



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

**OUR CONSUMER PLACE  
NEWSLETTER NOV-DEC 2010**



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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

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*\*Please note that we had hoped to include an analysis of the draft exposure paper on the proposed reforms to the Mental Health Act. The person who promised many times "yes I will get it to you" and then didn't shall remain nameless. But, we are disappointed, as we were really looking forward to some informed analysis. Oh well, we are always grateful for what we do receive!*

*\*\*Please also note this bumper end-of-year edition is the final newsletter for 2010. Happy holiday season from Our Consumer Place (yes, early to be wishing this)!*

## INTRODUCING ... “So, you’ve got a ‘Mental Illness’? ... What now?”

*In this edition, we engage in some utter shameless self-promotion! And we also tell you more about the process behind this ground-breaking consumer developed publication.*

We are delighted to be able to share this free new resource written entirely by consumers: “So, you’ve got a ‘Mental Illness’? ... What now?” This booklet is an introduction to the mental health system, to “consumer perspective” and to some of the diversity of how consumers respond to a diagnosis of ‘mental illness.’

The booklet is the first of a series produced by Our Consumer Place. The story behind this booklet is that we are a consumer-run resource centre, based in West Melbourne and funded by the Victorian Department of Health, with a commitment to networking and sharing resources with the consumer community nationally and internationally. We are focussed on projects that are consumer-developed, and more specifically *consumer-perspective*– that is, an approach that recognises the lived experiences of people who have been diagnosed with a ‘mental illness’ as a crucial source of insight, a different perspective to the approaches of other “experts” in mental health.



From this perspective, we are very aware that there is so much expertise, wisdom, experience and skill within the consumer community, and that most of this is under-appreciated and under-resourced: there is expertise on all sorts of things – from advocacy to living on a pension, from negotiating the psych system to telling our stories with conscious intent, from teaching clinicians from consumer perspective to running a consumer artists’ group (and not as therapy!). There is a

*... there is so much expertise, wisdom, experience and skill within the consumer community, ... most of this is under-appreciated and under-resourced ...*

great deal of collective wisdom that we share amongst ourselves informally. We believe it’s high time more people had access to this stuff!

So, over the last few years, Our Consumer Place has been asking members of the consumer community to write for us on various topics. They have all been paid for their writing. Merinda has been writing prodigiously, and more recently Flick has added to the writing base. Flick came on board in mid-2009 with project management, editing and theme-spotting skills. We picked a selection of these materials to form an introductory booklet.

At this point, we brought in a professional editor – Kathy Richardson – who is part of the team at Our Community. Kathy brought (ruthless) editing skills, and an external perspective – she was new to many of issues in the psych world, and asked invaluable clarifying questions. Then, each piece was returned to the author, to check they were happy with what we had done with their piece, and to ask how/if they wanted to be acknowledged. Then, a graphic design whizz was brought in (Amy Johannsohn, also from Our Community). The slowest part was waiting for our funder (the Dept. of Health) to launch the book. We spent agonising months waiting until we could officially share it!

Feedback has been overwhelmingly positive – some people have been rather gushy in their praise, which is always a joy to hear, knowing that this is striking a chord for other consumers (and for non-

consumers too!) We've also had some wonderful eagle-eyes pick up mistakes and slips, which we hope to correct in the next printing. Perhaps the most exciting news is that another state has started negotiating with us to use this material, adapting the parts that need to be revised for their state.

The booklet is available for free from our website ([www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au)), and we are able to send a free hard-copy to people – the order for is on our website too. Unfortunately, we can't afford to send out as many free copies as there is demand – many people have read the booklet and asked for 50 or 100 copies to be sent to their organisation. They cost us \$5 to print (not to mention the costs associated with all the work that has been put into them). So, our policy at this stage is to post out a free copy to anyone who asks (within Australia) and then to charge \$5 per book for subsequent copies. There is some capacity to negotiate small batches to consumer-run, un(der)-funded organisations, but this is very limited.

We hope you find this resource useful, engaging and thought-provoking. We have many more booklets planned – the next one is on the topic of “telling your story” and engages with some complexities of this apparently simple activity. Other topics include a deeper exploration of the psych system from a consumer perspective, advocacy, consumers as workers, and much more!

## STOP PRESS! How do YOU think consumer workers should be trained?

Are you interested in the training of peer workers? The Community Services and Health Industry and Skills Council is developing a framework for training peer workers (which includes both consumers and carers), and they are seeking feedback and input.

Our Consumer Place is concerned that this framework has been developed with minimal consumer involvement, let alone consumer leadership. It is profoundly disappointing to witness yet another example of control residing outside consumers, and of consumers being brought in well after most of the foundational work has been developed. The consumer workforce developed out of the energy, thinking and political passion of consumers who fought hard for these positions to exist. Consumers *are* developing our own models for training and workforce development (see two contributions to this newsletter – Vrinda Edan sharing some of the deep thinking occurring at Southern Health, and Cath Roper sharing the breadth of experience and expertise brought together as PAT), but in many ways, we are still collectively figuring out what consumer work could and should be.

In the meantime, however, many consumer workers do feel under-prepared, and workplaces expect far more from them than is appropriate given the resources allocated. Consumer-specific training opportunities are of course desirable – many consumers now undertake the CERT-IV in Mental Health, which is a non-consumer perspective on mental health, but many do so because they want a *qualification*. Our Consumer Place urges consumer workers to give feedback on the draft 1 materials – the deadline is 23 December 2010. The relevant documents are at:

[https://www.cshisc.com.au/index.php?option=com\\_content&task=view&id=545&Itemid=162&limit=1&limitstart=5](https://www.cshisc.com.au/index.php?option=com_content&task=view&id=545&Itemid=162&limit=1&limitstart=5)

## NEWS IN THE CONSUMER WORLD:

### Gender sensitive practice grant

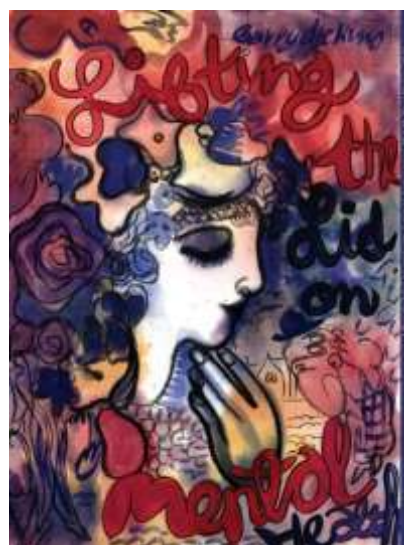
Congrats to the Victorian Women and Mental Health Network (VWMHN) for receiving a \$100,000 grant (!!) from the Victorian Dept. of Health. The grant is for training in gender sensitive practice. We wish you all the best with this project.

### Sandy Jeffs's book shortlisted for human rights award.

Sandy Jeffs's memoir, *Flying with Paper Wings: Reflections on Living with Madness* has been shortlisted for the 2010 Australian Human Rights Awards. Well done Sandy and good luck!

### Lifting the lid

Congratulations to VMIAC and Victorian Mental Health Carers' Network for a great day at Federation Square. On 31st October, consumers, carers and other people who care about mental health gathered on a blustery Melbourne day to raise the profile of mental health in the lead-up to the Victorian state election. There was comedy, art displays and an art auction (of the gorgeous piece left, by Barry Dickins), a variety of music (Heidi Everett shone as always), dancers, Sandy Jeffs reading from her memoir, Debra Byrne passing through to make a passionate speech, and many other contributions, MC'd by Rod Quantock. There were also many stall-holders and many wonderful people to hob nob with. T'was a rather splendid way to spend a Sunday afternoon.



### New Consumer-run radio show on 3CR

In their own words – “Tune into 3CR Community Radio Wednesdays at 5pm for Melbourne’s best radio show giving voice to people with mental illness, 1 in 5 have a mental illness ... but 5 in 5 can enjoy this great program featuring heart warming stories, great information - and some laughs as well! Find us at 3CR – 855AM on your dial. Sponsored by Mental Illness Fellowship Victoria.”

### The Minister for Mental Health, Mark Butler, wants to hear from us

The Minister for Mental Health is conducting an Australian tour, listening to consumers and carers. His invitation (see back cover of this newsletter) asks for us to share our “stories” and “experiences,” but we suspect he’s also likely to hear our analyses, insights, wisdom, recommendations, frustrations, differences of opinion, collective learning, etc. Having heard him speak at the TheMHS conference (on the first day after he was appointed), we suspect he has a few things to learn from consumers – he didn’t make reference to us *even once* in that first public speech. We do hope he’s up for a steep learning curve!



## INTRODUCING ... PAT (Psych Action/Activism & Training group)

*In this edition, Cath Roper, Australia's only consumer academic, introduces PAT, the (very exciting!) beginnings of consumer academic discipline in Australia.*

### What is PAT?

The Psych Action (or Activism) & Training group (PAT) is unique in the mental health landscape. The group was originally formed in 2002 and is convened by the Consumer Academic at the Centre for Psychiatric Nursing (CPN) located at Melbourne University. The aim of the group is to advance consumer perspective as a discrete discipline in mental health and group members believe that:

*the unique body of knowledge contained within consumer perspective needs to become routine in all research, education, and training activities pertaining to mental health.*

This aim is achieved through the inclusion of consumer perspective across the full range of teaching and research activities that the group represents and beyond. This is a dynamic, collaborative, interdisciplinary group, with membership comprising independent consumer specialists, mental health service based consumer employees, and academics in mental health nursing, and occupational therapy. The group spans substantial consumer expertise in the areas of education, training, research and policy development, including culturally and linguistically diverse consumer perspective. Several members have been awarded Department of Health, mental health program Fellowships as principal researchers. The group meets on a six weekly basis and membership is about 16 people, not all of whom come to each meeting.

PAT provides a mutual, collegial, collective and sophisticated articulation of the discipline of consumer perspective and as such, forms a peer support collective. But it does significantly more than this. PAT has gradually developed a way of thinking and talking about our work and our work environments that provides a solid foundation from which to critique existing ideas and practices and generate new ones.

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### What do we do?

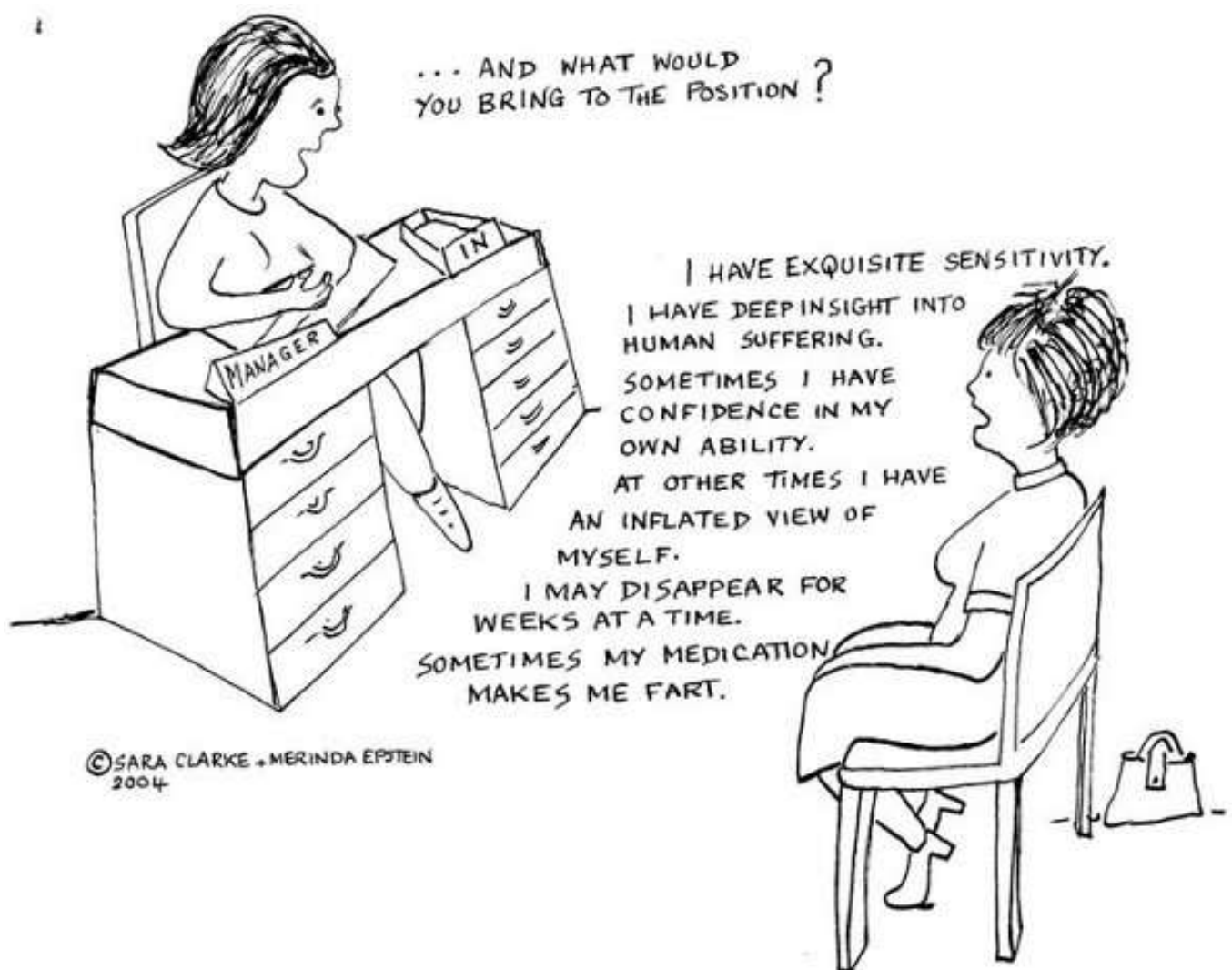
PAT acts as a kind of 'exchange' for upcoming training and research opportunities. If someone brings an opportunity to the group, they will usually find enthusiastic members who choose to be actively involved in research reference groups or curricula development and delivery. In this way, the group mutually benefits from collective ideas. The group also regularly responds to external requests for advice on research or education activities.

Group members are interested in the development of the consumer educator workforce and have presented several training sessions for consumers, some in partnership with the Victorian Mental Illness Awareness Council, with a focus on educating clinicians. PAT has also presented at several conferences and symposia about our work and what makes the group so unique and highly valued.

PAT has also:

- Developed submissions for enquiries and for various government consultations
- Developed research methodologies and participated in research focus groups such as the Routine Outcome Measurement study, the Coming off Antipsychotics Study and the Consumer Evaluation of a Strengths Based model of Case Management study
- Organised events in partnership with other agencies such as with VICSERV to host international activist and researcher, Judi Chamberlin; hear speakers such as David Webb, suicide survivor and human rights activist; and provide training such as with Sandy Watson, advocacy trainer.

PAT's longevity is testament to both its flexibility and the group's importance to its members. We continue to advance consumer perspective in research and education with the intention of establishing a consumer perspective academic program at the University of Melbourne.



## Instilling Hope” A 5 year plan for the Consumer and Carer Relations Directorate of Southern Health’s Mental Health, Alcohol and other drugs Program.



**Vrinda Edan** (Director of Consumer and Carer relations at Southern Health Mental Health, Alcohol and Other Drugs Program) explains her organisation’s approach to the development of the consumer and family/carer workforce. Many of you may be aware of the Community Services and Health Industry Skills Council’s current “Mental health peer workforce competency development project” but we here at Our Consumer Place felt that much good work is already being done that is led by consumers and draws on sophisticated consumer thinking. So, we asked Vrinda to share with our readers the work and thinking that her team have been involved in.



*Through lived experience and as an integral part of the Southern Health Mental Health, Alcohol and other Drugs Program, the Consumer & Carer Relations Directorate enhances the Program’s capacity to instil hope and provide an effective consumer and family/carer focused service.*

In 2005, Southern Health Mental health program implemented the role of Director of Consumer and Carer relations. Under this new role, the consumer and carer workers with in the program came together as a team and began to develop a cohesive approach to the work being undertaken. During this time, a number of important documents have been produced in regard to Consumer and Family/Carer Participation in the Mental Health, Alcohol and other Drugs sector.

Sarah Gordon’s 2005 article on Consumer leadership offers a concise and comprehensive argument for an increased involvement of consumers in the leadership and management of mental health services in Australia and New Zealand. Gordon concludes her article with “It is contended that the paradigm shift from consumer ‘participation’ to consumer ‘leadership’ may be more fruitful in realizing the considerable benefits that result from effective consumer involvement in mental health services.” (2005, p365)

*‘... the paradigm shift from consumer ‘participation’ to consumer ‘leadership’ may be more fruitful ...’*

A second key document is the research report ‘Real Lives, Real Jobs’ (Bennetts 2009) This research project was extensive and made a total of 30 recommendations across areas such as *The essence of consumer work, The dollars, Pathways, The Workplace and Leadership.* (p40 -41) Despite this being a government funded research project, there is no evidence that any of these recommendations have been implemented.

A final article to raise here is the Stewart et al (2008) article ‘Set Up to Fail? Consumer participation in the mental health service system.’ This article is an exploration of issues identified by consumer workers in NSW via a survey distributed to workers and via the NSW Consumer Advisory Group newsletter. Stewart et al (2008) come to the conclusion that ‘the rhetoric of consumer participation



is not matched by effective and timely strategies that ensure that consumer involvement is underpinned by relevant training and supportive infrastructure. The goal of meaningful consumer participation in mental health services, as outlined in policy, is yet to be achieved” (p.1)

*‘the rhetoric of consumer participation is not matched by effective and timely strategies that ensure that consumer involvement is underpinned by relevant training and supportive infrastructure. ...’*

In 2008-09 DHS developed and released “*Because Mental Health Matters*” (BMHM). This document, produced by the Mental Health and Drugs Division, is a 10 year plan for the strategic reform of mental health, alcohol and other drugs services across Victoria. BMHM provides extensive and broad strategies to reform services. Of specific interest to the CCR directorate are strategies that influence the experiences of consumers and their families, and improve their participation and involvement both in the provision of their direct care and the development of services.

Unfortunately BMHM does not specifically identify strategies to support or enhance the consumer and carer workforce and provides little opportunity to influence the direction of the planning. BMHM also makes no commitment to increased utilization of the expertise or resourcing of the consumer and family/carer workforce.

In response to these documents and Southern Health’s demonstrated commitment to improving Consumer and Family/Carer participation and involvement, the Consumer and Carer Relations directorate of the Mental Health Program has recently undergone an extensive period of planning.

The result of the planning undertaken at Southern health is a document titled ‘Instilling Hope - A five year plan for the Consumer and Carer Relations Directorate’. This document defines and outlines the variety of tasks that consumer and family/carer consultants currently undertake, and the growth in staff and skills that is required to meet the ongoing and expected need for service for the next 5 years.

While the range of duties and tasks undertaken by the consumer and family/carer workforce is very diverse, 7 key areas were identified:

- 1. Peer Support:** peer support can involve one on one work as well as support groups and involvement with planned ward activities.
- 2. Service / System advocacy:** this work consists of membership of program committees such as Patient Safety and Quality committees. The Director has membership of all executive level committees and has a role in all decision making including operational, clinical and financial decisions. This ensures a consumer and family voice is heard in relation to all decisions with in the program.
- 3. Education and Training (of others):** generally this is to clinical staff of the program but can include ‘guest’ speaking at community forums and universities. We have recently negotiated a complete day of training with the graduate Nurse program, and have been instrumental in the development of the training Southern Health does in collaboration with Latrobe Health regarding Families where a Parent Has Mental Illness (known as FaPMI or COPMI)

*While the range of duties and tasks undertaken by the consumer and family/carer workforce is very diverse, 7 key areas were identified*

**4. Professional Development (of ourselves):** this year the Family consultants have attended training organised and funded by the Victorian Mental Health Carers' Network. Consumer workers have attended the VMIAC consultant day and a number of other training opportunities both within Southern Health and provided by external agencies. In the last 12 months we have also supported the Senior Family Consultant undertaking a Cert IV in Training and Assessment and the Senior Consumer consultant undertaking a Diploma in Management.

**5. Information Provision:** We have a suite of information available including brochures on our services, plain English rights documents and "packs" of information for consumers and their families. This can also include referral to other agencies such as VMIAC and the Mental health Legal Centre.

**6. Community Development:** At this time community development mainly involves networking with community agencies and other groups, such as carer support networks and PDRS services. We also conduct an annual Art Competition during Mental health week that is part of a Mental health promotion framework for Southern Health.

**7. Culture Change:** is a major, although sometime invisible, aspect of our work. Every activity has an underlying goal of improving the lives of consumers and their families and this will be achieved in the most part by changing the culture of services from a crisis driven medical model to a socially inclusive model that addresses the consumers' identified needs. The consumer and family/carer workforce embrace this definition of Culture change:

"Culture change differs from other types of organizational change. The shared beliefs, values, and behaviors of organizational members become the target of the change process rather than solely focusing on the structures and systems within which people work."  
-Waterhouse, J. & Lewis, D. (2004). Communicating culture change. *Public Management Review*, 6(3), 353-376.

In the document these tasks are further explored and an implementation plan for the ongoing development of understanding as well as an increase in activities with these tasks is outlined.

The planning process identified a growth in the workforce is needed to fulfil both the community and services expectation of this specialist workforce. At this time the directorate employs 2 consumer and 2 family/carer consultants in Adult service, 1 consumer and 1 parent/carer consultant in Early In Life (previously CAMHS) services, a project worker, the Director and an Admin Assistant, with a total EFT of 4.4. By the end of the 5 year plan we hope to have a total of 12.2 EFT with specialist workers in Education and Training, Alcohol and other drugs, Early in Life and peer support specialists.

At this time the directorate has several implementation actions underway:

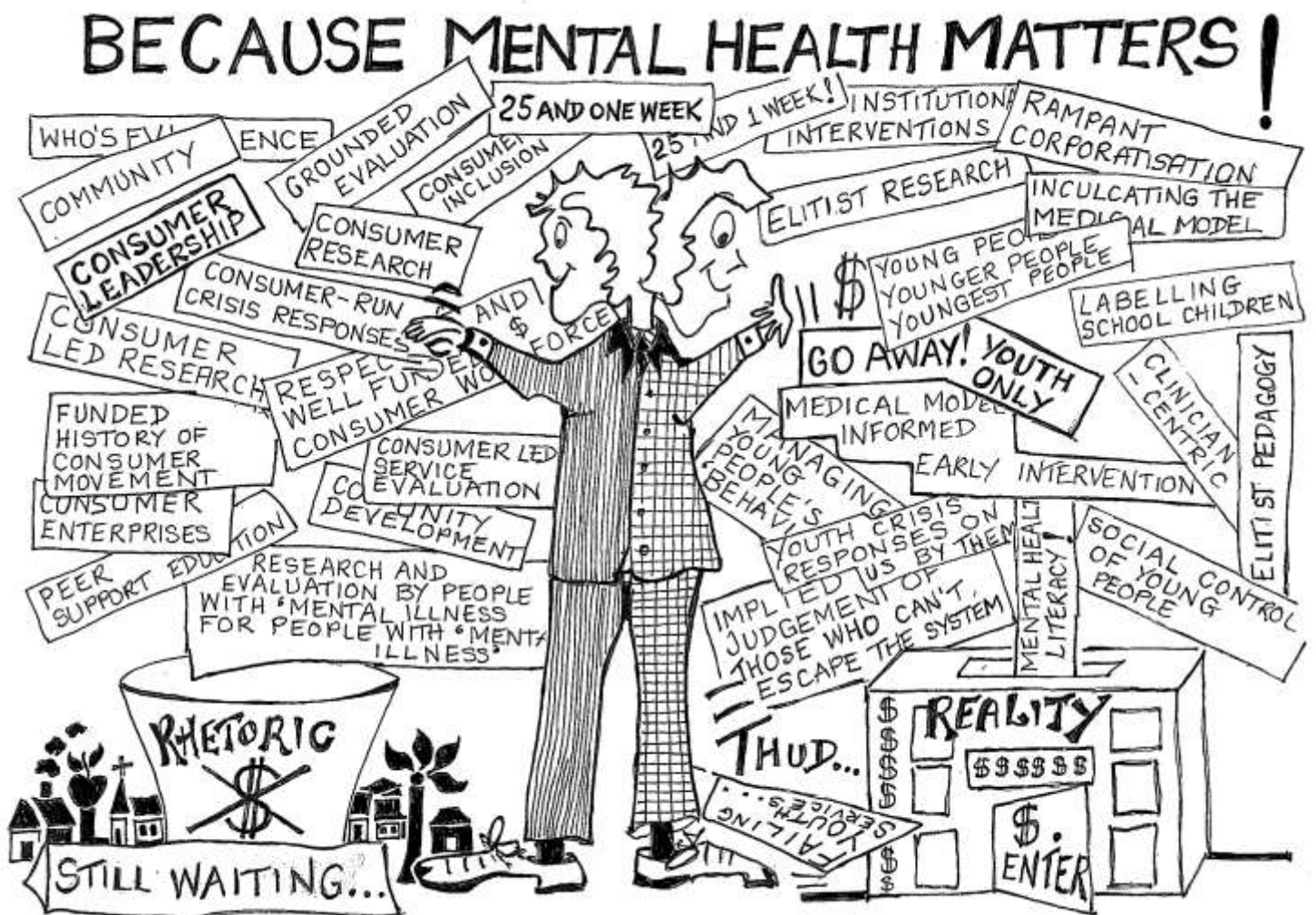
- Developing a model of consumer participation in the newly forming 'Early in Life, 0 – 25 years' directorate.
- Developing a model of Family/Carer support in bed-based Rehabilitation services, principally the CCU's and SECU.
- Developing a Consumer/Carer Education and training role.
- Developing a model of participation for the Alcohol and other drugs sector.
- The continued development of a career structure and a remuneration and classification system that accounts for experience and education.

This is an exciting time for the directorate with much enthusiasm about the potential for development and the types of involvement we will be able to achieve with the consumers, their families and carers and the staff of the mental health program at Southern Health.

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# For a copy of the complete document 'Instilling Hope' please contact Vrinda Edan at Southern Health. [vrinda.edan@southernhealth.org.au](mailto:vrinda.edan@southernhealth.org.au)



-Cartoon by Merinda Epstein



## READER RESPONSE TO A PREVIOUS EDITION!

*(In response to Flick Grey's Soapbox entitled 'No revolution in youth mental health without young people leading it!', originally published in Our Consumer Place newsletter August 2010, pp.4-6)*

As one of the youth co-convenors I had the pleasure of being involved right from the outset for the first international youth mental health conference. As a part of the organizing committee alongside Sarah Aliston – the other youth co-convenor – we were determined to get youth involved on the big stage.

It was a successful project right from the start. The opening welcome was conducted by Sarah – the other youth co-convenor and myself. That's right, the welcome to the first international youth mental health conference was not conducted by a delegate or even the convenor itself, rather special request was made for us to introduce the event. It was a delight to be given this opportunity to have the first voice.

This was truly remarkable as we reminded everyone attending why they were here for. In the leading months coming up to the event we worked solidly amongst our hectic schedules to ensure youth participation would be a key focus to this inaugural event.

Upon leaving the stage and breaking through intermissions we were often barricaded by a barrage of people voicing their appreciation and sheer excitement about how fantastic it was to see youth involved. With our busy schedule it was hard to even stop and soak it up, as we had another sixteen youth participants to coordinate, but one lady was game enough to stop me pacing away and say, "I have been working in this field for over ten years and have attended many conferences like these, but never before have I seen young people involved like this...keep it up". After hearing comments like this, I felt that the hard work had paid off.

These youth participants did an amazing job of representing the youth of this country. Their involvement was extensive over the two day event and across all streams throughout the conference. I got to witness an amazing delivery given by one young person. The stories these young people had to tell captured the hearts of the audience and the presenters themselves. One presenter even utilised the youth participant to help out with the presentation and give real life accounts about the aspects of how to successfully communicate with young people. This was a delight to see.

The involvement of youth was not just limited to giving personal accounts as a consumer of mental health. More importantly, all streams featured a youth participant, and either co-chaired the session with high profile people or was involved in the panel discussions, and some even both. The youth participants were given the opportunity to select the role they wanted to play and were matched up accordingly. Furthermore, the youth participation stream featured young people as the key presenters.

Overall, their presence was strong, welcomed and set a new benchmark for youth participation in mental health. Along with the spectacular keynote speakers that were able to present, the involvement of young people was definitely one of the highlights of the event.

*-Amran Dhillon, Youth mental health advocate, Youth co-convenor for the International Youth Mental Health Conference, 2010, Melbourne.*

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

It's been a big month (ok, 6 weeks) here at OCP. As always, we've had consumers and other people who support consumer perspective calling us, emailing, dropping in and joining up to Our Consumer Place. We've also been out and about, participating in consultations, attending book launches, teaching, and engaging with the consumer community. And then, on top of all of that, we launched our long-awaited book (more details below) and have since been inundated with requests and have spent innumerable hours stuffing envelopes ... Oh, and we also organised a one-day conference on Consumer Leadership. Yes, indeed, it's been a busy time (and between us we are only 1.2 EFT).

### The launch of "So, you've got a 'Mental Illness'? ... What now?"



**L-R:** Merinda Epstein (OCP), Dr Karleen Edwards (Executive Director, Department of Health's Mental Health and Drugs Division), Flick Grey (OCP) and Denis Moriarty (Group Managing Director of Our Community)

On Monday October 11<sup>th</sup> Our Consumer Place's booklet "So, you've got a 'Mental Illness'? ... What now?" was launched by Dr Karleen Edwards, as part of the Department of Health's official Mental Health Week activities.

The launch had originally been planned (and we had previously advertised it) as part of the launch of Mental Health Week, but for various reasons this was postponed. Sincere apologies to anyone who attended the MHW launch expecting to see our booklet launched – please know this was totally beyond our control and that we were unable to communicate the change of plans in a timely manner. Sometimes one has to work according to the priorities of one's funders...

### Our Consumer Place Leadership day

Our Consumer Place held its first "Consumer Leadership Conference" at Ross House in Melbourne, on October 14th, 2010. About 60 people attended, including both self-identifying consumers and supporters. The three keynote speakers (who were asked to speak on the topic of consumer leadership, but were otherwise unconstrained) were:

- **Cath Roper:** speaking critically about how leadership is constructed, and presenting a vision for group leadership. She also proposed an ongoing agenda for consumer leadership, stressing that we need to seek out those spaces where we are best placed to lead.
- **Catherine Smith:** speaking beautifully about stepping up to lead, drawing on her own lived experiences and her work at the Queensland Alliance.



Catherine Smith presenting

- **Merinda Epstein:** speaking eloquently as a consumer movement elder about the contemporary preoccupation with "youth mental health" and the loss of history this entails.



Attendees at one of the break-out sessions

Other sessions included:

- A panel and group discussion about "Youth Leadership," which included an exploration of the disjunct between developing leaders within the youth mental health arena and the consumer movement and consumer leadership more broadly. Concerns were also expressed about other disjuncts (e.g. between adult and aged services).

- Breakout sessions on (1) the interface

between consumer leaders and services; (2) groups operating outside of services, and often with minimal funding; (3) what it means to be a "real" leader or even a "real" consumer.

Feedback on the day was extremely positive, with attendees noting the rich and respectful discussions, the openness to differences of opinion, and the benefit of having no preset agenda as to what would come out of the day. We hope to focus more on this concept of consumer leadership in the future and are deeply grateful for everyone's involvement on the day.



Attendees enjoying a session



Jon Kroschel making a point



Jenny Speed and Cath Roper



Flick Grey making a very serious point



Attentive attendees



Larisa Trotter and Merinda Epstein at lunch

## Reflections on the Our Consumer Place Conference on Leadership

By **Jon Kroschel**, Consumer Consultant & Research Fellow in the Dept. of Psychiatry, Alfred Hospital

### Ross House is 'home turf' for me for many reasons.

I attended the Consumer Leadership Forum at Ross House. Ross House is a unique and special building because its specific purpose is to house community organisations providing low cost office space and meeting rooms for many small, diverse, community groups. It is an interesting place.

Ross House is intrinsically entwined with my own personal history through my membership of, and working with these groups over the years. It is also intrinsically entwined with the history of the consumer movement in Victoria as many groups both in the past and the present have been tenants. Ross House has contributed to the progress of our movement over many years.

I have fond memories of the people and meetings held as part of the Melbourne Consumer Consultants Group, facilitated by Ross Finlay. I also have fond memories of my association with the Action Research Issues Centre (ARIC) and Yoland Wadsworth's major contribution to research and evaluation of consumer initiatives. Also, I worked for a time with Disability Employment Action Centre (DEAC). This is just to name a few, not to diminish the importance of all the others.

Attending Ross House, walking the stairs, using the same lifts as years ago, walking the corridors, seeing the names of all the groups, either on the office doors or on the meeting room schedule whiteboards, felt comforting and safe, like returning to my parents' home. Fond memories of good times amongst good people came flooding back. I experienced a sense of belonging, re-enforcing that it is amongst 'the people' where I feel most comfortable, and not amongst the 'bureaucracies' of State or National Government Departments.

### Prejudice at the conference

At the beginning of the lunch break of the forum I asked the person in front of me in the coffee line;

*it is amongst 'the people' where I feel most comfortable, and not amongst the 'bureaucracies' of State or National Government Departments.*

*"What has been the most interesting thing of the day for you so far?"*

The person answered; *"I find it interesting that you consumers have the perception that you have the intellect and intelligence to manage anything".*

And there it was... the prejudice and ignorance.

My reaction was not as understanding or sympathetic as it might have been. I did not smile politely with my response. It was a reaction without forethought. I said; *"Did you know that amongst the 100 consumers who are members of the Consumer Participation Program of Alfred Psychiatry we have people who manage their own businesses, who are teachers and solicitors, accountants and real estate agents, and that none of us ever lose abilities, knowledge or skills, no matter what happens to us and our group manages multiple projects from multiple funding streams?"*

Maybe my response was in some way experienced as being discourteous because the person walked away while I was still talking. Maybe my response was a bit overwhelming, I don't know. Maybe the person had found the day too confronting already, I don't know. Maybe, maybe, maybe...

How is it that we, consumers, are only ever afforded 'perceptions' whilst other people have experiences that are facts? All people sometimes perceive rather than know and it is unjust and unfair that our experiences are rarely seen to represent 'the facts'.

### **The effects of prejudicial behaviour by others**

It is not the first time I have been confronted by this sort of prejudice and ignorance and I have experienced much worse. I am sure that other consumers have too. Many times however, those who are prejudiced against us outnumber us. We have to fight to stand up to this but we are often forced to do this on their home turf.

After all these times such comments still cut me deeply. Consumers often experience these attitudes and behaviours even when an activity is supposed to be about 'social inclusion'! Quite often after such incidents I have lost sleep, or had interrupted sleep, or failed to be able to get to sleep, due to the endless thoughts and feelings of worthlessness that these comments arouse. Many times too these thoughts become intrusive and interrupt my ability to work at my optimum level. It can be quite difficult to combat the effect of these comments when they reinforce the prejudiced and ignorant beliefs of many.

### **Maybe we just need therapy?**

In America the 'professional social inclusionists' have joined with the 'professional therapists' and developed 'special skin toughening therapies' for us, so that we become 'de-sensitised' to such prejudice, ignorance and attitudes!!!! I will not be signing up for any such therapies. Nor will I be returning to the use of older styled medications that 'zombified' me to such an extent that I felt nothing, and could relate to the people in John Cade Unit at Royal Park who walked one way endlessly round and round in circles around the lounge room. Our sensitivities are probably in direct proportion to the amount of trauma we have experienced and / or witnessed throughout our lives. I am sure that this is where sensitivities stem from. Being able to 'feel' and have emotions is what makes us human, and should not be 'therapised' out of us, leaving us with the emotions of a cyborg or robot.

*Being able to 'feel' and have emotions is what makes us human, and should not be 'therapised' out of us ...*

What would society be like if everyone was de-sensitised? Who would express outrage at the extent of domestic violence, or violence against children, or the plight of asylum seekers? Who would be concerned at the amount of violence toward people on the streets and trains? Who would be the litmus for 'measures of caring' in the community? Who would show compassion to any one else? Would we end up with a nation of de-sensitised people like Nazis Germany where there was no outrage from the people of that nation about the killing of millions of people?

No, I do not want to be de-sensitised. Being able to 'feel' is what makes me, me!

### **Early discussions at Our Consumer Place**

In the early days of establishing Our Consumer Place, Merinda, Cath, Denis and I had long discussions about membership. Should we keep it a closed consumer group or not? If we kept it a closed group, how would others (non-consumers) ever see what we were doing or capable of? If we opened the group up would we be inviting the people who hold prejudice and ignorance into the group? How would this affect the group? How would this affect the consumer members? How would



this affect the non consumer members? We held many discussions around this topic before deciding to have a 'more than consumer' membership.

Whilst the words of prejudice and ignorance cut deep the day of the Consumer Leadership Conference, I only had to lift my eyes and look around the room at 'us'. There were many examples

*... living proof that we  
are immensely capable.*

of consumers doing projects, both past and present, excelling at project management, research, lecturing, completing PhD's and other studies to having living proof that we are immensely capable. A quiet stroll down the hall way of Ross House brought back memories of other great projects and activities conducted and facilitated by consumers.

It was like I had experienced a deep cut that previously in another setting would have become infected and festered. However, this time there was a salve, a soothing balm, or some iodine to place on the cut so it would not become infected and fester. I had no trouble sleeping after the conference and the reason that it has taken me a while to write and send this feedback has not been due to interrupted work. Quite the contrary, it has been delayed because I have still been working at my optimum on many more projects.

#### **Combating Prejudice and ignorance – Does it matter where and with whom?**

Yes it does matter. Being on 'home turf' and where we (consumers) are the majority has lessened the impact for me. Others may have other experiences, but these are mine, and they are a fact.

Thank you to Merinda and Flick for holding the conference at Ross House, and to Merinda, Cath and Denis – I think we got the membership right.

Cheers and thanks

Jon

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## **What else has Merinda been up to? ... well you may ask!**

What's Merinda been up to (apart from mentioning the booklet at every possible opportunity and sending out copies to influential people and organisation)? Over the past two months I have been busy on the speaker's circuit.

### **Moreland Hall**

On the 31<sup>st</sup> October I spoke to staff from Moreland Hall in which is a drug and alcohol service. I could feel that the people in the room were engaged and this was great. Later Our Community received an email from Brandon Jones, the Manager of education Programs, who organised the talk. He wrote:

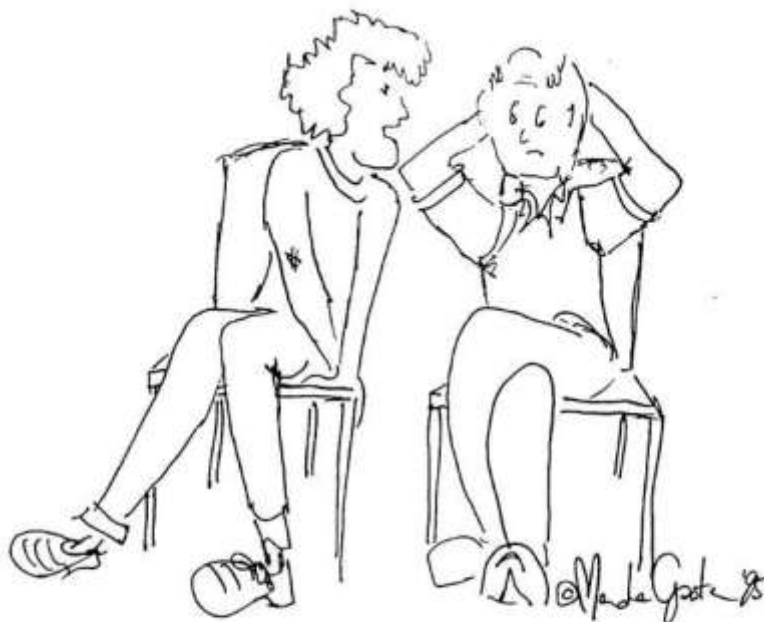
*I wanted to let you know – we had one of your staff (Merinda Epstein) provide a presentation on consumers and Our Consumer Place. We ensure that our workers are provided with numerous professional development opportunities- but our workers have not stopped raving about how good this presentation was. Many appreciated Merinda's wisdom, insights and perspectives and I have heard comments from senior clinicians such as "This makes me want to be a better worker". Great stuff. Thank-you for providing such an important service.*

## Advocacy in Beaufort

I was invited by Mark Lacey, the consumer consultant at Ballarat Mental Health services, to attend the weekend workshop of the newly elected Consumer Reference Group (CRG). It was held on a very wet Saturday (13/11/2010) in a rather lovely country school outdoors learning facility just outside Beaufort in country Victoria. The presentation was on advocacy. For the first time I used some of Sandy Watson's terrific learning materials. Sandy, from Sydney, has a huge reputation as a consumer educator, writer and advocate. These materials were outstanding. We played 'Advocacy Hot Potato' which is an interactive activity which invites participants to explore a range of challenging advocacy scenarios. Everyone was truly involved and the organisers ended up cancelling another planned session so we could continue on for a bit longer than allocated. My big thanks go to Sandy. I wish these materials could be mass produced. As it stands at the moment Sandy makes all her materials by hand.

## Peer Support at Northern Community Care Unit (CCU)

I have also been actively involved in Alan Pinches exciting new project exploring and developing consumer peer support at the Northern CCU. He has been strongly supported by the facility which is wonderful and together we have confronted the 'appropriate' (we wonder) research and ethics committees – which still don't get it when it comes to consumer research. Despite this Alan is moving along really well and we think this is a particularly interesting and important project because of the uniqueness of its setting. Our Consumer Place is proud to be involved and offer as much support as we can.



So, WHICH OF THOSE COMPLAINTS **DO** YOU  
THINK STAFF WILL BE HAPPY FOR ME TO MAKE ?

©MERINDA EPSTEIN



## THUMBS UP/THUMBS DOWN

1. **THUMBS DOWN** to Mental Health Laws that fail to comply with the United Nations Convention on the Rights of Persons with Disability (like ours, even with all the proposed changes).
2. **THUMBS DOWN** to the Orwellian doublespeak in the *Mental Health Act* review – claiming to fundamentally shift the terrain of mental health law, by introducing concepts like “capacity” while fundamentally maintaining a discriminatory, damaging and degrading system.
3. **THUMBS UP** to everyone who came along to our conference on Consumer Leadership and joined in our collective thinking.
4. **THUMBS UP** to consumers who have laid the ground for all the rest of us to make meaningful and important alliances with different social change movements including the disability movement.
5. **THUMBS DOWN** to expecting consumers to contribute our expertise without paying us, and to the constant excuses (like for example “no one is getting paid”, although everyone else involved has an employer who pays them to participate). This is structural inequality at work!
6. **THUMBS UP** to the wonderful creative and thoughtful outpouring during mental health week – the consumer community has such a wealth of creative brilliance!
7. **THUMBS UP** to self-care! It’s hard work being a consumer, hard work being a consumer worker, and hard working for social justice and a better world. Thumbs up to naps-as-needed, saying “no” to too many commitments or to tasks that don’t sit well with us, standing up for ourselves and knowing when to take a break or utterly spoil ourselves.
8. **THUMBS DOWN** to projects that involve consumers well after much of the foundational thinking has been done. Our insights make foundations so much stronger!
9. **THUMBS DOWN** to ethics committees that make genuinely ethical research by or with consumers so much more difficult than it ought to be!
10. **THUMBS UP** to people who give us feedback on our booklet. We love hearing what’s useful to people, what people want more of, and we also love the lawyers and bureaucrats (and other eagle eyes) picking up details that need tightening and clarification (we really are grateful for this feedback!)
11. **THUMBS UP** to all those committed to sharing resources and not “reinventing the wheel.” Goodness knows we have precious few resources so we put them to best use.
12. **THUMBS UP** to a consumer leadership agenda. “Participation” and “consultation” are no longer enough!
13. **THUMBS DOWN** to tokenism. It’s so rife in this area – how many times have we felt grateful to be included, only to realise down the track that ... yet again, we’re only there tokenistically.
14. **THUMBS UP** to all consumers who work in services and endure seeing and hearing staff doing and saying things that ‘make them sick’ but have found a way to stick in there without losing their own exquisite sensitivity.
15. **THUMBS DOWN** to all the pharmaceutical companies that make a huge amount of money and still make psychiatric drugs with loads of horrible, unwanted effects.
16. **THUMBS UP** to all the survivors! Whether you have survived mental distress, suicide, the psych system or another year, we say that’s fantastic!



## INVITATION

### to meet with the Minister for Mental Health, Mark Butler



Mental health carers and consumers are invited to attend Forums with the Minister for Mental Health and Ageing, the Hon Mark Butler MP. These Forums will be held in 14 locations around the country and present an opportunity to meet Mr Butler and talk about issues related to mental health care and reform in Australia.

Attendance at the initial round of Forums will be on a 'first in' basis which means that your earliest response to this invitation is needed if you wish to go. Further details, including location and an agenda, will be provided to those attending.

To express an interest in attending these Forums, please email the Mental Health Council of Australia (MHCA) at [admin@mhca.org.au](mailto:admin@mhca.org.au) and provide your contact details including your name, contact number, main language and details of any organisation or body you may be representing.

We must receive an expression of interest from anyone interested in attending by no later than **26 November 2010**, although we encourage you to RSVP as soon as possible if you would like to come along. The Forum dates are listed below and will be held for approximately 2½ hours, at or close to the listed locations.

There will be interpreter services available for individuals from culturally and linguistically diverse groups as we hope to attract people from a wide range of backgrounds to attend these Forums.

We look forward to hearing from you soon and you can call the MHCA on (02) 6285 3100 if you have any questions.

***A message from the Minister for Mental Health and Ageing, the Hon Mark Butler MP:***

*As you know, the challenges in mental health are complex and require a coordinated and careful balance of services. We need to look across the age and illness spectrum and plan a connected mental health service for the future that works for all people affected by mental ill health and their carers.*

*Since being Minister for Mental Health I have been meeting with stakeholders to devise a cohesive reform strategy, and this is why I am now travelling around the country to meet with consumers and carers and hear your stories first hand.*

*I hope you're able to come along and share your experiences with me. But if you're not able to attend a forum – please send an email through to [mhwebsite@health.gov.au](mailto:mhwebsite@health.gov.au) or visit [www.mentalhealth.gov.au](http://www.mentalhealth.gov.au) to leave your comments and suggestions.*

*I look forward to talking to you soon.*

*Mark Butler*

**Forum details:**

<b>Adelaide</b> 30 November, 2pm-4:30pm	<b>Brisbane</b> 6 December, 1:30pm-4pm	<b>Hobart</b> 13 December, 2:30pm-5pm
<b>Mandurah</b> 2 December, 9am-11:30am	<b>Canberra</b> 8 December, 1:30pm-4pm	<b>Melbourne</b> 14 December, 9:30am-12pm
<b>Perth</b> 2 December, 1pm-3:30pm	<b>Online with Inspire</b> 8 December, 6:30pm-8pm	<b>Darwin</b> 16 December, 2pm-4:30pm
<b>Sydney</b> 3 December, 9:30am-12pm	<b>Tamworth</b> 9 December, 10am-1pm	<b>Cairns</b> 17 December, 10:30am-1pm
<b>Newcastle</b> 3 December, 2:30pm-5pm	<b>Launceston</b> 13 December, 9am-11:30am	<b>Atherton</b> 17 December, 2:30pm-5pm

