



RECONNECTING ME WITH MY WHENUA, MY MOANA, MY MAUNGA AND MY MAURAE

"I first used mental health services in 1992. After my first episode I found my way home to the far north where I'm from. Back to my whanau (extended family). I'd been quite distant from my whanau and felt like a stranger. I had another episode there but I hesitate to call it mental illness. I experienced an emotional and spiritual and psychological upheaval. I choose to call a healing crisis because it brought my attention to things in my life I needed to change in order to heal and move on.

What hindered my recovery?

When I first went into hospital I went in with all my own in-built prejudices against people with mental illness. So that all of that was magnified, 'S*** I've become like that!' I was so totally traumatized and shocked with the whole experience, that it led me to be suicidal. You know, it's nothing to be taken lightly. It really impacts on people.

My first episode was quite a public episode. People who I thought were my friends were no longer there for me and the doors were slammed in my face. I felt very ashamed, given what had gone on. I couldn't cope with one day being a good parent, happy, active, popular, involved in the community, and then suddenly losing all of that and feeling like I was at the bottom of a pit. I experienced long periods of hopelessness and wondered if I would ever be able to recover and to reclaim my life. I did have a few helpful and understanding friends. Part of their advice was to leave the area if I could, and I did.

The services were inadequate and unhelpful and they made things worse. When I first went to hospital, there was definitely something happening but it wasn't dealt with. I had an experience of psychosis or mental illness or whatever, but on top of that I was re-traumatized through the hospitalization process. Nothing was explained to me. I had side effects from the medication, I wasn't fully informed or a part of decision-making. I didn't know about advocates. I didn't know what I was entitled to. Lack of information and support for myself and my whanau definitely hindered by recovery. It took two years for my healing and recovery to start.

After my first hospitalization I went home on a lot of medication to a seven year old child, and was just left to my own devices. I didn't know what on earth was going on. I can remember going back to the hospital and saying, "You've got to cut down on the medication, I've got a seven year old to look after, and I just keep falling asleep all the time.' I shouldn't have had to do that. I should have had support or some kind of follow up. I had to do it all myself, nobody helped me. I was lucky that my whanau looked after my daughter, but in terms of services or any kind of referral or assistance, once you leave the acute services, no way. And then they wonder why we keep



coming back. Because you actually aren't given any of the options and the tools you need to stay out. I was in and out of bloody hospital every couple of weeks. Jeez, it was terrible.

In my last admission there were posters on the walls for the patients about our rights, but look out if you go to the staff and say, 'Hey, I've been reading this, and I've got a right to b and c'. I've actually seen nurses kick over furniture and slam doors because you dared to actually say as a patient, 'I have a right and I would like what it says on that bit of paper on the wall'. The reaction is so scary, you learn to shut your mouth or you get a bit irate and put your foot down. No way. You're dragged off to isolation when you get angry. A complete denial of my rights as far as I'm concerned.

You learn very fast what to say and what not to say. And how to protect those things. And not to reveal them to others who don't understand. It's, 'Do what we say, comply with your pills, don't make a fuss, and you'll be able to get out of here'. That's a kaupapa (subject) of total concern.

What helped my recovery?

Cultural Context

The way my experience was viewed by my whanau (extended family) was very, very different from the way it was viewed by the psychiatrists and the nurses. What people call mental illness is what we call wairangi or poorangi (derogatory terms for 'madness'), which means existing in another worldly way. A psychiatrist from Switzerland will believe I'm hearing voices and have schizophrenic tendencies, but to a Maori I'm hearing my tupuna (ancestor) talk to me.

The whanau better understood what was happening for me than I knew myself, and they guided me through a process of kaupapa (subject) Maori healing. Mostly, reconnecting me with my whenua (land), my moana (ocean), my maunga (mountain -- note all tribal groups have 'mountains' which are 'treasures' and symbols of belonging) and my marae (meeting place), and guiding me through tikanga (correct protocol) and matters of wairuatanga (spirituality). Because it was lost to me. All my life I had been raised in the Pakeha (people of European ancestry) way and only had token involvement as a Maori. I was totally out of balance in terms of who I am, and by returning to my whanau I learned what it is to be Maori.

The key question my whanau asked me was, 'What were you doing when this first happened?' No one in the mental health services had really asked me that question, and so I would korero (talking) to them about the church I had been involved in, and that was identified as the key issue. One of the key factors in my recovery was leaving the religion that I was associated with at the time. However, I have continued to work on and nourish a very constant daily spirituality.

I need to be kept safe and looked after by the whanau where I go through that process. Other tangata whaiora (people seeking wellness) are better off finding their healing and recovery outside their whanau, because of stuff that may be going on there. That's a choice.

If one member of the whanau got tired then I went to the other one. That was good. As long as I was around normal everyday functioning people it gave me some sense of groundedness. But as soon as you're in a hospital all that goes and you think, 'I'm in the bin. I can be as stupid as I want to be now, I don't even have to try'.

There were some staff and some people in the mainstream services who were helpful. But they were definitely in the minority. There are more options now and it is helpful for Maori to have access to kaupapa (subject) Maori services. When I was offered a place in kaupapa Maori services I refused it because it was uncomfortable for me at the time. But after I went home and reconnected with my whanau, I was more ready to access kaupapa Maori services. I'm definitely all for it if the person agrees, and that will depend on where they are in terms of being Maori. I have seen a lot of progress in kaupapa Maori services in the far north. But takes time.

After a while I was lucky enough to be around people who had survived trauma and distress, or for want of a better word, mental illness. I would look at them and think 'Well, you're OK, your living your life, you have a family, and that gave me some hope. There wasn't a lot of hope in the messages I got through the hospital, 'Take these pills, this is a chronic illness, there is no hope of recovery, just accept it and exist'. The hope came from friends and others who had been through similar experiences.

It was very healing when we tangata whaiora (people seeking wellness) had waiata (song), mirimiri (massage), foot massage, korero (talking), went on van trips and collected kai moana (sea-food) and cooked it for ourselves. But that was generated amongst ourselves. I married a tangata whaiora (seeking health) and together we support and understand each other. So with his support and my ongoing focus on spirituality, staying in close contact with my whanau, knowing what my limitations are, this is all part of my recovery.

For the past five years I've been doing the mahi (work) -- to get back in the ring as a consumer representative, consultant or adviser to push the issues and say, 'Hey, you know, on paper this looks good, but what we're getting is bloody terrible'. But oh, I'm getting tired. I just want to go fishing.

I'm happy. I'm a very, very different person to the one I was seven years ago. Everything is kei te pai (it is okay). It has changed my life to an incredible degree for the better. I never thought I would say that. I don't consider myself living with an ongoing mental illness. I consider that I had a healing crisis and that I need to change something in my life. I reconnected with what it is to be Maori. I choose not to take medication. I tend more to be into homeopathics, meditation, herbs, vitamins, swimming, walking, karakia (praying). If I do feel I need help, I'll choose who I want

to korero (talking) with. -- they'll be the people who will support me to make my choices. They're some of the tools for my ongoing recovery.

From: New Zealand Mental Health Commission 2000. Four Maori Korero (talking) about their Experience of Mental Illness, Mental Health Commission Recovery series: one, March 2000.



TURNING MY LIFE AROUND: SYLVESTER'S STORY



Sylvester Katontoka
Sylvester Katontoka (back row,
fourth from the left) with
members of MHUNZA, the Mental
Health Users Network of Zambia

"I was 28, married, and a father of two lovely daughters when a terrifying life came in front of me. Grieving for my children after my wife got involved in an extra-marital affair, I began a six-year roller coaster ride through despair. For 28 days down in my blankets, the meaning of life escaped out of me, with plenty of self-guilt, loss of sleep and appetite. I grew very thin, which led me to suicidal thoughts."

"By the grace of God, I was diagnosed and hospitalized to save me from committing suicide.... The hospital appeared more a prison than a place for my clinical attention. My ward

possessed the jail-like structures with the famous seclusion rooms where patients are left to lie on the ice-cold concrete floor covered with urine and faeces and without anything to use as covering. I lived in a very dirty place with overflowing toilets, broken doors and windows, torn uniforms and at times patients were left naked..."

"This experience was too harsh and turned my life upside down, ending up [with my] being socially disabled. I was isolated from my society and often wandered in the wilderness with no food, decent shelter and decent clothes. Stigmatization and discrimination were the order of my days. Destitution became my life."

"Through a hard-fought empowerment programme with the hospital, I started my own business programme for my livelihood.... I started by going on a self-advocacy, talking about injustices in the hospital as an attempt to do away with an outdated and oppressive system.... This action eventually saw my colleagues come on board to make the voice bigger and louder and we disagreed with government, especially on the [issue of] taking power and control over our own lives because of diagnosis."

"Upon seeing our determination in our quest for justice, the government requested that we get registered legally as a non-government organization. This is how the Mental Health Users Network of Zambia (MHUNZA) was born in 2001."

-- from Sylvester Katontoka's testimony at the World Health Organization International Forum on Mental Health, Human Rights and Legislation in Geneva, 2003.

**Caroline Fei-Yeng Kwok, M. Ed., Toronto, Canada,
author of *Free to Fly: A Story of Manic Depression*;
Chinese version, titled 一個精神病患者的新生**

As a Chinese immigrant survivor of bipolar disorder living in Toronto [...] I would like to highlight two specific issues. The first is that people with mental health conditions are subject to stigma and discrimination. There is an intense social stigma towards people with mental illness in many communities. It exists because of the lack of mental health education and the traditional notion that mental illness is a loss of face for the family. It is reinforced by the negative portrayal of mental illness by the media. The second issue is that individuals with mental illness lack access to health and social services. As a new immigrant to Toronto, I did not know of any social or mental health support services after my hospitalization. I was at a loss and isolated in the cold winter in Toronto. Furthermore, my mother who spoke no English did not receive any professional support as a caregiver, in spite of her daily visits to see me at the hospital. Our world today has many people suffering from mental illness and it is my sincere hope that more services and programs will address our needs and those of our families.

From ***Mental health and development: targeting people with mental health conditions as a vulnerable group***. Funk M, Drew N, Freeman M, Faydi E. 2010. World Health Organization. Geneva, Switzerland. available at http://www.who.int/mental_health/policy/mhtargeting/en/index.html