

I have a dream...

...Consumer leadership in the community managed mental health sector

Indigo Daya: Project manager, Voices Vic, Prahran Mission's consumer-led program for people who hear voices

Published in: New Paradigm, Psychiatric Disability Services of Victoria, Melbourne, August 2012

I HAVE A DREAM. These words swept a whole country into challenging injustice and bringing about a new chapter in freedom. For the United States civil rights movement, Martin Luther King's words were a rallying cry. They are also a reminder that significant social change is always led by the oppressed. I believe mental health will be no different, and that the most important reforms will continue to be led by people with lived experience. But this does not mean that organisations working in mental health cannot be a part of the dream.

In this article I examine the need for significant and continuing change in the mental health sector, and why consumer leadership must lead the way. I explain what the community managed mental health sector can and is doing to enable this change and discuss what we, the consumers, must do ourselves.

I invite you, whatever your role, to take up one or more of the challenges I pose in this article, and become a part of the dream.

Do we really need more change – aren't we there yet?

Question: What do the following have in common?

- Friends
- Family
- Children
- Romance
- Pets
- Health
- Education
- Respect
- Safety
- Security
- A home
- A car
- A computer
- Travel
- Power of choice
- Respect of others

Answer: For mental health consumers, they are all aspects of life that we are told, in one way or another, that we cannot have.

The statistics bear this out. Here are just some:

- 85.2 per cent of mental health consumers are on government pensions (VICSERV, 2008)
- 42 per cent live with unstable or unsafe housing arrangements (VICSERV, 2008)

- 39 per cent do not have a best friend; 12 per cent have no friends at all (Jablensky, 1999)
- 64 per cent of those diagnosed with schizophrenia are single (Access Economics, 2002)
- average life expectancy is 50–59 years (VICSERV, 2008)
- 71 per cent are victims of violence or crime (Mind UK, 2012)
- 61 per cent of women interviewed in one study had personally experienced sexual harassment or assault from other patients and/or staff (VWMHN, 2007).

We have heard these statistics about the socio-economic impacts of mental illness so often that we become numb to what they really mean. But stop for a moment and imagine what your life would be like with no likelihood of romance, marriage, children, or pets. No car, travel, computer or home. No best friend, prospect of a good retirement, education or career. Poor physical health, obesity and poverty. Little respect or choice, less safety and no security.

How would you *really* feel about that?

The combined reality is clear: people who experience mental health issues face extreme socio-economic disadvantage, widespread stigma and violence, have very little power and are often under the control of others. That is, they demonstrate all the characteristics of an oppressed group. One must then ask: is it possible to be aware of this reality and *not* conclude that we still have significant change ahead of us?

Our increasing involvement in mental health will not be comfortable. It will be challenging and discomfoting. But perhaps community leadership and social change has to be this way.

Changes in the wind...

While we talk about reforms like the new National Mental Health Commission, the upcoming National Disability Insurance Scheme (NDIS), more outcome measures, and an increasing focus on recovery, we must not forget that the heart of our mental health system is still founded on a significant power imbalance (see Figure 1).



Figure 1: Power balance in mental health

While consumers are now frequently consulted, our power in relation to other groups remains minimal, and is often still tokenistic. I acknowledge the significance of our inclusion in many mental health arenas, and the increasing number of excellent consumer-delivered services – but the overall balance remain far from the disability movement’s ideal of ‘nothing about us without us’.

When we examine the history of other oppressed social groups, it has always been a shift in power which has opened the doors for significant change. Look at Mahatma Gandhi and India’s independence, the suffragettes and women’s liberation, Gay Pride and equal rights for the gay, lesbian, bisexual, trans-sexual and intersex (GLBTI) community, Eddie Mabo and land rights, and of course, Martin Luther King and the civil rights movement. Until consumers sit at the heart of mental health policy and practice and this power balance changes significantly, the human rights issues and socio-economic disadvantages we face will not be fully addressed.

Let’s look at the historical paradigm shifts in mental health (Table 1). Despite significant changes over time, it is still ‘others’ who decide who we are, what we need and where we go. Our choices are of course significantly improved, but they remain far from equal.

Period	Who we are	What’s wrong with us	Who decides	Where we go
Middle ages	Demons, sinners	Possession	The church	Exile or death
16 th – 18 th Century	Criminals, lunatics, idiots	Lunacy	The law	Prison, madhouses
19 th Century	Insane, diseased	Insanity	The law & medicine	Asylums
1900 –1980s	Mental patients	Mental illness	The law, medicine & allied health	Hospitals
1990s– today	Disabled	Psychiatric disability	The law, medicine, allied health & community services	Supported community

Table 1: Historical paradigms in mental health

I believe that, as consumer leadership grows within the mental health sector, the paradigm can shift again (Table 2). Eventually we will come to a place where we define for ourselves who we are and what we need and where mental health will apply to everyone, not just those with a ‘diagnosis’.

Period	Who we are	What’s wrong with us	Who decides	Where we go
Future	People	Nothing. We all have normal and understandable variations in mental emotional, social and spiritual wellbeing	Us... with support from law, medicine, allied health & community services, friends and family	Everywhere

Table 2: A future paradigm for mental health?

What consumer leadership brings to mental health services

The strength and perspective of consumer leadership comes from the power of having lived ‘the nightmare’ as well as holding the passion for ‘the dream’. And of course, it is actually *our* lives that are affected. We bring new ways of working and new ideas about recovery (indeed, recovery itself was originally a consumer idea). We also bring challenges, which can sometimes work against us.

Many consumers bring substantial anger to their leadership roles, which can be confronting for services. But this anger needs to be understood in the context of people’s experience. It is not uncommon for us, as we find our recovery paths, to look back on our lost years with anger, to feel the injustice of involuntary and sometimes ineffective treatments, of stigma, exclusion and inequality. To mourn for the people who have abandoned us, and for our friends who have died in the system.

Over my years of recovery and work, my own anger has transformed into a different kind of energy. I am still exceptionally driven, but these days I want constructive, collaborative change, rather than to blame and tear down ‘the system’. I have come to see that despite all the issues, the system is made of people, and ultimately we are all working towards the same end goal. This being the case, I believe that collaboration is far more helpful than confrontation (well, most of the time, anyway).

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Anger is a mechanism for alerting us to injustice and motivating us to make change. We are entitled to feel this anger, and we deserve spaces in which to express it and a sector that is willing to hear it and sit with the discomfort. We must also take responsibility for being respectful and non-violent with our anger.

On the other hand, this has been my personal journey, and I always hold a deep respect for those who are still feeling their anger very strongly. Anger is a mechanism for alerting us to injustice and motivating us to make change. We are entitled to feel this anger, and we deserve spaces in which to express it and a sector that is willing to hear it and sit with the discomfort. We must also take responsibility for being respectful and non-violent with our anger.

Our increasing involvement in mental health will not be comfortable. It will be challenging and discomfoting. But perhaps community leadership and social change has to be this way:

‘It can be about causing ripples when people want a smooth pond ... It can make people feel uncomfortable. Community leadership is often about getting back up after being knocked down – about spreading a message that nobody at the time wants to hear. It’s often about taking the wider community out of its comfort zone and forcing it to confront issues that it would rather not.’ Sir Gustav Nossal, OAM

It is helpful to think of consumer or peer work as a discipline, rather than a role. The consumer or peer discipline brings a new way of thinking about mental health, as do other disciplines. Psychiatry thinks about the brain; psychology about cognitions, emotions and behaviour; occupational therapy about functioning; social work about social factors and inclusion; community workers about goals. Consumer and peer workers think about the value of the lived experience and human rights. This perspective can be brought to any role in the mental health sector.

Enabling consumer leadership – down to ‘brass tacks’

“Leadership is not only an individual characteristic but a community characteristic, based on the presence of entrepreneurial social infrastructure.” (Flora, Flora, Bastian & Manion, 2003)

Looking at the history of other social groups which have experienced significant disadvantages and progress in recent decades, I have no doubt that consumers will eventually lead the changes needed in mental health. We *will* do it. It’s already happening, but the rate of progress is understandably slow given our challenges, some of which I have outlined above. As well-meaning as organisations or people may be, leadership cannot be ‘given’ to us. It cannot be ‘done’ for us. But the community managed mental health sector *can* help enable it.

A willingness to enable consumer leadership will increase the rate of change in mental health, and those services that do so will become the leaders in our sector – particularly when the NDIS allows increasing choice for consumers.

I outline below some of the ways in which organisations can help to enable this change.

a. Where does your organisation stand with consumer engagement?

Figure 2 illustrates a ladder of consumer engagement, and where consumer leadership sits on this spectrum. More than leadership, I consider **ownership** to be our end goal (internationally this is an increasing trend, but still in its infancy in Australia).

Organisations can ask of their programs and services: what level of consumer engagement exists? How deep is the engagement and what impact does it have on organisational values and strategy? How well are they supporting people in consumer leadership roles? What is stopping staff and management and the organisation from moving up the ladder of consumer engagement?



Figure 2: Ladder of consumer engagement

b. Shape and embed new organisational values and philosophies

A key area for enabling greater consumer leadership will come from reconceptualising organisational values and philosophies across the sector. This can include:

- external and internal acknowledgement of the need for significant change
- willingness to relinquish power and be transparent
- acceptance that increasing consumer leadership will be uncomfortable and messy
- deep respect for the wisdom and diversity of lived experience
- commitment to consumer engagement and leadership at all levels and in all roles
- genuine support and resources for consumer engagement

Sometimes it feels like the most excluding or 'non-recovery oriented' services have the biggest and most colourful posters about inclusion and recovery. Sadly, a nice poster does not equal change. It is therefore imperative that organisation's philosophies and values are converted into practice by embedding them in measurable and transparent ways. This is the step that makes the changes genuine.

Many consumers are cynical about this topic. Sometimes it feels like the most excluding or 'non-recovery oriented' services have the biggest and most colourful posters about inclusion and recovery. Sadly, a nice poster does not equal change.

It is therefore imperative that organisation's philosophies and values are put into practice by embedding them in measurable and transparent ways. This is what makes the changes genuine.

Every statement of vision, mission, philosophy or values should be accompanied by two actions. The first is to develop key performance indicators (KPIs) for every level of management and every program which are clearly linked to values, vision, mission and philosophy. In other words, how will we prove that we practise what we preach? The second is publishing performance against these KPIs in a transparent and public manner, with real-life examples. This models the changes, and promotes their continued growth.

c. Human Resources practice

Human Resources (HR) policies and practices can play a significant role in enabling consumer leadership. A great starting point is affirmative action for the employment of consumers, across all levels of the workforce.

Affirmative action employment within mental health can involve designating positions across the organisation to be consumer held, or setting 'stretching' targets for consumer representation. These types of employment initiatives must be supported, however, by other HR practices including:

- **Support for disclosure and non-disclosure:** the imperative to increase consumer representation cannot infringe on the rights of employees to privacy. The decision to disclose must always be a personal one.
- **Ensure consumers have the resources to succeed:** providing realistic budgets for consumer-led programs and projects; being aware of and avoiding tokenism.

- **Training and development budgets:** many consumers lack employment experience and qualifications, or have had a long break from working. Successful employment outcomes will depend on organisations being willing to invest in the development of their consumer workforce, including peer work training, and often general employability skills.
- **Reasonable adjustments:** disability legislation requires reasonable adjustments in the workplace but in practice this does not always happen. Often consumer employees are not even aware of this option, or may fear that such a request may endanger their tenure. Employers can assist by being proactive, offering adjustments like flexible hours or quiet work areas, and being open to creative solutions.
- **Don't put people on islands:** being the only consumer employed by a service can create a sense of isolation and pressure to be the definitive voice of all consumers. It is important to employ more than one consumer and provide opportunities for peer support and mentoring.
- **Support the emerging peer profession:** wherever possible provide peer supervision to help ensure that peer practice is not colonised by other disciplines. Provide scope for peer workers to utilise peer-specific practice and philosophies in their work, which may differ from other disciplines.
- **Wellbeing planning and support:** many organisations struggle with what to do when consumer employees become unwell. Given the emotional impact of mental health work, staff burn-out rates and the reality that every organisation will have employees with undisclosed mental health issues, it is good practice to implement wellbeing planning and support for all employees, regardless of consumer status. This should represent a holistic approach to wellbeing, be available for all staff and be modelled by management. Ideal plans will include the option for advance directives, giving employees control over what role or actions they wish employers to take if they become unwell. Employee Assistance Programs (EAP), regular supervision and debriefing, and realistic workloads should be standard practice.
- **Flexible employment arrangements:** consumer positions should have the option of part-time employment, job share and flexible work times wherever possible. Ideally this flexibility should be available to all staff as it creates family and disability friendly workplaces. In particular, it allows consumers who are new to the workforce a way of entering employment gradually, and adapting to workplace conditions. Consumers will need time to attend health appointments or to take self-care time, and those taking medication may struggle with early rising. If the focus is on the completion of duties rather than time, then flexibility becomes easy to implement.
- **Parity of pay:** many consumers are still employed at wages below those of other employees, particularly for casual roles such as speaking, sitting on interview panels or committees. Parity of pay and conditions is an essential element for respect and workplace equality.
- **No cotton wool:** it may be appropriate for consumers to begin with a lesser workload, to allow time to learn a new role, and to develop skills and confidence. Once consumers are established in a role, however, it is not appropriate to give them smaller workloads than other staff in similar roles. This becomes dangerously like tokenism, and creates unhelpful stereotypes about consumer capacity and potential.

- **Pathways:** if we are serious about increasing consumer employment, we must provide pathways to enter mental health employment. Volunteering, casual and part-time work are good segues into the paid workforce after long periods of unemployment, and also provide opportunities for people to assess their training and development needs. Traineeships can be valuable pathways for working and training for new starters, while career paths which include senior positions provide motivation and powerful role models.

d. Day to day practice

Consumers can take up roles in any part of an organisation. Our interests vary widely and can include:

- stigma and awareness, information provision
- equal opportunity and human rights activism
- advocacy
- service delivery (clinical and community)
- mutual support and connection
- policy development and implementation
- training and education

Some general principles can be helpful to adapt across organisations to nurture and embed the emerging consumer workforce:

- Policy and practice development which embraces the ideal of 'Nothing about us without us'.
- Consumers engaged with development of all policy, strategy and day-to-day practice.
- Organisations embracing discussion and debate about change, including creating spaces and opportunities for discourses to be challenged.
- **Never seeking consumer input without having the processes for utilising it.**

But as we promote increasing opportunities, it is important to remember that only a minority of consumers will want to work within the sector: most just want to recover and get on with their lives.

Consumers: what is 'our' responsibility?

Feminist Gloria Steinem said, 'Power can be taken, but not given. The process of the taking is empowerment in itself.' As much as the mental health sector can help to enable our leadership, it will have little impact unless consumers step up and take it. So, how do we do it?

- a. **Find allies, mentors, supporters:** don't be alone in your work or your passion for change. Connect with consumer organisations, groups and individuals.
- b. **Take, reshape and make opportunities:** my position as project manager was not offered to me. I wrote the job description then 'sold' it to my organisation. Likewise, Voices Vic

started with a relatively small scope and has grown into a statewide organisation that reaches hundreds of people and employs six consumers.

- c. **Indian spiritual guru Osho said, 'Be realistic ... plan for a miracle!':** to create sweeping change, it helps to dream LARGE. There are many of us who share these large dreams, and the more we talk about them, the closer they become.
- d. **Don't become what we're trying to change:** support fellow consumers, even if you have different views or experiences. Exclusion and disunity affect all of us, and is never really helpful. Be careful with dogmatism and remember we don't have all the answers – no-one does.
- e. **Learn and grow:** we are an emerging profession, and many of us have missed a lot of education and work experience. Take every opportunity to read, talk, listen and challenge yourself.
- f. **Shape our discipline:** be active in defining our emerging profession of peer work.
- g. **One step at a time:** While we may dream LARGE, small steps will get us there just as well as leaps.
- h. **Stand tall, even when things are getting you down:** Martin Luther King said, 'A man can't ride on your back unless it's bent.'

Conclusion

Change in the community-managed mental health sector is certainly on the horizon, but some of the biggest changes remain only a dream, particularly in terms of genuine recovery and equal rights. Consumer workers hold much of the passion and perspective that will drive these changes. The more organisations enable consumer engagement and leadership, the closer we will come to making this dream a reality. While the primary responsibility lies with consumers to take on leadership roles, the sector can make an enormous contribution by taking on some of the ideas in this article to create and nurture increasing opportunities for consumers.

Indigo Daya is a recovery expert by experience, and has a passion for transforming the mental health sector through collaborative consumer leadership in service delivery, policy and education. She is the project manager of Voices Vic, Prahran Mission's consumer-led program for people who hear voices. Indigo is also an independent trainer, speaker, consultant and human rights campaigner who has spoken at conferences across Australia and internationally. This article is based on her address at this year's VICSERV conference.

www.voicesvic.org.au
www.indigodaya.com

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