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Deep Insight:

Leaders in the international mental health consumer/survivor movement share their thinking



“Non-violently overthrow the mental health system and have a nice day.”



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consumer/survivor movement share their thinking

This is the third in a series of publications written by and for mental health consumers by Our Consumer Place, a groundbreaking mental health resource centre run by people with a diagnosis of 'mental illness' (consumers). Our Consumer Place (www.ourconsumerplace.com.au) is funded by the Department of Health (Government of Victoria) and auspiced by Our Community (www.ourcommunity.com.au).

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Deep Insight: Leaders in the international mental health consumer/survivor movement share their thinking

(Our Consumer Place Resource Centre Booklet Three)

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Cartoons by Merinda Epstein (www.takver.com/epstein/)

Foreword

This booklet forms part of a series of consumer-developed publications produced by Our Consumer Place (www.ourconsumerplace.com.au), a groundbreaking mental health resource centre run by people who have been diagnosed with 'mental illness' (we call ourselves 'consumers').

Funded by the Department of Health (Government of Victoria) and auspiced by Our Community, Our Consumer Place offers information and advice on consumer perspective and consumer leadership for individual consumers, groups of consumers and anyone else who is supportive of this orientation.

Most of the available information on mental health has been written by other sorts of 'experts' – mental health professionals, mental health charities, or researchers who are not consumers. Our booklets are different – they are written by people who have been labelled with 'mental illness,' based on our knowledge, and drawn from our lived experiences.

The interviews in this booklet are all drawn from the Our Consumer Place newsletter. This is a free publication sent regularly by email to all members of Our Consumer Place. To find out more, or to sign up, go to www.ourconsumerplace.com.au

We were honoured to have as our first ever interview subject Shery Mead, who is internationally renowned for developing Intentional Peer Support, a model of mental health support that is trauma-informed and grounded in a profound respect for lived experience. Shery provided the perfect beginning to a fascinating (and continuing) series of interviews with high-profile, inspirational and thoughtful leaders in the international consumer/survivor community.

These leaders have different priorities and emphases and don't always agree with each other – this diversity contributes to a robust dialogue that is continuing.

We thank all of them for sharing their wisdom with us, and for allowing us to share it with you.

A note on language

Throughout this booklet, you will read words like 'consumer,' 'service user,' 'people with lived experience' and 'survivor' – all of these terms refer to people with a lived experience of being labelled as having 'mental illness'. No word is perfect, not all of us know instantly (and identically) what a certain word means, not all of us will identify with the same term and lots of us dislike certain words! Our Consumer Place tends to use the word 'consumer', which is common in Australia, while terms like 'survivor' and 'service user' are more common internationally. Each interviewee in this booklet uses the term that they prefer. There are more thoughts about this issue on our website (www.ourconsumerplace.com.au).

In this booklet we put many words (e.g. 'mental illness') into inverted commas. People tend to use these words because they are commonly understood in the mental health field, but by putting them in inverted commas we are acknowledging that not everyone agrees with their use – these terms are contested. For example, the idea of 'mental illness' is not something that all consumers identify with – many reject it, often with sophisticated intellectual, political or spiritual critiques of this concept. Others find the term profoundly useful. Again, there is more discussion about this topic on our website.



Dedication & Acknowledgements

This series of booklets is dedicated to all people whose lives have been cut short or diminished by 'mental illness', and/or their experience of community prejudice and trauma.

Booklet #3, Deep Insight, is dedicated to the memory of Judi Chamberlin who died in 2010. Judi has been described by many as "the mother" of the consumer/survivor movement. Her 1978 book, *On Our Own: Patient-Controlled Alternatives to the Mental Health System*, was groundbreaking in its day and is still invaluable for its formidable critique of the mental health system and compelling articulation of the value (and values) of peer-led alternatives.

Thanks also to the Department of Health (Government of Victoria) and Our Community for providing the funding and the support that allows Our Consumer Place to exist.

Flick Grey & Merinda Epstein

Our Consumer Place

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Contents

- 5 Foreword**
- 8 Peter Beresford:** “Without involvement being central to the process”
- 11 Sylvia Caras:** “... we need to stop presenting ourselves as victims...”
- 14 Oryx Cohen:** “... when more sensitive people are freaking out ...”
- 17 Ron Coleman:** “The ideas around ‘empowerment’ came from the consumer movement ...”
- 20 Susie Crooks:** “There may be a little bit of envy from chronically normal people ...”
- 24 Chris Hansen:** “... we want to damn well own this table!”
- 29 Shery Mead:** “... genuine, positive alternatives, things that do work.”
- 32 Tina Minkowitz:** “If somebody was locked up ...”
- 37 Mary O’Hagan:** “...part of the cluster or continuum of human experience ...”
- 40 David W. Oaks:** “Non-violently overthrow the mental health system and have a nice day.”
- 44 Steven Onken:** “You need those people out in the extremes raising hell. ...”



Peter Beresford

“Without involvement being central to the process, the outcome won’t be right. Workers can come in and do tasks and tick all the boxes they like but without warmth, empathy, respect and equality, little will be achieved.”

Peter Beresford is Professor of Social Policy and Director of the Centre for Citizen Participation at London’s Brunel University. He is a long-term user of mental health services, is active in psychiatric system survivor organisations, and is Chair of Shaping Our Lives, the UK independent national service user-controlled organisation and network. Peter has a long-standing involvement in issues of participation and empowerment as an activist, educator, writer and researcher. He is a Trustee of the National Skills Academy in England, which works to develop all forms and levels of leadership in social care, and is author of ‘Being A Mental Health Service User’ (2010, PCCS Books).



Our Consumer Place: Has the heyday of progress in consumer participation and initiatives come and gone?

Peter Beresford: Definitely not, but it is always under attack and threat and in the UK I think this is getting worse. Strong efforts are made to reduce it to individualised consumerism and ignore its democratising and empowering impulse. Its future will be down to us as survivors and that is a big responsibility.

Our Consumer Place: Is there a place for activism in mental health? What areas would you target?

Peter Beresford: Of course, it is crucial, even more so I think as mental health service users/survivors have been targeted more as ‘welfare scroungers’ and increasingly negatively

stereotyped. I'd highlight:

1. Building links with the broader disabled people's movement.
2. Focusing on inclusion and addressing diversity in every sense, pushing for our non-medicalised, socially based understandings, and working for quality measures that are based on these and user defined.
3. It's crucial also to have in place a securely and adequately funded and resourced network of local service user-controlled organisations.
4. Developing new and effective forms of direct action.

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

Peter Beresford: It would be a lot more fun! There would be a lot less internalised oppression. It would be a lot less divisive. There would be a lot less conflict. Our contribution would make a real and positive difference.

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

Our Consumer Place: If you were asked to give government advice on how to spend \$500 million or \$10,000 for mental health, what would you advise them to spend the money on?

Peter Beresford: It would be no better me being in charge of the money than anyone else. I have seen what happens when large sums are made available without an infrastructure of involvement in place to put it to good use. So the key thing is to get a group of survivors with such experience together to set up an inclusive process of involvement to work out how best to use that money. It would be a one-off chance: We must do it right, ethically and practically.

If there was a small one-off sum, then I would try, through a transparent and fair process, to let survivors and survivors' organisations know about it so they could bid for a good idea to be taken forward and this would be decided by a group of survivors whom people would have confidence in.

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

One thing would be to know that the organisation I am part of – **Shaping Our Lives** – had secure funding for the future and was really sustainable with lots of good new people coming through to take it forward.

Number two would be that there would be a network of service user-controlled organisations in place with adequate and secure funding.

The other thing, for me personally, as I am someone who doesn't sleep well, would be a really nice relaxing day – including some time in tea and coffee shops. That would help me personally get a better night's sleep.

Our Consumer Place: Which is more important to you: the outcome or how you get there?

Peter Beresford: You just can't separate the two. Without involvement being central to the process, the outcome won't be right. Workers can come in and do tasks and tick all the boxes they like but without warmth, empathy, respect and equality, little will be achieved.

This interview appeared in the March 2009 edition of the Our Consumer Place newsletter.

Sylvia Caras

“We must reclaim the vocabulary, we need to stop presenting ourselves as victims, and we need to stop allowing families and systems and drug companies to use sympathy to generate funds.”

Sylvia Caras was an early adopter of social networking via email for ‘People Who experience mood swings, fear, voices and visions’. She now maintains the IRIS announcement list (www.peoplewho.org/iris). Sylvia is especially interested in the wide distribution of health and human rights information. She has served on several global and United States boards and committees. She cares about significant inclusion of people with disabilities at every phase, in all matters that affect them, and mindful attention to language that is respectful, graceful, and affirmative.



Our Consumer Place: Has the heyday of progress in consumer participation and initiatives come and gone?

Sylvia Caras: The language has changed. The funding streams have changed.

I think the focus could shift from carve-out to a seamless healthcare system. Carve-out is about separate mental health funding, people talking about mental and physical health as separate entities, mental health services delivered in separate buildings, drop-ins, etc. Carve-in is where there is one door – a community service with one seamless funding stream and no separation of physical health and mental health. Specialists may be called on later if necessary.

I think we should be arguing for transparency and inclusion. Illness and disease take us down a fenced road. Wellness is better as a conceptual starting point.

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

Our Consumer Place: What would transparency and inclusion look like?

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

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

Sylvia Caras: We must reclaim the vocabulary, we need to stop presenting ourselves as victims, and we need to stop allowing families and systems and drug companies to use sympathy to generate funds.

Our Consumer Place: Why do you think language is so important?

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

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

So words matter.

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

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

Sylvia Caras: We'd target some other group for exclusion – elders, people with AIDS, Hispanics, lepers – someone always seems to be at the bottom. In Australia it would be indigenous people I'd guess.

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

Our Consumer Place: If you were asked to give government advice on how to spend \$500 million or \$10,000 for mental health, what would you advise them to spend the money on?

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

This interview appeared in the December 2008 edition of the Our Consumer Place newsletter.



Oryx Cohen

“A lot of times, when more sensitive people are freaking out, it’s telling us something about the whole society, that something is wrong with the whole society - in terms of the environment, or what we’re doing to each other, the wars we’re fighting, the problems in our families and in our communities.”

Oryx Cohen MPA is the Technical Assistance Centre Director at the National Empowerment Centre (US). He has helped to spearhead innovative, peer-run approaches focusing on recovery, healing, and community. He’s also the co-founder of Freedom Centre, an independent peer-run support/activist organisation that works to empower and support people with psychiatric



labels while challenging oppressive mental health policies and practices. Oryx serves on several regional, national and international boards and committees, including the International Network Toward Alternatives for Recovery (INTAR). For many years Oryx volunteered with MindFreedom International, directing its Oral History Project, which collected and documented consumer/survivor/ex-patient stories of abuse, empowerment and healing in the mental health system. Oryx is now featured in a book by Gail Hornstein called ‘Agnes’s Jacket: A Psychologist’s Search for the Meanings of Madness’ in which he and colleague Will Hall are compared to the founders of Alcoholics Anonymous.

Our Consumer Place: How would you describe what consumers/survivors/mad folk (or whatever language you use) are doing at the moment in terms of changing the mental health system or the world?

Oryx Cohen: I think that the biggest thing that we are doing right now is we’re getting more active in terms of presenting an alternative view of extreme emotional states – trauma, madness, etc. We’re doing a better job of getting that out into the mainstream media and creating our own media as well.

There are more and more people who are having these views, who are questioning the establishment, questioning Big Pharma. There are more and more people all around the world who are thinking similarly, who are doing similar work and so it's just a matter of time until these ideas really catch on in the mainstream. It still hasn't happened yet.

That's my simple answer to a complex question.

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

Oryx Cohen: I think that activism has a really important place in the movement, and I think that independent activist groups are really important because peer-run or survivor-run organisations that are funded by the government have a real danger of getting co-opted. Even if they are not co-opted they still cannot do the kind of activism that independent groups can do.

The top three areas? Number one would be to protest against the mainstream mental health system for buying into the medical model that doesn't work – the 'broken brain' theory. Number two: I'd like to see a moratorium on the term 'mental illness' – a campaign to strike that term, to stop using that term! Number three would be a protest against Big Pharma.

Our Consumer Place: Can you elaborate on that term "Big Pharma"? We mainly hear that term from activists in the US.

Oryx Cohen: It refers to the big pharmaceutical companies – the companies that make all the medications, psychiatric drugs. In the United States, they are the most profitable industry, in terms of net profits. They have more lobbyists on Capitol Hill than we have members of the House of Representatives, they control the Federal Drug Administration, they fund all the research that is done on psychiatric drugs and other drugs.

There's really no independent watchdog. The pharmaceutical companies have spun completely out of control. Now they have direct advertising on TV all the time, which is completely illegal in every country except the United States. It's very bad news.

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

Oryx Cohen: Well, we'd be a much better society because we wouldn't suppress those states, we could learn from what's going on! A lot of times, when more sensitive people are freaking out, it's telling us something about the whole society, that something is wrong with the whole society – in terms of the environment, or what we're doing to each other, the wars we're fighting, the problems in our families and in our communities. I think we would be a much healthier society if we were more enquiring and just accepted altered states and tried to learn from them, instead of trying to suppress them. I think we would be much better off.

Our Consumer Place: If you were asked to give the government advice on how to spend \$500 million or \$10,000 for mental health, what would you advise them to spend the money on?

Oryx Cohen: Actually, my answer is about the same for them both. \$500 million I would put into community – true community – mental health, by which I mean building community from the ground up, and that having to be led by people with lived experience. And what could that



look like with \$500 million? There could be peer-run respite, safe houses for people to go and detox from medication or get through a crisis, community centres where people could go throughout the day with all sorts of things to do like yoga, acupuncture, support groups, exercise. These community centres would be open to everyone, to members of the public, they would be integrated, and they would fight stigma that way. You know, you could open up bakeries, clubs ... the sky's the limit with what we could do with \$500 million!

As far as \$10,000, well you could create a Freedom Centre for \$10,000! The Freedom Centre doesn't have any money, but they have done a lot of great stuff for almost 10 years now.

Our Consumer Place: Tell us more about the Freedom Centre.

Oryx Cohen: The Freedom Centre was started by people with lived experience who rejected the mainstream mental health system and decided to start something of our own. I was a co-founder. We went from being a little group that met once a week to become a group that has hundreds of people who are involved in the local area, and even more who have been involved online.

Locally, we have weekly support groups, weekly acupuncture for the community, yoga, a radio show that is syndicated nationally. Lots of people have healed through the Freedom Centre – and it doesn't cost that much money to create any of this.

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

Oryx Cohen: If one person makes a huge change in their life, that's really inspiring – and we see that a lot!

If I woke up tomorrow and the government decided to regulate pharmaceutical companies and had them stop lying to the public, that would also make me feel a lot better!

Our Consumer Place: What's more important: the outcome, or how you get there?

Oryx Cohen: I think it's all about the process, how you get there. I think you can make positive changes in your own life, and positive changes in your community, and that will have a ripple effect; but if you go about things the wrong way, then that's no good for anybody!

An example would be the way leaders like Gandhi and Nelson Mandela went about things – a peaceful, non-violent revolution is what we need!

This interview appeared in the October 2010 edition of the Our Consumer Place newsletter.



Ron Coleman

“The ideas around ‘empowerment’ came from the consumer movement, the ideas around ‘partnership’ came from the consumer movement, and now a lot of the ideas about ‘recovery’ are coming come from the consumer movement.”

Scotland-based Ron Coleman is a mental health trainer and consultant specialising in recovery and psychosis. Following his role as national co-ordinator of the ‘Hearing Voices Network,’ he used his experiences of recovery to design workbooks and training packages to enable voice hearers to gain ascendancy over the negative aspects of the voice hearing experience. Ron’s own route to recovery, after spending 13 years in and out of the psychiatric system, has given him many insights into the numerous difficult issues facing today’s mental health services. Ron is the author of ‘Recovery - An Alien Concept?’ and ‘Politics of the Madhouse’. He also co-authored ‘Working With Voices’ and ‘Working To Recovery’.



Our Consumer Place: How would you describe what consumers are doing right now in our work to change systems and/or the world? Do you think our political heyday has come and gone?

Ron Coleman: I think there are different levels at which we are changing things. It is a broad movement. A good example is that the ideas around ‘empowerment’ came from the consumer movement, the ideas around ‘partnership’ came from the consumer movement, and now a lot of the ideas about ‘recovery’ are coming come from the consumer movement.

I think what happens, though, is that after a while that’s all colonised by traditional and academic thinking, in a way that makes it totally acceptable to a broader medical model. But that’s never stopped the consumer movement and consumer individuals having an impact on the system. So now you begin to see consumers talk about ‘thriving’ or ‘wellbeing’, pushing



beyond 'recovery', pushing that boundary again. Clearly, any space, any discourse, has to be felt and the people that feel it at the beginning are the consumers, with academics and professionals coming along later on.

We're always pushing the agenda – we're not in total control of the agenda, but we tend to push and expand the boundaries of the agenda. An interesting question to ask would be: where would we be now without the consumer movement? If we didn't have any activists, I think we might just all be stuck in some kind of medical bubble, without any other discourse, for example, about the role of trauma.

And it's not all just consumers on their own, there are some great allies – there's John Reed from New Zealand, Michael White from Australia (in terms of his narrative work), Marius Romme in Europe, and a whole host of others who are allies, who are professionals who are more in step with consumers than with their own professions.

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

Ron Coleman: I think activism is absolutely essential. The areas we need to really target are the use of compulsion, where people are detained or forcibly treated; the relationship between the pharmaceutical industry and the medics; and also the need to grow peer support workers, who can take the lead within recovery-oriented services.

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

Ron Coleman: I dream of the day when I can walk down the street and talk to my voices and no one would take a blind bit of notice. People would just find that totally acceptable; they wouldn't feel alarmed by it or threatened by it, they would understand I was in a dialogue. I would see that as one of the most amazing things that would show, if you like, a healthy society, in terms of mental wellbeing.

Our Consumer Place: If you were asked to give the government advice on how to spend \$500 million or \$10,000 for mental health, what would you advise them to spend the money on?

Ron Coleman: If I had \$500 million I would say, "Don't spend it on hospitals and beds, or doctors!" I would argue that we should spend it on much clearer structures, recovery units, crisis houses, peer workers, and a whole host of things that would normalise the experience.

If I had \$10,000, I'd probably spend it on one of the self-help networks, like the Hearing Voices Network or some other self-help group, because they could create impact with \$10,000 in a way that I don't think any of our 'normal' organisations could.

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

Ron Coleman: I guess one thing that does that for me is when I've been doing training and one fellow comes up to me and says, "I've got it!" – they've had their own light bulb moment where they actually get what we're talking about in terms of recovery or working with voices. You go away feeling confident that that person's going to make the changes needed in their



practice to become a brilliant worker.

Or when a consumer comes up and says, "Look, I don't need you anymore, I know what I've got to do now and I'm going to do it. Thank you very much, but goodbye!" That gives me a real buzz. I think those are the great moments in your life!

Our Consumer Place: Which is more important to you: the outcome, or how you get there?

For me, it's often outcome. I remember I was working with this guy who was hearing voices and we couldn't find any rationale for these voices. When we asked him why he heard voices he said he was telepathic. Of course, in mental health services, telepathy is seen as a maladaptive, delusional framework which we shouldn't encourage.

But the way I work, you can't do that – you can't just turn around and say, "Well, that's just maladaptive and delusional." So I started reading up on telepathy – I thought it was a load of rubbish, but I read a book called *Psychic Self-Defence*, and, as it happened, it didn't make sense to me. I gave it to the guy and he said it was brilliant. I asked him, "What does that mean?" and he said, "Well, it tells me how to deal with this." And I said, "How do you deal with it?" He said to me, "I need to build a psychic wall around myself." I said, "OK, how are you going to do that?" He said, "With my third eye."

I thought, "Oh my God, I'm in trouble here. I have to go to this review meeting and his psychiatrist is going to say to me, 'Well, Ron, what are you doing with him?' And I'm going to have to say, 'Well ... we're building psychic walls with his third eye'." I thought, "I'm going to be in trouble."

But we did it and it worked for him! So, he was able to walk down the road and the voices would bounce off this wall he had created, the psychic wall.

I went to the review meeting, and the doctor said to me, "Well, what are you doing with him?" And I said, "Well, doc, we are exploring different forms of thought-blocking, using visualisation" – I used that as an explanation. What I did was translate the language! I thought the outcome totally justified breaching this idea that we shouldn't enter into a person's belief system – which is one of the common fallacies in mental health. I do find myself often having to break rules in order to achieve 'good outcomes'.

This interview appeared in the August 2010 edition of the Our Consumer Place newsletter.



Susie Crooks

“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.”

Susie Crooks is a much-loved founding mother of the consumer movement in New Zealand. She is renowned for her straight-talking, gutsy leadership. 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. She’s currently lobbying the NZ government to develop a strategy for consumer leadership and writing a book about the value of madness.

Our Consumer Place: How would you describe what consumers/survivors/mad folk are doing at the moment in terms of changing the mental health system or the world?

Susie Crooks: 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.

To put that another way, you really need people with the lived experience of recovery assisting at a leadership level, in policy development and service development, systems change, all the way down to the people who are currently receiving services, and allowing their experience to influence service development.

Our Consumer Place: Do you think our political heyday has come and gone?

Susie Crooks: 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 in 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; plus this new era of being more aware of getting value and having services more effectively meet the needs of the people accessing them will also help to spur a renaissance – peer support does have an evidence base for being the most effective lever in people's recovery. I'm a great believer in less meds and more talking therapies, I think that's a very effective and economic way for health provision to go.

Our Consumer Place: What place does activism have in mental health? What top three areas would you target?

Susie Crooks: Definitely reducing stigma and discrimination and challenging attitudes within the media – I think that's an important area.

Activism also 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 past 15 years, but there's been a widespread disappointment that the investment hasn't matched improvements. It's about time we started looking at ways to transform services, so that we don't keep getting more of the same, 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 percentage of the whole picture contributing to a person's wellbeing.

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

Susie Crooks: I would expect that everybody would be interested in their mental wellbeing, that there would be 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.

Our Consumer Place: If you were asked to give the government advice on how to spend \$500 million or \$10,000 on mental health, how would you advise them spend to the money?

Susie Crooks: 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, 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.

I think the key is to have people with diverse experiences; a combination of people who self-identify as having experienced madness but also people who have different fields of expertise. But it requires proper investment in peer support – if there are only a few lollies, you'll have people grabbing at those opportunities, just for the sake of gaining employment. It's a complicated scenario requiring training development, career pathways, as well as providing jobs and opportunities.



**CHRONICALLY
NORMAL**



**ACUTELY
BATTY**

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

Susie Crooks: 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, along with perhaps initiating a review and delivering a strategy for how that's going to be achieved.

Our Consumer Place: What's more important: the outcome, or how you get there?

Susie Crooks: 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.

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 – 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.

This interview appeared in the July 2010 edition of the Our Consumer Place newsletter.



Chris Hansen

“We might have gained a seat at this table, but actually we want to damn well own this table!”

A Kiwi by birth, Chris has spent the past 15 years involved in local, regional, national and international peer support and advocacy initiatives, and in mental health sector planning and politics from a service user perspective. Other roles have included leadership within NZ’s ‘Like Minds, Like Mine’ project, research for the NZ Mental Health Commission, and involvement in the development of the NZ national mental health strategic plan and workforce development strategy. Chris was a member of the New Zealand delegation to the United Nations for the development of the Convention for the Rights of Persons with Disabilities, and has served on the board of the World Network of Users and Survivors of Psychiatry. She has played a key role in the development of a number of peer-run crisis alternatives and has been co-teaching and developing Intentional Peer Support with Shery Mead for the past six years.

Our Consumer Place: How would you describe what consumers / survivors / service users are doing at the moment, broadly speaking, in terms of changing the mental health system or the world?

Chris Hansen: There’s an analogy I like to use for where we are at the moment in the consumer movement: it’s a bit like climbing a mountain. You get half way there, and you’re exhausted; you look up at the peak and you think, “Oh my gosh, I’ve made no progress, it’s still as far away as when I started!” And it’s very tempting at that stage to give up, or to bitch and moan about how far away this bloody peak is. But it’s really useful to turn around and look back and to realise how far we’ve come. At that stage, a bunch of people think, “Oh my God! Look how far we’ve come! We’ve already got there!” And they sit down and set up camp.

That’s my way of saying that I think we’re at a really interesting point in the process of social change, where we’ve made some significant changes, and some people are saying “Well, that’s fine, I’m really happy” and they are stopping there. And other people are champing at the bit and cracking the whip and saying, “Oh my God, we haven’t made any progress at all!”

The reality is that we need to very seriously consider what changes we need to make in our journey. For example, policy-makers are now using the language of ‘recovery’ a lot. The consumer movement has developed over many years a sophisticated understanding of what this means. But sometimes it seems to get used at fairly regular, random intervals in mental health policies, and they don’t really seem to understand the thinking behind the concept.

We’ve got past the vehement, agitating stage. We’re now at a point where we have to think about where we proceed from here. And it’s not the same as where we began, when we needed to be very confrontational and aggressive.

GRASS ROOTS ACTIVISM



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There's a bunch of people who are starting to come on this journey with us, and they are at hugely varying stages. We're needing to press ahead, because our intended destination is still a long way off, but also to affirm, nurture and encourage the people who are at various stages of that journey as well. That's a real challenge because many of us have become stuck in one way of doing things, and having to change our approach can be quite difficult. Others of us are tired and impatient with the people who 'don't get it', and we just want to get there.

Our Consumer Place: So, do you think our political heyday has come and gone?

Chris Hansen: Absolutely not! Actually, I'm not sure there is such a thing as a 'political heyday'. I think it's a journey and there are different stages and different accomplishments that you need to aspire to.

There's danger in thinking that there is only one kind of political heyday, and it's being out there picketing and being utterly obnoxious, knocking down doors and comfort zones and paradigms. There's adrenaline and headline-worthy interest in all of that, but actually there's a hell of a lot of hard work that needs to go on subsequent to some of those key changes to make them sustainable and also to continue to aspire to the real inclusion and equity that we're looking for.

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

Chris Hansen: Activism is vitally crucial in any process of social change. I like to call it the jackhammer. Beforehand, there is a groundswell of realisation of injustice and inequity, and then there's some gathering together, a 'rallying of the troops,' so to speak. Then there is the activism, usually spearheaded by certain individuals who have extraordinary ability to do that, and other people who feel similarly and are prepared to get out, do the hard yards, and articulate their message and find some pretty confrontational ways of doing it. It's vitally important because it's like hammering your way through a stone wall. Nobody's going to listen unless you make your point in a fairly confrontational kind of way.

Then, what happens is other people come in after that, saying the same message but saying it in a much more palatable way. And the powers-that-be, the people who we are targeting, breathe a sigh of relief and think "Ah! Here's a voice of reason!" We're actually saying the same thing, but the point has already been made, the initial shock has been absorbed, and those we've been targeting have been given some time to think about it. They actually believe they're hearing a voice of reason because it's not clothed in the confrontational outfit that the activists were wearing. That's how change happens.

I think the mode of activism changes as social change happens. We start to get allies, so we are not wanting to spread blood all over the offices or whatever. For example, if you think about Intentional Peer Support, we are wanting to create connection, and I think activism is often a stage before connection, where you actually have to make yourselves visible. When you've been invisible for so long, it's necessary to do something completely shocking to make yourself visible. There's a real art to this.

In terms of areas to target, I would target forced treatment – coercion of any description in the mental health system; legal capacity – guardianship orders, community treatment orders; and consumer/service user leadership – we're sort of doing participation, but we don't yet do leadership. We don't even do consumer participation very well, so that's an ongoing need.



One of the phrases we used in New Zealand was that we might have gained a seat at this table, but actually we want to damn well own this table!

Our Consumer Place: What would you expect to be different if we lived in a community that embraced people with mental health problems and/or experienced madness?

Chris Hansen: I would expect that we would have a very colourful community that celebrated difference and diversity.

I think our language would be really different – we would have ways of talking about our distress or our different mental states that were not laden with labels and shame or fear. We'd talk about it a lot more – probably about as much as we talk about our skin or our hair colour, that sort of thing. It would be like the weather, just part of our everyday existence, and we'd be happy to talk about it.

I think we would have workplaces that were flexible in what they were prepared to offer people – flexibility of hours, flexibility of environmental conditions, flexibility of learning styles.

I think that we would have communities where people actually had relationships – face-to-face relationships – that were committed to one another, concerned, and involved with one another, beyond our natural families.

We'd have neighbourhoods that were collaborating on environmentally sustainable energy options and people who were finding ways to enable older people or people with disabilities to stay in their homes for as long as they wanted to. People would have neighbours who were willing to exchange babysitting for someone to teach them how to do stuff on computers.

We'd have communities and relationships that were involved and committed to the face-to-face, real-time connections that provide for people in a meaningful way.

Our Consumer Place: If you were asked to give the government advice on how to spend \$500 million for mental health, what would you advise them spend the money on?

Chris Hansen: I would be asking them to do a lot of research, firstly on the damage that forced and coercive treatment does, secondly on alternative crisis options that work, and thirdly on resourcing and developing them.

I would also be looking at resourcing policy-makers and those at the grassroots around building the sorts of communities I was talking about before – community development, community networking.

And there would need to be some sort of public campaign – a good model for that is the Like Minds Like Mine campaign in New Zealand, which we based on some really solid literature and research, public awareness as well as grassroots level movements.

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

Chris Hansen: I guess one thing would be for funders and planners to start saying, "We've got to do something to get rid of coercion and force," and to acknowledge that it causes a lot of damage.

Another one is to hear people who have spent a long time absolutely enmeshed and entangled on the sharp end of the needle of the mental health system saying, "Wow, I never thought of it like that! This is really exciting, I can build a life worth living for myself. I realise that I've spent a lot of time focusing on what's wrong, I'm going to start thinking about what it is that I really want, where it is that I want to go and what it is that I want to create for myself – what are my dreams, aspirations and the life I want to live." I'm blessed and fortunate to experience this on a fairly regular basis.

This interview appeared in the June 2010 edition of the Our Consumer Place newsletter.



Shery Mead

“In the past we (people with lived experience) organised ourselves around critique - critique of services, critique of policy, critique of clinical behaviour, and so on. I believe that we must now move on to providing genuine, positive alternatives, things that do work.”

Shery Mead is the past director of three American peer support programs including a peer-run hospital alternative. An experienced speaker and trainer, Shery is best known for her work on alternative approaches to crisis, trauma-informed peer services, systems change, and the development and implementation of peer-operated services. She co-teaches Intentional Peer Support with Chris Hansen. Shery’s publications include academic articles, training manuals and a book co-authored with Mary Ellen Copeland, ‘Wellness Recovery Action Planning and Peer Support’.



Our Consumer Place: Has the heyday of progress in consumer participation and initiatives come and gone?

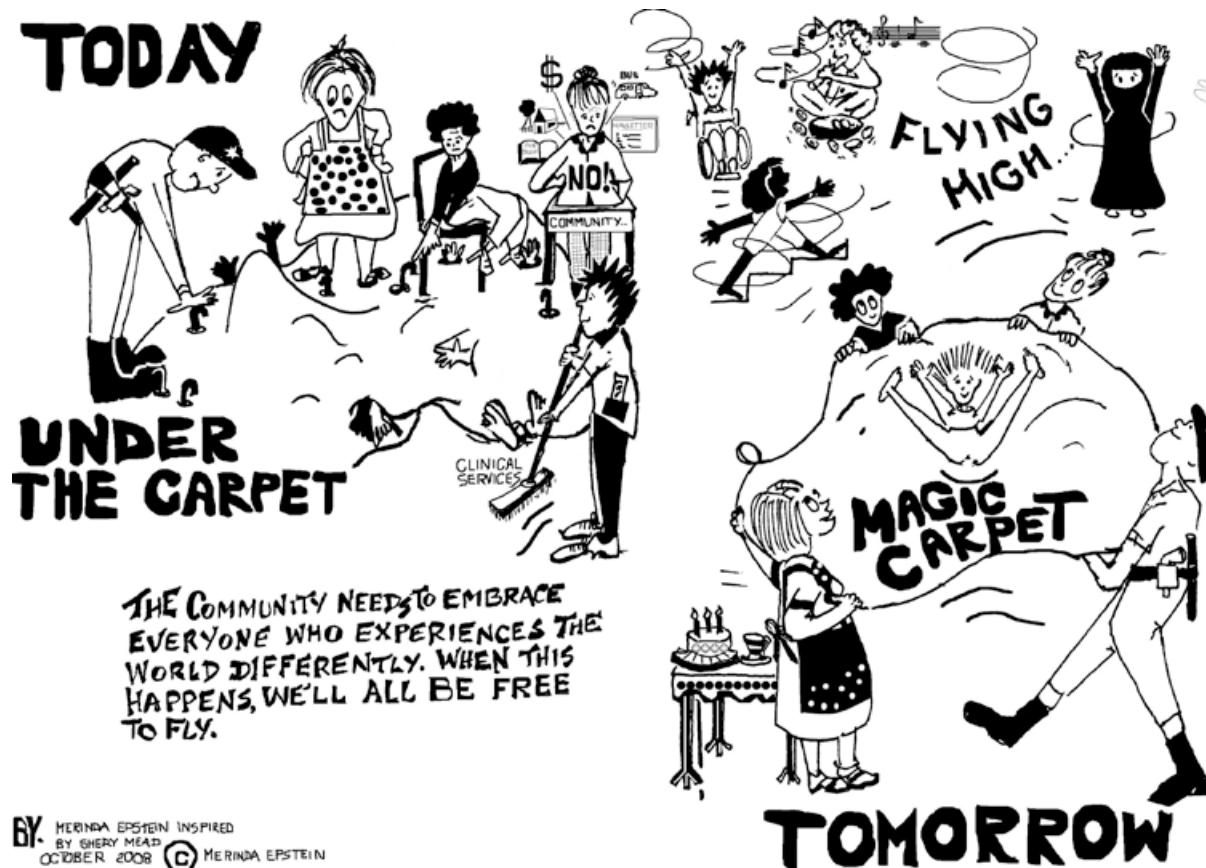
Shery Mead: It hasn’t come and gone. It’s different now. The focus is different. Before it used to be about fighting for the treatment we want; today it is more about people with lived experience focusing on alternatives.

I think people are still co-opted into ‘the system’. This is a big problem because the people with lived experience can be working in a mental health setting and it looks like there is real participation but this is illusionary. The status quo is not challenged.

There can be a tendency for mental health services to ‘show off’ the number of people with lived experience they have working for them and tick off the box that says, ‘consumer participation’, but actually it is the same old, same old.

Mostly services are not upfront about this veneer of consumer participation. They are just





covering their backs in terms of regulations that now sometimes stipulate that people with lived experiences must be involved. It is a 'tick the box' situation.

This pretence has the potential to be very dangerous. I would never set myself up as representing people with lived experience – I can't do that.

Consumers often get jobs in services because they need the money and there is nothing wrong with that except that they are not required to have any expertise in activism, advocacy, and ethics of 'representation'.

Our Consumer Place: Is there a place for activism in mental health? What areas would you target?

Shery Mead: YES! Absolutely. In the past we (people with lived experience) organised ourselves around critique – critique of services, critique of policy, critique of clinical behaviour and so on.

I believe that we must now move on to providing genuine, positive alternatives, things that do work. The areas I would target are:

1. The development of crisis alternatives – the development of real alternatives to any sort of coercive treatment.
2. Research. I don't understand why there has not been a greater outcry by us about traditional research methods that treat us like statistics. We need to lobby for collaborative research methods that see people with lived experience not as the 'subjects' but as the people with the power to create the 'truths' that drives practice. We also need

to be activists in promoting the research that supports our community-based, peer-run alternatives to forced treatment, for example. I think there's really no activism in research. People don't get mad about the fact that we're measured with numbers and old hypotheses.

3. I think we need a new kind of activism that focuses on development of what has worked. I think of activism as people actively taking a role in making the changes they hope to see. My big thrust has been the development of peer-run crisis alternatives. Actively developing anything that's alternative to coercive treatment is important.
4. The other one that for me is really important is a focus on trauma. If I were to be really active in that area, I would think we would be building alliances with people working in the area of domestic violence and working on violence prevention as opposed to picking up the pieces after the fact. There's been a lot of activism around getting services to be trauma-informed but I still don't think we put energy into violence prevention. People with similar issues have a lot more power working across disciplines. I'm working with a group in Chicago that's doing a partnership between mental health and domestic violence and they're developing their practices for shelters and I think that's really exciting. There's a lot to be done between cross-disability groups; there's lots to be done between community development and peer projects; there are lots of areas where you can partner.

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

Shery Mead: I would be out of a job, which would be wonderful! One of the things that is problematic with the question is that we target people as having mental health problems. What would be different is people wouldn't identify each other as having mental health problems, but just as having different experiences.

In my own experience, my community can deal with me as an outsider by saying, "Oh, she has mental health problems". If the community had just said, "Wow, Shery has a lot of different ways of dealing with her experience," then people would have come around and been supportive.

It's a bugbear of mine that mental health, by default, individualises people. We don't work on relationship building. So in a different type of world, the focus wouldn't be on one person's problem, it would be on communication between two or more people and what works.

This interview appeared in the October 2008 edition of the Our Consumer Place newsletter.



Tina Minkowitz

“It was people coming together in a very grassroots way - no one had any money, we were fighting against forced treatment and we were doing advocacy for each other. If somebody was locked up, someone would go over to the hospital and try to argue them into letting the person out.”

Tina Minkowitz is a human rights lawyer and survivor of psychiatric abuse. She is the founder of the Centre for the Human Rights of Users and Survivors of Psychiatry, international representative for the World Network of Users and Survivors of Psychiatry, and has played a key role in the drafting of the UN Convention on the Rights of Persons with Disabilities. Tina is the author of ‘The UN Convention on the Rights of Persons with Disabilities and the Right to be Free from Non-consensual Psychiatric Interventions,’ which includes arguments on torture and ill-treatment, and contributed to a report by the UN Special Rapporteur on Torture on this subject. Please see www.chrusp.org for current projects and activities.



Our Consumer Place: How would you describe what consumers/survivors/service users are doing - changing systems and/or the world? Do you think our political heyday has come and gone?

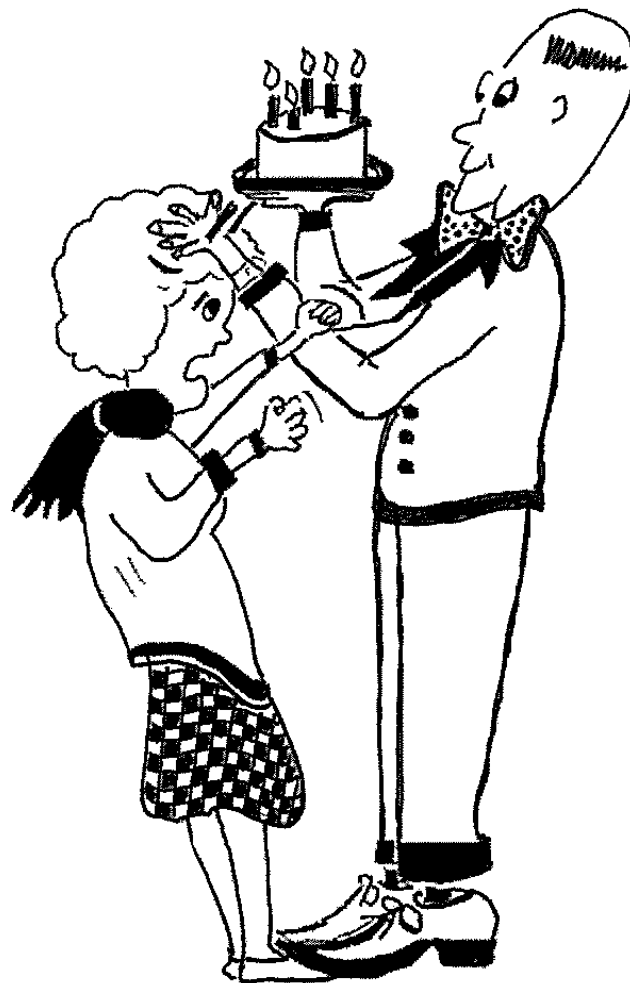
Tina Minkowitz: I wouldn't say that our political heyday has come and gone, I think there have been at least a few different waves of what I call the user/survivor movement, at least that I know of.

I came into the movement at the end of the 1970s, when it was still very radical. It was people coming together in a very grassroots way - no one had any money, we were fighting against forced treatment and we were doing advocacy for each other. If somebody was locked up, someone would go over to the hospital and try to argue them into letting the person out. Some of us would take the person into our homes until they could get on their feet. It was just really helping each other out, and at that time - at least in the part that I was in - it was very

clear that the forced psychiatric system was not our friend.

Then there was a period when the government started funding people in the movement to do all kinds of things. But the one thing they couldn't and wouldn't fund – because the funding was coming through the mental health system – was advocacy against forced treatment, advocacy against being locked up. At that point, to some degree, there was a split. Many people started thinking that the ones who were taking money from the mental health system were co-opted, and those who were working within the system, I think, felt that other people were just being utopian and weren't ever going to be able to make a difference.

I think we now have a third phase, and I think that it's directly related to the work that the World Network of Users and Survivors of Psychiatry has done in bringing people from around the world together. What we've been trying to do is to put all of this work on a basis of human



I DON'T WANT YOUR CAKE!
I WANT HUMAN RIGHTS
NOW PLEASE GET OFF MY FEET!

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rights – to put self-determination, or advocacy for self-determination, at the centre: whether you identify as a ‘user’ or ‘survivor’ or ‘person with a psychosocial disability’ or whatever, self-determination should be something that unites us. Nobody should be mistreated, nobody should be thrown into a hospital or institution against their will. Let’s try to work out together what are the kinds of things that people need.

We’re not all going to need or want the same things. If we can agree on self-determination, then there’s a lot of room for discussion about what kinds of services people want; if they want peer support, or housing, or employment, or working to get better services from the mental health system.

The work that we did in creating the Convention on the Rights of Persons with Disabilities (CRPD) established that the right to self-determination – the right to have full legal capacity to make decisions in all areas of life, including mental health treatment – is guaranteed to people with disabilities equally with others under international law. The CRPD prohibits psychiatric hospitalisation against a person’s will and requires governments to abolish the laws that allow psychiatric commitment and forced treatment. This is a huge accomplishment for our movement as well as a challenge and opportunity to take it further at the grassroots, national and international levels – to ask and answer the questions about what we do want, and what the process of transition away from violence and abuse, and towards healing and justice, will look like.

Our Consumer Place: What place does activism have in mental health? What areas would you target?

Tina Minkowitz: The first area is abolition of mental health laws. These are the laws that say psychiatrists can lock somebody up and force treatment, and these are the conditions under which they can do it; we need to abolish those laws and instead make sure that free and informed consent applies. We have to deal with legal capacity to make sure that people aren’t being judged to be incapable of making treatment decisions for themselves, which is just a back roads way of doing forced treatment.

Policies have to be changed to get away from the medical model that sees people as chemicals interacting with each other. The medical model is what the World Health Organisation (WHO) has been promoting. WHO puts the prescription of drugs and diagnosis of mental illness by primary care doctors at the centre of mental health policy, but this is contrary to the evidence of their own studies showing better outcomes in countries with fewer medical model services and stronger community ties. Policy has to move in the direction of a less scientific-evidence-based, more human-interaction way of looking at what is needed for people who are seeking help with emotional distress and life challenges.

There’s an interaction between this and abolishing mental health laws. It’s easy, if you have a mental health law, to forcibly drug somebody. But if you can’t do this, then what are you going to give people that they actually want, and how are you going to treat them in a respectful way?

Thirdly, the role of the mental health system and mental health professionals in people’s lives needs to be diminished. This is counter to the trend we’re actually seeing in the world. We are seeing the mental health system expanding, and making partnerships with all kinds of

other systems – the criminal justice system, the services serving children. The mental health system also plays a bigger role than before in people’s lives after they are released from a hospital. Due to the lack of cheap housing, it is easy for a person who is locked up and loses his/her home to end up living in mental health housing and having many aspects of life tied in to mental health services, rather than just carrying on afterwards.

We now have a lot of peer-support programs that are serving people who are linked into the system; this is good, but I would like to see more peer-support and advocacy that are independent of the mental health system, so that they can provide meaningful alternatives for people to get out of the system entirely if they so choose.

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

Tina Minkowitz: One thing that I think is that communities need to be aware of the harm that’s been caused by the mental health system, and be able to deal with some of the ways that we have traumatic reactions in relation to that.

And, as kind of a bigger picture of that, I think communities would have to become more trauma-sensitive overall. In the US, we’re having a lot of discussion about the needs of veterans coming home from war, and there’s some good work being done. There’s also been some discussion of trauma in relation to being aware of incest and child sexual abuse. But, the trauma of the mental health system, and traumatic reactions in general – like, if someone’s acting angry in a way that other people think is too much – isn’t always acknowledged. I would like to see some acceptance of a wider range of emotion.

I remember in New York, after the planes hit the World Trade Towers on September 11, things were so topsy-turvy that people’s emotional reactions were suddenly OK. I saw a guy walking down the street, talking to nobody that was there, and it was just kind of, “Yeah, he’s going through his pain.” But that’s what people are going through all the time, for all kinds of reasons.

Our Consumer Place: If you were asked to give the government advice on how to spend \$500 million or \$10,000 for mental health, what would you advise them spend the money on?

Tina Minkowitz: One way to answer this would be to say, “Make the society as a whole less traumatic for people” – look at what’s traumatic in this society and figure out how to change all those things. This doesn’t necessarily mean putting money into a particular kind of service.

Another way to answer it would be to let the people who are using services decide, in a real, democratic way (‘democratic’ meaning not just that something is pronounced and then everyone takes a survey, but with some real information and investigation). What do people actually want? I don’t use mental health services – I can say the kinds of things that I’ve seen or read about that seem good to me, but the people who actually use services should figure out what that should be. And that can only be done in a context where there’s no coercion. Asking people what they want should be the basis for individual services also.

Our Consumer Place: Which is more important to you: the outcome or how you get there?

Tina Minkowitz: A few years ago, I probably would have said, unequivocally, the outcome, but at this point, I'm more concerned about the process.

If someone is stepping on my feet, and won't get off, and I'm just hitting them to make them get off my feet, then that's going to look like violence. If they're standing there calmly, it's going to look like I am the aggressor. From my perspective, I think many people in our movement are getting sucked into thinking, "We have to be nice while they're stepping on our feet." That's why my advocacy stands outside the system, and says, "You have to be held to human rights. If you want to work with me from a basis of recognising and respecting my human rights, then everybody's welcome." When you're fighting in that kind of way – as I was a few years ago to affect changes to international law – I think you have to focus on the outcome.

But at the same time, to really make something work, you have to work with people's needs and people's fears. There are questions that all of us have to decide together.

This interview appeared in the April 2010 edition of the Our Consumer Place newsletter.



Mary O'Hagan

“Madness itself would be considered part of the cluster or continuum of human experience - not just an oddity, but something that we can all learn something from.”

Mary O'Hagan experienced severe mental distress and used mental health services for several years as a young woman. She slowly realised that, like her, many people were not helped or understood in the mental health system and some were deeply harmed by it. Society, in collusion with the mental health system, had also failed to uphold the rights and participation of some of its most marginalised citizens. In response to this, Mary initiated the user/survivor movement in New Zealand in the mid-1980s. From 1991 to 1995 she was the first chair of the World Network of Users and Survivors of Psychiatry. Mary was a mental health commissioner in New Zealand between 2000 and 2007. She is now an international consultant in mental health specialising in peer support, recovery based services, human rights, as well as the perspectives and leadership of people with lived experience.



Our Consumer Place: Has the heyday of progress in consumer participation and initiatives come and gone?

Mary O'Hagan: Twenty years ago, people were reasonably earnest in the pursuit of consumer participation, and it wasn't just consumers but people who ran services.

It didn't take long to realise that consumer participation, as a concept, wasn't going to be strong enough. So we came up with the idea of consumer leadership. We have that in our policy documents in New Zealand, but it doesn't translate, unfortunately, into anything very meaningful.

I think at the moment, in New Zealand anyway, and I get this sense from other parts of the world too, that the whole thing has gone into decline, the idea of people who use services having a power base and having an influence and leadership in what goes on.



Our Consumer Place: Is that being driven by something internal or something external, do you think?

Mary O'Hagan: I think there are all sorts of things going on. I think there is a bit of a conservative backlash. I think the recovery stuff has gone nowhere – I mean, it couldn't be implemented because actually it requires a fundamental change in the way things are done, and that's just not happening. You can't really have recovery-based services until people change some fundamental views and practices, change how we think about 'what is madness' – madness as a full human experience – and how we respond to people as full human beings. These are fundamental issues that aren't being looked at by services.

Our Consumer Place: Is there a place for activism in mental health? What three areas would you target?

Mary O'Hagan: Yes, there is a place for it. There's a place for people to be inside the system and a place for people to be outside, acting as an irritant.

I think compulsory treatment should be one of the targets. I don't think we're going to get anywhere until we do something about compulsory treatment.

Also, we need to acknowledge the urgency of the development of a peer workforce.

Thirdly, we need to target the discrimination that is rampant within mental health services. Discrimination is rampant elsewhere too, but particularly in mental health services because everyone ignores it – it's "too hard" – but really, the worst stuff goes on in mental health services themselves.



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

Mary O'Hagan: I think in a way we have a great opportunity. We live in much more pluralistic communities than we've ever done and we've got a great opportunity for this to happen now, more than ever.

But what would it look like? Well, people with mental health problems would have partners, they'd have children, they'd have decent housing, they would have the usual freedoms that everyone else enjoys, including the freedom to take treatment or not.

Madness itself would be considered part of the cluster or continuum of human experience – not just an oddity, but something that we can all learn something from.

Our Consumer Place: If you were asked to give the government advice on how to spend \$500 million for mental health, what would you spend the money on?

Mary O'Hagan: I would spend it on developing the peer workforce, on creating alternatives to compulsory treatment and hospitals, and on initiatives that assist people to find jobs and houses and friends.

Our Consumer Place: What about if you had \$10,000 to spend?

Mary O'Hagan: A holiday! I'd go on a holiday! ... \$10,000 of public money? I would probably hold a meeting and have a forum for opinion leaders, from all over the place. And get them together and try to get their commitments to take some action.

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

Mary O'Hagan: Some of the good things that could happen in one day and give me a good night's sleep? Temazepam? ... I suppose I would get a good night's sleep if I thought that people who are currently in the unfortunate position of having to use services could go into them and feel that those services are helping them – if people felt that those mental health services were assisting them in their recovery.

Our Consumer Place: Which is more important to you, the outcome or how you get there?

Mary O'Hagan: I think they're both important, because how you get there determines the outcome to a degree.

Having said that, I am quite an outcome-oriented person – I don't want to think that I or other people have been doing all this work for all these years for no outcome. That would really depress me.

This interview appeared in the February/March 2010 edition of the Our Consumer Place newsletter.



David W. Oaks

“Non-violently overthrow the mental health system and have a nice day.”

David W. Oaks is executive director of MindFreedom International, an independent nonprofit coalition for human rights and alternatives in mental health that is celebrating its 25th year. He is on the boards of Oregon Consumer/Survivor Coalition and United States International Council on Disability. As a student at Harvard on scholarship, David experienced psychiatric institutionalisation five times. Through peer-run alternatives, David recovered and graduated with honors in 1977. He has been an international community organizer of mental health consumers and psychiatric survivors ever since. With his wife Debra, he lives in Eugene, Oregon, and loves camping and gardening. Email: oaks@mindfreedom.org



Our Consumer Place: How would you describe what psychiatric survivors, mental health consumers and users are doing currently? What's the current state of play, in terms of changing systems and/or the world? Do you think our political heyday has come and gone?

David W. Oaks: I call myself a psychiatric survivor – a lot of people refer to themselves as consumers or users, but at MindFreedom, people tend to identify as survivors of abuse in the mental health system. That voice tends to get lost a bit, but it's important to remember it.

There have been two big changes over the past few decades. If you go to a meeting about mental health issues in a developed nation – say, at a county, or local, or city, or district, or province, or state level – you will now have a fair chance of finding an individual who identifies as a user of the mental health system on that council. Also, there is some acknowledgement in the language to include users/survivors.

So the main change, really, is that we exist! The key achievement is that our social change movement exists. For centuries there has been this kind of oppression, this abuse, but now there is actual organising going on, internationally, and has been for decades – nowhere near what we had hoped, but the fact is that we're here.

And the struggle is that much more important now, because the biggest change in the history of mental health is about to take place over the next 10 to 20 years. What has been happening in the richer countries hasn't been happening in the vast majority of the world. Now the battleground for the mental health system is in poor and developing countries, in Asia and Africa. This is the globalisation of the mental health system. As never before, we are poised to engage with challenging the system on this global stage.

So our heyday is definitely in front of us. How well will do, though, is up to each one of us. The key question is unity, whether or not we can unify. By unity, I don't mean lock-step conformity, and I don't mean hierarchy. I mean people working together in a spirit of mutual co-operation, even when – especially when – there are significant differences of opinion. I think that is the key for oppressed people – are we going to work together or not? If we do, I think we will have one of the most exciting and beneficial non-violent clashes ever. Martin Luther King said, "We who in engage in nonviolent direct action are not the creators of tension. We merely bring to the surface the hidden tension that is already alive."

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

David W. Oaks: The big challenge – the elephant in the room, as they say – since the mid-'80s is mental health system funding of this field. The mental health system is eager to bottle the spirit of empowerment, but we need non-violent revolution, not more reform. The system will not fund real activism.

For example, I think we need to be questioning the power of the drug companies, what we call "the bully model". Having only one choice is no choice, and we are pro-choice! We don't want to be cornered as being anti-this and anti-that, anti-drug or anti-psychiatry. We're pro-choice or anti-bullying. So a top issue is to point out the bully in the room, which is the very narrow, very medical model that is used as the organising system.

It's not the model itself that is the problem – we have members who very much utilise the medical model – it's the bullying. The system-funded change has tended to leave that out. I'll go to several day-long conferences about recovery, and peer-support, and mental health alternatives, and hear nothing about the power of the drug companies.

I'm not denouncing the system-funded folks – system funding is crucial; we should be asking for more of it! But we need to be smarter about also supporting independent activism. That's often the missing part in a lot of organising. People start getting money for conferences, drop-in centres, consulting, peer support and all that, but they need to keep aware that everyone needs to support activism as an ingredient.

There are other human rights issues. We've been talking about involuntary electroshock, because that's very unifying. People are sometimes not so sure about forced drugging, but most people are sure that involuntary shock against the expressed wishes of the subject has got to go. How can there be any empowerment, any recovery, or any self-determination,

in a system that allows that electricity be forced through our brain? It's worse than water-boarding. It's torture. Things like forced shock are growing internationally as the Western medical model is exported. Drugs are expensive, so shock is going up. We need to bring this up, for example at the United Nations, now that we're in the tent of the UN and the human rights scene. We need to push really hard that this is torture – and use the 't' word.

The third key issue is to promote a range of humane, empowering alternatives, especially peer-run, peer-support alternatives. You can now hire people who were formerly considered un-hireable, disabled – now they are providing peer support, and being a role model.

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

David W. Oaks: One of the big issues for us is the universality of our issues. I talk about 'sanism', although some people prefer 'mentalism'. In the Western model, we are apparently thinking, rational beings – but, in fact, we know that to be human is to not have a grip on reality. We see that in the tragedy of the climate crisis, the nightmarish environmental devastation – what is called 'normal' behaviour is in fact dangerous to the planet!

We're all interconnected. If any human is considered crazy, all of us are crazy. I tend to think everybody is crazy. For example, I just came from a meeting where one of the participants was cutting herself and weeping in the toilet over a relationship. Yes, she was having an overwhelming crisis, but her similarity to the world is more than her difference. The world is cutting itself.

When people really get in touch with that universality, that is an overwhelming thing. We need to be going to the people who have had extreme and overwhelming emotional issues, who have gone through it and have reached some level of recovery, and take notes about what works – because this is about everybody, and humanity may learn something important from our movement.

So with this vision what would the world look like? Well, it wouldn't be different just for the 5 or 10 or 20% of us who are considered 'troubled'. Would the emergency rooms look better? Yes, that's important, but it takes a village to heal a mind. There would be enormously more support for a huge diversity of mental and emotional feelings and thoughts, and enormously more listening to one another and connecting with each other. Martin Luther King used to say, "The salvation of the world lies in the hands of the creatively maladjusted."

The reason the oppression against us is so fierce is that we are a reminder – that person weeping in the corner is a reminder that your heart is weeping right now. Don't look down, because the floor is glass and you're looking at the whole universe below you and you may fall. So let's turn to each other and hold each other, and support one another, because nobody has a grip – we're in universal crisis, every moment.

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

David W. Oaks: As Judi Chamberlin reminded me, on the wall of the drop-in centre for the Mental Patients Liberation Front, 30-something years ago, we had a sign that said, "Overthrow Psychiatry by Tuesday." Since then, one of my sayings has been, "Non-violently overthrow the mental health system and have a nice day."



For me personally, it involves being in nature, being outdoors with wilderness and friends and directly challenging oppression in a creative way, such as creativity, art, peaceful activism, mutuality and healthy movements and supporting one another in a thoughtful way ... With those in place, I'd go to sleep with a grin on my face!

I have glimpses of that. My partner Debra and I, we have our little garden and our cat and our friends, and I'm in a men's group and I seek to take care of myself and to enjoy things, not get totally absorbed by the movement. But it's a struggle. I think we all struggle with that.

This interview appeared in the May 2010 edition of the Our Consumer Place newsletter.



Steve Onken

“You need those people out in the extremes raising hell. That allows some of the quieter people in the middle to make changes.”

Steven J. Onken, Ph.D., has been described as a recovery scholar and practitioner. He would disagree, describing himself as a ‘recovery guide’. A research specialist, Steve holds appointments with educational institutions in Hawaii, conducting applied services research and evaluation. His 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 Hawaii’s Mental Health Transformation State Incentive Grant.



Our Consumer Place: How would you describe what consumers are doing – changing systems and/or the world?

Steve Onken: There are three major components to what consumers are doing in terms of changing the way we do things, changing the paradigm. 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 – providing that social network, 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.” Sometimes, people’s experiences 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 unpaid support, peer-to-peer, person-to-person – that human contact – that’s a really important component towards substantial and sustainable change.

A second, very critical component is in terms of being a paid professional within the workforce, or a 'paraprofessional'. In the United States, we talk about 'peer specialists', whereby 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 as a result of those experiences – mostly misunderstanding by others of those experiences – give us a lot of tactical survival tools and wisdom, that when supported and groomed can be of critical help in supporting other people's journeys of healing and recovery, moving into wellbeing.

Workforce development is an important part of making this possible. Consumers' lived experience can inform policy making, budget planning, strategic planning, service delivery, outreach – it has to be integral to all parts of the system. Workforce development efforts also have to provide a career path for people to both develop in their knowledge and skills, and a professional ladder that allows them to be recognised, promoted and engaged in more advanced work.

It's also important that it's paid – and that the wages are competitive! There's been a tendency for peer specialist efforts to be started and peer specialists to be 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.

The third critical component – if we're really serious about substantial and sustainable change – is collective action. We need people to have access to and use information, to raise consciousness, to ask serious questions – to question, question, question, to organise, to challenge and challenge more and not to accept the way things are just because they are that way. We need a social movement. The movement 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 need angry people out there at times – I 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. You need 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 with lived experience on the board of directors 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.

All three of those things are very important if you are 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 efforts and skills.

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

Steve Onken: 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 side by side with each other, seeing how to

organise and take action, mutual support to take those first activist steps, lighting the fire within each other, and role-modelling. It can start with helping out with a newsletter or mail-out at the local self-help centre.

When people gather, they share stories. As they compare stories they start to see the pattern of things; for example, people picked up for misdemeanours who also happen to have a psychiatric disorder tend to be in jail for longer periods of time than those without psychiatric disorders here in the United States. What's up with that? Why is it acceptable? Questions need to be raised – is there another way of doing things? Are we setting up a pattern where we're criminalising a person's condition, as opposed to criminal activity?

We need to be continually raising questions. For example, is there true accessibility to education? Which colleges? Are there scholarships? Are the professional schools' practices of gate-keeping weeding out everyone with a psychiatric disorder? How hard is it to move from benefits to a job and back to benefits, when required?

Are our people – the lived experience community – evident and represented in decision-making bodies? Until they are, we need activism, because the people who are making decisions need to hear from us, even if it makes them uncomfortable. By the way, my examples just covered three critical issues facing us at this time: (1) the criminalisation of psychiatric disorders, (2) meaningful access to higher education and advanced career development, and (3) restructuring of the world of work and of benefits such that there is more flexibility to work when well but also having paid leave when you need time to maintain/regain your wellness – without crashing, without falling back into poverty.

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

Steve Onken: That community is going to be one that shows a lot of flexibility. Boundaries are still there but they are pretty fluid – they can shift as more knowledge is understood, more things are known, and they can then embrace that knowledge and that change.

People with psychiatric disabilities would be a regular part of the community – it wouldn't be that everyone would be mainstream, but people on the edges of the stream would be valued as much as those in the middle of the flow. Fringes are nice! A lot of creativity can come out of those kinds of spaces.

The community would be one where there might be quite a lot of different ways of expressing oneself and living within that community. There needs to be some basic structure, principles that we live by – respect, dignity, non-violence, those kinds of things – but no rigid dogmas. Extreme dogmas allow us to distance ourselves from other people and devalue them, i.e., “They aren't like us” “They are not one of us” kind of thing. Then a pattern, a way of being emerges. I call it the Grand Narrative of Less Than, that of the soft discrimination of low expectations. “They aren't like us; they can never be as good as us.” “They can never achieve the expectations we hold for ourselves.” Thus, people start to so strongly believe in these lowered expectations and reinforce these low expectations that soon “those people” start believing it themselves. “Nobody like me ever went to college; I'll never be able to go to college.” “Look at me; I'd make a bad parent.” “Why bother, sooner or later I'll end up in jail like all my friends.” The most common and overlooked societal error is holding inappropriately low expectations ... of everyone.



It's also got to be a community where everyone feels safe – where they experience physical safety, social safety, moral safety, emotional safety, psychological safety. There are a lot of experiences out there that are difficult, adverse, traumatising. If we work hard to build communities where people do feel safe, and something does happen to someone, they will know they can go somewhere and share that experience and they're not going to be looked down upon, they're not going to be stigmatised. 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.

So you would have 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 where psychiatric disability is not dehumanising.

Our Consumer Place: If you were asked to give the government advice on how to spend \$500 million or \$10,000 for mental health, what would you advise them to spend the money on?

Steve Onken: Here in the United States, if there was one area in which 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, that's the central issue that they're struggling with. They are being treated for a set of symptoms – generally, treatment is trying to control or eliminate these – but these symptoms are really a set of adaptations to trauma, that help the person to survive in this dysfunctional, traumatised state. We need to respect those adaptations as we work together to find areas in which one feels safe enough to explore different, less costly ways of coping – of self-soothing and self-regulating.

I would also do training so that people with lived experiences become part of the workforce developed to address trauma, i.e., assessing and treating and supporting people – for example, Shery Mead's work in Intentional Peer Support.

Of course, that's not a magic bullet. Poverty, housing, employment, all these things are really important too. But this is one area that has been neglected that we can change right now without much fiscal cost – we are not truly listening to people, listening to what has happened to them, hearing their stories, and honouring their stories and the cumulative impact that multiple adverse experiences have had on them. We say, "They're making it up" or, "It's a symptom," or, "It's an exaggeration" – but the more we research it, the more we realise how wrong that assumption is. They are recalling real experiences that profoundly impacted their abilities to self-soothe, self-regulate, cope and function.

If I had a much smaller pool of money, I would like to see that go towards grooming and supporting leadership development among people with lived experience.

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

Steve Onken: I live in Hawaii, so a good day is when I see a rainbow! I don't have much control over that, but we have lots of them. Something about a rainbow is hopeful – things will get better, the storm is over. An experience in the day that conveys hope – whether that's

somebody saying, "OK, so next time I see you..." so you know that you'll be connecting with them in the future; or some small gain, like someone saying, "Good job!" – distinguishes a day that I feel good about from a day that I just sort of survived.

A "taking on the world" kind of day – when it feels like I'm moving forward with purpose? It's one where I am on a path, and there's something good that I am striving for, that I can ... that I WILL ... accomplish in the future, and ultimately I will reach my destination – AND enjoy a hell of a ride along the way! In fact, it's about finding a moment to stop and celebrate what I've – what we've – accomplished. We might not be there yet but look at what we did today! Look out world, here we come!

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