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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES



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We want to hear from people who have used services provided by the Psychiatric Disability Support Sector (PDSS).

We are writing three new booklets. The first two are on clinicians/workers and services. We want to hear from people who have found these services useful and people who have found them less useful. Everyone's experience is important to us. What worked for you and what didn't? If you have anything you think we should know or that people new to the sector should know *please* contact Merinda. You only have to write a little bit or you may prefer to speak on the phone. If you ring us we'll ring you back so you don't have to pay for the phone call. The more information we get the more we can represent the sector fairly and thoughtfully. You can contact us at on: 9320 6839; service@ourcommunity.com.au, or 51 Stanley Street, West Melbourne 3003

If you have used any or several of the following services we'd love to hear from you either about the program itself or about the qualities that make a good worker: Personal Helpers and Mentors Program (PHAMS), Prevention and Recovery Care Services (PARCS), Day Programs and Groups, Respite Care, Residential Rehabilitation, Supported Accommodation, Outreach Programs or Individual Support Packages (ISP).



INTERVIEW OF THE ISSUE –Susie Crooks

Suzie Crooks is a much-loved founding mother of the consumer movement in New Zealand. She is renowned for her straight-talking, gutsy leadership.



Susie Crooks with Roy Brown, organisers of the National Nutters' Conference

Amongst many things she was a prominent organiser of the 2006 inaugural National Nutters' Conference – the first of its kind – marking a milestone in consumer leadership, moving from participation in mental health services to leadership.

Much to the delight of consumers in Melbourne the Nutters' conference made it into the Odd Spot column in the Melbourne Age newspaper.

Flick Grey: How would you describe what consumers/survivors/mad folk are doing at the moment – a broad brush picture – in terms of changing the mental health system or the world.

Susie Crooks: I think the more that you have people with lived experience in leadership positions, the more likely it is that services will be more responsive to the needs of the people that they're serving. So, to put that another way, you really need people with the lived experience of recovery assisting at a leadership level, and policy development and service development, systems change, all the way down to you need to be listening very closely to people who are currently receiving services, and allowing their experience to influence service development. I hope that's not too top-down an answer.

FG: Do you think our political heyday has come and gone?

SC: Certainly, the golden days are well and truly over in New Zealand. We were once world leaders and drivers of innovation and the recovery agenda. We were definitely cutting edge approximately 10 years ago. Since then, there's been a huge retraction from the sector. We no longer have a [consumer] commissioner within our mental health commission, we don't have any people in strategic leadership places, like the ministry or the workforce development centres or any of the offices that influence

funding and planning or service delivery. I think they will inevitably come again, mainly due to the fact that it's just ineffective and uneconomic to allow drug companies and psychiatrists to drive service development. And in this new time of being more aware of getting value for services and having services more effectively meet the needs of the people accessing them, I think we will see a renaissance. Peer support does have an evidence base for being the most effective lever in people's recovery. So I'm a great believer in less meds and more talking therapies, I think that's a very effective and economic way for the health provision to go.

... it's about time we started looking at ways to transform services, so that we don't keep getting more of the same...

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

SC: Definitely reducing stigma and discrimination and challenging attitudes within the media, I think that's an important area. Activism has its place politically in agitating and lobbying for the transformation of services. In New Zealand we've had huge investment, we've increased funding to services by over 100% in the last 15 years but there's been a widespread disappointment that the investment hasn't matched improvements. And it's about time we started looking at ways to transform services, so that we don't keep getting more of the same, but so that we start doing things differently. The third area would be workforce development. I think the workforce mix is wrong, we really need about 80% of the workforce to come from people with diverse backgrounds, including a broad range of life experience, and non-clinical backgrounds. Excellent clinical care and drug therapy is a very small percent of the whole picture contributing to the person's well being.

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

SC: I would expect that everybody would be interested in their mental wellbeing, that there would be

There may be a little bit of envy from chronically normal people... no "them" and "us." There may be a little bit of envy from chronically normal people about the experience of extreme mood swings. People who experience unusual things like visions and hearing voices and seeing colours and such things would be highly sought after as partners and employees and politicians. There would be no fear or shame associated with mental distress.

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

SC: I think my answers would probably be quite similar, although I'd prefer the \$500 million. If I had \$500 million, I would spend about a third on research and development, from the view of the people accessing services. I would possibly spend another third on training and development of a peer workforce and the other third on developing career pathways and transforming systems and services so that the leadership of all services was governed by people who experience madness.

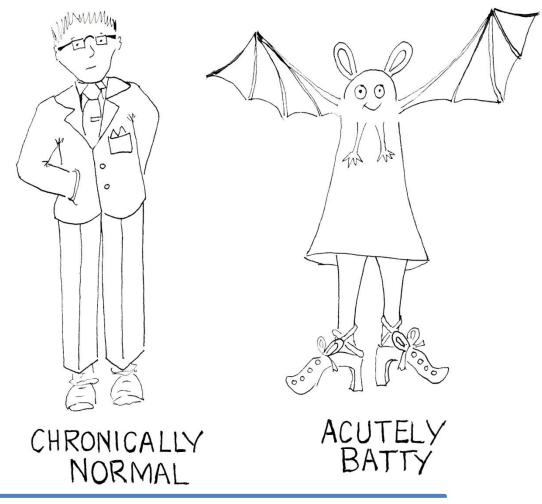
If I had \$10,000, gee whizz. I would probably use the money to pay an organisation that could lobby for the interests of people who experience mental distress and represent them in a sophisticated way to the people that have decision-making power, to release more money. In New Zealand, less than 1% of our mental health budget is invested in peer support or research from the point of view of the people currently using services. It's possibly worse in Australia – I just have this suspicion from my experience at conferences and things. Although you might be gaining ground these days, given that our situation is fairly dire.

I think the key is to have people with diverse experiences and a combination of people who selfidentify that they have experienced madness but also people who have different fields of expertise. But without any investment in peer support, you know, if there's only a few lollies, you'll have people grabbing at those opportunities, just for the sake of gaining employment. It's a complicated scenario of training development, career pathways, as well as providing jobs and opportunities.



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?

SC: Something that could happen in one day would be our Minister of Health declaring that service user workforce development is a top priority for re-engineering the delivery of mental health services and perhaps initiating a review and delivering a strategy for how that's going to be achieved.



FG: And now the final question, what's more important, the outcome or how you get there, and can you give an example?

SC: I think they're both important. Obviously, I'm interested in outcomes. One of the mistakes that the New Zealand consumer movement made was that we challenged the use of force and seclusion therapy and the outcome of that was that the sector very firmly closed its doors on allowing any leadership to be initiated by service users. So, even though the fight might have had merit, the outcome was disastrous. It's possibly the reason we lost our consumer commissioner. But in saying that, there's still an active group currently lobbying and I guess the process of lobbying is far more sophisticated than in the early angry-activist days where we were really sort of knocking at the front door of services. These days the journey, or the process of gaining outcomes is a lot more academic, bureaucratic and more sophisticated and the outcomes that we're getting are generally speaking more hopeful. We've just had a commitment from the Associate Minister of Health here to undertake a review of our workforce development centres to see what needs to happen regarding the service user workforce development strategy. So, it's sort of more boring, but the outcomes are potentially much greater in challenging the status quo. I think we might be going through the back door more these days.

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INTRODUCING ... THE TILED PATH (A CREATIVE PIECE)

In this edition, we introduce the creative work of Lynnie Worth. Introducing herself, Lynnie writes: 'I am compelled to write sometimes - hah! I don't have much choice when that happens. ... The Tiled Path I wrote to cheer and encourage someone who was struggling bitterly with the pieces of her life, and feeling very 'grey and dirty' and I wanted her to see how broken and damaged things have a peculiar beauty of their own, sometimes - which she did. And she showed her therapist also, who asked my permission to use the story for her other clients, with I was glad to give.

I have no specific project, no web page - I am living with mental illness and physical disability, I am just me - and somehow, sometimes, I am compelled to reach out into nowhere, and throw words - cast a line into World, baited with words - sometimes I send out pictures also ...'

The Tiled Path

There was once an artist that made the most beautiful pots - wonderful shapes, amazing vivid colours - and she created a pot one day that was the most wonderful pot ever, in shape, size, colour, it was tremblingly beautiful. She never sold it; she kept it out on her table so that its beauty could always be there for her and her visitors.

One day an angry nasty person came to her house, shouting and yelling and abusive; and beat her badly, broke her kiln, and smashed her beautiful pot to pieces.

She gathered up the pieces of the pot, wrapped them in an old cloth, and retired inside herself. She healed on the outside but not on the inside. She was afraid to go out, and she saw only death and decay where once she had seen love and beauty.

Her friends repaired her kiln, but she would not use it. She ate and drank, but did not taste. She sat in the sun among beauty and peace and knew no peace, saw no beauty. She stayed like this for a long time, living like the palest shadow of herself.

One day a friend came with a small child and the child unwrapped the pieces of the broken pot, and set them out in a pattern on the soft sandy path. The artist saw the little one sit back with awe, and smile with such loving joy at the picture she had made from the pieces. The artist could not help it, and suddenly she went and sat beside the child, and saw that the pot though broken, was still most beautiful. She woke from her torment, and began to look around her. Her life was still there, though very changed by the attack on her. All her things were still there, her paints and glazes, the good big blocks of clay, the fine tools for carving patterns, and her heart started to sing again - she began to live again, to see beauty again, and tentatively, to make pots again. She was still very fearful until one day she made a set of tiles out of the broken pieces of pot, and tiled her sandy path with such grace and beauty that all who saw it were amazed.

She made much more art in her life before she passed away into *that* night, but none so amazing and complex and brilliant as the tiled path made from the shards of her broken masterpiece. She used to say that she had been given the most gracious gift of all time - the ability to use her broken pot to make a lovely path that pleased everyone. But of course what she knew was that she already had the help, and the tools, with which to mend her broken heart. It took the child's joy in her colours to awaken her to use what she had to build her life again.

Having the tools, and being shown the way, is indeed a gift. But the using of them to build with; is a very precious grace from within ourselves.



CONSUMERS AND 'CARERS' SHOULD NOT BE JOINED AT THE HIP – IT CAUSES HIP DYSPLASIA – by Merinda Epstein

One of the things that really bugs me is when the interests of consumers and the interests of 'carers' get arbitrarily joined at the hip. In saying this I am fully aware that:

- there is give and take on both sides and the two groups *can* work together to increase the voice of lived experience;
- there may well be issues where some 'carers' and some consumers have a strong combined stand and another group of consumers and 'carers' have a differing point of view;
- there are some consumers and 'carers' who truly believe this is a non-issue either because they have worked things out together or because, considering every other fight we are up against, they don't prioritise this one.

However, I think that there are important issues that supersede any of these considerations. The considerations below are fundamental. I get really angry when they are not even considered worth thinking about by those who would mix up the different voices. They are:

1. Simplistic models of understanding family dynamics in relation to 'mental illness'

This is a real example of a friend of mine (with her permission). I hope it will illustrate why I hate the stereotype of a perfectly normal family with one recalcitrant 'mentally ill' outrigger.

My friend comes from a family of 7. His father, a very successful lawyer, lived with '*Bipolar Affective Disorder*' for most of his adult life. It was a secret well kept by his family – his standing in the legal fraternity depended on it. After the death of my friend's younger sister from cancer, his mother (a generous and lovely lady whom many of us have adopted) became increasingly disabled by severe '*Obsessive Compulsive Disorder*.' My friend's older sister, just 18 months older than him, became depressed at 16 holding her Mothers' situation as something she couldn't cope with. This sister struggled on for another ten years in total despair before killing herself. During his sister's tussle with 'Depression' my friend's father's Bipolar took a dive for the worse and he too became distressed and suicidal. My friend was first diagnosed with '*Bulimia' at 19 and* then all sorts of '*Personality Disorders*' and only relatively recently with '*Bipolar Affective Disorder*.' His younger sister also has a diagnosis of '*Bipolar Affective Disorder*.' There is one brother who appears to be relatively stable but the youngest child in the family grew up with undiagnosed autism – a situation which baffled the whole family. (Some of the details have been changed to de-identify the family)

So, who is the 'carer'? Who is the person with a 'psychiatric illness'? Everyone seems to be both a 'carer' and a 'consumer' and just about everyone is in this situation. However, power, professional standing, social class, gender and age all play significant roles in determining who gets the status of the 'carer' and also who gets the 'sick role.' It's a social and economic construction. Consumers know that this is common and yet time after time after time we fail to see this truthful representation of the interconnectedness of so-called 'illness' and so called 'caring for' relationships acknowledged.

2. Consumers are often 'carers' also!

I don't think I actually know any consumer who has not intimately cared for another consumer. It is a community of shared caring and this is often totally forgotten. As consumers we understand that the job of people who 'care for us' can be incredibly hard but we do our share of it as well, particularly those of us who are linked into the consumer movement.

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3. Different Discourses: Different amounts of power

The 'carer' messages to mental health professionals, the media, other 'carers,' bureaucrats and their friends and neighbours are extremely important. Many speak with an extraordinary degree of insight into the lot of 'carers' and this voice is unique and worthy of privilege, especially because they do not have the same speaking power as mental health professionals.

Nonetheless, this is a very different voice from people who choose to speak from firsthand knowledge of being diagnosed with 'mental illness'. Although many of us are both 'carers' and consumers there is no doubt that choosing to speak from one's experiences as a consumer is more difficult because it is yet another step less powerful. The consumer body of knowledge is very different from the 'carer' body of knowledge. These differences should not be blurred for exactly the same reasons the 'carer body of knowledge' and the 'professional body of knowledge' should not be blurred. They are different in substance and socio/cultural authority.

4. What society does to 'carers' (it's not all their fault)

Although I get extremely angry when 'carers' choose to speak on our behalf it is tempered when I think about what society expects of 'carers.' Many 'carers' get a message from the community that their role as 'carers' is only to 'care for us' and not for themselves. This is harsh. It pushes many into believing they **must** 'speak for us.' This causes all sorts of problems because many of us would prefer



them to talk about what they know best – their own experiences including feelings of being blamed, silenced and misunderstood.

5. Lack of experiential breadth amongst politically active 'carers'

My experience of the 'carer movement' is that it tends to be very narrow. By far the largest number of active 'carers,' loudest 'carers' and 'carers' in positions of authority tend to be parents of adult children with psychotic illness. This warps the process of representation enormously. Other groups often don't get a look in.

6. Medicalisation of the debate

Many 'carers' involved with 'carer politics' are comfortable with a 'medical model' understanding of 'mental illness.' I know that some consumers are too, but not to the extent of the 'carer lobby.' Indeed as we get more and more experienced as advocates, many of us become less convinced by the 'medical model understanding' of our lives and our circumstances.

Conclusion: five pet gripes

- (a) I hate the term '*consumers and their carers.*' It really bugs me to continually read information that is about ownership. Nobody owns us and we are certainly not granted the social power or standing to own the 'carers' in our lives.
- (b) I hate the way the term '*perception*' is used so liberally in the literature. Consumers are deemed to 'perceive' things whilst other groups are deemed to 'know' things.
- (c) The term 'stakeholders' is also problematic. It suggests that all the different groups (including 'carers') have an equal interest in *our* mental health. This is nonsense. As many consumers say;
 "I am more than a stakeholder in my own life."
- (d) When the groups are combined *consumers should come first*, ie. consumers and 'carers' (not 'carers' and consumers). This is precisely because we are not just 'stakeholders,' a point made clearly by the Australian sociologist Yoland Wadsworth in her book, *Do it Yourself Social Research*.* She uses the term, the 'Critical Reference Group' to describe the centrality of our position.
- (e) Sometimes the 'family' lobbyists talk about 'the family and the person with 'mental illness.' What!? Since when was that person not a real member of 'the family.' Says it all, I think.

* Yoland Wadsworth, Do It Yourself Social Research 1997, Allen & Unwin, Sydney

HEY YOU! (yes you!)

Have you got something to say about PEER WORKERS?

This is a call out for writers (or artists, cartoonists, networkers, etc, we're grateful for all your contributions) for a newsletter edition specifically devoted to the topic of **peer workers**. Let us know what kind of contribution you have in mind – we're interested in soap-box style rants, snippets of trivia, engaging descriptions of consumer-run projects/groups, jokes, deep thinking through important issues, cartoons, etc. ... Just get in touch ok! (And keep sending in contributions on other topics too.)

Due date for submissions for Peer Worker special newsletter edition: September 15th, 2010

INTRODUCING ... SOME PICTURE BOOKS ABOUT LIVING WITH MENTAL ILLNESS

This list of picture/illustrated books about living with mental illness has been compiled by Ann Tullgren, who has also compiled lists of anthologies, personal accounts and novels about living with 'mental illness.' These lists are a great resource and will all be available on our website soon. If you have comments or suggestions, please send them to Ann at: <u>hatpinhouse@internode.on.net</u>

 'I think cartoons are especially useful for showing feelings and telling very short but important stories. It is as though the simple lines of the drawing let us look directly at emotions and help us understand, quickly and simply, what is happening.
 Cartoons keep us safe as we journey through parts of human experience which sometimes seem too painful to contemplate.'

-Neil Phillips (psychiatrist and author) in the preface to *Too Blue*

Matthew Johnstone, 2005 I had a black dog. His name was depression. Pan Macmillan, Sydney.

Matthew and Ainsley Johnstone, 2008 Living with a black dog. How to take care of someone with depression while looking after yourself. Pan Macmillan, Sydney.

Nathaniel Lachenmeyer, 2003 Broken Beaks. Michelle Anderson Publishing, Melbourne.

Neil Phillips, 1999 Too Blue. A book about depression. Shrink-Rap Press, Sydney

Neil Phillips, 2010 Lost in a Mine Field: Schizophrenia and other psychoses. Shrink-Rap Press, Sydney.

Tohby Riddle, 2000 The singing hat. Puffin, Victoria.

*Shaun Tan, 2000 The Red Tree. Lothian, Sydney.

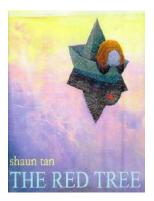
Colin Thompson, 2004 The Violin Man. Hodder, Sydney

Colin Thompson, 2008 The Big Little Book of Happy Sadness. Random House, Sydney.

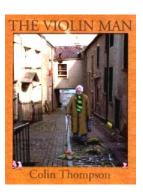
Colin Thompson, 2009 Free to a Good Home. Random House, Sydney

Colin Thompson and Amy Lissiat, 2005 The short and incredibly happy life of Riley. Lothian, Sydney.

Colin Thompson and Amy Lissert, 2006 Norman and Brenda. Lothian Books, Melbourne







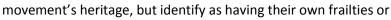
*Gratuitous editorial note: this is Flick's favourite book in the whole world. Highly recommended!

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THUMBS UP/THUMBS DOWN

1. **Thumbs up** to those who stand outside the consumer



sensitivities of mind, expressed in a different way - they are our friends and allies.

2. **Thumbs down** to those who would judge us without searching their own minds to find out what is in there to explore.

3. **Thumbs up** to those who came before us in fighting for our freedom as people diagnosed with 'mental illness.'

4. **Thumbs down** to the lack of recording of our collective history. Consumers have much to be proud of in our collective histories, and much collective wisdom awaits our unearthing.

5. **Thumbs up** to people who have been diagnosed with 'mental illness' who see themselves as fighters for a more just and equitable world for everyone.

6. **Thumbs down** to the logic that divides us and creates hierarchies, through statements like "*we*'re not criminals" or "*we*'re not crazy" or "*we*'re not disabled." Such statements so often imply that someone else deserves to be treated poorly, but *we* don't!

7. Thumbs up for the trees and the grounds in the old asylums.

8. Thumbs down for most of everything else in these horrible places.

9. **Thumbs up** to technology, which has brought together consumers who would otherwise be disconnected (due to distance, limited money, difficulty finding each other otherwise, social withdrawal, etc). Many of us draw much needed nourishment from these virtual communities.

10. **Thumbs down** to technology-induced stress! What a mixed blessing technology is! Sometimes it feels like technology *causes* a great deal of psych distress!! Maybe your inbox has 100s of (guilt-inducing) old emails, or your computer gets some bug and does random irritating things, or you drop your mobile phone or lose all your numbers, or you can't afford to call mobiles and that's all some people seem to have these days ...Or you come home and have to check email, check facebook, check home phone, check mobile, then check the letter box, ... aaargh ... can't keep up with it all!

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

We have been incredibly productive recently, perhaps because Flick was overseas so Merinda could get some work done! As always, we have consumers and groups contacting us for various forms of support, most of which we are able to offer. We try as much as possible to think systemically and to prioritise, support and develop sustainable projects. At the moment, we are particularly excited about a project on consumer history, which you will hear more about in the coming months!

We've been developing our training program, including Intentional Peer Support training (we now have a date for an introductory session, see next page), consumers volunteering, and an introduction to what advocacy is about. There are others in the planning stage.

We've printed our first booklet "So, you have a 'Mental Illness'? ... What next?" and are preparing for its launch – how exciting! It really is quite a wonderful resource, collectively produced. It is free and will be distributed far and wide once it is officially launched. We are writing three new booklets- the first two are on clinicians/workers and services, the third on consumers changing the world. These are all well under way and will be coming out in the foreseeable future (so put that in your diaries)!



OUR CONSUMER PLACE UPDATE (continued from previous page)

Flick enjoyed a whirlwind two-and-a-half week trip to America, visiting various consumer-run initiatives and consumer leaders. Relevant highlights include:

• Presented my research at the *Society for Disability Studies* conference, an intellectual/creative/ activist community producing extraordinary critical work on disability (including psych. disability). And I got to chat, network and dance with some fabulous consumers and other disabled thinkers.

• **Icarus Project** (New York). Great support/activist group that endeavours to "navigate the space between brilliance and madness." They loaded me up with resources and inspiration.

• **Freedom Centre** (Massachusetts). Peer-run activities, support and activism. Because they don't have a physical space and I was time-pressured, we made electronic contact, but impressed so far.

• **Recovery Learning Centres** (Massachusetts). Peer-run drop-in centres offering an array of groups. I met some truly inspired peer workers and got some ideas for navigating difficult group conversations.

• **Mad mentors** (upstate New York and New Hampshire), I spent a few days enjoying the hospitality of some of my favourite mad mentors (Tina Minkowitz, Chris Hansen and Shery Mead) and had some truly mind-altering conversations. I feel enormous gratitude for this time!

• **Esmin Green vigil** (New York, organised by 'We the People'), protesting/commemorating the deathby-neglect of Esmin Green, at King's County Hospital psych. ward 2 years ago. This was a powerful gathering of psych activists. My fondest memory was someone (unsuccessfully) encouraging us all to chant "Deconstruct the myth of mental illness," but the conversations that emerged were just great!

WHEN	EVENT	ABOUT/DETAILS
Fri 30 th July	First consumer* think-tank	Come share thoughts, inspiration and cups of tea. Feel free to just listen. 5-7pm Errol's Cafe, 69 Errol St, North Melbourne. Look for the batty people (really, there will be some bats, so you know who we are)
Tues 14 th Sept.	Consumer Forum The Mental Health Services (TheMHS) conference, Sydney	Nothing to do with us, really, but a great chance to network with other consumers. And we'll be there, so isn't that a good reason to come?
Wed 15- Fri 17 th Sept.	The Mental Health Services (TheMHS) conference, Sydney	 Merinda and Flick are presenting a 1-hour introduction to <i>Intentional Peer Support.</i> Merinda is presenting a paper called: "The power of language: coopting the consumer imagination" Flick is presenting a paper called "Can the Consumer Speak?" about systemic issues that prevent consumers being heard.
Thurs 14 th October	One-day conference on Consumers and Leadership	This is currently being organised by us, Our Consumer Place. If you have any thoughts about issues you'd like to see covered at this conference, let us know asap! We want to make it as relevant as possible.

SAVE THE DATE!:

*Wide welcome - so if the term "consumer" doesn't resonate for you, come anyway! But please, only attend if you are coming from your own experience, not some other form of expertise. So, if you are a 'carer' or a worker, or for whatever reason you are "not a consumer," please come as a human being, with your own history and emotional life (not that you necessarily have to share these!), rather than wearing any other hat. Yoland Wadsworth calls us "the group who are united by being attracted to creating the movement of people who have not yet got a name." Hopefully, you know who you are!

