

**Cath Roper (Australia)
and
Arana Pearson (New Zealand)**

**“The Lyre Bird and the Huia:
Voicing Song - Dreams”**

**Keynote address arising out of a consumer “Cultural”
exchange**

**TheMHS Conference
Melbourne Convention Centre
Melbourne**

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QUOTES

“When you speak and when you are heard you are committing a political act. Those who are silent, who are silenced, have no access to change, to choice, or to control over their own lives”. (Sara Paretsky) 1994.

“Our emotions are the only clues to our identity. The only true meaning in life is passion. The passion to learn, to paint, to love etc. Don't dare destroy your passion for the sake of others. When you do you've lost the beauty of life and that's what a sin is. By robbing yourself of your very reason to exist you have cheated.” (Candy Darling) diary excerpts 1970-72.

“art consists in bringing the memory of things past to the surface. But the author is not a passeiste, a worshipper of the past. He is linked to history - to memory - which is linked to the common dream. That common dream is a part of the public good. It is the disinterested past, which acts both as a warning and a guide. (John Ralston Saul quoting Le Clezio, French novelist) “*The Unconscious Civilisation*” 1997.

“I think Tir's a born artist. Not a craftsman; a creator. An inventor - destroyer, the kind who's got to turn everything upside down and inside out. A satirist, a man who praises through rage. We force a man outside the sphere of our approval, and then condemn him for it. We've made walls all round ourselves, and we can't see them, because they're part of our thinking. Tir never did that.....he never could build walls. He was a natural rebel”.(Ursula le Guin) “*The Dispossessed*” 1974.

Unruly boys	A crack on the head
Who will not grow up	Is what you get for not asking
Must be taken in hand	And a crack on the head
Unruly girls	Is what you get for asking
Who will not settle down	
They must be taken in hand	

“*Barbarism begins at home*” (Morrissey) 1985

“One of the most highly developed skills in contemporary western civilisation is dissection: the split up of problems into their smallest possible components. We are so good at it. So good, we often forget to put the pieces back together again”. (Alvin Toffler) From the forward to “*Order out of Chaos*” Ilya Prigogine and Isabelle Stengers, 1984.

If reality bites, dreams can bite back.

Between the idea and the reality	Between the conception and the creation	Between the desire and the spasm
Between the motion and the act	Between the emotion and the response	Between the potency and the existence
Falls the Shadow	Falls the Shadow	Between the essence and the descent Falls the Shadow

(T S Eliot) “*The Hollow Men*” 1925.

“...she wrote, that memory is fragile and the space of a single life is brief, passing so quickly that we never get a chance to see the relationship between events; we cannot gauge the consequences of our acts and we believe in the fiction of past, present, and future, but it may also be true that everything happens simultaneously - as the three Mora sisters said, who could see the spirits of all era mingled in space”. (Isabel Allende) “*House of Spirits*” 1985.

“Society blindly regards psychiatry as safe medicine. I found out that the psychiatric institution was not about healing but about the oppression of the human spirit. It taught me to accept being terrorised because these were ‘medicine’ and I was ‘sick’. The intensity of suffering that this experience produces shatters the walls of tolerance like a sledge hammer on porcelain”. (Jeanine Grobe) “*Beyond Bedlam*” 1995.

Obsession is the cancer of mental health

The essence of mental health is the ability to see good everywhere.
(Emerson, from the 1860’s)

“For too long - for half a century, in fact - psychiatry tried to interpret the human mind merely as a mechanism, and consequently the therapy of

mental disease merely in terms of a technique. I believe this dream has been dreamt out. What now begins to loom

on the horizon is a medicine...of a humanised psychiatry". (Victor Frankl - psychiatrist)

"The health professional can't really explain it (mental illness) except in vague or incomprehensible terms of chemical imbalance. So relief is in the personal care and attention and time that are offered to you. They are just as important as the medications". (The Mason Report, May 1996)

"I have to remind myself that some birds aren't meant to be caged - their feathers are just too bright. And when they fly away the part of you that knows it was a sin to lock them up does rejoice - but still, the place you live in is that much drab and empty when they are gone". (*Shawshank Redemption*) 1994 Castle Rock Entertainment.

It's up to the less broken to look after the more broken.

Cath sits on the steps of the auditorium, in the audience, with 24 cardboard labels around her neck, her mouth taped over. As the song "*Sounds of Silence*" by Simon and Garfunkel begins, she rises, walks towards the front of the auditorium, taking labels from around her neck, and placing them gently around the necks of the people in the audience. The labels read: not credible; disinhibited; psychotic; schizophrenic; sick; insightless.....etc. As the music finishes, the following extract from Cath's file note is read out by Arana:

Excerpts from report on continued detention for the Mental Health Review Board, 17.2.95

At assessment she was restless, disinhibited, disorganised, agitated and unable to give account of actions. Very labile mood. Recommended and brought in by police with restraint.

Has a history over the last nine years of multiple admissions to psychiatric hospitals with relapses similar to this one. They respond to medication, + high functioning in between admissions.

Current Mental State:

Well groomed, short greying hair. Behaviour: reasonably settled on ward but some irritability and guardedness. Gradually becoming less hyperactive. Affect remains labile. No perceptual disturbances, speech quite pressured. Content - doesn't see her admission in terms of psychiatric illness. Quite dogmatic Somatic complaint subsiding. Little insight.

Patients Attitude to Treatment:

Catherine is very unhappy about taking thioridazine though does comply. She is willing to continue the sodium valproate long term.

Why is Treatment Not Possible in a Less Restrictive Setting?

Because of Catherine's lack of insight into her illness and her unwillingness to take medication other than sodium valproate.

Pre-hearing Steps

The patient has been given an opportunity to read the materials from his/her file which have been presented to the Board.

No.

From the audience, with a hand-held microphone, Julie Shaw and Mandy read out the following text - some of the kinds of questions that Cath wishes *she* could ask, instead of being asked thing like: "Can you count backwards from one hundred by sevens?" "Do you know who the Prime Minister of Australia is?".....

Do you want to know how to care for me?
Can you hear me?
Will you hear me?
Can you give me safety?
Do you want to know what keeps me safe?
Can you see that I am also you, and you are also me?
Can you become curious about what I am?
Can you not judge what I am?
Can you regard me, not monitor me?
How precious is your freedom of will?

Cath's Introduction

Cath takes the tape from her mouth in order to speak:

I have no space to speak until I cast off the labels I have been given. Until I discard the medical model - become the 'insightless creature'. Because how *do* you speak when you are only asked certain questions which have certain answers.

How do you speak when you hear the gavel of dismissal: the rules are all pre-determined, the court is in session, the way you demonstrate insight is to say you know you have no insight. As far as your eye can see and your ear can hear this is no place for you - there is no insight in you here, and I cannot live in that place, that has been marked out for me - that narrow, arid, sterile place, that hopeless place, where dreams are only disease.

I have been filed, taken, classified, named, categorised, abused, labelled by your institutions. Here I can only be either credible, or not credible, I can have no credence, for that is something you *give to* another, out of innate respect for them. Credibility is about *seeming* to be something - it is a judgement made by another. Interestingly, it is a word often used these days, in keeping with a world in which 'seeming' is everything.

I have spent many years and much energy trying to hold a mirror up to you, to show you what it has done, and spent much time, and devoted much energy in point to other ways - *poured* creativity and ideas into this monolith which seems only a coating, a rusting layer, absorbed into the walls, leaving no trace.

Reality is something that partly is so because of who gets to define it, and who gets to say this is “unreal” and this real. What happens if we say that all experience is lived experience and therefore real? Who owns the language that names the reality? Who leaves unnamed the language that describes our experiences, dreams, our expectations, our aspirations. What *are* our dreams, collectively, singly? What effect does it have on behalf of another that something is *not real*?

I wish to acknowledge those of us who have not spoken, do not speak, have not been given an opportunity to speak. We who have used psychiatric services know well what it is to be rendered speechless, to be unheard, passed over, judged lesser - our sight labelled faulty.

And it doesn't matter how many or how great the speeches that can be given - the truth is that at any time I could be subjected to the most offensive and violent intrusions into my very person. Isn't that a strange thought. I cannot be *safe* among many of you here. That is real also.

At this point, the people in the audience who were 'given a label' are asked to turn them around and hold them up high, so that they now all read “LABELS SUCK”. The whole audience is then invited to join in, yelling out: “LABELS SUCK”.

The Exchange

Late last year, I was asked by Merinda Epstein, co-chair of Melbourne TheMHS conference organising committee, whether I would like to do a co-keynote address with Arana Pearson from New Zealand. We had both given a paper the year before at the Hobart TheMHS Conference. And then I started thinking. I started wondering about the choice of speakers. I knew very little about Arana except that he had seemed to inspire those who attended his presentation into believing that what we call consumer consultancy here in Victoria, can work and is working over there.

Then I thought “hmmm, this is interesting”. Mine was a paper on how I fell off the collaboration boat, and how I have to advocate for a dismantling of our current psychiatric system (the monolith).

“What hi-jinks are they hoping for?” I wondered. And then I sat down and thought some more. I thought, well, if there are significant differences in the experience of doing similar work, in different places, what's it all about? And I thought there are some things you only get to really know about if you get to see for yourself.

Within five minutes, I had jotted down all of the things I thought were interesting, in my journal, about the differences I already knew about. Two different countries, a male and a female perspective, the cultural differences, the historical differences in white treatment of indigenous people, and I was trembling, the way I do when I get excited about something. And I wondered, what would happen if I got to see for myself this other place, and Arana got to see my place, and put *experience* first to see what we could learn.

I can't recall how long I left it before I got the courage to ring up Merinda with this flight of fancy. I had even thought through a possible time frame. To my horror and delight, Merinda said she would float the idea and see what would happen.

Suddenly, at Auckland airport, stopping over before a flight on a tiny Brazilian plane to Rotorua, I realised this was no longer a dream. We were on a do-it-yourself 'exchange programme'. No turning back. Dream becomes a reality.

We had organised this through teleconference, with a number of three- and four-way calls. One of the first things we did was arrange to hear tapes of each others' talks. It was very exciting to rip open a package, stick it in the tape deck, and..... we'd each received copies of our own talks! (This was rectified in no time.)

We made a decision that we would use all different ways to record our work, much of which cannot be reflected in this keynote speech. We each kept a journal, we wrote letters, we noted all our ideas, we had long conversations on the phone, we posted each other articles and cartoons, we swapped books, even fiddled around with song writing. We looked at past consumer keynote speeches, we posted each other recorded tapes of our ideas.

It occurred to me that since I had got on the plane at no time had I said to Arana "I'll be the one wearing the carnation." I was expecting to meet a Maori man called Arana. For about fifteen minutes I hung about, watching the little lounge clear of people. In desperation, I went to Information and asked if I could have myself announced (along the lines of 'white courtesy phone' from American movies).

The woman advised me to write a sign for myself with my name on it. Then I thought, I know, I'll go over to the rent-a-car desk and see if they'll announce me. (Arana's words had been "I'll arrange to have you picked up" so I wasn't sure if he'd actually be there.) So there we were.

My introduction to Rotorua was via a number of outstanding tales about the lakes and the legends and the mountains we were passing, but I couldn't concentrate very well.

The most memorable part of my visit to Lakeland Hospital where Arana worked was the Maori welcome I was given. Many Australians will not know what this is like. It was as though all my own ancestors and those of the people who welcomed me filled the room. Although I could not literally understand the words spoken, I sure *felt* them. Then each person greeted one another with a hongi. It's hard to describe the effect. It feels like you are welcomed as a whole person, and your reason for being there is given importance and a blessing. I am used to trying to hide and underplay my existence, so it was both unfamiliar and a little scary.

I saw how different it is when an indigenous culture is celebrated through the most basic of social rituals, such as a greeting. Customs with which all New Zealanders would be very familiar *as a matter of course*. Here in Australia, for example, it is only relatively recently that we have publicly acknowledged the Aboriginal tribe, on whose land we are, as a natural and necessary part of our responsibility at gatherings such as this one.

General Observations

I have no authority to speak about this, but I came away feeling that there is still a lot of misunderstanding about the historic treatment by white colonialists of Aboriginals in this country. It's true also of some Australians, but it was something I first noticed at the Sydney TheMHS Conference. It seems to me that it is not just about the difference of having a treaty such as the Treaty of Waitangi.

For example, I was surprised at how comparatively "modern" Maori occupation of New Zealand is compared with the history of Aboriginal civilisation in Australia. And obviously, the legal conception of Terra Nullis and what was acted out under that clause, has no parallel in New Zealand. I have been afraid of the over-simplifying of comparisons between the two countries, especially if it bends towards looking at cultural differences between indigenous people, and fails to take into account their radically different encounters with white colonialism.

Arana's Introduction

God doesn't choose fit people to do His work - He fits people to do His work. But I did not realise some fifteen years ago that my 'consumer' experience would qualify me to become a keynote speaker at an Australian TheMHS conference.

God doesn't choose fit people to do His work - He fits people to do His work. But I didn't know the value of my being diagnosed with a major mental illness would shape me into a person who could come to value others labelled with mental illness and do something positive about it.

We both start with our 'consumer' identification because this is the beginning for us. Our experiences of being labelled with a major mental illness and receiving the stigmatising treatment for this within mental health services is the common denominator. Mental illness is the great leveller for us all and it is what binds us together as a culture. My experience of mental illness and the stigmatising hospital treatments have forever conspired to irrevocably change my life. My life's path has never been the same since.

"Mental illness is different from physical illness. Mental illness is a very personal thing, a personal experience. You can't see it, so you can't distance yourself from it. It's you. It's for life. It takes your soul. Sometimes it's like dying. No one else sees it, so they often don't believe you or they don't understand. You don't understand it yourself; often you don't understand yourself. The health professional can't really explain it, except in vague or incomprehensible terms of chemical imbalance. So relief is in the personal care and attention and time that are offered to you. They are just as important as the medications".¹

So if relief is in the personal care, attention and time that are offered, (and some of us think these are more important than the medications) - then the question we ask mental health services is to evaluate and measure for us your quality in providing personal care and attention and time that you offer us.

And to policy makers, governments, and writers of reports, we ask - beyond the hope and dreams of your paper documents: "are good things happening to people who receive services from you?" "And to go further, where is the leadership within the sector to ensure citizens of New Zealand and Australia are receiving personal care, attention and time?" - because

¹ Dr Don Quick, psychiatrist, *Inquiry Under Section 47 of the Health and Disability Services Act 1993 in Respect of Certain Mental Health Services - Report to the Minister of Health Hon Jenny Shipley - May 1996*

even if these documents read well, they really mean little to me if my experience of receiving services does not reflect quality time, care and attention.

Anomie

Strung up the rope of convention strangles
Hanging limp they feel no pain
Ask them direct they are oblivious to their
Blatant
Superficial
Shield

“For each a gold brick masque
to each a uniform justified in consensus”

The lyre bird has no voice of its own. (1977) □ AJ Pearson

This poem of mine was added to my file notes once. In what way does this file entry correspond to a person’s life and how would this note help a service to understand what kind of time, attention and care this person would need?

There are disparities between policy and practice; there are disparities between file and life. In a deep sense, the unacknowledged problems of mental health service delivery is a literary problem involving the record and notes archived in a file: a problem of *metonymy*. My record diary keeping vs file; my journal in exchange vs the paper we present today. If you re-organise the letters of the word “file” you can make out of it the word “life”.

And so this is where we begin. This is the reality of our experience as mental health consumers: using mental health services. What naturally flows from here is the stigma contributed to by those services and the resulting discrimination within our communities.

And so it was useful we in New Zealand just happened to be organising a consumer hui in March this year when Cath was available to visit - a hui that was designed to contribute to the Government-funded project to counter stigma and discrimination associated with mental illness in New Zealand.

A definition of the terms:

<u>hui</u>	gathering, meeting, conference
<u>powhiri</u>	welcome, greetings ritual followed by:
<u>kai</u>	meal, breaking of bread, hospitality

mahi or taki the work or agenda to be discussed

poroporoaki closing speeches after the final kai

karakia prayer

wairua spirit, spiritual, the binding/connecting glue that animates and leads the successful outcome of the ??

..... and it meant an aeroplane flight from the Lakeland Health mental health services in Rotorua to Wellington where the hui was held at the Tapu te Runga Marae.

The Hui (Cath)

We have chosen to spend a fair bit of time on this part of the exchange because it stands out as a deeply extraordinary event.

The marae was made up of recycled materials such as packing cases and second hand wood. The land, the designs, pattern shells, rocks, wood shapes. You take your shoes off when you enter the marae. Everybody sleeps communally, eats together, and works together so that there is an atmosphere of gradual getting to know everyone, their ideas, their perspectives. The first evening began with sharing something about ourselves in turn, where we came from, why we were involved.

In my (limited) experience, it has never happened that funders have been invited to a gathering of consumers, rather it is usually the other way round, and then, it is usually only a couple of people who get to meet the 'real' decision makers. This is something amazing that I can't really describe - what it does to be part of an orchestration, where the usual roles are reversed, and all parties are seated on the floor, shoeless, and very much unable to hide behind bureauspeak. All conversation was painstakingly recorded, during the entire hui.

But the evenings stand out too. We were up late at night, singing, drumming, and I felt so nostalgic for a time that I never knew anyway, where everybody knows the same songs, and they all obviously have a significance that is built on over time. It reminded me so palpably of the importance of music and comedy and drama in the nourishing of the work that we do (or we'd all go mad). That having fun is not a luxury, and should we lose that, we would indeed find we had become *part* of what we should be fighting.

My role at this hui was as an invited guest. It was a great honour (although I feel like I stuffed it up) to pin up the promotional banner for the campaign and wish for its success.

Who's going to talk about the difference between Australia's campaign and this one in terms of consumer participation, process etc - ???!!!

Huia birdcall (play the tape recording over the internal music system)

What you are hearing is the best guess. This is the call of the huia bird. We do not have recordings of the actual bird. The huia became extinct by the turn of the 20th century.

The huia exhibition which we saw in Rotorua came with a warning - if we are to keep our environment healthy, if it forces us to think - then hopefully the extinction of the huia bird will not have been in vain.

These birds were usually hunted as pairs. A pair was much more valuable than a single bird. One of the reasons for this was their complementary differences. The male had a short, pointed beak, the female a longer curved beak. Whether human romanticism or not, people thought that the pair helped to feed one another, the male's beak being good for pecking for ground food, and the female having a better beak for foraging inside tree trunks.

The thing that got me most is that one bird, once caught, would give a cry of distress, which usually led to the giving away of the location of its mate, which echoed its distress cry. A hunter's dream.

But why is it such a powerful symbol? It is strange to think that during the nine months of this exchange, there have been events around the globe which in some way reinforce the lesson to be learned by keeping the notion of extinction in our minds, if we are to avoid it.

Non-aboriginal people from Australia, unhappily, should be well aware of their own history of human interference and human design towards extinction of flora, fauna, people and culture.

It was while we were in the middle of the hui in Wellington that the first news came through that NATO forces were going over Kosovo and bombing targets, bringing us such concepts as 'acceptable loss of life', and the killing of civilians on a large scale as 'accidental' or a ploy to make NATO 'look bad'.

At this moment, in East Timor, Australian and other United Nation signatory countries are preparing for a 'peace-keeping' mission. Surely for us this has been a continuous warning about the extinction of a people and its culture?

But why did I stand and stare, transfixed, and revisit this exhibition? Some people have likened those of us with 'mental illness' to the canary birds of shaft miners.² That our response labelled as 'mental illness' is a natural consequence of our toxic colonised/social environment. It somehow speaks to me of those whom I know whose environments are not what they could be, for those whom I have known who are no longer with us, and for the necessity for all of us to keep on dreaming, knowing that without dreams and visions, there may only be a status quo which will prove to be unable to sustain anything or anyone.

If we have something to learn about extinction, let us learn it right now - about the way we treat and view, and provide the best environment for each of us as it is our right to enjoy. For, those of us who experience the hardest of lives, know also about what makes for ease, and you will often find that it is we who continue to dream the good dream, and fight the good fight, even if it seems to meet with indifference or obstacle.

Australia (Arana)

I could choose from a wealth of material to share about my exchange visit to Australia, such as my participation in the Lemon Looing boardgame training in Australia, and its enthusiastic reception back in New Zealand; my copy of the 'advocacy kit'; of the Victoria mental health services and consumer participation research programme.

But instead I will share from my dream journal an actual dream I had while visiting Australia.

The background to my dream is my frustration at not being introduced to local Aborigine people at all by those consumers and others who had arranged my visit. (Dated March 25, Tuesday morning, 7am. Melbourne.)

"A school - similar to Boys' High School in Palmerston North and also Intermediate. It is "break-up" ie/ the end of term for the year. A school hall with a curtain. I put on my white 'long Johns' over top of my black trousers. Kids are beginning to get out their instruments behind the curtain on the stage. The 'clang' of a drum kit. I walk down corridors, looking up at the Roll of Honour board I over-hear the choir warming up to the choir teacher. I realise it is far too hot with my Long-Johns on and I will need to take them off. Just then I bump into a female student who appears lost. 'what is your name?' I ask. 'Dodijerdo' she replies (which I thought was something aboriginal like "didgeridoo"). "Oh, your name is Deirdre", I answer in easy interpretation.'

² Merinda Epstein, 1997 "Discrimination" paper to TheMHS conference

I shared this dream with Cath on Tuesday, so she is my witness to the events the next day which are as follows as per my journal entry:

Wednesday 26 March

Cath and I visited an Aboriginal women's welfare league in Thornbury. We did not have an appointment. The director of the service was a very busy lady who made time to see us. She introduced herself, shook my hand and told me her name was Deirdre. She gave me this book: *History of the Aboriginal women's Welfare League in Victoria*.

What are the statistical odds of this name coinciding with the dream event I had the previous day, wonder?

Cath's dream

I dream that we will come to see that when things are done against a person's will, it is of the utmost gravity. We have to own when this is done. If we are to continue to perform acts against a person's will, then we have to see it for what it is - a sin, a human sin. If you argue that it is necessary, you must still acknowledge that it is sinning against humanness. When you do this to another - understand what you are doing. Don't turn us into sick objects so that you can exonerate yourself. I am you, you are me.

Arana's dream

"Psychiatry Rehumanised: For too long a time - half a century, in fact - psychiatry tried to interpret the human mind as merely a mechanism, and consequently the therapy of mental disease merely in terms of a technique. I believe this dream has been dreamt out. What now begins to loom on the horizon are not the sketches of a psychologised medicine, but rather those of a humanised psychiatry". (Victor Frankl "Man's Search for Meaning")

What are your dreams?

We ask now for your help with our keynote. On your seat you should have found a small sheet of paper with the heading "What are your dreams?" printed on it. For the final five minutes, we invite you to have a think about this, and write, draw, or symbolise in any way you wish, what your dreams or visions might be as we hurtle our way into the year 2000. They do not have to be restricted to the psychiatric field.

During the afternoon of the first day of the conference, four people spent over an hour sticking adhesive on the back of over 300 collected 'dreams' (which the audience had taken the time to write or draw) and then putting them on display for the duration of the conference.

These were later rescued (from rubbish bags) and have been printed in the October 1999 edition of *New Paradigm*, produced by Psychiatric Disability Services of Victoria (VICSERV) Inc., 370 St George's Road, North Fitzroy, 3068.

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