

Consumers as Educators in the Mental Health Field:

*Bridging the Conceptual and Attitudinal Divide and Getting
Positive Systems Change.*

From a talk by Allan Pinches,
Consumer Consultant, at a discussion forum on February 27, 2003, for the
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Consumer participation in mental health services – both clinical and Psychiatric Disability Support – is increasingly becoming recognised as an important resource for planning and development within services and a vehicle for positive systems change.

An emerging theme is that consumer participation, when properly implemented, is not just an add-on but can be a whole new way of doing things. That is the spirit of this talk.

It's a pleasure and a privilege to be speaking to you today, as consumers, psychiatric nursing educators and other interested service providers and distinguished overseas guests. For graduate nurses entering the psychiatric nursing profession and seeking to uphold the quality and standing of this important discipline, in the face of what might be called "slings and arrows" within the healthcare system and the wider community, regarding all matters psychiatric, I commend your courage and determination. For you, and the consumers striving for better understanding – you're going to need it.

Today I'll be talking particularly about Consumers as Educators in the mental health field. I will seek to draw out some key themes which I hope will stimulate discussion in a short while.

I want to emphasise that the points I make today are drawn from the work of many scores and hundreds of people active in the mental health consumer movement -- making diverse contributions, over a long time, in many places, largely voluntarily, with courage and vision, often with considerable personal risk and sacrifice.

As with any genuine human rights and social change movement, the mental health consumer movement through dedication and hard work of many people slowly and often painfully has gradually brought about positive change -- emerging from cumulative "streams" of thought and activity, coming from many tributaries, which retain their individual importance.

Consumer Consultants throughout Victoria and many consumer reps working with them are basically working in a systems advocacy role – with limitations on the amount of

individual advocacy we can do. We do provide some information and advice to consumers on request and receive feedback and suggestions through a number of methods such as: forums, advisory committees, interviews, surveys, focus groups, ward visits, suggestion boxes, etc. This all follows on from the world-class consumer-based research and development work of the Understanding and Involvement Project. (U & I) which was a bridgehead for consumer participation from the late 1980s to about 1996.

In the Northern Area Mental Health Service, which includes the Cities of Darebin and Whittlesea, I convene a 12-member group called "*Thinking C.A.P.*" – northern Consumer Advisory Panel – which works on a three point model as an advisory group, a pool of consumers to work on other committees and interview panels within services, and as a special project group in its own right.

The name "*Thinking C.A.P.*" denotes not only that the group is a consumer advisory panel, or that it aims to be a source of bright new ideas – but to make the somewhat political point that, yes, consumers can think!

Projects this group has been involved with – in collaboration with the Consumer Consultant Project and with great support from management and key staff -- includes pioneering consumer advocacy training, consumer participation in employment interview panels within clinical services, preliminary research on consumer gender issues, designing a "modular" inpatient unit group program adapting people's needs, and a new system of receiving and processing consumer feedback and suggestions.

We have developed a good relationship with the Area Manager and service managers, and a number of staff who hold "Consumer Relations" portfolios. We also work closely with the Quality Improvement Worker, Clinical Nursing Educator, Senior Occupational Therapist and others.

The members of the panel are becoming more and more immersed within consumer rep roles within the Area MH services, and beyond.

While consumer participation can be defined in a number of ways – perhaps one of the most useful ways is: for the consumer to be involved with the development and implementation of their own treatment plan; with full information; a range of choices; psychosocial and alternative approaches as well as medication; informed consent; and for the consumer's preferences and concerns to be factored in.

Well documented international research shows that consumer participation in treatment planning provides enhanced outcomes and more chance of co-operation with treatment regimens. Consumers often have good insights into what treatments help in particular situations or what support would be most effective. Problems can also be picked up earlier, and corrected. Better recovery and long term outcomes can often result. Consumers gain in self esteem, empowerment, and have greater control over their lives.

However the consumer participation that gets the most "press" within publications in the field, is consumer participation in service planning and development. And the list often goes on to include service evaluation, recruitment, delivery, training & education. Consumer participation is based on the idea that consumers have unique knowledge and insights into problems and possible solutions within services.

Consumer participation has the potential to be a powerful engine for innovation and change in mental health services – with consumer-driven reform agendas and collaborative projects in mental health services making some headway -- but many improvements are still needed.

Emerging potentials of Consumers as Educators and surrounding issues...

Consumers as Educators in the Mental Health field would seem a logical further step -- one which Merinda Epstein and other consumer advocates have been calling for over a long time and which Cath Roper in her Consumer Academic position at the Centre for Psychiatric Nursing Research and Practice here at Melbourne University, is attempting to translate into reality. A key strategy Cath is using is the gathering together of a new coalition of interested consumers – called Psych Activism and Training, or “PAT” – to try to advance such initiatives.

Change will come with collaborative efforts, hard work, consistency and dedication -- as many movements in history have shown.

From a synthesis I have drawn from many settings, it seems to me that change often involves:

- having a vision as a guiding influence for positive change;
- keeping most “enlightened” principles in the forefront;
- using creative thinking;
- asking questions about how and why certain things came to be, and how things might be made better;
- looking at problems from many perspectives;
- seeking commonalities and understanding differences;
- exploring many possible solutions to the problems;
- assessing the barriers and constraints to change;
- working out many possible ways to overcome barriers so that all parties can benefit;
- trying to build a case for change;
- developing alliances or partnerships;
- trying some small goals and being ready to graduate to larger ones;
- being willing to evaluate, discuss, review and try something else... etc.

When it comes down to it change processes are not just a matter of cogs and levers, policies and practices...bringing about meaningful change is largely about winning over hearts and minds. It is about changing cultures within services. It is about seeking to minimise any and all attitudinal barriers. There are also many conceptual barriers in the mental health field which also need to be addressed. These can be embedded into the service procedures or in aspects of medical model approaches.

Some possible consumer participation activities with an education approach

There are many exciting ways that consumer participation could be developed in the interests of disseminating unique consumer knowledge and insights -- if the good ideas and energy are backed up with financial, organisational, intellectual, informational and "people-power" style resources.

It is possible to imagine innovative projects such as:

- Consumer conducted participatory action research projects, in social, service and clinical areas.
- Consumers as speakers at many service provider conferences.
- Consumers contributing articles to professional nursing, social work, psychiatric or psychosocial rehabilitation journals. This already happens to some extent, particularly in disability support.
- Starting a consumer-run journal/ newsmagazine. Such a project, and in fact any consumer-driven work would need to allow for a diversity of voices reflecting the wide range of conceptual understandings, emphases and philosophies about mental health that all stakeholders bring to the discussion table. There is a wide range of views, among consumers as much as any other group. It is a highly subjective matter whether we are talking about: "madness"/ or difficult life crises/ or spiritual emergency/ or alternative views to the dominant social order/ and etc.
- Publishing of consumer perspective material on the Internet, in various kinds of books, in media outlets, and issues papers. This could include community radio programs and community TV. Perhaps a MH consumer media unit could be established. Media production starting at the community level and building up to mainstream programs have been an approach that has worked well for Aboriginal communities, women's organisations, gay and lesbian groups, and culturally diverse groups.
- Consumer perspectives presented in video, CD ROM-multi-media, audio tapes and other educational and training materials in the field. Ideally, these would be largely consumer produced.
- Music, theatre and film presentations. Street theatre/ community theatre in schools. Sketch comedy or variety revue in the interests of professional and community

education, giving messages in entertaining ways. This could help to liven up conferences of professionals.

- Consumers speakers bureaus, and a pool or register for consumer advocacy and rep work which service providers can access. The VMIAC has been developing such a register and looking at enhancing its information and education functions.
- Training courses for consumer speakers/ educators. And, perhaps, in line with an idea Merinda Epstein has proposed in a recent paper and again tonight, it would be wonderful for a centre for mental health consumer studies to be set up at a tertiary institute.

Many other ideas are possible – and I expect there will be many good ideas explored by all of you here tonight – but we need to coordinate our efforts, gain the support of governments and education authorities, and lobby for adequate funding and support.

A really important issue is for consumers to be properly paid for their work, in recognition of their unique knowledge and experience – and frequently insightful ideas for developing better service systems which better fit the need of consumer's needs.

Some difficult areas we all need to discuss...

Some of the matters I am about to touch upon are not meant particularly as criticisms of service provider attitudes and practice. They are instead an attempt to illustrate, ask questions about and, understand what are the dynamics at work and what are the causes of problems in the way consumers say they are often viewed and treated by staff.

And they are intended to stimulate discussion today about how such issues might be addressed – and in particular to highlight the need for the consumer perspective to be included in professional education in the mental health field – so that staff can have a clearer understanding of the lived experience of consumers. This would also contribute to better communication and more collaborative and effective implementation of treatment.

VMIAC research, and many surveys and focus groups, have heard from consumers that if there is one thing about the mental health system they could change, it is the attitudes of mental health service staff.

Users of mental health services often say that in addition to the stigma in the community about mental illness, some of the worst stigma they encounter is within the mental health system itself. They express the wish that service providers – doctors, nurses, social workers etc – would show greater respect for their humanity and dignity.

Many consumers say that the perceived disrespect and judgemental attitudes often coming from staff can be most unhelpful and set back chances of recovery – but when staff “go the extra mile” to be friendly, polite, affirmative of the consumer as a person, engender hope and provide constructive advice and assistance -- for instance about setting goals and steps to achieve them -- these positive factors can make a tremendous

difference in people's lives. It's not exactly rocket science. Consumers often say: "Treat us well and we will get well sooner!" There is a growing body of anecdotal evidence and even empirical research to back this up this arguably self-evident clinical reality.

Possible helpful factors that consumers talk about is for staff to be able to listen, empathise, take into account people's stated needs and wants, try to meet those needs, refrain from judgements, and for staff to engage in critical self-reflective practices, wherein practitioners self-challenge prejudicial and stereotypical thinking about people with mental illness or particular diagnostic groups.

Lets face it, there is a lot of baggage in the early history of psychiatry about patients with mental illness having "moral weakness" or being somehow to blame for their own fate, which can creep in, especially in stressful clinical environments. There is also a lot of cultural "crap" – that's a new scientific term I think -- about mental illness within society – you know "Ken Bwooze has gone absolutely mad" and misleading media headlines about "psychotic killers", and even the huge number of colourful synonyms for being crazy people use every day -- and service providers are not immune to this.

And the medical model often seems to have systemic side effects which can create various sets of pejorative ideas about people, where patients or consumers in a busy service setting – and we consumers can sometimes be difficult or demanding in some ways, or have inner experiences that can result in outer, supposedly "strange" behaviour, as well as making very reasonable requests or challenging things we find unacceptable -- become seen as something like naughty children who need to be put back in their place.

Questioning or resisting any aspect of treatment, or even seeking alternative treatments, can often be pathologised – labelled as non-compliant or lacking in "insight." Our actual knowledge and insight is often discounted and ignored.

Consumer problems with some medical model approaches

We consumers often feel that the focus of the medical model is too narrow, and thus damaging.

Problems for consumer health and wellbeing can arise if the medical model is implemented in treatment in ways consumers may claim:

- focuses on symptoms and not the whole person. There is a tendency within the medical model for service providers to in some ways "objectify" the patient;
- is reductionistic of the many complex factors of a human life, concentrating mostly on a supposed "chemical imbalance of the brain" which only medication can "fix."
- locates the "illness" discretely within the individual, without considering the wider context of other social pressures and issues that contribute to mental health problems.

- does not seek to “know” the person and his or her individual circumstances, character, or coping efforts – but is based on a rather superficial application of a symptom checklist from the D.S.M. IV text.
- contains strong elements of self fulfilling prophecy because of the way it downplays hope of recovery, and routinely hands out starkly negative prognoses;
- tends to overlook the role of the individual’s own efforts in recovery and illness management;
- looks mainly at people’s deficits and not abilities;
- largely ignores the many and complex social underpinnings of mental illness. This includes the life difficulties often experienced by people who seek to explore alternatives to the dominant paradigm. It is hard for people to “swim against the tide” but it can be argued that our society is richer for its poets, artists, visionaries, dissenters, and mystics;
- eschews the spiritual dimensions of mental health and illness;

One sometimes gets the sense that whatever we say is judged through a filter of our supposed “madness” – so our stories, needs, concerns and requests are often discounted because we supposedly don’t know what we are saying, and we end up getting little say in treatment decisions.

Towards improved MH service environments: can we build new bridges together between “Us and Them?”

I think that in busy mental health services, perhaps most particularly but not exclusively on Inpatient Units, service provider staff can, over time, become somewhat worn down and frustrated by the stresses, slowness of patients’ progress and sudden setbacks, the negative emotional charge that the work often carries, shortages of staff, time, and resources, a sense of trying to hold back a never ending tide of mental illness, low recognition and adverse career factors of psychiatric nursing within the healthcare industry and unfavorable community attitudes about mental illness, and the ongoing sense of attrition – or daily grind of difficult work – does take its toll.

Even workers who start out with the highest of ideals and aspirations, wanting to help and bring comfort to people with mental illness -- can experience a slippage in attitudes and reduced resilience, because of a wall of negativity that can slowly but surely build up between the staff and patients.

Part of this is the familiar “us and them” – or siege mentality – that can build up in many service locations, with staff or the “usses” in their fisbowl glass “nurse’s station” increasingly disconnected from the patients, or the “thems” out there.

But it seems to me that there’s more to it than that.

- One commonly occurring factor appears to be what has been termed “clinicians illusion.” Service provider staff, particularly those on wards, tend to see us when we are at our most unwell, and form ideas about consumers as a group based on the caseload experiences. This can lead to a truncated view of consumers lives. We do have difficulties and needs within our lives in the community But we also do have real lives, with complex matrices of relationship, involvement and meaning.
- The “Othering” of people with mental illness is a phenomenon that has been discussed by a number of psychiatrists critical of some aspects of the field, philosophers and consumer advocates in many settings. This seems to be a carry over from social and cultural attitudes which place mental illness as something to do with “those people over there” – rather than a part of a continuum of human experience. Philosopher Michel Foucault is one proponent of this concept of “othering” which was noted in many settings within society.
- Any “Us and Them” dynamic, being largely a by-product of stigma, means staff are often afraid of showing vulnerability or so called “weakness” – not being “like them” or – heaven forbid – having any psychological difficulties themselves! This can lead to a kind of defensiveness which can interfere with the way staff regard and communicate with consumers. Training and rules about strict maintenance of “professional boundaries” combined with warnings not to let patients “manipulate you” don’t enhance relations with consumers, therapeutically or interpersonally.
- Medical model and the clinical gaze; pathologising all behaviours, speech and expressions of need, preference or protest.
- “Power relations” within a service can be negative and self reinforcing; There is a tendency toward bureaucracy, use of authority, and hierarchical systems – not to mention the need to cover yourself with legal requirements and endless “form-filling” and be able to justify yourself at a second’s notice. This type of service environment doesn’t tend to be very empowering for individuals – either staff on the ground or patients. It does not reward risk taking of doing things differently or more collaboratively, tends to discourage initiative, imagination, or getting involved with patients beyond the bare basics.
- “Turning off” or “de-sensitising oneself” when exposed to difficult situations, sensing the suffering of consumers and emotionally charged issues, is a common survival tactic – but it does not make for good or responsive nursing, or other service provision. Better solutions might include: de-briefing, or dare I say, peer support. Professional supervision is also very important. It may also be helpful to do some further study on particular issues, because understanding an issue can make it easier to handle emotionally.
- Fear of violence can emerge within what can be in many ways a negative environment. Consumers have many ideas about how to make things more pleasant and constructive for everyone, and it would pay to listen.
- Not understanding altered systems of meaning etc. assuming nonsense babble etc of consumers’ talk. There is often subsumed meaning in such talk, and an internal

logic, which makes it wrong to dismiss talk or reports about the voices as being about “their junk.”

- Shortcuts. There is a human tendency to seek easy answers. M Scott Peck posited in his classic self help book *“The Road Less Travelled,”* that the Original Sin was taking shortcuts to get what we want – nothing irrevocably aligned to sexual relations, (except in that example, matters of the context of the relations, such as consent, motivations, or true or not declarations of love.) It is often easier and more expedient to coerce and seek to control people than to seek to understand and asks them about and try to meet their needs. Expediency is a questionable virtue.

The challenges are ahead of us. There is much potential for Consumers as Educators to make a very substantial contribution to the mental health field.

As an emerging and potentially very influential application of consumer participation practices, Consumers as Educators has the potential not just to improve mental health services, and not just to improve clinical practices, and not just to make services better and create more favourable environments for staff, consumers, carers and others alike – which are all likely outcomes.

But the interplay and ongoing collaborative blending of consumer perspective knowledge and professional “practice” knowledge can create new and mutually empowering dynamics, and base of shared learning and partnership, which can “unlock” many new potentials in the work between staff and clients.

Allan Pinches,
Consumer Consultant for Mental Health.

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