

# **SUBMISSION TO PRODUCTIVITY COMMISSION INQUIRY INTO MENTAL HEALTH PROVISION**

## **Background**

My daughter was in the care of the Isle of Man Mental Health Service for over nine years, until we returned to Australia late August last year. During that time she was sent to the UK National Psychosis Unit in London for six months. I was in the Isle of Man looking after my parents when she, in Sydney, lost her confidence and started showing signs of a depressive illness. She was 23 and a talented Theatre graduate with the prospect of a substantial career. As her family member in Sydney was not prepared to help, in the end I had to get her over to the Isle of Man for treatment. We were able to return permanently when both her beloved grandparents had died. She was discharged from inpatient care into community-based care only weeks before we flew back.

I feel it is important to make this small submission as we have experience of the Manx, English, and now Australian provision for people with serious and longstanding mental illness. My daughter is currently detained as an inpatient under the Mental Health Act.

I had been desperate to get my daughter back to Australia for years, thinking she would be better based back in her own country, with the expectation of uncomplicated access to a good standard of appropriate co-ordinated treatment and support. How wrong I was!

## **Scope**

My focus is on the following three areas of the Terms of Reference:

- the effectiveness of current programs and initiatives across all jurisdictions to improve mental health, suicide prevention and participation
- assessing whether the current investment in mental health is delivering value for money and the best outcomes for individuals, their families, society and the economy
- drawing on domestic and international policies and experience.

## **Comments**

We returned to live on the NSW Central Coast, with a population around 400,000. My daughter was born and brought up on Sydney's Northern Beaches, but in the ten years away, systems and bureaucratic requirements had dramatically changed.

- **Access, integration and inefficiency**

Mental health services in Australia are fragmented, labyrinthine, inadequate and difficult to access.

We returned to Australia with documentation from my daughter's Manx consultant psychiatrist and the expectation that accessing the necessary ongoing support and treatment would not be a problem. Instead, I spent weeks trying to find out the correct channel of access to the service and how to obtain the necessary support. Meanwhile my daughter, with no focus, in an unfamiliar environment and distanced from her friends and the supportive environment on the Isle of Man, deteriorated.

- The Mental Health Line appeared to have no function unless hospitalisation was required.
- On referral from a GP, we finally accessed the community mental health team, and my daughter was under the care of a psychiatrist
- She could not be put in the care of the acute team, which would have been appropriate for a recently discharged inpatient, as, counterintuitively, they can only provide support for 6 weeks.
- Therefore the community support comprised an occupational therapist visiting once or twice a week.
- The acute community team included a psychologist, but for my daughter I discovered had to go back to the GP, who had to prepare a care plan and a referral to a psychologist. This was for only 6 sessions, possibly extending to 10 sessions, *per year*, and for CBT only.

I asked the community occupational therapist what happens to people who do not have someone to do the research and legwork for access to a psychologist. She said they just don't get the service.

**The 'system' is riddled with inefficiencies.** For example, why does the GP have to develop a care plan for referral to a psychologist when the person is already in the care of a psychiatrist? What certainty is there that the GP's care plan lines up with the psychiatrist's plan? How does the GP know what care the person needs when they are already in the community mental health system? Apparently communications can take place between the various doctors, but this is not transparent to the patient.

Fragmented and onerous **bureaucracy** is inefficient and ineffective. Each application for some service requires a different medical report. eg, Why can the documentation from the psychiatrist not be used for both the Disability Support Pension, the NDIS, and Care Allowance?

I gave up trying to apply for the Carer's allowance as, apart from the form having only one question relating to mental health, it required yet another, quite differently formatted medical report. Life sometimes is too short. But, having

given up work to look after my parents eleven years ago, I am now an age pensioner, and money is important.

Apart from the delays and frustrations in accessing appropriate necessary care and support, the need to attend multiple assessments by different people (eg Community Mental Health, Centrelink Newstart, Centrelink Disability Support, NDIS) exacerbates anxiety and confusion in the mentally ill person.

- **Health workforce, informal carers and social services**

**There appear to be no care co-ordinators in the mental health system.**

(Although this may be a NSW policy.) Therefore the care provided to a person with ongoing mental health problems, or recovering from a serious mental illness, is inadequate, disjointed and not timely. The system also assumes a level of awareness, competence and organisation that a mentally ill person is not likely to possess.

In the **Manx** (and I believe the UK) system a **care co-ordinator**, who has mental health qualifications, is involved in meetings with all concerned mental health professionals before the patient is discharged, draws up a care plan, which is agreed with the patient and the responsible medical officer, and organises appointments and support from various mental health and lifestyle support professionals to implement the plan. The care co-ordinator is also responsible for facilitating access to financial support such as a disability pension, and housing assistance. This system also is in place for people who are receiving support in the community, without previously having been an inpatient.

In the National Psychosis Unit in London a social worker was attached to the ward, with the responsibility of providing practical support, such as organising medical certificates for benefits and liaising with the patient's home area on housing and ongoing living support.

Meaningful care plans and co-ordination are essential to prevent relapsing and return to hospital. Which, tragically, is what has happened to my daughter, at much greater expense to the state. If a timely and comprehensive plan of support had been developed, and implemented, then I do not believe hospitalisation would have happened. People trying to recover from mental illness need to have hope. Without a structured plan, properly implemented, there is none.

**Timeliness** is critical for recovery and maintenance. The other major inefficiency and fragmentation is **NDIS**. Apparently for long term support we will have to apply, and there is a long approval process, with more interviews and 'assessments'. Again, people with serious, recurring or longterm mental health problems cannot wait for the bureaucratic wheels to grind. Neither can mentally ill people necessarily research, determine and arrange appropriate support. Another requirement for a care co-ordinator!

I suspect care co-ordinators have disappeared from the mental health service as they would bridge federal and state funding areas, and so fall between the two. If this is the case, then again bureaucratic considerations are leading to greater financial burden on the state, as people fall back into hospitalisation.

Apart from possible financial support, it would appear, certainly in this area, that only charities are involved in providing services for carers, and even then only 'chat groups'. I personally am not comfortable joining a church-based self-help group. I'd prefer an organised trip to the theatre or even dinner!

**Family (or informal) carers would benefit from access to psychological counselling.** Our personal lives are very often subsumed to the needs of the mentally ill relative. It is difficult to pursue interests – or for that matter, to work. It can be isolating as it is difficult to maintain friendships and involvement in community life.

Managing a mentally ill person is often frustrating and stressful. Even more so when there is no guidance or advice on how best to deal with situations, and what would be appropriate responses. Medical professionals should keep carers informed of issues such as side effects to medications, and how to respond to them. And carers should be included when plans are being made for support.

A **carer Helpline** where carers can get advice, or just let off steam would be invaluable. Friendships can be strained by the carer's need to 'unload'.

From years of experience on the **Isle of Man** the best support for carers is having someone take the person regularly to activities such as swimming, gym, running groups, art and creative writing classes. Community health staff, with the equivalent qualifications of a nursing or personal care assistant, were organised for these functions by the care co-ordinator. Again, in this area all that appears on offer are excursions or 'drop in centres' run by charities.

Carers can save the state a considerable amount of money, but they also need support. And giving the mentally ill person a break from the carer is essential to minimise the role being viewed as a 'minder', engendering resentment, and also to encourage rebuilding independence and self-reliance.

- **Appropriate, adequate and effective care across sectors**

Comprehensive appropriate mental health care appears to be inconsistent and patchy across different areas. I was dismayed to discover that in this area there is not a rehabilitation facility, nor any group homes or supported living for those recovering from serious and/or long term mental illness.

For all its size (population 80,000), the Isle of Man several years ago built a rehab ward separate from the acute facility. Rooms were more comfortable, security was diminished, and activities were scheduled with the aim of restoring life, work and social skills pre discharge. As well as practical sessions such as cooking, budgeting, IT skills and gardening, mindfulness and exercise groups

were scheduled, together with group therapy and psychological support. Patients were accompanied to sporting activities such as swimming, badminton, sailing, and unaccompanied leave was available.

Unfortunately when the rehab facility opened, a medium stay supported group house, staffed by a mental health nurse, was closed. This removed a higher rung on the ladder towards the ability to survive independently and re-integrate into the community.

If only acute inpatient mental health facilities are available, then the odds are stacked against effective recovery, and there is a revolving door back into hospital.

Another aspect of integration is the need for facilitated access to dental treatment, treatments for obesity and diabetes, and other physical health issues that are the side effects of medication delivered to the mentally ill.

## **Summary**

As Professor Ian Hickie of the Sydney University Brain and Mind Centre has said in the press on several occasions, a little bit of scattered service for everyone is no use in the treatment and rehabilitation of the serious and long term mentally ill. Six sessions with a psychologist would barely even build enough trust to achieve effective therapy. Six weeks post discharge community mental health team support would barely overcome the challenges of institutionalisation.

To be effective, care for the seriously or long term mentally ill must be integrated across inpatient, community mental health and social services. Care and support in the community must be

- **timely**
- **wholistically planned**
- **facilitated**
- **inclusive**
- **integrated**
- **consistent**
- **sustained**
- **and properly funded.**

The current arrangements – the term ‘system’ doesn’t apply – are wasteful and do little to adequately support recovery from mental illness. A well designed and implemented system would pay dividends in facilitating the re-integration into society and meaningful contribution of the mentally ill.

**Lorna MacKellar**