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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES

Our Place NEWSLETTER



Welcome to Issue 2 of the Our Place Newsletter

Merry Christmas to everyone

Don't forget to join up and become a member of Our Consumer Place for 2009

Instructions for becoming a member on back page

State of the Nation



Sandy Watson is an independent consumer activist and educator, living and working in Sydney.

Mark of shame

I remember sitting in a waiting room of a community mental health service many years ago, and looking at a large poster on the wall about stigma, a poster that said things like: "Stigma = Tagism" and "Stigma = a mark of shame" and "Stop the stigma". I am in a waiting room looking at a wall that reinforces the idea of *shame*. The mental health industry is the main promoter of the idea of shame, through anti-stigma campaigns that achieve the exact opposite effect, by keeping shame alive in people's minds.

I am going to be controversial about stigma. I object to the focus on 'stigma' as it relates to mental illness and/or psychiatric disability. This focus is misspent, and I argue, a waste of time and resources. I believe it is counterproductive to talk about stigma and to continue to emphasize it! I look forward to the day when consumer/survivor movements around the world make the decision to stop talking about stigma, and get down to the real issue, that of discrimination.

Whenever any of us in the consumer/survivor movement make this an issue about stigma, we are *reinforcing shame*; and we continue to associate mental illness with shame, in much the same way as mental health services and organizations do that are funded to reinforce stigma and the 'mark of shame', (holding anti-stigma campaigns and producing posters, videos, postcards etc).

If someone tells you not to think about a pink elephant what do you do...? Think about a pink elephant. The more thinking and discussion about stigma, the more we keep it alive, and let's be clear about this, the more we keep shame alive.

'Stigma' is the most discriminatory and wicked concept that ever existed in western cultures, in relation to people who have different experiences of reality. Stigma is the shortened term for stigmata. Stigmata were the wounds of Christ as recounted in Christian history, suffered on the cross for our sins. The association between stigmata and marks of shame comes from a Christian view of disease: people who had disease were people who were sinners, and their disease was a punishment from God because they were inhabited by the devil.

So why do so many consumer/survivors keep promoting the concept of stigma and by inference, the social construction of shame?

The real issue is about discrimination. When the focus is on stigma, we keep the idea of shame alive and we locate the problem with the person living with mental illness or emotional distress, since it is they who feel the shame. On the other hand, when the focus of the debate is on discrimination, we put the emphasis on the discriminatory behaviour (the discriminator) rather than on the person experiencing discrimination. Only then can discrimination be tackled, and the responsibility for it placed squarely on the shoulders of those doing the discriminating.

I would be delighted if the mental health consumer/survivor movement officially decided not to continue the promotion of shame through the constant focus on stigma.

Instead of consumer/survivors talking about stigma I want the advocacy and political effort to focus on discrimination and subsequent critical distinctions, namely: positive discrimination; negative discrimination; unlawful discrimination; lawful discrimination; discriminatory attitudes (instead of stigmatizing attitudes); direct discrimination and indirect discrimination.

Stigma is the most discriminatory concept of all. We can't fight discrimination by using the stigma idea, an offensive and discriminatory construct, as the main mechanism for challenging the status quo. It is impossible because all that is achieved is that shame is perpetuated.

This focus on stigma severely weakens the advocacy about discrimination. Talking about stigma *and* discrimination weakens the issue because it again, makes the issue about those people who experience the shame rather than on the people who are treating us less than fairly. Let us collectively dump odious 'shame' by dumping the stigma construct, and let's get serious about tackling discrimination. It isn't hard to do.



1. At home...

Continuing to introduce ourselves

Over the last months lots of people have visited us seeking information and getting to know what Our Consumer Place does and how we can help each other. It has been wonderful to start to feel part of the consumer community in Victoria in a really concrete way as people explore the physical work space we share with OurCommunity.

Engaging with rural and metropolitan groups

Our intuition and experience driven commitment to grassroots community development approaches was affirmed when we met with the two advocates, Tony Salter and Liz Carr from the Victorian Mental Illness Awareness Council (VMIAC). We will be 'travelling with them' both literally and symbolically during the first part of 2009, getting to know rural and urban groups, and how we can support their initiatives. This will enhance the capacity of Our Consumer Place and VMIAC to support CDIs and strengthen our partnerships.

A great new initiative from MIND (formerly Richmond Fellowship of Victoria)

An example of how Our Consumer Place can provide information and technical assistance to an organization that wants to support the growth of Consumer Developed Initiatives (CDI). Jon is working on a complex project with MIND, (a Non-Government Organisation (NGO)). The question to be answered was this: because MIND provide a range of services across sites in Victoria and South Australia, how could consumers, located in different places, access the MIND computer system to form a 'computer network group' so people could talk to each other? Jon came up with a fairly simple solution so any member of a consumer group at MIND can message another person or group, or send messages to all the groups.



2. Out and about...

Maine Connection

Over the last month and a half we have hit the road visiting the wonderful space that houses the Maine Connection group in Castlemaine. It's a converted farm shed with an open fire and spaces for a clothes swap centre, a kitchen, a bank of computers, a tool shed and workplace for creative carpentry and much more. Not only was the space impressive but so too were the people. The workings of the group left a lasting impression. Independent, well known and admired within the local community MAINE CONNECTION is, we believe, a consumer group that shines like a beacon, showing what can be achieved from a genuine grassroots approach to consumer peer-support.

Getting to know...

We have also been visiting lots of organisations and groups, establishing partnerships, finding out what consumers want and trumpeting our wares...from a program managers meeting at Vicserv (the peak body for organisations in the Non-government sector in mental health) to the Victorian Branch of the Private Mental Health Consumer and Carers' Network, to a gig at Melbourne University speaking to mental health nursing students who will be able to refer consumers to Our Consumer Place.



3. Training, capacity building and community development

We are now into the next phase of the life of Our Consumer Place. Our priority over the next six to twelve months is to provide learning opportunities for an array of people and groups with differing needs in a variety of settings to help support the development of consumer initiatives. While some of what we provide will be 'training' in the traditional sense, our definition of what constitutes 'training' is broad. We want to make sure that we have the time it will take to gradually get to know individual groups across the state and to gain a picture of what people want from us to help support their CDI ideas.

Some of the training provided will be responding to specific requests as they arise, but a significant proportion of our time will go towards getting to know local groups and communities, capacity building, peer support, and knowledge sharing. We will be holding quarterly state wide training events with a focus on Consumer Developed Initiatives. Our December workshop aimed to guide participants through the Our Consumer Place website, our hard copy resources and our helpline facilities and offered participants opportunities to learn how to get the most out of what we have to share.

Interview of the Issue: Issue of the Interview



Introduction:

This issue's highlighted interview is with Sylvia Caras. We, at Our Consumer Place were so pleased when Sylvia agreed to speak with us. Many people know Sylvia's website: People Who

<http://www.peoplewho.org>

About Sylvia Caras

Sylvia Caras is the founder of an 'e community' of people who experience mood swings, fear, voices and visions. She is especially interested in the wide distribution of health and human rights information. She has served on several global and United States boards and committees. She cares about significant inclusion of people with disabilities at every phase, in all matters that affect them; and mindful attention to language that is respectful, graceful, and affirmative.



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

The language has changed. The funding streams have changed. I think the focus could shift from carve-out to a seamless health care system. Carve-out is separate mental health funding, people talking about mental and physical health as separate entities, mental health services delivered in separate buildings, drop-ins, etc. Carve-in is where there is one door- a community service with one seamless funding stream and no separate physical health and mental health. Specialists may be called on later if necessary. I think we should be arguing for transparency and inclusion. Illness and disease take us down a fenced road. Wellness is better as a conceptual starting point.

In the US mental health advocates compete with other under-served groups for funding. This model is driven by profit and puts social and environmental factors in the background. I regret that other countries are copying us.

The hardest for me was feeling so alone. I learned to re-understand my life so that my psychiatric experience and my mood experience became my credential, and an opportunity to use my facilitation, organisational and language skills.

What would transparency and inclusion look like?

Hmm. Well not so much secrecy around mental health issues, less discrimination which could lead to less prejudice and more of us disclosing. When we are at the table here, we do not get respectfully listened to, and then the system proceeds on its own merry way, so we are there but not part of the decision making. I know New Zealand has done much better. I don't know about Australia.

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

1. We must **reclaim the vocabulary** - media, coalitions, local participation in other than mental health community activities – politics, service, sports, ... I think we need to stop presenting ourselves as victims, and stop allowing families and systems and drug companies to use sympathy to generate funds.

Can you please tell us more about why language is so important?

We think with words. And there are few neutral words. So when we describe a person we choose words that match our own stereotypes and our listeners or readers absorb those words to match their own internal patterns.

For instance, if I say to you I have a brain disease, I am conveying an understanding of my situation as medical, and maybe managed by medication. If I say to you I have problems with living, I am conveying that my social structure, my environment, managing my life interactions is hard for me and I need support.

So Words Matter

Some words also carry political messages. "The mentally ill" is a phrase used by people who endorse forced treatment and managing symptoms with medication. "Consumer/survivor" is a phrase used by advocates who have lived experience with psychiatric disability. So if I am speaking to my local governing body about services for 'the mentally ill' I am conveying a different message than if I ask for services for 'consumers.'

2. I think we need to understand more about **resilience**.
3. And I'd like to reposition mental health as only one part of community health. For example, in a public health media campaign, healthy communities, clean air, green, exercise, diet, kindness, ...



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

We'd target some other group for exclusion. Groups such as elders, people with AIDs, Hispanics, lepers, ... Someone always seems to be at the bottom. In Australia it would be indigenous people I'd guess.

But I think the world **is** moving towards a different kind of social organising. Some are clinging tight to tradition. But I think we are moving towards a tipping point where a steady maintaining of caring and community might be possible. The alternative is a reversion to mean ghettos of likeness such as gated communities where wealthy people have built homes within a high fence and locked gates. There is an entrance and a guard who must let in guests. We have become fearful of difference.



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?

I think caring has been distorted by dollars. I'd use funding to provide internet access for all, access to knowledge, access to others. Everyone has problems in living; not everyone can yet find others with whom to exchange about those problems.



Language to Think About See: <http://www.peoplewho.org/documents/wordsmatter.htm>

Courtesy of Harold Maio, M.A and Sylvia Caras, PhD from *Words Matter* © Sylvia Caras 2001

Are people who have been diagnosed with mental illnesses all the same? If they're not why do we call them, 'the mentally ill'?

One of the most divisive uses of language in 'psych-speak' is the use of the terms 'high functioning' and 'low functioning'. It pigeon holes consumers and divides us according to someone else's judgement of our skills and capabilities. This creates winners and losers and jeopardises peer work. Why might peer work be endangered by this language?

In the next Issue of the newsletter we will have more word challenges from Sylvia Caras and Harold Maio.



Vrinda has been employed in a number of areas, including the health industry prior to her involvement with the consumer perspective movement. She has undertaken tertiary studies at undergraduate and post graduate level. Vrinda has been employed in mental health services as a consumer worker for 8 years and been involved in local, state and national committees and projects for over 12 years.

Vrinda is passionate about helping Mental Health Workers to understand the impact that service use has on the person, particularly in providing opportunities for the clinician to hear directly from consumers about their experiences and how it can influence change in practice. Vrinda currently works at Southern Health as Director of Consumer and Carer Relations in the Mental Health Program. Vrinda has a partner of 18 years, two wonderful children, and loves to go on weekend quilting retreats with her local quilting group.

Management is doing things right; leadership is doing the right things.

Peter F. Drucker

What do we mean when we talk about LEADERSHIP?

The word leadership is used to describe many activities all of us undertake. We lead teams, both work teams and sport teams. We lead discussions and committees. You might lead a small company or a large multi national corporation. And many of us lead our dogs on a daily basis! What do we really mean in all of these situations?

When most people think about leadership they focus on what it means to be at the top of a group hierarchy, the CEO, Managing Director, team leader, or ruler. In reality being at the top of the hierarchy does not make you a leader, or even necessarily a manager. You may sign the right forms and make important decisions but does this make you a leader?

This leads us to the question of how to define leadership. Wikipedia defines leadership as

- The ability "to get people to follow voluntarily."
- Those entities that perform one or more acts of leading.
- The ability to affect human behavior so as to accomplish a mission designated by the leader.

Whatever else we might say about leadership, all these definitions focus on one person as a central figure. That person in some way motivates us to do things we wouldn't otherwise do. This might lead us to decide that leadership is whatever moves us. This wouldn't be useful because then our definition is too all-inclusive. It would not be helpful to think of salespeople, teachers or our mothers as leaders just because they succeed in persuading us to buy something, do our homework or eat our vegetables.

Why is a teacher, salesperson or our mother not a leader? Because leadership is a group function and a group means having a common purpose. Also, there is something about leadership that is not self-interested. Should we really regard a politician as a leader who convinces us to vote for her by offering to lower our taxes? Is buying votes really leadership or salespersonship? As a community we tend to admire the leader who convinces us to do something we wouldn't otherwise do by appealing to the greater good of the group, as Martin Luther King or Nelson Mandela often did.

"Leadership is about having the self-confidence to do what is right even when it is not popular."
Lee B. Salz



But what does this mean to consumers?

Some may think that the issue of leadership does not apply to consumers. The consumer workforce is small and the movement is disjointed. We have so many things on our agenda we want or need to fix about the system, who has time to think about leadership? As a collective, consumers are disempowered and subjugated by many people, systems and organizations. However if we are going to advance the many concerns we have regarding the Mental Health Service sector we need to have leaders. Gordon wrote about the involvement of consumers in the management and leadership of mental health services:

Although acknowledging that the health sector has begun to recognize service user participation, it was highlighted that a future challenge is moving from a paradigm of service user participation to service user centredness and service user leadership, which has three critical dimensions (Second Mental Health Plan: Report of the Sector Leaders' Forum, unpubl. data, 2004 [NZ]):

- Central leadership in the managerial and governance structures that plan, fund and deliver mental health services.
- The provision of service user managed and delivered services.
- Central involvement of service users in mental health advocacy, training, education and promotion.

(Gordon 2005 Australian Psychiatry V13, N4 p365)

The reality for Victorian consumers is that despite over 12 years of paid consumer workers, we have been unable to develop these dimensions in an ongoing and sustainable way.

- ❖ To date DHS and the Mental Health and Drugs Division has resisted any advances by consumers to employ people with service use expertise within the department to develop policies and protocols that impact on the delivery of services.
- ❖ Very little funding or encouragement has been given to the development of consumer delivered services.
- ❖ After more than 20 years, VMIAC remains the only organization that is currently funded to provide advocacy services specifically for consumers of mental health services.
- ❖ The funding and development of Our Consumer Place will assist and enable more consumer initiated and delivered services to develop and is to be applauded as an excellent beginning but it has only been funded as a three year project.
- ❖ There has been no increase in real funding for consumer participation activities within mental health services for over 12 years, and despite some growth with services providing funding for some increase in EFT, consumer workers are not in management roles and have no real governance accountability within services.
- ❖ Despite the existence of a Consumer Academic position at Melbourne University for over 8 years, no other university has taken the initiative to employ to a similar position.

I am not sure how we can provide leadership in an environment so fraught with day to day issues and problems. How is it possible to provide vision and incentive to make changes when you don't have a job that reflects your expertise and experience? How can you lead in an organization that employs less than 1EFT of consumer workers and barely supports a Consumer Advisory Group? How can you lead in a community that is so ill informed about Mental Illness and Psychiatric Service use? How can you lead in a workforce that doesn't want to go where you want to be?

And you thought Research was Boring



A mental Health service quality improvement Initiative

By Lei Ning – Project Manager of the Consumer Research and Evaluation Unit of the Victorian Mental Illness Awareness Council

“...from designing the mental health system around the consumer to co-designing mental health services with the consumer and carer...”

Consumer and Carer experience (C&C Experience) is an exciting new initiative in mental health service quality improvement activities. It is based on the review and recommendation of the previous satisfaction surveys that were conducted by the Department of Human Services in 2005. The Initiative moves away from rating the satisfaction of consumers and carers to eliciting their experiences in the notion that satisfaction rating had minimal impact on service quality improvement, whereas consumer and carer

experience of mental health services will provide concrete evidence that can be smoothly translated into meaningful service quality improvement activities.

One of the main characteristics of the Initiative is an effective model of a high level of consumer and carer participation, and the primary researchers are consumer and carer representatives. The Consumer Research and Evaluation Unit (CREU) of the Victorian Mental Illness Awareness Council is contracted as the main research body for the initiative. CREU is a consumer managed research unit and has three full-time consumer researchers.

Gathering experiences of consumers and carers is the first step, using the information to improve their experience with mental health services is a primary focus of the Initiative.

As an integral part of the C&C Experience, the Mental Health - Experience Co Design (MH-Eco) applies the most recent theory and practice of Experience-Based Design in health service quality improvement. The core of this approach is to engage consumers, carers and service providers to actively work together to co-design the services with a strong commitment to change. This Initiative is well supported by all stakeholders, and has been drafted into the strategic plan of the Victorian mental health reform, which has gained national and international attention.

For further information, please contact Mr. Lei Ning on 03 9387 8317, Projectmanager@vmiac.com.au

Tech. Corner - Sara Clarke



E-mail is good for much more than trying to decide who the cheapest supplier of Viagra is and getting your bank account details stolen but care is needed or it can become more of a problem than a really useful tool for communication.

Protect yourself. I talked about protection last time and I meant it. No up to date antivirus software = no turning on the modem. Another way to protect yourself is to see if you can read your mail in [plain text instead of HTML](#). It has an added advantage over just the security stuff talked about in the link for controlling folks like me who like to decide how big and in what style I want the text to be on my screen. When I am sad I sometimes read all my email in 16 pt bright yellow [comic sans](#) on a pink background. It never helps. It is also a very good thing to send your mail out in plain text and those settings are usually in the same place. If you don't know if you can make the switch spend some time looking through the help files and learn your program. It can probably do all sorts of great stuff you don't know it can.

See if your provider has [spam](#) filtering in place and how you can turn it on and off and remember to check the spam folder occasionally as legitimate mail you do want may incorrectly land there. Be careful where you leave your address lying around, people can sell addresses to spammers who look to collect them all over. There are programs scouring the internet looking for underlined links with an @ in the middle and malicious programs sneaking into unprotected computer systems and searching for every email address findable and sending them on. Grabbing a [webmail](#) address you don't use for anything important is always a good idea for net use until you know and trust the people sending you the mail.

Bcc stands for Blind Carbon Copy and dates back to archaic instruments of torture called typewriters which we should all hate because they gave us the silly QWERTY keyboard layout I still have to look at to use. If you are sending something out to multiple people it is really good to send the mail with the addresses put in the "Bcc:" area of the mail form so nobody who gets it sees all the other addresses you have sent it to. This is for a few reasons:

- nobody can accidentally hit "reply all" and send some embarrassing story to all your friends and family and workmates (deliberately hitting "reply all" is a big no no by the way unless it is intended to be a group discussion via Cc (Carbon Copy) or someone has been repeatedly asked to use Bcc and failed - of course Mum may never have you over for dinner again)
- if they have an infection or ever get one the only address that can be harvested from your mail is yours, not everyone you showed your new tattoo picture to back in the day.
- It just isn't polite to give my email address out without my permission.

Now they can bury Bcc and make it a little hard to find but seriously, find it. It will be there somewhere, often hitting the "Cc:" button will bring it up. Just put the addresses in there instead of the usual "To:" box.

If you do want everyone to see your new tattoo consider putting the photo online using a [picture sharing service](#) and sending them a link rather than the picture itself. That way they can choose when to view, you are not tripping their download limits, creating virus concerns (they can be hidden in attachments like pictures) and wasting time if someone is on a slow connection or checking mails via a mobile phone or at work with the boss just walking by.

NEVER WRITE IN ALL CAPS FOR IT IS CONSIDERED SHOUTING AND IS VERY RUDE.

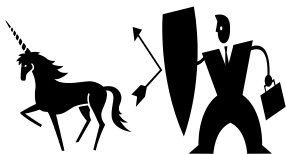
Just seeing that makes me sad. I have to go change my email to big yellow comic sans on a pink background now.

Thumbs Up, Thumbs Down



1. **Thumbs Down...**To all those who use and support an idea of 'consultation', which enshrines a process where everything is almost decided before we are allowed to make comments on 'draft documents'.
2. **Thumbs Up...** To the person who initiated, and all the people contributing to the 'Adopt a Pensioner Program'. A truly inspirational program where community people show they care about people by donating what they can to help others in the community. No funding proposal needed, some-one just started doing it. Absolutely brilliant!!!!
3. **Thumbs up...** To the consultant psychiatrist who asked the registrar to try and use language that was less judgmental. The registrar was embarrassed but I really noticed it when I talked to her the next time.
4. **Thumbs down...** To the worker who accepted our brochures and offered to give them to clients attending the service and then we found them still dumped in a pile in the staff room two weeks later.
5. **Thumbs up....** To my psychiatrist who never sends anything off to another doctor, lawyer, psychologist, bureaucracy like Centrelink, or work cover or anyone else without letting me read it first and who usually gives me a copy for my records.

Stories from the Trenches



Working as a regional/rural consumer consultant – the script life wrote me

By Mark Lacey

A bit of history

A role in a rural/regional service is one that has largely been thrust on me, rather than chosen. I spent my senior secondary years in Ballarat. From there, my intended trajectory was to Melbourne for university studies and then on to the larger world. But things don't always go according to the script we write in our heads and hearts, do they?

I made it through first year uni only to be admitted to hospital with psychosis the next year. Through the next decade I struggled to come to terms with my illness. Gradually, I crawled, walked, and eventually ran

towards recovery. Over those first ten years, I don't think I was well enough to move out of home, or to try to head back to Melbourne. I needed time to rest and recharge from the pain of a changed life and the exigencies of battling a serious illness. It is a cliché, but I couldn't have done it without my family, or the new circle of friends I built as I recovered.

That's a long way of saying that if I had had my way in life, I wouldn't have been a consumer, and therefore I wouldn't have been a consumer consultant, or stayed in my home town of Ballarat.

That's not to say that my life has been a long saga of unhappiness. I love it! Which brings me, circuitously, to what I am meant to be writing about – my ten or more years experience as a consumer consultant in a regional centre.

Consumer Consultant: Ballarat Health Services

I am employed by Ballarat Health Services and work as a solo consumer consultant. I work 0.75 EFT – enough to pay the mortgage, but also with enough wriggle room for a late start each day, and flexibility for other commitments. Our region is physically the largest in Victoria, but the smallest in population.

Ballarat, with a population of around 80,000, provides something like half the population of the region. It takes about 2.5 hours to drive from Ballarat to Horsham (including the obligatory cup of tea at the halfway point). I make that trip at least once a month.

The rural/urban divide

I find the rural/urban divide something of a red herring. People are people, aren't they? The idea that country consumers are all fresh out of the hay shed is a bit of a falsehood. The IT revolution means the only significant disadvantage that comes from living in the bush occurs if you don't have the IT skills you need to be part of the digital revolution, or if your Disability Support Pension (DSP) doesn't provide the resources you need to pay for a computer or internet connection.

Video-conferencing means that a farming family in Nhill can easily connect with their loved ones many miles away, while split-screen video-conferencing means that my consumer advisory committee can meet at three separate venues, with members driving to the facility that's most convenient.

Having said that, there are some differences, for better and for worse, between rural and urban services. For example, the smaller population removes some of the burden of invisibility/anonymity – that means that there really is a community of care. The long-standing psych. nurse, knows, for example, if a particular consumer will need a packet of cigarettes for the weekend (and if the Adult Acute Unit staff are busy, he will go across the road and get them for her).

On the flip side, once a person is known to have an illness, behaviours that in another person would be seen as acceptable are perceived as episodes of illness. In one instance, I watched as a young consumer battled to maintain his business whilst he was in hospital – an eagerness that was seen as the workings of an overwrought mind. This man left hospital a month later to a failed business. Access to a wireless internet connection would have prevented this unfortunate outcome.

Establishing and working with groups

A major part of my role as a consumer consultant is to build communities of consumers that both support one another and have input into charting better services.

There are now consumer-only groups across the region. Their meetings usually involve discussions (sometimes feisty, sometimes quiet) about service quality and improvement. Some of our gains have been internal – people learning the skills of advocacy and representation. Others have been external – for instance, new programs that consumers have suggested and staff have developed.

I have also established or rebuilt support groups for people with bipolar disorder and, to a lesser extent, depression. Each group has been successful in gaining annual funding. These support groups allow people to come together to share their angst, support one another, get ideas on how to move forward, and just enjoy the friendship and good times.

Then there is the consumer advisory committee, which is linked to the clinical service. This is a closed group, so people apply for and are interviewed for membership, as they would for a job. I see this as the lead group to drive consumer participation in the region. Wins have included the provision of stencils in seclusion to explain people's rights and responsibilities, and deciding what should and shouldn't go in information packs for consumers across the service.

In all of these consumer-driven groups we see the ongoing frustrations and angst that can arise from life with an illness, but also the wonder and mystery of seeing people recover and move on.

Conclusion

Despite the fulfilment I derive from my work, there remains for me the question of an unrealised ideal self that in different circumstances would now be happily married, a medical specialist perhaps, living somewhere with easy access to Somalian and Vietnamese meals, live music and exciting conversation.

But I tell myself (and usually believe) that life is about people; that it's about the day-to-day struggle to live out a coherent ethical and moral framework, of doing what you can to make a difference.

While the Somalian meal and a doting family still sound pretty good, I reckon having a life like mine – one in which you do occasionally make a real difference – is not a bad alternative.

Ideas You Can Nurture



Advance Directives

Introduction

An Advance Directive is a document written by a consumer to identify what needs to happen should we 'become unwell', 'hit the wall', or 'fall in a heap', especially if we are threatened with being held under the Mental Health Act. There are several different ways of interpreting what is meant by an Advance Directive, however, they are **not** the same as End-of-Life decision-making documents.

Currently, there is **no State or Territory in Australia that legally mandates Advance Directives**. This is not the case in all countries. Scotland has legislation in place to enforce Advance Directives (or, as they are called there, Advance Statements). To find out more follow this link:

<http://www.scotland.gov.uk/Publications/2004/10/20017/44081>

Victorian consumers are lobbying for Advance Directives to be introduced as a separate piece of law from the Mental Health Act. This would ensure that Advance Directives are owned solely by the consumer and could be much broader in scope than just treatment.



IMPORTANT TRIAL --- GET INVOLVED

The Mental Health Legal Centre has created a [form](#) and some notes about advance directives for mental health. They can be found at http://www.communitylaw.org.au/mentalhealth/cb_pages/Advance2.php and we hope people will use them and send them into clinics and hospitals and have a say in what happens should a crisis happen for them.

We are also looking for consumer feedback about both the [form](#) and the [explanation](#) on the page. If you would like to join the discussion happening on the Our Consumer Place message board just go to <http://www.ourconsumerplace.com.au/login> and become a member or email comments using the link on the [webpage](#).

We also need consumers interested in meeting and discussing this in the New Year so if you would like to be involved please leave a message for Sara Clarke at the MHLCLC on (03)9629 4422 or email sara_clarke@clc.net.au

It needs to be noted that you can save the form as a blank document, fill it in on your computer and then print out the pages that you use. It will not save with your data in it. This is for a couple of reasons, the biggest is technology, another is privacy, also these documents mean nothing unless they are printed and witnessed.

You can also print out the pages of the form that you want to use and fill it in by hand.

Sara Clarke

Introducing



Private Mental Health Consumer Carer Network (Australia)

We just want people to be aware that the *Private Mental Health Consumer Carer Network (Australia)* has been in existence for the last 5 years and is there to advocate for consumers with a mental health problem or mental illness and those that are close to them, who receive care from private mental health settings. These are psychiatrists, psychologists, GPs who have their own rooms or private hospitals with mental health beds. People can have private health insurance or access some of the services via medicare.

As our title implies, the Network is the authoritative voice for consumers and carers of private mental health settings.

We provide a strong voice in key policy and decision making processes and promote effective advocacy as the driving force behind all changes in mental health services delivered within these private sector settings.

We advise on issues which affect people, build and enhance relationships with providers, governments, funders and consumers and develop links with professional bodies to improve services.

Our mission: *engage, empower, enable choice in private mental health*

Go to <http://www.spgpps.com.au/tn/home> to find out how to join.

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

Tell us what you think of this 'our place' issue

If you'd like to tell us your thoughts about any of the pieces in this issue, or you have an idea for an article, please contact us.

If you found this newsletter helpful and interesting, please send it on to your friends and fellow consumers, workers, managers and clinicians. If you would like to reproduce anything in this newsletter or website you are free to do so. Please just add a small credit line, "courtesy of www.ourconsumerplace.com.au" and a direct link to the www.ourconsumerplace.com.au site on a webpage. Reproducing hard copies is also encouraged.



Feedback from the first issue

We ran a discussion group with consumers about our first newsletter. People liked the cartoons, loved the photo of "Shery" and found the interview thought provoking. People related to the supermarket story and the story of fear of flying – many had been in similar situations. As a result of interest in Sara's net savvy, we have asked Sara to be a regular contributor to *Our Place*. We would like to sincerely thank all the people who took part in these discussions as well as everyone who contributed to the last issue of *Our Place*. Much to our joy we received some feedback from overseas. Chris Hansen, a 'consumer' activist in the United States sent us an email saying: "LOVED your newsletter by the way- I have a small obsession with newsletters (what makes a good newsletter, what makes one not-so-good etc.). I keep the ones I really like as examples for peer centres (a newsletter is a funding requirement of some centres over here, so you can probably imagine what goes out with the best intentions...)Yours is in the 'kept' folder!."

Did you spot the problem with the magic carpet cartoon??? That's right, have you ever tried to fly on a **Magig** Carpet? (If you want the corrected version of the cartoon, contact Merinda).

In the last issue we gave some information about the Victorian disability legislation, the Disability Act and the Charter of Rights for people with Disabilities. This information was not accurate and a member of Our Consumer Place has kindly submitted more accurate information and some further thoughts published below:

Victoria does not have a "Charter of Rights for people with Disabilities". We have the Charter of Human Rights and Responsibilities Act of 2006 (to give it its full name), but no specific legislation on the rights of people with disabilities. The nearest we have is the (generic) anti-discrimination legislation of the Equal Opportunities Act which, although important, is rather limited as a pretty strictly defined complaints based mechanism, rather than anything like a charter or bill of rights for people with disabilities.

And although it's not quite an error in the strict sense, it is a 'mistake' to even ask the question whether we're "entitled to the protections of disability legislation" - we are! It's also not altogether correct to say that mental health is not seen as a disability issue, even though it is correct to say that psychiatric disability was outrageously excluded from the definition disability in the Disability Act (2006). Psychiatric disability is recognised as a disability in national and state legislation, including Victoria's the Equal Opportunities Act and the federal Disability Discrimination Act -i.e. basically everywhere except for Victoria's Disability Act.

What we do have is a UN Convention on the Rights of Persons with Disabilities that Australia has now ratified, which means it accepts and agrees to abide by this Convention as international law. It would be good to raise awareness of this as it will have a major impact on our mental health laws - hopefully sooner rather than later, though I'm not optimistic about this. Despite the significance of this massive breakthrough for the rights of people who experience disability - including psych disability - there is a stunning silence in Australia about the Convention as it relates to mental health, which is in stark contrast to other disability sectors where it is at the forefront of all their conferences, seminar, public debate etc.

Thanks for taking the time to read this newsletter. Have a happy and safe Christmas and join us again in the new year.

The Our Consumer Place Team



ourconsumerplace.com.au

RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES

Contacting Us

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To become a member of our consumer place

Please encourage you to sign up and become members of Our Consumer Place to receive the free newsletter. People can sign up in the following ways;

1. On the net type in www.ourcommunity.com.au/consumer/becomeamember/
 - Click on 'Become a Member Now'
 - Fill in the Membership Form (Name, email & phone number to be used just in case an email message or document from us bounces back)
 - Click on 'Next Step'
 - Fill out the following. If you are an individual click on 'None'. If you are part of a group click on 'Group', if you represent an organisation 'Click Org.'
 - Click on 'submit membership'.
2. By ringing Merinda (9320 6839) and asking her to lead you through the website. She is on deck Monday to Thursday and is happy to help.
3. Emailing us at Our Consumer Place ourconsumerplace@ourcommunity.com.au and asking for help to sign up