

The Consumer Movement and A Post-Institutional Mental Health Environment – Is There A Tension Emerging?

The emerging role of the consumer movement in shaping the reform of mental health services in New Zealand since the mid 1980s and in particular in the last 5-10 years, has been profound. The following suggests that challenges now face a consumer movement born out of institutional oppression, as the successful evolution of community-based service delivery increasingly becomes a reality – changing not just the location, but the culture, understandings, expectations and exclusivity of mental health services. The experience of being a “consumer” of mental health services now takes place not so much at the extremities of social life following acute rejection, but within communities that are increasingly diverse, complex, reflective - and often unsure and contradictory.

Mental health services in New Zealand now bare little resemblance to the reality of the late 1980s. While the mental health consumer movement continues to challenge, increasingly people who have experience of mental illness are employed in a variety of roles within mental health services – operationally and strategically; locally, regionally and nationally.

That mental health service development and provision in New Zealand is admired and envied by many countries around the world is, in so many ways testament to the efforts and contributions of some remarkable people. These people survived the degradations, human contempt and often sheer cruelty of the old asylums that masqueraded as care and treatment. Their often harrowing chronicles consistently provoked and reinforced an environment for change – in fact a critical re-think in how services should operate. Their experience shaped an emerging discourse on consumer empowerment, the powerful role of consumer perspectives in development and delivery, and an articulation and promotion of understandings of recovery. These events did not occur as a part of a strategic development; they were driven by a blend of advocacy, challenge and militancy; they were in fact revolutionary. They reflect the truth of Martin Luther King: “Change does not roll in on the wheels of inevitability”.

The consumer movement has, through assertive advocacy, presented an often vociferous protest against what has been clearly wrong within the system. The consumer movement contributed fundamentally to an acceptance of the need for change and of the right for recovery. However it is particularly since the acceptance of social inclusion as a principle to guide service provision and an outcome by which to measure effectiveness, that I believe a new range of complex tensions have emerged to challenge and sometimes torment the mental health system. And I would suggest that this also applies to the consumer movement.

I’ve pondered on this for some time; wondered if I’m qualified to hold - let alone express - an opinion on such a topic. A reflection that was answered for me recently when I was told in the most definite terms that in no way should I be expressing any opinion on this topic. I don’t wish to be un-necessarily defiant, but this directive in itself reinforced to me the fact that I do need to express this opinion, my concerns. Some colleagues I’ve shared my concerns with have responded with apprehensive grimaces with remarks such as “You’re brave...”. It would seem a deceit to hold the position I do and at the same time harbour such (what appear to be) contentious doubts and concerns and not express them openly.

When any issue is regarded as being beyond challenge and robust debate, when silence is the default position, when dissent is regarded as a heresy, this in itself becomes a fundamental cause of concern.

This Hasn't Just Happened!

My first hint of this emerging tension was delivered in 1993 when I was developing a supported employment service. What I was learning was that it wasn't just the social inclusion of clients (through employment) that needed to be a goal, but the social inclusion of services themselves. There was more than a hint of arrogance in prescriptions about how we needed to educate the community – and employers in particular. Yet one of the first employers I met, after hearing that my mission (and believe me I was on a mission) was to support “psychiatric consumers back into meaningful, paid employment” stopped me mid-spiel and asked: “What on earth is a psychiatric consumer?”. After hearing my sincere explanation, totally bemused, he demanded, “Why don't you call them people?”.

Quite fortuitously (I cannot claim that it occurred deliberately) my formative years in the mental health sector were enormously influenced by service users; not because it was “in vogue” but because it just made sense. I have been enlightened and richly blessed to have been “trained”, shaped and guided by people with enormous experience of being on the receiving end of mental health services, and with a remarkable reflective insight to be able to clearly articulate that experience. Being able to assimilate episodes from my own life into an emerging appreciation of the role of mental ill-health in our community equipped me to support people who were looking to get a job – and who were willing to place so much trust in my ability to support them in this.

What's The Problem?

It's not that I now disagree with some of the fundamental tenets which now increasingly inform the continued development and delivery of mental health services. Nor am I oblivious to the major role people who have used mental health services have made in shaping the revolution in New Zealand mental health services that has occurred since the early 1990s.

However for the last few years I've increasingly been feeling as though I'm listening to the teachings of a church that I have been growing disenchanted with. I still admire and respect the elders; I understand what is being said but wonder about hearing the same messages in what is a different world. I appreciate the basis for their message, but get concerned about a kind of fundamentalism that is emerging. I admire their faith, but find that mine is floundering; it is becoming weak. What had inspired and sustained me during the 1990s, feels increasingly out of place in 2007. It's like being in a long marriage that is becoming increasingly troubled when all the long-repressed incompatibilities appear to be coming to light.

There is emerging a very strong double bind. On the one hand social inclusion and such initiatives highlight the value of recovery through the development and use of community-

based mental health services. Such services focus upon understanding and responding to an individual's unique support needs, goals, aspirations and potentials. As Rufus May, a former user of mental health services in the UK who is now a psychologist, noted in an article in *The Independent* in March 2007: "the dividing line between the mentally ill and the sane was more a question of social boundaries than actuality".

However on the other side of this double-bind is the need to establish and maintain an exclusivity (eg. consumer only forums / meetings) based upon a lack of "sameness" - and in fact highlighting difference. And by this I am not insensitive to the needs of interest groups (particularly those who have emerged from a history of oppression) to establish a shared identity, consciousness and shared values in a safe and accepting environment. My real concern is how the experience of "being a consumer" risks being captured and defined to meet what may be quite narrow and exclusive objectives - and at the same time being quite exclusionary. "I'm sorry, this is a consumer only meeting..." and "This is a meeting for people who experience mental illness... you are welcome to join us and participate..." provide the same information. The difference is that one is about exclusion, the other about inclusion; one directs the other provides a choice. Arguments that only people who have publicly "come out" and have identified themselves as a "consumer" and adopted consumer values can possibly provide peer services, loses sight of the prohibitive and limiting aspects of such criteria. Increasingly mental health services are employing people who have their own experience of mental illness - in a broad range of roles and responsibilities. With 1 in 20 people at any one time experiencing mental illness and nearly 50% of the population having experienced a period of mental ill-health during their lives, it would be virtually impossible to avoid this reality.

The issue here is the risk of such a strong emphasis upon the collective notion of a consumer movement / identity reinforcing (or even creating) the notion of "difference" where no fundamental difference actually exists - if we are to believe a principle tenet of the Like Minds Like Mine campaign. Given the history of psychiatry, the exclusion of "others" because they don't meet criteria that permits them to fit in, is a poignant irony.

Are Mistakes Of The Past Being Repeated?

When I first entered the mental health business I was confronted by two perspectives: psychiatry and anti-psychiatry. It was a polarised black versus white world that had long since lost sight of any notion of grey. It was a world view which pre-dates, though shares similarities with President Bush's call to arms, "...you are either with us, or against us". Psychiatrists tended to shun, if not resist the developments in the outside world, and the gathering momentum of more community-based approaches to service delivery. The desire of psychiatry to simplify complex problems led to both dogma and a reliance on single facts as proof.

Unfortunately paralleling that process, the consumer movement has arguably likewise simplified and polarised considerations of what inhibits the development of contemporary mental health services. Now appeals to guilt in lieu of argument, personal testimony of abuse and tragedy, speculative ideas and slogans that perpetuate and rely on that guilt, demonise the

role, competence and motivations of the majority of people employed within mental health services. Only occasionally does there appear to be any middle ground; you are either “with us”, or “against us”.

Efforts now exist to legitimate the experience of mental illness. From the perspective of promoting healthier attitudes to mental illness, “normalising” the experience as one which may affect anyone, this should be supported. A concern here is the emerging notion of “re-claiming” the word “madness” by some consumer groups (or any group for that matter – we have already seen what occurs when medically trained psychiatrists “claim” it). It worries me that it potentially leaves others (for example people dealing with their first experience of illness) fewer choices in defining, understanding and owning their own experience. Similarly the romanticising of mental illness (as a something akin to an epiphany in people’s lives) risks minimising the torment, chaos and bewilderment that so commonly is the experience of people (service user, family, whanau, friends...) whose lives have been affected by mental illness. Where illness has contributed positively to a person’s life it is usually an appreciation only gained in hindsight – and often at great personal cost.

It is difficult to try to describe the psychology that shapes the mental health environment within which a consumer movement has evolved. One of idealism and moral authority, justified by a history of oppression and abuse, expressed within an environment that is aware of its history, acutely sensitive to its complicity, and struggling to resolve its guilt. And I do wonder the extent to which this psychology seems to be reflected in mental health services where bumper sticker slogans have been used to promote key directions, beliefs and provoke inevitable questions at conferences (eg. “what are you doing to implement nothing about us without us?; “...what consumer input has there been?”). Expectation and demands for consumer / service user “participation” and “leadership” have become unquestioned givens in mental health services and challenges for the further development and reform of services. My concern here is not so much around the notions themselves, but 1) the fact that they are unquestioned, 2) they are commonly expressed in terms of entitlement or obligation expected of mental health service providers, and 3) not meeting such expectations can attract summary disregard, contempt and confrontational moral rebuke. This in an environment where for some years the mental health sector has attempted to integrate a “strengths-based” approach to service delivery and development.

I was challenged some years ago, for example, to account for how consumers of WALSH Trust services have input into how organisational funds are budgeted and spent. “What procedures are in place should they disagree with a particular line of spending?”. While these rights were demanded (rather than articulated), the responsibility - particularly should matters go awry – was to remain elsewhere. At another time the response to a disciplinary meeting to address very serious (and potentially dangerous) performance issues was “I feel you have disempowered me...”. I couldn’t disagree. I did state that in future “I expect similar situations to be addressed in the following way...”. There remained however a belief that “because I have experience of mental illness” 1) I know better, and 2) you do not have the right to say such things to me. The most concerning aspects was that these were statements that I was expected to accept as givens, rather than (what may have been more helpful) opinions that could be articulated and supported by reasoned argument.

The consumer movement / perspective now has considerable power and influence within the delivery of mental health services in New Zealand; and I would regard this as a desirable outcome. However if this power has been earned as a compensation to institutional guilt, a sacred and exclusive covenant guaranteeing unchallenged regard of perspectives, it becomes a very fragile and contingent form of power. It is power that is more congealed around “difference” rather than energising expressions of morality, commonality, citizenship, and social inclusion. While psychiatric power was used to oppress, consumer power has more justification, but risks being no different. It essentially determines criteria for entry and status – to say who is a consumer and who is not. Which does then beg the question: is being “a consumer” about a shared label or a shared experience? And this is quite critical. For example, referencing a “consumer centred approach” in introducing a document arguing a particular perspective provides a powerful mandate to whatever conclusions and perspectives that follow.

The realisation and experience that “somebody out there is like me” is a profoundly uplifting, affirming and life promoting realisation. In narrowing understandings and definitions of a person who experiences mental illness to consumer/service-user or in the context of a movement, we risk inevitably excluding many people from the experience and opportunities that accrue from recognising “someone like me”.

On Being A Victim In The New Millennium

To say we live in a very different world compared to even 10 years ago is a cliché few would argue with. And yet our approaches to understanding people now presenting as mentally distressed appears to be lagging with changes in our communities. They have no experience of large asylums; there is increasing awareness of social determinants of mental health, even some prophetic psychiatrists recognise the emergence of an environment where mental health services risk "becoming the "repair shop" and repository for communities break-downs, faults, human carnage and wreckage...". People who experience mental distress are emerging from and are seeking to return to, very different communities.

Not unlike many who find their faith has become fragile, I have been casting about in a post-institutional wilderness to understand again a place where I can stand; to resolve my mental health agnosticism. A post-institutional wilderness where faith in the ability of science and technology to resolve human and social problems is diminishing. Call it growing old, premature curmudgeon-hood or my descent into social fundamentalism, but over the last couple of years I've found it difficult not to be concerned and distressed about what seems to be increasingly large numbers of people who basically display a sheer ignorance in how to live. This no doubt is a by-product of 1960s liberal idealism, rapid and unbelievable advances in technology (and access to that), and the consequent remarkable social change. Much of the latter part of the 20th Century was based around making life easier. A new age of “enlightenment” seduced people into believing that life was a principally a hedonistic pursuit; a culture of cheap tricks and instant gratification, and rebellion against community mores, standards and structures.

Now in the 21st Century a pervasive deceit entwined in “PC-ness” risks euphemising life; a deceit that is exposed by stark contradictions. It bans young people playing bullrush and replaces the kudos of winning with the bland exercise of “participation”. Meantime the Black Caps are damned for being thrashed again, the All Blacks are lauded for wasting every one who stands in their way, and television is dominated by shows that exploit the indignities of losing (“You are the weakest link. Goodbye!”), and being voted out by your “comrades” and humiliated (Big Brother). Even winning is given an Orwellian twist as we search for the “Biggest Loser”.

Making sense of life and finding a place and a role for ourselves has rarely been more difficult. Life is not simple; the confronting reality is that life can be complex and a challenge. It is contradictory, deceptive and confusing; how else could you describe a market driven economy that by necessity makes a virtue of selfishness? Life is not a benevolent provider of all we desire; it can be very ugly and unfair. Coming to terms with reality and its challenges is a part of life. We live in an era where coping with existential angst has increasingly become a contemporary norm.

We moreover live in a world where other people can also make life even tougher out there. People – and even people who are fundamentally “good people” - can be cruel. It may be that an outcome of contemporary services is to support clients in responding to the realisation that they will not always be judged simply on merit or the content of their character, but on how they look, how they behave, how they socialise with others....¹.

This is not an argument to suggest that this is right; it is an argument to suggest that perhaps, unfortunately, this is sometimes how it can be. Coming to terms with this – and with support if necessary - can often be a key step in our being able to express our potential, achieve our aspirations to find meaning and purpose in life. As such, there are times when seeking to “understand” so-called problems can no longer be regarded as a kindness, but rather a self-serving indulgence favouring providers of services. For example, few would doubt the obvious imbalance of power between a person who is vulnerable through unwellness and the holder of information, expertise and community sanction to address such unwellness. The not unreasonable response to this within mental health has been an acute awareness of people’s rights – as human, moral and even therapeutic imperatives. What is at risk of being commonly overlooked is the often clichéd notion that for rights to be exercised within any civil society, then responsibilities must be equally embraced and exercised. How then should services respond to the emerging discussion in the literature about client’s / patient’s responsibilities - particularly with reference to the growing costs of unhealthy lifestyles and the fact that people can actively influence the outcomes of care for the good - and for bad?

The most common consequence is a special kind of cruelty that deems that some people may no longer attempt to better themselves or their behaviours. It is a soft bigotry of low expectations most of us in the mental health sector will have borne witness to – if not been guilty of indulging. We can happily smother people who appear disadvantaged with choice and empowerment while accepting expressions of antisocial behaviour or educational deficit as unfortunate outcomes to be accepted and accommodated rather than being challenged, re-

¹ My thanks to Jerry Espinson, Schmidt, Crane and Poole,. Boston

directed and/or responded to. It represents a powerful example of a sentimentalisation of society in which emotions are more important than facts, where the moral high ground rapidly becomes over-crowded by propagators of a kind of virtual or alternative morality. Unfortunately the most powerful and appealing condition consequent to this, is that of comfortable victimhood. By this I refer to a situation where the role of victim is legitimised and adopted predominantly as a means to represent a particular perspective.

And this so worry's me. There is much in society these days that seems to encourage people to regard themselves as victims of abuse, racism, stigma, prejudice or circumstances about which little can be done. In passively rejecting choices and actions that have brought them to where they are – while equally as passively accepting bare minimums of support and assistance – people risk being condemned to a state akin to perpetual victimhood. In essence, people who see themselves as victims and resent their victim status; yet at the same time finding themselves being rewarded through maintaining their victim status. Resilience, pride, confidence and competence to effect change in their lives, to stand up and declare “I will accept this no longer..” are gently and subtly eked away - often by societal institutions that themselves maintain people within a victim status. The result is people continuing to lead impoverished lives, but lives that are contingent upon the beneficence of others, and that are controlled by the passing vagaries of social policy.

The civil rights movement is often highlighted as a parallel struggle and inspiration for a consumer movement. I too think there is a great deal to be learned through study of other great social movements. I recall Shelby Steele (in a commentary on the civil rights movement) arguing that a damning side effect of the approach to black emancipation through the 1950s and 1960s was a conditioning of the wider population to view victimisation as a claim to moral authority, and through that authority so political power. The resultant consequence has been an ever expanding culture of victimisation where every small pressure group fights to provide and establish facts that lay claim to its special victimisation, its unique suffering as a means to power and restitution.

Seeing oneself as a victim means clinging all the more to an identity of consumer, risking the suppression of identity as a human being, member of the community, lover, parent, employee.... This in turn risks cutting a person off from all the resources that might be available. I recall a conversation with a person (who experiences mental illness) who did have other things happening for them in their life, but felt compelled at times to contrive to be a “consumer” in order to gain acceptance and access to support. Another person I met in the UK lamented a similar dilemma: “I don't feel alienated or marginalised, I am employed, I have hope in my life... but I still value the support of peers and being visited in hospital...”.

It is a reality that the more we focus mental health services on the patient as a “person” (not a patient, nor as I'm arguing, a consumer/service-user/tangata whaiora...), the more we will emphasise the uncertainty and limitations of less contemporary approaches. Community-based, recovery focused mental health services recognise that opportunities for community participation, contribution and integration are promoted through supporting access to education, justice, housing, employment; through change and achievement in these areas. Supporting people - sometimes preparing people - to live, to find meaning and hopefully to

flourish in the “outside world”. A world where people may choose to remain anonymous citizens, but who may also become agents of change, challenging the status quo. A world where people can become the kind of person they want to be. Such services recognise as fundamental the latent and transformative power of people taking full advantage of their rights and their responsibilities. They need also to recognise and reflect the importance of values such as self reliance, work ethics, independence and interdependence, “getting ahead”, the crucial role of stable communities in shaping healthy communities and a successful New Zealand.

These last comments may seem a little old fashioned, quaintly parochial and a little out of place in thinking about mental health service provision. This is because we have not at all debated what kind of New Zealand we would wish our commitment to mental health to contribute to? The fact that such a question is not explicitly considered, answered and providing a beacon to development is at best an oversight; at worst an irresponsible deception. Our commitment to “community-based” mental health services, by definition, means that there is no neutral position. Mental health services fundamentally play a role in shaping our society – if only in maintaining (and, by association, endorsing) the status quo.

...And So The Point Is?

Enormous change and reform remains to occur within mental health services. It concerns me that continued framing of this reform as predominantly a struggle; a movement against the powers of psychiatry. The fact that social inclusion is becoming such a dominant driver of mental health service development means that psychiatry has in fact shifted (how far is always arguable) from a previous sacrosanct position. It will inevitably be required to shift further; and these conversations are also starting. I attended a workshop earlier this year (led by a psychiatrist) which asked the question: Is Current Training For Psychiatrist’s A Best Fit For Purpose?

Maintaining – and I believe creating - difference where tangible difference may no longer exist, is in tension with notions of social inclusion – and in fact could promote new forms of exclusion. The language of social movements, generously littered with the vicissitudes of Marxist thought and echoes of the great social movements of the last Century have played a important role in framing issues. Like those movements have discovered however, such an approach also has its limitations.

The sustainable power and influence to effect change, to inform development, to contribute to the mental health of our communities will emerge through collaborative and synergistic relationships. Relationships that are more clearly an expression of our shared values and experiences, rather than shared labels promoting continued separation and fragmentation. The social inclusion of mental health services is the next frontier. I’m in no doubt that the participation, contribution and leadership of people who have experienced of mental ill-health is needed to effect further reform. We need to allow for and provide mechanisms by which “potential consumers” - those who do not yet have a mental illness - can shape and engage with a dynamic and responsive mental health service “system”. Do they realise that to access the full array of mental health services they will become a “consumer”? are they

happy with this? how do we know? We do need a system that adapts to people's needs for support, hope and meaning – rather than defining it for them and expecting them to adapt. It needs also to be a system which has matured beyond the self-serving convenience of fixed polarised. To support people to aspire, achieve, and exploit what opportunities exist in those communities to hopefully live lives that are rich in meaning, satisfaction and fulfilment.

There is a growing recognition of the need to effect a paradigm shift that would transform how mental health services are conceived and delivered. It's not possible to conceive or understand one paradigm through the conceptual framework and terminology of another. I don't believe this is about building on or expanding an existing pool of knowledge; nor is it about reversing oppressive power dynamics. "Post psychiatry" mental health services have to take account of the diversity, dynamism, volatility and contradictions of people living in our communities. This needs to be an era where scientific/medical interventions may comprise one element of an array of options, rather than being the primary informer. Their focus needs to be aimed at contributing to the economic, social, physical, mental and spiritual well-being of people. The culture, beliefs, needs and priorities of communities need to form the theoretical background and framework for such services. In this sense, the community (through community owned and governed organisations) has to be involved at the most basic level of defining mental health services, ideas and notions about mental health and illness. Idealistic? Maybe so; but if mental health services are not based upon, defined by and responsive to community need, then whose needs do they serve?

I believe the social *exclusion* of services, professionals, knowledge, understanding regarding mental illness is bad for people who use services and limits the effectiveness of services themselves. I believe this now extends to a "consumer movement". The more effectively mental health services are integrated into community, where social determinants of health might assume greater importance, the less important will become the need to define, determine and isolate the notion of "mental health consumer". Such approaches recognise more the place of a person (not a patient or consumer) in the community; appreciating that mental health happens in the community, not in a hospital or a mental health system. The social, economic, spiritual and cultural life of people need to be considered. Housing, employment, income support, the ability to change one's life, to succeed, to develop a sense of meaning, being heard and understood, are commonly major factors impacting upon a person's well-being.

Perhaps the next transformation of mental health services will occur when issues of social exclusion and inclusion become redundant. Exclusive people shaping inclusive communities; now that's a bumper sticker I could support.

Rob Warriner. October, 2007