People diagnosed with 'mental illness' doing things for ourselves

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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

Contents

Our Consumer Place Newsletter Bumper edition!

This is a MUCH bigger than usual edition of the Our Consumer Place newsletter in time for the end of the year and the summer break (and, yes, we just wanted to Include All The Things).

Wanda Bennetts' discussion paper on "representatives" is a particularly significant piece and we are very proud to be able to publish it here in our humble newsletter (it's already been cited by an academic journal!) Piers Gooding's thoughtful and thorough analysis of the proposed changes to the new *Mental Health Act* provides an in-depth study of how Victorian law measures up. Plus, there's LOADS of news, a very personal soapbox and other goodies. Enjoy!

And if you're having a break over this festive season, we wish you rest and enjoyment!

Consumer rep wanted: must speak for all of us? A discussion paper on “representatives”

- by Wanda Bennetts in ongoing collaboration with Flick Grey, Cath Roper, Ellie Fossey, Vrinda Edan and other members of PsychActionTraining group.

Introduction

Often when consumers speak publicly, we are expected to speak as a “consumer representative.” However, little thought is given to what it might mean to be “representative”. There are a number of challenges, including:

- different ideas of what it means to be representative, or people/organisations not really having thought through what it means to be representative;
- the word being used quite loosely or as a substitute for other types of consumer leadership and participation;
- ethical questions about whether or not consumers should even seek to be representative;
- a legitimate concern to avoid ‘speaking for’ other consumers in ways that risk silencing their voices; and
- inadequate resources for consumers to be able to act as representatives, if this is desired.

The purpose of this paper is to tease out some of the complexities surrounding the issue of representation so we can come to a better understanding of these issues. This paper does not seek to create consensus or provide a position. Instead, the intention is to highlight the issues and create a basis for reflection and dialogue. Also note that this paper has not sought representative views, although several people have contributed to the development of it.

> *Often when consumers speak publicly, we are expected to speak as a “consumer representative.” However, little thought is given to what it might mean to be “representative”. There are a number of challenges...*

Definitions

The Collins dictionary defines a representative as:

- a person or thing that represents another or others
- a person who represents and tries to sell the products or services of a firm, esp a travelling salesman. Often shortened to: rep
- a typical example
- a person representing a constituency in a deliberative, legislative, or executive body ... (http://www.collinsdictionary.com/dictionary/english/representative)

All of these definitions are relevant to our work – firstly, consumer “representatives” are typically expected to represent other consumers. This should involve consumers having a say in who represents them and there being means and resources for communication back and forth between the group and their representative. For example, if a consumer advisory group chooses someone to be their “representative” and this person has opportunity and resources to consult with the group and to communicate back and forth, then s/he might be able to represent the group.

Secondly, in some ways we are “selling” consumer perspective, we are “representing” consumer perspective. Thirdly, we are often expected to speak as a “representative, typical consumer”, and our contributions may be rejected if we are not seen to be “typical” (or not like “our” consumers). “Representativeness” has different meanings and is often used against consumer workers who may be accused of “not being representative”. One understanding of “representativeness” – more common in quantitative research – is whether a view/opinion is “typical” or “representative” of a defined group of people. This view of “representativeness” relies on the assumption that if a group of people are sufficiently alike, then their views/opinions are also likely to be similar or the same. Using this assumption is neither accurate nor useful when considering the contribution of consumer perspective in organisations. The other – which is more common in qualitative research – focuses on the views/opinions/experiences themselves, rather than on whether the people expressing them are “typical” of a group. In other words, views/opinions/experiences on an issue/topic are acknowledged as diverse, so that it is considered important to maximise the range of views/opinions/ experiences that one can draw on in order to “represent” those views/opinions/experiences. To capture the breadth of views needed to be “representative”, resources are needed for extensive engagement and dialogue.

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When “representation” or “representativeness” is questioned, there is often an unspoken issue/agenda that is about power and undermining the credibility of the person(s) and/or their views (Happell and Roper, 2006). Interestingly, this is also evident in gender relations, interprofessional relations and staff-management relations, as well as in consumer-non consumer relations in services. These kinds of dynamics are always most potent for the least powerful in any of these relationships.

The final definition of representation is a more formal, political idea. Political theorist Edmund Burke elaborates on this final definition, suggesting that a political representative shouldn’t simply communicate the wishes of those who have elected them, but also use their own judgement, even when their own views do not reflect the majority of the electorate:

> ...it ought to be the happiness and glory of a representative to live in the strictest union, the closest correspondence, and the most unreserved communication with his constituents. Their wishes ought to have great weight with him; their opinion, high respect; their business, unremitted attention. It is his duty to sacrifice his repose, his pleasures, his satisfactions, to theirs; and above all, ever, and in all cases, to prefer their interest to his own. But his unbiased opinion, his mature judgment, his enlightened conscience, he ought not to sacrifice to you, to any man, or to any set of men living. These he does not derive from your pleasure; no, nor from the law and the constitution. They are a trust from Providence, for the abuse of which he is deeply answerable. Your representative owes you, not his industry only, but his judgment; and he betrays, instead of serving you, if he sacrifices it to your opinion.
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> -*The Works of the Right Honourable Edmund Burke. Volume I*. London: Henry G. Bohn. 1854. pp. 446–8, quoted on Wikipedia - http://en.wikipedia.org/wiki/Representative_democracy.

Questions:

- How do you define representation?
- Is there a definition of representation that is more useful or more ethical in the context of consumer perspective?
- If the goal is to get a sampling of views, how many views would be considered to be sufficiently “representative”? How do we know what is “enough”?

Context

The consumer movement provides ***expertise*** to the mental health sector. Representation is just one way of doing this. Other ways of providing expertise are through education, systemic advocacy or the provision of consultancy, to name just a few.

When “representative views” are sought through consultation, there must be adequate resourcing to enable an ethical and effective process. Too often, consultations are approached in a way that sees them as a default and ‘the easy way out’. There also needs to be accountability, so that advice received from a consultation is acted upon, unless there are compelling reasons not to. All too often, “consumer representatives” are consulted with, but no action is taken as a result of these efforts, thereby substantially undermining the process. Organisations often leap into representative mechanisms as they are relatively cheap and easy to set up and they tick the participation box. The organisation also retains control over who is selected and can ignore expertise that may not be welcome.

By functioning on ‘automatic pilot’ over the years, people have come to ask for a consumer ‘rep’ without much thought of what that really means in practice or in principle.

Sometimes representation can merely be the word that is used, with no real thought or sense to the meaning of the word. By functioning on ‘automatic pilot’ over the years, people have come to ask for a consumer ‘rep’ without much thought of what that really means in practice or in principle.

It is important to recognise that representation is just one role or function. It has its place like other functions and needs to be selected as the most appropriate way of doing the work when this is the case. Representation may be sought when we want to know either the most common view of consumers, or the range of common views, for example. But the provision of expertise is a different function from representation - experts can agree or disagree; indeed, disagreement can be a valid and useful way to grow views, critique arguments, and develop novel strategies and solutions for moving forward on issues.

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Representative mechanisms are limited in what they do for the consumer movement. For a start, they can be discriminatory (because only some people are allowed to participate as “representatives”). They also do not of themselves lead to capacity building, broader development of consumer leadership, critical mass or the embedding of consumer perspective in all endeavors. If there are no resources attached, then the “representative” is put in a bind because all their consulting may have to be done voluntarily or within paid time (of which there is usually precious little). Someone in this position is then vulnerable to being seen as “unrepresentative” by both service users and by the organisation. This leaves consumer “representatives” at times in an unenviable position. Conversely, it may provide an opportunity for a consumer to feel s/he has the only important view and this person is able to put the view across under the guise of being representative.

Questions:

- When you ask for a representative, what are your expectations?
- Do you usually think about the most appropriate way to facilitate consumer leadership and participation or do you generally just ask for a representative without thinking much about what you are really wanting?

Philosophical/ethical/political questions

Consumers working in the field are generally employed by an organisation, or put themselves forward for selection, and become recognised as "representatives" by the mere fact they are employed/selected.

People doing consumer perspective work can face an ethical dilemma in positions where they are understood to be representing or pressured to represent others. Do the people being represented know that they are being represented or what is being represented? There is also a principle governing the practice of representation regarding the person doing the representing being selected by those they are representing. This is mostly ***not*** the case in mental health consumer perspective work. Consumers working in the field are generally employed by an organisation, or put themselves forward for selection, and become recognised as "representatives" by the mere fact they are employed/selected.

Questions:

- How should consumer representatives be selected?
- Are selection processes entirely open and transparent?
- What are the implications for consumer workers in organisations being employed by the organisation and then being asked to be representative?

A further issue for consumers as representatives is the potential danger of replicating what has at times been done in the system – people speaking on behalf of others. There are people who use services who do not want others to speak on their behalf, even if the "representatives" may express views closely resembling their own thoughts. Therefore, it is essential that representatives and organisations are very cognizant of:

- not speaking on behalf of others, unless they have expressly been given permission to do so;
- whether the representative is comfortable, ethically able and adequately resourced to speak on behalf of others;
- whether consumers want anyone else representing them.

A further issue for consumers as representatives is the potential danger of replicating what has at times been done in the system – people speaking on behalf of others.

Where a "representative" is aware of the ethical dilemmas involved, they may choose to work in ways that clearly reflect an ethical stance, for example, sending out their own meeting minutes to networks to try to keep the movement engaged with the work. While this might principally be one way communication, it is at least transparent and others are able to know what is happening if they are interested. Other things consumer workers might do include:

- drawing on their own experiences;
- speaking with colleagues and peers constantly;
- hearing from consumers using services to keep a finger on the pulse;
- drawing on information gathered via surveys, research, books, newsletters, etc;
- transparently declare their position by noting things like – "I hear many consumers saying ...", or "I have heard a few people say ..., but most seem to have a different opinion", or "My own opinion on this is ...", or "the info we gathered from 'x' says ...", or "the literature on that states ...", or "My colleagues and peers have said ... and I agree (or disagree) ..."

If the aim is for a representative view to be gained, there needs to be processes, time and money put aside so that this can be done properly. If it is expected to happen in a few minutes here and there within the usual working time of the 'reps', it does not allow for a process that adequately reflects what is trying to be achieved. In addition, if 'reps' are simply attending one meeting with no other formal time or links to do this work, it can make a mockery of the notion.

Questions:

- If you are expected to act as a representative (or expecting someone to act as a representative), what kinds of resources and practices would you need to have in place for this to be possible, both ethically and practically?
- Are you aware of the power relations behind a "representative" way of working?

Representation can be seen at times to be about trying to get a consensus view. However, there are crucially important alternatives to consensus including:

(1) Even if only one person holds a certain view or has a certain experience, that still matters (although it shouldn't be mistaken for being the majority view – we all know of instances where the squeaky wheel gets the oil);

(2) Consumer leaders can build up a form of collective expertise over time, building on their own lived experience and speaking extensively with other consumers, even if not specifically consulting. This often results in a capacity to speak of a diversity of consumer views, in a grounded way;

(3) Expertise may have a truth that stems not from being a majority view, but from deep thought and consideration, of an individual or a collective. This type of expertise is respected in other fields (e.g. a respected psychiatrist who differs from her colleagues), but often gets marginalised when coming from consumer leaders. Instead, we are urged to be "representative".

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Consumer perspective work offers the opportunity to capture a diversity of views. It is often not possible for these views to be condensed to a "representative" view and a question might be asked whether they should.

Questions:

- Should all views be condensed down to a single "representative" view? Why?
- Are you aware of practices of silencing?
- How do you deal with issues that are raised, but are not "representative"?

Representation is not generally what is expected of others from different disciplines, although it should be equally an issue for every member of a committee/team/group discussion. While the question "What do consumers think?" is frequently asked, people rarely ask "What do doctors think?" or "What do nurses think?" Although this may come from a well intentioned starting point that shows an interest in what consumers have to say, an underlying assumption that accompanies this question is that consumers can, should and do represent other consumers much of the time.

> *... we don't generally ask other staff to represent all others of their discipline ...*

This is an important issue as consumers are not a homogenous group any more than are people from other disciplines and backgrounds. There are many views shaped by many experiences. It is interesting that there are no guides on how to select a doctor/nurse/occupational therapist/social worker/psychologist etc. to be on a committee or share their point of view. Other disciplines are not generally asked to be representative in the same way consumers are - we don't generally ask other staff to represent all others of their discipline e.g. every time a nurse speaks or a doctor speaks, we don't expect that they are speaking on behalf of all nurses or doctors.

It would appear that people in these groups/disciplines do not trouble themselves nearly enough about the issues around their power and legitimacy to 'speak for' others from their own group/discipline and perhaps this contributes to not 'getting' the issue from a consumer perspective? In comparison, consumers are alert to issues of legitimacy surrounding 'speaking for' other consumers and take care about these issues in a way that might be good to see more among people in these groups/disciplines.

Questions:

- How do you feel about others speaking on your behalf?
- Are you comfortable speaking on behalf of others?
- Do we ask others to be representative of their disciplines? Should we?

An argument can be made that speaking or taking a view that is against the masses is, at times, the right thing to do and sometimes this is demonstrating leadership or knowledge that others don't yet have: other professionals are respected for this and consumer leaders should be too!

Conclusion

Representing is a role or function just like advocacy or education. Providing expertise is another function and it is noteworthy that experts can disagree. Indeed, disagreement grows views, helps develop consumer perspective as a discipline and can be a vehicle for critique. Expertise is not grown out of representing. Consumer workers are employed to bring expertise from our lived experience.

> *Representation has a place and it can be useful if it is done for the right purpose and the right reasons, it is properly resourced and it is translated into meaningful activity.*

Representation has a place and it can be useful if it is done for the right purpose and the right reasons, it is properly resourced and it is translated into meaningful activity. When there is no time within jobs to do all the consultation necessary to do representation properly, it may be time to take stock and make decisions about how to support representation or consumer leadership in the most appropriate way.

Questions:

- Having read this paper, have you changed your thoughts on representation?
- Is there anything you may do differently now?

Reference

Happell, B. and Roper, C. (2006) 'The Myth of representation: The case for consumer leadership.' In *Australian e-Journal for the Advancement of Mental Health*, 5(3).

Are there any links between being transsexual and Dissociative Identity Disorder (DID)?

-a request for help and information from a reader

I am writing this article in the hope of gaining some help and information. There are only two small articles on the internet concerning people who are transsexual and have DID - Dissociative Identity Disorder.

During my childhood, from about the ages of 4 to 17 Dad sexually, physically and emotionally abused me. I was born female and Dad was the only male I knew, the rest of my siblings were female and we went to an all girls' school. Probably from 4 years of age I started to dissociate, which put simply is leaving the body because of the horror that Dad was inflicting on it. So I would leave and watch from a distance and therefore be somehow distanced from the sexual abuse.

At 16 years of age I was introduced to the psychiatric system, this was in Brisbane in 1978 and even though I told the psychiatrist at the hospital about the sexual abuse, after 3 months I was returned home. For about the next two decades I was in and out of psychiatric hospitals, resulting in lots of labels, the main one being Borderline Personality Disorder; lots of large doses of medication of various kinds; lots and lots of E.C.T.; and of course lots of time in seclusion. All the psych system wanted to do was to dope me up so I would stop self-harming. They wanted me to stop my socially unacceptable behaviour. They never wanted to help me sort out the reasons why I used self-harm as a coping strategy.

During all this time I hated being seen as a female, all I knew was that females got sexually abused, ... In 2000 I had been accepted for gender reassignment surgery. It wasn't that I wanted to be a boy, I just couldn't live as a girl.

During all this time I hated being seen as a female, all I knew was that females got sexually abused, so my hair was kept short and baggy clothes were always worn. In 2000 I had been accepted for gender reassignment surgery. It wasn't that I wanted to be a boy, I just couldn't live as a girl. I have never had a relationship nor do I ever want one, that whole area is still very yucky for me. I had a Mastectomy and a Hysterectomy and my gender was legally changed to a male. That was the best thing I have ever done. I don't feel scared and vulnerable any more as I'm not in a female body.

For the past couple of years I have been seeing a counsellor, she deals with sexual abuse and the resulting effects of that, so she has some experience with DID. It has been during this time that a lot of our 'parts' have come forward and more cooperation is taking place. This counsellor is helping us to understand our past and the role each of us has played in keeping us safe. She is filling in a lot of the blanks and unravelling events.

Unfortunately the counsellor has never had a client who is transsexual and has DID and both of us are finding it hard to locate information about this. Hence my request to those of you reading this. If you know of anyone, or of any information out there about people who are transsexual and have DID, we would be very interested to hear from you. Thank you.

-Mark/Ballarat: chidgeyk@yahoo.com.au

National Mental Health Consumer Organisation Establishment Project

Consumer Reference Group Communique Sydney, 12 – 13 November 2012

Engagement, Communication and Participation

This work is being informed by the recommendations of the final report of the *Scoping Study to Inform the Establishment of a New Consumer Peak National Mental Health Consumer Organisation*[1] and the Australian Government response.

The CRG and the MHCA had their second meeting in Sydney on 12-13 November 2012. The NSW Consumer Advisory Group (CAG) boardroom was the venue for the two day meeting. NSW CAG is co-located with the Mental Health Association NSW (MHA) and Mental Health Carers ARAFMI NSW.

Engagement and communication

The CRG are keen to ensure the views of the diversity of people with lived experience of mental illness are heard and inform the establishment of the new organisation.

CRG members and the MHCA project team appreciated the opportunity to meet with NSW CAG, MHA NSW and ARAFMI NSW to discuss their core activities and current priorities, as well as their thoughts on the future national mental health consumer peak. The CRG and MHCA are committed to developing and strengthening collaborative partnerships and will be looking for opportunities to meet with other state and territory mental health consumer peaks over the course of the project.

> *The Consumer Reference Group (CRG) and the Mental Health Council of Australia (MHCA) are working towards the establishment of a robust and sustainable National Mental Health Consumer Organisation (NMHCO).*

The key communications consultant on the *Every Australian Counts* (NDIS) campaign spoke to CRG members and the MHCA project team about strategic communications and community engagement. Her presentation highlighted key strategies, which will be considered by the CRG and MHCA in the development of a NMHCO Establishment Project Engagement and Communications Strategy.

Outcomes

The CRG have maintained a high level of energy and enthusiasm and this contributed to a productive two day meeting. Agreed meeting outcomes include:

- the CRG and MHCA are beginning to shape a comprehensive NMHCO Establishment Project Engagement and Communication Strategy. Key aims of the Strategy will include:
    - communicating the broad project objectives
    - building and strengthening collaborative partnerships with state and territory mental health consumer peaks
    - identifying potential stakeholders and future national consumer peak members
    - developing processes to ensure the voices of grass roots consumers are heard, including people with a lived experience of mental illness who are marginalised and hard to reach
    - identifying and promoting shared opportunities.

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[1] Final Report *Scoping Study to Inform the Establishment of a New Peak National Mental Health Consumer Organisation* (2010). Craze Lateral Solutions: www.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-s-nmhcorep-toc

The Strategy will use a broad range of approaches to engage and consult with consumers, with a commitment to the use of appropriate language that reflects the consumer movement's history and vision for social justice.

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- following consultation with the CRG, the NMHCO Establishment Project Plan and the Environmental Scan on Governance and Related Issues[2] have been completed
- CRG Terms of Reference and Committee Handbook have been drafted and will be finalised out of session
- early work on a broad vision for the new organisation will be considered further by the CRG
- the CRG and MHCA will begin to canvas the views of people who have registered their interest on the www.mhconsumer.org.au website.

Promoting participation

The CRG has identified the engagement of marginalised and hard to reach consumers as a priority.

While the project website is an important communication tool, some people may not have access to information technology and a range of engagement and communications approaches are needed.

To help expand our reach and encourage greater participation, we encourage you to discuss engagement and communication with your friends and colleagues, particularly those without internet access. Please then visit the project website and complete a short engagement and communication survey [http://www.surveygizmo.com/s3/1100351/Engagement-Communication-and-Participation], including responses from the people you have spoken to, if appropriate and with their consent.

Register your interest

The CRG is committed to fostering genuine participation in this process by people with a lived experience of mental health issues and other stakeholders across Australia. Anyone interested in mental health reform and social justice is encouraged to register for updates via the project website. The website will also be used to post important messages that will alert stakeholders to opportunities to participate.

If you would like to keep up to date on the establishment of the NMHCO please register at www.mhconsumer.org.au.

Who are the CRG?

The CRG is populated with talented and skilled mental health consumer advocates committed to shaping a better future. Profiles of CRG members are included on the NMHCO Establishment Project website www.mhconsumer.org.au.

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[2] *Environmental Scan on Governance and Related Issues for the New Mental Health Consumer Organisation* (2012). Craze Lateral Solutions: http://www.mhconsumer.org.au/__data/assets/pdf_file/0014/1139/NMHCOEP-Report-Environmental-Scan-Final-Report.pdf

Plunging out of your Social Class! – By Merinda Epstein

This is an issue that has entertained my mind for many years. There are many reasons why I have not spoken about it before and many of these are around the fact that since I was 18 I have been embarrassed about my privileged background. For years I have gone out of my way to deny and critique it. Also, talking about this is a bit 'personal pronoun' and this feels selfish, certainly self centred. However over the last few years I have seen this syndrome in a number of other consumers and I wonder how common it is. No one speaks about it – or rarely. I've taken a gamble to explore this in the only way I can – just speaking for myself.

> *It wasn't a major psychotic breakdown or anything as clear cut as that.*

My Twenties

My twenties brought together several forces that were to largely shape my life:

1. It was when I was as a youth that mental distress caught me, largely by stealth. It wasn't a major psychotic breakdown or anything as clear cut as that. For most of my twenties I dropped in and out of university courses all over Victoria: from Melbourne to Deakin to Monash. No institution was spared. My fearful, disoriented, choking approaches to study and, more important, to people and institutions that totally phased me. Failure. My frayed and mixed up self running, running, running away.
2. I had no idea that I was running in front of demon illnesses of the brain and family denial. Instead, I just thought I was pathetic, a failure, useless, too dumb to do any good, a laughing stock, naive, plain crap really. Shame filled my body and my life.
3. My dealings with universities also handed me opportunity to rethink my ideas and dream about something very different from horses and farmers. We had opportunities within the Universities then to think about the big ideas in the world and this is the bit I hooked on to instinctively. A heady radicalism enveloped me eventually fuelled by the fact that I found my academic bearings in the fields of sociology and politics.
4. Emotional turmoil followed me shadow-like. My 'troubles' (everyone in my social class always called everything 'troubles') started to bring together diagnoses of anorexia, depression, anxiety, dysthymia but nothing much more than this and I desperately wanted more. Instead of something that would help me feel OK these "nothing" diagnoses led me further into the overwhelming conclusion that I was unbelievably hopeless and a disgrace to my family, my social class and my school.
5. A weird triage of my shame reflex came into my life at this time. Always it came back to my privileged education. I had let everyone down. I had been taught that I was born to rule and here I was drowning. I pretended lots of things at that time. I pretended I had kicked privilege out of my life, that I didn't care, that my education was elitist nonsense, that the school created the huge hurdle that I had so far totally failed to jump. In truth, my beliefs and the pretence all got mixed up fuelling social passing.

My School

Elite schools teach you a lot more than academic success. At my old school there was a religious underpinning, an over concentration in science and maths which disadvantages some, a sense of civic duty and lots of stuff about fulfilling promise and expectations. The motto of my old school is *Vincit qui se vincit* (She conquers who conquers herself). This is cruel and potentially damaging to all women with mental distress in their lives. Why can't I conquer it – this 'mental illness'? Am I perhaps a conquered soul rather than a victorious hunter? Do I even want to be a hunter? The one thing I do know is that I no longer want to be the hunted.

Falling Out of Your Social Class

I'm angry that such an institution as my old school heralds the fact that, "*Our gals* [it was an all girls school] *will be the future leaders, will reach heady heights in business and commerce, will be scientists, doctors, lawyers and opera singers."* Those schools never say, "*Our girls will be skilled and confident in staying on the right side of Centrelink and keeping appointments, our girls will have the capacity to live with tiny incomes and survive with their pride intact, our girls will have the sort of drive and self-confidence that will enable them to thrive as public 'nutcase' figures fighting for the rights of people diagnosed with 'mental illness' from within the 'movement' rather than from outside it*." These schools can't maintain this message because they must forever offer a prospectus that will sit well with those parents they wish to attract and hold. Bleeps and bumps, smears and pimples are all smoothed out of existence.

Two years ago I approached the school offering something very precious. A good speaker, I sold my credentials in mental health which are considerable now after twenty years. I spoke to the Headmistress (no principals here) and vice head but I totally failed to convince them I had much to offer. They said they were interested in relation to me perhaps talking to staff but I was obviously untrustworthy to let loose on the gals. They said they would contact me and were incredulous that I did not want to be paid. It is now a year and a half ago and I have heard nothing. I'm not surprised. They don't want us to exist. I'm a black spot on their radar.

[Schools in this class] pay attention to the civic duty inherited by those of us who are privileged to help 'the poor', 'the sick', 'and the less fortunate'.

Civic duty

Schools in this class of exclusivity pride themselves on teaching 'their gals' about their civic responsibility. They prepare young women for futures in philanthropy. They pay attention to the civic duty inherited by those of us who are privileged to help 'the poor', 'the sick', 'and the less fortunate'. They speak about humility sometimes but more often they speak about the duty of the upper class to 'give back' to the needy in some way. Contemplating this over many years I have decided it needs addressing.

The assumption is always that 'our gals' will be the benefactors rather than the receivers of this largess. In the world of this social class system and the schools they create and support in this country this lopsided view of social reality is a necessity. 'We are educating girls for leadership roles in society' is an everyday assumption but this leadership is conditional. Someone with a 'mental illness' who is a recognised leader in the mental health sector precisely because she speaks from the perspective of the person with the label doesn't quite cut it. An absolute division is made where no absolute division exists: the sick and the needy versus the well and the need fixers or the expert 'professional' who plies a trade versus those of us who must (by definition) lack expertise because we are the recipients of this trade in 'help'. Undercutting all this heady semantics are major issues of social class and privilege.

The reality is that we come away from class-controlled educational institutions with no emotional, pragmatic or social skills to survive in the tough world of disability pensions, receiving charity or public housing tenancy. Probabilities would suggest that there are many more 'girls' or 'boys' than me who have not ended up running the country, returning to leafy suburbs from which they came nor fulfilling their privileged promise. The sadness of this is that these schools actually de-skill adolescents for what might be the very real world for more than we all might at first think. I have a friend who was born into a multigenerational public housing family. I am constantly in awe not only of her skills at living on the breadline but also her pride in the way she lives. No matter how hard I try I rarely find pride in my day to day existence. I envy her and I praise her. She's a genius in areas we didn't cover in our curriculum.

I have a friend who was born into a multigenerational public housing family. ... She's a genius in areas we didn't cover in our curriculum.

Falling out of the nest. Thud

This is not a joke. It is a terrible reality for some of us (others have their own terrible realities). Growing up in a family that is privileged economically – which most certainly does not assume that this economic privilege equates also to social privilege, sexual safety or any other aspect of our existence – has its very own sets of admonishment. Shame is the main attribute in my life; profound, unshakeable shame. This is reinforced in a myriad of daily interactions with my extended family starting from how I could possibly say anything intelligible about mental health when I'm not a trained medical doctor (like them all – well almost), through to elephants in the room and a less than subtle silencing of me talking about things that are important to me. Highly successful siblings and extended family with attitude drive inner conflicts in me and I don't know whether to cry or punch them.

Meaning in the Landing

It is difficult to know whether the aspects of the way I am in the world are a product of nature or nurture and probably for me this is academic. However, I am sure that crashing out on my upper middle class life has been powerfully influential. I recognise my terrible hunger for praise which I seem unable to give myself, my need to prove myself constantly to myself and others, the fact that despite a National Human Rights Award and other signifiers of fame I know I am nobody of any import in my old world. The difficulty I have in accepting well meant criticism, my volatile interest in politics and my anger with both the economic and social right (my politics of origin), my tendency to want to verbally assert myself (listen to me, listen to me) and the myriad of other behaviours I so wish were not me. I know that some clinical psychologists would have a field day with this but I don't give them permission. The knowledge that has most helped me to understand my world is sociological in origin and not psychological. Crashing out of one's social class is a reality that deserves and needs sociological intervention not psychological.

I've tumbled out of acceptability long ago.

Conclusion

I'm proud of my radicalism although I would like a horse. I know that the representatives of the ruling class I was born into find me and my life incomprehensible. I've tumbled out of acceptability long ago. This piece does not pretend to speak for all people who were born into upper middle class, ruling class or professional families. Nor does it pretend to speak for all 'gals' who went to ruling class schools. However, I hope that by me being as honest as I can I might encourage other people to accept, respect and then push past the lesions of pervasive social class which leaves too many with deep scars of failure and shame. If by telling this story I can help even ten people reclaim pride in their lives I will be happy.

FEATURED ARTICLE

Victorian Mental Health Law Reform: Appraising the Summary of Proposed Changes to the Mental Health Act (Vic) 1986

– By Piers Gooding, PhD Candidate at the Centre for the Advancement of Law and Mental Health, Monash University.

Introduction

Each state and territory in Australia has its own mental health legislation, many of which are currently under review. As reported in the last two OCP newsletters, the Victorian Government recently released a summary of proposed changes to the *Mental Health Act (Vic) 1986*. The summary 'describes the government's policy intentions' for the new Bill in order to 'provide the community and mental health services with an opportunity to begin planning for implementation.' The proposed new Mental Health Bill, released as an exposure draft on 7 October 2010, is expected to come into effect within the next 2 years.

Mental health legislation is relevant to all consumers because it regulates and makes lawful the 'detention and compulsory treatment of people with severe mental illness in defined circumstances.' (p.1) The Victorian Law Reform Commission highlighted the significance of these powers in its recent guardianship law review, noting that '(t)hese actions would constitute false imprisonment and assault if not expressly permitted by law.' (24.11)

'(t)hese actions would constitute false imprisonment and assault if not expressly permitted by law.'

The implications of the reform of Victoria's Mental Health Act will resonate throughout Australia, particularly in the Australian Capital Territory and Western Australia, where similar reviews are taking place. While the contents of the summary tell us a little about the proposed new Bill, it also provides many reasons to consider that which *didn't* make it to the law reform process.

The Summary

First, what does the summary tell us? On the one hand, very little. It is written in fairly general policy terms (and, at times, in eye-glazing policy speak).[3] The disclaimer on page 1 indicates that 'as the legislation is developed and the Bill is drafted, specific words, phrases and terminology may change.' This is important because, as they say about law generally, the devil is in the detail. Until the proposed legislation is made public it is hard to know exactly how the new Act will really work.

The summary suggests there will be new criteria and processes for involuntary detention and treatment. The current criteria under the Mental Health Act 1986 are typical of mental health legislation worldwide. They include when a person:

- poses a risk of harm to self or others
- has an apparent or diagnosed mental disorder
- requires immediate treatment to prevent severe deterioration in physical or mental health
- and cannot be treated by less restrictive means.[4]

The summary doesn't indicate that any of these criteria will change under a new Act (though it suggests a person would need to be *diagnosed with*, rather than *appear to have,* a mental disorder for an involuntary treatment order to be made, unlike under the current Act). (5)

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[3] See, for example, page 7: 'A number of the legislative mechanisms discussed elsewhere in this paper... form part of this integrated suite of safeguards built into the legislation.'

[4] For the specific criteria, see *Mental Health Act 1986* (Vic) s 8(1)(b)(c)(d) & (e).

That said, the summary does indicate that a **new mental capacity test** will be introduced *on top* of existing criteria for involuntary treatment. The summary states that '(t)he legislation will establish a capacity test to assist clinicians to determine whether a patient can or cannot consent to treatment at the time the decision needs to be made.' A capacity test would mark a slight shift in mental health law which currently allows for involuntary treatment even when a person holds mental capacity, which is not the case in general health settings. In other words, a person could freely refuse lifesaving medical treatment such as chemotherapy but could not refuse psychiatric treatment when subject to mental health law, even if they retained mental capacity. As one consumer consultant pointed out at a recent conference, this means the onus will be on the clinicians to *prove incapacity* where, under current mental health legislation, it doesn't matter if you have mental capacity or not. Introducing a capacity test to mental health laws would seemingly address this discriminatory gap.

> *... the summary says little on what this capacity test will be and how it will relate to the other criteria. For example, if someone has mental capacity but is seen as posing risk to self or others, does the risk criterion trump the capacity test? And what type of mental capacity test will be used of the dozens that exist throughout the world?*

However, the summary says little on what this capacity test will be and how it will relate to the other criteria. For example, if someone has mental capacity but is seen as posing risk to self or others, does the risk criterion trump the capacity test? And what type of mental capacity test will be used of the dozens that exist throughout the world? Will traditional tests be adopted, which assess whether a person understands a decision, can see available options, and can communicate their decision? Or will specific mental health-related capacity tests be used, which draw on clinical concepts such as 'insight'? Again, until the actual wording is released it is impossible to know how the testing will work. (There are also human rights issues around capacity I'll return to later).

Another new feature of the proposed Bill will be 'a right for compulsory patients to seek a **second opinion about their treatment.**' (8) However, the summary does qualify that the 'authorised psychiatrist will be required to consider the second psychiatric opinion report provided to them but will not be required to change the course of treatment if they disagree with the recommendations.' (8) That is, the authorised psychiatrist can dismiss some or all of the second opinion report. Were this to occur, an application could be made to the Chief Psychiatrist to resolve the dispute between psychiatrists.

> *The legal power of advanced statements varies throughout the world.*

'Advanced Statements' will also appear in the new MH Act. (Note: The Mental Health Legal Centre and OCP's own, Merinda Epstein, have been longstanding advocates for this innovation in Australia). The proposed Bill will enable a person to make an advance statement about their wishes and preferences regarding treatment in the event of a personal crisis leading to involuntary treatment. (4) What the summary doesn't say is what legal standing the advanced statements will have, including the degree to which the statements must be followed by treating clinicians. The legal power of advanced statements varies throughout the world. For example, in Germany advanced statements can stipulate treatment refusal during periods of crisis and these advanced directives are as binding to clinicians as they are in non-psychiatric settings**.** (There is always some caveat for overriding them, though some are stronger than others. For example, the exception in Germany is if there are strong and substantiated reasons to believe that the person has changed their mind and/or if the statement is ambiguous.)

The summary sets out other new features which can be gleaned fairly easily from the summary. A 'nominated persons' scheme will allow people to appoint a support person to receive information and assist in decision-making and discharge planning. Mental Health Tribunals will replace the Mental Health Review Board and the Psychosurgery Review Board. A Mental Health Complaints Commission will also be introduced to seemingly resolve the conflict of interest where the current complaints handling body for the sector is Office of the Chief of Psychiatry, the same as the peak office representing clinical services. However, the new complaints commission mentioned in the Bill is limited to addressing individual complaints, and will not address systemic sector issues, as with many mental health commissions in other states and overseas. But at this early stage, the specific make up of a new commission remains unclear. Again, until we see the actual legislation... well, you get the point.

... the new complaints commission mentioned in the Bill is limited to addressing individual complaints, and will not address systemic sector issues, as with many mental health commissions in other states and overseas.

In this sense, the summary is important not just for what it includes but also for what it leaves out. It is useful then to consider some important issues which didn't make it to the mental health law reform process in Victoria.

A Decision to Discriminate

It is uncontroversial to say that mental health legislation is discriminatory against people diagnosed with mental disorder. People with a diagnosis of mental disorder are typically the only members of society who can be routinely detained in hospital and treated, including in the community, without their consent. Where there *is* controversy is whether this discrimination is unjust.

Perhaps the main argument in favour of keeping mental health legislation is that mental illness constitutes a special case which gives rise to emergencies requiring special laws. From this view, differential laws allow for the regulation of emergency treatment powers, detention in hospital, and forced treatment during emergency mental health crises. By regulating this power through mental health legislation these interventions can be monitored carefully to prevent gross abuses (such as people being restrained indefinitely without oversight) and to establish legal procedures by which people subject to those laws can challenge their treatment. In other words, if emergency powers are needed to intervene during some mental health crises then these powers need to be clearly authorised and regulated—a function best provided by mental health legislation.

Campbell charged that separate mental health legislation 'institutionalises the idea that there is something about "mental illness" itself which invites a system of control and coercion.'

The main argument against separate mental health legislation is that it creates 'institutional discrimination,' as Tom Campbel has argued (see http://anp.sagepub.com/content/28/4/554.abstract). Campbell charged that separate mental health legislation 'institutionalises the idea that there is something about "mental illness" itself which invites a system of control and coercion.' These arguments aren't new. Campbell's criticism was made in 1994, echoing arguments made as early as the 1960s. However, there is renewed interest in this thinking lately, particularly since the coming into power of the United Nations Convention on the Rights of Persons with Disabilities in 2008. Professor Bernadette McSherry recently outlined some of these arguments in an article for *The Conversation* (see: http://theconversation.edu.au/time-to-rethink-mental-health-laws-for-treatment-without-consent-9302). 'The CRPD,' McSherry noted 'is providing the impetus for challenging the justifications for why we have mental health laws at all.' (Her article addresses the particularly scant evidence to support the risk of harm criteria being used in mental health legislation.)

> *'The [United Nations Convention on the Rights of Persons with Disabilities] ... is providing the impetus for challenging the justifications for why we have mental health laws at all.'*

People with disabilities – including mental health consumers and survivors of psychiatry – played a significant role in drafting the CRPD, having rallied behind the slogan 'Nothing about us without us'. These activists (among them, lawyers, professors, physicists, the unemployed, and many others) formed an International Disability Caucus which played a central role in drawing up the first draft of the Convention. (More background information can be found at http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1563883).

As early as 2009, the United Nations Committee on the Rights of Persons with Disability, which has authority to interpret the CRPD, recommended that Tunisia 'repeal legislative provisions which allow for the deprivation on the basis of disability, including a psychosocial (mental health) or intellectual disability.'[5] The Committee's position echoes a 2009 report by the United Nations Office of the High Commission of Human Rights, which called for the repeal of disability specific legislation, and singled out mental health legislation as unfairly discriminatory against persons with a diagnosis of mental disorder.[6] Tina Minkowitz, a human rights lawyer and psychiatric survivor, has elaborated on the implications of the CRPD for mental health law (see: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1481512), arguing that such laws contravene the CRPD on a number of key articles, including by facilitating cruel, inhuman and degrading treatment.

Which sections of the CRPD are relevant to medical treatment of people with disabilities?

- Article 25(d) of the UN Convention on the Rights of Persons with Disabilities (CRPD) requires state parties to ensure health professionals deliver healthcare on the basis of free and informed consent.
- Art. 5(2) of the CRPD prohibits all forms of negative discrimination on the basis of disability.
- Art. 14.1(b) of the CRPD requires signatory parties to ensure that persons with disabilities '[a]re not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that *the existence of a disability shall in no case justify a deprivation of liberty'* [emphasis added].

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[5] UN Committee on the Rights of Persons with Disabilities 'Compliance Review: Tunisia', adopted 15 April 2011, CRPD/C/TUN/CO/1: 22 5www2.ohchr.org/SPdocs/CRPD/6thsession/CRPD-C-ESPCO-1%20.doc4 accessed 02 February 2012 (emphasis added).

[6] UN General Assembly, OHCHR, Tenth session Agenda item 2, 'Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary-General: Thematic Study by the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities' Distr. GENERAL A/HRC/10/48 26 January 2009.

- Art. 17 protects the right to physical and mental integrity on an equal basis with others. From a legal perspective, the full implications of Article 17 are not well understood but it can be said to raise some serious issues when it comes to involuntary psychiatric treatment. Australia's 'civil society report' to the UN Committee on the Rights of Persons with Disabilities, which was compiled by disability representative, advocacy, legal and human rights organisations in Australia, have said the following on mental health legislation and Article 17: 'Existing mental health legislation, policies, and practices, especially in relation to compulsory treatment orders (CTO) and the lack of safeguards and resourcing do not adequately protect the integrity of the individual and in some cases actively harm a person's integrity.'[7]

'Existing mental health legislation, policies, and practices, especially in relation to compulsory treatment orders (CTO) and the lack of safeguards and resourcing do not adequately protect the integrity of the individual and in some cases actively harm a person's integrity.'

And finally…

- Art. 12 of the CRPD requires state parties to ensure that all persons with disabilities enjoy legal capacity on the same basis as others. It also directs countries to 'take appropriate measures to provide access to persons with disabilities to the support they may require in exercising their legal capacity.'
- Art. 12(4): 'States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.'

The wording seems fairly ordinary but Article 12 is often pointed to as the thing that really makes the CRPD a 'game-changer'. And here's why: Art. 12 implies States prefer support for disabled people to make their own decisions on all matters which affect their lives, rather than to allow others to substitute their decisions. This directive is often summarised with the term 'supported decision making', which is exactly as it sounds, supporting people with disabilities to make their own decisions, and leading self-directed lives more generally.

It is near impossible to argue that our Mental Health Act could ever be consistent with Article 12 of the CRPD.

It is near impossible to argue that our Mental Health Act could ever be consistent with Article 12 of the CRPD. Tina Minkowitz points out that you can't reconcile an Act that relies on finding an 'apparent or diagnosed mental disorder' with a disability neutral threshold for deciding on capacity and placing restrictions on autonomy.[8]

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[7] Disability Representative, Advocacy, Legal and Human Rights Organisations Australia, 'Disability Rights Now: Civil Society Report to the United Nations Committee on the Rights of Persons with Disability,' August 2012: 15 http://www.disabilityrightsnow.org.au/node/15

[8] T. Minkowitz, 'The United Nations Convention on the Rights of Persons With Disabilities and The Right To Be Free From Non-Consensual Psychiatric Interventions' [2007] 34 *Syracuse Journal of International Law and Commerce* 405.

The criticism that mental health law is discriminatory has also come from prominent psychiatrists. Perhaps most prominently, George Szmukler and John Dawson have argued for a single, capacity-based law that would not use mental disorder as criterion for involuntary treatment at all.[9] This suggestion, often referred to as the 'fusion model' (because it 'fuses' mental health and guardianship law), would rely *only* on a capacity test to determine eligibility for involuntary status. This idea, bolstered by the CRPD, is gaining momentum and beginning to affect laws throughout the world, as McSherry pointed out in relation to Northern Ireland:

> 'Northern Ireland has signalled it will abolish its mental health legislation and instead enact one capacity law for all those with severe mental and intellectual impairments. A draft bill is in the process of development and, if enacted, will provide an interesting test case for how such law could work in practice.'

Given this level of activity internationally and in other arms of government, it is curious then that Victoria's recent mental health law reform summary does not once mention these discrimination or human rights issues ...

Enacting one capacity law is not without controversy. It is not likely that such a law could be truly non-discriminatory against people with disabilities (after all, if it is mostly people with psychosocial disability being subject to such laws then it is discriminatory in *effect*).

Nonetheless, the example from Northern Ireland points to a willingness by some governments to engage very seriously with the challenges posed by the CRPD to mental health law. This can also be seen in Germany, where international human rights law plays a more prominent role in domestic law as compared to Australia. Though translations are scarce at this point, it appears some states have found mental health legislation to be in breach of the German constitution in light of their human rights obligations.[10] Closer to home, the Victorian Law Reform Commission's report into the reform of guardianship law includes an overview of the challenges brought by the CRPD to mental health law, as well as by the 'fusion proposal.' The Commission did not go as far as recommending an end to mental health legislation, but the section on mental health law provides a very useful summary of the arguments for and against its continuation. (Anyone interested can read the report here - http://www.lawreform.vic.gov.au/projects/guardianship-final-report).

Given this level of activity internationally and in other arms of government, it is curious then that Victoria's recent mental health law reform summary does not once mention these discrimination or human rights issues, nor do the supporting documents of the 2010 draft Bill, in any depth. The Law Institute of Victoria raised this point in a submission to the Law Reform Commission, charging 'that the Mental Health Act Review (undertaken by the Victorian Department of Health) had not engaged

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[9] J. Dawson & G. Szmukler, 'The fusion of incapacity and mental health legislation', (2006) *British Journal of Psychiatry* 504-509

[10] However, medical treatment without consent is still applied but strictly as a measure of last resort, permissible only when the person presents a life-threatening danger to themselves or a serious to others due to their condition and the medical treatment is necessary and proportionate when balancing conflicting interests. Nonetheless the Constitutional Court protected the decision-making of a person with mental illness who has capacity to decide and it significantly increased the threshold for overriding the person's wishes or treatment choices, if he or she is not capable of decision-making. For more on the decision, see http://www.bverfg.de/pressemitteilungen/bvg11-028en.html

with the threshold question of whether there is an ongoing need for mental health laws in any depth.'

… the Department's resounding silence on the major issue raised by the CRPD raises questions about the integrity of a reform process whose stated aim is to 'protect the rights of compulsory patients.'

Despite this curious silence, the Victorian Department of Health have drawn heavily on one feature of the CRPD: its language. 'Central to these reforms,' the summary document notes, 'is the establishment of a supported decision-making model in the legislation.' Further, the 'model will be informed and guided by a new set of legislative principles reflecting the *Charter of Human Rights and Responsibilities Act 2006* (and) the United Nations Convention on the Rights of Persons with Disabilities.' If we take the terms of the legislative reform in good faith, the authors would have to be aware of the issues raised by the CRPD more broadly. And yet the Department's resounding silence on the major issue raised by the CRPD raises questions about the integrity of a reform process whose stated aim is to 'protect the rights of compulsory patients.' (7)

Finally, it is important to emphasise that the issues mental health legislation seek to address are enormously challenging. These issues raise questions with no easy answers. For example, how *should* the law work when someone is unaware of the harm of their actions, such as when a person tries to leap off a building because they think they can fly? If another person blocks them from jumping should they be charged with assault? If not, how should that scenario be seen in law? And when can coercive responses be justified and can such responses remain non-discriminatory? How do we make sure that the extreme scenarios do not dominate the rules for the majority? And how would a transition away from mental health legislation occur? Again, there are no easy answers. And any efforts to solve them will require great effort on the part of government and the people they represent, including mental health consumers. The Victorian Law Reform Commission has demonstrated that government agencies can undertake rigorous and transparent law reform on challenging issues raised by the CRPD and other international trends in law. Their report could serve as a useful template for lawmakers wishing to engage seriously with the implications of human rights for mental health law in Australia.

Conclusion

There are two major issues arising from the summary of the proposed new mental health Bill in Victoria, at least as far as the issues discussed here. The first is that the Victorian government has decided to retain mental health legislation. The second is that they have done so without justifying their decision, nor seriously considering alternatives in light of international trends in mental health and human rights law. Instead, the Department appears to have actively ignored major challenges to the justification for mental health law, particularly its discriminatory nature. Considering the millions of dollars spent on anti-stigma campaigns by state and federal government and NGOs it is puzzling that the Department's silence has remained largely unchallenged.

... the Department appears to have actively ignored major challenges to the justification for mental health law, particularly its discriminatory nature.

Victoria's new mental health legislation is likely to appear in the next two years, and other states will follow. Those wishing to influence the development of these laws will have to decide where to direct their efforts. This focus may centre on the *content* of proposed new laws, such as strengthening 'advanced statements' and second opinion processes, challenging the decision to retain the risk of harm criteria, or expanding the scope of the proposed Mental Health Complaints Commission, and so on. Others will direct their efforts to the overall *processes* of law reform, and promoting that they occur within a human rights framework which better includes consumers and their representative organisations. This last point was made in Australia's recently released shadow report[11] to the CRPD Committee, compiled by numerous disability representative, advocacy, legal and human rights organisations. One of the reports major recommendations in relation to mental health law is that 'in consultation with people with disability through their representative, advocacy, and legal organizations, Australia conducts a comprehensive audit of laws, policies and administrative arrangements underpinning compulsory treatment.'[12] This would be done 'with a view to ... introducing reforms to eliminate laws and practices that relate to compulsory treatment that inherently breaches human rights.'

The wholesale reform of legislation is a rare event. The last Mental Health Act in Victoria came into power over twenty-five years ago. The new Bill will deeply influence our mental health system for decades to come. It is all the more important therefore that we get this current round of law reform right. As a starting point, this demands an honest appraisal of the major issues facing mental health law today, including considering Australia's obligations under international law. Only then can debate proceed beyond the minor tweaking of existing arrangements, and move toward a system of justice which can truly lay claim to protecting the rights of all.

NEWS IN THE CONSUMER WORLD:

Second Consumer Partnership Approach Forum

The second governmental Consumer Partnership Approach Forum is to be held at:

Date: Thursday, 20 December
Time: 10:00 am-12:00 pm.
Room: 1.10, 50 Lonsdale Street, Melbourne

Regional and country members can take advantage of video and teleconferencing facilities, - please contact Keir to arrange the best option for you keir.saltmarsh@health.vic.gov.au; Ph: 03 9096 1395.

2013 meetings are all planned for 2:00-4:00 pm on: Thursday 31st January; Thursday 28th March; Thursday 23rd May; Friday 26th July; 26th September; Thursday 21st November (same location).

Victorian Mental Illness Awareness Council (VMIAC) Christmas Party

VMIAC are having their Karaoke Christmas Party on Tuesday 18th December, from 12pm. At 22 Aintree St, Brunswick East, Vic. Bookings are essential on (03) 9380 3900, RSVP by Tuesday 11 Dec.

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[11] The 'shadow report' refers to the report required by the CRPD Committee under the terms of the CRPD to indicate how a particular country is or is not in compliance with the CRPD. The report is compiled by civil society representatives, particularly disability people's organisations, and submitted alongside the government's own compliance reporting. The shadow report is meant to counterbalance the government's own, potentially biased, reporting.

[12] Disability Representative, Advocacy, Legal and Human Rights Organisations Australia, 'Disability Rights Now: Civil Society Report to the United Nations Committee on the Rights of Persons with Disability,' August 2012: 15 http://www.disabilityrightsnow.org.au/node/15

Expressions of interest for an ECT group

Have you had ECT (Electroconvulsive Therapy)?? Have you had any concerns about effects ECT has had on your life? You are not alone! The Victorian Mental Illness Awareness Council is seeking to determine the interest in establishing an ECT survivors peer support group:

- Opportunity to talk about and share with others what your experiences of ECT has been (before, during and after treatment)
- Sharing information on ECT
- Raise issues and advocate about the involuntary use of ECT
- Learn about your rights in regards to receiving this type of therapy.

If you are interested, please contact Bill or Dominic on (03) 9380 3900.

COPMI (Children of Parents with a Mental Illness) want to know what you think

The COPMI (Children of Parents with a Mental Illness) national initiative is developing a new online training course for health professionals. They would greatly appreciate your feedback on which topic you think will most help professionals who work with children and families where a parent has a mental illness.

Choose the survey that best suits your experience. You may choose to fill in more than one survey below if it applies to you. They will all take less than 5 minutes to complete. Your responses are anonymous and confidential, and you are not required to provide any personal details that could identify you. COPMI sincerely thanks you for your honest feedback and your time.

- Survey for health professionals: https://www.surveymonkey.com/s/VDLG3JY
- Survey for people with lived experience of parental mental illness: https://www.surveymonkey.com/s/VD9SGDZ
- Survey for workforce trainers: https://www.surveymonkey.com/s/VDVQXYH

Radio team with lived experience of mental illness takes out radio award

The Brainwaves radio team is “over the moon” at having won a Community Broadcasting Association award in November for its weekly program on 3CR Community Radio. Brainwaves first went to air just over two years ago, and is produced and presented by a team of volunteers who live with mental illness. The program is funded by Mental Illness Fellowship Victoria and coordinated by MI Fellowship peer support worker Ben Rinaudo.

The program won the category for Excellence in Training in the annual Community Broadcasting Association of Australia Awards, and was judged as having achieved outstanding benefits for both the newly trained broadcasters and community radio generally. Nine Brainwaves volunteers completed 3CR radio training this year. The Brainwaves team includes people with interests in music, comedy, media production, poetry and journalism. The program has not only enabled the producers/presenters to develop new skills and confidence, but has also provided a public forum for people to discuss mental illness and recovery, and to share stories, news and laughs with a growing audience of people with an interest in mental health issues.

Congratulations to all the Brainwaves team members and 3CR on their award!

Tune into Brainwaves at 5pm Wednesdays on 3CR Community Radio (855am) or download the podcasts at http://www.3cr.org.au/aggregator/sources/7816. *[adapted from MIF media release]*

Not just another report: *Your Voice Can Make a Difference: Neami's 2012 Continuous Improvement Report*

It is a requirement for community health services to publish an annual Quality of Care Report, so why don't mental health services? In order to maintain accountability to its partners, the consumers who utilise the service and the community, Neami recently published its first annual Continuous Improvement Report.

In writing this report, we made a conscious effort to get as much consumer input as possible- and of course those who contributed were paid for their input and supported throughout the process. It highlights two projects run by people with a lived experience: one around developing a responsive and accessible feedback process for consumers and carers and one around Consumer Advisory Groups and consumer participation (see *soapbox* in the OCP August 2012 newsletter) plus some of the new consumer participation initiatives. The report showcases consumer artwork and includes pieces on peer support, consumer input into research and health promotion at Neami. Your Voice Can Make a Difference: 2012 Continuous Improvement Report can be found here: http://www.neami.org.au/wp-content/uploads/2010/08/Continuous-Improvement-Report-2012.pdf

Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP)

The Centre for the Human Rights of Users and Survivors of Psychiatry (CHRUSP) is currently seeking your support. CHRUSP is an organisation that works both internationally and within the U.S. specifically. CHRUSP works for the abolition of forced psychiatry including the goal of bringing U.S. law into line with international human rights standards. CHRUSP is involved with activities at the United Nations – both to create new international standards (on the rights of prisoners, and on the rights of older persons), and to appeal to existing standards to call attention to violations in the United States. In 2012, CHRUSP inaugurated human rights education activities with a 2 ½ day training, sponsored by Voices of the Heart, Inc and are conducting discussions with potential partners to produce additional training workshops and an online course.

Mission:

The Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP) provides strategic leadership in human rights advocacy, implementation and monitoring relevant to people experiencing madness, mental health problems or trauma.

In particular, CHRUSP works for full legal capacity for all, an end to forced drugging, forced electroshock and psychiatric incarceration, and for support that respects individual integrity and free will.

CHRUSP continues to provide advice and consultation to user/survivor organizations and allies throughout the world. This activity has been conducted mainly via the Internet but experience shows that in-person meetings are also highly valuable.

For more information, go to: www.chrusp.org; or email info@chrusp.org.

Interested in human rights, law reform, social justice and mental health?

Then you might be interested in the growing facebook page for the Australian Mental Health Human Rights and Law Reform Coalition: http://www.facebook.com/pages/Australian-Mental-Health-Human-Rights-and-Law-Reform-Coalition

Upcoming events from the Music Network for Mental Health

audience required! no experience necessary

This is Heidi from the Music Network here - part of Wild@heART Community Arts. I've got an invite for your Christmas cool-stuff calendar, for all people in your Mi world (sounds like a 007 movie!). An inexpensive way to spend a brilliant few hours of life.

Strumarama! - The Music Network's songwriter's excuse to party - The Espy stage will be alive with Music Network songwriter's trading snazzy riffs, rhythms and rhymes. This is a great way for people to see the Network in action and get a taste for what you and your friends could be doing too. ‘If you want to protect borders, join the army. If you want to cross borders, join a band’ This is my saying for the awesome way music brings people together, heals a broken heart and invokes pure joy! Nowhere is music more vital than around people who have been wounded by life. It is truly the elixir of the spirit. Where/when you can witness this amazing gift:

The Espy Hotel Basement Bar
The Upper Esplanade, St Kilda
Wed 12th December 7pm-10pm
Gold coin entry goes to the Music Network project

Songwriting & Music Performance Workshops - Ongoing

Everybody's got a story in them. Songwriting is a great way to find and tell these stories. Weekly workshops on individual songwriting, band development and performance skills are held in South Melbourne, Heidelberg West and regional areas with *real* musicians facilitating the lessons. People come from all over greater Melbourne area to enjoy these sessions and hang out with people with similar interests. No experience needed.

Everybody's got a story in them. Songwriting is a great way to find and tell these stories.

For more info on the Music Network, contact Phil (MN super-nova): 0402 812 428. Please check out the awesome Wild@heART website and join the cool online MNX community on Facebook: www.wildatheart.org.au/Programs.html; www.facebook.com/musicnetwork4mentalhealth.

Please RSVP if you can to Heidi Everett skybeanz@gmail.com.

Help the Mental Health Legal Centre plan community legal education

As many of you may know, the **Mental Health Legal Centre (MHLC)** is a specialist community legal centre based in Melbourne that, for over 25 years, has provided a range of legal services to Victorians whose legal issue relates directly to their mental illness.

A critical part of the MHLC’s work is providing **community legal education** to enable mental health consumers to understand and exercise their legal rights. We conduct education sessions and provide community legal education materials on a range of topics including:

- Your rights as **an involuntary patient under the Mental Health Act** (including the *Patients’ Rights Booklet*, in partnership with Victoria Legal Aid)
- How to challenge an **involuntary treatment order** or **community treatment order**
- Your rights when **State Trustees** are managing your money
- How to get an **administration or guardianship order** revoked
- How to access and **correct information** on your medical file

- Where to make a **complaint** about your psychiatric treatment
- Your rights if you are **apprehended by police** and taken to hospital for a psychiatric assessment

and on many other topics.

We want to hear from you!
If you're a consumer or a consumer representative, you can assist MHLC to plan its community legal education sessions for the coming year by completing this short survey: http://www.surveymonkey.com/s/NNWQKK8. It only takes a few minutes to let us know about the kinds of education sessions you or your consumer clients might be interested in!

Please be aware that we prioritise education sessions for mental health consumers.

You might want to hear about one of the topics above, different topics or what the MHLC does and how we can assist individual clients. Thank you - we appreciate you taking the time!

Want to request a Community Legal Education session directly?
Please direct all specific enquiries and direct requests for community legal education (CLE) sessions to Catherine Leslie at the MHLC tel: (03) 9629 4422 or email: Catherine.leslie@mhlc.org.au.

Please be aware that we prioritise education sessions for mental health consumers.

Madness Radio kickstarter campaign: *The human voice tells a powerful story.*

- **Campaign launched:** Dec 3, 2012; **Funding ends:** Jan 2, 2013

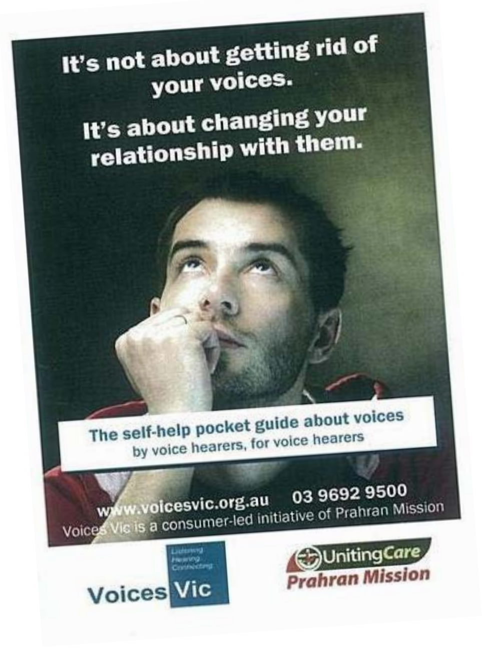
Madness Radio: Voices and Visions from Outside Mental Health is a radio show heard on community stations around the US and online. Since 2005 Madness Radio has explored the question "What does it mean to be called 'crazy' in a crazy world?" through powerful and provocative in-depth interviews. Madness Radio believes that personal storytelling and thoughtful conversation are powerful ways to create change. Listening to each show conveys an urgently needed message: **YOU ARE NOT ALONE**.

Check out Madness Radio at our website: http://www.madnessradio.net. This is Madness Radio's first fundraising campaign! We need your support to produce 12 new episodes for 2013 -as well as publish a book of Madness Radio interviews.

Some of the interview topics include alternatives to medication, exposing psychiatric abuse, living with suicidal feelings, what is Mad Pride, healing trauma, pharmaceutical company scandals, Open Dialogue, electroshock, the Hearing Voices movement, Soteria House, shamanism, poetry, autism, mad science, breaking the silence of sexual abuse, being transgender, the DSM, racism, activist history, abolishing prisons, and much, much more. Past guests include Robert Whitaker, Susan McKeown, Daniel Fisher, Leah Harris, Dr. Peter Breggin, Gary Greenberg, Daniel Hazen, Rufus May, Jim Gottstein, Alisha Ali, Jacqui Dillon, Ron Coleman, and Dr. Joanna Moncrieff. Each interview will include an introductory essay by Will Hall.

Madness Radio believes that personal storytelling and thoughtful conversation are powerful ways to create change.

Introducing ... (a consumer developed initiative): the Self-help pocket guide about voices by voice hearers for voice hearers.



It's not about getting rid of your voices.

It's about changing your relationship with them.

The self-help pocket guide about voices by voice hearers, for voice hearers

www.voicesvic.org.au 03 9692 9500

Voices Vic is a consumer-led initiative of Prahran Mission

Strategies for tough times.

Do a deal... tell the voices you'll listen later if they give you peace now. But stick to the deal. Or write their messages down to clear your head & read later when you feel stronger.

Set some boundaries... tell the voices you will only listen if they speak to you with respect. If they don't comply, distract yourself.

Distract... Try different styles of music via headphones or wear ear plugs (one ear or both ears), call or visit a friend, talk to others on the net, watch TV or DVDs, read a book, get some housework done, do puzzles, cook a nice meal for yourself.

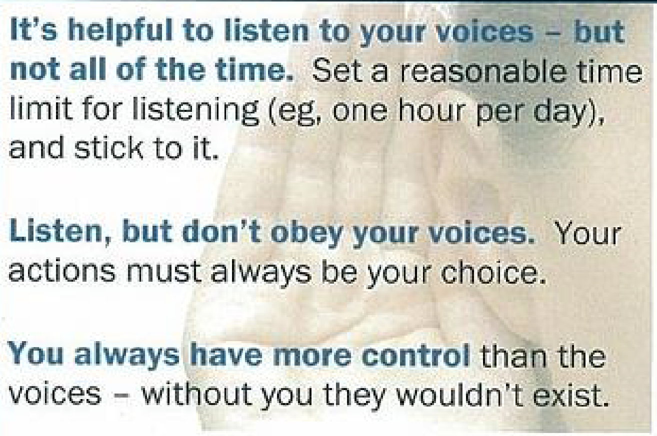
Get some emotional release... Run! Hammer nails into wood. Take a cold shower. Beat up a ball of clay. Yell into your pillow. Go to the gym—try boxing! Put on loud music and dance it out. Watch an emotional movie. Let it all out in writing or art.

My own strategies...

This pocket guide (available from Voices Vic – www.voicesvic.org.au) offers tips for changing your relationship with your voices. The tips are based on strategies used by voice hearers around the world. Hearing voices is a common human experience. In fact, arguably, *we all hear voices!* Perhaps we don't all hear auditory voices that others can't hear but we do all have different parts of ourselves that we can dialogue – e.g. an inner critic or an inner child. [More tips on the back cover]

THUMBS UP/THUMBS DOWN

1. **THUMBS DOWN:** to the silly season traffic. Definitely brings out impatience and lots of cars!
2. **THUMBS UP:** to those families who are able to support us in our times of distress, crisis, confusion and despair. We know this can be very challenging for our families too.
3. **THUMBS DOWN:** to the assumption that all of us have supportive families, or that our chosen "family" is related to us by blood.
4. **THUMBS UP:** to Brainwaves on their media award. Well done guys!
5. **THUMBS DOWN:** to a service who gives artists a $25 Coles voucher for their work. This devalues their labour, creativity and talent. And it encourages a culture of welfare dependency.
6. **THUMBS UP:** to Voices Vic's research project (a double blind trial no less!) into the impact of receiving peer support from another person who also hears voices. We wish them luck!
7. **THUMBS UP:** to the Victorian government establishing Partnership Dialogue Forums to engage more systematically with consumer workers.
8. **THUMBS DOWN:** to these forums being almost exclusively for consumers who are currently in the consumer workforce – this excludes many talented, intelligent, thoughtful consumer voices.
9. **THUMBS DOWN:** to the undermining of our confidence in our own abilities and thinking – sometimes sudden and catastrophic, sometimes gradual and subtle (but just as catastrophic).
10. **THUMBS UP:** to those organisations and workers who work to embed consumer thinking as early and as deeply as possible.



It's helpful to listen to your voices – but not all of the time. Set a reasonable time limit for listening (eg, one hour per day), and stick to it.

Listen, but don't obey your voices. Your actions must always be your choice.

You always have more control than the voices – without you they wouldn't exist.

Talk with your voices as well as listening. A good relationship takes two (at least!).

Speak to your voices with compassion and respect – how you wish they spoke.

It can help to remember that voices usually have good intentions. They give voice to a part of you that is hurting and can't express itself any other way. In a way, they are like a hurt child, crying out.

Challenge your voices if they make threats. Threats can be frightening, but remember that voices lie about their power. To prove this to yourself, set them a simple task such as "go and wash the dishes" or "trim my nails". We think they'll fail. If it feels scary to challenge the voices, ask someone you trust to sit with you.

How to change your relationship with your voices.

Read other people's recovery stories.

Don't argue with voices – they usually win!

Don't take your voices too literally. Voices often don't mean what they say, or they talk in metaphors. Eg, violent suggestions from voices could mean you need to change something that's not right in your life or that you're feeling angry or scared.

Do your voices have names? If not, find out what their names are and use them - you'll reduce your fear and increase your control. If the voices won't tell you, then you can give them names.

Recognise trauma from your past. Most voice hearers have difficult experiences in their past – you are not alone. What was happening in your life when you first started hearing voices? Your voices may be a sign that it's time to try counselling, or to talk with someone you trust.

Join a hearing voices group. Share your experiences and learn with others who have been there too. Don't be alone.

Give yourself time & hope. We know these are not easy changes to make. It takes heaps of practice & support. But you can do it. Believing in yourself is the first step.