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LIKE MINDS, LIKE MINE  
Whakaitia te Whakawhiu i te Tangata

# Like Minds

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WHAKAITIA TE WHAKAWHIU I TE TANGATA

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## Mental health consumers take the lead!



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

**Thanks to the Lighthouse Trust, 22 – 24 November 2006 saw the very first conference organised by and for people with experience of mental illness.**

The National Nutters' Conference marked a milestone in consumer leadership – the need to move from participation in mental health services to taking a leadership role. The conference was a prime example of moving this talk into action.

Launching day two of the three-day conference, Mary O'Hagan, Mental Health Commissioner, expressed her belief that "we were just as human when we were mad as we are at any other time in our lives".

She presented a vision for services in 2020 where consumers have an established voice in community, mental health and academic discourses. She underlined this vision with a quote

from Theodore Hook, "The best way to predict the future is to invent it".

Part of this process includes reclaiming negative language, starting with the nickname of the conference – "Nutters".

Roy Brown from the Lighthouse Trust explains the nickname developed after noticing that internationally other civil rights groups are slowly making everyday slang their own.

"We've seen how stigma and discrimination can be reduced against groups of people once those groups start using what used to be derogatory terms themselves.

"In America, homosexual and African American civil rights groups have taken words that were used against them – like 'gay' and 'black' – and absorbed them into their own cultures. That was our aim with Nutters'."

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Lighthouse Trust general manager Susie Crooks said the name was received with mixed responses. "Some people were very supportive of the name and others didn't like it – it offended them."

Case Consulting who organised the pre-conference workshop on consumer leadership were initially among those who were dubious.

Said general manager Colin Slade, "We knew from the start it was an event that we absolutely had to be at. But that name... some of us really worried that people would be turned off by it.

"We knew it was partly calculated to arouse media interest and of course it succeeded magnificently! But I know one or two people who refused to attend because of the name."

120 mental health professionals and people with experience of mental illness attended the conference. One of the key messages of the conference was that communities should value people with experience of madness.

Susie explains, "The conference was all about pushing boundaries and really standing up and saying that our 'mad' community should be valued and have the same rights as every other citizen.

"Recovery occurs when people with experience of madness have their human rights respected and when we don't face stigma and discrimination from others."

Governor-General Anand Satyanand opened the conference by saying, "Having your own voice... is the most important catalyst for change because the more you are involved, the more positive change you can effect.

"By embracing rather than rejecting your stories, and by sharing them with others, you are able to de-stigmatise your experiences and improve your recovery.

"This responsibility also gives you the dignity and courage you need for changing outside perceptions of what mental illness actually means.

"By changing outside perceptions, you can help create a safer, more embracing environment in which you can thrive."

He went on to say that through their combined voices, people with experience of mental illness would have far more opportunities in employment, for strong and supportive relationships and for participation in every aspect of community and family life.

"With every step we take towards this vision of greater participation, the further our darker moments recede into the past.



Anne Helm,  
Consumer  
Consultant

And the less likely we are to ever make those same mistakes."

Other key messages that participants came away with were:

- The need to embrace stories of people who have survived mental health services

- Recognising the tension between the medical model and the recovery movement
- The importance of opening opportunities [for people who experience mental illness to take leadership] at every level
- Mental health is everybody's business – with more New Zealanders interested in mental health, how can they support people with experience of mental illness?
- A unified call for people who experience mental illness to have increased leadership in their own recovery.

Guest speakers included human rights lawyer Tony Ellis, the President of the New Zealand Council for Civil Liberties, Mary O'Hagan, Mental Health Commissioner, Anne Helm, Consumer consultant and Human Rights Commissioner Warren Lindberg.

## Farewell to a *Like Minds* champion

**This issue we farewell Gerard Vaughan who has project managed the *Like Minds* campaign for the past five years. Gerard takes up his new position as CEO of the Alcohol Advisory Council of New Zealand (ALAC) from 12 February.**

During his time as National Project Manager for *Like Minds* at the Ministry of Health, Gerard has stewarded the project through important development phases and worked with key people and organisations in mental health to bring about changes in:

- raising awareness and creating understanding and acceptance of people with experience of mental illness
- increasing public awareness of how behaviour can be discriminatory
- emphasising the importance of inclusion for recovery
- lessening public fear and the association of violence with mental illness
- ensuring Maori and Pacific peoples' attitudes are influenced to the same extent as other audiences.

Gerard Vaughan says, "Working on *Like Minds* for the last five years has been full of highlights. Seeing the results through the research, the feedback from people and also the recognition through winning awards has been great.



Gerard Vaughan,  
National Project Manager,  
*Like Minds, Like Mine*

"However the real highlight for me has been the opportunity to work with such a broad range of incredibly interesting and talented people who are passionate about reducing discrimination. I think a big challenge for the future will be to keep the project fresh and relevant, and help people to understand what it is they need to do differently to be more supportive."

Gerard's dedication to the *Like Minds* work to reduce stigma and discrimination has been a major factor in the success of the project and he leaves the project in great shape for the upcoming phase four advertising campaign to be launched later in 2007.

A big thank you to Gerard for his unstinting commitment to *Like Minds* and we wish him all the very best for his work at ALAC.

*The Ministry of Health is currently recruiting for the role of National Project Manager, Like Minds, Like Mine and we will update you in our next issue.*

# Freedom just another word?



Tony Ellis, President of the New Zealand Council of Civil Liberties

## **Tony Ellis believes that using force on people with experience of mental illness (real or suspected) is a human rights issue.**

“People are frequently being forcibly taken into hospital, assessed, treated and detained by health professionals.”

Tony is the founding member of New Zealand’s only Human Rights Law Practice and sees any persecution of marginalised groups as the thin edge of the wedge.

“I’m entirely committed to human rights,” says Tony.

“Like many other areas of human rights, it is not uncommon for people with experience of mental illness who are being detained to be poorer members of society who need clear, helpful and fairly instant legal advice – but the system does not provide this type of quality legal advice.”

As current President of the New Zealand Council of Civil Liberties, Tony voiced his opinions at the recent national Nutters’ Conference speaking on ‘Human Rights for People Detained by the State’.

Critical and outspoken about the mental health sector, Tony is not a fan of compulsory treatment and told conference attendees, “Current service provision in mental health services is not an issue of power and control – it is systemic abuse of human rights.

“While society continues to treat people experiencing mental illness as *others* [despite the recent New Zealand Mental Health Survey: Te Rau Hinengaro’s statistics that one in two Maori will experience mental illness in their life] stigma, which leads to discrimination, is reinforced.”

Tony believes the current lack of a national body advocating for the human rights of people suffering at the hands of the mental health system is concerning.

“We need a national network of people advocating in all regions of our country, ensuring that procedures are followed correctly, and following through with complaints.

“Mental health treatment should respect human rights and the New Zealand Bill of Rights that are applied to each of us.

“But until people with experience of mental illness stand up and protest about

the current system, the struggle for equality, fair and humane treatment will continue into the future.”

One recent international development that has some significance for people with experience of mental illness is the United Nations (UN) Convention on the Rights of the Disabled, which was adopted by the UN General Assembly on 6 December 2006. (For the purposes of the convention, people with experience of mental illness are included as part of the ‘disabled’ the convention covers.)

New Zealand took a leading role in the convention with Ambassador Don McKay describing the adoption as an historic event. He added that those involved in the process could be pleased with the convention, as it will be extraordinarily far-reaching.

Tony says that the convention contains Articles that are of relevance to the mental health community. As they are the latest advance in the human rights of people with experience of mental illness we should adopt it whole-heartedly.

“The UN Convention comes into force when twenty countries ratify it – hopefully NZ will be one of the first – after it becomes open to ratification after 30 March 2007.”

There are at least five (of 50) Articles that are relevant to the mental health community:

- Article 8 Awareness-raising
- Article 12 Equal recognition before the law
- Article 13 Access to justice
- Article 14 Liberty and security of the person
- Article 25 Health of reasonable accommodation.

Reasonable accommodation is a theme running across a variety of Articles.

“It is important that both consumers and media become aware of Article 8 and actively lobby MPs and government influencers to ensure prompt progress on ratification,” says Tony.

“After ratification (if not before) we need to get on with awareness raising. I think that people with experience of mental illness are still treated like second-class citizens and it will only be through education campaigns that raise public awareness that this situation will change.

“The government needs to dedicate money and resources for it to work.”

The full convention text is available at [www.un.org/disabilities/convention/conventionfull.shtml](http://www.un.org/disabilities/convention/conventionfull.shtml)

## Article 8

States Parties undertake to adopt immediate, effective and appropriate measures:

- To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
- To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
- To promote awareness of the capabilities and contributions of persons with disabilities.

Measures to this end include:

- Initiating and maintaining effective public awareness campaigns designed:
  - To nurture receptiveness to the rights of persons with disabilities;
  - To promote positive perceptions and greater social awareness towards persons with disabilities;
  - To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
- Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
- Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
- Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

Tony Ellis is the author of a commentary in *No-Force Advocacy by Users and Survivors of Psychiatry*, published by the Mental Health Commission and a paper for the Mental Health Commission, *Mental Health: The Cinderella of the Detention System*. He’s always had an interest in human rights and started as a commercial law barrister in 1990 before moving into human rights law in 1995/96.

# Christchurch mental health radio show wins gold at NZ Radio Awards

**Picture this: You're a staunch *Like Minds* activist. You unexpectedly find yourself on the podium at Sky City Auckland.**

You have just received the top national award for the mental health radio show you present each week, and 2000 pairs of ears belonging to the nation's broadcast media are intently awaiting your message... what do you say?

"I can't remember exactly what I said," says Pam Barnett, broadcaster, consumer and presenter of *Quiet Minds*, the Christchurch mental health radio show that's been bringing the consumer message to Cantabrians for more than two years, "but I know I was talking anti-stigma and kept going for 2 or 3 minutes!"

Whatever she said struck home: "The people loved you!" gushed Paul Holmes to Pam afterwards. "Tell me more", said Marcus Lush. So Pam and the show's producer, fellow consumer, Debbie May told him what it was like to live with Bipolar disorder and how people's attitudes were sometimes more difficult to cope with than the disorder itself.

The night among the glittering stars of New Zealand broadcasting was the

culmination of more than three years of work for Pam, Debbie and many other supporters guiding the show's progress from its rather shaky beginnings.

The show was the brainchild of Terry Lynch, consumer, poet and occasional broadcaster, who first approached Plains FM 96.9 in late 2002 before gathering together a group of colleagues to develop the proposal. The station's programme manager Nicki Reece believed in the venture from the first but wanted to ensure that the would-be broadcasters had sufficient material recorded before letting the show go to air.

"It took us a bit longer than we had planned!" laughs Debbie. The first show was broadcast in June 2004. Since then, its consumer broadcasters have put psychiatrists in the interview chair, anti-ECT campaigners up opposite pro-ECT lobbyists, interviewed previous health

minister Annette King and other health ministry hopefuls before the last election, run programmes on specific psychiatric disorders, consumer artists and musicians and Mental Health Awareness Week. "You name it, we've done it," says Pam, "and if we haven't, we'll do it."

The show that scooped the national radio award was an interview that Murray Cameron did with recovering problem gambler, Steve Penrose who now works as a consumer advisor. Among Steve's more bizarre experiences was being banned from the Christchurch Casino, yet still managing to outwit security by sneaking in disguised as a woman.

CDs of all the *Quiet Minds* shows are held by the Christchurch Mental Health Education and Resource Centre and if you're from outside Canterbury you can catch the show on podcast at [www.plainsfm.org.nz](http://www.plainsfm.org.nz).

*A couple of weeks after the radio awards ceremony, Marcus Lush was enthusing on his nationwide talk show Radio Live, "We'll have a Bipolar Monday or Tuesday or whenever. I want one of those awards!" He was as good as his word. For three hours on the evening of November 14th, Bipolar was the only subject of his show, which received many calls from consumers and family members all over New Zealand and even one from an internet listener in Australia. Lush was so impressed by the response to the programme he is keen to do another.*

## Blame it on the boogie – positive risk taking in *Like Minds* education and training

**Risk can take many forms, but would you be willing to disco dance in front of up to 100 people (many of them strangers) in an effort to reduce stigma and discrimination associated with mental illness?**

That was the challenge audiences faced during Ruth Jackson's (Case Consulting) "Positive Risk Taking" workshops at the Building Bridges Conference in Christchurch and the Nutters' Conference in Napier.

Perplexed and reluctant participants were encouraged to get up and dance to the tune of ABBA's "Take a chance on me".

Afterwards, people agreed the rather unusual training technique lowered barriers and 'jumpstarted' the workshops so that further discussions between people with experience of mental illness, clinicians and other service providers were far more open and co-operative.

Education and Training workshops presented by people with experience of mental illness play a key role in the *Like Minds* Project. Through use of music, dance and other innovative and interactive facilitation techniques, *Like Minds* providers around the country are using positive risks to increase the effectiveness of *Like Minds* Education and Training.

Studies have found that 'contact' (between people with experience of mental illness and those without experience of mental illness) is the most effective strategy in countering stigma and discrimination associated with mental illness. Researchers have discovered that 'contact' must be of a specific nature in order to be effective. Several conditions must be present. These are:

- Equal status
- The chance for individuals to get to know each other
- Information challenging negative stereotypes
- Active participation
- Pursuit of a mutual goal.

Contact can be facilitated through the development and delivery of structured education programmes. This approach has been used in several different initiatives, both internationally and in New Zealand, with positive results.

*This abridged excerpt is taken from "The Power of Contact" (an unpublished project report) by Sarah Gordon.*

# Valuing the lived experience

## **In 2005 Joyce Waddington rediscovered something she thought she had lost – herself.**

As a person with experience of mental illness, she already had a successful career as a nurse with the Hutt Valley DHB Mental Health Service and supportive whanau, family and friends. But something was missing.

“Living through mental illness can impact on a person to the extent that you no longer feel any connection with yourself,” says Joyce.

“Although I felt connected to everyone close to me, I couldn’t seem to find that voice inside myself that said I was OK.

“There was this underlying feeling of emptiness that I knew I had to do something about.”

Joyce says self-stigma is still an unseen and unrecognised issue faced by people with experience of mental illness. One she believes needs to be acknowledged and addressed.

The tipping point for Joyce was attending the Recovery Training programme run



Joyce Waddington,  
Whakaturia Mauri

by Ron Coleman in August 2005. That’s when she realised that in order to be true to herself, she needed to integrate all her experiences, including those of mental distress.

So Joyce identified the many worlds she inhabits: her strong cultural identity as Maori (drawing from tikanga her wellness and conservationism); connecting with the environment and nature; art (writing and poetry); and her professional worlds.

Then she changed roles within her organisation – from nurse/clinician to consumer/tangata whaiora advisor – basically hopping from one side of the fence to the other.

It was not an easy move to make. “There were challenges along the way that I had not expected.” But reconnecting to herself was too important to Joyce and

she continued her journey to recovery.

“When all the worlds we inhabit in our lives are woven together we are able to reconnect with ourself, and reclaim our identity. It is a matter of embracing all of our selves in order to be whole,” says Joyce.

It is Joyce’s realisation and acceptance of her personal experience of mental illness, and the internal stigma she has carried about that experience, that has allowed her to make changes in her life and tackle the challenges that come with those changes. Now Joyce shares her experience with like-minded people through her association with the National Association of Mental Health Services and Consumer Advisors – NAMHSCA – (the association for DHB Consumer Advisors).

“My reconnection came about through my lived experience, which impacted my well-being and life and let me open the doors of my inner being to let go of my internal stigma,” says Joyce, “I would recommend the experience to anyone.”

Joyce spoke about her experiences at the first National Nutters’ Conference 2006.

## Depression campaign gets the phone ringing

### **“I wish I could hug John Kirwan” says lifeline counselor Helen McKinley, in relation to the overwhelming response to the National Depression Campaign in which John Kirwan talks about his experience of depression.**

The ads resulted in a flood of calls to the dedicated helpline and had people talking publicly about their experiences.

An average of two hundred calls a day flowed into the confidential 0800 111 757 depression support line, indicating the need for easy access to quality information about depression to those who need it, when they need it.

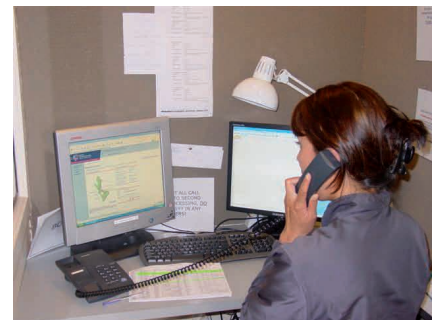
Lifeline counselor, Helen McKinley says, “We assess callers’ needs and provide information about services in the person’s community. Nearly a quarter of callers were advised to see a GP or other services for further help. The most important aspect of the support we have been providing is the follow-up care call where we ring back callers within a month to make sure they received the professional help they needed and were feeling supported. People have been

overwhelmed by the real sense of being cared for, which for some has been a really important step in their recovery. “

One encouraging sign was the significant number of men who called the information line for help, making the gender balance of callers nearly even. The television advertisements, which feature the legendary All Black winger John Kirwan speaking about his experience of depression, clearly have an impact on men, who would usually respond at a lower rate.

“I’ve been with Lifeline for 17 years and the John Kirwan ads have been beyond anything I could have imagined because it has been so liberating for men. They [men] usually get told to “harden up” but seeing a man they admire like John Kirwan talking about seeking help has made many men make the leap of faith they need to find someone who can help them,” Helen said.

“One man in his forties I spoke to, just out of a broken relationship, which he was unable to sustain because of his depression, felt utterly hopeless and felt he had no one to turn to. He had reached



Lifeline counselor answering depression helpline calls.

the point where he felt he had nothing to live for, which was not a safe situation for him to be in.

“The Kirwan ads freed him up to call us and he was extremely grateful for the help and support he received. He says if he hadn’t called he would have taken his life. We have arranged more care calls to make sure he is making positive progress.

“Another man in his sixties, who was from a generation of men who didn’t talk about depression or related issues,

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# Mental health nurses promote improved media coverage

“Negative portrayal of mental illness is of concern to all mental health nurses and as nurses we need to be talking publicly about the stigma and discrimination that is perpetuated by negative stereotyping” says Heather Casey, National President of the New Zealand College of Mental Health Nurses.

She was speaking following a panel discussion on ‘Perceptions of Mental Illness in the Media’ hosted by Te Ao Maramatanga – The New Zealand College of Mental Health Nurses. At the discussion Carol Seymour, Chair of the Auckland Branch, which organised the event, said the college would like to positively influence media coverage of mental health issues.

Carol says the college is going to discuss how they can take up some of the recommendations made by the panel. A key conclusion was that it would be beneficial for the college to form more positive relationships with journalists and media. Some ways to do this could be by responding positively to media stories that are non-discriminatory and training a pool of people that are mandated by the College to talk to the media. Carol also talked of the possibility of members of the College being included in the journalists’ curriculum to present current research that challenges discriminatory stereotypes associated with mental illness.

“The Auckland branch is to be congratulated for leading the way ...” said Heather Casey, adding that “it is often difficult for nurses to speak out about topical issues that appear related to individual service users because of confidentiality issues.”

Anthony O’Brien, Lecturer of Mental Health Nursing at the University of Auckland and former College President, says it is important to work in partnership with people with experience of mental illness on this issue.

“We could speak for the [mental health nursing] profession but it is important to engage with service user groups so there is some commonality of voice.”

Heather supports this view on the importance of nurses and services users working together for change, “Mental health nurses can only speak about their experiences of working with service users – [they can]not speak on behalf of service users who have their own voice.”

TV3 reporter and recent Carter Fellowship recipient, Ingrid Leary, spoke on the panel about some of the systemic barriers journalists face when advocating for balanced and non-discriminatory coverage of mental health issues. Ingrid credited her working relationship with Te Ao Maramatanga as the key factor in improving her own understanding of mental health issues.

Other speakers at the gathering included Jan Gordon Walters, Consumer Advisor to Waitemata District Health Board Mental Health Services, who gave a first person account and overview on discrimination and cited some examples of reporting that negatively affects recovery.

Brian McKenna, Senior Lecturer of Mental Health Nursing at the University of Auckland and Advisor to Auckland Regional Forensic Psychiatry Services, spoke about his recent research which examined the myths around mental illness and violent crimes by surveying media reports of homicides.

Gerard Vaughan, National Project Manager for *Like Minds, Like Mine*, gave an overview of the *Like Minds* campaign and told how research on the effectiveness of the campaign has shown significantly positive results in improving people’s knowledge and attitudes about mental illness.

Both Gerard and Ingrid talked about the need for clinicians and professional groups to develop positive relationships with journalists. Ingrid cited an email she had received acknowledging her balanced and informed reporting on a mental health issue and the positive impact that had for her.

The panel discussion was well attended by people with experience of mental illness, family members of people with experience of mental illness and mental health nurses. Carol said audience feedback was extremely positive. The College plans to host further seminars on these themes in 2007 and is keen to keep the discussion going.

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had found it extremely difficult to talk to anyone about his experience of depression. After a very nervous start to his call we were able to put him in touch with appropriate resources.

“During my follow-up care call he told me he had gone to his GP and was on medication he felt had definitely helped him, and was referred to a psychiatrist. He is totally indebted to John Kirwan’s message of hope and has realised that he does not have to only live ‘half a life’. He has asked us to pass on his thanks to John Kirwan.

“I have lost count of the people who have asked us to thank John Kirwan who has touched so many people through this campaign,” Helen said.

“While not directly linked to the *Like Minds, Like Mine* campaign the National Depression Campaign has never-the-less had an important role to play in reducing stigma and discrimination” said *Like Minds* Project Manager, Gerard Vaughan.

“The messages given by John Kirwan in the ads were designed to encourage people who were worried about depression to get help. This was a big step

for callers to the 0800 number, many of whom had resisted seeking help, in part because of the stigma and discrimination they felt was associated with mental illness. Reducing stigma and discrimination is an important aspect of recovery for people who experience depression or other mental illnesses,” he said.

The need to reduce stigma and discrimination will be reinforced in the coming months with the launch of the phase four *Like Minds, Like Mine* national advertising scheduled to commence in July this year.

# A Town Like Alice: A documentary about madness and incarceration

**Produced by The Lighthouse Trust, Napier (with support from Like Minds, Like Mine and the Mental Health Foundation)**

*Director and editor, Jim Marbrook (2004/05 Carter Center Fellow)*

In July 2006, the Whanganui District Health Board sold Lake Alice Hospital to a private buyer.

The sale prompted Roy Brown and Susie Crooks (from The Lighthouse Trust) to take on a national project to capture on film one of the blackest periods in New Zealand's medical history.

Their team will be filming at all nine of the old mental asylums that have been in operation over the last 100 – 150 years, before they are pulled down or lost forever.

Susie Crooks said they were interested in challenging some of the attitudes that have been perpetuated through the practices of psychiatry in the asylums.

“We're going to profile all the old 'bins' – the first was Lake Alice – and walk through them with people who have survived the horrors of these institutions.

“Each one has its own footprint and we'll be trying to create the profile that made that particular institution unique and try to understand exactly what happened – before any changes to the sites.”

Roy Brown said the experience of being held in Lake Alice needed to be documented and archived.

“What did Lake Alice and other institutions mean to people held within those walls? What were the horrific things that happened to them and what were the good things that happened?”

Susie, who believes that everyone has a bit of madness in them somewhere, says, “Some people who went into the old institutions had one moment of madness, and then they lost their lives through the practice of psychiatry.”

“We want to record those experiences for history's sake and as a check for any future risk of categorising people with experience of mental illness as less than human.

“This first documentary and the ones that follow will give people a bit of a wake up call that institutionalisation didn't work in the past.”

Some of the challenges in making the documentary involved coming to grips with film production.



The team behind *A Town Like Alice* receives thanks and healing after the preview at the First National Nutters' Conference. (From left) Roy Brown, Susie Crooks, John Tovey, Anne Helm, Jim Marbrook and Manny Downs.

“While Jim [Marbrook] is an experienced media professional, Roy and I are not,” Susie says.

“We found the filming process extremely intensive with the crew working round the clock over 3 days to keep the production costs down.

“It was also emotionally draining for the people we interviewed who said the Lake Alice site felt a bit like a cemetery – it was very haunting.”

*A Town Like Alice* leads people into what life as an ‘inmate’ was like, drawing on music, sound and imagery to establish the mood. Through interviews with former inmate John Tovey, Manny Downs (a former attendant at the hospital) and psychiatrist David Codyre viewers see Lake Alice as a place in a time when institutions served the needs of system and staff; of buildings designed for order and control rather than as therapeutic healing spaces.

John Tovey found the experience of being involved in the documentary demanding. “I felt lucky to have been asked to take Susie and Roy through Lake Alice, but I was apprehensive about going back. I was one of the ones who survived and moved forward in my life – for many others it damaged them badly.”

Dr Codyre spoke of the strange, dehumanising atmosphere of Lake Alice Hospital.

“Lake Alice had a strange culture. It was in a world of its own. Most of the staff working there did their training at the hospital and some came from successive generations of the same family. Staff beliefs and practices were based on internal training which led to idiosyncratic views on mental illness and treatments.”

Is there a chance that we'd ever go back to putting people with experience of major mental illness into places like Lake Alice?

Susie and Roy hope not.

“We asked Dr Codyre the same question and in his capacity as a psychiatrist, he said the time for ‘incarceration for life’ was gone,” says Susie.

“He said – and in our experience he's correct – that with the treatments available now to people, with the right support and care and with housing sorted out, people can make their own changes and their lives can improve.”

*A Town Like Alice* debuted at the National Nutters' conference in Napier last year to a receptive audience. It can be borrowed from The Lighthouse Trust or purchased from them for \$30. Contact Susie Crooks or Roy Brown on phone (06) 843 3952 or email: onelight@xtra.co.nz

The next documentaries will take a look at the northern asylums of Kingseat, Carrington and Tokonui.

# Award honours local pioneer in mental health care

**A prestigious award, honouring Linda Simson, was presented to Sarah Gordon, Managing Director of Case Consulting, as part of the biennial community mental health conference, Building Bridges, held in Christchurch in November 2006.**

Linda Simson, who died early last year while indulging her passion for 4x4 driving, was a real pioneer in mental health care and services. Linda used her own experience of mental illness and recovery to inform improvements in systems of care and make changes that worked for consumers. Her national and international profile as a consumer adviser, and later service manager, inspired and encouraged professionals, consumers and clinicians



Sarah Gordon, Managing Director Case Consulting

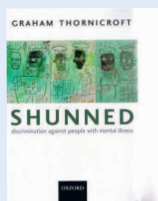
alike. Linda lived life to the full, enjoyed robust debate and never shrank from challenges, personal or professional.

The \$10,000 Linda Simson memorial award was presented by the Building Bridges Trust to Sarah Gordon to develop a resource that will benefit the wider consumer community. The eventual form and purpose of the resource will be decided in negotiation with the Trust and people with experience of mental illness nationally.

Vicki Burnett, chair of the Building Bridges Trust said "We unanimously selected Sarah because she exemplifies all the attitudes and attributes Linda herself modeled and valued. She draws on her own experience of mental illness to inform, challenge and change."

Sarah Gordon founded Case Consulting several years ago as a totally consumer-run consultancy working in the mental health field.

Vicki Burnett says, "Linda was a founding member of the Building Bridges Trust and was to be the convener of this year's conference. She is a huge loss to us all but while people like Sarah are following on we know the spirit is alive and Linda's legacy lives on."



## Book Review: *Shunned*, by Graham Thornicroft

by Debbie Peterson, Senior Policy Analyst/Researcher, Mental Health Foundation

**After something that will inspire you to action in the New Year? *Shunned: Discrimination against people with mental illness* by Graham Thornicroft, might just about do the trick.**

It starts with a thought provoking foreword by Judi Chamberlin, which places an emphasis on the rights of people with experience of mental illness. Chamberlin challenges people to address discrimination, not stigma, and argues that the issue is to ensure "that people labelled mentally ill retain their basic citizenship rights, particularly the right to challenge both the label and the treatment, and to retain basic control over one's own life."

The book's author is a UK psychiatrist based in South London. *Shunned* presents a detailed, well referenced account of the issues associated with discrimination against people with experience of mental illness. It focuses on most aspects of discrimination, for example employment, social and health care, the media and self-stigmatisation. Each chapter updates the reader on the latest research, including some New Zealand studies. The chapter on the media is a good example of where New Zealand appears to be leading the world in its research.

At the start of each of the first five chapters, individual stories are presented, giving examples of the discrimination people have faced related to the topic

of the chapter. What I liked was in his concluding remarks, Thornicroft addressed each person in turn and updated the reader on what had happened to them. Each example provided a story of hope and the realisation that whilst discrimination can be a powerful negative force in people's lives, people can get over it and lead positive lives.

Another positive aspect of the book is that the author freely admits what he doesn't know. There are many examples provided where he has found no research to inform the topic being studied. This book could be seen as a challenge to researchers worldwide to fill in the gaps. There are few surprises however, providing a summary, rather than new material, but I did like that most of the research referred to was fairly recent.

The focus of *Shunned* is on discrimination, as opposed to stigma – though Thornicroft does tend to confuse the two terms at times. I found it easy to read, but in places it was not well edited. The book is full of quotes from people with experience of mental illness. In general, they provide an excellent illustration of the points that Thornicroft is trying to make. However, some of

the quotes seem in limbo, not relating immediately to the text around them, and others are repeated – in one case, the same quote appears on consecutive pages.

Whilst the emphasis of the book is on what is known (or not known) in regards to research about discrimination, it is by no means a dry boring read. Anyone interested in the issues will find this book a useful summary. It seems less theory driven than the book I reviewed last newsletter (*On the Stigma of Mental Illness* edited by Patrick Corrigan). Both books try to move beyond mere description to advising reader on what can be done to tackle stigma and discrimination, and although both books are covering the same territory, you can tell that one comes from the UK, the other the US. They come from different theoretical perspectives, and because of this, my advice would be to read both of them.

*Shunned: Discrimination against people with mental illness* is published by Oxford University Press and is available from [www.amazon.co.uk](http://www.amazon.co.uk) or [www.amazon.com](http://www.amazon.com)



# Carter Center Fellowship recipient

## PHIL SMITH

*Executive Producer Spoken Features, Radio New Zealand*

### *How did you find out about the Carter Fellowships?*

I was prompted to follow Mike Gourley's example. Mike was one of the first two Carter Center fellows and the talented former producer of Radio New Zealand's disability experience programme, One in Five. He told me about the fellowships and encouraged me to apply. Ingrid Leary and I were the final two New Zealand recipients.

### *What motivated you to apply?*

The Carter Centre does impressive international work in the fields of health, mental health and democracy – a major motivation to apply.

The Center is especially strong in developing world health and democracy building, but it has a developing mental health programme under the particular care of former first lady Mrs Rosalynn Carter.

### *Tell us about your project ...*

I used my fellowship grant to produce two radio programmes.

One was an exploration of the myth that people with mental illness are very dangerous and how this myth impacts their lives. The other a survey of the current level of mental health services available in New Zealand prisons.

In the first programme I focused on the 'myth of dangerousness'. Based on work done over the last decade around the world, it illustrated that people with experience of psychosis are not a significant threat to society and indeed are more likely to be victims of crime than other groups.

If society were to call for preventive detention of groups with a high risk of violence we would first have lock up all

young males. People with experience of mental illness would be well down the order of risk.

This piece allowed me to record some wonderful stories of personal experience and triumph, as well as the impact of ignorance and stigma. The mental health community was exceptionally generous and helpful on this subject making it a very positive experience.

The second programme – looking at the current levels of mental health services available in New Zealand prisons – was a less encouraging one. It highlighted we appear to be failing prisoners that genuinely require better assistance than we give them.

I intend to keep making radio programmes in the area of mental health. There are so many important stories to tell.

### *What were your trips to Atlanta like?*

Atlanta's a fascinating place. In terms of mental health it is not a good model with poverty and rough-living common amongst people with mental health issues. A lack of health care also has all too obvious impacts on mental health consumers – as victims, as street people and as sufferers of secondary health conditions.

### *What have you learnt?*

One strength of this kind of fellowship programme is that it has the potential to open neglected topics to journalistic enquiry and public knowledge. It points media in the right direction and says – see, there are interesting and worthy stories here.



Phil Smith, Executive Producer Spoken Features, Radio New Zealand

### *What is the future of mental health journalism in NZ?*

The Carter Center Fellowships have been a valuable resource for New Zealand journalism. After having provided a range of kiwi journalists a unique opportunity, they are now inspiring an ongoing project to improve the reporting of mental health issues through New Zealand based media grants to work on mental health stories.

I look forward to the introduction of the first round of the New Zealand Mental Health Media Grants, administered by the Mental Health Foundation. I believe the Mental Health Media Grants have the opportunity to produce good outcomes for both media and society alike.

Applications for the New Zealand Mental Health Media Grants open in February and close on 31 May 2007.  
Application forms can be obtained by emailing Alex Stone at the Mental Health Foundation [alex@mentalhealth.org.nz](mailto:alex@mentalhealth.org.nz)

## Doors opening to recovery and inclusion in Poland

A boutique hotel and a publishing company are two of many initiatives used to fight stigma and discrimination against people with experience of mental illness in Poland.

The local Polish Action Group of the international organisation, Schizophrenia – Open the Doors, highlights these initiatives and others during their annual “Day of Solidarity”.

Held each year on November 15, in 2006 their tagline was ‘Together in work – together in life’. Crowds in Krakow stepped through a symbolic open door as part of the celebrations.

Of special interest was an initiative called “U Pana Cogito” – a local boutique hotel, restaurant and conference facility – run by a social firm that employs people with experience of mental illness.

The hotel hosts tourists, business people and even holds mental health services functions. As well as providing training and employment opportunities for people with experience of mental illness, “U Pana Cogito” works to reduce stigma and discrimination by showing in a very practical way social inclusion in action.

Another Polish initiative, run by people with experience of mental illness, is the ‘Otwórzcie Drzwi’ (Open the Doors) owned magazine ‘Dla Nas’ – For Us. The magazine contains articles about people’s personal experiences with mental illness as well as poems and information about conferences. Every cover features a symbolic photo of ‘open doors’ from various cities around Poland.

This is the first in a series of regular articles on what other countries are doing to fight stigma and discrimination. We will feature another countries initiatives in the next issue.

For more information, please visit [www.openthedoors.com](http://www.openthedoors.com)

## Get Up, Stand Up... to review Te Korowai Whaimana

**“Reducing discrimination requires people to change their behaviour, and behaviour change requires individuals to assert their right to be treated with dignity and respect.”**

These were the words of Human Rights Commissioner Warren Lindberg, in his keynote address to the first National Nutters’ Conference.

Empowering service users/tangata whaiora to assert their rights is the mission of Te Korowai Whaimana – an education and training project jointly developed by the Human Rights Commission and the *Like Minds, Like Mine* Project.

Translated as ‘the empowering cloak’, Te Korowai Whaimana started in 2001 with an initial focus on systemic discrimination. A train-the-trainer initiative provided intensive training on human rights issues relating to mental health legislation, and avenues for redress, to people with experience of mental illness. Following this training, the new trainers were supported to organise and facilitate human rights workshops for people in their local communities with experience of mental illness. In the past 18 months, more than 600 people have taken part in 272 workshops around the country.

Bruce Coleman, of the Human Rights Commission, believes that the time has come to pause and reflect on the success of the project. While firmly committed to furthering the project, he asks “Is this the best or only way to pursue better human rights for people with experience of mental illness?”

The anecdotal evidence that the workshops are useful and empowering is encouraging and he would like further consultation and guidance to steer future directions of the project. His objective is to improve on the winning formula; this requires information on the “bigger picture... what else do we need to do?”

Finding out more about the barriers to resources and avenues for redress that people with experience of mental illness face will make the information more relevant and useful for applying to real situations. Bruce wonders if trainers could be upskilled to support people in the complaints process, advocating for people where the system is too daunting.

One such trainer is Karyn Walker of Te Kōwhao, a group that provides *Like*



Left: Gareth Edwards, Te Korowai Whaimana  
Right: Warren Lindberg, Human Rights Commissioner

*Minds* services for Te Roopu Pookai Taaniwhaniwha. Karyn describes Te Kōwhao as a “Māori roopu whose members have experience of mental illness who live and work in Wellington, Porirua, Kapiti and Hutt Valley areas.”

Karyn says her experience with Te Korowai Whaimana is a good vehicle for empowering people about their rights and responsibilities. Looking forward, she believes the review of the project will help develop the workshops to be flexible enough to adapt to the needs of local communities and their kaupapa.

Gareth Edwards (Te Korowai Whaimana evaluator), who will be conducting the upcoming evaluation and consultation process, is enthusiastic about the future possibilities for Te Korowai Whaimana. He acknowledged the difficulty of evaluating a trailblazing project which will include the Human Rights Commission, *Like Minds, Like Mine* Project leaders, the Korowai Whaimana Steering Group, trainers, participants and other key informants for their thoughts on progress.

Te Korowai Whaimana shows promise in the wider service user/tangata whaiora movement. It is the start in a long campaign. As acknowledged by Mental Health Commissioner Mary O’Hagan, this struggle is similar to the experience of the “women’s movement, the gay rights movement, the disability movement and Indigenous movements... [which] share... an underlying analysis of oppression and liberation.”

That service users/tangata whaiora lead this movement is not only sensible but a right, because they are the people who know first hand the experience of discrimination.

Gareth Edwards is keen to gather feedback on Te Korowai Whaimana and looks forward to sharing the results on completion of the evaluation.

# What about the Workers?

**Aim/Mission:** to expand and enhance the service-user workforce.

“By 2010 people with experience of mental illness will be a skilled, powerful, pervasive and openly identified part of the mental health workforce.” (The Mental Health Commission’s Service User Workforce Development Strategy)

**The operative:** Carolyn Swanson, Te Pou’s Service User Workforce development specialist.

**The organisation:** Te Pou.

**Their philosophy:** Valuing the experience of madness as useful when working in mental health recovery and support services is not only common sense but also logical, ethical and (on a policy level) it is the expected thing to do.

## What does Carolyn do?

“My job is to support the development of the talent, experience and knowledge of people with experience of mental illness into service delivery and ultimately, leadership,” says Carolyn.

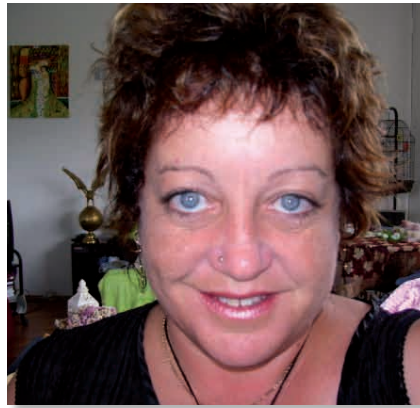
“I educate and champion in the strongest, most consistent way for the development of an effective, powerful, respected and professional service-user workforce.”

Carolyn talks with major mental health stakeholders (whether they are service user, mainstream, hospital, NGO, Maori and Pacific Island or other ethnic communities), to find out what is needed and what is preventing participation. She then works towards the solutions. The answers often lie in connecting the right people to each other.

## What does Te Pou do?

The ultimate goal for Te Pou’s Workforce programme is to ensure better mental health outcomes for service users. It is working to achieve this by building both the capacity and the capability of human resources within the mental health sector. It offers:

- Workforce Development Infrastructure – to develop the ability of DHBs to progress the capability and capacity of the workforce to satisfy future service demands.
- Training and Development – to coordinate these across education, health and employment sectors, and within the mental health sector, to align pre-service entry, orientation and ongoing development of mental



Carolyn Swanson, Te Pou’s Service User Workforce development specialist.

health workers with service provision requirements.

- Retention and Recruitment – to develop national and regional responses to issues of retention and recruitment.
- Organisational Development – to assist mental health services to develop the organisational culture and systems necessary to sustain their workforce.
- Research and Evaluation – to ensure there is information available to the sector to inform workforce development.

Te Pou’s projects include:

- Human Resource development and training.
- Consumer Advisor training
- Developing chat forums and information sharing
- Building a database of service-user workforce
- Developing an international forum for consumer evaluators
- Providing governance toolkits and management of services for service-users
- Exploring the development of consumer research positions.

## Benefits:

The upside for services provided by people with experience of mental illness is:

- Non-service user staff can see recovery in action
- Empathy cannot be taught but is earned through actual lived experience giving greater understanding of another’s struggle
- Service users gain through continued growth and learning.

- Their experience and knowledge can provide a career and income, changing often less than positive experiences of using mental health services into strengths.
- Service-user advocacy forces services to be accountable to the people they serve, and gives value to a formerly marginalised group.
- People with experience of mental illness can see gaps in services and discrimination at work in the system where others may not.

## Challenges:

For people with experience of mental illness the challenges that need to be met are many:

- Self stigma and external discrimination stop service users even applying to, and doing well, in services
- Normal emotions can be medicalised, and service users discovered a long time ago that they have lost the right to anger or frustration
- It is painful to watch people suffering knowing how it feels
- Improving services can seem hopeless and overwhelming at times
- Our own pressure to be endlessly available to help (permeable boundaries between worker and supporter) is immense
- Work/life balance can be threatened when everything is “mental health” with nothing outside of this – burnout is an occupational hazard
- Walking the fine line between the people we serve and the people we work for can present a challenge, especially when the service gaps and discriminatory practice appear in the organisation that pays us
- Constant self review
- Difficulties when you work for a service provider while still using the service.

“The key,” says Carolyn, “is to value your own experience, make sense of some of it and work in a positive way.

“You should also appreciate your personal experiences and celebrate strength, courage and resilience that comes with it; everyone is a hero.”

# Extended term for Mental Health Commission good for *Like Minds*

**The fight against stigma and discrimination has been strengthened by the news that the Mental Health Commission – due to finish in 2007 – will now continue through to 2015.**

The Like Minds, Like Mine project welcomed the news that new legislation has been introduced to extend the life of the Commission, which is tasked with promoting mental health awareness and advocating for the needs of people with experience of mental illness.

Health Minister Pete Hodgson said since its establishment in 1996 there had been significant gains in the recognition and treatment of mental illness.

“The mental health community should be proud of the Commission’s record of tackling stigmatisation and expanding services for people with mental illness,” he says.

The Government has given the Commission six key functions to align its work with future directions and priorities in the mental health sector. The six key functions include the Commission having an ongoing role in reducing stigma and discrimination in relation to mental illness and promoting public awareness.

Like Minds, Like Mine National Project Manager Gerard Vaughan believes that extending the life of the Commission can only produce more positive benefits for people with experience of mental illness

“To have a Commission working at a

senior level in Government opens a lot of doors.

“Whilst their brief is wider than addressing the issue of stigma and discrimination in our society, the work they do tends to challenge people’s beliefs on many levels.”

Judi Clements, Chief Executive of the Mental Health Foundation agrees, saying the Commission has been a key player in a number of fundamental developments in the structure and shape of mental health care and service delivery.

“The Foundation supports the continuation of those developments in the sector to ensure the progress we have made is not lost.

“ We’ve been particularly encouraged at the Commission’s ability at promoting better understanding of mental illness and eliminating discrimination. This is something that the Mental Health Foundation also strives to do through its work. It is good to see that combined efforts will continue for the benefit of all.”

With ten years of experience now behind them, the Commission believes it can add significant value and leadership to the sector.

For Commission chairwoman, Ruth Harrison, extending the life of the Commission allows the organisation to help the country’s mental health system to be a world leader in providing a recovery-based mental health system that promotes wellness.



Mental Health Commissioner Ray Watson with Chair Ruth Harrison.

“We can also continue to reduce the stigma and discrimination associated with mental illness – this allows people with experience of mental illness to remain connected to their families, friends and communities,” she says.

The Mental Health Commission was established in response to the Mason Inquiry into Mental Health Services, one of the Commission’s achievements has been the development of its Blueprint for Mental Health Services, a plan which sets targets for resourcing and services for mental health consumers.

More information about the Mental Health Commission and its work is available at [www.mhc.govt.nz](http://www.mhc.govt.nz)

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LIKE MINDS, LIKE MINE  
Whakaītia te Whakawhiti i te Tangata

The project to counter stigma and discrimination associated with mental illness is an initiative of the Ministry of Health.