People diagnosed with 'mental illness' doing things for ourselves

OUR CONSUMER PLACE NEWSLETTER APRIL 2010

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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES

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NEWS IN THE CONSUMER WORLD: Upcoming conferences!

This month, we've chosen to share information about upcoming conferences that consumers may be interested in attending.

1. **VICSERV: Unfinished Business – Pathways to Social Inclusion** is the bi-annual conference for VicSERV, the peak body for psychiatric disability services in Victoria. It will be held April 29th–30th 2010 at the Melbourne Cricket Ground. Bursaries are available for a limited number of people – go to their website: http://vicserv.org.au/conference2010/ to find out more. Or, you can ring VicSERV – ph. (03) 9519 7000. Tina Minkowitz (an incredible psychiatric survivor and human rights lawyer –see interview in this edition) is the keynote speaker on the Friday (April3 0th). She is ***definitely*** worth coming to hear!

2. **Communities in Control: Power Up! Who has it, how to get it & how communities can useit** – the annual conference for Our Community (which is the organisation that Our Consumer Place is part of). It will be held May 31st – 1st June 2010 at the Moonee Valley Racing Club. Mary O'Hagan (who we interviewed in the previous edition of our newsletter) is a keynote speaker on the Monday (May 31st). For more information, check the website: www.ourcommunity.com.au/cic2010. This conference is relatively expensive, but Our Consumer Place are able to give away up to 10 free tickets to consumers if they contact us. Please ring – ph. (03) 9320 6839 – or email us – service@ourconsumerplace.com.au by April 30th if you are interested in a free ticket.

3. **THEMHS: 20 Years Strong: and now a Renaissance** is the annual Mental Health Services Conference (THEMHS). It will be held September 14th–17th 2010 at the Sydney Convention Centre. There are bursaries for consumers and reduced conference fees so check it out. Leonie Manns (a consumer) will be giving the keynote on the History of the Consumer Movement in Australia. She should know as she has been around for well over twenty years and this is something worth hearing.

4. **"MENTAL WELLBEING Conference 2010": Innovative Integration: roadmap for mental wellbeing** is the 2010 conference of the Royal Australian College of General Practitioners (RACGP). It will be held September 14th –17th 2010 at the Sydney Convention & Exhibition Centre . At first glance there doesn't seem to be any special place for consumers at this conference – e.g. there are no consumer key note speakers. GRRR!

INTRODUCING ... (A CONSUMER DIRECTED INITIATIVE)

The Brook R.E.D. Centre Inc.

In this edition, we share with you the Brook R.E.D. Centre Inc, in Brisbane, which Merinda and Flick had the pleasure of visiting earlier this year to attend training in Intentional Peer Support.

A Peer Run, Intentional Peer Support Community

The Brook Recovery, Empowerment, Development (RED) Centre began life in 2000 out of an outpatients clinic of the Princess Alexandra Hospital in the inner South Brisbane suburb of Highgate Hill. At that time the hospital decided to cease the outpatients clinic and in its stead fund a small non government, not for profit service to cater for people with a lived experience of mental health concerns in the local area. At its inception, the new Brook RED centre was to be peer run and peer driven.

> *The centre slowly developed a community of peers. This community in turn started to support and challenge one another and in the process many members of the community improved.*

The centre slowly developed a community of peers. This community in turn started to support and challenge one another and in the process many members of the community improved. Recognising this peer support as central to people's recovery efforts, peers and workers at the centre began searching for ways to enhance their and the community's knowledge of the practice of peer support. After much research, trial and error, the community at Brook RED came upon the work of Shery Mead and Intentional Peer Support. Intentional Peer Support supplied a process of learning and teaching one another about how we know what we know in a way that was mutual and respectful.

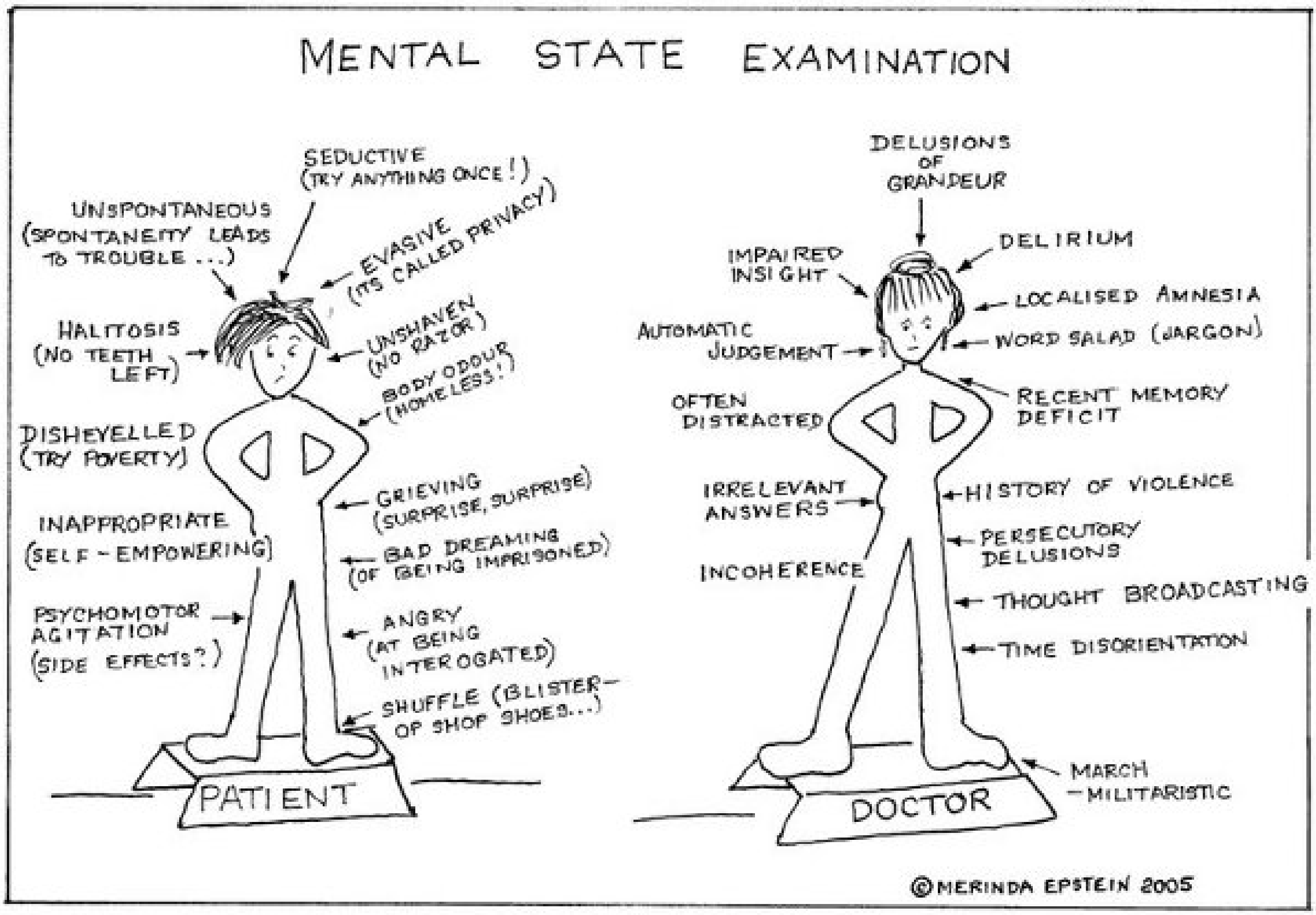
Intentional Peer Support is a process where peers come together as equals (or work towards equality) and mutually support each other to re-evaluate how we know what we know about our lives. The central theme of Intentional Peer Support is "What has happened to you?" as opposed to a more traditional helping model of "What is wrong with you?" Peers support each other in this journey by following the four tasks of Intentional Peer Support: -

1. Connecting with each other. This may be around their shared lived experience but this is NOT the be all and end all of connection. We connect so we can get to a space of understanding and trust between ourselves.
2. We talk about our world views. Basically, world view is how we have come to know what we know about the world. The "lenses " we've learnt to see the world and our relationships through. Once we talk about our world views we move on to the next task,
3. We talk about Mutuality. That our relationships are not just based around what you can do for me, but around what each of us can do to improve the relationship. That in essence means being open to talk about the good the bad and the difficult and being present to hear the feedback.
4. Finally, we talk about moving towards. Many of us do our best to avoid getting sick again, but that focuses us on being ill, and not on leaving illness. So we talk together about moving towards what we want.

The ethics and philosophy of a peer run, intentional peer support community are expressed in everything the centre does. The majority of the board of management members identify as having a lived experience of mental health concerns, as do all those who are paid to support the community. All the groups run through the centre have their content and activities planned by their participants and peers are involved in the planning and policy development of the centre through a "Think Tank" – a kind of Brook RED Senate.

The Brook RED community has over 200 people on the books. The centre is funded through the Queensland Department of Communities (DoC) and the federal Department of Health and Ageing (DoHA). DoHA funds the centre to undertake a Day to Day Living program for people with a lived experience of mental health concerns. This allows people to select a peer worker as a point of contact and a person to undertake Intentional Peer Support with. In the past DoC's funding has provided running costs and supported drop in sessions. Recently, the centre and its community were recognised for their outstanding work and awarded funding for Queensland's first Consumer Operated Services Program. This will allow the centre to "bud off" a second centre/community and build a respite service.

-By Adam Dunne, a peer worker at Brook R.E.D.



INTERVIEW OF THE ISSUE – Tina Minkowitz

Tina Minkowitz *is a psychiatric survivor and human rights lawyer. She is the founder of the Centre for the Human Rights of Users and Survivors of Psychiatry, co-chair for the World Network of Users and Survivors of Psychiatry and has played a key role in the drafting of the UN Convention on the Rights of Persons with Disabilities (CRPD). She is the author of "The UN Convention on the Rights of Persons with Disabilities and the Right to be Free from Non-consensual Psychiatric Interventions," which includes arguments on torture and ill-treatment, and has presented with the UN Special Rapporteur on Torture on this subject.*

Flick Grey: How would you describe what consumers/survivors/service users are doing – changing systems and/or the world? Do you think our political heyday has come and gone?

Tina Minkowitz: I wouldn't say that our political heyday has come and gone, I think there have actually been at least a couple of different waves of what I call the user/survivor movement, at least that I know of.

I came into the movement at the end of the 70s, when it was still very radical, it was people coming together in a very grass-roots way. No one had any money, we were fighting against forced treatment and we were doing advocacy for each other. If somebody was locked up, someone would go over to the hospital and try to argue them into letting the person out. Some of us would take the person into our homes until they could get on their feet. It was just really helping each other out, and at that time – at least in the part that I was in – it was very clear that the psychiatric system was not our friend – the forced psychiatric system, being locked up and all that.

I came into the movement at the end of the 70s, when it was still very radical, it was people coming together in a very grass-roots way. No one had any money...

Then – and my perspective is in the US, but I think similar things started happening all over the world, at least in all the countries in which there had been a movement up until that time – there was a period when the government started funding people in the movement to do all different kinds of things. But the one thing they couldn't and wouldn't fund – because the funding was coming through the mental health system – was advocacy against forced treatment, advocacy against being locked up. They were committed to that. So, to some degree, there was a split and many people started thinking that the ones who were taking money from the mental health system were co-opted, and those who were working within the system, I think, felt that other people were just dreaming and being utopian and weren't ever going to be able to make a difference.

Now, what I think we have now is a third phase, and I think that it's directly related to the work I've done with the World Network [of Users and Survivors of Psychiatry], and the work that the World Network has done as a whole in bringing people from around the world together. In a lot of countries, the user/survivor movement got started because human rights advocates went in and said, "oh the mental health system has all kinds of abuses in it, let's help people to organise," or even sometimes the mental health system was trying to promote people to organise in some way. So we have a lot of organisations in various countries that have gotten started in all different kinds of ways. Of course, there have also been independent initiatives– there's really a mix all over the world.

In the World Network, what we've been trying to do is to put all of this on a basis of human rights and particularly in the work that we've done on the disability convention, to put *self-determination* or advocacy for self-determination at the centre: everybody, whether you identify as a 'user' or 'survivor' or 'person with a psychosocial disability,' or whatever, self-determination should be something that unites us. Nobody should be mistreated, nobody should be thrown into a hospital or institution against their will. Let's try to work out together what are the kinds of things that people need. You know, we're not all going to need or want the same things. If we can agree on self-determination, then there's a lot of room for discussion about what kinds of services people want, if they want peer support, or housing, or employment, or working to get better services from the mental health system. So I guess that's how I see the current state of the movement.

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FG: What place does activism have in mental health? What top three areas would you target?

TM: I see the need for activism in relation to the laws that govern mental health, in relation to the policies and in relation to the role of the mental health system and the role of mental health professionals, in the lives of people who experience madness or mental health problems.

So, in relation to the law, I would say that mental health laws have to be abolished. In a way it's almost easy to say it, conceptually, because usually these laws are discrete laws, they're isolated, they're just their own little thing, and it's easy to say, well, there's nothing of value in them that even has to be changed. It's just something that says that you can lock somebody up in psychiatry and you can force treatment, and these are the conditions under which you can do it. So, let's get rid of all that, and instead make sure that free and informed consent applies. We have to deal with legal capacity to make sure that people aren't being judged to be incapable of making these decisions, which is just a back roads way of doing forced treatment.

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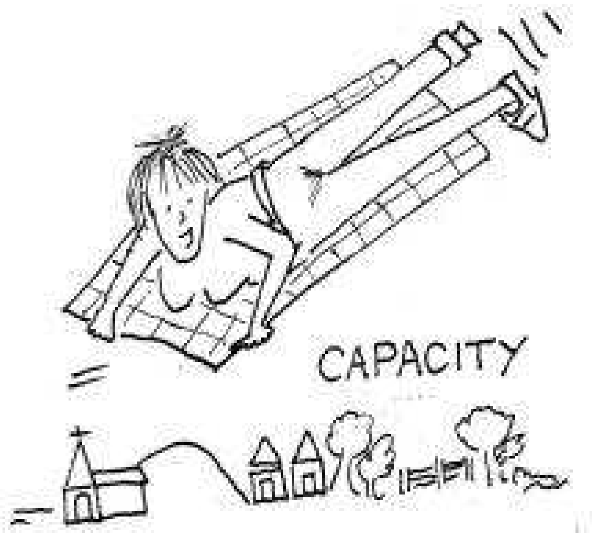
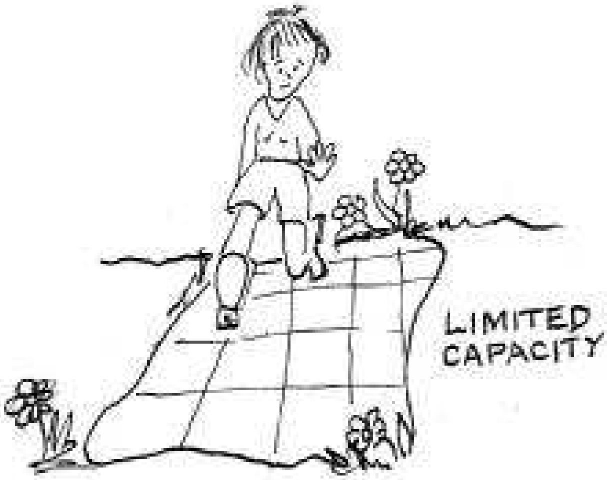
And so, then, I think policies have to be changed, to get away from the medical model that just sees people as bunches of chemicals interacting with each other. The medical model is what the WHO [World Health Organisation] has been promoting. They put the prescription of drugs and diagnosis of mental illness by primary care doctors at the centre of what they really advocate for, even when they put human rights as a kind of window dressing. And it's going on in the United States, where our health care reform has just included screening of women for postpartum depression. So, when you've just given birth, somebody's going to come and give you a test to see if you're feeling bad, and give you drugs for it. I think that policy has to move in the direction of a less





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scientific-evidence-based, more human-interaction way of looking at what is needed for people who are seeking help from the mental health system.

There's an interaction between this and getting rid of the mental health laws. It's easy if you have a mental health law to force drug somebody. But if you can't do this, then what are you going to give people that they actually want, and how are you going to treat them in a respectful way? Drugs have a place – there are certainly people who feel that the drugs benefit them, and it's not for me to say what should be the role of drugs, because I haven't experienced drugs benefiting me. But, clearly, there are people who do feel that, and there's no reason why drugs couldn't be part of a good system.

So, then, the third thing is to say that the role of the mental health system and mental health professionals in people's lives needs to be diminished. This is counter to the trend we're actually seeing in the world. We are seeing the mental health system expanding, and making partnerships with all kinds of other systems – for example, the criminal justice system, with all the services serving children. And even beyond that, I think that in my lifetime, I've seen an expansion of the role of the mental health system in many people's lives after they get out of a hospital. If you're locked up and you lose your home, and if you don't have anybody who will take you in, you end up going to mental health housing, and go to a clubhouse or a day treatment program.

A lot of what's happened in the user/survivor movement I think somehow builds on that – I'm not sure, but it may even feed into it. You have a lot of peer-support programs, that are serving a lot of people who are still linked into the system. This is something I'm only seeing a little tangentially, but I would like to see more peer support and advocacy that are completely independent of the mental health system, in ways that help people to get out of the system, and not be so dependent on it. But that's a choice that everybody needs to make. A lot of people end up relating to one service system or another as their primary social environment, and that's a problem of the complex society we have now. I think there are some people doing this kind of work, really trying to look at building relationships, with banks, and with libraries and businesses, and other kinds of community institutions, to push them to just be more inclusive and be able to provide services to people coming out of the mental health system.

FG: What would you expect to be different if we lived in a community that embraced people who have mental health problems or experienced madness?

TM: I have to think about this one, I feel like I have to come to my own experience a little more. One thing that I think – almost as an interim – is that communities need to be aware of the harm that's been caused by the mental health system, and be able to deal with some of the ways that we have traumatic reactions in relation to that.

And, as kind of a bigger picture of that, I think communities would have to become more trauma-sensitive in some ways overall. So, for example, now in the US, we're having a lot of discussion about the needs of veterans coming home from war, and there's some good work being done – there's a program called "Vet-to-vet" that seems very interesting. And there's been some discussion of trauma in relation to being aware of incest and child sexual abuse – there's been a lot of consciousness-raising about that. But, the trauma of the mental health system, and a lot of traumatic reactions in general – like if someone's acting angry in a way that other people think is too much – isn't always acknowledged. I would like to see some acceptance of a wider range of emotion.

I would like to see some acceptance of a wider range of emotion.

I remember in New York after the planes hit the World Trade Towers on September 11, it was almost like things were so topsy-turvy that people's emotional reactions were just OK. So, I saw a guy walking down the street, talking to nobody that was there, and it was just kind of "yeah, he's going through his pain". And, that's what people are going through all the time, for all kinds of reasons. It sometimes seems to me that the changes that we really need are so big and so complex, I don't know how they are going to be able to happen. At the same time, while I would like to see society change in that way, you know society is becoming more complex all the time, there are more and more forms we have to fill out that we don't understand, and all kinds of bureaucracy and laws that we don't understand, so I don't know how that's all going to turn out.

FG: If you were asked to give the government advice on how to spend $500 million for mental health, what would you spend the money on? What about if you have $10,000 to spend?

TM: I don't know how much these things cost! It's an interesting question to ask, it's like asking "What should a mental health budget actually be?" In some ways, one way to answer this would be to say – make the society as a whole less traumatic for people. Look at what's traumatic in this society, and figure out how to change all those things. This doesn't necessarily mean putting money into a particular kind of service. So, that's one way to answer.

Another way is let the people who are using services decide, in a real democratic way. 'Democratic' meaning not just that something is pronounced and then everyone takes a survey, but with some real information and investigation. What do people actually want? I don't use mental health services and I can say the kinds of things that I've seen or read about, that seem good to me. But the people who actually use services should figure out what that should be. And that can only be done in a context where there's no coercion. Whenever people have to make decisions about services, based on the fear that, if they make a wrong decision, they will be locked up and injected and whatever, it's going to be a very limited range of imagination, and mostly what you're going to get is within the status quo. So there has to be a way of asking people what they actually want, and I also believe that asking people what they want should be the basis for individual services also.

And then, if it were $10,000, I think that would also be what I'd say. It doesn't have to be a huge budget, it's about how you do it.

FG: What are some things that could happen in one day that would give you a really good night's sleep where you woke up feeling hopeful and ready to take on the world?

TM: I guess I could say some things that have happened and then some things that I would love to see happen.

When I've seen a standard come out from the international community – the UN, that sort of thing – that actually says we should have our freedom – that always makes me feel like there is an opening. So, the first time in the work on the Convention that our proposed language about people not being locked up on the basis of disability (I forget exactly how it was phrased) made it into a draft text that was being compiled by other people, I could imagine that freedom more concretely. When the report of the Special Rapporteur on Torture came out, recognising that forced psychiatry could amount to torture and ill-treatment – it used a lot of the language and arguments similar to what I have put forward, about how forced intervention to "correct" disability has to be looked at as a violation.

When I see people really grabbing on to this, demand, desire for human rights and not letting go, it gives me a lot of strength.

Another is when I see people in the user/survivor movement in other countries really sinking their teeth into the fight and taking it up, and taking it to the health ministry. When I see people really grabbing on to this, demand, desire for human rights and not letting go, it gives me a lot of strength. Without that, it's just a few of us being lone voices in the wilderness. Without our advocacy, no government is going to just read the CRPD [UN Convention on the Rights of Persons with Disabilities] and just say "Ok, wow, this says we have to get rid of our mental health laws." It's not going to happen without our advocacy.

And so, I hope and maybe it will happen sooner than I think, I would like to see it enacted into actual law. I would like to see some country or some state respond to this advocacy and say "OK, we're going to take away this repressive law and we're going to acknowledge that we've been promoting a lot of fear, and that we've been excluding a section of our population shamefully and unnecessarily. We apologise and we welcome you back in." I hope to see that in my lifetime.

FG: Which is more important to you, the outcome or how you get there? Can you give an example?

TM: I think a few years ago, I probably would have said just unequivocally – the outcome, when I was just in the midst of the work on this Convention. I felt that the advocacy that I brought to that had come out of the 30 year user/survivor movement. And it seems to me it was just really important to have that reflected in international law. And that outcome was what I was working for more than anything else.

I think at this point, I'm more concerned about the process, compared with before. The problem that I have with being concerned about process is kind of like if someone is stepping on my feet, and won't get off, and I'm just hitting them to make them get off my feet, then that's going to look like violence, and they might be standing there, being really, really calm. It's going to look like I am the aggressor. And so there are things that may look like you're fighting and like you're being hard in some way against other people, when you're trying to get oppression off your back. And so, in that sense, when you're fighting in that kind of way, I think you have to focus on the outcome.

But at the same time, to really make something work in society, in a particular society, in a particular culture, in a particular locality, you have to work with people's needs and people's fears. And so that's what I was saying in relation to what a mental health system should do, and spend money on. I think there are questions that really depend a lot on that kind of process, and that all of us have to decide together. It's like it's a kind of hard-and-soft balance. I don't want to have to negotiate with the mental health system for my human rights, and that's been a trap. From my perspective, I think many people in our movement are getting sucked into thinking "well we have to be nice while they're stepping on our feet." That's why my advocacy stands outside the system, and says "*you* have to be held to human rights. If you want to work with me from a basis of recognising and respecting my human rights, then everybody's welcome.

Some thoughts on Language

From the work of Sylvia Caras (reproduced with permission)

Is the lived experience of mental illness important in the language we use?
If you say, "Peter is depressed," how is this different from saying "Peter feels hopeless" or "melancholy" or "worthless"? Which one respects lived experiences?
If you say, "Josie hears voices," how is this different from saying "Josie is Schizophrenic"? Which one respects lived experience?

Why 'not' ?
In English we often prefix a negative word by putting the word, **NOT,** in front of it. It is supposed to change the meaning to the opposite but it also *plants the negative idea in the listener's ear.* This is what happens when you say something like, '… people with 'mental illness' are **NOT** dangerous."

SOAPBOX – Consumers and smoking?

By Kristen Moeller-Saxone

In the Thumbs up/Thumbs down section of the last [Our Consumer Place] newsletter there were four points made supporting smoking and critical of smoke free policies. I would like to balance this out with presenting some of the issues for consumers who want to cut down and quit smoking.

Inpatient settings have been perhaps the last bastion of smoking venues in our community. Smoking bans have been steadily rolling out since the 1980s and it is only some 30 years later that they have finally arrived in psychiatric units. At the same time the general community has embraced smoking cessation and the commensurate improvements in their health and life expectancy. The same cannot be said for people who experience mental illness, whose health and life expectancy have not improved over the same period. Much of this can be attributed to their lack of smoking cessation. These cold hard facts actually make me feel angry that we accept this status quo. Why should people with mental illness be forgotten in the goal to improve the living standards of Australians?

> *The problem for mental health services is that by allowing environments that encourage smoking, they contribute to the illness, disability and early death of the very people they are trying to help*

One of the factors that influence a person's ability to stay quit is the frequency with which they encounter reminders to smoke. It is a recurring theme among the people I have spoken to in my work helping people to quit smoking, that being in mental health services is something that they fear will jeopardise their quitting success. As Will Elliott put it when he described what it was like being hospitalized for schizophrenia for the first time, "Cigarettes were the best way to pass time, which was how I got hooked again in earnest." (*Strange Places,* p.170)

As Will Elliott pointed out, the best place to be in the psych ward was out with the smokers, otherwise the experience was boring, distressing and lonely. Wouldn't it be better if consumers worked with mental health service staff and management to deal with the issue of why these places are boring, distressing and lonely? I know of one hospital ward that has tried some new ways of making the experience tolerable and guess what? The problems around smoking on the ward decreased. Surely rather than fighting a self-defeating battle to maintain smoking in mental health services, we would be better off using this opportunity to push for better conditions? Surely no one really wants to protect the rights of people with mental illness to die 20 to 30 years earlier than other people in the community because of smoking? I know there are many good ideas out there about how we can make contact with mental health services more humane and tolerable. Let's use the smoking bans as leverage to get them enacted. Three out of four smokers with a mental illness want to do something about their smoking. Let's help them too.

About the contributor:

Kristen Moeller-Saxone has been working with people with mental illness to help them quit smoking for almost 20 years. She is currently doing a study exploring the experiences of successful quitters who use mental health services. She is deeply interested in the interface between experience, rationality and spirituality.

FEATURED ARTICLE: Body Integrity Identity Disorder

This month's feature article is from ***Sean O'Connor****, about Body Integrity Identity Disorder (BIID) and the fight to be recognised in the DSM.*

[Editor's note (Flick): From a few preliminary discussions I've had with other consumers unfamiliar with BIID, I suspect that this issue pushes the boundaries of "legitimacy" for some of us, while raising deeply interesting questions about the politics of experience, legitimacy, medicine and disability.]

BIID, Legitimacy, DSM

Body Integrity Identity Disorder. A mouthfull! It's usualy shortened to BIID. But... What is it? Why are BIID advocates trying to get it included in the DSM5? Why are we mostly unconcerned by being pathologised in such a way? People with BIID have a need to have a specific physical impairment. The problem is, most people, including medical professionals, have never heard of BIID, much less know what it is. Which means those of us who have BIID are left with no help at all.

I need to be paralysed "from the waist down", to be paraplegic. For the last 15 or so years, I've been using a wheelchair full time. This is my way to "treat" BIID, to keep it under some sort of control. Other people with BIID need to be amputees, or blind, or deaf. We didn't ask to feel this way. For most of us, it started when we were very young, pre-puberty. It goes back to the age of 4 for me. Over the years, I've tried several forms of psychotherapy, and different courses of pharmacotherapy. Neither helped BIID. The little research there is on BIID confirms my experience with therapy. The only thing that appears to help is to become an amputee, or paraplegic. Once the body is aligned with the psyche, the individual finally finds peace. I could list what BIID isn't about, but it is easier to say what it is about - Our body, which we know to be normal, simply isn't right for us. The closest analogy I can give you is that of a transsexual. We grow up in a body that doesn't feel right; we didn't ask to feel this way; psychotherapy doesn't resolve it. Obviously, GID is not the same as BIID, nor does it come from the same place, yet it is the best example. There are arguments about whether BIID is a psychological condition or a neurological condition. Neurologists in California have found evidence of a neurological aspect to BIID. It may very well be a neuropsychological condition. The nature of BIID is nearly irrelevant as long as we aren't getting the help with need.

I have been advocating for Body Integrity Identity Disorder to be included in the next edition of the DSM. I realise very well that many people are advocating to get their own conditions out of the DSM. I support the social model of disabilities, which might appear contrary to seeking inclusion in a diagnostics manual and the inevitable pathologising of our "boo boo". The thing is, surgery is the only thing that has shown to get rid of the BIID pain and anguish. And surgeons won't do such surgeries as elective amputations or elective spinal cord transections. In great part because, right now, BIID doesn't exist. It is not written down in any book or manual, so it is easy to dismiss.

But even if we forget access to surgery, it is important for physicians, psychiatrists and psychotherapists to have a basic understanding of this condition. Too many times people with BIID have been dismissed by medical professionals. They think we have Obsessive-Compulsive Disorder. Or that we have Body Dysmorphic Disorder. Or that we're just dealing with a weird sexual fetish. Or that we have an odd "little fantasy". And while therapy cannot get you rid of BIID, it certainly can help you get to grips with it and understand and accept yourself better. That can't happen if the medical professional hasn't got a clue about Body Integrity Identity Disorder.

It is as if BIID doesn't exist, as long as it is not included in the DSM. Coming "out" to family or friends is complicated. They won't accept the reality, and seriousness, of what it means to have BIID. Because, they say, it's not a legitimate condition, you see? It is just a clever invention to make ourselves appear more interesting, they say. Between family and friends, and medical professionals not taking BIID seriously, we are left with no help at all.

In the end, how important is it to not be pathologised, if it means we're left alone with BIID, and no hope of help? I say "label me, then help me", if that's what it takes. Just like in Maslow's hierarchy of needs, for those of us with BIID, some things are more important than others. A fight for not being pathologised is the least of our worries right now. We need to be taken seriously when we seek help. And that is unlikely to happen until Body Integrity Identity Disorder is seen as a legitimate condition. And as I told my father who was telling me "but, you're crazy!" - "Yeah, so what?"

About the contributor:

Sean O'Connor is a man in his early 40's who has felt the need to be paraplegic for over 35 years. He uses a wheelchair full-time as a way to mitigate the intense pain and anguish of being in a body that doesn't feel right. He is passionate about disability rights.

For more information about Body Integrity Identity Disorder, please see http://biid-info.org and http://transabled.org

OUR CONSUMER PLACE UPDATE: WHAT HAVE WE BEEN UP TO?

Booklets:
The Our Consumer Place team has been busily completing the first of a set of booklets. Number one will be ready for distribution sometime in April/May. We received a lot of wonderful material from over fifteen outside consumer authors. This first booklet is an introductory one – it's an introduction for both people who are newly diagnosed and are searching for information, and people who are new to "consumer perspective." What makes these booklets different is that they are written for consumers by consumers – this is material that doesn't come in the glossy pamphlets from pharmaceutical companies or non-government organisations.

Training:
Flick and Merinda are preparing to share our knowledge of Shery Mead's model of Intentional Peer Support (see the article in this edition on Brook R.E.D. centre which uses this model). We plan to be providing workshops in Intentional Peer Support from the middle of the year.

THUMBS UP/THUMBS DOWN

1. **Thumbs up** to consumers who tell us what they like / don't like or need or would like to see happening, etc.
2. **Thumbs down** to Patrick McGorry's calls for increased "early intervention," which seems to be leading to more teenagers having their emotions pathologised and medications prescribed.
3. **Thumbs up** to David Webb who was a guest on Jon Faine's 'Conversation Hour' (on Wednesday March 31st 2010) about mental health reform with Patrick McGorry (Australian of the Year) and Megan McQeenie (Mental Health Foundation). David's contribution was brilliant as he kept brining the discussion back to issues of human rights. He was also the only one in the discussion who had the guts to talk from a personal perspective. Well done David!
4. **Thumbs down** to the emphasis on 'resilience' which leaves many of us who have experienced 'mental illness' feeling even more ashamed – "we even failed the 'resilience test !'"
5. **Thumbs up** to all psych. survivors and consumers who put themselves out there on the radical fringes of the debates and often elicit anger not only from those who they criticise but often from other consumers who don't understand that we can only achieve our small gains because of the work of these outriders.
6. **Thumbs down** to consumers who seem to believe that they individually 'created the consumer movement'. Our achievements, modest as they might be, are due to the tireless work of many people since the early 1970s or even earlier than this. No one owns history.
7. **Thumbs down** to the clinician who publicly said that we should be starting to diagnose children from as early as three months to three years!
8. **Thumbs down** to everyone who refuses to acknowledge the role of trauma in the lives of the majority of people who are diagnosed with 'mental illness.'
9. **Thumbs up** to the 'Intake Nurse' in a public mental health service who makes it his business (against the explicit directives of management) to find out, follow up and offer concrete alternatives to the many people who are otherwise lazily told: "No, we can't do anything for you because you don't fit our criteria, Goodbye"
10. **Thumbs up** to Patrick McGorry for saying, 'sometimes we have to lend people some hope for a while' (Jon Faine Conversation Hour, 31st March 2010)

10 WAYS OUR CONSUMER PLACE CAN SUPPORT YOU (AND YOU CAN SUPPORT US!)

1. **Membership:** To join Our Consumer Place, go to our website – www.ourconsumerplace.com.au. It’s free and we won’t send you any spam! Membership is open to *anyone* interested in what consumers are doing and thinking. Members receive our regular newsletter and advance notice for events. Also, you need to be a member to participate in the ‘message board’ section of our website. Maintaining a membership is important to funding bodies, so sign up your friends, family and pets – this helps us stay alive.
2. **Newsletter:** Our newsletter is a way to connect, inform and inspire consumers and consumer groups. We aim to share a range of consumer ideas and practices and to reflect on what consumers are doing and thinking. We send our newsletters to members (semi)regularly and they are also available on our website.
3. **We can visit you:** We can visit your consumer group to discuss what we do and how we can help strengthen what you do. Over time, we are getting a stronger sense of what consumer groups are needing – individually and systemically. We are working to link groups to resources and producing resources where nothing yet exists.
4. **Website:** Have you checked out our website? It contains a wealth of written materials, drawing on the expertise of many consumers as well as Our Community. There is extensive information about building robust consumer groups (or “Consumer Directed Initiatives”).
5. **Rants:** Do you have a rant inside that you’d like to share with others? Let us know and we can discuss contributing to our newsletter. We *love* debate on issues consumers care about.
6. **Message board:** Alternatively, you might have an idea you want to discuss with other consumers – post a message on the ‘message board’ on our website and see what other consumers have to say.
7. **Publicising groups:** Are you a consumer group? Would you like to be publicised through our website? Send us your details and we’ll include you in our directory. If your group has something to say or is doing something particularly interesting, contact us about being profiled in our newsletter.
8. **Interested in training?** Heard about Intentional Peer Support and want to know more? We are keen to roll out training around Intentional Peer Support (as developed by Shery Mead in the US). We’re open to suggestions for any training consumers would like to see.
9. **Interested in reading up?** Our website has a “clearinghouse” (ie. a collection of resources – websites, books, reports, radio programs, etc) written by or recommended by consumers. Check it out, and let us know if there’s more we could add – it’s growing!
10. **Got ideas?** If there’s something we’re not doing that you think consumer groups need, let us know! We can’t do everything, but we also can’t think of everything ourselves, so we always appreciate input.