RECOVERY: CHALLENGING THE PARADIGM (a consumer perspective)

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ABSTRACT

The twentieth century saw the rise and development of public mental health services in Victoria (and about the world) as psychiatry and psychology became established branches of enquiry into the human condition. The rise of consumer voices have been a feature of recent mental health service development and so some reflection upon the meaning of that contribution is considered here with particular reference to practice, service systems design and innovative practice about consumer lead service delivery. As recovery becomes a new paradigm, the question 'what does recovery mean' and 'what does a recovery focused mental health system look like' is defined and discussed. Throughout the discussion, the paper assesses the place of the recovery concept in mental health and asks whether the current rhetoric about the sector is merely 'a case of the emperor's new clothes', or has there been a fundamental shift in Mental Health.

Key words: paradigm, recovery, psycho-social, person-centered, medical, culture.

Acknowledgement: To the people whose ancestral land this is, the Kulin Nation, the traditional custodians of the land: Aboriginal land. And to the elders of other custodians who have lived on this land on which the Vicserv conference was held.

INTRODUCTION

I am honoured to be invited to present this paper to the *New Paradigm Press* of Vicserv for publishing as my contribution to the topic of the conference which is 'Recovery: challenging the paradigm'. My contribution on the day of Friday 30th April was one mark of a process of reflection, construction and reconstruction, which remains a work in progress.

The topic engaged me thoroughly at a personal and professional level. On a professional level I work for Keepwell Ltd, which is, a consumer run organisation charged with a mission of delivering 'real recovery solutions in mental health' across Australia and New Zealand. And so I was challenged to consider whether the work of my organisation understood the paradigm of recovery which is articulated in the mental health sector in Australia and what contribution it makes to that sector. I had written on paradigms in a keynote paper previously (Pearson 2000) and I was interested in how those ideas may have developed. On a personal level, I reflected whether I could consider myself as working to recovery regarding my previous diagnoses, which in mental health include: major depression, schizophrenia, schizoaffective disorder, borderline personality disorder, and alcoholism. Of course, I was aware

of the Vicserv publishing arm being *New Paradigm Press* so from the outset, the conference topic appeared dangerously loaded. For while we invite challenge, most of us prefer to have other people's paradigms challenged and not our own! I will now define the words *paradigm* and *recovery* with some examples of both as they relate to mental health. Following this is a discussion about consumer participation, a critique of the diagnosis of schizophrenia, and a discussion on person centred recovery.

DEFINING PARADIGM AND RECOVERY

Definitions of the word paradigm

The word *paradigm* comes from ancient Greek. It was originally a scientific term, and is more commonly used today to mean a model, theory, perception, assumption, or frame of reference. A useful way of defining paradigm is a way of seeing or viewing the world. We don't see the world as it is, but we see the world through our worldview. Thomas Kuhn introduced the term paradigm shift in his highly influential landmark book, *The Structure of Scientific Revolutions*. Kuhn shows how almost every significant break-through in the field of scientific endeavour is first a break with tradition, with the old ways of thinking, with old paradigms.

Historical examples of some Mental Health paradigms

An historical example of mental illness would include the challenge of the early twentieth century of the Moral Hygiene movement, which constructed behaviour such as masturbation, homosexual activity, and a desire to persevere with solo mothering moral issues that caused mental illness (Garton, 1988). This was then countered by the response of illness classification (or medical model) that interestingly, called for more humane treatment of people. This new understanding lead to a change in societal beliefs about the experiences of homosexuality, masturbation, and solo parenting which are not now thought to be moral or medical conditions. Much of the debate of the mid twentieth century within psychiatry centred on social and psychological views of radical psychiatrists such as R.D. Laing and arguments made for the closure of large psychiatric asylums, towards a community delivery of mental health services. Although the majority of mental health service delivery is now community based, the assumptions, practices and ideas from this paradigm remain influential.

Examples of some Current mental health paradigms

The current discourse in mental health reveal a set of beliefs about the way things are viewed by those engaging in the work of mental illness. Some examples of the ways of seeing mental health may include the following paradigms:

- "Mental health is really about issues of mental illness"
- "The crisis in mental health is about staffing numbers and beds"
- "Mentally ill people in crisis must be treated in a hospital institution"

- "Mentally ill people must take medication"
- "Mental health is about more and better mental illness services".
- "Mental illness services are under funded and the issue of funding beds is central to the issue of mental health".
- "The media story about mental health is about violence of patients and threat to society" (Pearson 2002)

Defining recovery

Historically recovery was first articulated by consumers recovering from alcohol addiction and dates back to the 1930's in the United States of America. These consumers described a psycho-spiritual 'programme of recovery' within 12 steps alongside peer support recovery groups. Later, consumer activists in mental health adopted the term in the 1960's alongside a rhetoric of consumer rights.

Yet it should be acknowledged there are many and various different understandings of the word recovery and what it means in mental health. In a *medical* understanding, recovery would describe recovery as an absence of symptoms. A *psycho-social* understanding of recovery will look for connectedness and participation with social networks to assess recovery. For indigenous services, *cultural recovery* is evidenced by a person's participation and understanding of their cultural roots. Each of these defining paradigms of recovery is legitimate and holds some value. There is a fourth understanding of recovery and this is described as *personal recovery*. I think the present challenge of recovery is a paradigm shift within mental health towards person driven service delivery. When the person themselves gives meaning to their situation by defining their recovery (a spiritual exercise), then they will drive the other three domains of their recovery (medical, social, cultural). A recovery-focussed sector will be a mental health sector that structurally supports person-centred recovery. Person centred recovery has been referred to as *consumer participation* within Australasian mental health standards. These concepts will now be discussed.

2 PARADIGM OF SECTOR PARTICIPATION OF CONSUMERS:

Consumer participation across the health sector

Consumer participation is a central value in current mental health service development and delivery (Meadows & Singh 2001). Consumers have attempted to be explicit about defining power dynamics (Meagher 1995,2002) but have not been successful in capturing the discourse (Clinton, & Olsen, 1998). The sustained effort to share the power of the management, running and delivery of mental health services with consumers is a long-term goal that requires clarity of focus and agreement that has some way to go as yet. There is a Victorian model and research regarding acute mental health services (Wadsworth & Epstein1996) and in New Zealand, every state mental health service and larger NGO's employs consumer advisors. However even after decades

of this newer paradigm of supporting people with an experience of mental illness, there is little movement towards funding consumer run services. Some consumers are openly critical about whether the consumer advisor industry is slowing down the development of patient run alternatives (Chamberlin 1977).

Participation outside government and health sectors
However, not all influence to act for better mental health lies within the government sector or the health sector. If we are holistic in approaching mental health, then services and people will connect across a range of sectors. Certainly employment issues for people with experience of mental illness may be best solved within the private sector who are employers. Some effective personal supports may be accessed via the voluntary sector, and communication to the general public regarding mental health may be better expressed via the arts and media sectors rather than ministerial or medical reports. So far, much of our consumer effort has been located within participation initiatives in the public and mental health sector and clearly there is a long way to go yet in achieving the goal of a consumer responsive sector. This is good but hardly satisfactory. I believe a key issue lies in consumer culture finding greater expression *outside* the mental health sector. And this may involve the Mental Health sector supporting consumer participation outside of mental health. As we enter a new century, it is clear that a shift in thinking has occurred and this shift is summarised by Tessa Thompson (2000) when she writes: "work to promote social inclusion is fundamental to recovery …(it) is not a sideline to mental health services - it is the heart". If this is representative of the emergent philosophical shift that has occurred, what can we say about ground level initiatives? There are glaring gaps in our participation within Australasia. This includes:

- The lack of meaningful political engagement with governments,
- Lack of consumer involvement in the NGO service sector;
- The largely unrecognised and unfocused voluntary sector requires engagement around consumer peer support and self help initiatives in furthering recovery in mental health
- More visible representation within the business sector
- More visible representation within the media sector
- It is evident that 'consumer culture' is filtering into the arts sector with movies, literature, visual and performing arts becoming avenues for expression, and this can be further developed.
- We do not see people with experience of Mental Illness as community opinion leaders
- We do not see people with experience of Mental Illness as key dissemination agents leading the discourse on recovery process and further articulating human potential for those experiencing mental illness. (Pearson 2001)

3 PARADIGM OF SCHIZOPHRENIA

> *"While there is no cure for schizophrenia, it is a highly treatable and manageable illness and most people's symptoms can be controlled with medication. The primary medications for schizophrenia are called antipsychotics or neuroleptics. They help relieve the hallucinations, delusions, and thinking problems people have with the disorder. These drugs seem to work by correcting an imbalance in the chemicals that help brain cells communicate with each other."* Vicserv publication Volume 1 - Towards Recovery (Pepper Ed 2002, Pg 22)

If we consider the above quote from *New Paradigm Press* we would note this reflects a paradigm which does not provide hope for recovery for people with schizophrenia. The general assumption here includes 'there is no cure for schizophrenia', and implicit is the idea of chemical imbalance being the cause of schizophrenia. There is also the assumption that medications work for all people who experience schizophrenia.

In New Zealand the Like Minds Like Mine project to counter stigma and discrimination associated with mental illness national television advertising campaign includes mention of the major mental illnesses but refuses to include a person with experience of schizophrenia, citing that the people of New Zealand are not yet ready to face the implications of discrimination associated with this label.

In fact, most drug company research demonstrates a 33% recovery rate for management of symptoms of schizophrenia in western nations. Therefore it is an untruth to suggest medications fully manage symptoms such as hearing voices. And the medical recovery rate for schizophrenia in western nations is a poor percentage when compared with some other centres of excellence about the world (WHO 1979).

> *'The general conclusion is unavoidable. Schizophrenia in the Third World has a course and prognosis quite unlike the condition as we recognise it in the West. The progressive deterioration which Krepelin considered central to his definition of the disease is a rare event in non-industrial societies, except perhaps under the dehumanizing restrictions of a traditional asylum. The majority of Third World schizophrenics achieve a favourable outcome. The more urbanised and industrialised the setting, the more malignant becomes the illness. (Warner 1985;156)"*

This research supports the western paradigm described in the Vicserv publication yet raises questions about why we don't do better than third world countries. It would appear there is urgent need for the mental health sector to work with people experiencing symptoms of schizophrenia in a way that promotes recovery. Many authors have

discussed ways forward (Bentall, 1990; Boyle 1990; Romme & Escher1993; Thomas 1997; Smith 2003).

There are no hearing voices peer support groups in Australasia
Many of us with experience of psychosis are finding ways of living in recovery even if our symptoms remain (Smith, Mike (ed) 2003, Smith & Coleman 2003). Clearly there is much work to be clarified here about prevailing paradigm of schizophrenia. Still with all the destigma type programmes, radical psychiatry, and research, the communities of Australia and New Zealand mental health persist in treating people with schizophrenia with less hope for recovery than any other diagnosis label. A key to recovery being articulated in Europe has been the growth of consumer run hearing voices peer support groups. At present there are no nationally coordinated consumer run support groups in either New Zealand or Australia yet over-seas research demonstrates effective recovery for many people involved in a support group (Romme & Escher 1993).

4. PERSONAL RECOVERY: A NEW PARADIGM?

Rationale of personal recovery
It is generally acknowledged personal empowerment is strongly correlated with recovery from mental illness (Meagher 1995, 2002). The goal of recovery has been defined as people liberated to a self-defined ability to live well in the presence or absence of symptoms (O'Hagan 2001). Recovery is about a person reclaiming their life after experiencing mental illness. If this is true, then mental health needs to acknowledge issues of power and find safe ways to discuss them in order for recovery of consumers to be an effective outcome. Person centred recovery is therefore a radical paradigm shift from the present practice of mental illness, which labels people from the DSM and treats people as a diagnosis (Deegan 1997). We will now discuss elements of a recovery process and reflect upon consumer and staff roles in support a recovery process.

Personal and collective truth telling about personal story
Finding a personal voice and your individual truth being heard is part of personal recovery. The need for consumers is to articulate their story about their symptoms in relation to the context of their life. Honouring personal truth is the beginning of healing.

However, I am not just alluding to the telling of the personal individual story here. There is the collective consumer perspective that needs articulating and a call here for consumers with the skill to articulate it. There is also a need for consumers to articulate their story about 'mental illness' in relation to discrimination, personal power, and powerlessness. This is part of our own recovery process, as well as what this teaches society. The lived experience of survivors is not often acknowledged or heard. We need more stories about individuals who

take their empowerment and recovery out there in the discourse. These truths and stories help frame' or 're-frame' the mental health paradigm. An example of this is the Mental Health Commission of New Zealand's *Gift of Stories* (Leibrich, 1999). And the content is about consumer story overthrowing a) the dominant medical story (about people described as chemicals who are out of balance) and b) overthrowing the pervasive community media story (about people objectified as violent time bombs ready to explode).

Role of consumer workforce
There are a range of roles mental health consumers have traditionally developed such as personal advocate, systemic advocate and advisor or consultant to the mental health system. Regarding personal recovery, the most effective role for people who have been there already is one of peer support. Much of the funded consumer workforce in New Zealand and Australia has been developed through a history of systemic advocacy and advisor to the mental health system. And the Consumer movement needs to re-assess the paradigm which it has worked in, for after over one hundred years of mental health patients' rights and consumer rights activity (Tomes, 1998), the Mental Health Sector is still largely untouched in their understanding and attitudes towards people labelled with major mental illness. (Clinton, & Olsen, 1998). It has been said many times an effective role of consumers in recovery is to embody hope for others (Simon Champ as quoted in Traynor, 1997) and some of us have articulated the need for consumer run services (Fisher 1994).

Role of the mental health workforce
And mental health sector staffs also call for their empowerment within the sector in order for them to take action in supporting consumer outcome (Wadsworth, & Epstein, 1996, P153). Yet the paradigm mental health staffs often work with is one of professional agent of the state who safeguards society from violent attack through the instrument of compulsory assessment and treatment legislation. Little wonder there is a systemic challenge in implementing a personal recovery paradigm in Australasia. Stephen Covey has stated, *if you want small changes in the workforce then work on attitudes. But if you want quantum changes, then change a person's perception of their role* (Covey 1994). A person's perception of their role may be called a paradigm (Pearson 2000). Paradigms such as key worker and support role are problematic. The *key worker* role has not really proven to be *key* as in practice the power dynamics between the psycho-social sector and the acute mental health service can make coordination tricky (Meadows and Singh (eds) 2001). Of interest is the approach of Wellink Trust; an NGO in Wellington New Zealand. Wellink is attempting a staff role change by systemically supporting a coaching relationship between their staff and their clients in preference to a support role. And a personal coach role may well be proven to be an effective relationship in supporting a person in their recovery.

CONCLUSION:

I have defined the word *paradigm* as a way of viewing the world and noted that *recovery* has a range of valid meanings from medical, social, cultural to individually defined meaning. I have preferred person centred recovery as a definition. I have discussed consumer participation and found encouraging developments with consumer advisor roles yet much development of the consumer workforce is still needed, particularly for consumers to be involved in practice and consumer run services. I have also discussed the diagnosis of schizophrenia and found little hope for recovery articulated in Australian and New Zealand literature and a lack of peer support groups for people who hear voices.

In summary and conclusion, I will now challenge the paradigm of consumer empowerment by leaving the penultimate words as a quote from an Australian psychiatrist and the final words to the CEO of Vicserv:

"What are the challenges of the next decades for such community services? The first challenge is just to endure and provide consistent services to individuals and their families despite regular organisational attempts to destabilise us through cost-cutting. The second challenge that underlies it is the budgetary one. The third one is to become partners with consumers and families, and we're not there yet. Consumer will point out to us that to be partners you've got to be able to negotiate from equal power.
The main challenge is to first of all get these services to endure. It's always easy to keep cutting back these services without people seeing. They'll see if a hospital closes, but they don't see what happens immediately if community teams go. It's the service-users and their families who feel the full impact in the first instance.
There's been a lack of hard, courageous decisions to make sure that budget cuts are targeted away form the community-based services, because as hospitals get smaller, we take more of the de-institutionalised as well as the un-institutionalised – those who spend most of their time out of hospital, even if they are homeless.
The third most exciting and crucial challenge, however, is to implement what we have been learning from consumers and their families: to be able to build empowering services and real recovery – that is, to seek the maximum common ground with them, to start sharing power by involving them directly in the management, running and planning of our service." (Rosen, 1997;201-2)

At the conclusion of the Vicserv conference in his farewell speech, Dave Clark (the CEO of Vicserv) summarized the conference and shared these words or something close to this effect:

"We developed a key mission at Vicserv a few years ago which went something like this 'Rehabilitation is our job'. Perhaps now after listening to the discussion over the past couple of days, we may consider amending it to something like this statement which would be a message

to the people who use our mental health services: 'Recovery, that is your job – how can we help'.

I can think of no better words to convey to the mental health sectors of Australia and New Zealand the type of paradigm shift needed for us to move closer towards delivering recovery focussed services to the Australasian population.

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