

THE CONCEPT OF COMMUNITY SUPPORT IN MENTAL HEALTH

– A CONSUMER PERSPECTIVE

By Debbie Waddingham

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Some years ago I was sitting in my psychiatrist's office at a clinic undergoing psychosis and discussing admission to hospital. My psychiatrist suggested that because I hated hospitalisation so much I should try getting through the psychosis at home. I agreed to do this but all I was offered in terms of support was large doses of Thioridazine (Melleril). This was all I got but I wanted to try anyway. Without support it was destined to fail and did so, with some cost to me. It led me to believe that internment in Graylands was the only option for someone like me.

While this was going on, my neighbour downstairs was suffering multiple sclerosis. She was wheelchair bound and came under the care of Disability Services. First, her unit (purchased with a loan from Homeswest) was converted to accommodate wheelchairs at taxpayer's expense. Her husband, a full time student, received a carer's pension. She had a paid carer from 9 to 5, Monday to Friday. She was visited by both community nurses and Silver Chain nurses. She had Silver Chain home help and received meals-on-wheels. She was also picked up (Monday to Friday) in a minibus and taken to either occupational therapy, doctor's appointments or MS Society activities and despite being legally blind, received a grant of several thousand dollars to buy oil paints, canvas etc, so she could paint at home. This level of intensive community care was not available for just a few weeks which would have been what I required, but was ongoing until she either left the state or died.

After coming through my psychotic episode, my psychiatrist said to me " You see, you could not do it at home. You had to go to hospital" I felt that I hadn't failed but he and the mental health system had let me down. I could not do it without the same level of support that my neighbour received from Disability Services. The only action as a result of my experience was

a drug alert sticker on my file banning use of Melleril. (Melleril, by the way, has been withdrawn from the market. It is considered too dangerous for anybody to take.)

What exactly does hospital offer that can't be provided in the home with community support?

Of course, some people need intensive care, but I am talking about your run of the mill voluntary patient enduring psychosis. Care could be provided more cheaply, with less trauma, less disruption to your life and less stigma, in your own home. For consumers who need respite or a higher level of care, places like those provided by Saint Bartholomew's or the Milpara model could proliferate. Again at a cheaper cost than hospitalisation. All it needs is a change in thinking and a redirection of funds by mental health service

Disability Services have been doing it for decades. The idea is not new. Why can't Mental Health Services modify and transfer the Disability Services model to mental health? It would be very easy and cost effective. Why are we blind to the lessons learnt in Disability Services with regard to quality of life?

My neighbour had a good social worker to coordinate and liaise with community services on her behalf. Social workers are trained in the process of social change. In mental health, social workers bear closer resemblance to agents of social control trying to bring about change in the individual through therapy.

What change or efforts towards change in social work practice that may be happening is too invisible. While social workers may want to align themselves with the powerful by becoming pseudo doctors in mental health, consumers are finding their welfare needs neglected. Social work has the ability to deal with whole systems. There may be a role in the therapeutic process but part of the strength of social work is the ability to achieve practical outcomes and systemic change. The profession, alas, has not made a significant mark in mental health practice. Where is the strategic focus? Where is it being diverted to?

Definitely not community support

As a consumer, community support is the highest priority but whose needs are being met? Are they organisational needs? Part of the problem is the invisibility of the mental health consumer as compared with the wheelchair stereotype in disability services. Visible mental health consumers on the streets become a social shame to be driven off the streets and locked up.

Consumers are their own best advocates but have less power. We need strategic and systems analysis skills to bring about change. There needs to be collaboration and partnership between service providers and consumers to bring about effective sustainable change. The relationship should not be patronising or patriarchal. The tension is that people who are consumers have to drive the change through their advocacy but are powerless to do so. Professionals have more power and must use this power in a manner consistent with what consumers want and need from a consumer perspective. Social work must develop a strategic position to bring about change but if it does not do it properly, it will mirror the powerlessness of the consumer or abandon the consumer.

As a mental health consumer in this state, it is rare to come across a psychologist. If you do it is usually a clinical psychologist. Since the demise of the Community Development Centre (CDC) there is apparently no community based psychology in mental health. Clinical psychologists use a diagnostic and treatment model rather than counselling and community based models. This results in a lack of continuity of care for mental health consumers who want to move from a clinically dependent state in treatment to an independent mode of living, ie to move from the role of the patient to being a person integrated into community living. Without community psychology you are reducing the likelihood of a person successfully moving into community living. The model in use promotes a crisis care model with little assistance with reintegration into the community.

Psychologists generally are very accepting of the medical model. It is accepted that they have a duty of care but there must be a change in practice to bring about a more holistic approach. Psychologists should consider consumers within the social context which they operate and examine ways of developing appropriate support other than a major focus on changing individual behaviour.

Consumers and carers are calling out for community services. Appropriately trained psychologists have a role to play in this. There needs to be a change in thinking by the profession. The value of community based psychology must be recognised and supported. Without greater professional input current community integration programmes have an increased risk of failure, leaving the mental health consumer vulnerable and reluctant to try again with no support.

At present fragmented service delivery limits the scope of services. Piecemeal approaches and an overemphasis on boundary issues prevents a more holistic approach to successfully rehabilitating people into the community. The concept of a team approach goes beyond individual agencies. Multidisciplinary interagency teams including community psychologists would seem to provide an alternate model of service delivery for the mental health service aimed at reintegration into the community rather than diagnosis and treatment. In the broad field of disability, community based models are used successfully in conjunction with medical care. Mental health services need to examine and act upon these.

Consumers are well aware that lived experience disproves theories.

Psychiatrists and Mental Health Division control the purse strings. Funding is scarce, but miraculously \$1million appeared on the demise of the Metropolitan Mental Health Service to fund Anglesey in the area of community residential rehabilitation. There was no planning, no consultation and there is no way it can be considered as a potential template for a community based model. It is effectively a hostel in a ward at Graylands. A million dollars has been spent in a year on it and in no way do consumers endorse it. Even the symbolism of the name is an indicator of wrong thinking. It is fitting that continued funding for Anglesey has been withdrawn but a million dollars has been wasted in the process.

Consumers were also disappointed that the previous health administration expressed active opposition to the employment of consumer consultants in Mental Health Services. In a sleight of hand worthy of 'Yes Minister', it appears now that new funding will be available in 2002 to employ 'consumer advocates'. There is grave concern that these will be non-consumers whose role will be to identify ways of 'enhancing consumer participation.' This decision was reached once again without consumer consultation.

The Mental Health Consumer Advocacy Programme, whose employees are all consumers, has been 'enhancing consumer participation' for the last six years and has continually had its initiatives stymied by Mental Health Division. This new 'initiative' locks up the money for consumer advocacy for four years. What haste? What waste? Why bother, unless it is a cynical effort to apparently fulfil an election commitment for the new government. These appear to be desperate efforts to control consumer advocacy and community service. Steps must be taken to prevent and /or amend these feudalistic follies. Money is scarce. We cannot afford to indulge egos and turf disputes. Through strategic lobbying of the Minister and his advisors, non government organisations and consumers have hopefully brought about a change to the 'consumer advocates' proposal. This is heartening but the criticism still stands.

Policy makers in Mental Health Division barely give lip service to community services. The words 'community service' and 'consumer advocacy' have been hijacked. The concepts have been abandoned.

Overworked and under trained general practitioners are doing most of the frontline work with people with mental illness. Now with the introduction of shared care, they will be doing the maintenance work as well. Psychiatrists, seemingly safe in their institutions, are making themselves irrelevant. What is now an omnipotent elite is fast becoming an inexorable effete. Psychiatry faces the same dichotomy as social work. They must decide whether to remain in their ivory towers or embrace the community. It seems there are a lot of little emperors in mental health services who think that their present set of new clothes look rather spiffing...

I have selected social work, psychology and psychiatry as three examples but all professionals and all professions are accountable. All are complicit in the lack of action. In protecting your own territory we are losing common ground and the opportunity for collaborative relationships.

Consumers are the common ground and we are dependent on altruistic courage to seize hold of you and guide you along the path to change. If you cannot do it individually, use your professional associations. Now is the time to act.

There are some harbingers of hope. Ruah Inreach, the general practice street doctor programme, the new Clarkson community mental health service (a toe in the water, yet untested.) But we need coordinated community programmes and services, not millions of dollars siphoned off into building more tertiary services, more monuments to misery and mediocrity (our misery, your mediocrity).

In the 1970's, the Italians closed the mental hospitals in their country. Through misguided altruism they did it without developing community services. The result was that the mental health consumers were destitute on the streets. They died in droves, of exposure to the weather, of not being able to look after themselves, of assaults and exploitation. Thirty years later, Italy has the second best health system in the world (according to the United Nations). They learned the hard way. But they learned and with the Italian government changing annually since the War, it was not the politicians who brought about the change.

It was the dedicated, visionary, brave, committed workers.

In Western Australia, what have we learnt? There is a remarkable rise in acute psychotic homeless people, a rise in social shame, an increase in mental health consumers dying early or dying in violent incidents, a rise in mental health consumers in gaol. We are aware of it now and without action, it will only increase. The vulnerability and desperation of mental health consumers can only increase. The community, through the media, will call for "these people" to be locked up resulting in the creation of more monuments to misery and mediocrity as the present ones are full. History is cyclical. It is proven through the effortless inertia of the public mental health system on which if you lift the lid, you will find the frenzied activity of thousands of workers desperately trying to hold the system together overwhelmed by their caseloads. The outcome for consumers does not change. The challenge is to consider innovative and imaginative ways of delivering services to people beyond the asylum model.

Sometimes a great notion indeed!

Note: 1. Community includes all levels of government, their agencies(including the education system), voluntary organisations, employer organisations, trade unions, recreational organisations, women's organisations, professional bodies, political parties, business organisations, companies, industry, doctors, lawyers, families, consumers and so on

2. You may try to dismiss these comments as the rantings of a madwoman. I can assure you I am not psychotic or deluded. I and others like me are your reason for being and are omnipresent observers and participants of the mental health system. We will not go away and we demand better services – proper community services.

3. "Sometimes a Great Notion" is the title of the second book by Ken Kesey.

The first, "One Flew Over The Cuckoo's Nest" is well known