



Consumer Submission to the Senate Inquiry on Mental Health – The ARC Group

Since the Richmond Report, people who were confined in an institutional setting, many for long periods of their lives, have been moved into the community – with the idea that funding would be transferred from the expensive psychiatric hospitals into community-based treatment and support. However, many have been left wandering the streets, without skills or support to function as part of the community. Many are caught up in the criminal justice system, and end up in jail, when what they need is treatment and services, e.g. counselling, health care/medical treatment and supported accommodation.

Community mental health centres and supported accommodation systems are under-resourced and under-funded. There is simply not enough financial support to cope with the amount of people who have been diagnosed, or have the potential to be diagnosed, as mentally ill. Pleas for increases in government funding to support the mentally ill, whether through community health centres or supported accommodation or general health services have been ignored.

Examples:

- By Christmas night 2003, there was not a single psychiatric bed available in the state of NSW
- There is no longer any respite service (support for people having mental health problems without being admitted to hospital) at Rozelle Hospital
- Many non-government organizations and charities are overloaded with cases the public health system cannot handle, and have to refuse requests to take on patients from the public hospitals on discharge
- 1 in 10 people with bipolar disorder kill themselves
- 1 in 40 people suffering from mental illness generally kill themselves
- 1 in 40 people living with a mental illness are homeless
- A man with schizophrenia and chronic emphysema in his early sixties, who had been institutionalised for about 30 years, has been homeless for over three years as he has been unable to learn the skills to maintain independent living
- There is a 10 – 11 year waiting list for the Department of Housing

The public hospitals themselves are under funding pressure to move people on as quickly as possible. The question “Why was Cornelia Rau released?” (despite in actual fact her having left the hospital before official release) when she was still perhaps suffering from psychotic symptoms, is easily answered by the statement that *everyone* is released as soon as they are perceived to be somewhat stabilised and able to take care of themselves, even if they could benefit from a longer stay in hospital. When people are close to being discharged, they are also allowed short excursions from the hospital, based on professional staff judgement of their wellness and competency to take care of themselves. It was on one of these excursions that Cornelia Rau fled the hospital.

Also involved in her early release was the fact that she had a caring friend who was prepared to present to hospital staff and deceive them into believing that he was her partner. He told hospital staff he planned to and would be able to look after her – and this he apparently genuinely intended to do. This would perhaps have helped him convince the authorities of the closeness of their relationship, as he did genuinely care about her. However he had only met her three months before, and obviously did not

understand the complexity and danger to the patient of the physical and thought-altering effects of psychosis.

Another factor involved in the Cornelia Rau case is that prior to her impending release, she was due to face the Mental Health Review Tribunal, a formal legal requirement if an involuntary patient wishes to leave hospital early. The Tribunal was to determine whether she should be placed under a Community Treatment Order (CTO), which is a legal document compelling someone to take medication, or in some instances to subject themselves to electro-convulsive therapy (ECT). If one contravenes one's CTO, for example by smoking a joint when ordered not to, one can be ordered to return to hospital. If a CTO is to be enforced on a person because the authorities don't believe the person will voluntarily take their oral medication, the police can be called in to transport the person to hospital where they will be forcibly injected by nursing staff. Until this year (2004 – 2005) a lot of the newer medications were not injectable, so injection treatment would have been limited to older medications, which generally have worse side effects. These facts, and the fact that Cornelia Rau was described by her family as "health conscious" and didn't like taking medication, could go a long way towards explaining why she fled hospital.

It is worth bearing in mind that for some patients, while enforced hospital stays are beneficial, it can be the one place the person desperately does not want to be, the worst place in the world, a place of horror, torment and dehumanisation. Some people also have these feelings about medications, that they destroy the person's unique sense of self or identity, 'wholeness', spirituality or 'soul', sexuality, personality, ability to think fully or independently, or affect cognition and other brain functions in an intrusive way. There are many issues, including human rights issues, involved in the power of the state to compel people to take medications when this is the person's greatest fear or nemesis. Often the attitude of the state and health professionals is paternalistic, if benevolent.

The profound physical side effects of medications include toxicity, noticeable weight gain and fluid retention, nausea, blurred vision, dry mouth, change in appetite, constipation, diarrhoea, sexual dysfunction, change in libido, hormonal variation, change in personality and change in cognition, all of which influence the person's very 'soul'. For example, certain psychotropic drugs may cause a woman to lactate, which with other side effects may result in 'phantom pregnancy', which has a detrimental effect on the woman's psyche, thus further compounding her problems. This can lead to patients rejecting medications.

Generally the psychiatrists role is based on solving an appalling dilemma – how do they judge when someone is mentally ill? They often have to rely on the patient's self-reporting of symptoms. From the perspective of the person with a mental illness, it is even more complex.

- The person has to know and/or admit there is a problem in the first place.
- There are trust issues involved – the person has to trust the mental health team that is treating them – it is a very intimate relationship and involves the person's own private thoughts
- The person has to be able to articulate their problems to a mental health professional
- Diagnosis and dialogue with the psychiatrist unavoidably involves their subjective opinion of the psychiatrist, and the psychiatrist's subjective

opinion of the patient. As human beings, it is impossible to completely overcome this.

There is obviously a need to look at how people judge/diagnose – whether it is by what people say, or apparent behavioural symptoms. How much treatment a person gets access to often depends on how much the person knows about the system and the criteria of diagnosis, and sometimes how they can use the system to their advantage – often by exaggerating symptoms in a desperate attempt to get treatment, or by trying to minimise symptoms in an equally desperate attempt to avoid treatment, depending on the person's subjective perception of the intensity, painfulness or danger of their symptoms.

Apart from there being not enough mental health services, there are also not enough suitably qualified and experienced staff – there is currently an initiative to offer nurses who have left the mental health system a \$3000 bonus to entice them back. Many nurses experience frustration at the limitations of their role – psychiatric nurses in the public hospitals are expected to spend much of their time in their stations dealing with administration and paperwork, and simply do not have enough time to interact one-on-one with patients.

The Richmond Fellowship, which provides supported accommodation and other support to people suffering from schizophrenia, has to train social workers and other less qualified people to deal with psychiatric patients in the community in regional areas because there are not enough mental health nurses or community nurses. The Richmond Fellowship has a 2-year waiting list, and looks to remain that way indefinitely if current trends continue.

When attempting in despair to suicide (whether from depression, hopelessness, mental illness or gender issues) the person may survive the attempt not only with their original condition but also brain damage and/or para/quadruplegia. Such people often end up in nursing homes for the elderly at a young age, with compounded disability.

There exists basically one long sustained cry of desperation – people locked in psychiatric wards can relate to the desperate and disempowered state of refugees in the immigration detention system, as Cornelia Rau unwittingly found herself so placed. Here is a poem written by one of the authors of this report, a person living with a mental illness:

Woomera

We were just following orders
We were just trying to do our jobs
We had a contract to fulfil
You should have seen the state of the camps
You can't imagine
Having to manage all those people
Such terrible working conditions
But we soldiered on
The only thing that kept me going
Was coming home every night
To my family

Knowing I had put food on the table
Doing this terrible work that has to be done
It is a heavy burden sometimes
To do one's duty for the state
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One of the main problems is that of accountability, and the disputes and arguments over State versus Federal funding. No one is ultimately accountable, and the system will not change until someone is held accountable in health care in general and in mental health care services in particular. Appeals for more funding have failed at both the State and Federal level.

People trying to judge for themselves which medications to take and at what dose are trying to achieve a delicate balance between controlling symptoms and being able to function in the community, whether through work, education or other activities. This requires a high level of knowledge, functioning and experience which not everyone has. One also needs to be incredibly in touch with one's body, being aware of the effects of diet, medication and exercise.

There is no Bill of Rights for persons living with a mental illness. There are no habeas corpus provisions, except for those covering involuntary admission to a psychiatric hospital – a person must be considered a danger to themselves or the community, or may be at risk of behaviour which damages their reputation or standing in the community. There are no intellectual property protections, for the content of their thoughts or discussion of their own work in healing themselves, when in discussion with a mental health professional. There are issues to consider about a person's right to privacy, when they are being treated either in hospital or in the community, when so much of psychiatric treatment is based on getting access to a person's private and intimate thoughts, particularly those about oneself, one's relationships with others, and one's identity. There are also no protections against slander or libel – persons living with a mental illness are of course like any other Australian citizen covered by anti-defamation law, but this is usually only at issue if the person is 'famous', i.e. has a reputation to uphold. In Australia persons living with a mental illness are not covered by that part of anti-discrimination legislation which protects against vilification and harassment (except in Tasmania). There are issues concerning freedom of conscience or belief which become grey areas when the person is considered psychotic or thought disordered, or simply as 'having a mental illness', because of their beliefs.

There is also the issue of total control vs. virtual total abandonment – people have largely been kept in permanent confinement or abandoned to their own devices. The proposal that a person with a severe mental illness will be cared for solely by occasional 15 minute consultations with a GP is inadequate. GPs are not trained mental health professionals, and under recent Liberal Party policy the number of GPs who bulk bill has been drastically reduced. Many people with a mental illness are on low-income earners or dependent on welfare, as having a mental illness restricts a person's ability to work. People need access to psychiatrists, social workers and community health nurses through Community Health Centres, and both staff and clients complain that there is never enough time to deal with counselling needs.

We believe the Senate Inquiry Into Mental Illness should consider the Human Rights and Equal Opportunities Commission's Report on the State of Mental Health Services in Australia. This is an important document which was produced in consultation with consumers, their carers and families, and mental health professionals from across Australia, and should not be ignored as it is a valuable resource.

People working in mental illness, at least in the public sector, are prevented from engaging in political agitation or criticism of the government on behalf of the mentally ill or their workplace. That is why we feel we are able to make these comments as we are currently in an independent position.

If one feels that it is 'just you alone against the world', which can often be the case for person's living with a mental illness, one's situation can feel very unfair and frightening, if not threatening; this can lead one to do desperate things, whether out of fear or anger. One has to be determined to survive, often to resist suicide. However, even though people can be desperate and psychotic, the person can still be somewhat themselves and care about others as much as they are able. As a final example a woman considering jumping to her death from the Gap didn't want other people to have to clean her up from the rocks below afterwards; the tide was out so she decided not to jump that day. She is still alive today.

We identify ourselves as part of the ARC Group, a group of consumers of mental health products and services, committed to improving the lives, self-esteem and empowerment of people living with a mental illness.

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