PEACE-MONGERING:
CONSUMER LEADERSHIP IN BUILDING COLLABORATION BETWEEN CONSUMERS, CLINICIANS, FAMILIES AND THE COMMUNITY SECTOR AT THE 2013 WORLD HEARING VOICES CONGRESS

Indigo Daya and Neil Thomas, † VIC

ABSTRACT
The 2013 World Hearing Voices Congress, reportedly the largest consumer-led mental health event in Australia’s history, aimed to address past conflicts between consumers and clinicians in creating an event which promoted respect and collaboration. In particular, the congress aimed to respect individuality over stereotyping, diversity over dogma, collaboration over exclusion, and to promote non-violent ways of communicating about emotional and challenging issues. The congress utilised many innovative practices to demonstrate its messages. The event attracted over 770 people from all target groups (consumers, clinicians, community, family, and academia) who were actively engaged in discussing new ways of working with people who hear voices. Delegates reported feeling included and respected, that the event changed their thinking about hearing voices, and that they felt more able to work with voices (their own or others). The congress was an example of consumer leadership delivering a strong personal and professional impact within mental health.

INTRODUCTION
The consumer movement has been a strong advocate for change in mental health services, which can sometimes generate an unwanted dynamic of division. This remains an ongoing tension within the mental health sector, particularly when it comes to issues of human rights.

All systems are naturally resistant to change, and those seeking change can often be seen as problematic outsiders – or they can find themselves colonised by the very system they originally wanted to change. A particular challenge for consumers can arise when, as we argue for change, we unexpectedly find ourselves exhibiting the very behaviours that we are trying to shift, such as stereotyping or being dogmatic. This may be particularly likely when anger about personal experiences in mental health systems become directed at those who work in them.

The Hearing Voices Movement (HVM) has been a persistent advocate for practitioners paying greater attention to the experiences and wants of voice hearers. This has included advocating practices that help people learn to live with voices rather than seeking to eliminate them, and that give greater attention to the role of past traumatic experiences in hearing voices (Corstens et al., 2014). Voices Vic, the peer-led program at Prahran Mission, has led the Victorian Hearing Voices Network since 2009 and has been advocating locally for these same changes. Voices Vic had managed to strongly engage consumers and the community managed mental health sector, but until recently had a limited relationship with clinical services.

In 2013 Voices Vic hosted the 2013 World Hearing Voices Congress, the international meeting of...
Intervoice, the co-ordinating organisation for international hearing voices networks. We saw this conference as an opportunity to engage more strongly with clinicians and researchers.

**CONCEPTUALISING A DIFFERENT KIND OF CONGRESS**

In hosting the 2013 World Hearing Voices Congress, Voices Vic wanted to create a conference that was consumer-led, but which actively tried to bridge the usual divides between the clinical/research world and the usual audience of the Hearing Voices Congress. In particular, there was a strong intent to avoid the congress becoming dominated by ‘anti-psychiatry’ or ‘anti-medication’ rhetoric, which would risk deepening a divide with a clinical audience, whilst also to avoid ‘buying-in’ to disease-based conceptualisations of hearing voices which are inconsistent with the HVM.

Planning for the congress was informed from the beginning by a desire to enact the words often attributed to Mahatma Gandhi to ‘be the change we wished to see in the world’. In practical terms, this meant considering some of the core issues around which the congress sought change, and then enacting this change in the way we planned, managed and delivered the event.

The topics listed below were defined as areas in which change was sought, yet also areas in which the congress could easily find itself re-enacting past problems rather than changing them.

**Stereotyping vs Individuality**

The consumer movement in general, and the HVM in particular, often take issue with consumer experiences being reduced to diagnoses, and behaviours stereotyped using simplistic labels such as “non-compliant” or “lacking insight”. We did not wish to respond by in turn stereotyping the mental health system, or clinicians, or families. While we understood that services and individuals attending the event may engage in practices inconsistent with HVM and consumer movement philosophy, we also appreciated that these services and individuals were usually motivated by good and professional intent, and it would be unproductive to reduce the complexity of mental health service provision with labels of bad practice and so on. Hence we strove to approach each person and experience as individual and to be cautious about generalising or stereotyping. Voices Vic was also keen to bring multiple perspectives into the congress – specifically families and friends of voice hearers, and different cultural and indigenous perspectives.

**Dogma vs Diversity**

Many consumers and the HVM take issue with what is often described as a dogmatic approach to mental health systems and services, evidenced through the widely accepted thinking that hearing voices is pathological and a symptom of brain disease, that causation of psychosis is informed by genetics and biological factors, and that treatment is primarily pharmacological. In contrast, the HVM promotes an approach to hearing voices which facilitates people living with, and accepting the experience of hearing voices, finding meaning in this experience, and using creative strategies drawn from a range of therapeutic traditions and peer work to support people to change their relationship with voices. The HVM also emphasises the role of past trauma and adversity in relation to voice hearing experience, something which has long been overlooked in favour of disease-based conceptualisations.

These ideas remain central to the HVM (Corstens et al., 2014). However, the fact remains that many voice hearers consider the potential elimination, as opposed to acceptance, of voices appropriate as a goal, and many consumers find relief and express satisfaction with drug treatments. Further, there are many other different conceptualisations of the hearing voices experience beyond a manifestation of past adversity – including from psychology, cultural, spiritual and indigenous fields. In planning the
What we share makes us strong

– Proceedings of 24th TheMHS Conference 2014

classification we wanted diverse ways of thinking and approaches to be given a space, and to create
discussion to learn from each other rather than promote a singular view.

Exclusion vs Collaboration
Historically consumers have often not been part of their own assessment and treatment planning, let
alone involved in research and academia. Over recent decades the consumer movement and
increasing acceptance of recovery-oriented practice has begun to influence an increasing inclusion
of consumers, however this has only been a small beginning.

The aims of the congress were to include all stakeholders in the planning and delivery of the congress,
whilst maintaining consumers in the lead role. We did this by including clinicians, community workers,
family, academics and consumers in all committees and congress events, but ensuring that
consumers always made up at least 51% of each group. This allowed for diverse consumer
leadership, while also ensuring that everyone had a voice. It was intentional ‘reversal’ of usual
representation on these types of committees.

Violence vs Non-Violence … and a space for anger
Despite significant reforms in mental health systems, violence has taken a central role in mental health
service delivery, and in relations between the consumer and clinical sector. Involuntary treatments,
seclusion and restraint, and police involvement are violent interventions from a consumer perspective.
In some cases even treatment aimed at eliminating voices or beliefs that are valued by the person
can be experienced as violent.

From the opposite perspective, our experience was that events run by the consumer movement and
HVM have sometimes responded to these experiences with verbal violence towards clinicians and
mental health leaders. While these responses may be driven by an understandable anger and
experience of injustice, they have done little to bring the different stakeholders together or to promote
genuine change.

The aim for this congress was to recognise that many people will have a justifiable anger or frustration
that may need expression, but to provide spaces for people to express anger in non-violent ways,
while still retaining respect for others and promoting possibilities for engagement and conversation
rather than conflict.

In this area in particular the consumers involved in planning the congress reflected that we each had
often been considered by clinicians to be defensive, non-compliant and resistant to change. Generally
this had been because we felt attacked, unheard and powerless. We recognised that we did not wish
to create an event where mental health service staff felt attacked, unheard or powerless and as a
result adopted a defensive position.

Further reflection led the team to see that consumers were not the only people who felt angry about
the mental health system (see Daya, 2012), and so space was needed for all parties to express the
difficult emotions that we knew would surface as we promoted difficult conversations.

Many workers have told me how awful they feel about coercive treatments they have
participated in during their work history…. I suspect many bureaucrats and senior decision
makers may also be angry. They just want good, effective and efficient change – but no one
seems to be able to talk about it in productive ways. The depth of difficulty in achieving
constructive, peaceful conversations is significant. (Daya, 2012)
COLLABORATIVE EVENT

The congress was held during November in Melbourne, and titled: ‘Journeys to Understanding – Sharing Experience, Expertise and Wisdom’. This three-day event was not only the largest ever World Hearing Voices Congress, but, with 770 attendees, it was the largest consumer-led event we are aware of in Australia’s mental health history. There were 119 sessions over eight concurrent streams, and more than half of these were led by people with lived experience. We also intentionally created a program which also included a range of prominent clinical, research, family and indigenous speakers. This enabled us to engage with a wider audience for the conference, and to create opportunities for dialogue during sessions.

Acknowledging diversity by doing away with keynotes

To support dialogue, we took the unusual but successful approach of replacing almost all keynote sessions with round-table discussions that brought together many different perspectives, rather than putting forward one speaker as holding the primary expertise. This was an effective strategy for bringing speakers towards shared ground.

The event opened with a roundtable discussion talked directly about the philosophy of the congress and was called ‘A conversation about voices, non-violence and change’ and it set a strong platform for the rest of the event. Speakers included Professor Alan Rosen, well-respected psychiatrist, Indigo Daya, consumer leader, Dr Rufus May, voice hearer and psychologist from the UK, Lyn Mahboub, voice hearer and psychologist, and Dr Lewis Mehl-Madrona, psychiatrist with a Native American perspective (US). We asked this group to explore how congress delegates could take on the challenge of having difficult conversations throughout the three days, expressing their emotions, yet remaining respectful and collaborative.

Other panel conversations, each of which included a wide range of perspectives, professions and experiences:

- The pros and cons of medication
- Indigenous experiences of voices

Figure 1: Opening panel discusses voices, non-violence and change (L-R: Lyn Mahboub, Dr Rufus May, Dr Lewis Mehl-Madrona, Prof. Alan Rosen, Indigo Daya)
Voices and trauma
What are voices?
Clinical practice
Families and voices
Visions and other sensory experiences
Dissociation and voices
Research and voices

Active, ‘PowerPoint-free’ stream and self-care spaces
Another strategy was to make one of the congress streams ‘PowerPoint-free’. Rather than delivering presentations, speakers in this stream were required to demonstrate or lead practical activities in which delegates ‘did the work’, rather than talk about it.

There were several intentions behind this strategy. The first was to acknowledge the large consumer group in attendance and to provide space for keeping well. The second was an acknowledgement of the difficulty of passive listening encountered at so many conferences. The third was to demonstrate what the organisers wanted to see in an average psychiatric unit – active recovery work rather than passive listening.

This stream resulted in some unusual sessions: laughter yoga, body work, sound meditation, sacred voice theatre, boxing, brain gym, and prayer and spirituality. One of our international psychiatrists ran a discussion entitled: ‘How to have fun with your psychiatrist’ which was well attended. This stream was fully attended throughout the congress.

Figure 2: The active recovery zone

Next door to the active recovery zone was a chill-out space called ‘Tranquility Cove’. The room was designed to be a calming space that utilised concepts from ‘sensory rooms’ and a wide variety of recovery ideas. The room included:

- Audio players and headphones with meditation and mindfulness recordings
- Soft seating
- Sensory items – along with instructions for use
- A DVD of a fish tank on rotation
- Soft lighting
- Counsellors and peer workers available to talk
- Yoga mats and advice on stretching and exercise

What we share makes us strong – Proceedings of 24th TheMHS Conference 2014
Open space approach
The last afternoon of the congress employed the ‘open space’ or ‘un-conference’ format where congress delegates jointly decided the topics for 26 separate, concurrent sessions. This meant that every person could be a speaker, and led to many new ideas and networks being formed.

A voice for everyone: The Voices Wall
Throughout the congress ‘The Voices Wall’, a large graffiti installation, was available where every delegate could share their ideas. The space was well used throughout the event, and there were several examples of conversations emerging on the wall.

Voices for Reconciliation
A project ran throughout the congress to provide a space for discussion about overcoming anger and past harms. Led by Dr David Denborough from the Dulwich Centre, the Voices for Reconciliation area provided journals for delegates to write their own experiences and thoughts about how people can express and acknowledge past harms, and work together towards reconciliation and change. Each day David Denborough provided updates from the stories shared.

CONGRESS OUTCOMES
In determining whether the conference was successful in its vision to generate a more collaborative space, we considered the mix of delegates who attended, and the feedback we received.

Did we attract a mix of delegates?
The event was successful in attracting delegates from all of the target groups:

- 25% clinicians
- 12% carers
- 20% consumers
- 3% both consumer and carer
- 12% community sector
- 9% peer workers
- 19% not specified

In particular, there was a critical mass of clinical service staff attending, which has been unusual in our experience of conferences run by consumers.

Did delegates feel included and respected?
We then considered whether delegates felt included and respected in feedback we received from anonymous feedback forms. We found that in spite of the wide range of delegates, only 5% indicated not having felt included and respected.

![Image](image_url)

*Figure 5. Reports of whether felt included and respected on feedback forms.*

Did the conference have an impact on delegates?
We then examined whether the conference made an impact on delegates in the areas being targeted:
Figure 6. Reports of whether congress changed thinking on feedback forms.

Figure 7. Reports of whether learned useful information on feedback forms.

Figure 8. Reports of whether felt included and respected on feedback forms.
Comments on congress delegate evaluation forms gave further detail on the impact of the event on delegates.

What were the most important things you learnt at congress? (representative comments)

- Recovery is possible. I was blown away by the expertise of the presenters with lived experience.
- I spoke to a voice hearer and was actually able to ask questions openly about how it was for her and what it meant for her life, listen to her, and ask how I, as a Div 1, could be most helpful to a person in distress coming to the hospital. I could ask her straight and not be hindered by protocol, rules & regulations of the hospital.
- The impact of trauma on an individual and that people cope and survive differently. The information about narrative practices was very helpful and inspiring. The spiritual aspects was the most enlightening experience overall and appreciated the discussions with a Maori Elder and Sharman Psychologist.
- The value, power and inspiration of consumer-led events.
- I went to the talks from carer/family perspective. I realised that they need a lot of support and understanding too. I think I never thought of it that way! That was a real eye opener to me!
- I learnt that I am not alone. I learnt that there are brilliant, caring, real psychiatrists out there. I learnt that I need to a lot more work around trauma.

Other delegate feedback (representative selection of comments):

- I learned a great deal from the sharing of voice hearers’ experiences and will be implementing that in my practice.
- The conference has made me realise I am not alone as a clinician and I am part of something very special that I will fight for, it has given me renewed resilience to keep planting seeds for change wherever I can.
- It was the most egalitarian, inclusive and respectful conference I have ever attended.
- The most significant, life changing experience.
- Highly valuable. What stood out to me on the last day was hearing clinical professions discuss how this has challenged their way of working with clients... and that is no mean feat!!!
- The congress was amazing!! Having attended many conferences over my working life this was most definitely the most insightful, honest, exciting and engaging conference I have ever been to. It was a credit to everyone involved and the care and consideration taken to all was
exceptional. Working with young people who hear voices and other experiences I am confident that this congress will increase the awareness of their experiences and have a new momentum for the Hearing Voices Movement.

- Enlightening! Confronting! (at times). Educational. Friendly! Honest! Fabulous!
- As I received funding for congress and accommodation to attend it was a valued gift I could not otherwise had exposure to. Away from my norm a little respite too. I valued the experience overall immensely.
- I have a concession card so the cost wasn’t great, so I felt the value was excellent. The really frustrating thing about the conference was that I couldn’t go to two or three presentations at once.
- Absolutely life changing. This congress has opened my eyes and my heart, and given so much hope.
- It was one of the best learning events I have ever attended.
- Its success sends an important political message.
- I think for me the value in this congress was that it was so human and real. Instead of discussing people often in technical terms when they are not present, like mental health training events often run, the congress was about the voice hearers/carers, their stories and what really matters to them. I think it would be hard to leave such an event without it making an impression.
- It was like a music festival of voices.

On the third day of the congress, during a plenary session, a 69-year old man stood up and told the audience that he has heard voices all his life, and this was the first time he has ever found the courage to tell anyone.

Since the congress, a substantial number of new partnerships between Voices Vic and different clinical services began to form. The act of discussing change together, of listening deeply to each other’s stories, and of working with a spirit of collaborative partnership opened many new possibilities for the future.

IN CONCLUSION
The 2013 World Hearing Voices Congress demonstrated that consumer leadership can create a new type of learning space and collaborative enquiry within mental health, that widely diverse perspectives can co-exist and learn from each other, and that there is a willingness to work in nonviolent and collaborative ways within mental health.

By all measures – financial, attendance, delegate profiles, qualitative feedback and overall event engagement – the congress was a significant success. Through reflective planning and a creative approach, the congress was indeed a ‘Journey to Understanding’, and a ‘sharing of experience, expertise and wisdom’.

ACKNOWLEDGEMENTS
The conference program planning committee comprised David Denborough, Indigo Daya, Judith Drake, Flick Grey, Sandra Hacker, Carol Harvey, Simon McCarthy-Jones, Lyn Mahboub, Lindy Moffat, Sandi Noble, Fi Robinson, Susan Rossell, Neil Thomas and John Watkins. The clinical advisory group, who contributed to considering how to engage clinical staff comprised Dominika Baetens, Phil Benjamin, Sandra Hacker, Indigo Daya, Carole Harvey, Greg Keane, Quinn Pawson, Justin Rowe and Neil Thomas. We would like to make special mention of Judith Drake and Chelsie Falconer for their massive co-ordinating role in operations of the conference, and the support of Intervoice. The conference was financially supported by funding from Victorian Department of
Health, Australian Department of Health and Ageing, City of Melbourne, and a large group of sponsors and supporters.

REFERENCES