SURVIVING PSYCHIATRY: THE NEW ZEALAND MENTAL HEALTH USER MOVEMENT

AN INTERVIEW WITH MARY O’HAGAN

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Prologue

This interview with Mental Health Commissioner Mary O’Hagan is part of a series through which I have been piecing together the history of the disability movement in Aotearoa/New Zealand by interviewing people who have played important roles in that history. Previous interviews in the series were published in the New Zealand Journal of Disability Studies.

The present one was conducted through a number of long taped phone conversations between Mary and me throughout 2004. I am extremely grateful to Mary for agreeing to be interviewed, for her friendliness and patience as I bombarded her with seemingly endless questions, for the thoughtfulness, thoroughness and intelligence of her responses, and for her willingness to spare me even more of her time to check the following text.

PRB

Childhood and School Years

Mary O’Hagan was born in the small Southland town of Winton in 1958. Throughout her childhood and school years there were only occasional premonitions of the emotional condition that was to devastate her life from the age of eighteen. There was no known family history of mental disorder. Her father was a doctor, her parents were happily married, and she had a secure middle class childhood, free from social alienation and from personal neglect or abuse. Her parents were liberal Roman Catholics who tolerated a wide range of beliefs and behaviour in their children, and encouraged a questioning attitude. Mary derived particular emotional support from her friendship with her admired older brother Sean. By and large, she had a happy and secure childhood, devoid of the kinds of stress or trauma that have predisposed others to later mental disorders.

There was one family tragedy, however, which may have planted the seed of what was later to develop into psychosis. At the age of ten, a new-born baby brother died shortly after birth. She had been looking forward to his arrival with great excitement, and his death plunged her into a state of despair and isolation. She was old enough to realise the enormity of the loss, but too young to be able to cope emotionally.
The grief she experienced as a result of this bereavement went underground in her teenage years, though. During her secondary school days, she was often depressed, but in what she terms a "moderate everyday way", not the extreme form it was to take later. Indeed, the Mary O'Hagan that emerges from her recollections of herself as a secondary schoolgirl seems more of an active rebel than the passive victim of emotional alienation. It may be worth quoting some of those recollections, as they suggest the inner-directed and challenging disposition that she was later to transfer from the microcosm of school to the macrocosm of the mental health establishment. Refusal to knuckle under to externally imposed rules and authority makes for a troublesome schoolgirl, but is a useful personality trait for a social crusader in adult life:

I didn’t suffer from the low self-esteem which is often associated with poor mental health. I wasn’t socially isolated. Although I was a bit reserved, I had a reasonable number of friendships, particularly with my older brother’s circle. I was just one of those rebellious and challenging kids. The main tension in my life back then came from the fact that I pretty much despised the school. In fact, I couldn’t stand institutions of any sort. I saw that approval went to the girls who conformed to the rules, but it suited my sense of personal integrity better to refuse to do what I was told. I didn’t want to be one of the good girls. I wasn’t interested in cooperating with authority. I didn’t go totally off the rails, though. I didn’t do anything really destructive - I didn’t have child welfare officers visiting my parents or whatever. It wasn’t really wild stuff. I was just a bit of a rebel: wagging school a lot, getting detentions, answering back in class, biffing things at the Latin teacher, not doing my homework, smoking dope with the other bad girls down amongst the trees - that kind of thing.

Her general anti-establishment attitude apart, Mary’s main dissatisfaction with her school was that it left her “untested”. She had the frustrated feeling that it had not provided her with the opportunity to discover, explore and develop her own inner potential. On leaving school, she did not know where her talents lay or who she really was. This in turn generated a sense of something approaching terror in face of the vast, uncharted tracts of adult life stretching out in front of her.

She thus entered student life at Otago University in 1976 with a sense of insecurity about her own identity and her place in the wider scheme of things. This feeling was made more acute by another family death, this time of her loved grandmother. The depression that she had first experienced when her baby brother died eight years earlier, but which had only dogged her in the background since then, returned with renewed force.
Inside the Black Box

Soon after the loss of her grandmother, Mary slid into a deeply depressed state that lasted on and off for a couple of months, followed by a short “high”. The latter phase was not very intense on this first occasion, but as time went on the mood swings became more extreme - the lows lower, the highs higher. This pattern was to dominate her life to the detriment of study, work and relationships for the next eight years.

For the first three of these years (two spent at university, one doing casual work) she struggled with the worsening condition more or less on her own, although her friends were always supportive. In her second year at university, she did go to the campus doctor about her chronic lack of appetite (a condition that often accompanies depression) and was sent on to a psychiatrist who prescribed a small dose of anti-depressants. For the most part, however, her way of coping when depression struck was to go to the pub or smoke dope. With the benefit of hindsight, she realises these forms of self-prescribed drug therapy probably did more harm than good, “but you can’t tell a 20-year-old that!”. She does not think that in her own case there was a causal link between her mental condition and her consumption of alcohol and marijuana, but she would certainly warn young people with mental health problems to be cautious of mind-altering substances.

When she returned to Otago University in 1979, the mood swings had become so extreme, regular and disruptive that she knew she could no longer cope on her own. In desperation she went again to the psychiatrist she had seen two years earlier. She was diagnosed as having a “bio-chemical imbalance in the brain”, and packed off to a psychiatric ward at Wakari Hospital. “I walked off down a highly polished corridor to the women’s dormitory, where I was stripped of my clothes, my credibility and my dreams.”

For the next five years, that hospital, along with a rather awful but short sojourn in Sunnyside, was to dominate her life. Desperately in need of help and understanding, she became a regular visitor to A and E, sometimes off her own bat, on other occasions taken there by friends. The only consolation was that her episodes were never very long - three months in the worst case - so that unlike many patients of the time she did not become institutionalised for lengthy periods. For the same reason, she was never subjected to electro-convulsive therapy (ETC), which was a treatment of last resort for those with chronic depression. Mary’s form of depression was severe, but it was only intermittent, and alternated with bursts of elation and with periods of emotional stability.

She was also fortunate that her friends and brother Sean stood by and supported her. She did not experience the communal and even family rejection which is sometimes the lot of those who slide into psychosis. For that reason, perhaps, she was not afflicted with the sense of shame and stigma that often accompanies the experience of mental illness. Not being
rejected by those close to her, she consequently did not reject herself. In all events, she saw no reason for such possible self-rejection. Her condition had invaded her from the outside, as it were. She was in no way personally responsible for its onset, and she therefore refused to feel shame about it.

Even so, her extreme mood swings dictated the terms on which she lived as she advanced into her twenties. They made university study difficult, when not impossible - she dropped out of more papers than she passed, and eventually ended up with only half a degree. They also prevented her from getting her feet on the first rungs of a career ladder. Furthermore, it was difficult for her to form close, one-to-one relationships. While her peers were graduating from university, forming stable partnerships, getting jobs and laying the foundations of adult lives, Mary was left behind clinging to a raft to nowhere. In her quest for professional assistance, she had allowed herself to be inducted into the mental health system, from which there seemed to be little possibility of emerging. She was officially designated “mentally ill” - a psychotic depressive with malfunctioning neurotransmitters that would, the experts said, probably prevent her ever leading a “normal” life.

Her condition seemed to warrant this pessimistic prognosis. She was flung between the poles of pathological depression and manic euphoria, laced at times with psychotic delusions and paranoia. The depression side was different in kind, not degree, from the run-of-the-mill “downs” everybody experiences in the course of everyday life. Mary says that to call it a “mood disorder” was itself inadequate, as it affected every part of her being - emotional, cognitive, physical, sensory and even spiritual (although the latter is a word Mary tends to shy away from). During her depressive episodes, it was as though somebody had turned off all the switches in her brain. There was a major loss of energy and vitality, accompanied by a lack of appetite and a blunting of the senses. It was more than just being tired and listless: she was haunted by an unshakeable sense of futility, hopelessness and despair. Life lost all meaning and living seemed pointless. The former teenage angst about who she was and where she fitted in was pushed into frightening new dimensions.

At the same time, the world around her grew threateningly invasive. She could not bear its jabbing gaze upon her, and the physical touch of others left her feeling bruised. She was acutely vulnerable, as though her skin had been peeled off. Her only way to protect herself from this external bombardment was to retreat to bed for long periods.

Even within this protective cocoon, the invasion continued. Her mind swirled in confusion. She could not hold onto thoughts or words, which kept slipping away from her into meaningless chaos. Furthermore, there was only room for one in this chaos, so she was confined there in a state of extreme solitude.

Mary evokes this condition of external and subjective emptiness in an image that has arresting philosophical resonances. It was as though she were
imprisoned in a black box. She had been there all her life, but had previously colluded with cultural constructions of reality to hide the truth from herself. She and those around her had concealed the black walls with brightly coloured decorations. They had even painted windows which gave the illusion of looking out onto beautiful views. Now the illusory vistas and the sensory distractions were stripped away. The bright decorations vanished, and she was left confronted on all sides by nothing but the bare, black boards of her box. Profound, impenetrable darkness was the only reality. Everything else was a culturally constructed delusion. Her only small consolation was that if her own life was meaningless, so too was Life in general. That is, her despair was not compounded by the self-destructive conviction that she alone lacked value.

The black box of depression, however, was only one dimension of her condition. It was the most obtrusive one at the outset, and it was this which led her to seek psychiatric help in the first place. As time went on, though, the flip side of her mood swings made its presence felt with more insistence, and even provided some light relief to compensate for the dreariness of her bouts of depression. The depressed lows alternated with bursts of high-energy activity, when her whole life sped up. She became a euphoric prankster, who just couldn’t sit still. The highs oscillated with the lows in fairly rapid succession, and the more intense the depressions, the quicker she got onto the compensating high.

Some things about these manic states were quite enjoyable. When depressed, she felt she was walking through a faded watercolour, but when high, the bluntness of depression was replaced by sensory vibrancy. Colours became brilliant, and she derived intense pleasure from pieces of music which haunt her still.

Even so, she did not really feel comfortable living at such a level of intensity, despite the aesthetic pleasure she derived from it. Her mind buzzed with chaotic thoughts she could not catch onto. For one who set high store by mental concentration, the inability to focus was extremely frustrating. This was compounded by temporal blinkers that seemed to block out both past and future. She lived in the perpetual now, the present speeding past her in a blur. Furthermore, the experience was as isolating as the depressions. She was moving at top speed in a tiresomely slow world. Nobody around her was living with such intensity, so again she was alone. Even the good parts, such as the amazing colours and sounds, were a bit shallow and “tinselly”. On the whole, it was not a comfortable state to be in, even if exhilarating. When the manic episode persisted she would become paranoid and believe people were trying to kill her.

To put the finishing touch to this portrait of Mary’s brand of madness, her delusions and hallucinations must be added in. These were the reason for the diagnosis “psychotic” to be linked by the psychiatrist to the plain “depression”. From time to time she heard voices, which was a little disturbing, although not the main feature of the condition. The paranoid delusions mentioned above were more distressing and disruptive. On one
occasion, for instance, she demanded to be taken to the police station in order to confess to a murder she was convinced she had committed. Another time, she was certain she was metamorphosing into a giant insect. She had to keep touching her bones to check they were not crumbling away as her insect self took over. On yet another occasion, she embarked on an interplanetary voyage, an adventure which many years later was to provide the name for her book *Stopovers on My Way Home from Mars*. Here is how she described it in part of the epigraph to that book:

One dark night the long polished corridor turned into a glowing ramp. The ladies’ dormitory at the end of it became my private spaceship bound for Mars. Mars was incomprehensible. No-one else had seen it through my eyes. There were no maps or signposts there. No-one else was with me to point the way. So I turned back.

**Recovery**

The above quote ends with the laconic but surprising words “so I turned back”. Why this is surprising is that when Mary’s psychosis was diagnosed, she was told the condition was probably a life sentence. She was destined by her untrustworthy neuro-transmitters to being chronically lost in inner space, despite respite periods on terra firma. Turning back was not on the prognostic agenda.

Mary is still not entirely sure precisely what allowed her to make the unexpected return journey. It was probably the combination of two factors, one medical, the other personal, which coincided in 1984-85 when she was 26. On the medical side, she was put on new medication which, unlike all the previous drugs that had been tried on her, seemed to stabilise her debilitating mood swings without causing equally debilitating side effects.

On the personal side, she developed the will to recover as a paradoxical response to yet another family bereavement in early 1985. This new tragedy caused her even more intense grief than the deaths of her baby brother and her grandmother. It was the death by drowning of her loved elder brother Sean. Had she not been on the new drug, Sean’s death might well have plunged Mary even deeper into chronic depression. They were close friends, they lived in the same town, they shared ideals, and Sean had always supported her. He was a lifeline to the normal world, having completed his degree, begun a career and established his own family. That is, he had succeeded in the three areas from which Mary’s condition had excluded her. In a way, she lived vicariously through his achievements. When he drowned, the space he had successfully occupied was suddenly vacated. She felt called upon to occupy that vacant space. It was as though when drowning he had passed the responsibility for achieving their shared ideals on to her.

At the same time, his death jump-started Mary out of any temptation she might have felt to wallow in self-pity. She had thought of Sean as “the lucky
one”, as he had a future to look forward to. Now that future was snuffed out, and it was she who had life in front of her. His death made her appreciate her good fortune, and gave her the determination to make the most of the life Sean could no longer enjoy.

Thus, although she experienced intense grief, it was the unexpected source of new resolution and purpose. She stresses the difference between “grief” and “depression”. The latter is global and self-absorbing. Grief, on the other hand, while intensely painful, is localised, and is directed to an object outside the self. In her case, grief had the unexpected effect of enabling her recovery from depression. It was the launching pad for her return trip from the incomprehensible inner landscape of Mars. She is aware, however, that the tragedy might have affected her in a very different and perhaps more calamitous way if the bio-chemical grounds for her recovery had not already been prepared by the new medication she started using a few months before Sean’s death.

Recovery did not come over night, of course. Her mood swings slowly diminished in intensity, like a bouncing ball that loses velocity with each bounce. It took some years for the bouncing to cease altogether, and even then she had to keep taking anti-depressants and mood stabilisers. When she tried to go off this minimal form of medication in future years, she found herself standing on the brink of the old precipice, and had to give up the experiment. Apart from what plummeting into the abyss once more would do to her personally, she felt she could not risk it for fear of its possible destructive impact on her family and work responsibilities. Thus, if she regards the years 1984-85 as the watershed between madness and recovery, the transition was in reality slower and less complete than this image suggests. “Recovery” is a long journey, not an instant cure – but more of that anon.

**Criticisms of psychiatry**

Back on earth in her mid-twenties, Mary had to orientate herself and decide in what direction her future lay. The answer emerged from her reflections on the experiences she had undergone in the preceding eight years, both of madness itself and the response of the mental health system to this madness. It was the outcome of these reflections which set the main directions for the career path on which she was now to embark.

She felt strongly that she had been let down by the system and by the psychiatric professionals who ran it. She had turned to them for help - help she hoped would be based on understanding of her subjective experiences, and on respect for her as the subject of those experiences. It was precisely such understanding and respect she did not receive. In a moment we shall explore in some detail her criticisms of the psychiatric establishment as she encountered it a quarter-century ago. Before doing so, though, a few qualifying words are required.
Mary stresses that she was never actively abused by those running the mental health services. In this respect, she differed from many patients with horror stories to tell of the cruelty inflicted upon them in the name of care and therapy, such as those recounted in Janet Frame’s writing about the barbarism of the old “lunatic asylums”, or those which have emerged in more recent class actions against places like Lake Alice and Porirua. For instance, she was never forcibly committed (although the explicit threat of compulsory treatment hovered in the background, looming up on occasions when she refused to take her medicine, or tried to bolt from A and E). She was not subjected to ECT as a form of punishment, was not menaced by the possibility of a lobotomy, was not locked up in solitary confinement, nor abused by staff or other patients. “They weren’t cruel to me. They just missed me by a mile. All they really did was provide me with a crash pad when I couldn’t cope in the outside world”.

It should be added that despite her resentment of the way she was treated, Mary has some sympathy for the conditions under which mental health providers had to work. They were - and still are - under-resourced and under-staffed. Working constantly in crisis situations, they suffered fatigue, frustration and burn-out. If they were not always considerate of their patients, in part it was a product of their dysfunctional work environment. Mary does not envy them their job.

Her disaffection with the mental health services, then, did not stem from personal victimisation, but from a more thorough-going and fundamental critique of the whole psychiatric ethos of the time, and the power invested in it.

The root of the problem lay in “the medical model” of mental illness. From this root there grew whole thickets of interlocking attitudes, assumptions and practices in which patients became ensnared, and from which many never succeeded in liberating themselves. It was in the cause of such liberation, and the more radical task of uprooting the medical thickets themselves, that Mary was to dedicate her future career.

Her opposition to the medical model was derived in part from her own first-hand experiences and observations, but these were further amplified and reinforced by her reading into the “anti-psychiatry” movement. Through the writings of people such as R D Laing and Thomas Szasz, she discovered that far from being alone in her alienation from mainstream psychiatry, the profession had been under fire since at least the 1960s. The first major broadside was probably delivered by Szasz in his still-influential 1961 essay The Myth of Mental Illness. (Readers interested in finding out more about Szasz can go to the website www.szasz.com/. For a discussion of anti-psychiatry generally, they can consult www. Anti-psychiatry.org/.)

One of the main criticisms Mary makes of her own diagnosis and treatment, which is echoed by countless other users of the mental health system and given weight by scholars in the anti-psychiatry tradition, was the excessive credence attached to bio-medical explanations of madness, and the
consequent over-reliance on pharmaceutical solutions. Mary was required to swallow a diverse range of anti-depressants, anti-psychotic and mood-stabilising pills, on occasions being threatened with involuntary committal if she did not take them. A form of medication was eventually hit on that kept her condition permanently under control, but this was only after years of trial and - mainly - error. The drugs she was given before that were of little use in alleviating her symptoms, while the anti-psychotics she was prescribed for her more extreme states had particularly disturbing side effects. “They took away your soul. You became a complete zombie.” They could also bring on states of acute anxiety, during which she could only pace around nervously. Even the comparatively benign drug she has been on since she was 26 has its unpleasant side effects, including chronic constipation, and dryness and a disagreeable taste in the mouth.

Mary is not totally opposed to pharmaceutical solutions to mental problems - after all, she herself still takes pills. She accepts that there may well be a biological component in some forms of madness, for which a bio-medical intervention is appropriate. That conceded, she also feels they have done a great deal of damage, often wreaking more harm than the condition for which they are prescribed.

Her objection to medication, however, goes deeper than its potentially destructive side effects. She is concerned by the way that psychiatry became dominated around the middle of the twentieth century by purely biological explanations and pharmaceutical fix-alls at the expense of more insightful alternatives. Psychiatric attention became fixated on physiological malfunctions in the brain - those famous chemical imbalances and misfiring neuro-transmitters - largely to the exclusion of social, psychological and even spiritual dimensions of madness. Whatever the problem, the answer was a pill. The mental health system became an adjunct of pharmaceutical corporations, and psychiatrists became dispensers of chemicals.

This had the bureaucratic merits of being easy to administer and uncomplicated to fund, but the profound drawback of leaving the heart of the matter largely untouched. There was no recognition of the subjective world of those experiencing madness. Psychiatry became a predominantly “positivist” discipline, by which term is meant the attempt to explain complex human phenomena through the rigorous application of objective scientific methodology. In the case of psychiatry, positivism involved reducing the subjective workings of the mind to the objective physiology of the brain.

The corollary of psychiatric positivism was that biology appeared to be destiny. The chemical imbalance with which Mary was diagnosed looked unpleasantly like a life sentence. She was told she had a flawed brain - a situation quite beyond her own control. Her fate lay in the hands of those dispensing the chemicals. That is, the biological paradigm robbed her of hope. She appeared doomed to what is termed “chronicity” - the state of being a chronic patient, forever dependent on the psychiatrists who prescribed the drugs:
They told me gravely that I would have mood swings for the rest of my life, and that drugs were the only things that could help me. I passively accepted their verdict that I was condemned to a marginal life and it took me years to question their self-appointed monopoly on competence and insight. They made dire predictions about my life which just didn’t come true. You have to have a mental health service based upon hope. That is precisely what people often lose when they go into one of those states we call madness. If that loss of hope is reinforced by the people around them, it’s very destructive.

However, positivism did not entirely rule the psychiatric roost. Psychotherapy, which attempts to probe the hidden pathologies of the subjective mind, was also practised on Mary in various guises from psychodynamic to group therapy. If anything, she resented these intrusions even more than being externally bombarded with chemicals. Instead of trying to discover any positive meaning or value in her madness, it operated deductively from preconceived assumptions about the pathologies of the human psyche and their probable causes, often traced back to events assumed to have happened in early childhood. Thus, if the bio-medical approach was useless at best and harmful at worst, its psychotherapeutic alternative was no better.

As much as the inadequacies of the treatments themselves, be they positivist or psychoanalytic, Mary strongly objected to the inter-personal power dynamics of the mental health system, which was paternalistic, even authoritarian. It was run from the top down by an elite group of medical experts who diagnosed the illness, ordained the treatment, prescribed the drugs, probed the mind, presided over group therapy sessions, and had the ultimate power of ordering people to be locked up. On the receiving end there were the patients - helpless, hopeless, sick people with damaged brains and inadequate personalities. It was an “us and them” situation, where “we” (the medical profession) were always superior, strong and wise, while “they” (the patients) were subordinate, weak and incompetent. Furthermore, it was an institutional world where professionals made the rules to which patients had to adhere. This was a re-run, in an amplified form, of the school ethos to which Mary had been by temperament so adverse. It was scarcely surprising that the rebel in her mutinied against this new form of authoritarianism. Here’s how she evokes the ethos:

I found it a very arrogant system. I always seemed to be in the position of the one who was wrong, who didn’t understand, who was quite incompetent, up against doctors and other mental health professionals who always seemed to think they knew what was best for me. They wouldn’t take my point of view seriously. There was always the same smug underlying attitude: “You’re a really buggered person. We know what’s best for you. You can’t do anything to help yourself”.
The underlying rationale for the relationships of domination and subordination in the mental health system, of course, is that those who use its services are “ill” and in need of professional help. As such, they are naturally dependent upon those with the expertise to treat them.

On the face of it, this seems a reasonable proposition, and one which many users of psychiatric services would probably endorse. Mary herself is not totally opposed to conceiving mental conditions as forms of “illness”. It is appropriate for some people under some circumstances. They may even find it reassuring that their disturbing experiences have a diagnostic name. Unlike extreme radicals such as Thomas Szasz, she does not dismiss the whole conception of mental illness as a myth. What concerns her are the consequences that flow from the blanket imposition of the medical model. For her, the issue is not whether calling madness an illness is right or wrong - it is what happens as a result of such labelling.

The crux of the matter is that the medical model and its diagnostic categories attach no value to the subjective experience of madness. For psychiatrists, psychologists, therapists and nurses, it is a pathology that must be eradicated, or at least kept under firm control. It has no intrinsic value or meaning.

Although her experience of madness was the hardest period in Mary’s life, and although at the time she resented the apparently wasted years, it was also the most significant experience she has ever had. There was, of course, the exhilaration of the highs, and the heightened sense perceptions with which these rewarded her. Even the times spent in the black box of depression, though, contained a profound significance for her. She cannot dismiss that experience as being “not really her”.

Her encounter with the darkness inside the black box gave her a first hand glimpse of the most profound issues of human existence with which philosophers and theologians have wrestled down the millennia. Although not religious in the orthodox sense (she moved progressively further away from the Catholicism of her upbringing) she cautiously uses the term ‘spiritual” when evoking the insights she gained back then. They link up with the philosophical premises of the ancient Greek philosophers she had been studying at university, encapsulated in intellectually nihilistic statements such as: “I can know nothing for certain - not even that”. Her discoveries were also akin to the teachings of certain Eastern religions with which she was acquainted, such as the Buddhist metaphysical notion of a total void lying behind the surface play of what we mistakenly believe to be reality. In such systems of thought, our sense impressions and our cultural beliefs are illusions. They are the bright decorations and make-believe windows of Mary’s box, concealing the bare black boards.

Her madness thus rewarded her with glimpses of what some philosophies regard as the ultimate wisdom - an awareness of cosmic Nothingness. This, of course, could be terrifying, but in a strange way it also gave her peace.
Some mystics express their revelations in imagery of Light, but Mary finds reassurance and tranquillity in the dark. Her most positive symbolism comes in the form of blackness, and strange as it may seem it was in the depths of her depressions that she eventually discovered spiritual tranquillity.

Whatever the metaphysical implications of her glimpses into the heart of darkness, Mary’s point in speaking of them is that they had profound meaning for her. It was the mythical side of her madness. Doctors could only see the external symptoms, they could not plumb the depths of the mythical well from which they sprang. Indeed, our entire Western culture lacks the concepts in which her experiences can be captured and given meaning. We have space in our culture for other intense experiences beyond the scope of reason - tragedy, love, even the divine light that blinded Paul on the road to Damascus - but there is no place for the subjective content of madness to be comprehended and valued.

Despite their undoubted destructiveness, Mary felt her experiences had both value and meaning. Here, then, is the nub of her rejection of the medical model. For psychiatrists, therapists and the rest of them, madness is simply an aberration to be got rid of with some rather nasty drugs. It has no positive worth or legitimacy in and for itself, no intelligible place to fit into a person’s overall biography. Doctors are not interested in the content of madness, only its dysfunctional manifestations.

Mary refused to accept that her eight years encounter with madness was worthless. True, her emotional state left her floundering behind the more worldly success of her peers, but it gave her a valuable alternative angle on life. Orthodox psychiatry ignores the content of madness: for Mary it is the most important part. True, even today, she cannot fully grasp the meaning of what she herself learned in the black box, but her experiences made her determined, once she emerged again into the clear light of day, to persuade others that madness is an alternative state of being with significance in its own right.

**Absence of the User Voice**

In formulating the challenges to orthodox psychiatry outlined above, Mary initially felt pretty much on her own. The overseas anti-psychiatry writings of Laing, Szasz and others, which helped her clarify and focus her own ideas, had seemingly made little impact on the New Zealand mental health system. Above all, the voice of those who actually used the system had no way of making itself heard. Mary felt it would have been of immense help if service users who had survived the system had been around to support her, and to act as mentors and role models to give her hope. As it was, there was no peer support. Mental health providers made no attempt to harness the first-hand expertise of those who used their services. In an “us and them” world, patients were subjected objects of medical treatment, not respected agents of their own destiny.
When she first joined “the tribe of the mad”, Mary herself came equipped with the standard stereotypes about “us and them”. To the extent she had thought about mad people at all, she presumed them to be sad, weak, unattractive creatures with lives that were probably not worth living. When she became one of this stigmatised group herself, she had the choice of clinging to her former stereotypes, and thereby accepting that her own life was not worth living, or rejecting it in the light of the human realities she discovered amongst her fellow patients. She opted for the latter.

Far from dissociating herself from the group to which she now belonged, she positively identified herself with it. The people she met in hospital did not fit the stereotype. Most had been psychically maimed by terrible experiences, and often faced them with a great deal of courage. Mary made a number of good friends during her hospital sojourns, and although there was no systematic user movement at the time, a tenuous spirit of comradeship developed amongst patients that prefigured, in an underground form, the more organised and overt user movement that was later to develop.

That organised movement, however, was yet to be forged in New Zealand. Mental hospital patients informally discussed their sense of alienation from the psychiatric system amongst themselves, but no systematic challenge based on an alternative vision had yet been mounted in New Zealand. True, there were diagnosis-based groups such as a manic-depression support group in Christchurch, and there was the Mental Health Foundation which promoted the interests of psychiatric patients generally, but there were no rights-based services in this country run by those with first-hand experience of mental illness.

Mary was acquainted with other social movements which had taken root here, like those promoting the causes of feminism, gay rights, indigenous people, peace and the environment, which provided a possible template for a mental health user movement, but she could not at first figure out how these could be applied to psychiatric patients. Overseas, however, developments were occurring which showed that such an alternative vision could not only be contemplated but actually put into practice. A seminal book in this respect was Judy Chamberlin’s 1977 *On Our own*.

This book was something of a revelation to Mary. In it, Judy Chamberlin, a leading crusader for patient rights in the USA, expressed her opposition to the notion of “illness”, condemned the use of force in the mental health system, and described patient-run alternative services where there was no coercion, no imposition of harmful drugs, and consumers were treated with respect. Mary read the book in 1984, around the time she herself was emerging from psychosis, and it opened up a new world of possibilities. Nothing like this was happening in New Zealand, but Chamberlin’s description of the user movement in the States infused Mary with the conviction that here, too, survivors of the psychiatric system could take control of their own destinies.
This was a cause worth fighting for. For the last eight years, she had been living more or less in limbo. Now, in her mid-twenties, her life took on purpose, the future became a challenge rather than a threat, and her untested potential had something against which to prove itself. The years in the psychiatric wilderness had not been entirely wasted, as from them she discovered a cause worthy of a lifetime’s commitment. Furthermore, they had toughened her up to undertake that commitment. They had provided a testing ground for her powers of endurance and survival - she felt if she could come through psychosis without breaking, she could take anything else life might throw at her. Armed with this sense of hard-won resilience, she set out in 1985 on what was to become a lifetime vocation.

The Mental Health Foundation and the research project

Her first intention was to write a book exploring her own experience of extreme mood swings, that would look at them from all angles and possibly serve as a kind of self-help manual for others. This initial project, however, was eclipsed by a more ambitious one that was to lead her from private contemplation to public action.

In order to gather ideas for the book by making contacts, in the middle of 1985 she went up from Dunedin to a large conference on mental health held in Wellington under the aegis of the Mental Health Foundation (for information about the Foundation, see www.mentalhealth.org.nz). She was struck by the fact that out of the 200 or so people there, only two had actually been users of mental health services, all the rest being providers of one sort or another. It seemed ludicrous that those professionals could talk amongst themselves for three days about mental health issues as though those most concerned were totally invisible. Mary felt what was needed was a dialogue between all parts of the system, in which service users themselves played the central role. It was they who should be calling the shots, not the psychiatrists, nurses and bureaucrats. To achieve this, she realised, it was necessary to create an organisation run by and for such users, that would speak with their voice alone and advocate single-mindedly for their interests. As the conference unfolded, Mary decided to abandon her proposed book and devote her energies instead to the creation of such an organisation.

Striking while the iron was hot, she got up at the concluding plenary session amongst the assembled throng of professional experts and pointed out the fundamental flaw of the whole conference - the absence of a strong consumer presence. They had been talking about people like her for three days: why not talk with her? To their credit, a number of those present took her criticisms on board, and came up to discuss them with her after the session. In particular, her words struck a chord with members of the Mental Health Foundation, who were already advocating for a stronger user voice.

These and subsequent discussions with key people in the Foundation were a crucial turning-point in Mary’s life. It was mutually decided that she would
move up to Auckland, be given an institutional base at the Foundation, and undertake a research project amongst users of mental health services. This, in turn, would lay the foundations for the eventual formation of a self-advocacy organisation.

At the end of 1985, Mary put the bad experiences of Dunedin behind her and moved up to Auckland. She was provided by the Mental Health Foundation with office space and equipment. Just as importantly, her base there enabled her to make useful contacts, and cast the mantle of credibility over her research project. She was not officially on the Foundation’s pay roll, however, and had to cobble together a rather hand-to-mouth existence on a welfare benefit, alternating with grants from charitable trusts and the state-funded work scheme of the time.

Back then, the Foundation was active both in promoting mental health and in advocating for patients rights, although from the mid-1990s it concentrated mainly on just the public health side. Its high-profile, long-standing director was Max Abbott, and its deputy director was Hilary Haines (now Hilary Lapsley), the latter acting in a supervisory capacity to Mary.

Amongst the Foundation’s diverse activities, it was deeply involved in the de-institutionalisation process which was under way at the time, involving the movement of mental health patients from hospital to community-based care. It also employed a legal officer to work on the formulation of a new Mental Health Act which was eventually passed in 1992. This was to replace the draconian 1969 Act, which routinely deprived committed patients of a whole range of basic rights, such as those to vote, to drive, to have legal representation during committal procedures, and to have their cases reviewed. Under the old Act, there was a blanket abrogation of such rights, regardless of individual circumstances.

Mary herself did some work on the new Act, but her main project involved qualitative research amongst service users. It was to comprise around 50 in-depth interviews with people who had experienced or were still experiencing severe mental disorders, and was to provide the information base from which a user organisation would be formed.

In the event, Mary only completed around 20 of the proposed interviews, and her report was not as full as originally intended. There were several causes of the truncation of the project. For a start, she became disaffected with the research process itself. One reason for this was that although those she interviewed had very moving stories to relate, most of them dwelt on individual experiences, and had not gone beyond these to query the whole ideological basis of the mental health system. Mary admits she was probably naive at the time to have expected everybody to have done the kind of in-depth analysis she herself had been engaged upon. They had other and more pressing things to preoccupy them. The fact remained that it was clear her research was not going to produce the kind of powerful statement about the fundamental flaws in orthodox psychiatry she had hoped for.
She was also uneasy with her own role as researcher, and in the methodology her research imposed on her. She had the uncomfortable feeling that the relationship between herself as researcher and the subjects of her research duplicated the asymmetrical power relationship between mental health providers and users. She was assuming a dominant, quasi-professional role, where people were furnishing her with information but had no control over what use she made of it. She had further concerns on the purely methodological front as well. For instance, she only interviewed her subjects once, which did not give them a chance to reflect upon and to add to what they originally said. She felt she would probably have gained more valuable insights through group discussions, where people could have exchanged ideas in a participatory way.

The Birth of Auckland’s Psychiatric Survivors

The main reason for curtailing the research project, however, was that it had been overtaken by more important events. It had been intended as the precursor to the establishment of a self-advocacy group, but it became redundant when the organisation itself came into being rather sooner than expected. The momentum for the creation of such a group had built up between Mary and some of her research subjects, along with other service users with whom she had established a rapport, and she decided to direct her energy into its creation rather than carrying out the full research plan.

Thus in 1987 the Auckland Psychiatric Survivors was born in something of a rush. The name was suggested, as Mary remembers it, by Debbie Noble. The term “psychiatric survivors” was already being used quite widely in the States, but so far as Mary knows nobody in New Zealand had actually heard of it. In all events, they did not base themselves on an American model, and she thinks it was a pure coincidence that the name was the same.

It was a small group - there were only about 20 of them, and not all of these came to every meeting. Most members wanted it to be just a mutual support group, giving users the opportunity to meet together every two weeks or so and share experiences and problems. A small activist core, though, notably Mary, Rod Davis and Corinne Curtis, had a more ambitious agenda. For them, proactive advocacy of the consumer cause was the top priority. They wanted to do more than just support users of the existing system: they wanted to create a new and better one where they would be in control.

In the early days, they held their meetings in private homes or various venues attached to the new community-based mental health services. By 1988, however, the core group had found itself a permanent base to serve as the headquarters for its radical self-help philosophy. They had approached Peter McGeorge, the superintendent of Carrington Hospital, to see if they could set themselves up in a house in the hospital grounds. It was to act as a kind of drop-in centre for Carrington patients where individual advocacy work could be conducted. Not all hospital superintendents would
have been happy with this idea (none of the people involved had formal qualifications at this stage) but they were fortunate that McGeorge had the imagination to take the risk. Mary left her base at the Foundation and joined Rod Davis and Corinne Curtis at Carrington.

Though officially under the Carrington umbrella, the activists in Psychiatric Survivors were determined to be as independent and self-sufficient as possible. It’s whole point was that it should be an organisation run for and by users themselves. To this end, they developed something approaching a separatist ethos, eschewing assistance from professional outsiders. The latter, even if well-intentioned, tended to adopt a rather condescending tone when dealing with ex-patients, and had a habit of trying to take over. The group wanted to distance itself from mental health providers, and indeed from all outsiders to the user community, even including potentially useful advisers such as accountants. Rejecting external help had its practical drawbacks, but was felt to be important if they were not to be under someone else’s thumb.

There is, of course, an in-built difficulty which people with mental conditions encounter when aspiring to total self-sufficiency. The condition itself may on occasions make sustained work difficult, and also place a strain on the inter-personal relationships of those engaged in it. The activities of Psychiatric Survivors was not exempt from such problems, and Mary herself, whose mood swings were stabilising but not completely eradicated, was sometimes obliged to take time off work.

Nevertheless, the principle of independence was staunchly maintained. Looking back on those days, Mary feels it was essential for the user movement that its first pioneers should have made this attempt to go it alone and assert their distinct identity. As with other social movements, separatism was a necessary early growth phase.

However, as 1988 unfolded, there were some aspects of the Carrington project in particular and the ethos of Psychiatric Survivors in general with which she began to grow a little uncomfortable. For one thing, she was not convinced that the kind of one-to-one advocacy being carried out at Carrington was the right strategy for the group to be pursuing. Whether or not it was successful (and a review of their work raised some doubts in this respect) Mary felt that their energy would have been better directed towards analysis of the mental health system as a whole and the advocacy of fundamental reforms at the national level, rather than piecemeal individual work.

She had some practical managerial concerns as well, relating to the effective administration of an on-going organisation, such as keeping systematic records and accounting for funds. Here she faced something of a dilemma. In principle, she was extremely democratic in outlook, espousing the ideal of a fully participatory, bottom-up user movement - the diametric opposite of the authoritarian, top-down medical system to which she had been subjected. In practice, this ideal of anarchic liberty threatened to
undermine the evolving functional requirements of the organisation. Their paid staff of four had undertaken certain responsibilities, and had various forms of accountability to observe, including the administration of financial grants. These matters did not concern other core activists as much as they did Mary. Furthermore, they were of no interest at all to the majority of Psychiatric Survivor members, for whom it was mainly just an informal support group.

Mary, on the other hand, grew increasingly preoccupied with the need to keep records, account for cash flows and generally adopt a responsible attitude to the bread-and-butter business of organisational administration. Everything was too ad hoc and chaotic for her liking. The others had rushed in like a storm and set up the Carrington project, but paid insufficient attention to essential if routine administrative details. Mary felt they were getting into a hopeless mess, and needed to clean up their act. She had begun her career in the mental health system in quest of one “M” – Meaning. As her vision for a New Zealand self-run user organisation began to take shape, the importance of a second “M” reared its head – Management.

By the end of 1988, something approaching a crisis was building up within Psychiatric Survivors, generated by the three issues just mentioned - individual vs systemic advocacy, chaotic personal liberty vs administrative structure, and the distinction between a paid core of dedicated workers and the sporadic involvement of grassroots members. The tensions were to lead one or two people to leave the organisation in 1989, and in that same year new horizons opened up for Mary herself at both national and international levels. These enabled her to extend the range of her activities, tackle systemic rather than individual issues, and to gain overseas perspectives on the problem with which she had been wrestling within Psychiatric Survivors - that is, the dilemma of reconciling non-authoritarian participatory democracy with managerial effectiveness.

The Churchill Fellowship

Mary and her associates had improvised their own Auckland version of Psychiatric Survivors pretty much off their own bat, apart from ideas drawn from books like Judy Chamberlin’s *On Our Own*. In 1990, a three-month Winston Churchill fellowship gave her the opportunity of travelling to the United States, Britain and the Netherlands to meet other people in the user movement, and look at a wide variety of consumer-run alternatives to the mainstream medical establishment. On her return, she wrote a report of her travels which was published in Britain in 1994 as the succinct but insightful book *Stopovers on my Way Home from Mars*. (This was later re-published in a Japanese translation, after Mary visited that country, and has possibly been more widely read in Japan and Britain than in New Zealand.)

Her book is much more than a factual account of the organisations she visited. It combines a swingeing criticism of the mental model of mental illness with shrewd sociological observations about the strengths and
weaknesses of user-run alternatives. From visiting places where the user movement had been longer established than in her own country, Mary was able to gain a clearer idea of the possibilities it opened up for New Zealand consumers, while glimpsing some of the potential pitfalls they would be wise to avoid.

In the latter respect, patterns of behaviour had developed in some agencies she visited which made her distinctly uneasy. The whole point of user-based services was to accord people experiencing mental illness the respect and dignity they were frequently denied by professional providers. In two or three instances, the old hegemonic mentality seemed to have re-emerged in another guise. The disturbing thing was that it was happening amongst users themselves. The new hierarchical divide was between waged agency staff on the one hand and rank-and-file clients on the other. The former sometimes slipped into a paternalistic stance towards other users, on occasions with the latters’ tacit acquiescence. Mary cited: a group leader delivering moral lectures about his fellows’ sexual activities; notices ordering people not to smoke; shared rooms in a house where the beds were numbered as in a hospital ward; workers allocating themselves separate toilets from the rest. Mary’s ideal for the user movement was of democratic equality. Even if they were exceptions, the instances of paternalism she witnessed brought home how easily this ideal could be subverted by what sociologists call “the iron law of oligarchy”.

Thus, if she came home inspired, she had also had some of her own misgivings reinforced. She was convinced that the user movement back home needed an injection of managerial rigour, yet equally determined to avoid New Zealand organisations developing the new brand of “us and them” that could divide users-as-providers from users-as-clients.

The Aotearoa Network of Psychiatric Survivors

Back home, Mary had another project to tackle which was to extend the range of Psychiatric Survivors from Auckland to the whole country. The seeds of this new development were planted early in 1989, before her overseas trip, when she was asked to write a paper for a mental health consortium. This was a committee under the joint aegis of the Departments of Health and Social Welfare to give policy advice to the government about the transference of mental health services from institutional to community-based care. Mary was commissioned to sound out user views on the de-institutionalisation process. She had already begun to make contacts with user groups around the country before this, beginning with a Mental health Foundation conference in 1987, and her new brief involved an intensification of such networking. The consultation process included her convening of a large meeting in Auckland in mid-1989, where groups from around the country came and expressed their views on the move to community services. She herself was not a born networker, but she acquired the art of establishing collaborative working arrangements with others to whom the business of initiating contacts came more easily.
Work for the consortium, however, was only the prelude to a more challenging project which was to occupy her on and off for the next six years or so. When the consortium wound up, it had an unspent fund of $750,000 from the Department of Social Welfare. Mary and Pauline Hinds from Dunedin - the two users involved in the consortium’s work - conceived the plan of setting up a nation-wide consumer network. They put in a successful application for the left-over consortium money to be directed into this project, and in 1990 the Aotearoa Network of Psychiatric Survivors (ANOPS) came into existence. The original Auckland organisation which Mary had founded in 1987 still continued operating, but Mary left it to help set up the new network, which would give the term “psychiatric survivors” wider currency around the country.

The function of ANOPS was not to provide day-to-day services such as drop-in centres at the grass roots. It was formed, rather, to advocate for the user perspective at the level of national policy, and to facilitate the exchange of information country-wide. Its governance body was a national collective, comprising representatives from the various regions, and it had a few paid workers including Mary herself. It was also to employ a Maori networker called Iwa Natana.

A brief digression on the role of Maori in the network is in order here. From the very start of the user movement there had been a strong tangata whenua presence, which the founders of ANOPS were keen to maintain. Thus its constitution required there to be six regional Maori representatives on its governance body. Maori people were over-represented amongst users of psychiatric services, so it was important that they should have a strong presence in any self-help organisation speaking for their interests.

Mary says that there were always good working relationships between Maori and non-Maori in the user movement. This ethnic tolerance stemmed, Mary feels, from the understanding and supportive nature of the movement generally. Themselves victims of alienation, stigmatisation and even oppression, survivors of the psychiatric system felt an affinity for others in the same situation. In particular, Pakeha users perceived the parallels between their own desire for self-determination on the one hand and Treaty-based Maori politics on the other.

Now back to ANOPS. Despite initial high hopes, the Network got off to a rather hesitant start. The main problem was the chilly policy environment created by National when it came to power just as ANOPS was trying to get off the ground in 1990. It lost its $250,000 when Finance Minister Ruth Richardson froze public spending at the end of that year, was given a little in compensation by the Department of Health, then again lost its financial lifeline in the restructuring of the health system from 1992. Amongst other casualties, the newly appointed Iwa Natana had to be told there was no money to pay her after all, and Mary herself was out of a job. She felt thoroughly disillusioned at thus having her vision of a nation-wide user movement and her own personal vocation frustrated by New Right ideology.
There is going to be a jump in chronology at this point in the story. Just when Mary’s job with ANOPS was kicked out from under her in 1992, another and even more challenging opportunity opened up in England, where she worked throughout 1992-1993. We shall come back to the London side of the story later. First, though, for the sake of narrative tidiness let’s follow through the rest of the ANOPS chronicle.

In 1994, Mary was back in New Zealand after her detour through England. Despite the bleak outlook at the start of the health reforms in 1992, the Survivors were still surviving when Mary rejoined them. However, she found that while she was away, the funding basis of the Network had changed. ANOPS was no longer funded as a national entity, but instead there were four inter-related regional networks financed by the four newly-created Regional Health Authorities (RHAs).

Even so, the country-wide network still existed in principle, and she made a successful application for the job as national manager. She stayed in this job for the next two years, spending four days a week working for ANOPS and one day for the northern RHA.

Mary feels that ANOPS did some good work, even if it did not succeed in radically transforming the mental health world. Here are some examples of its activities while she was leading it. Its representatives sat on a number of committees. It facilitated the distribution of information and ideas between the regions. It put out a useful booklet about drugs from consumers’ perspectives, advising them about questions they should ask the doctors who prescribed them. National hui were held, and a newsletter called New Moon was distributed. With Iwa’s help, they got the Maori network up and running. They also fulfilled a small contract to provide feedback and advice to the Ministry of Health.

One of the major issues that preoccupied them was de-institutionalisation. Although in principle endorsing the move from hospital-based to community services, they were unhappy about the way this was working out in practice. Emptying out the old residential ghettos did not in itself guarantee the empowerment or wellbeing of their former patients. The new community services such as half-way houses and trust homes were sometimes operated on paternalistic and authoritarian lines, with residents having little say in how things were run. Worse, many people ended up isolated in squalid boarding houses, at the mercy of sometimes exploitative landlords. The housing issue was thus high on the Psychiatric Survivors’ agenda, within the wider context of the sometimes problematic brave new philosophy of community care (or lack of it).

Despite such activities, Mary felt frustrated that the organisation was not really serving the function she had first envisaged. Its operations were skewed by its region-based contracts for service delivery, as opposed to the national grant with which they had started, and by the nature of the work for which they were commissioned by the RHAs. This primarily involved
going round developing consumer networks, mainly in the Northern and Midlands regions. Though useful in itself, this was not really what ANOPS had been set up for – namely, to act as a national advocacy body.

Mary’s frustrations mounted to the point where half-way through 1996 she resigned her position as manager of ANOPS to take up new career challenges (to be described later). The Aotearoa Network of Psychiatric Survivors remained in existence for another two years after she left, but in 1998 went into abeyance. AT the time of writing, there are instead four autonomous regional user networks, funded through Vote Health. They are centred respectively in Auckland, Hamilton, Wellington and Christchurch.

This, however, was not the national network that Mary and Pauline Hinds had conceived back in 1989. At the time of the present interview, people in the user movement were hoping to start such a country-wide network up again. A steering group had been formed to this end, mainly comprising members of the four regional networks mentioned above. Mary herself has not played an active role in this attempt to revive the national network, but does what she can to support the initiative.

If she felt thwarted by the way things panned out with ANOPS between 1994 and 1996, Mary was equally frustrated in the other part-time work she was doing during that period. This was a contract job with the Northern Region Health Authority, which involved networking with mental health users in the Northland and Auckland area, and providing feedback to the RHA. It also required purchasing services from user-run community groups on behalf of the RHA. She was not actively unhappy with this work, but it had two aspects about which she was not entirely satisfied.

On the one hand, it required her to work alongside a small team of mental health workers, rather than filling the leadership role that was more her bent. She had always been very much an inner-directed kind of person and didn’t like being managed. Although she liked the team members, and there was no major inter-personal conflict, it wasn’t what she would describe as “a peak working experience”.

Thus by the middle of 1996, Mary’s enthusiasm for both her jobs - the one with the Northern RHA, the other with ANOPS - had ebbed away. She took a deep breath, turned in both positions and opted for the rather more precarious career of freelance consultant.

The World Federation of Psychiatric Users

In the foregoing, we have been following Mary’s crusade for the cause of New Zealand psychiatric survivors in the first half of the 1990s. There was an international side to the story as well, however, which we have not yet mentioned. Let’s now track back from her decision to go freelance in the middle of 1996, to catch up with other things that were happening in her life. These will see Mary moving from the national to the world stage.
This side of the narrative begins with a 1989 congress of the World Federation for Mental Health (WFMH) held in Auckland under the aegis of the mental Health Foundation’s director Max Abbott. The WFMH had been pushing for some time to have users involved more actively in the psychiatric system internationally, in order to ensure greater respect and equality for people experiencing mental illness. At the Auckland Congress, it was decided that their next summit meeting in Mexico City in two years time would be the springboard for launching a world-wide user network.

In 1991, Mary and Pauline Hinds attended the inaugural meeting of this new international users’ organisation in Mexico. Mary presided over the meetings and was elected the network’s first Chair. They initially called themselves the World Network of Psychiatric Users (WFPU), but were not entirely happy with the name and in 1997 changed it to the World Network of Users and Survivors of Psychiatry (WNUSP).

There has always been a certain amount of tension within the user movement over the issue of how much to collaborate with non-users generally and the psychiatric establishment in particular. This can be seen in the name change just mentioned, from an organisation of “Psychiatric Users” to “Users and Survivors of Psychiatry”. The term “user” was preferred by moderates, who felt there was scope for mutually respectful cooperation between themselves and the psychiatric profession. “Survivors” reflected a more radical, separatist approach. The most radical of all amongst the latter group wanted to totally abolish orthodox psychiatry. The name adopted in 1997 thus represented an attempt to reconcile moderate and radical ideologies by embracing both in its new title. Those willing to work with the mental health establishment tended to call themselves “users”, those who preferred to go it alone tended to call themselves “survivors”.

Like the survivor network back home, the World Network of which Mary found herself head in 1991 spluttered along fitfully rather than blazing out as a global beacon. There were a host of practical tasks to get done, such as informing user groups of the World Network’s existence and recruiting members, drafting rules, arranging teleconferences, producing newsletters, discussion documents and policy positions, attending conferences, and sitting on the United Nations panel on the Standard Rules for the Equalization of Opportunities for People with Disabilities. Mary had to undertake most of these tasks herself, operating in an administrative and funding vacuum.

At the Mexico City meeting, a world-wide organisation had been ambitiously willed into existence, but as the poet T S Eliot wrote: “Between conception and creation falls the shadow”. Mary did her best to turn vision into reality, using her own home as the network’s administrative HQ, but the logistics of establishing a global network with practically no infrastructure or resources was daunting. After an up-hill struggle for four years, she quit the hot seat in 1995. However, she still maintained her involvement in the network, and
was on deck when it set out to revitalise itself under its new name at its 1999 meeting in Santiago, Chile. Mary chaired meetings at the Santiago conference, and was selected by its participants as a special committee member over and above those formally chosen to represent different global regions. She finally resigned from the board in 2004, after 13 years involvement.

The London Interlude

We are getting ahead of ourselves, though. Let’s jump back in time from Santiago in 1999 to New Zealand in 1992. That was when Mary and Pauline’s newly-hatched Aotearoa Network of Psychiatric Survivors was being stomped on by the National government, and Mary was out of a job. Just as that door was closing back home, however, a window opened in London. At the Mexico City WFMH Congress, Mary met John Jenkins, who had created a mental health consultancy called the Centre for mental Health Services Development, based in London University’s King’s College. The centre gave policy advise to sectors of the English mental health system as it undertook the transition from institutional to community services. Jenkins wanted someone to orchestrate user feedback into the de-institutionalisation process, and while out in New Zealand in 1992 offered Mary the job.

Her mission was to travel around the regions, make contact with psychiatric users at the grass roots, and encourage them to get organised and participate in the transition process. In principle it was a good idea, even a visionary one, but a number of factors combined to thwart the transformation of John Jenkins’s vision into reality. Some of these concerned Mary herself, some the agency, some the whole nature of the mission.

On the personal front, while Mary was in England she attempted to rid herself of dependence on the drugs she was still taking regularly to control her mood swings and depressions. In part, this was an ideological issue. She was opposed on principle to the bio-medical model of madness, yet in practice was herself reliant on pharmaceuticals to keep it at bay. She wanted to align her practice with her principles. The experiment was not a complete success, however, as although she did manage to kick the mood stabiliser, without the anti-depressants she found herself dangerously close to the brink of the old precipice. Eventually she bowed to bio-chemical necessity and went back on anti-depressants. Her unsuccessful attempt to wean herself from pharmaceutical dependency impaired her performance on the new job, as she was not always able to work at peak capacity.

Her own problems apart, the nature of the job itself was vast and intractable. It required her to make personal contact with users around southern England at the community level (in itself a formidable logistical task) and motivate them to participate in mental health reforms. She got on well with the individual users she met, and also benefited from meeting weekly with a support group in London. She still maintains some of the
friendships she made back then. However, she felt that she did not make much headway with her major brief, which was to transform passive users into politically conscious activists. She could not set to and organise groups herself - she could only plant motivational seeds. She had a few successes when individuals with whom she talked picked up her ideas and ran with them, but for the most part she felt the seeds fell on barren ground. Those who did turn up to meet her were often rustled up for the purpose by mainstream mental health agencies, and were perhaps not ideal raw material for the forging of an independent user movement. She concluded that the historical moment was not propitious. In some places, users were so habituated to the old dependency mind set, the time was not yet ripe for a major transformation in their collective consciousness.

To compound her problems, she did not feel particularly at home in the organisation for which she worked. It gave her little logistical support in carrying out her difficult field work. More fundamentally, she was the only user employed full time by the agency, which was otherwise dominated by fairly conservative professionals with whom she had little rapport. Basically, they lacked any awareness of where she was coming from philosophically. They did not share her experiences nor empathise with her world view.

The upshot of all these adverse circumstances was that she decided to terminate her contract with the Centre for mental Health Services Development after a year and return to New Zealand. Her suspicion that the agency for which she had been working was rather dysfunctional was confirmed when it totally unravelled shortly after she left, and John Jenkins himself departed.

**Going Freelance and the Mental Health Commission**

Now is the time to re-unite the divided paths of Mary’s story, which have become a little chronologically scrambled. Let’s briefly recapitulate: in 1990 she and Pauline started up the Aotearoa Network of Psychiatric Survivors; in 1991 she went to Mexico City, helped create the World Federation of Psychiatric Users and became its first head; at the end of 1992 she went to London for a year; in late 1993 she became a user consultant for the Northern RHA and in late 1994 manager of ANOPS; in 1995 she stepped down as head of WFPU though remaining on its board until 2004; in the middle of 1996 she left her position with the NRHA and with ANOPS in order to chance her fortunes as a private user consultant. Now read on!

1996 was an auspicious year for someone with Mary’s experience, skills and outlook to try making a living as a freelance consultant on mental health services. Those services were given a severe shake-up that year by the hard-hitting report of a committee headed by Judge Ken Mason (always referred to as “The Mason Report”). The report was highly critical of many aspects of New Zealand’s mental health system, and made a number of recommendations for its improvement. The two which were probably to have most relevance to Mary’s own career were for the creation of a new
Mental Health Commission and for a campaign to combat the widespread discrimination against users of psychiatric services.

Let’s start with the Mental health Commission (MHC). Interested readers can find a wealth of material about it at the website www.mhc.govt.nz. The following are a few snippets of information adapted from that site.

The Mental Health Commission came into existence as an independent Crown agency under its own Act in 1998. It has three Commissioners appointed by the Minister of Health and a staff of about 18. Its main functions under the Act were to:

- Monitor and report to Government on the performance of the Ministry of Health and Health Funding Authority in the implementation of the Government's National Mental Health Strategy. [Note: its watchdog role has now been transferred from the old Health Funding Authority to the Mental Health Directorate within the Ministry of Health.]

- Work with the sector to promote better understanding by the public of mental illness, and eliminate discrimination.

- Strengthen the mental health workforce.

The Commission promotes recovery approaches, whereby meeting the needs of service users and their families is a priority in mental health services. It has the flexibility to undertake whatever tasks are required to meet its responsibilities. This includes reviewing, examining and reporting back to the Minister on the status of the mental health system, the progress being made toward achieving the mental health strategy and finding out what barriers are preventing the objectives being reached. Key documents guiding its work are:

- Looking Forward: Strategic Directions for Mental Health Services.


- Blueprint for Mental Health Services in New Zealand How things need to be.

- Mental Health Standards.

The Commission has played a major role in Mary’s life since its creation in the wake of the Mason Report. Up till 2000, it provided her with the on-going contractual work which is the life blood of a private consultant. Between it and other agencies for which she worked, she was assured of a good income. It became an even more significant feature in her life in 2000, when she replaced Julie Leibrich as one of the three actual Commissioners.
The Recovery Approach

As both a self-employed consultant before 2000 and Mental Health Commissioner afterwards, Mary devoted considerable time and energy to the development and implementation of a new ethos within the mental health world. It was an approach for which she herself had been advocating ever since her own brushes with the psychiatric establishment in the early 1980s, but one for which the time had apparently not previously been ripe. By the mid-nineties, however, a new attitude towards mental illness was beginning to gain traction overseas. Mary, along with a handful of other New Zealand user advocates, set out to adapt this approach in the light of their own local philosophy. It was called “the recovery approach” to mental illness.

Today, the word “recovery” is a prominent feature in mental health discourse in this country. It made its first significant public appearance in the 1998 Mental Health Commission document Blueprint for Mental Health Services in New Zealand: How things need to be (www.mhc.govt.nz). Most of the document comprised detailed, technical proposals for implementing the nation’s new Mental Health Strategy, such as how many services should be funded per 100,000 of the population. Amongst all the facts and figures, however, there were some pregnant hints of a new philosophy gestating within the mental health establishment. This philosophy was considered sufficiently important to be given top billing in the Blueprint’s vision, as set out in its Executive Summary:

The focus of this Blueprint is on a recovery approach in service delivery. This approach is consistent with the guiding principles of the Strategy, which state that services must empower consumers, assure their rights, get the best outcomes, increase their control over their mental health and well-being, and enable them to fully participate in society. This focus on recovery reflects the shift of thinking which is happening throughout the sector.

If you visit the MHC’s website, you will find the same prominence given to the term recovery: “Our vision is for New Zealand to be a place where people with mental illness have personal power, full participation in their communities and access to a fully developed range of recovery-oriented services”.

Nowadays, “recovery” has found its way into the language (though often not the practice) of mainstream psychiatry. This new centrality of the recovery approach is due to a degree to Mary’s own work in the area, first as a freelance consultant and then as Mental Health Commissioner. Amongst other things, it was she - along with fellow pioneers such as Julie Leibrich and Tessa Thompson - who were instrumental in having the recovery concept incorporated into the 1998 Blueprint, even if back then it was only an embryonic vision. She has subsequently developed and promulgated a set
of key recovery “competencies” to be incorporated into the training of all mental health workers, which interested readers can find on the MHC website.

Despite the prominence which Mary and others have given the term, however, its usage may cause confusion amongst outsiders to the mental health world (and even to some on the inside). In common parlance, recovery from an illness, accident or disability implies total cure. If we say we have recovered from the flu, for instance, it means we have shaken off all the symptoms and are back in perfect working order. This, in turn, implies that the illness was a passing aberration in an otherwise healthy biography - a meaningless pathology that came and went, leaving behind no traces.

Thus, when we hear mental health workers proposing “recovery” as their goal, we assume they mean finding a remedy for conditions like schizophrenia, depression or bipolar disorder. We might also be tempted to feel they are being somewhat unrealistic, as such conditions are notoriously intractable, even to modern drugs. It is therefore important to stress that “recovery” in mental health circles implies something slightly different from the way is often applied to physical health.

We shall come back to this point in a minute. First, however, it must be mentioned that Mary and her user allies, such as Julie and Tessa, were acutely aware of the semantic problems surrounding the term “recovery” when they first started promoting it back in the mid-1990s. In fact, there was considerable debate amongst leaders in the user movement here about the term’s suitability. Some argued they would never fully recover from their condition, some that they had nothing to recover from in the first place, others again that it implied going back, when they wanted to push forward. Eventually the term was adopted, but only because they could not come up with a more satisfactory one to encapsulate their vision.

One reason why they opted for the term was that it was already gaining currency and credence in other English-speaking countries since the 1980s, as a result of the influential writings of campaigners in the user movement like Patricia Deegan, and of William Anthony of the Center for Psychiatric Rehabilitation at Boston University. The New Zealanders felt it made good strategic sense to use terminology that would situate them in a wider international context. However, Mary thought that the Americans put too much emphasis on recovery as a personal journey. This individualistic emphasis did not pay sufficient attention to factors in the social environment, such as discriminatory attitudes, that can interfere with recovery. The New Zealanders therefore took the main orientations of the overseas movement but adapted it in the light of their own more collectivist approach. While aligning themselves with international mental health reforms by adopting the same terminology, they tried to give it their own distinctive flavour, whereby recovery was regarded as much as a social process as well as a personal one.
What, then, does “recovery” stand for? There is no one simple answer to this, as it is a holistic, multi-dimensional approach that cannot be adequately captured in a short, snappy definition. An excellent survey of the field can be found on the website www.surgeongeneral.gov/library/mentalhealth/chapter2/sec10.html. Here we shall just sketch the broad general outlines.

“Recovery” means living well whether or not you still experience mental illness. It is not a simple, fix-all formula, but rather a process, an outlook, a vision, a guiding principle. The overarching message is that hope and restoration of a meaningful life are possible, despite serious mental illness. People may or may not be able to rid themselves of psychiatric symptoms, but even if the latter persist they need not be totally disabling.

Instead of focusing primarily on symptom relief, as the medical model dictates, recovery takes a wider approach to the restoration of self-esteem and identity, and on attaining meaningful roles in society. Bio-medical and psychotherapeutic assistance may still be involved, but these are only a part - and probably not the most important part - of a more global approach that includes families, friends, housing, employment, mutual support amongst users, anti-discrimination campaigns, cultural sensitivity and empathy with the experience of madness. In this multi-pronged approach, patients are not “treated” by professionals. They are no longer passive objects of the medical model, their brains addled by inappropriate pharmaceuticals, trapped in chronicity and sometimes victims of forced treatment. Rather, they are active and equal partners on the road to recovery. In a word, the recovery movement offers hope - something of which Mary felt robbed by the mental health system a quarter-century ago.

A significant part of her life since 1996, then, has been dedicated to formulating a New Zealand version of the recovery philosophy, gaining acceptance for it by the mental health establishment, and promoting its inclusion as an integral component in the training of all mental health providers from community support workers to psychiatrists. In the process she has contributed to a paradigm shift in society’s attitudes towards mental illness, and in users’ feelings about themselves. The process is by no means complete, and she suspects that in many quarters people’s lip service to recovery is not matched by their practice. Nevertheless, the ground is not as barren now as it was when she first attempted to sow the seeds of user self-determination in 1985.

**Against Discrimination: Like Minds, Like Mine**

As noted above, the recovery approach advocated by Mary and her co-workers in the New Zealand user movement focused as much on the social context of mental illness as on the personal one. That is to say, they replaced the medical model, which locates mental pathology within the individual, with a social model, which asserts that negative attitudes and behaviour amongst mental health providers, employers, families,
communities, the mass media and the general public are the major barriers to recovery. After all, it is not much use for psychiatric survivors to aspire to dignity, equality and fulfilling lives if doors are regularly closed in their faces. This was something which Judge Ken Mason highlighted in his influential 1996 report (www.mhc.govt.nz): “There is no doubt that the feeling created by stigma is one of the significant reasons cited for loss of hope and relapse by those who experience mental illness.... It is fundamentally wrong that a vulnerable group in our society should be continually subjected to the comments and actions of those who possess an outcast mentality.”

To combat stigma, prejudice and discrimination against mental illness, a vigorous campaign of public education was required. Here is Judge Mason again (ibid): “We support a public awareness campaign - it is a must... We are optimistic enough to believe that a well-informed New Zealand public will then realise that people with a mental illness are people whom we should nurture and value”.

Like Ken Mason’s recommendation for the creation of a Mental Health Commission, his proposal for a systematic campaign to eliminate discrimination was taken up and acted on. Mary was one of the key actors, first during her years as a consultant, then as a Commissioner. Her anti-discrimination work was the flip side of the coin to her development of the recovery approach. The one complements the other: you can’t recover from mental illness if those around won’t let you.

The vehicle for the anti-discrimination campaign was the multi-pronged Like Minds, Like Mine (LMLM) project. It was launched soon after the release of the Mason Report, and was originally intended to run for five years. In the event, its shelf life has been extended twice since then. Its administrative HQ is the Mental health Directorate in the MOH, but it regularly solicits user feedback, notably from its National Advisory Group currently headed by Chris Hansen. It also keeps its finger on the pulse by commissioning research agencies, such as Phoenix Research, to undertake surveys gauging the impact of the campaign on public attitudes towards those experiencing mental illness. You can find out more about the project at the website www.likeminds.govt.nz.

The best-known aspect of Like Minds, Like Mine is the series of TV ads it has run over the last few years, and the documentary Sticks and Stones. In the first instance, these featured high-profile celebrities such as the All Black John Kirwan, Mike Chunn of Split Enz fame, model and Shortland Street star Sonia Gray, fashion designer Denise L'Estrange Corbet and singer-songwriter Mahinarangi Tocker. The idea was that if such celebrities were prepared to chat candidly about their brushes with mental illness, it would help lift the taboos associated with it in the public mind. They also demonstrated that it was possible to lead a fulfilling life despite conditions such as depression and agoraphobia.
The third series of ads dropped the celebrity angle and came down to the level of “ordinary folk”. Called “Know Me before You Judge Me”, it presented the lives of three people with experience of mental illness through the eyes and words of their parents, partners, children, siblings, friends, neighbours, bosses and workmates. So far as intangible things such as “public attitudes” can be measured, surveys suggested that the ads were moderately successful in reducing the level of stigma attached to mental illness. (Whether people’s behaviour changed to the same extent as their attitudes was another matter.)

Mary was an advisor in the long-drawn-out process of getting these ads to air and monitoring their appropriateness. Negotiating with media experts in an ad agency was a totally new experience for her, and involved a steep learning curve. It required compromises on both sides. For activists such as Mary, the ad agency seemed to be taking an over-cautious approach to public sensibilities. They felt the ads were pussy-footing around the hard issues. For instance, they dealt with “easy” mental conditions - that is, ones with which people felt comfortable, like depression and anxiety - rather than more extreme and perhaps frightening ones, like schizophrenia and bipolar disorder. Another concern was that the ads were unrealistically up-beat in their determination to accentuate the positive: they shied away from the grim realities of life with a distressing mental condition. On another front, the TV campaign did not confront prejudice and discrimination head-on. It showed it was okay to have a moderate disorder like depression, but held back from the more challenging assertion that it was not okay to discriminate against people who had such conditions. Some users involved in the consultation process also objected to the original deployment of high-profile figures like John Kirwan. They didn’t see what the far-off lives of privileged super-stars, mentally ill or not, had to do with their own day-to-day struggles.

Those designing the ads took on board the latter criticism and, as noted above, switched in the third series from celebrities to everyday people. However, they warned users off adopting an excessively challenging approach towards public attitudes and behaviour. Those experienced in the delicate business of wooing the general public knew it did not take kindly to being brow-beaten, and could be easily scared off. Mary bowed to their expertise and accepted that a “softly softly” approach was necessary. She realised the ad agency people were in the game of social marketing, and knew how to reach out to the public in ways she did not. For their part, the media experts were prepared to listen respectfully to user views - more so, in fact, than many mental health professionals.

Although the ads were the best known feature of Like Minds, Like Mine, they were only the tip of the iceberg. They were underpinned by a whole variety of public education projects around the country at the grass and flax roots. A regular Like Minds newsletter was circulated, and a whole diverse variety of non-government agencies were contracted to spread the anti-discrimination message by running workshops, holding meetings, arranging speakers, putting out fact sheets and teaching kits, etc. At the top of the
pyramid, the Mental Health and Public Health Directorates published updated National Plans reviewing the progress LMLM was making and charting future directions. On another front, journalists and the mass media were targeted in an attempt to have the issues surrounding madness treated more accurately, and in a less sensational and stigmatising way.

Although Mary felt that the TV ads had on the whole been reasonably well-managed and successful, she was more cautious about LMLM’s community activities. She thought that some of the non-governmental agencies contracted to promote public education about mental illness were themselves not well informed about the issues, and lacked insight into the experience of mental illness. “They just weren’t up to the job.” This was due in part, she believed, to the failure to adequately incorporate the voices of users themselves. Her doubts about the efficacy of the project were echoed in a number of evaluative reports commissioned by the Ministry of Health, which interested readers can find summarised in its National Plan for 2003-2005 (www.likeminds.govt.nz).

At the core of Mary’s partial disappointment in the anti-discrimination campaign with which she has been engaged since the mid-1990s is her suspicion that although it may have softened attitudes, it has not necessarily changed people’s actual behaviour towards psychiatric survivors. This, in turn, may be due to the fact that even though people may be less fearful of mental illness and more accepting of those experiencing it, the experience itself is still accorded no value. Her long involvement with the user movement began with her conviction that her own madness “meant” something, despite the distress it caused her at the time. Her public career was, at one level at least, a personal quest to discover and valorise that meaning. Like Minds, Like Mine may have made mental illness more acceptable, and demonstrated that people could lead successful lives despite it. It has not, however, fulfilled Mary’s ultimate vision of a world where madness is positively valued. We can sense this disappointment, but also her continued commitment to the vision, in the Foreword she wrote for the LMLM National Plan in 2003 (ibid):

To stop discrimination against people with mental health problems we need to look two ways. This plan looks forward, by creating a vision for a world free of discrimination and some strategies for getting there. But we also need to look backwards to where discrimination starts. People often say it starts with fear, ignorance, misunderstanding, pity or malice. But these are just some of the clothes discrimination wears. Take off all the clothes and we are left with one thing; the devaluing of madness and the entwined assumptions that mad people are full of nonsense and incompetence.

All discrimination stems from the devaluing of madness. The wider community often responds by excluding mad people and madness from its cultural, social, economic and political activities. Friends and families sometimes respond by
excluding mad people from intimacy, companionship, social networks and family responsibilities. And mental health services too often use the rituals of diagnosis, mind-numbing treatments and compulsion to devalue the people they are supposed to serve.

To move forward the Like Minds, Like Mine project needs to challenge the root of discrimination by putting value back into madness. Without denying the pain of madness we need to amplify the voices of people who value madness in different ways. This includes seeing madness as a crisis of being, a reasonable response to trauma, a spiritual awakening, a transformation of identity or a protest against oppression.

The User Work Force Strategy

We now come to the third major strand of Mary’s career since 1996, and more particularly since she became a Commissioner in 2000. It is the logical corollary of the other two activities we have been describing - promoting the recovery approach and fighting discrimination. The people best placed to promote these causes, and also to spread the message that madness is a state to be valued rather than denigrated, are those who have experienced it themselves. When Mary went through the psychiatric system back in the ‘eighties, her only contacts with those like herself were fellow patients. She felt it would have been of enormous benefit to her if there had been service users working alongside professional providers to give her support and advise, and to act as role models and mentors. Their presence would have given her hope for her own recovery.

Since she became a Mental health Commissioner, she has devoted much of her thought, time and energy to filling this hole by developing a strategy to involve users as integral members of the mental health work force. Users should be active and equal partners in the system, not just passive objects to be medically processed. Indeed, it is they who should take the lead. We can see the importance attached by Mary and others to the development of leadership amongst users in the top priority it was accorded amongst the goals set out in the LMLM National Plan 2003-2005 (ibid):

Leadership and participation by people with experience of mental illness at all levels of the project are critical to its long-term sustainability and eventual success. People with experience of mental illness are experts by virtue of their experience, they have a living interest in reducing discrimination, and they have an important role in challenging the stereotypes and unfair policies and practices that exist. The leadership abilities of people with experience of mental illness must be valued, encouraged and developed so that they
are increasingly employed or contracted, and remunerated for their skill and contribution in the project.

The development of a user work force is now one of Mary's top priorities in her work for the Commission. She wants to see those with experience of mental illness involved in a wide variety of activities at every level of the mental health system, from giving hands-on practical assistance to their fellows right up to directing national policy. There are a number already employed as consumer consultants, trainers, LMLM educators, community support workers and so on. In the latter role, they befriend fellow users, perhaps giving them some basic counselling, introducing them to community agencies, going along with them to see a doctor and in general acting as combined buddy, advocate and mentor.

A great deal more needs to be done, however, to develop a fully operational and effective user work force. More financial resources are required, as most users currently work for very low wages. Indeed, much of their input is on a voluntary basis - quite different from the fees commanded by consultants in other fields.

There is also the question of training. Although a certain amount of in-service training is provided for those working with District Health Boards, and there are a number of tertiary diploma courses on offer, the matter of formal qualifications needs more systematic attention. Furthermore, once formal qualifications are gained, they require more acknowledgment in terms of remuneration and career opportunities. The user work force is very much the poor relative in the mental health labour market.

If the user labour force develops as Mary hopes, the matter of professional training is going to loom ever larger. Just because people have had the experience of mental illness does not in itself guarantee they will be effective communicators, educators, advocates, consultants and so on. A number of users are doing excellent jobs in such respects, but it can be a bit of a hit-or-miss affair. Some have the right personalities and skills, others don’t.” Just because you have been a user of services does not automatically make you a good provider of them”. For the new work force to be successful, systematic and professional educational programmes are required for those going into it, and career paths opened up.

One area of particular strategic importance where further skill development is required involves working with the mass media. They have a major role to play in shaping public perceptions of madness, so it is crucial that those working for the media should be well informed on mental health issues. Maori and women lobbyists have had some effect on the ways in which they are depicted in the media: psychiatric survivors must bring similar pressure to bear on journalists, editors and programmers. Articulate consumers are needed to communicate with the media and comment on mental health issues.
Although the development of an effective user work force has been one of Mary’s top priorities since she became a Commissioner, she is not saying that everyone experiencing mental illness should enter a career in the mental health system. Users should have the opportunity to work right outside the system if they so wish. There are certain tensions built into the job of service provider that some may wish to avoid. It involves being incorporated into “the system”. If you take someone else’s money, you have to play by the rules they lay down, and perhaps compromise your radical philosophy in the process. Some refuse to make such compromises, preferring instead to work with other independent survivors right outside the psychiatric system. Mary feels you need both groups – one operating inside mainstream services, the other robustly independent of them. Which you opt for depends on your temperament and philosophy.

For those who do enter the mainstream work force, there may be tensions of another sort. They sometimes experience a certain amount of role conflict, tugged one way by their user identity, another by their job as provider. Wearing two hats may be particularly uncomfortable when user/providers interact professionally with the very people who had formerly treated them. Sitting round the same table may make both ex-patients and psychiatrists feel a bit uneasy.

These problems apart, Mary recognises that there are many people who have recovered from madness and just want to put the whole experience behind them. They do not want to re-cycle themselves through the mental health system, even if in a new guise. They prefer to get other kinds of jobs, make friends and pursue interests in the main swim of the national community. For them, this is what “recovery” is all about.

Mary accepts and supports this desire to break free from the gravitational pull of the mental health system. “People must be encouraged to go in whatever direction they choose”. Having said that, though, she is aware of how much people with experience of mental illness have to offer their fellows, and is committed to promoting their on-going involvement in the system, in a properly trained and remunerated way. Indeed, her vision for a thorough reformation of this country’s mental health services, and for a more general sea change in social attitudes and behaviour towards mental illness, can only be achieved through the greater participation of users themselves.

Recapitulation and Conclusion

Mary’s own life over the last 20 years in itself provides a striking illustration of the benefits which can accrue from user involvement in the mental health system - benefits to psychiatry, to those experiencing mental illness, and to the individual who dedicates her time and energy to the cause.

She made that commitment in her mid-twenties, when she emerged from eight years of disabling psychosis. Now at 46 she has no regrets about the
course her life has taken. During her time as a patient, she was in the demeaning situation of having nothing useful to offer others in the same situation. She was just the passive recipient of the psychiatric services on offer back then. What is more, those services themselves were inadequate on a number of fronts. Let’s briefly recapitulate Mary’s main criticisms of the mental health system as she first encountered it a quarter-century ago.

It relied too heavily on drugs whose side effects could be worse than the condition itself, supplemented by half-baked psychotherapy. The velvet glove of therapy only thinly camouflaged the iron fist of coercion. Patients were sometimes deprived of basic human rights. They were denied respect, dignity and equality. There was a massive power imbalance between mental health providers and users, the latter being patronised if not actively ill-treated. Philosophically, madness was regarded as a pathological aberration to be eradicated or managed, not a meaningful state in its own right - an integral component of an individual's overall life history. Its symptoms were treated, its content ignored.

When her extreme mood swings stabilised around age 27, Mary could have walked away from all this, finished her degree and embarked on a career such as journalism. Instead, she made the conscious decision to explore the meaning of her own and other people’s experiences, while at the same time promoting the voice of users within and outside the mental health system.

For the first ten years, it was the “outside” side of the equation on which she concentrated. She and a handful of other activists set out to create a mental health user movement run for and by themselves, marching under the Psychiatric Survivors banner. It began with an Auckland group of that name, then extended its range nation-wide in 1990 with the creation of the Aotearoa Network of Psychiatric Survivors. A year later in Mexico City she went global, becoming the founding head of the World Federation of Psychiatric Users (now the World Network of Users and Survivors of Psychiatry). These organisations tended to be separatist in outlook. They wanted to establish and assert their own distinct identity, with little or no interference from the “straight” world - notably mental health professionals.

In 1996, she adopted a slightly different tack, although her goal remained the same. She relinquished her role as a leader of the user movement, while still retaining some involvement in organisations like WNUSP. Instead, she focused on the development and implementation of three inter-connected strategies - the recovery approach, the anti-discrimination campaign and the creation of a user work force within the mental health sector. The catalyst for some of this work was the Mason Report of 1996, the subsequent launching of Like Minds, Like Mine, and the formation of the Mental Health Commission.

Although as strongly committed to the user movement as before, over the last decade she has shifted her strategic location from outside to slightly more inside the mainstream mental health system. Thanks in part to her
own efforts, it is no longer quite as necessary for psychiatric survivors to be as intransigently independent as they were in the first ten years of her involvement. Professional providers today are more willing to accord users respect and to heed their voices than when Mary was a patient. There is more scope for a symbiotic partnership today. Mary’s top agenda item currently is to foster that partnership through her work on a user work force strategy.

Although her voyage from hospital patient to Mental Health Commissioner has been a personal odyssey, she has not, of course, travelled alone. The present interview has focused solely on Mary’s role in the user movement, but similar stories could be told of fellow workers for the cause, such as Rod Davis, Corinne Curtis, Pauline Hinds, Iwa Natana, Julie Leibrich, Tessa Thompson, Chris Hansen, Susie Crooks, Te Wera Te Kotua, Lina Samu and John Tovey - just to mention a few of the names she mentioned in the course of the interview.

She has also received institutional backing at strategic turning points in her career, such as from the Mental Health Foundation in the mid-eighties and the Commission in the mid-nineties. In the background there were overseas writers and activists in the anti-psychiatry, patients’ rights and recovery movements like Thomas Szasz, R. D. Laing, Judy Chamberlin, William Anthony and Patricia Deegan, from whose writings she gained inspiration and who strengthened the courage of her own convictions.

Furthermore, Mary’s journey took place against a background of major transformations in the mental health world. She and the many others in the user movement here and abroad were in part the agents of these changes, but they also benefited from them. In New Zealand, the 1992 Mental Health Act created a more propitious climate for people experiencing mental illness, even though it contained some objectionable features, such as compulsory treatment in the community, against which they are still campaigning. On a wider front, the international shift from hospital to community-based services radically altered the rules of the mental health game, throwing up daunting new challenges but also opening it up to new approaches. At the start of the 1990s, Mary felt she was sowing seeds on barren ground. By the end of the decade, the soil was better ploughed and more receptive. Ideas that were revolutionary when first proposed, such as the recovery approach, are now widely-accepted orthodoxies amongst mental health professionals (even if in some circles they are still only paid lip service).

Mary’s conviction that those who themselves have experienced madness have much to offer their fellows is graphically illustrated by the story of her own life thus far. She has manifestly contributed greatly to the user movement at the local, national and international levels, and thereby to significant reforms to mainstream psychiatry - and she is still only in mid-career.

It is not all selfless dedication, though. If she put a lot in, she got a lot out as well. Her work has benefited others, but has also been personally
rewarding. At the purely pragmatic level, it provided her with an upward career path and good financial remuneration. It was endlessly fascinating work, allowing her to meet a wide range of people and to share their experiences, both here and abroad. If she ran out of steam in one area, such as setting up networks, there were always new challenges in related ones to re-energise her, like the recovery approach and the user work force strategy. Above all, perhaps, it furnished her with an ideal to fight for - an existential project with which to fill the void she had glimpsed during her years inside the black box. Back then, life had seemed meaningless. Through her work on behalf of others in the same situation, she has created ample meaning for her own existence.