People diagnosed with 'mental illness' doing things for ourselves

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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

Contents

SAVE THE DATE! Friday November 11th 2011.

Our Consumer Place forum/workshop: "Consumers as Clinical Educators"

Some history: In the 1990s, a series of workshops that came to be known as "The Deakin Workshops" were held to discuss embedding consumer and carer lived experience into the education of mental health clinicians. The findings of these visionary workshops were published as *"Learning Together: Education and Training Partnerships in Mental Health."*

This one-day forum/workshop will ask the questions "Where are we now?" and "What does the future hold for consumers as clinical educators?" It will bring together consumer educators and non-consumer mental health educators who respect and value the role of lived experience in clinical education. More information will be coming over the next few months, but if you either were involved in "The Deakin Workshops" or are involved in clinical education, please do get in touch with us so we can work out how best to structure this forum/workshop!

INTRODUCING …

In this edition, we hear from ***Heidi Everett****, a local singer/songwriter, blogger and community organiser.*

We asked her to write for us about what she has been up to because she is such a gem – speaking her own powerful truths with clarity and insight, and fostering real, grassroots change.

Photograph by Josie Hayden

On a no-name August day in 1994, I sat down opposite a psychiatrist in a psych ward. He said much, I said little and I walked out with the word schizophrenia tattooed on my soul.

Since that very first minute, on that very first day of the first year of the rest of my life, I've been in a state of flux. On my bad weeks I have schizophrenia. On my good weeks, I want to go back to that psych ward and wrestle back my dignity and identity. When I bowed down to the diagnosis, I didn't know I was greeting a lifetime of disease - the abandonment of liberty, the forfeiting of my ability to look after myself, the awkwardness of nowhere.

A particular diagnosis just means you have a different sprinkling of herbs and spices to finish off the dish. We're all just plucked chickens at the start.

The word schizophrenia is a deft juxtaposition of two languages that some fuddy old men fashioned in the 20th century. But all those knotty letters do still hint at the pain within. All mental illnesses seem to contain 5 main ingredients – deep depression, anxiety, emotional stress, self-doubt and a difficulty processing information. A particular diagnosis just means you have a different sprinkling of herbs and spices to finish off the dish. We're all just plucked chickens at the start.

The psych wards are a micro-climate of emotional poverty enhanced by social injustice.

The word 'Psycho' was once enough to strike fear in cinemas but the known threat of antipsychotic medication should be enough to bring about world peace. We know the side effects are as endless as the list of pills that cause them. We also know there are class actions against drug companies for life-cancelling side effects like diabetes and heart disease. The drug marketers themselves appear to have curious opposing side effects – the life-affirming sort.

The psych wards are a micro-climate of emotional poverty enhanced by social injustice. I mean, where else would you send someone whose heart and soul is well and truly broken, than to a barren lifeless desert? It feels that the hospital staff never really know my name, as they pollinate my body with medications. I meet other people with stories like mine and we sit and stare at each other for 10 hours a day, thinking how great it will be when the psych staff consider us 'recovered' enough to go home. (But don't they know I don't actually 'have' a home to go home to?).

> *I was always too shy to talk up about much, but since learning to sing I've also learnt to speak.*

WARNING: THIS PARAGRAPH CONTAINS EXPLICIT LANGUAGE. Some of my friends have died in psych wards and on the way to psych wards.

There are contrails of having a mental illness. I opened a library account yesterday and I suddenly panicked that 'BEWARE this person has schizophrenia" was emblazoned across the librarian's computer screen. Is that just my paranoia?

So what to do? Option One: I could just go on for the rest of my life, as I have, with a conveyor belt of case workers and psychiatrists rotating questions off their Base 32, while I daydream of a better world. Or, Option Two: Dream of a better world and wake up. I like the proactive sound of the second option, so a few years ago, I woke up.

I'm a singer/songwriter and I've been performing music for nearly ten years. They plonk a microphone in front of me at gigs. I've found this to be one of the most compelling tools I have ever learnt to use. I was always too shy to talk up about much, but since learning to sing I've also learnt to speak. In our world of mental illness, there's a huge discrepancy between those who have ample opportunity to talk and those who are not given the chance to talk. But there's a few of us out here who feel it's time that balance of power was shifted. We feel the emergent need to do this for others still without a voice. Those walking in to their first ever psych ward. Give a musician a guitar, he will happily play other people's songs. Give him a voice and he will suddenly find his own.

Heidi's websites:

- *Creativity and the positives of mental illness* - www.skillness.org
- *Facebook group for consumers who've experienced trauma in the MH system and are interested in bringing in change* - https://www.facebook.com/home.php#!/home.php?sk=group_151267884927359
- *Heidi's own website (music, illustration, mental health)* - www.heidieverett.com.au
- *Heidi's Music* - www.myspace.heidi4ever

Mental Health Peer Support Work Project

Certificate IV in Mental Health Peer Work,
Community Services & Health Industry Skills Council.
Analysis and commentary by Flick Grey

As many of you will know, a national training package (at the TAFE level) is being developed for mental health “peer workers” – a term that includes both consumers and carers. The intention is to provide appropriate training for peer workers, in all our various roles – including peer support workers, consumer consultants, consumer representatives (and in theory also roles like ‘recovery specialists’, ‘experts by experience’ and consumer educators). The qualification includes carer workers in all their various roles too – but the focus in this discussion here is on consumer workers, as this is OCP’s focus.

The Community Services & Health Industry Skills Council, who are the body developing the training, have a systematic approach that they must take whenever they develop a new training package. This involves consulting with “the industry,” who have the opportunity to discuss, feedback, critique, etc, what is being developed. In our context, however, this concept of “the industry” is a bit tricky – blurring important differences in perspective (and politics): consumers, carers and mental health services are all considered equal voices in “the industry.” But this training is for “*peer workers*” (us!). Consumers have *fought* for these positions to exist at all. I urge you to participate in this process if this is an area of interest for you, as this is an opportunity for us to shape how *our workforce* is trained. It’s also likely that other voices will be stronger than consumers’ if we don’t speak up – we don’t want our training to be conducted (or co-opted) in a way that doesn’t meet our needs and interests.

What the training currently looks like

The training package is currently up to its second draft. Currently, it has this overall structure:

- **A Certificate IV in Mental Health Peer Work (Cert IV):** A qualification that involves completing 14 subjects (or units of study). 8 of these units are the following “core” subjects:
    - *Orientation to mental health peer work*
    - *Work effectively in mental health peer work*
    - *Contribute to the continuous improvement of services to mental health consumers and/or carers*
    - *Promote and facilitate self-advocacy*
    - *Apply lived experience in mental health peer work*
    - *Contribute to OHS processes*
    - *Work effectively with culturally diverse clients and co-workers*
    - *Work effectively with Aboriginal and/or Torres Strait Islander people.*

  The other 6 units are “electives,” where you choose from a number of different possible subjects.

- **A shorter course, called a “Mental Health Peer Companion Skill Set”:** which involves just 3 core subjects (the subjects ‘Orientation’, ‘Work Effectively’ and ‘Apply Lived Experience’). This course is designed to meet the training needs of consumers (and carers) who have less responsibility – including those who work voluntarily. It can also function as a stepping stone into the Cert IV, for those who don’t have a lot of confidence or educational experience, or where there are other factors that might make a shorter course more appropriate. The name of this course, is (obviously) pretty silly, and up for negotiation (as most things really are, still), but there is definitely merit in having a pathway like this.

- **A course for managers/leadership:** This course is not just for consumers/carers but also other mental health workers who might be in a management/ leadership position working with us. This skills set includes one subject in common with the other two courses above, (‘Orientation’), but adds 3 other management subjects.

Unresolved issues to be explored:

(1) What “core” training do we all need and what content should be left to electives?

Some of the subjects listed as “core” material could actually be electives, since not all peer workers engage in all of these areas of work. I leave it to you to form your own opinions on this. More troubling, perhaps, is that most of the elective subjects have come from other, pre-existing TAFE courses (the people developing this training are *obliged* to use existing courses wherever possible). I have serious reservations about ALL these elective options, as I discuss later in this article.

(2) What place does a Medical Model approach have in peer work training?

At the moment, the core subject for all the courses (“Orientation to Mental Health Peer Work”) includes this as a core element:

2.4 *Apply knowledge of common mental health issues and associated signs, symptoms and effects*

There is no place for this kind of learning in peer work training. This is not just my personal opinion either. For example, Larry Fricks (from Georgia, US) was invited to come and speak about his vast experience in peer worker training, in a peer workforce forum in Sydney. He very clearly and repeatedly stated that “there is no place for learning about signs and symptoms of mental illness in peer work.” Similarly, Shery Mead’s work on Intentional Peer Support is unequivocal on this issue. There is a danger that approaching our learning in this way (putting medical model knowledge in the heart of our training) shifts our approach from peer expertise to a very different kind of expertise – expertise by medical training. Some degree of familiarity with the medical model of mental illness can be useful, but we have to be very cautious about why we are focusing on such things. If we are not mindful of staying peer, we may lapse into being mini-mental health workers, which is a fundamental shift in our role.

In my opinion, this element MUST be removed. This material is adequately covered elsewhere in the unit description – it talks about us needing to understand the *Context* of mental health work, including: “facts and myths about mental illness and psychiatric disability.” This training is training in peer work, and so is fundamentally different to other sorts of existing training where the medical model is at the core (e.g. Cert IV in mental health, Mental Health First Aid).

A similar, related element is the emphasis on mental health services: e.g.

4.1 *Demonstrate knowledge of mental health systems and services,*
4.2 *Identify the range of different service options available*
4.3 *Demonstrate understanding of the contribution of different service options to the recovery process.*

This idea of “knowledge” and “understanding” are contested: so long as these are consumer perspectives on these issues, then I have no problem with these elements being included in our training. Consumers are well aware that theoretical “knowledge” of the system is very, very different to the knowledge that comes from lived experience! There is also massive diversity amongst consumers – of course, when our knowledge comes from our lived experience, and we have vastly different (even incommensurate) encounters with the mental health system. Where do our legitimate critiques of the mental health system come into this training? What about our grief, rage and trauma? What about the diversity of our experiences of the system - ranging from experiencing mental health services as compassionate and life-saving to traumatising and abusing our human rights (and often some combination or something in between)?

Finally, on a related point, the "range statements" suggest that we should access other consumers' file notes. We are peers, not mini "case workers" and to be accessing people's file notes would shift the peer relationship irrevocably. This is not the direction I would want our training to be heading.

(3) "Peer" as bringing together both consumers and carers?

This issue caused a great deal of heat at one of the consultations that I was at in Melbourne. OCP is committed to consumers leading in this field. I always deeply appreciate space in which consumers are a critical mass, and are explicitly understood to be *the critical* (as in most important, central) *voice*. But where does that leave the training of carer workers? If they are trained separately, then do they lose the opportunity for being exposed to consumer perspective? Are our different perspectives better discussed in the one classroom, rather than outside? What about if a class is mainly carers, where does that leave consumers in the room?

The way the course is structured at the moment, it is clear that consumers must be assessed by other consumers (or someone with the appropriate qualifications in assessing these kinds of courses, assisted by a consumer who might not have those qualifications – yet!). Likewise, carers are to be assessed by other carers. This is a wonderful approach, and is critically important in my opinion.

Some of the issues around how carers are referred to in the training documents are deeply problematic. For example, there is often a blurring of the term "lived experience": whose experience is being talked about! Carers have their own very legitimate experiences, but these are separate to those of the person who they are in a caring relationship with!

(4) What is the place of "giving hope" and "being positive"?

There is a great deal of emphasis in the training on the need to "be positive" and "give hope." This is an interesting issue, to my mind, because having *hope* is so important to most people's recovery. BUT, where does this leave our truths about terrible things that happen, about injustices, grievances and suffering? I rail against being pushed to necessarily "be positive" – I want to be honest, albeit with an underlying hopefulness.

(5) What does lived experience mean anyway?

One of the subjects addresses how we apply our lived experience in our work. As it currently stands, I am highly critical of how this unit is oriented. Firstly, it states the need to:

1.4 *Maintain an awareness that peer work is not confined to sharing your own experience,*

but most of this unit goes on to focus on how we "use our stories." There is far too much emphasis on "our stories" as being the only way we use our lived experience. OCP is currently finishing off a booklet exploring how we can and do use our stories, but it is important to be mindful that we use our experiences in other ways too! For example, I *very rarely* use stories of my own lived experience in either my teaching work or my work here at OCP. That doesn't mean I'm not using my lived experience! I am sure there are many others like me who choose not to use "our story" as our primary tool for using our lived experience in our work. On the other hand, Merinda uses stories *extensively* in her work, but they're usually not "illness stories." She weaves stories and parables from her 20+ years of experience, work and activism in this area, drawing on her "lived experiences" in complex ways.

Secondly, this unit has an alarmingly top-down approach. The first 3 things we are expected to understand are:

1.1 *Confirm organisation's expectations of the use of lived experience in the course of peer work.*
1.2 *Clarify and follow organisational policy and procedures in relation to using lived experience in peer work, especially in relation to safe disclosure and public disclosure.*
1.3 *Where appropriate provide feedback on organisational policy and procedure.*

In my experience, as well as many conversations with peer workers about how they work – this approach is completely backwards: this top-down approach subordinates us, rather than recognising the value and necessity of our leadership (ie. a bottom-up approach)! WE tend to be the ones who are educating the organisations in which we work. For example, the idea of "feedback" trivialises the potential for our roles to be *transformative* of mental health services (as, I believe we can and should be). As it stands, this unit thoroughly domesticates our experiences, and denies our leadership.

(6) What kind of electives do we want?

Having looked over the list of electives, I'm concerned with the non-peer orientation throughout. Yes, it might be useful to have knowledge of the alcohol and drug sector, or how to work with young people, but how do we keep this in line with our work as peer workers? These units have been developed for very different agendas than ours.

The problem is structural – the people developing this course are obliged to look at existing units offered elsewhere and can't add units where something similar exists already.

I would love to see electives that are specific subjects for the kind of work that *we* do. They should provide enough specific detail to be relevant, useful, engaging and practical for *our work*. My fear is that in the current state, this training shifts us into different kinds of workers (non-peer), mini-mental health workers. And I think that's a huge loss for us, and for our potential.

The kind of electives I imagine are (and this is not something I've given nearly enough thought to, and I'm *positive* that other people have more ideas. I also realise that they have to start with a verb, but that grammatical stuff is their job not mine!):

- *Using Intentional Peer Support*
- *Using your personal story: Advanced skills*
- *Individual Advocacy Skills*
- *Systemic Advocacy Skills (mental health services)*
- *Systemic Advocacy Skills (Non-mental health services)*
- *Consumers as Educators (Community education)*
- *Consumers as Educators (Teaching mental health professionals)*
- *Turning your lived experience and peer work skills into a micro-business*
- *Co-supervision*
- *Telephone peer support skills*
- *Staying peer: advanced skills in navigating your own growing expertise while staying peer.*
- *Robust Support Structures: advanced skills in supervision, navigating systemic power dynamics and role playing conflict situations.*

… OK, now I've started to really dream, and I should probably wrap up! (I do have many more things to say, but that's probably enough for now!!)

What to do if you want to provide feedback?

Feedback is being invited currently, until Thursday April 21st. The way the Industry Skills Council works is that they must account for all the feedback they receive – that is, they must explain how they have taken on board the feedback. Links to all draft materials can be found on the project page:

https://www.cshisc.com.au/index.php?option=com_content&task=view&id=545&Itemid=162

And now for something completely different ... a new cartoon by Merinda.

What has Our Consumer Place been up to?

It has been a funny old time lately. Merinda has had a major back operation and is now in rehabilitation mode. All seems to be going well on that front. This has meant that Merinda has had time and head space for prolific cartooning, knitting and other brilliant creative ideas. This has also meant that Flick has been holding the fort here at OCP... So things have been a bit slower than usual.

We've nearly finished our booklet on *Consumers Telling Our Stories*, and this promises to be a wonderful resource (the cartoons alone make this a gem!). We've had to put Intentional Peer Support (IPS) Training on the back-burner a little bit, although Flick pulls little bits of IPS out in almost any training context. We are aware that there is a great demand for IPS, and it is a huge priority for us. So, do stay tuned. As always, we have been meeting with consumers, consumer groups and people supporting consumers; participated in consultations on all sorts of issues; and have been heavily involved in consumer perspectives in clinical training.

THUMBS UP/THUMBS DOWN

1. **THUMBS DOWN:** To the Mental Health Act review not even considering abolishing the compulsory treatment framework. We will never have a non-coercive mental health system with the threat of compulsory treatment hanging over us. Many service providers would like to believe that they are acting with kindness and care, but the system itself is fundamentally coercive, regardless of individual (or even service-level) goodness.
2. **THUMBS DOWN:** To recent political announcements, suggesting changing welfare policies towards an increasingly punitive attitude to people whose lives depend on welfare. This approach is shaming, cruel and targets those who have the least power to speak back.
3. **THUMBS UP:** To the groundswell of grassroots organising we are witnessing ... many groups are popping up at the moment, passionate about radically changing how we as a community respond to mental distress.
4. **THUMBS UP:** To conversations between consumers and service providers, when you KNOW in your bones that there is real, human connection.
5. **THUMBS DOWN:** To the increasing emphasis on funding web-based and telephone-based services, when the driving motive seems to be cost-effectiveness, at the expense of physical, embodied, human presence. While we (of course) applaud the use of new technologies to increase and diversify accessibility, we are concerned about these forms of support *replacing* human contact (and we wish more of this money would go into resourcing peer support).
6. **THUMBS UP:** To the exponential growth in interest in peer support and the conversations that are being had around how to properly resource, train and design peer support structures that are sustainable.
7. **THUMBS DOWN:** To how isolating consumer work can be. Often we are working alone – in the sense that we are the only ones paid to work from a consumer perspective – and this can wear us down, cause us to doubt ourselves and see our difficulties as personal failings.

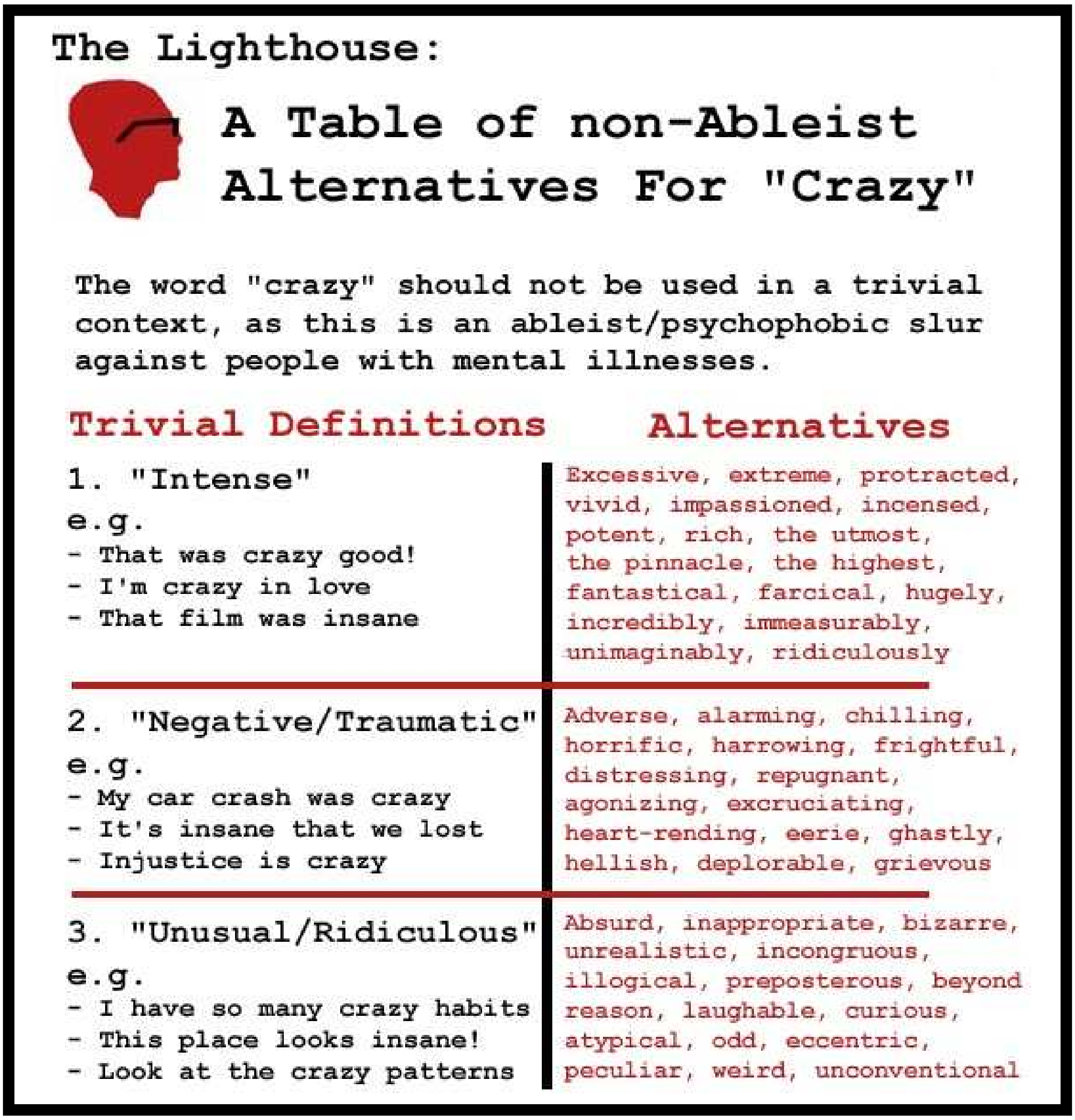
8. **THUMBS UP:** To the many ways in which consumers are coming together – to network, debrief, scheme, support each other, challenge each other and share ideas, stories, frustrations and jokes.

9. **THUMBS UP:** To amusing typos. Am still laughing about the idea of "cute units" – they probably have little ducklings on the wallpaper and fluffy toys for you to cuddle. How cute!

10. **THUMBS DOWN:** To Blueprints (prepared by Patrick McGorry, Ian Hickey and others, and taken up by the Federal Minister for Mental Health) for the future of mental health that barely mention (let alone fund) consumer initiatives. All that it mentions is "consumer and carer experiences of care". What about the paradigm shift that consumers are calling for!? We want funding for peer support, consumer leadership, non-medical alternatives, non-coercive alternatives, real accountability mechanisms (such as a Consumer Ombudsman)... but none of this is in the Minister's plan. Alas.

And just because we love language here at Our Consumer Place, here's a little tid-bit about language that we stumbled upon from "To the Experts":

http://totheexperts.tumblr.com/post/2763657651#mentalhealth



The Lighthouse:

A Table of non-Ableist Alternatives For "Crazy"

The word "crazy" should not be used in a trivial context, as this is an ableist/psychophobic slur against people with mental illnesses.

Trivial Definitions	Alternatives
1. "Intense" e.g. - That was crazy good! - I'm crazy in love - That film was insane	Excessive, extreme, protracted, vivid, impassioned, incensed, potent, rich, the utmost, the pinnacle, the highest, fantastical, farcical, hugely, incredibly, immeasurably, unimaginably, ridiculously
2. "Negative/Traumatic" e.g. - My car crash was crazy - It's insane that we lost - Injustice is crazy	Adverse, alarming, chilling, horrific, harrowing, frightful, distressing, repugnant, agonizing, excruciating, heart-rending, eerie, ghastly, hellish, deplorable, grievous
3. "Unusual/Ridiculous" e.g. - I have so many crazy habits - This place looks insane! - Look at the crazy patterns	Absurd, inappropriate, bizarre, unrealistic, incongruous, illogical, preposterous, beyond reason, laughable, curious, atypical, odd, eccentric, peculiar, weird, unconventional

Our Consumer Place's submission to the Exposure Draft Mental Health Bill (Vic)

In February, Our Consumer Place made a submission on the Exposure Draft Mental Health Bill. We had hoped that our submission would appear on the government's website, with previous submissions; since this doesn't appear to be likely, here is the majority of our submission (with some parts omitted or edited, such as introducing ourselves and some typos!).

Our priorities in this submission

There are many issues to be addressed – while the review [of the Mental Health Act] has suggested some important changes, which we applaud, there are also some areas that are of deep concern. We have chosen to focus on the ones that we feel best placed to comment upon. These are:

1. Compulsory Orders and Compulsory Treatment (ie. involuntary hospitalisation and treatment)
2. Supported Decision Making and "Capacity," and
3. Advance Statements.

We also make some brief comments on:

4. Provisions for the "Emergency ECT,"
5. Nominated Persons,
6. The involvement of Carers, and
7. Hearings "on the paper."

1. Compulsory Orders and Compulsory Treatment

We are fundamentally opposed to both involuntary hospitalisation and involuntary treatment, as we understand these to be violations of human rights and human dignity. They are also discriminatory, since they are forced upon people on the basis that they have (or are believed to have) a psychiatric disability. This is in direct violation of the *Convention of the Rights of Persons with Disabilities (CRPD)* – specifically, we point to Article 14 (1b), which states: *"... that the existence of a disability shall in no case justify a deprivation of liberty"* and Article 17, which states that *"Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others."* We understand that the review has retained provisions for both involuntary hospitalisation (Part 5) and involuntary treatment (Part 7), and we strongly urge that these be reconsidered.

We do recognise and applaud that in this Draft Bill, voluntary patients are able to refuse treatment. However, we question the effectiveness of this legal provision in practice. ***The possibility of involuntary treatment fundamentally structures the mental health system.*** Innumerable consumers have experienced the threat of involuntary treatment being used to coerce them into compliance (e.g. if they are a voluntary patient and want to leave a service or want to refuse a treatment, they are threatened with being made into an involuntary patient). This is such common practice that we consider it a structural issue, rather than one of individual service providers abusing the law. Moreover, an unknowable number of consumers have hidden their experiences and hence been denied support, due to a legitimate fear of involuntary treatment and the loss of autonomy and dignity this would entail. So long as there is legal provision for involuntary treatment, we believe the mental health system will continue to be both coercive and mistrusted.

We also take issue with the criteria for Compulsory Orders and Compulsory Treatment. There is an assumption inherent in the legislation that psychiatric hospitalisation and involuntary treatment entail safety and healing. So, for example, Part 5 (70) *Criteria for an Inpatient Treatment Order*, states that a person can be made subject to an Impatient Treatment Order in circumstances where *"...(d) if the person is not detained and treated in an approved mental health service there is ... (ii) a significant risk that the person will suffer serious physical or mental deterioration."* This implies that if the person is "detained and treated," they will not suffer serious physical or mental harm. However, in reality, ***psychiatric hospitals are deeply unsafe places***: involuntary patients have their mental and bodily integrity violated – legally – through forcible treatment, ECT and seclusion, as well as more subtly damaging and humiliating practices (e.g. violations of their dignity, autonomy and self-respect). Moreover, many other (non-legitimated) forms of violation – sexual, emotional, physical – are rife in psychiatric hospitals.

While we appreciate that it is the experience of many consumers that involuntary treatment has helped them – by preventing suicide or an escalation of their distress, or by providing access to appropriate treatment – the fact that anyone can be involuntarily detained and involuntarily treated means that all consumers are systemically disempowered, violated and coerced.

Fundamentally, we believe there is an urgent and pressing need for voluntary, non-coercive alternatives to psychiatric hospitalisation. This is already implicit in the legislation – both as it stands, and in the Exposure Draft. One of the criteria for an Involuntary Treatment Order is that: *"(e) all reasonable less restrictive options, including whether the person can receive the treatment on a voluntary basis, have been considered and are not suitable."* In our view, this is the essential flaw in the current system: those who are deciding that people be involuntarily treated tend to have no other '*reasonable less restrictive options'* to give genuine consideration to. This deplorable lack of alternatives means that many people will end up in coercive, violating situations, due to there being no alternatives. In this light, we applaud the growth of Prevention and Recovery Care (PARC) centres, but urge that Consumer Developed Services are a viable and important alternative model.

2. Supported-decision making

In the Objectives and Principles outlined in the Exposure Draft, a supported-decision making model is suggested:

> *(4) A person with a mental illness must as far as is reasonably possible in the circumstances—*
> *(a) be consulted in accordance with this Act in the making of decisions about their mental illness;*
> *(b) be supported to enable the person to make his or her own decisions, including in developing a treatment plan;*
> *(c) be provided with the support and information necessary to enable the person to exercise their rights under this Act;*
> *(d) have their preferences and wishes considered in the making of decisions affecting the Person.*

We fully support a paradigm shift towards a supported-decision making model. We understand this supported-decision making model to be integral to emerging international human rights frameworks, including the CRPD, as well as to the dreams and aspirations of disability advocates nationally and internationally. This is an important paradigm shift, which needs to be actively supported and promoted.

However, the substance of this Draft does not operationalise a Supported-decision making model, and in fact falls far short of this ideal. This is partly due to the provisions for involuntary hospitalisation –

which fundamentally allows for a substituted decision-making model to remain as a fall-back option – and partly because the support provisions are not robust enough to make this paradigm shift a reality. The fact that every provision for supported-decision making (e.g. Advance Statements, Nominated Persons and informed consent to treatment) can be over-ridden at the discretion of the Authorised Psychiatrist means that this paradigm shift has not actually occurred, despite the statements to the contrary quoted above.

We argue strongly that the law should take seriously this paradigm shift as it has been articulated at an international level, and examine how supported-decision making could be genuinely put into effect. Our recommendations are:

1. that involuntary treatment be abolished,
2. that resources be increased to increase and strengthen *voluntary* alternatives,
3. that support provisions be strengthened, including:
    a. Embedding legal provisions for Nominated Persons to act as support people, to enable the person to retain their decision-making capacity, *with appropriate support*. This would be one way to honour Article 12(3) of the CRPD, which states: *"States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."*
    b. Strengthening the legal status of Advance Statements (see below).

3. Advance Statements

We applaud the introduction of Advance Statements into the mental health law, and wholeheartedly embrace this as a step in the right direction for human rights and self-determination for mental health consumers. However, we believe the legal status of these Statements must be increased, if they are to be part of any genuine shift in practice.

Firstly, Advance Statements must not be seen as merely stating the "wishes and preferences" of the person. Such language is dismissive of the person's capacity to have *knowledge*, *will* and a right to *self-determination*, all of which must be respected as having legitimacy. Wishes and preferences should form part of an Advance Statement, albeit with less binding force. We prefer the language of "Advance Directive," which should be understood as stating the will of the person. Article 12(4) of the CRPD states that *"all measures that relate to the exercise of legal capacity"* must *"respect the rights, will and preferences of the person."* We see Advance Directives as having the capacity to put into law this important provision.

Secondly, the provisions for ensuring compliance with Advance Statements are far too weak. Part 10, s.154(1) states that decision makers *"... must have regard to an advance statement"* but that they can make decisions *"inconsistent with the wishes and preferences of the patient expressed in their advance statement."* Rather than this very weak language of "having regard," we believe that there should be a presumption that Advance Statements will be complied with, unless there are compelling reasons not to comply. In the event of non-compliance with the Advance Statement, these "compelling reasons" must be documented and provided in writing to both the consumer, their Nominated Person (or Nominated Persons), the authorised psychiatrist and the Mental Health Commission. The Mental Health Commission ought to take seriously its role in monitoring the non-compliance with Advance Statements.

4. Emergency provisions for ECT

We applaud the addition of mandated involvement of the Mental Health Review Board in cases of ECT use. However, we are concerned about:

1. the “Emergency” provisions in the Bill. We don’t believe ECT could ever be considered a necessary “emergency” procedure. We oppose the inclusion of this provision in the law, as we strongly suspect that this will be over-used to bypass the (“inconvenient”) safeguards.
2. We are also deeply concerned that ECT could be used on people under 18, whose brains are still developing.
3. We believe that people should have an inalienable right to refuse ECT (and any other psychiatric intervention). This could be articulated in their Advance Directive. Given that there is a great deal of controversy about the use of ECT, we believe that this would be a safeguard so that those who choose not to be given ECT would be able to have this choice honoured.

5. Nominated Persons

We commend the idea of including a ‘Nominated Person,’ who must be kept informed. However, there are three issues that we would like to raise. Firstly, we believe that it is extremely limiting to have only the capacity for one ‘Nominated Person.’ Reflecting on our own lives, this seems both impractical and limited. We may have more than one relevant person in our lives – a family member, our partner, more than one mental health professional (e.g. we may have both a psychiatrist and a psychologist, or a GP). This limitation also means that if for some reason this person is unavailable (or perhaps is just unwell, or has little time to keep fully abreast of our situation), then we are left with no support. The Exposure Draft explicitly points to this potential (in Part 5, 7(a): *“... unless after taking reasonable steps to do so, the nominated person cannot be identified or found”.*

Secondly, it is unclear at what point one would appoint a “Nominated Person.” Given that the process has to be conducted similar to a statutory declaration, it is not obvious how someone being admitted for the first time (and unprepared for such an admission) would engage in this process. Such people are incredibly vulnerable and so there must be a process that allows for them to nominate an appropriate person. Thirdly, we are concerned that there are provisions for the Nominated Person to be deemed “not an appropriate person to fulfil that role.”

So, we recommend that the law allow provision for more than one Nominated Person (perhaps up to three). We also recommend that there be a provision that makes it obligatory, during the intake process, to ascertain who the relevant Nominated Persons would be.

6. The involvement of Carers

We applaud the insistence within the Exposure Draft that any involvement of Carers (or family members, guardians, advocates or other persons) be contingent upon the consent of the person. We believe that the “Nominated Person” provision is a reasonable way to include significant others in their treatment, without assuming that any (“Carer”) relationships should override consent provisions.

7. Hearings “on the paper”

We are concerned about the provisions for hearings to be held “on the paper.” We believe that there are no circumstances in which decisions should be made without the involvement of either the person themselves, or their Nominated Person. So, rather than having provisions for hearings “on the paper,” we urge that the person have a substituted representative involved. We suggest that a Nominated Person would be the most appropriate person.

HEY YOU!

... Now, more than ever, Our Consumer Place needs YOUR input

Here are some specific ways in which we desperately want to hear from YOU (and as many people as possible!!):

1. Is there something exciting, interesting, infuriating or vaguely relevant going on that you think others might be interested in?

We would love to be able to share more of what is going on, but find that so much goes “under the radar.” OCP is committed to ferreting out the tid-bits of what’s going on, so that the consumer world can be as informed, inspired and invigorated as possible. Please feel free to send us promotional materials for events, courses, jobs, happenings, etc. We know of some things, but know there is more to be known too.

2. Have you read something that changed your life? Know a website that talks about madness in transformative ways? Stumbled across some other little gem?

Our Consumer Place’s website has been sadly neglected for ... well, ahem, ... too long! We are in the process of adding new material, removing old links (some of which we would desperately like to repair), etc. As we have only a handful of eyes between us, we would greatly appreciate your eyes too. We have our own specific interests – you’ll probably know stuff that is of interest to other people. *If there are any good resources that other consumers might be interested in, please let us know! This includes websites, books, YouTube clips, poetry, academic articles, political rants, etc etc.*

3. Are you running a consumer group or project or network?

We are always on the lookout for people who would like to write about their experiences running their own group or project *from a consumer perspective*. We believe passionately that there are many amazing things going on out there – most of them under the radar – many lessons to be learnt, many mistakes to be learned from (or perhaps avoided), money to be scrounged, etc. We want to hear MORE, so do contact us if you are onto a good thing.

4. YES YES YES! ... but what do I do now?

Our Consumer Place is a resource for the consumer community. We do whatever we can to support, disseminate, and share. The best way to contact us is by email: service@ourconsumerplace.com.au; or by phone: (03) 9320 6802. Please be aware that we may be slow to respond (we are hopelessly understaffed at the moment), but we will do our best!!