SUBMISSION TO SENATE SELECT COMMITTEE ON MENTAL HEALTH
18 NOVEMBER 2005

Background information:

In 1995, when I realised my son was suffering from schizophrenia, I joined the Schizophrenia Fellowship and have been an active member ever since.

From 2000 to the end of 2003 I was a member of QCAG (Queensland Consumer Advisory Group) and worked on a number of projects.

In 2004 I was an active committee member working on the THEMHS Conference, which was held on the Gold Coast in September 2004.

I have a very high regard for the staff of the Integrated Mental Health Service, who are committed and caring people, working under extreme pressure in an environment which is clearly seriously under-resourced in terms both of staff and facilities.

Introduction:

My son James Jacobs, who had been diagnosed as suffering from schizophrenia, was shot and killed by police on the Gold Coast whilst suffering a psychotic episode, on 24 March 2005.

As a society, we failed James, as we are failing countless other Australians every day in the ways we treat people with mental illness. I believe the failure is systemic, and this failure encompasses not only the health system, but also housing, the criminal justice system and the police service.

James' story reflects what has happened to many other Australians as they have battled with finding ways to deal with mental illness. My experiences as a carer are not unusual but are in common right across the states and indicate serious systemic failures in the ways we deal with our most vulnerable, most defenceless citizens.

As individuals and as a society, we need to ask ourselves: Is this who we really are, and is this really who we want to be?

1 FAILURE WITHIN PRIMARY HEALTH CARE IN PROMOTION, PREVENTION AND EARLY INTERVENTION

In 1995 I became concerned that my son's behaviour, which had become erratic over the past year, was more than "just teenage behaviour" and, on the advice of my sister, a trained nurse, we took him to see a private psychiatrist, who prescribed medication and left it at that. All that we were told as parents was that his problem was 'none of our business as he was over the age of 18 years old.'

2 FAILURE IN THE ADEQUACY OF TRAINING AND SUPPORT FOR PRIMARY CARERS AND FAILURE IN THE PRIMARY HEALTH CARE SYSTEM

During the next few years, we stumbled about searching for information on mental illness and, from time to time, begging the staff at the Gold Coast Hospital to help us to help him.

Eventually, James was admitted into hospital but was released a few days later. By the time he was contacted by a case manager some weeks later, he had stopped taking his medication and was again unable to recognise that he had a problem.

3 ONGOING INADEQUACY OF EDUCATION IN DE-STIGMATISING MENTAL ILLNESS

James was always extremely aware of the **stigma** attached to mental illness and insisted he was not 'psycho' or 'schizo' or any of the other derogatory terms he had heard used in general conversation, at school and in the wider community.

4 FAILURE IN PRIMARY HEALTH CARE IN CHRONIC CARE MANAGEMENT

The 'revolving door' pattern of crisis intervention and treatment followed by a lack of support due to under-resourcing of services, was repeated several times between 1995 and 1998.

5 FAILURE IN DEALING WITH SPECIAL NEEDS, INCLUDING CO-MORBID SUBSTANCE DEPENDANCE

By 1998 James had developed a **co-morbid condition** of drug and alcohol dependance. Whilst all the anecdotal evidence linked the two conditions, when I sought help on how to deal with them I was told that the 2 issues were treated separately. Each service told me there was no point dealing with 'their' issue until the 'other' issue had been dealt with, although the IMHS did try to provide understanding and emotional support at those times when he was seen by them.

ATODS advised me that their focus was on harm minimisation unless the person themselves was seeking treatment. Here on the Gold Coast there seemed to be no interaction between ATODS and IMHS at all.

6 FAILURE IN PROVIDING APPROPRIATE FUNDING TO ENABLE PRIVATE / NGO ORGANISATIONS TO PROVIDE ONGOING SERVICES WITHIN THE COMMUNITY

After a major crisis in late 1998, James was hospitalised for some months and subsequently provided with **supported accommodation** at Tekapo, which is run by the Schizophrenia Fellowship.

James thrived in this environment but unfortunately the Fellowship's own limited resources do not allow for an indefinite stay and after some 18 months, James left **in 2001** to make his own way.

At the same time he was also discharged from the IMHS clinic, and told to visit a GP for any future requirements. There was no further support at all.

He could not, and did not cope.

6 FAILURE OF THE HOUSING DEPARTMENT IN DEALING APPROPRIATELY WITH PEOPLE WITH A MENTAL ILLNESS

After running into difficulties and being unable to pay his rent, James spent the next years coping as best he could, with a partner, living in various caravan parks, motel rooms and other – awful - places.

James' clear understanding was that, having been unable to pay his rent, he was precluded from accessing any services and therefore had to rely on the informal network of friends and aquaintances – most of whom have similar difficulties and are equally disadvantaged - for his accommodation needs.

7 FAILURE IN PRIMARY HEALTH CARE IN CHRONIC CARE MANAGEMENT

From time to time I would see that James was becoming unwell and was usually able to persuade him to go to the **Emergency Department** at the hospital for treatment. On those occasions we waited an average of 5 hours, and sometimes as long as 7 hours. James would not have had the courage or the patience to stay had I not waited with him.

On almost all occasions there was no bed available and so he was given some medication and sent home. Once or twice he was kept in ED overnight and sent home the next day, as there was still no bed available.

8 THE OVER-REPRESENTATION OF PEOPLE WITH A MENTAL ILLNESS IN THE CRIMINAL JUSTICE SYSTEM AND IN CUSTODY

In April 2004 James was arrested after threatening a service station attendant and stealing a packet of cigarettes. He was refused bail and was taken to **Arthur Gorrie Correctional Centre**.

When I was notified of this some two weeks later, I was appalled to see that he was extremely psychotic and immediately advised the authorities at the Centre. A week later nothing had changed and I then wrote to the medical officer to insist that James be seen by a doctor. From a subsequent telephone call to the Centre, I understand there is just one doctor for 700 inmates at this centre, a statistic I find shocking, given the high incidence of mental illness in prisons.

In October 2004 (5 months later) James was **given bail and released**. He was not provided with any medication, nor was I notified, or anyone else that I am aware of. He also had no money, or clothes, or home to go to. As it happened he met up with some friends, who are equally disadvantaged and equally defenceless, who allowed him to 'doss' with them, and Centrelink gave him an advance.

I believe this total lack of concern for the well-being of someone who is ill and vulnerable is a disgraceful indictment of the systems we have put in place. **Where was the referral to Housing, Health etc? Where was the necessary support?**

After his experience in prison, James understandably became further convinced that the police would harm him if they came near him.

9 FAILURE TO MEET THE SPECIAL NEEDS OF GROUPS WITH COMPLEX AND CO-MORBID CONDITIONS AND DRUG AND ALCOHOL DEPENDENCE

Over the next few months there were a few times when I believed James was becoming unwell. On one occasion I rang the hospital to ask if they could send a crisis team to see him, but since he had not requested this they could do nothing.

James had long since lost any contact with the case management team and believed he simply had to make his own way and that no-one could help him. By and large he was coping reasonably well and spoke about his plans for the future.

Shortly before his death James and his partner went to Centrelink to declare their de facto relationship, a brave move especially since they both had their fortnightly payments reduced as a result.

PERSONAL NOTE:

I am unable to comment further with regard to what happened on the night of James' death as an inquest is still to be held. Suffice it to say that I believe there is insufficient and inadequate training given to police regarding how they could or should deal with psychotic behaviours.

Over the years I learned - by trial and error - what was necessary in order for me to deal with James when he was psychotic. I learned how to recognise psychotic behaviour, how to keep calm, and how to calm him. I also understand, both from the staff at IMHS and through the Schizophrenia Fellowship, that "psychosis is psychosis". It is treated in the same way (ie both by one's actions and by medication) regardless of whether it is a result of drug usage or mental illness or both.

If the police service is to continue to be left to deal with the results of an inadequate health service, they need to be given whatever training is needed to help them deal appropriately with people with mental illness.

With the exception of the final, tragic outcome, James's story is not uncommon. It happens every day in our society. Every new day sees people who don't know how to deal with mental illness, who are unable to obtain proper services and who sink into a miasma of despair and disadvantage, when they could so easily be provided the care and encouragement they need. Recovery is so achievable, but is simply out of reach for so many Australians.

Jan Kealton