



**People diagnosed with  
'mental illness' doing  
things for ourselves**

**OUR CONSUMER PLACE  
NEWSLETTER JUNE 2010**



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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES

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

We don't have a great deal of news to report – things have been chugging along rather quietly here at Our Consumer Place. Some things to note:

- Keep sending us your expressions of interest in **a consumer "think tank"** (if you are interested in being part of such a meeting of the minds). It has been delayed as Flick is off overseas for a few weeks and doesn't want to miss anything! At this stage, we are planning a relatively informal few hours, in a cafe, where we can throw ideas around.
- Also, if you are interested in being involved in **Intentional Peer Support** training, drop us an email so we can make sure you are included in our plans as they become more developed. We are presenting a workshop introduction to Intentional Peer Support at The Mental Health Services conference (TheMHS) in Sydney on September 16<sup>th</sup>. But, this is just a beginning! It helps us plan when we know who is interested.
- Do keep emailing us, calling us, and generally letting us know what you think and want. We are always looking for people to write for the newsletter too.
- Contact us! Email us at [service@ourconsumerplace.com.au](mailto:service@ourconsumerplace.com.au). Call us - (03) 9320 6839 or (03)9320 6802. Or go onto our website [www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au). Be in touch!

PS: If you are interested in using Merinda's cartoons, please contact us.

## INTRODUCING ... Community Healthfulness Co-operative

In this edition, **Nick Meinhold** introduces his vision of a Community Healthfulness Co-operative in the stunning Yarra Valley. He is keen to emphasise that this is his personal take, and does not represent the entire collective.

At the age of 18 I was into drugs, like a lot of my friends. I was troubled, pushed the limits and eventually found myself confined to a psychiatric ward with drug-induced psychosis. In the following 18 months as an out-patient, I was diagnosed with bipolar and schizo-affective disorder. I do not fully accept those labels but I was experiencing life threateningly intense mood swings and paranoid delusions. Over the next 5 or 6 years I fought my own mind every second of every day and slowly climbed out of the dark place in which I had suddenly found myself.

Without the incredible support of some amazing people I probably would not be here today. I spent most of my time during those years thinking about what was going on and how I could find my way out. I now believe that there are several things that can make a difference and give people the greatest chance of recovering from mental illness. First, by giving the body everything it needs to be healthy, including a nutritious diet, daily exercise and the removal of toxins and poisons. Emotional and spiritual health is also important and activities such as meditation, yoga, nature walks, and

*The project aims to provide respite and true asylum, a space where people will have the chance to rest and recuperate...*

creative activities such as art and acting give a sense of ease and peace that is conducive to health and recovery. We also benefit greatly from having the sense of belonging that comes from working in a team and contributing to the community in a meaningful manner. This builds self-esteem and self worth and gives the confidence that is necessary to take on the challenge and the responsibility of taking control of your life. I believe a person needs to take

responsibility for the choices they make in response to their set of circumstances in order to become free from their mental illness. Toward this end, giving people gradually increasing levels of challenge and responsibility gives them the greatest chance of recovery.

Having identified these requirements, I tried to envisage a facility that could provide all of these components and after discussing my ideas with many people over a long period of time, I am proposing the establishment of a non-profit health retreat business, primarily staffed by people recovering from or dealing with mental illness. Several acres of land in Yarra Glen have been generously supplied, on which accommodation will be built. People experiencing mental illness will be given the opportunity to live on the property in exchange for working as part of the team helping to provide a Health Retreat service for the general public. The realities of mental illness can of course be complex and difficult and so the business will also be run by a team of workers trained in various aspects of mental health and community relations.

The project aims to provide respite and true asylum, a space where people will have the chance to rest and recuperate, as well as being

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given the opportunity to begin rebuilding their lives and creating their future. Using practices of sustainability and a holistic approach to mental health, the cooperative will be aided by a paradigm where the health of the individual is viewed as a singular aspect of the health of the entire environment. By maintaining a self-sustainable environment people recovering from mental illness will gain skills in balancing the many aspects of a healthy environment and learn to apply these skills in managing their own health.

A co-operative is a business owned and controlled by the people who use its services, and who, by working together, can reach an objective unattainable by acting alone. Together we can turn tragedy and adversity into a new beginning.

*If you are interested in finding out more, you can email Nick: [nick.meinhold@gmail.com](mailto:nick.meinhold@gmail.com), or check out the collective's website [www.communityhealthfulness.org](http://www.communityhealthfulness.org) (currently under construction)*

And now for a new cartoon from Merinda, which emerged from some persistent spelling issues while writing about "complementary therapies." We rather liked the idea of ...





## Don't ever tell me I'm not a "real" consumer

-JA (name withheld)

I was travelling in America some time ago and I met David Oaks, director of MindFreedom – I was pretty excited because he's a big name in the mental health consumer/survivor world. My diagnosis came up in conversation and David laughed and amiably replied that I'm not a "real consumer." I don't know how much truth was intended, but it stung.

I've been recently told by mental health services that I'm not "serious" enough to get any help from them. I stopped self-harming a few years ago – after about 12 years of self-harming and occasional suicide attempts – due to bloody hard work on my part, and some useful mental health support (though not all helpful, if I'm to be honest). I still sometimes slip back into those despairing feelings but in the logic of service providers, I'm "well" enough to be ignored.

*When I come out to acquaintances as having a "mental illness" diagnosis, people invariably assume that I have either depression or anxiety. I think people have been taught that these are the diagnoses that "respectable"-looking people like me have.*

I've never been involuntarily admitted to hospital. I have been incredibly fortunate to have people in my life who have kept me safe when I've been in danger of such incarceration. But I have heard many survivors/consumers imply that this experience is necessary to be a "real" consumer. To counter this assumption, Chris Hansen (an America-based consumer/survivor) jokes about a bunch of consumers vying with each other "that's nothing! I was locked up for 13 days straight and given ECT every day!" to which another replies "huh! I was locked up for 2 months in solitary, and all I was given to eat was psych drugs," etc (she makes up hilarious situations). You get the point. I respect that the experience of people who have been incarcerated must be at the centre of our politics, but my experiences are no less valid.

Mental health public education *never* mentions my diagnosis (OK, it mentions one of them, but not the other two) – I feel invisible.

The "psychosocial" model often seems to portray "mental illness" as if it's inevitably linked with poverty, destitution and general dishevelled-ness. Of course there's some truth in this. Like most of us, my experiences have led me to be "downwardly mobile" – my siblings and the people I went to school with all have far more money than me. I've done some night-time, bare-foot, distressed street wandering and received hostile looks from respectable people. And it is bloody hard living on a pension, and I'm incredibly fortunate to be working again and be able to afford such luxuries as clothes. BUT, this association makes those of us who do work completely invisible – just because I'm no longer desperately poor doesn't mean I'm "recovered," back to "normal" or whatever else is assumed. We have to separate socio-economics from mental distress.

Actually, I pass as pretty "normal" and "sane" most of the time. Part of this, I suspect, is that I am middle-class and work in an office job. When I come out to acquaintances as having a "mental illness" diagnosis, people invariably assume that I have either depression or anxiety. I think people have been taught that these are the diagnoses that "respectable"-looking people like me have. I also think it's partly because my upbringing involved me being taught that you *DO NOT*, under any circumstances, express emotions in public. Maybe a contained smile is ok, but no uncontrolled emotion. I've been pretty good at hiding my deep inner turmoils, but invisible doesn't mean insubstantial.

This brings me to my final points. My background of feeling that my emotions and experiences are invalid (starting as a child) is at the heart of my distress – I believe these experiences are fundamental in shaping how I express my distress today, including self-harm and suicidality. When consumers divide people by diagnosis, or by the treatment we get from services, or class or income, we are behaving no better than the mental health system, in fact we are copying its faults. Our different experiences are all legitimate and deserve to be heard, held and honoured. If we can't do this with each other, who will?

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## THUMBS UP/THUMBS DOWN



1. **Thumbs up** to us! We have finally finished collaborating, writing, collating and editing our first in a series of resource booklets, written from consumer perspective. This booklet is called “So, you’ve got a “mental illness”? What now?” and is an introduction to both the mental health system and mental health consumer perspective. This process has been long and has involved many wonderful consumer minds. Now, it’s off to the printers! Stay tuned ...
2. **Thumbs up** to consumers who are working within “the system” to bring about cultural change. This work is often incredibly lonely, under-resourced and under-appreciated. We say thanks!
3. **Thumbs up** to those work outside the current system, creating alternatives and projects that resonate with their own beliefs about how things should be. Brilliant work!
4. **Thumbs up** to New Zealand’s *Like Minds Like Mine* campaign that uses television advertisements and grassroots consumer educators, to humanise “mental illness” and shift the behaviours of those around us (ie. it challenges *discrimination*). This is in stark contrast to “anti-stigma” approaches in Australia that tend to teach people medical, diagnostic, labelling responses.
5. **Thumbs down** to services which don’t treat consumer knowledge with respect and try to turn consumer workers into ‘mini clinical workers’ – underpaid, lacking in seniority or influence, reporting to clinical or bureaucratic staff rather than senior consumers, provided with no consumer-perspective training and expected to waste time going to silly meetings where we are treated tokenistically and generally have little or no effect on outcomes.
6. **Thumbs down** to Dr Norman Swan (who is a medically trained ABC broadcaster) declaring publicly that the quality of clinical relationships “has absolutely no effect” on people’s recovery.
7. **Thumbs down** to the many mental health services that treat us like naughty children, labelled, terrified, locked up against our will, lectured to, banned from our bedrooms, made to feel like we are ‘lesser people than those in the street’, left in a state of utter boredom or taken on humiliating excursions to the local coffee shop.
8. **Thumbs up** to “out” consumers who speak publicly as having a lived experience of “mental illness.” These people create more space for the rest of us to speak our truths.
9. **Thumbs down** to the lack of research into the weight-gain effects of psychiatric drugs – this issue is incredibly important to consumers, but not to the research establishment (thanks to Kathy Griffiths’ work at the Consumer Research Unit in Canberra for publicising this discrepancy)
10. **Thumbs down** to professionals who “disidentify” with us, i.e. think of themselves as being fundamentally different to us, where *they* are like other “normal” people but *we* are not.

## INTERVIEW OF THE ISSUE – *Chris Hansen*

*Chris Hansen hails from New Zealand. Before her promotion to service user work Chris worked as a manager of a Community Mental Health Service. Over the last ten years she has been involved in local, regional, national and international peer support and advocacy initiatives, and in mental health sector planning and politics from a service user perspective. Other roles have included leadership within the “Like Minds, Like Mine” project (NZ’s award-winning project to counter stigma and discrimination associated with mental illness), research for the NZ Mental Health Commission, and involvement in developing the NZ national mental health workforce development strategy. Chris was a member of the New Zealand delegation to the United Nations for the development of the Convention for the Rights of Persons with Disabilities, and has served on the board of the World Network of Users and Survivors of Psychiatry. She played a key role in the conception and development of a peer-run crisis alternative. She has been co-teaching Intentional Peer Support with Shery Mead for the past four years. She is also incredibly funny, with a dark, rich sense of humour.*



**Flick Grey:** *How would you describe what consumers / survivors / service users are doing at the moment, broadly speaking, in terms of changing the mental health system or the world. Do you think our political heyday has come and gone?*

**Chris Hansen:** ... All my thoughts are racing around, going crazy, so hang on a second, I’ll just round them up (which is a bit like herding cats)...

There’s an analogy I like to use for where we are at the moment in the consumer movement: it’s a bit like climbing a mountain. You get half way there, and you’re exhausted; you look up at the peak and you think, “Oh my gosh, I’ve made no progress, it’s still as far away as when I started!” And it’s very tempting at that stage to give up, or to bitch and moan about how far away this bloody peak is. But it’s really useful to turn around and look back and to realise how far we’ve come. At that stage, a bunch of people think “Oh my God! Look how far we’ve come! We’ve already got there!” And they sit down and set up camp.

That’s my way of saying that I think we’re at a really interesting point in the process of social change, where we’ve made some significant changes, and some people are saying “well that’s fine, I’m really happy” and they are stopping there. And other people are champing at the bit and cracking the whip and saying, “Oh my God, we haven’t made any progress at all!” And the reality is that we need to very seriously consider what changes we need to make in our journey. You know, we’ve ascended some vertical cliffs and now we’ve got to a place where people are, for example, starting to talk about recovery. ... Now, they may not have any understanding of what recovery is, you know, it may be just a word that they use at fairly regular, random intervals in their policies, but they actually know that it is something that they do need to understand.

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So, we’ve got past some of the vehement, agitating stage. We’re now at a point where we have to think about where we proceed from here. And it’s not the same as where we began, when we were needing to be very confrontational and aggressive. There’s a bunch of people who are starting to

come on this journey with us, and they are at hugely varying stages. We're needing to press ahead, because our intended destination is still a long way off, but also to affirm, nurture and encourage the people who are at various stages of that journey as well. And that's a real challenge because many of us have become stuck in one way of doing things, and having to change our approach can be quite difficult, and others of us are tired and impatient with the people who 'don't get it', and we just want to get there...

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**FG: So, do you think our political heyday has come and gone?**

**CH:** Absolutely not! ... Actually, I'm not sure there is such a thing as a political heyday. I think it's a journey and there are different stages and different accomplishments that you need to aspire to. So for example, in New Zealand we *had* – for seven years – a Mental Health Commissioner who was a very out consumer activist. And that hasn't happened elsewhere in the world, to my knowledge. There are other political achievements to aspire to and I think that the "heyday" is often used to describe the stage in a process of social change where you're so angry that there is a commonality of anger, there's a unity that comes from that. And yet, political pressure and activism actually requires a huge and diverse range of skills, achievements and efforts.

I often look at the women's movement as a good model of a movement that is streaks ahead of us. We're now getting presidents and prime ministers who are women. There are landmarks and I think one of the dangers of getting stuck in that looking back, "moving away from" place is this thinking that there is only one kind of political heyday, and it's being out there picketing and being utterly obnoxious, knocking down doors and comfort zones and paradigms – there's adrenaline and headline worthy interest in all of that, but actually there's a hell of a lot of hard work that needs to go on subsequent to some of those key changes, to make them sustainable and also to continue to aspire to the real inclusion and equity that we're looking for.

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

**CH:** Activism is vitally crucial in any process of social change and I like to call it the jackhammer. Beforehand, there is a ground swell of realisation of injustice and inequity, and then there's some gathering together, "rallying the troops" so to speak. And then there is the activism, usually spearheaded by certain individuals who have extraordinary ability to be able to do that. And other people who feel similarly and are prepared to get out, do the hard yards, and articulate their message and find some pretty confrontational ways of doing it. It's vitally important because it's like hammering your way through a stone wall. Nobody's going to listen unless you make your point in a fairly confrontational kind of way.

Then, what happens is other people come in after that, saying the same message but saying it in a much more palatable way. And the powers-that-be, the people who we are targeting, breathe a sigh of relief and think "Ah! Here's a voice of reason!" And, we're actually saying the same thing. Because the point has already been made, and the initial shock has been absorbed, those we've been targeting have had some given time to think about it. When other, more moderate people come in saying the



same thing, they actually believe they're hearing a voice of reason, because it's not clothed in the confrontational outfit that the activists were wearing. And that's how change happens.

Yes, there is a need for ongoing activism. I think the mode of activism changes as social change happens. And we start to get allies, so we are not wanting to spread blood all over the offices or whatever. For example, if you think about Intentional Peer Support, we are wanting to create connection, and I think activism is often a stage before connection, where you actually have to make yourselves visible. When you've been invisible for so long, it's necessary to do something completely shocking to make yourself visible.

Until social change has created the equity and the inclusion that causes us to be valued and respected, activism will have to continue to happen. But the mode of activism, the vehicle is going to change as we target different people and as we develop allies. There's a real art to this.

In terms of areas to target, I would target forced treatment; coercion of any description in the mental health system. I'd target legal capacity, guardianship orders, community treatment orders. And ...



consumer /service user leadership. We're sort of do *participation*, but we don't yet do *leadership*. We don't even do consumer participation very well, so that's an ongoing need. I do look very seriously at the women's movement and think – how many ministries of women's affairs (or whatever they have in that particular country, policy bodies) have more than 5% of men? Probably most of them have 0%. In New Zealand, in Maori affairs, it would be entirely exceptional to be non-Maori and sit on such a body. One of the phrases we used in New Zealand, was that we might have gained a seat at this table, but actually we want to damn well *own* this table!

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

**CH:** Love that question! I would expect that we would have a very colourful community that celebrated difference and diversity. I think our language would be really different – we would have ways of talking about our distress or our different mental states that were not laden with labels and shame or fear. We'd talk about it a lot more – probably about as much as we talk about our skin or our hair colour, that sort of thing. It would be like the weather, just part of our every day existence, and we'd be happy to talk about it.

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I think we would have workplaces that were flexible in what they were prepared to offer people, in terms of flexibility of hours, flexibility of environmental conditions, flexibility of learning styles. I think that we would have communities where people actually had relationships – face-to-face relationships – that were committed to one another, concerned, and involved with one another, beyond our natural families. We'd have neighbourhoods that were collaborating ... on environmentally sustainable energy options and people who actually were finding ways to enable older people or people with disabilities to stay in their homes for as long as they wanted to. And people would have neighbours who were willing to exchange babysitting for ... someone to teach them how to do stuff on computers, and things like that. So, we'd have communities and relationships that were involved and committed to the face-to-face, real-time connections that provide for people in a meaningful way.

***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 if you have \$10,000 to spend?***

**CH:** I would be asking them to do a lot of research, firstly on the damage that forced and coercive treatment does. Secondly on alternative crisis options that work, and thirdly on resourcing and developing them.

Secondly, I would be looking at resourcing policy-makers and those at the grassroots around building the sorts of communities I was talking about before – community development, community networking. And there would need to be some sort of public campaign – a good model for that actually is the *Like Minds Like Mine* campaign in New Zealand, which we based on some really solid literature and research, public awareness as well as grass-roots level movements. I think those two things would easily take up \$500 million. Well, it would depend on where you are. In New Zealand, it would go a lot further than in the United States.

\$10,000 is not a lot of money. It might pay for one Intentional Peer Support training! I am biased because I teach Intentional Peer Support, and I believe in what it does. I guess one way to spend \$10,000 on what I believe, but in a way that doesn't necessarily line my coffers (which feels like it would be a conflict of interest!), would be to develop an education program to roll out to mental health services managers about Intentional Relationships. To develop and write that would be a good way to spend \$10,000.

***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 hopeful and ready to take on the world?***

**CH:** I guess one would be for funders and planners to start saying "We've got to do something to get rid of coercion and force," and to acknowledge that it causes a lot of damage. Another one – and it's something that I'm blessed and fortunate to experience on a fairly regular basis – is to hear people who have spent a long time absolutely enmeshed and entangled on the sharp end of the needle of the mental health system saying "Wow, I never thought of it like that! This is really exciting, I can build a life worth living for myself. I realise that I've spent a lot of time focusing on what's wrong, I'm going to start thinking about what it is that I really want, where it is that I want to go and what it is that I want to create for myself, what are my dreams, aspirations and the life I want to live."

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

**CH:** That's not a binary that I think in, at all. I talked about stages of social change. I think there is a stage when the outcome is really important. However, it's really important for us, at all stages along the way, to walk the talk and to model the way we want that to happen. And I say that because I am fundamentally opposed to violence in the way that we create our social change, because violence is what we are fighting against. Why descend into the same bad behaviour that we are against? I think it's really important that we focus on the outcome, but it's also really important that we are grounded in our values and an understanding of what it is that we are trying to achieve. I think that the process falls into place if we keep being grounded in those values and not blinded by our anger. We lose the message, if we are so blinded by our anger that we descend to the same bad behaviour that we are trying to change. However, I do think our modes of social change evolve over time, as we develop allies; we don't want to alienate the people who are starting to come on board. We need to be mindful that relationships are a journey, they are a process, and we want to nurture the connections that we make, and at the same time be giving those hard messages. I think that it just becomes a more complex process as time goes on.

A good example is at this stage in our journey raising awareness about the damage that force and forced treatment does. We have actually made some successful granny steps in reducing and minimising the use of seclusion and restraint in some areas. And so, whereas we need to be out there lobbying loudly in most areas because most areas need change, there are places that have made significant gains in building policies and putting practices in place to successfully reduce and minimise the use of seclusion and restraint. We need to be affirming that work, we need to be working with those people, building relationships with those people and organisations that enable us to move on and be very clear about what it is that we are creating. We need to be co-creating with those we are connected with. As well as still using that jackhammer, we now have an extra tool, we've actually got tools and examples of success that we've achieved in some areas. We can do our advocacy and our activism in different ways.

## **INTRODUCING ... the GROW Community Mental Health Movement -By John P.**

GROW is a consumer driven movement which evolved from a 12-step framework. It is focused on recovery and community building, as well as being an educational program that encourages individuals to develop and use their own strengths. It is designed to alleviate distressing symptoms, enhance well-being, improve functioning and enable participants to take an active place in the wider community. GROW began in Sydney in 1957, but today operates internationally. In Victoria, it is funded by the Department of Health. There are approximately 50 GROW groups in Victoria, including in the general community, in prisons, in AOD (Alcohol and Other Drugs) centres and in youth and Culturally and Linguistically Diverse settings.

GROW was originally called "Recovery". A group of people experiencing mental illness appreciated the friendship and support offered at Alcoholics Anonymous meetings and decided to meet together on a similar basis. Weekly meetings were then supplemented by meeting discussing successful strategies, learnings and wisdom – these were recorded and evolved into the GROW program. The name was changed in the early 1970's to meet the increasing demand for the group's services in prevention as well as rehabilitation, and more broadly for a school of life and leadership for mental health.

These days, weekly meetings are structured, run by group members, and based on a 12-Step framework. Meetings conclude with a written evaluation involving all participants. GROW meetings are understood as group rehabilitation, not group therapy. In between meetings, practical tasks and phone calls between members maintain focus. GROW has never used professional counsellors or psychologists; meetings are understood as complementing professional mental health services. GROW recognises the importance of friendship, empathy and understanding from others who have been in a similar emotional place - "Friendship is the special key to mental health" is a basic principle.

Involvement in GROW also involves actively working on one's own recovery: members are encouraged as well as resourced to discover (or rediscover) their own capacity to deal with the issues they face. GROW's approach is cognitive and behavioural: change of thinking and talk, change of ways and the subsequent change in relationships. GROW has never seen itself as groups of people with a mental illness; rather, it has always been people working together towards improving their mental health in a caring and supportive environment.

Meetings are open to all adults. There is no intake procedure, no client files and no fees. Only first names are used, and every meeting has a commitment to confidentiality. There is no time limit on how long a person may attend. In fact GROW's success has been built on recovering and recovered members continuing in the movement so that they can give back to others.

Organisational structures developed early. Each group has an elected Organiser who is responsible for preparing the room for the meeting, ensuring that all necessary information is available and keeping the meeting on track. There is also an elected Recorder, who is responsible for the evaluation process at the end of the meeting. Training is provided for Organisers and Recorders, as well as for all Group members. Groups are located in geographical regions. There are State and Territory branches, GROW National and GROW International. There are also paid staff. Each branch has a Manager and administrative support. The 1800 telephone line is open during business hours for enquiries and referrals. A Fieldworker for each Region provides a resource and quality control function – attending some GROW meetings to observe and give constructive feedback. All dimensions of GROW are overseen and controlled by ordinary GROW members.

Contact GROW at 1800 558 268, website: [www.grow.net.au](http://www.grow.net.au)