People diagnosed with 'mental illness' doing things for ourselves

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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

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Welcome to this edition of Our Consumer Place newsletter, the first for 2011.

Firstly, our thoughts and well-wishes go out to all the people around Australia affected by this incredible season of overwhelming environmental intensity. We have witnessed floods in many areas here in Victoria (close to home for us), devastating fires in the West, an unbelievably massive hurricane, and of course the terrible flooding in QLD. What a month! Our thoughts are with all those affected, directly or in other ways.

Secondly, please be patient with us as we are terribly under-staffed at the moment, due to Merinda being on extended sick-leave (for her back). Merinda is the back-bone of OCP (please excuse the unintended pun!). We wish her speedy recovery and seek your patience in the meantime.

Finally, welcome especially to all our new members. We have had a flurry of new members recently, which is just wonderful! Welcome and we do hope you'll keep in touch.

NEWS IN THE CONSUMER WORLD:

So much is going on in the consumer world! Between the Mental Health Act review process being reopened here in Victoria, the peer workforce development consultations powering ahead, Intentional Peer Support training scheduled in QLD (those lucky northerners get Shery Mead and Chris Hansen all the way from the US), new e-lists popping up, reports being published, various consumer projects going from strength to strength ... it's such a privilege to witness and be a part of!

Some key events we want to bring your attention to are (more information for most of these is available on our website):

Project report released: *Neami Consumer Participation & Leadership Audit Project* (National)
Congratulations to Allan Pinches, Jan Hatt and NEAMI for their recent publication examining consumer participation within Neami. Allan Pinches has written a summary, which is included in this newsletter (see pages 4-8), and the full report will be made available on the Our Consumer Place website (with kind permission from Neami).

Forum: What Consumers Want from New Mental Health Laws, Feb 17th (Melbourne)
The Mental Health Legal Centre are running an information and discussion forum on the proposed changes to the Victorian mental health laws. What do consumers think about the proposed changes? In fact, what are they anyway? What is the same and what is different about the draft new mental health law? What do the proposed laws mean for consumers? Share your views and get information and tips on making your own submission. Please RSVP to the Mental Health Legal Centre by 15th Feb (see flier on the back of this newsletter).

Mental Health Act consultation time extended until Feb 28th (Victoria)
The time frame for the Exposure Draft Mental Health Bill has been extended. The deadline for submissions has been extended until 28 February 2011. To find out more information or to make a submission, go to www.health.vic.gov.au/mentalhealth/mhactreview.

National Mental Health Peer Workforce Forum, Feb 22nd (Sydney).
Are you interested in the development of the peer (consumer) workforce? If so, you might be interested in attending the National Mental Health Peer Workforce Forum. For more information, see www.mhcc.org.au, or contact the Mental Health Coordinating Council: (02) 9555 8388. Places are limited.

Consumer & carer views about stigma experienced in mental health services (National)
The Mental Health Council of Australia is undertaking a consumer and carer survey of stigma, and the behaviour of health professionals towards people with mental illness. For more information, contact Rachelle Irving, Acting Deputy CEO on (02) 6285 3100 or via email at rachelle.irving@mhca.org.au.

Training: Transforming Lived Experience into Expertise (Melbourne)
Facilitated by Indigo Daya, Voices Vic. 19 July & 23 August: The course aims to prepare peer workers for facilitating group work. While Voices Vic training is usually tailored to working with people who hear voices, this course is applicable for working with any mental health diagnosis. Participants will learn a range of concepts and practical to facilitate peer support groups while also taking care of themselves. Course registrations can be made via Voices Vic website www.voicesvic.org.au (click on training and workshops).

FEATURED ARTICLE

The development is in the detail: Neami's Consumer Participation & Leadership Audit project

By Allan Pinches, Consumer Consultant in Mental Health

In 2009 and early 2010, Neami – a large national (PDRS) Psychiatric Disability Rehabilitation and Support Service operating in five states – undertook an innovative Consumer Participation and Leadership Audit project, to help form the basis of some new strategic directions for the organisation.

Consumer consultants Allan Pinches and Jan Hatt were employed by Neami to explore what had been taking place in consumer participation and leadership within Neami, and what were some areas of potential development. This involved consultation with a range of Neami consumers, staff, managers, board members, and some others.

The approach was grounded in a strong consumer perspective/ consumer collaborative approach and informed by a Community Engagement Development focus.

The project was initiated by the Board in recognition that despite a very long history of consumer participation in Neami, it had been some time since the organisation had looked closely at the methods it was using. It was intended as the first step in a longer process. The key aim was to cover some of the groundwork needed, ahead of the development of a strategic framework for consumer participation and leadership.

The consumer consultants carried out a systematic audit based on a modified version of the '*Organisational Self-Assessment and Planning Tool for Consumer and Community Participation – A tool for organisations involved in health policy and education'* as developed by the National Resource Centre for Consumer Participation in Health (2003.)

The Audit Tool covered the categories defined as: individual service planning, governance, strategic planning, policies, operations, education/training, research & evaluation. Various consumer participation activities were nominated for discussion under these categories.

The consumer consultants facilitated eight workshops comprising of approximately 100 participants including consumers, staff and board of management, across all states in which Neami operates. Several other interviews were conducted.

The project was facilitated by Neami's Service Development Team, which helped the consumer consultants to be linked in strongly to the organization's systems and resources and to be well supported in their work.

In the history of Neami, consumers have been involved widely throughout the organisation and in many of its key processes: on the board, Consumer Advisory Groups in each state, interview panels for all staff, participation in evaluation and planning activities participation in conferences, presentations to funding bodies and other forums, contributions as guest speakers at induction, as Peer Support Workers. These contributions are acknowledged with sessional payments.

Neami broadly supports the importance of consumer participation and has been a training ground for many consumers who have become very active in the field. It has also been a champion of the notions of community based psychosocial rehabilitation and community participation. Neami was one of the earliest Australian proponents of the notion of journeys of recovery in mental health and has campaigned for more availability of safe, secure, affordable housing, and other issues.

The case for consumer participation

- "Nothing About Us Without Us"
- We get better and more effective services
- People who are actively involved and have a sense of control over their health care get better outcomes
- Consistency with principles of recovery

I believe we have to keep ready the strongest evidence base we can muster, at all times, to be able to demonstrate the benefits of consumer participation.

A strong rallying call for people in the consumer movement and our supporters is: "Nothing About Us Without Us." This is a matter of social justice and human rights. Consumer Participation has established a standing over time as an important and a critical element of quality mental health service delivery, treatment and support.

But I believe we have to keep ready the strongest evidence base we can muster, at all times, to be able to demonstrate the benefits of consumer participation. Consumer participation in its many forms is often noted to contribute to personal recovery, consumer outcomes, greater community participation, lowered readmission rates, formal and informal peer support, and improved personal educational and employment progress. In the current crisis-prone political environment we need to stay prepared.

More positively, consumer participation can be demonstrated to be a valuable resource for consumers and service providers, in terms of service quality, understanding consumer needs and wants, and building upon the creative insights and ideas of consumers.

Some reasons I found the Neami Consumer Participation and Leadership Audit Project very encouraging to have been part of was due to the nature of the ideas, exciting potential and evidence of effectiveness that emerged – and that it holds the potential to strengthen the whole notion of consumer participation partnerships within every type of mental health service. In fact, there are encouraging implications right across health and community services.

The Neami project was significant in many ways as a consumer participation project – it was well resourced; the consumer consultants were better supported than usual in the field...

The Neami project was significant in many ways as a consumer participation project – it was well resourced; the consumer consultants were better supported than usual in the field; it was well structured, using an audit tool developed through wide consultation, which provided accurate data collection yet allowed free flow of consumer input and a creative approach; and a great deal of rich contextual data had been gathered, and was able to be embedded into the report, forming an extended learning resource underpinning the document, which would have widespread value.

I have personally seen much evidence that consumer participation is a good thing, over the past two decades in consumer role. There is a fairly straightforward rationale: for too long the consumer voice has been not sufficiently listened to. For example, mental health consumers were "discharged" out of the large institutions between the late 80s and mid 90s, in the name of “deinstitutionalisation” and “integration” into the wider community. But many of the promised community-based services are perilously under-developed, and are a long way from meeting burgeoning needs among people experiencing mental health issues. Consumers should have a say about the need for community services and a wider range of treatments and supports because consumers are legitimate and knowledgeable parties to the issues being discussed. We can do some very effective self-advocacy. As documented in numerous pieces of research and policy including the Victorian Government’s *Strengthening Consumer Participation In Victoria’s Public Mental Health Services Action Plan* released in 2009, both consumers and services benefit greatly from active consumer participation.

There is substantial research evidence about the benefits to service delivery of having active consumer involvement in planning and evaluation processes. From Neami’s point of view consumer involvement enriches all aspects of the organisation. It is important that an organisation “walks the talk” – you can’t promote individual recovery unless the organisation’s structures and processes are congruent with the principles. Recovery is a process and an outcome.

> *When consumers were asked to identify the five most important things Neami should do... they came up with the following: ...*

Supporting consumer participation and leadership in the future:

When consumers were asked to identify the *five most important things* Neami should do, based on discussion workshops, they came up with the following:

- Improve Communication and ensure all consumers are aware of participation opportunities;
- Create more opportunities for consumers to meet each other – both social and structured (friendships are an important pathway to participation, building confidence and social inclusion);
- Increase consumer control of (CAGs) Consumer Advisory groups – agenda setting, chairing, being well-resourced – and building in feedback loops to other consumers;
- Creating participation pathways from Neami to the broader community;
- Follow up consumer suggestions and honour commitments to consumers.

What we found …

Consumer participation is not an end in itself. We found a wealth of knowledge within the consumer population in the organisation – which in a way was largely untapped, and has not been formalised. In the course of the project we spoke to about 100 people and most engaged with the project enthusiastically – hearts and minds. The key benefits articulated were:

- Consumers overwhelmingly identified that the reason why consumer participation should be supported and encouraged in all its forms, is ultimately to support the development of meaningful connection with others.
- Consumer participation is a means to support people to recognise and build on their strengths.
- Within the organisation, consumer participation provides a safe place to practice skills.
- Active opportunities for genuine consumer participation are an important demonstration of the key principles of Recovery – hope, empowerment, meaningful activity and responsibility. Tokenistic approaches are just the opposite, and must be avoided so that people do not experience a sense of being set up to fail, being patronised or ignored.

Different dimensions of participation

At the *individual* service delivery level, there was a very strong sense of collaboration and control at nearly every site. At the *operational* level, consumers felt they had less information and less influence in shaping the type of services delivered and the avenues for influencing what happens were unclear. Most people were also quite uninformed about complaints and grievance processes and there were few formal communication processes.

> *At the operational level, consumers felt they had less information and less influence in shaping the type of services delivered and the avenues for influencing what happens were unclear.*

Consumers are reliant on their relationship with their (CRSWs) Community Rehabilitation Support Workers for information about the opportunities available to them. The other area of concern to consumers is that there are few opportunities to meet other consumers – benefits of mutual support and the development of social networks is not being realised in programs.

At the *governance* level – the consumer experience was varied: most people were pleased to know that there were consumers on the board, and for those involved in CAGS this was a good experience. But there is some confusion about the way the CAGs operate and this needs to be reviewed to ensure their intended structure and purpose are reflected in practice – for example ensuring they are chaired and the agendas are developed by members in collaboration with management. At present consumers serve a maximum two year term and many consumers and staff felt that after this term, there needed to be avenues for people to express or further develop the skills they have developed at the CAG, in other avenues – in the consumer movement and the community generally.

What made the project work?

> *Strong grounding in consumer perspective from a lived experience of mental health issues was the touchstone for the project.*

- *Strong grounding in consumer perspective* from a lived experience of mental health issues was the touchstone for the project.
- *Commitment to the project at all levels of Neami.*
- *Well-resourced, conceptualised and planned.* It was supported by management but was not locked down – was an open process looking for fresh and innovative ideas to link participation to strategic directions.
- *Supervision & planning assistance* was generously provided for by Service Development Manager and Team.
- *Action Learning Approach*. This was one of the most exciting aspects of the project – a sense of understanding some of the greater possibilities of consumer participation and leadership and identification of areas where there may be barriers and thinking of ways of breaking through.
- *Clear framework & approach*. The attention to staying within these structures was helpful in keeping the project steadily on course.
- *The Audit Tool* made the process achievable and maximised useful, high-quality learning outcomes.
- *Critical Reference Group*. This group of consumer workers, which met three times during the project, helped to hone down the issues and practicalities, as well as visions and hopes of the growing and diversifying consumer movement.
- *Collaboration – walking the talk*!

The project consciously took into account lessons from some earlier projects in the sector – avoiding many pitfalls and occupational hazards that sometimes occur in consumer worker roles. This meant putting in place a range of supports to make the work of the consumer consultants more sustainable and more likely to succeed. This included factors such as the importance of support at all levels, adequate resourcing (money & time), project management framework (regular project meetings) and Critical Reference Group (a major knowledge resource and shared in peer support.)

> *The project consciously took into account lessons from some earlier projects in the sector...*

Considerable support was provided by a range of Neami staff for very busy logistics needs including booking a lot of interstate flights.

The Neami board initiated the project and the project team included a senior management team member. Written information and verbal presentations about the project had been made to managers and to the Consumer Advisory Groups prior to commencement of the project so people were "primed" to participate.

Experience of the project highlighted how important detailed planning is – this was short-term project with a turnaround time of about 14 weeks, and there had already been quite a lot of thought and planning beforehand. There was a very strong focus on thinking about what needed to be in place to ensure the success of the project and this laid strong foundations for a really strong project.

REFERENCES:

Bennetts, Wanda (2009) *"Real lives, Real jobs*" – Developing good practice guidelines for a sustainable consumer workforce in the mental health sector, through participatory research

Primary Care Self Assessment Tool for Community & Consumer Participation, V1.0, May 2002 and *Self-assessment and Planning Tool for Consumer and Community Participation Version 1.0, May 2003* National Resource Centre for Consumer Participation in Health

Strengthening consumer participation in Victoria's public mental health services Action plan, DHS 2009

Creative Inspiration:

Frontier

Some days when I approach my own barrier the guards are kind and let me reach my hand through the angry wire and touch the clarity I know but cannot see.
Those are the good days
and I keep them close
letting them slide like silver florins secretly through my fingers on the bad days when I'm jackbooted black.
For I must have reassurance
when the brutal guards are on duty -

I must have reassurance of that other world beyond the totalitarian state of my five senses.
I must have hope to hug.
There is death without hope.

-Margot Clare, (Originally published in *The Colour of Love* (1968), Cheshire Books. Reprinted with permission).

INTERVIEW OF THE ISSUE – *Steve Onken*

Steven J. Onken, Ph.D., has been described as a recovery scholar and practitioner. He would disagree, describing himself as a recovery guide. ʻAʻohe pau ka ʻike i ka hālau hoʻokāhi (one can learn from many sources) and he is only one such source. Steve, a Research Specialist, holds an associate faculty appointment with the Myron B. Thompson School of Social Work and an affiliated appointment at the Social Science Research Institute of University of Hawaiʻi at Mānoa, conducting applied services research and evaluation. Steve's practice and scholarship includes mental health recovery and wellbeing, its measurement, trauma informed care, indigenous and cultural wellbeing, sustainable development of consumer self-help and peer support services, adaptations of mental health evidence-based practices, and fostering social networks and supports. Currently Steve is the director of evaluation for Hawaiʻi's Mental Health Transformation State Incentive Grant.

Flick Grey: How would you describe what consumers are doing – changing systems and/or the world?

Steve Onken: The way I think about it is that there are three major components to what consumers are doing in terms of changing the way we do things, changing the paradigm. And sometimes we'll focus on one more than the others, but they're all equally important.

One is the provision of support to each other, natural support. That social network, that natural support, being there as a friend, as a companion, as somebody who has experienced a struggle in their life, worked through it, and can convey "Oh, that happened to me! And this is what I did, this is who was helpful." That *unpaid* support, peer-to-peer, person-to-person – human contact – that's a really important component towards substantial and sustainable change.

Sometimes, people's experiences of the process of the psychiatric disorder and the labelling and how you are treated is very isolating. Just as a cancer survivor can be really helpful to another cancer survivor, a consumer can be really helpful to another consumer – as a support, friend, neighbour, mentor. That's one component – unpaid, natural, peer-to-peer. That what we're going through isn't that uncommon, it's a natural experience, it's part of the human experience. It's not very well-understood, but we can get through this.

> *That's one component – unpaid, natural, peer-to-peer.*

A second very critical component is in terms of being a paid, professional within the workforce, or a paraprofessional. In the States, we talk about "peer specialists" – part of your credentials, what makes you qualified for the position is that you have that lived experience. Lived experience is a school of knowledge, a school of wisdom that is as credible as a department in social work, or psychology, or a trade school in plumbing. What we experience and how we are treated differently as a result of those experiences – mostly *misunderstanding* those experiences – give us a lot of tactical survival tools and *wisdom*, that when supported and groomed can be of critical help in other people's journeys of healing and recovery, towards wellbeing.

Also, workforce development. Consumer's lived experience can inform policy making, budget planning, strategic planning, service delivery, outreach. You know, it has to be integral to all parts of the system, not just limited to "they will help us to engage people." That's a good step, but it's also a kind of tokenism, and isn't really providing a career path for people to both develop in their knowledge and skills, and a professional ladder, to be recognised and be able to do more advanced work. And that it's paid – with the wages being competitive! There's been a tendency for peer specialists to be set up and trained, but it's like they become the working poor – some aren't even paid what would be a living wage. That reinforces the notion that lived experience is not as important as professionally trained experience. And many of us have no interest in this work, and that's OK! But where people have the interest and the potential, they should have the opportunity to develop it and if it's a good fit that they are supported and groomed to be able to continue their development and be recognised for that with meaningful career ladders.

> *Lived experience is a school of knowledge, a school of wisdom that is as credible as a department in social work, or psychology, or a trade school in plumbing.*

The third critical component – if we're really serious about substantial and sustainable change – is collective action. We need people to get information, to raise consciousness, to ask serious questions not to accept the way things are just because they are that way. We also need a movement. And it can be made up of allies as well. If you're really going to create a shift in the way we are perceived by society, you need people to be pushing on the edges of what that society sees, and is comfortable with, as a norm.

We really do need angry people out there at times – I tend to call it righteous anger. I'm firmly in the school of non-violent political activism. Anger is actually a very energetic, powerful emotion, and directed in the right ways, it can really help promote over the long term, a social shift. So you need that, those people out in the extremes raising hell. That allows some of the quieter people in the middle to make changes. All of a sudden hiring a peer specialist or getting someone on the board isn't such a big issue. The social movement allows for the people in the middle to make subtle or incremental changes towards the larger goal of societal change.

And the movement needs to be prepared for backlash. Because every time you move people out of their comfort zone – change is uncomfortable – there's going to be people who fight back because people feel less safe when it's not familiar. And how do you address that? How do you plan for that? You can't plan for everything, but you can do some thinking and have people who can tell strong stories of healing and recovery and wellbeing. So, for example, to counteract a media story about somebody who has hurt someone and they say "oh, and he's deranged." you can help to provide a counter, and you can go in and proactively train the media.

All three of those are very important. But there's a tendency to focus on one and not the others, or to the neglect of the others. And so you might have a community where there is a very strong activist organisation but you're not really seeing them in the system. And so people working in the system get told "oh, you've been co-opted." Well, no, it's just another component that's important. Or you might see a system that says, you know "We're really responsive, really consumer-centred, because we have people that we pay from their lived experience" but they don't support that bigger advocacy organisation raising bigger issues. Or you might have consumers socialising with each other, but you don't have any paid staff that understand the lived experience. All three become very important if you are really looking at the kind of societal shift that we would need for a real, deeply rooted transformational change in how we perceive people with psychiatric disorders. They require different kinds of strategies and different kinds of support, media, skills.

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

SO: As I mentioned, I see collective activism as one of the three fundamental pillars. Solo activism is really important, but those people can be very vulnerable and can burn out so quickly! Collective activism involves people learning, and seeing and role-modelling. It can start with helping out with a newsletter or mail out.

It is very helpful to look back and see the *pattern* of things. Like, for example, people picked up for misdemeanours who also happen to have a psychiatric disorder tend to be in jail for longer – that happens here in the States. Someone might get picked up for sleeping in the park, or for public intoxication. And then you look at how long they stayed in jail. It's less likely that they had someone they could contact, to bail them out, they might not have any place to go, so there's no place to release them to, they may not have the kind of skills to be able to articulate an explanation. So, we see a disproportionate number of people held for misdemeanours. If that's happening, then questions need to be raised – is there another way of doing things? Or are we really setting up a pattern where we're almost criminalising a person's condition, as opposed to criminal activity.

But work environments tend to be very rigid – you either have to be well all the time, or you're punished.

So, looking at those patterns, raising questions. Is there real accessibility to education, to colleges – and which ones? Scholarships? Some professional schools talk about gate-keeping, so that people who can't do this work are weeded out. But to what extent is the very nature of their gate keeping weeding out everyone with a psychiatric disorder. And we look at maybe their lived experience, paired with this training, could really make a difference in this job!

Or how hard it is to move from benefits to a job and back to benefits? A psychiatric disorder for many people can be very cyclic. They can be very well, at one point in time and really engaging in their wellbeing, and at other times they need to use all their resources just to get back to their well-being. But work environments tend to be very rigid – you either have to be well all the time, or you're punished. It should be "Oh, you're not doing so well, we have a medical leave policy that allows you the time to take off, to regain your gains, and to be able to come back and continue and contribute in this job and carry your load." It'd be nice if leave was all kind of combined – vacation, sick – and you could just use it for whatever you need to do! And not have to make up something to get a break from a job to focus on your wellbeing, to keep your gains up.

You make progress and it's going to get questioned, you're going to push people out of their comfort zone, they're going to react, want what's familiar ...

I think activism is really, really important. Our people – the lived experience community – are they evident and represented in decision-making bodies? And until they are, we need activism, because the people who are making decisions need to hear, even if it makes them uncomfortable. I see it as critical, particularly on that larger picture, and as I mentioned earlier, particularly to think about and plan for the push-back. You make progress and it's going to get questioned, you're going to push people out of their comfort zone, they're going to react, want what's familiar, and you need to prepare for that and help educate, increase awareness, role model and get people to experience that life is still going to be ok with this change.

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

SO: I would expect that the community is going to be one that shows a lot of flexibility. Boundaries are good but they are pretty fluid in a way where they can shift as more knowledge is understood, more things are known, and they can then embrace that knowledge and that change.

There are many ways of healing and so there might be a cultural practice that certain people have found really restorative for their healing – like there might be an indigenous practice, where people who were the first people of the land, that helped them clearly see their strengths as a people and their roots. And those practices need to have an opportunity to be explored, and to see how they help, and in what kinds of contexts. And then be supported in that way. It would be a community that is *open to consider* things that come along. Where I see the challenge is very rigid or very closed systems – service systems or communities – in terms of really being able to embrace something that would be new to them.

> *There are many ways of healing and so there might be a cultural practice that certain people have found really restorative for their healing...*

People with psychiatric disabilities would be a regular part of the community. I really wouldn't see it like everyone's mainstream, I would see that it's such that the people that were on the edges of the stream are *valued* because fringes are nice! A lot of creativity can come out of those kinds of spaces. Not to say that every experience has value, but you also don't want everything to be so homogenised that there's no diversity, there's no variety, no spice!

So it would be one where there might be quite a lot of different ways of expressing oneself and living within that community, and just being a part of that community, and accepted for that. There needs to be some basic structure – respect, dignity, non-violence, those kind of things, but in the name of many kinds of dogmas, we can distance ourselves from other people and devalue them, and then there becomes a pattern, I call it a "Grand Narrative of Less Than." I talk about soft discrimination, the causes of these lowered expectations.

So that becomes really important, that notion of flexibility. Integral to that, it's got to be a community where everyone feels safe. It's almost like a sanctuary of safety. There's a lot of experiences out there that are difficult, adverse, traumatising, and if we work hard to build communities where people do feel safe, and that if something does happen to them, they know they can go somewhere and share it and they're not looked down upon, they're not stigmatised, less than for it. This would require that these communities see psychiatric disorder, however you see it – schizophrenia, cutting behaviour, whatever – that this behaviour is a natural part of the human experience. This is a valued person, they're trying to communicate somehow. They might not look like the way you or I would do it, but it would provide a place where they feel safe and that they wouldn't need to be cutting to get something out. We would be able to start at that place with them, and find out what's going on that's preventing them from expressing what's inside, so they can gain that fuller understanding and start their healing journey. So, yeah, flexibility and safety. And it's got to be physical safety, social safety, moral safety, and emotional safety, psychological safety, all those domains.

> *... fringes are nice! A lot of creativity can come out of those kinds of spaces.*

Women, young girls, young boys, if they're in an environment where they are victimised, like maybe domestic violence, that's not an environment of safety. And again, I'm not saying a community that is rigidly politically correct, because again, that's not safety either! That's not very flexible. But really pay attention to that. Is it going to be perfect all the time? No! But to be able to see that, understand the experience, learn from it, incorporate it into the fabric of the community and move on. Really having a community that is flexible, that is open, that does have boundaries, that *is* respectful of the human spirit, of human rights and human dignity, and that is safe. That is a society in which people can then move in and be a part of, where psychiatric disability is not dehumanising. And I think in that kind of situation too, they will just be able to more early on engage in the kinds of things that help them maintain their wellbeing, however that may be. Like the example of hearing voices, if it works to incorporate that, as opposed to fighting it, then incorporate it, with the right kinds of supports to be able to do that.

I'm not saying a community that is rigidly politically correct, because again, that's not safety either! That's not very flexible.

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

SO: Good question. Here, in my experience, in the United States, if there was one area where I would really concentrate the spending, it would be in the area of trauma. Because I think that many, many people's lives are complicated by trauma, particularly people with psychiatric disorders. Often, it's the central issue they're struggling with, but they're treated for a set of symptoms which are really a set of adaptations to trauma. So it would really be in that focus, an avenue that is really un-addressed, or under-addressed. And I'd do incorporating training so that people with lived experiences are part of working in the area, assessing and treating and supporting people – for example, Shery Mead's work in Intentional Peer Support.

I'm doing a lot of work in Corrections right now, and we see a lot of people there right now because they have substance abuse histories, and physical health histories, you know, lots of interfaces with these systems of care – foster care, mental health care systems and such and poverty and such, but when you dig down, they have a lot of very adverse conditions, and not a lot of help and support in working through those. It's an area where I find you can reach out and bring together the psychiatrists and the sociologists and the psychologists and the social workers and the nurses and the spiritual leaders and the cultural specialists and the lived experienced specialists, you can find common ground.

... they're treated for a set of symptoms which are really a set of adaptations to trauma.

And a core requirement of the money would be that you do it all with people with lived experience side-by-side, in terms of them being trained in recognising and supporting. Which also means at times having the opportunity to work through their own trauma histories and experiences so that they can in turn help others and not be triggered by others. Sometimes I think where we fall down in paid peer support is that we haven't done enough work in helping people recognise when they are getting into a situation where it is very triggering, things that they haven't had the opportunity to work through in their own healing. And they start burning out as a result, or retreating. So, now when I help set up peer specialist programs, I ask "What are you doing about trauma?" So I just think that's a really important area of focus.

And of course, it's not a magic bullet. Poverty, housing, employment, all these things are really important too. But this is one area where we have neglected listening to the people, and what has happened to them and have not given consideration to their stories and their adverse situations which they are describing. We say "Oh, they're making it up" or "it's a symptom" or "it's an exaggeration". But the more we research it, the more wrong that assumption is. They are recalling real experiences that profoundly impacted their abilities to cope and function.

Now if I had to make it much, much smaller, like you said, a very small pool of money? That's really tricky. In some ways I would really try to see that go towards grooming and supporting leadership development among people with lived experience. Because there's not enough resources coming to you – you have to start building your movement, helping figure out a better way to redistribute the resource pie. I would look at who's showing interest, potential and are there ways and perks that I help provide them with opportunities where I can help nurture that leadership within and start expressing it externally. And helping us to start changing the social discourse. But we're only getting a few thousand dollars? [Laughs] OK, so we need to challenge that!

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

SO: I live in Hawaii, so a good day is when I see a rainbow, that's great! I don't have much control over that, but we have lots of them! Something about a rainbow is hopeful! An experience in the day that conveys hope, some small little thing that conveys hope, whether somebody mentions about "OK, so great, so next time I see you..." So you know, like we'll be connecting in the future. Or some small little gain, like "yesterday we were here, but today we've now actually taken the first step with starting a new class, or starting to write a proposal – taking action." Taking some of those leaps of faith – like we might finish it, that conveys hope.

So things that happen in the course of a day that conveys hope – really distinguish for me a day that I feel good about versus a day that I just sort of survived. It's something where I feel like I'm part of something bigger than myself, even a tiny little contribution. So sometimes it might be just some trash in a really pretty area, like a park, and the park looks better. You know, Hawaii is beautiful, so it's keeping it beautiful!

Maybe something about where I feel connected with the future – you know, we're planning this so we'll have this gathering in the future. It feels like I'm on a path, and that there's something in the future, and that I can see an end to that journey. We can stop and celebrate what we've already accomplished – you know, we might not be there yet but look at what we just did today. That celebration feels like "we're in this journey and we are making progress" You know, that action is happening, that it is purposeful, so it's wherever I see that. And sometimes it is really small things – you know, an email from a niece or a nephew – children convey hope to me, you know because they are about the future. The things that convey hope to me make the distinction between a good day and a not-so-good day.

... we might not be there yet but look at what we just did today

Telling your story to yourself

> ***A poem is never finished, only abandoned***
> \- Paul Valery

My Story, Myself

By Ann Tullgren

When I was born, I was whole and full of promise; a Rubik's Cube still packaged for sale, before anyone twists, turns and distorts the colour pattern only to find it near impossible to get it back to 'normal'.

At least that's what I thought.

Looking back, the stories I told myself as a child resembled fairy tales: I was Sleeping Beauty, or Snow White, or the Ugly Duckling, or the girl child in the story of the gingerbread house and the wicked witch. It was no great leap of imagination to think I was the eighth member of The Secret Seven, always ready for adventure. Whatever the trials and tribulations, the ending always came good.

In similar manner, as I grew older, I embraced the plot-lines others had for me: work hard at school, keep the Faith, go to uni, travel, find work which is meaningful. Then, get married and have kids….

But when I was in my mid to late teens the storylines became fractured and I no longer had words for the evolving plot.

This was the onset of mental illness.

I embarked on conventional treatment: I consulted a psychiatrist and spent a lot of time in hospital. I learned a new language to describe this radically reshaped life; it was the language of diagnosis and treatment.

It was useful to have words and concepts to make some sense out of my experience and to explain it to others. And, at the same time, I felt rather clever that I had learned so quickly (and could spell and pronounce) the labels, concepts, names of the medications, and the sad prognoses. Embracing science, I cast aside those quaint and comfortable colloquialisms: 'a touch of the vapours', or 'a kangaroo loose in my top paddock', or 'fairies at the bottom of my garden'. Instead, I had endogenous depression, and later on, bipolar disorder.

Looking back, I was imprisoned by a web of jargon and ideas. Michel Foucault says that the postmodern use of power isn't about manacles or walls. He says we learn to become our own jailors by using the official discourses of failure and brokenness - a far more effective confinement.

In the end, the language of medicine was the language of disease and deficit, not the language of strengths, possibilities and transformation.

Yet, to think about it another way: did the dog (myself) wag the tail, or did the tail (this madness constrained, contained and replicated by the jargon and ideas of medicine and science) wag the dog?

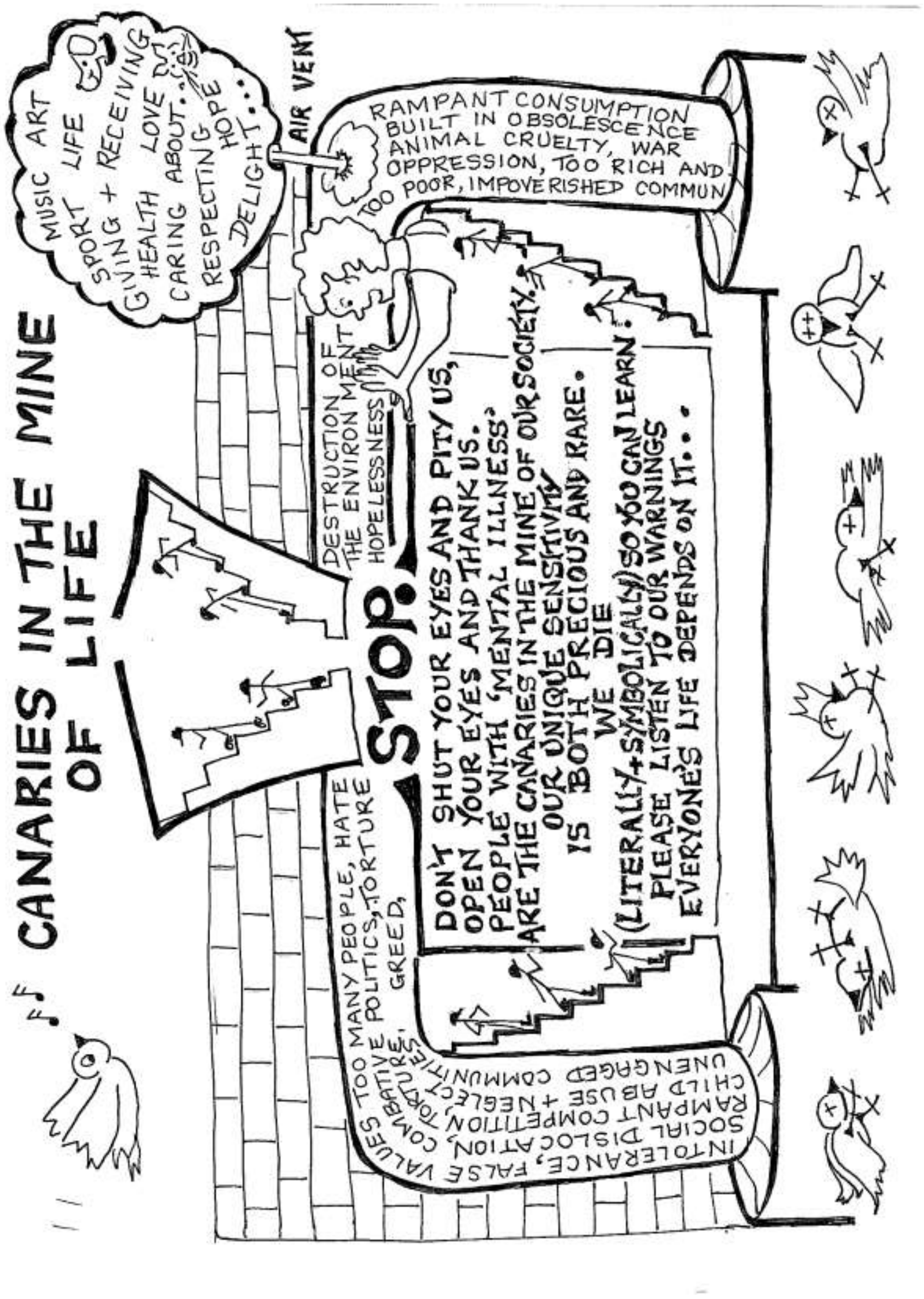
It was much later in life that I learned other ways to story my life, ways informed by literature, poetry, sociology, religion and philosophy. Alongside biomedical understandings of madness sit other meta-narratives: class, gender, poverty, religion, family, sexuality which layer the storying, making it more subtle, opening up possibilities. But, in the end, the language and stories of possibility, of redemption and change come most poignantly from poetry and art.

Hope comes in a Haiku.

I have moved beyond the facile fairy book construction of childhood where I thought that I could only reach ‘heaven’ (a better place) by keeping the Rubik’s Cube of self unsullied and safe from harm. I am content to keep the books of science and psychiatry on a shelf, where I can consult them when I need to. My pills are in the dosette box next to a glass for water (they help). But, I have learned that my route to ‘heaven’ (what is possible) is through the back door: what really matters is how I story for myself my suffering, my heroism and my humour. The language of poetry is indeed fit-for-purpose. It can heal the wounds left by reason.

THUMBS UP/THUMBS DOWN

1. THUMBS DOWN: to the Federal Minister for Mental Health’s ‘Mental Health Expert Advisory Group’ (established just before Christmas) having only 1 consumer member! How can this kind of tokenism still be happening?!
2. THUMBS UP: to international solidarity! How inspiring it is to be in contact with our wonderful friends, allies and partners across the globe.
3. THUMBS DOWN: to a certain Professor of Psychiatry (who shall remain unnamed) who upon meeting a consumer representative on a committee was rude and ignorant enough to say (as first words of greeting) “Oh, you’re a consumer rep? Are you a consumer at Myers or David Jones?!? I mean I do hate the whole idea of “consumers” ... can’t they just call themselves “patients” like they used to?” Ah, no points there for respectful open-mindedness and curiosity about things you might not understand, Professor! Many of us choose other terms for ourselves these days, not all of us like the term “consumer” but it’s *our* word and these are *our decisions*, thanks! You might want to ask around... and not just your medically trained colleagues...
4. THUMBS UP: to professionals who truly understand mutuality – knowing in their bones that we are all human together and that they has as much to gain from their relationships with us as we have to gain from them.
5. THUMBS UP: to consumers who have a dream of owning land with trees and an Australian view and dream of building our own respite place: a place of quietness, relaxation, spirituality in our own ways, of tasks and stories and growing friendship.
6. THUMBS UP: to the consumers who have started to make this happen -who have already bought the land, held working bees, fundraising and are making this dream come true.
7. THUMBS DOWN: to all the media reports in America who focused so much on the psychiatric disability of the man who shot the US congresswoman Gabrielle Giffords, and killed 5 people.
8. THUMBS UP: to all the hard work that has educated journalists and targeted reporting standards in the Australian media, which meant that that kind of sensationalising, stigmatising and unhelpful reporting wasn’t replicated here. The contrast was a testament to truly effective work.
9. THUMBS DOWN: to health problems all coming at once. It’s an unfair law of the universe that when our immune systems is already down, we are more prone to get sick again.
10. THUMBS DOWN: to unrealistic expectations of consumer workers – too often expected to be “sort of a peer-support-worker-cum-consumer-consultant-cum-dogsbody” without proper role clarity, training, support or even a decent allocation of (paid) time.



More creative inspiration: One of Merinda's recent cartoons.

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

Merinda has been out of action with a back injury, and will be out of action for a while yet. So it's just Flick holding the fort for the moment (supported as always by wonderful networks and all the staff here at Our Community). Please be patient with us as we will no doubt be a bit slower getting things done!

We've been laying the foundations to teach ***Intentional Peer Support*** this year. What is Intentional Peer Support? How is it different to any other sort of peer support? Keep your eyes peeled (isn't that a rather horrible image?) for more information about Intentional Peer Support, which we will be rolling out over the next few months.You can watch a bit of Shery Mead herself talking about her approach to peer support at: www.recoveryxchange.org/SheryMead.html.

We have been working up ***our next booklet, on telling our stories*** (see the Ann Tullgren's wonderful piece earlier in this newsletter for a taste). We see stories as an amazing resource for making meaning, sharing important lessons, and communicating things that are not always well-captured by other ways of communicating. Telling our stories can be so much more than the heart-warming or tear-jerking "human interest" paragraph in a media story where the bulk of the "real information" comes from other experts! This project, as always, has been excitingly collaborative and generative. So, watch this space!

Flick's been ***teaching at various universities*** – providing some consumer perspective guest lectures, mainly in social work and psych. nursing. Both Merinda and Flick have been passionate about the expansion of consumer perspectives in education. We need to train up our allies so they can support us better!

As always, we've been involved in ***various events, committees, collaborations and projects***. Closer to home, we have put some energy into ***re-jigging our website***; while it's full of brilliant materials, for a while has been a bit of a dinosaur (or perhaps a maze? or a black hole?). And, of course, we spend much time on the phone, visiting and receiving visitors here – some days it feels like a cross between delightful conversation, community engagement, networking and peer support!

What is Our Consumer Place for anyway?

Periodically, we think it's good to clarify what we're here for, why we exist, and how we remain accountable to our members, the communities we serve, and our (ahem) funders! Our Consumer Place is funded as a resource centre for Consumer Developed Initiatives in the State of Victoria (we are funded through the Department of Health). This term "Consumer Developed Initiative" (or CDI) is simply an attempt to find language that captures something incredibly exciting and quite different to what has happened in the past – it's about consumers being in control of projects, groups, ideas, work, processes, etc.

> *Periodically, we think it's good to clarify what we're here for, why we exist, and how we remain accountable to our members, the communities we serve, and our (ahem) funders!*

Having spent a number of years now on the ground, communicating daily with CDIs – consumers working on projects, in groups, employed in the sector, or engaging with the world informed by their lived experience – as well as connecting with those supporting consumers and consumer perspective (in political terms, I'd call them "allies"), we have learnt a great deal about patterns, issues, challenges, needs and joys. Today, we function as an umbrella to support a wide array of initiatives – we believe that there are many ways to make meaning and purpose from lived experiences of being a consumer. And our orientation is towards strengthening what we call “consumer perspective” and “consumer leadership” – two pillars that we see as fundamental to effective and strong Consumer Developed Initiatives. All of our work is underpinned by these ideas – we don’t want to perpetuate the tokenism, patronising approaches, perpetual disappointments, hierarchies and bitter divisions that have plagued this area. We are committed to recognising and building on our strengths.

Connecting into Our Consumer Place (or making the most of our resources).

If you’re not already a member of Our Consumer Place, join up immediately! Membership is free and is open to anyone interested in what consumers are doing and thinking. Our membership is what makes Our Consumer Place exist. Members receive our newsletter and advance notification of any training or events.

> *we also try to remain what Merinda calls “response-able.”*

But it doesn’t stop there! Our Consumer Place is first and foremost a *resource* – we produce written and training resources where we understand there to be a need. This is usually in response to requests from members or from noticing patterns in what we see and hear, as well as based on many years of collective experience in this area. We have material on our website, in our newsletters, and we run training by request and we have much more material “in the pipeline” as they say. Most of this material is produced collaboratively, drawing on the strengths of the consumer community – OCP staff write some things where we are knowledgeable, passionate and experienced (or sometimes just have a bee in our bonnet!), but often other consumers are better placed. Sometimes we solicit, sometimes people offer. Keep in touch if you have something you’re passionate about or have thoughts to offer (or a bee in your own bonnet) – we see this sharing, networking and dialogue process as how communities and individuals grow and flourish! And this isn’t limited to consumers – we believe deeply in engagement amongst consumers and our allies.

As well as producing resources, we also try to remain what Merinda calls “response-able.” By this she means that we really try to be open and able to respond to consumers as the need arises. We are always balancing our time between projects that require devoted, sustained planning and attention, and staying open to whatever springs up (hopefully Steve Onken would call us flexible – see the interview earlier in this newsletter). We often receive calls or visits (or sometimes we visit) from consumers who are working on projects where they are stuck, need a sounding board, an understanding ear/solidarity or information. While we don’t have the time and people resources to do this as much as we would dearly love, we do strive to honour both these types of work.

We see networking as fundamental to sustainable and strong consumer groups and projects. So, we try to stay in touch with and publicise and profile consumer initiatives and events, show our faces around the place so that we’re not a faceless organisation, organise events where consumers can meet and share ideas, etc. Please do use our resources to connect with others, if you want to!

Finally, we strive to remain open to feedback. We especially like the “I just love your newsletter/ training/ book/talk!” variety (of course, who doesn’t thrive on positive feedback), but we also deeply value it when people are able to feed back to us how things could be better, where we’ve been misinformed, where there are gaps that we could be attending to, etc. So, please, do keep in touch!

A forum for consumers of mental health services
from the
Mental Health Legal Centre

What Consumers Want from New Mental Health Laws

Do you want to know more about:

- What is the same and different about the draft new mental health law?
- What the proposed new laws mean for consumers?

Do you want to participate by:

- Sharing your views about the benefits and disadvantages of the proposed new laws?
- Get information and tips on making your own submission?

Then come along to the forum to hear and talk about:

- Supported decision making including Advance Statements / Directives & Nominated Persons
- ECT
- Compulsory Treatment & Refusing Treatment
- Reviews and Appeals at the new Mental Health Tribunal
- Complaints to the new Mental Health Commissioner.

Date: Thursday 17th February 2011

Time: 9:30 am - 2:30 pm

Where: the Lionel Murphy Centre at 360 Queen St Melbourne

This is a free event for consumers, light lunch included
Please RSVP by 15th February. Numbers may be limited
Ph: (03) 96294422 or 1800 555 887 (country callers)
or email: mental_health_vic@clc.net.au