Submission to the Senate Inquiry into Mental Health Services

Summary of recommendations:

1. Early intervention in psychosis programs and assertive community case management.
2. Improved access to treatment for people with coexisting mental health and substance use disorders.
3. Disability support services in the community, including supported employment programs.
4. Improved availability of support for carers and families, including emotional support and respite care.
5. Improved availability of services in rural and regional areas.
6. Competency training for mental health professionals, particularly psychiatrists, in working with families and recognising the valuable role of families in support their family member
7. Clarification of the role of Federal and State governments in the provision of the mix of services required across the intervention spectrum.

We are the parents of a young man, now aged 25, diagnosed with schizophrenia in 1997, at the age of 17. We reside in NSW, in a rural area. I am a psychologist, currently working within the mental health sector. My husband manages a treatment program for young people with substance use problems. Last year he was awarded a Medal of the Order of Australia, for his work with youth. We both have worked for over 20 years with young people with complex needs, including abuse and neglect and mental health problems.

We are Australian citizens, who had always believed that we live in a country that provides the necessary care and treatment for those who require it in our community. Our experience over the past 8 years as carers for our son, and talking to other family members of people with a mental illness, has shaken our confidence in the health system in Australia. We would like to document some of this experience.

During the first period of his illness from 1997 until May 2001, our son remained at home in our care. During this period, and the 12 months prior to his diagnosis, when he was also very unwell, the level of care and support to him and our family was limited to regular appointments with a private psychiatrist. Our son was compliant with medication, but was not responding adequately to the medication he was receiving. He continued to have psychotic symptoms daily throughout that period. He had a number of suicide attempts. His illness was exacerbated by the daily use of substances, particularly alcohol and cannabis. His condition continued to deteriorate.

Our son's illness had a devastating effect on our whole family. We have two other sons, younger than the one with schizophrenia. We were overwhelmed by the unpredictability and uncontrollability that overtook our family life. We suffered extreme grief, anxiety and distress. Our family became progressively more dysfunctional, as we failed to cope with the circumstances of our son's illness. I personally suffered clinical depression. For many years, I cried constantly and had trouble sleeping.

By May 2000, we were desperate. We had come to the end of our tether. I approached the local mental health service for assistance. For the next year, I was unsuccessful in obtaining the support of that service, despite a brief admission by our son to the local acute mental health unit. In order to access community case management, our son was expected to be motivated to take the initiative to engage with the service. When he didn't appreciate what they might offer him, and wasn't willing to go in to see them, they refused to provide a service. I have likened that expectation to expecting a person in a wheelchair to climb a 20 story building.

We became progressively more distraught during that year. My husband and I were struggling to maintain our employment. We were coming to the opinion that without support we would be forced to separate, with my husband caring for the son with schizophrenia, while I looked after the other children. One of the things that I found particularly distressing was the stigma that I experienced from mental health professionals, who refused to talk to me, and suggested that my son's illness was none of my business. I got the impression that I was seen to be a hindrance or impediment to my son's recovery, rather than a critical part of his care and support network.

In May 2001, following a couple of months of very intensive and desperate efforts to try to get our son admitted to hospital, he burned our family home to the ground. We thought that now maybe something might happen. However, as the local service still refused to admit our son to treatment, the police charged him with malicious damage by arson in an attempt to facilitate his entry into treatment. Even so, the hospital again refused to admit him and sent him to prison. Our son was now 21 years old and had had a chronic and severe mental illness for 5 years with inadequate access to treatment.

We were advised that the only way we would be able to gain our son admission to a non-acute mental health hospital in Sydney was if he had a Forensic Order (found not guilty by reason of mental illness, under the NSW Mental Health Criminal Procedures Act 1990). We understood that this would require him to be in a prison hospital for about 6-9 months before being transferred to the non-acute hospital. With our son’s agreement (as far as he was capable of understanding), we pursued this option, as we believed that he would end up killing himself if he didn’t receive treatment. We were also convinced that we would never be able to get the treatment for him that he needed in any other way.

Our son spent the next 2 years at Long Bay Prison Hospital in Sydney. He was incarcerated in appalling conditions. During all of that time, he was locked for at least 11 hours a day, and often longer, in seclusion in a prison cell and was not allowed by have a TV in his cell. He was frequently hungry, due to the inadequate quantity of food provided. His behaviour throughout that period was exemplary.

Our assertion about his very severe mental condition was vindicated by his slow response to treatment in the hospital, despite the best efforts by the very skilled clinical team at the hospital. It was 21 months before they finally found the right medications for him. Since then, he has continued to progress in treatment.

Finally, in June 2003, our son was transferred to the non-acute hospital, where he currently remains in a cottage ward for young people with dual diagnosis. We have been delighted with his progress to recovery. He is now attending TAFE and visits home on a regular basis. He has a good understanding of his illness and how he needs to look after himself, and no longer uses illicit drugs. Were he not on the Forensic Order, he would certainly have been discharged from hospital many months ago.

The circumstances of his Forensic Order have been an ongoing struggle for all of our family. Every step of progress in his treatment needs to be approved by the NSW Minister for Health. The process is highly politicized, and the minister takes a highly conservative approach in approving transfer and changed leave conditions. We have had to advocate hard for improved conditions for our son. He has now spent 4 years ‘sentenced’ for his crime of failing to be able to access adequate treatment for his mental illness.

Our son has experienced the very best and the very worst of treatment over the period of his illness. We are now seen to be ‘very supportive’ family rather than ‘to blame for the illness’. We are grateful for his recovery, although he continues to have significant levels of disability. Sadly, we are aware that there is research from both Australia and the United States showing the benefit of some evidence based treatment strategies, particularly early intervention strategies, which would have lead to better outcomes for our son and less likelihood of ongoing disability. These approaches would have avoided the gross human rights abuses which he has had to endure, and the extreme trauma to our family. These early intervention strategies could have been provided in the community at a much lower cost than his many years in hospital.

We would have liked early intervention in psychosis and assertive community case management to have been available to our son and our family during the early stages of his illness. We believe he should have been able to access treatment, even though her was also using illicit substances. In addition, we would have liked support to be available to our family, including counselling and emotional support. Families and carers are still unrecognised for their role in mental health treatment. We would appeal for improved training for mental health professionals, especially psychiatrists, about the role of families and skills to support and work with families.

As we contemplate the years ahead, we would like to see community based care and disability support available to our son, as well as respite care for ourselves. Currently, these services are thin on the ground to non-existent for people with a mental illness or psychiatric disability and their carers, particularly in rural areas. The Housing and Accommodation Support Initiative (HASI) model in NSW is a very good model of accommodation support, but requires a very substantial increase in numbers of places, particularly in rural and outer metropolitan areas.

We believe that the demarcation of roles between the Federal government and the States has contributed greatly to our experience of mental health services. Even now, as the NSW state government finally acknowledges the inadequacy of services, they seem to be putting the great bulk of resources into acute inpatient hospital beds. This effort will largely be a waste of money, while people continue to be discharged into the community, still very unwell, and with virtually no support for themselves or their carers. We believe that there is no recognition by governments of the level of disability that people with a mental illness experience, especially those with chronic schizophrenia, and the burden on their carers. The disability support services and respite care available to people with other types of disabilities and their carers, should be as equitably available and accessible to people with psychiatric disabilities and their carers. These services should be delivered in ways which are appropriate to the particular needs of those with psychiatric disability.

Finally, we would like to say that our experience can only be described as disgraceful. Our family has been shattered. Thankfully, we and our son are still alive. We are an articulate family, who have ultimately been able to advocate for the services our son required. Most people do not have the understanding of the system or the communication skills to be able to fight for treatment in the way we have. Nor should they have to! As we look around us at the suffering of many others we know, we appeal to you to use this opportunity to bring about the necessary reforms to ensure that Australia can be proud of its treatment of people with a mental illness and their families.