue to silence some of the critics. It also gets consumer programs away from government grants, which always come with strings attached and a huge amount of annual reporting, taking up a disproportionate amount of time to the money made available. Of course, small business also comes with its fair share of paperwork and risk.

Thirdly, it enables consumers to make up their own minds about whether something is worth their time or not, and finally, it can, if pitched well and run efficiently, put emphasis on ‘peer support from a consumer perspective’⁴. It’s about being recognised, being creative, being organised, being good with money, being reflective and, for many, demonstrating publicly what we know privately: that in terms of pedagogy we are more accomplished than most educators who are brought in to educate us.

We all need to live. Consumer run enterprises need to make a profit. However the likely participants may have no discretionary funds. Because of the rapidly growing number of consumer employees, particularly in the psychiatric disability support sector, most of the places in some private consumer-run courses are used up by employed consumers, whose places are paid for by the organisations they work for. Even though it is usual for a few places to be set aside for unwaged consumers, this invariably raises the possibility of creating a ‘scholarship kids’ mentality. Unintentionally, perhaps, emphasis will swerve towards the majority and the curriculum can be compromised. Knowledge is power, but in this scenario, some can afford to get the knowledge and others cannot⁵.

Some entrepreneurial consumers are attractive ‘finds’ for non-government organisations with money. Quality control is sometimes questionable. Rabid self-promotion and making decisions on the basis of profit rather than the content and pedagogy of the programs offered, not only to the people undergoing the training but also to the consumer movement in general, is becoming a big problem.

Finally, some ethically questionable practices have taken place, such as using copyright law to register terms, ideas and content that the consumer movement has been using collegially for generations – “Mad Pride,” for example.

The Growth and Growth of Psychiatric Disability Support Sector

Over the past decade a phenomenon has taken place around Australia that has seen governments across Australia pumping huge amounts of money into the non-government sector.

The psychiatric disability support sector (PDSS) used to be our oath buddies. They were small, underfunded and had to fight very hard to wrestle any money from the clinical sector. We were given space to write and found political friends and allies there. They supported and protected activists, advocates and would-be writers, poets, artists and those yearning for fame. We liked their buildings that were often run down, but that so lacked the shiny refurbishments of competitive managerialism.

These organisations now have new, profitable roles. They are being funded to provide services. And with all this money come rules, regulations, throughput and performance indicators

⁴ See Mary O’Hagan’s Peer Zone and Shery Mead and Chris Hansen’s Intentional Peer Support.

⁵ Some courses are organised in such a way that they are purchased by an organisation and the organisation carries the cost of providing the education free to participants (see Peer Zone, for example). It is then up to the organisation to do the moral thing and provide half the places to consumers who are not their employees.

affecting how organisations are governed and how they must use their money. More than this, they are competing with each other, failing to share ideas because of commercial-in-confidence imperatives and ... they are expanding exponentially.

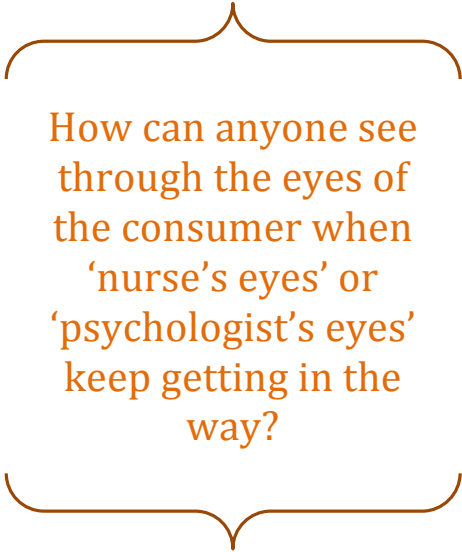
What has evolved is a sector that can no longer be the crucible for consumer activism and dissent⁶. The ethos that once underpinned the PDSS is being seriously undermined by its own prosperity.

At the same time, other forces are at work in this rapidly expanding environment. Some services and organisations have truly embraced the 'peer' ideology. Psychiatric disability organisations are providing leadership and resources to enable consumers to perform potentially powerful roles within the organisations. Unfortunately, these positions are largely unregulated and consumers are being asked to do things, such as consulting and recording in the private records of other consumers, which totally contradicts a consumer code of ethics.

Other ethically suspect practices are being forced on consumers who come into these low-paid positions. Often they do not have a background in the consumer movement, they do not have connections, networks, grassroots ethics, or a grasp of the consumer and survivor literature. Neither do they necessarily have a commitment to not only work from a strong consumer perspective but also to find some way to challenge and change harming and/or hurtful practices. Many are either being supported/managed by workers who know nothing or very little about the consumer body of knowledge and expertise, or they are not supported at all.

In some organisations, and in some towns, there is a lack of trust between those who use services and those consumers who are now working in those services. Money and power cause rifts. It is hard for some paid consumers to admit their lack of knowledge of the consumer agenda, the movement and the importance of critiquing power when it is precisely that power that runs the institutions that employ them. Some are proudly ignorant. They affiliate themselves with mental health 'professionals' and see themselves as different from 'their' clients. Some trade consumer authenticity and core knowledge for status. No one seems to be picking this up and challenging it.

All this is being made worse by the criteria that are being used to create good interview questions for potential consumer workers. Many employers still look for people with clinical or 'case work' qualifications and experience for these positions, believing that their position as consumers is secondary. This is problematic as the most fundamental criteria for appointment must be a strong consumer perspective. Those who wear two hats (are both qualified clinicians and consumers) often find it even more difficult to fulfil their role and critically reflect on and resolve the tensions. Unintentionally perhaps, the service is creating a most difficult job. How can anyone see through the eyes of the consumer when 'nurse's eyes' or 'psychologist's eyes' keep getting in the way?



How can anyone see through the eyes of the consumer when 'nurse's eyes' or 'psychologist's eyes' keep getting in the way?

⁶ A small example is the disappearance of drop-in centres, which were places where people gathered and shared lots, including insight into what it's like to be a consumer in this world. These places were smoke-filled and coffee cultured but they were enormously important; a bit like the Maltese Bocce club at the end of my street or the gatherings of housewives in the 1950s that turned into mini think tanks for women's emancipation. However, new funding arrangements have forced PDRS services to 'program people to death' and they call it 'recovery-centred'!!!

Struggles for identity are common. At this point in the ebb and flow of the consumer movement tussles and ideological debates about how, when, why and who should be employed and under what conditions are, and will remain, central issues.

Consumer Body of Knowledge

The final major change in this era of consumer employment has been our capacity to think, research and write about the consumer body of knowledge. For the first time we are able to be proactive and not react to others' critiques, discourses, or agendas.

We now see ourselves as 'experts' and over the past few years this has morphed again so that instead of claiming that we are 'experts by experience' or 'experts in our own lives' we now argue that we are experts in the mental health system, experts in alternatives to psychiatry: all sorts of experts in all sorts of things. In the early days of the movement we didn't have amongst us people who were paid to think, research, write, critique and present from a position of expertise. This is something special.

We also have unpaid consumers who provide a complex and sophisticated contribution to the consumer body of knowledge. These are unsung heroes. It's imperative to remember that only a small number of consumers have paid work within the sector and our brains are no bigger, our arguments are no more persuasive, and our contribution is no greater than others who also want to be part of the debates. In the early 1980s all we had was a big closet and tokenistic storytelling. Today everyone is, rightfully, horrified that during that period of time we were so marginalised. We have come some way **and** we have lost some ground to money.

The importance of moving from 'representative' to 'expert' is a hallmark of the mental health consumer movement of 2013. Traditionally, within our movement disempowered consumers put their hands up for every committee, every consultation, anything that was coming along that had the potential to turn us from a drop-kick to a hero – or that's what we thought. We were desperate to change our lives, we wanted reparation... and a tiny bit of power.

We now have a situation, so much more efficient, where we are respected for our areas of particular expertise and we feel OK to handball other tasks and committees on to someone else who has made this field their area of interest. This reflects a maturing mental health consumer movement.

Second National Mental Health Consumer Network

After the sorry demise of our first attempt to have a network, everyone has been circumspect about this new one, particularly around how it is set up. It's desperately needed to fill the huge hole in consumer 'representation' to the Mental Health Council of Australia. We know that. What we don't know is how to set it up in a way that will prosper regardless of the pressures we know will be placed on it.

This enormous pressure to succeed is the name of the game for consumers everywhere. It's bound up in the politics of oppression, the politics of gender, the politics of ethnicity, the politics of envy, the politics of self-importance, the politics of born-to-rule, the politics of capacity, the politics of disability and the politics of recovery. It's a complicated affair not helped by poverty. Even relatively small sitting fees are fought over, understandably, by people who have nothing. It emphasises our reality that money earned is worth so much more than money gained by someone else's largess.

We know this new network is coming very soon and we wait hopefully for a network that is functional, fair, furious in championing collective need, and strong enough to stand up to institutional forces which pervade every decision made ostensibly for our benefit.

The last five years

By the end of the decade I received a reprieve from my downward trajectory from my pioneering career. Thank goodness. Despite still raw scars, my history and work was about to be appreciated. With Our Community, we made a successful application for a tender from the Victorian Mental Health Branch to provide initiatives including education and resources for Victorian Consumers.

Our Consumer Place

Our Community, a major resource for the community sector took us on board and was surprised. Our groups were different from their other initiatives; smaller, grounded, idiosyncratic and sometimes disorganised. However our responsibility fairly quickly broadened to try and reach as many consumers as possible. I was in my element. Thinking, writing, teaching, community development were in my blood. Unfortunately, like so many people who have been bullied at work, my confidence was down. Far too frequently I hid my work assuming that displaying it would lead to yelling, slamming doors and constant criticism. This did not happen and slowly I came around if but somewhat idiosyncratically. Thankfully Our Community and our funder, the Victorian Department of Health supported us materially and in other ways.

We named ourselves Our Consumer Place (OCP) remaining totally ignorant of the fact that our acronym OCP was exactly the same as the Office of the Chief Psychiatrist. Oops! I believe that this is one of the most sophisticated initiatives of this government. It is such a privilege to have paid time to think and write – at last to use my intellect as it was supposed to be used. We have reclaimed material from the past which is priceless and explored new ways of understanding very old problems. This was urgently needed. Amongst the conceptual work we have undertaken we have rewritten the rule book about how meetings with consumer members should be run, relooked at consultations and new ways to make them work, written about clinicians from a consumer perspective and consumers who are qualified educators have taught others how to run participatory workshops rather than lecturing.

The list of tangible achievements go on and include a Mental Health Services Gold Award in 2011 which helped us to cement our achievements and me at last to feel that my 2004 Australian Human Rights Award was deserved. Thank you to all the consumers who have contributed so much to Our Consumer place since our inception – Cath Roper, Jon Kroschel and Flick Grey - people that have given so much time, passion and intellect to our consumer cause.

Conclusion

All social change movements change through time and adapt to changing social conditions. The consumer movement now supports a determination to have operatives 'inside' powerful institutions such as psychiatric hospitals, Area Mental Health Services and so on to enable incremental change to continue. The movement also supports those consumers who stand outside and demand revolution. None of us should demean the other. Social change can one day be incremental and the next day be a landmark court case.

In the end, as important as the mass movement is and should be, what matters most is the health of the consumer workers and political fighters; regardless of whether they are inner-operatives or warriors-from-outside. This caring, supporting, educating, listening, facilitating, story-sharing and sometime 'bumptious interfering with that which is wrong' is what the consumer movement is actually all about. The winners will be consumers everywhere.

What emerges in the future will depend not only on the success we can make of whichever of the different courses the movement takes, but hopefully we can (with all our differences) also remain sufficiently humble individually and temperate collectively to enable the movement to steer safely through strife and avoid any more internal combustion.