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**OUR PLACE NEWSLETTER
MARCH 2009**



Funded by:

Department of
Human Services



Auspiced by:



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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES

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Fast Forward: What we have been up to

Since the last newsletter was circulated in December 2008 the team has been busy in three areas of our work:

1. Pamphlets

We are producing up to 60 pamphlets that will be promoted and distributed across the mental health, primary health, disability and drug and alcohol sectors. The pamphlets will provide information and resources directed to different groups including :

- People who know there is something wrong, are wanting help and don't know where to find it
- People who have recently been diagnosed with 'mental illness', 'psychiatric disorders' and know very little about 'the system', may be very confused and want to know more
- People who want to get out of 'the system' and proceed on their own but might not know how to do this.
- The pamphlets are designed to span preliminary information, through to encouraging the reader to start thinking about how they can nurture their own ideas (Consumer Developed Initiatives).

2. Training with Shery Mead and Chris Hansen

We have been planning for our two very special events in the last week of March. These are:

- A five day interactive workshop on Intentional Peer Support run by Shery Mead and Chris Hansen from the US. (This workshop is now full)
- Shery is also offering us a **half day seminar** on Monday 23rd March from 1.00pm – 4.30pm.
- Shery and Chris's work is at the cutting edge in the education and practice of intentional peer support in mental health. For those who are unable to attend the half day workshop or who would like to know more about Shery's work, the website is <http://www.mentalhealthpeers.com/>

3. On the Road

We are about to go on the road with Liz and Tony from the Victorian Mental Illness Awareness Council to meet some of the rural groups and introduce Our Consumer Place. We're off to Mildura in March and Horsham in April. We are very much looking forward to this phase of our work



Ten ways that you can be involved in Our Consumer Place

1. Book us to come and show the Our Consumer Place website to your group
 2. Get us to come to a group or organisation to talk informally about Consumer Developed Initiatives and your needs
 3. Fill out our Training needs survey and submit it to us
 4. Membership – encourage your relatives & friends to register on our website
 5. List your group on the Consumer Developed Initiatives Directory
 6. Tell us what you think of our help sheets/starter kit
 7. Give us your ideas for new help sheet topics
 8. Send us your ideas for new help sheets
 9. Write something for the Our Place newsletter
 10. Ring us up & email us about the ideas you have for Consumer Developed Initiatives
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Soap Box

Moving Beyond the era of REPRESENTATION

“when the committee agrees with you, that’s representation, when it doesn’t, then you’re ‘not being representative’ “(Anon)

1. The charge by many clinicians that activist consumers do not represent ‘my patients/clients’ or ordinary patients/clients.

Many of us have come across detractors who constantly raise the question of our failure to represent. Most often this is aimed at those of us who are louder, politically astute, associated with more radical positions and who are committed to fighting for human rights and service and policy reform. Very rarely are we thanked for giving up time and emotional energy to help people working in the system to do a better job. Instead we are often accused of ‘pushing our own barrows’. These attacks on our capacity to represent silence us. It is a very effective political tool wielded by groups which already have much more power in mental health political debates than we do.

2. Moving from representation to ‘expertise’

Insisting on representation from consumers when it is not expected from other groups is a form of discrimination. For example, clinicians are rarely asked to represent a constituency. It is more likely that they will be invited on to committees because they have expertise in the area that is central to the committee’s charter. Why is it not the same for us? We now have many consumers who are experts in areas ranging from the education of the mental health workforce to public education campaigns and research. It is imperative that consumers start to recognise their own knowledge bases and handball positions, work, committee membership on to those who can most knowledgeably contribute to these discussions and debates.



3. Does anybody who supposedly represents a constituency actually do so?

It is impossible not to have special issues that are important to us no matter who we ostensibly represent. To deny this is expedient but silly. One of the reasons we become active in the consumer movement is because we have been badly hurt, we have seen others badly hurt, or we have seen practice that has angered us and we are driven by a conscience, a dream for something better. Instead of trying to claim an impossible impartiality we would do better to put our cards on the table but also make sure there are others involved who are driven by a shared commitment but a different set of experiences, skills and attributes.

4. There is rarely a budget for consumers to speak to 'their constituency' in a regular and systemic manner.

How can we be expected to listen to disparate groups of consumers and bring their responses together to present to a committee or body which might or might not listen to us (depending on the degree of tokenism) without the resources to do so. Consumers often don't have phones, computers, cars, or money.

5. Even when consumer 'representatives' try and talk to others and bring their accounts to the table the feedback is often dismissed as just anecdotal and non-scientific

When we eventually find the resources to talk to others and find out about their experiences we are often dismissed. This enters a wider debate about what constitutes knowledge.

6. The charge from within the 'consumer movement' that some of us are don't represent grassroots consumers and are elitist.

This is unfortunate. Attacking each other is rarely helpful. There is no accepted description of what constitutes 'grass roots consumers' or what constitutes 'consumer elites'. It divides us when we desperately need to be united and it fuels the arguments of our detractors who thrive on using this sort of disunity to discredit our voice.

7. The charge from within the 'consumer movement' that some people are the 'chosen ones' who are rolled out for the political purposes of the bureaucracy, government, services seeking more funding and charities.

An example of this is the famous footballer, newsreaders, politician or actor --people who have not tapped into the wider consumer movement but seems to have an awful lot to say. We **DO** have a major problem with this. These people often make little effort to become acquainted with us, the foot soldiers. It is interesting but the charge of a failure to represent is rarely laid at the feet of these 'famous' people.

8. Consumer participation versus consumer leadership

The new era we herald is the time of **Consumer Leadership** rather than Consumer participation. Once we start to internalise the thought that we are (and should) be leaders in all forms of systemic advocacy related to mental health the importance of representation starts to lack relevance.

"Within this model of consumer leadership, the issue of ensuring that the voice of all consumers is heard by mental health services becomes the responsibility of all leaders not merely that of those consumers who choose to participate. " (Happell & Roper, 2006: 6)

9. Alternatives to representation

It's not so much that consumers need training in how to represent but rather that committees need training in how to hear from everyone who wants to be heard. For example, committees need to learn skills of working with interpreters, hearing what people are saying without re-interpreting, listening to people who 'speak' in different ways, different levels of education, different degrees of trust in the process, different ages, different cultures and different levels of confidence in their own knowledge.

References:

Gordon, S (2005), The role of the consumer in the leadership and management of mental health services, *Australasian Psychiatry*, 13 (4), 362 --365

Happell, B and Roper C, (2006), The myth of representation: The case for consumer leadership, *Australian e-Journal for the Advancement of Mental Health (AeJAMH)*, 5 (3), 1-8

Interview of the issue - Issue of the interview - by invitation

Peter Beresford

Peter Beresford is Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University. He is a long term user of mental health services and active in psychiatric system survivor organisations. He is Chair of Shaping Our Lives, the independent national service user controlled organisation and network. He has a longstanding involvement in issues of participation and empowerment as an activist, educator, writer and researcher. He is a Trustee of the Social Care Institute for Excellence in England, which has the responsibility to develop the knowledge base of social care and also a member of the Advisory Board of the government's National Institute for Health Research. He is co-editor of the forthcoming book, *This is Survivor Research*.



Has the heyday of progress in consumer participation and initiatives come and gone?

Definitely not but it is always under attack and threat. Strong efforts are made to reduce it to individualized consumerism and ignore its democratizing and empowering impulse. Its future will be down to us as survivors [consumers] and that is a big responsibility.

Is there a place for activism in mental health? What top three areas would you target?

Of course, it is crucial.

- Building links with the broader disabled people's movement.
- Focusing on inclusion and addressing diversity in every sense. Pushing for our non-medicalised, socially based understandings and working for quality measures that are based on these and user defined
- Crucial also to have in place a securely and adequately funded and resourced network of local service user controlled organisations.

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

A lot more fun. A lot less internalized oppression. A lot less divisive. A lot less conflict. Perhaps some of the very powerful people who are clearly unhappy and distressed would be able to do something about it, would feel comfortable to work through it, rather than working it out on the rest of us through their greed, ambition and aggression so we live in such a conflictful, violent and damaging world.

If you were asked to give state 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?

It would be no better me being in charge of the money than anyone else. I have seen what happens when large sums are made available without an infrastructure of involvement in place to put it to good use. So the key thing is to get a group of survivors with such experience together to set up an inclusive process of involvement to work out how best to use that money. It would be a one off chance. We must do it right, ethically and practically. If there was a small one off sum, then I would try through a transparent and fair process to let survivors and survivors' organisations know about it so they could bid for a good idea to be taken forward and this would be decided by a group of survivors whom people would have confidence in.

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?

- One would be to know that the organisation I am part of --Shaping Our Lives --had secure funding for the future and was really sustainable with lots of good new people coming through to take it forward.¹
- Number two would be that there would be a network of service user controlled organisations in place with adequate and secure funding
- The other for me personally, as I am someone who doesn't sleep well, would be a really nice relaxing day – including definitely some time in tea and coffee shops – that would help me personally get a better night's sleep.

¹ www.shapingourlives.org.au SOLNET – networking website: www.solenet.org.au

Which is more important to you, the outcome or how you get there? Can you give an example? You just can't separate the two. That is what involvement is all about. Without that being central to the process the outcome won't be right. It's what service users say about the stress on outcome measures in health and social care services. Workers can come in and do tasks and then they can tick all the boxes they like but without warmth, empathy, respect and equality little will be achieved.



Introducing – Our Little ‘OASIS’ in HEIDELBERG WEST (A story about friendship-led recovery in a sometimes uncaring world.)

Allan Pinches – Consumer Consultant

A small group of a people whose lives have been affected by mental illness have found something of an “oasis” at a church hall in Heidelberg West.

A weekly drop-in session at 1 pm – 3.45 pm Wednesdays, is a key activity of the **hope springs** community at Heidelberg West Uniting Church, and has brought friendship, comfort, hope, and personal healing, to members of the group. These are qualities they often find somewhat lacking in the wider community.



The group is growing in numbers, and what started as just a few, now attracts as many as 26 people. Many of the participants are in poor circumstances, and may have stresses related to housing, support services, nutrition or medical treatment.

Mental health consumer and some service advocates say that many older clients in recent years have tended to have been hived off from some mainstream mental health and psychiatric disability support services – with Drop-In type services falling into disfavour in recent years.

At the same time services are re-directing more resources towards a growing population of young people needing treatment and care for mental health related issues, often including dual diagnosis (mental illness combined with drug and alcohol issues.) It can be argued that both of these groups equally need and are entitled to a range of appropriate services.

The drop-in is conducted by **hope springs**, a local mental health ministry affiliated with Kildonan Uniting Care. The co-ordinators, Rev Peter Sanders and Dana Robson-Garth lead a small number of willing volunteers, who very much place themselves in the midst of the participants as a friendly and listening presence, rather than claiming authority or being directive about activities or things like "group dynamics."

For the participants it is easy to share in an atmosphere of warmth and friendship, and a sense that this is “our place.” Together there is strength. Wednesday, for us, is a special day, and something to look forward to, punctuating the week.

To a large extent how the participants use the facilities is self-determined, and many people like to have simply the chance to come along, have a coffee and a chat about anything -- from the news, social issues, spirituality, or sports, or what’s been on TV, or anything. People also can compare

notes about ways of somehow getting heard by the limited local services. Sometimes a guitar will be brought out for some shared musical fun.

The **hope springs** drop-in at Heidelberg West takes place with shoestring funding and relies heavily on the mutual co-operation of volunteers and participants together to make it work. One might even say that this wonderful example of community development is run on the smell of a home-brand coffee tin and some assorted biscuits.

I have been involved with **hope springs** for several years – mainly a participant, but occasionally as a volunteer with various projects, when I thought I had something particular to contribute.

The Heidelberg West Uniting Church has some picturesque qualities that seem to compliment the “oasis” theme I have brought forward here. In the front yard of the church there is a lovely palm tree and some foliage to match. (*See picture.*)

This special “oasis” is a place where people whose lives can become a place of increased fulfilment. One place where opportunities can emerge, to assist in bringing about changes whereby the sadness, loneliness and stigma of mental illness can to some degree be replaced by self-acceptance, sharing and friendship.

For further information about hope springs:

http://www.kildonan.unitingcare.org.au/hope_springs.php

Tel: 9459 8859



FEATURE ARTICLE

A few reflections on change and ways forward

By Simon Champ

I am no historian; few of us are in the mental health consumer movement. Though I do know that my own understandings in life have changed with the shifting politics of that movement. Twenty-five years ago, to have a hearing in our society, as a person living with a mental illness was a very rare thing.

Back then, I felt an enormous pressure speaking out, knowing that the average person, mostly viewed people with a mental illness through rigid, narrow stereotypes and typically in a negative light. One usually had very little time to turn those attitudes around, and as much as one could say about one's own experience, the real challenge was to arouse curiosity in the media about the many and individual ways that different mental illnesses could affect people.

At every opportunity one had to try to get their audience and the media aware of the issues of human rights for those who lived with mental illness. That we were not being allowed to live life as fully as we could, even if attitudes, would change towards us.

I found I needed to remind myself of this sense of speaking out about mental illness when I heard of the demise last year of the Australian Mental Health Consumer Network (AMHCN). The AMHCN was formed as a body that might represent our concerns at the highest levels. However, even when it was established (1996), the consumer movement had become a much wider movement, taking a myriad of forms and with a momentum of its own --beyond the capacity of any one single organization.

Many more people have become involved and groups have evolved since then utilising and implementing developments in consumer understandings of activism and philosophies coming from their own lived experience. It is in becoming aware of these initiatives, adapted to the challenges of this new century, that one can be humbled by how generally attitudes to people with a mental illness are really changing, changed by consumers themselves.

I can still become discouraged and distressed with the challenge of my own illness at times. Whilst I may sometimes feel alone in my own journey, the availability of the many help lines and NGOs that have formed or grown sometimes amazes me. All the forms of support, information and advocacy that have evolved in these last twenty five years, some consumer conceived and run, others created in real partnership, is gratifying.

To survey any library or bookshop is to find a plethora of new titles, especially in the rapid growth of autobiographies and biography by consumer and carers. The Internet that has been developed in a parallel time frame to my own history with the emergent consumer movement has allowed a reach and forms of connection and communication, unprecedented for the consumer movement. It has also given access to debates that have been invaluable given the size of Australia and the remoteness of some communities.

As to leadership, if the Australian Mental Health Consumer Network (AMHCN) has ultimately failed us, at a national level, I still see many consumers taking initiatives and giving example by the lives they live and roles they take on in this Century which is already presenting Global and national challenges, few could have fully anticipated.

Before Sept 11, who could have foreseen the difficulties in promoting and upholding human rights, when in the names of Homeland security, Anti terrorism, Patriotism and sedition laws, sometimes to uphold any group's human rights has been seen as unAustralian by powerful elements in our society.

As the effects of global climate change come upon us more powerfully and sooner than some had predicted, there are costs for us all. Beyond the human suffering of droughts, flooding and fires there are disproportional economic costs, to the poor and marginalized in societies around the world. Many pensioners here have seen costs of electricity, water and basic commodities especially healthy foods actually spiral at times beyond reach.

The losses and tragedies of many minorities do not register in the world's news other than as the voyeuristic or to serve as propaganda for the politics of the more powerful nations.

There are unprecedented challenges and hopefully new thinking and solutions emerging for their lessons that we will need to protect and empower society's most venerable in the future. This includes those in our society who live with a mental illness.

Ultimately as consumers we are human and being so, we are for the most part wise, vulnerable, mistaken, and all the other traits of being human in varying measure. In the progress of the change that people with a mental illness are making to become more accepted in our society so often our success or failures are less to do with any disability or mental illness that we may have but to do with the qualities we share in being human.

Let Us Spray

There is no doubt, vandalism and then there is art.

Sometimes in certain territories, the dividing line between the two is blurred and has to be contested.

Let us spray.

Announced last week that the possession of a can of spray paint can now be deemed a criminal act.

I guess someone still has to prove intent.

Maybe, just maybe, dissent grows. Maybe there are voices of some, that don't feel heard in our society. Our democracy.

Let us spray

Maybe dissent grows.

Why else has it become possible to be charged for the possession of a texta?

A traditional instrument primarily designed for teaching and drawing.

I am sure someone would still have to prove intent.

Let us spray!

Or rather in this time, when God is so often invoked in the passing of new laws.

Let us Spray!

Let us spray!

Let us try to understand new artists.
Let us listen to and try to understand the nature and reasoning of dissent.
The still silenced voices.
Let us, in our real democracy and with open minds, keep trying to explore the disputed territories in art and in all aspects of our society.

Let us spray!
Let us spray!

By Simon Champ



THUMBS UP/ THUMBS DOWN

1. Thumbs down... to people who assume our group won't last just because we are all people who have mental illness.
2. Thumbs up... To my friends who had the courage to tell me that they are sometimes scared of me when I lose it. I didn't realise my anger was having this effect.
3. Thumbs up... To this really good worker at the service I go to who has fought really hard to get the service to give us our own budget.
4. Thumbs down... To the boss at my service [Psychiatric Disability Support Service] who doesn't understand that we need to make our own rules and our own mistakes. Unless we can do this we are not being treated as adults.
5. Thumbs down... to the psychologist who is so scared of us being in a position of supporting our peers through hard times that he's insisted on properly qualified psychologists being involved where they don't belong.
6. Thumbs up... to the group which tries hard not to owe anything to anyone or any organisation which might wish to control what they do.
7. Thumbs down... To people who imitate the professionals and want to wield power over our group in exactly the same way that clinicians, workers and service providers have done in the past.

8. Thumbs down... To control freaks who don't want to let us do anything just because they have diagnosed us with mental illness.
9. Thumbs up... to workers who recognise that being a 'good patient' might not be good for your mental health.
10. Thumbs up... To my mother who apologised to me the other day and said she now realised that since I was diagnosed with mental illness she has been bossy and patronising.
11. Thumbs down to the G.P. who said, "we don't treat people like you here!"
12. Thumbs up to fellow consumers who say hello to us on the tram.

P.S. Reminder about intentional peer support training

Don't forget that Shery Mead will be running her half day workshop on Monday 23rd March. If you haven't yet put it in your diary please do so and organise to attend. If you have applied for a place and don't think you will be able to make it please let us know as soon as possible because places are filling up fast. There are some places left for people who have not yet responded to the flyer. If you need more information about the half-day workshop please email Jon Kroschel: jonk@ourcommunity.com.au.

P.P.S. If your email box is full can you please empty it so we can email you confirmation and other important information.

Thanks

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IT'S FREE!

Go to: www.ourconsumerplace.com.au/becomeamember

