Thank you for the opportunity to contribute to the Productivity Commission Disability Care and Support Public Inquiry.

I don't think I am qualified to address all of the questions in the issue paper published by the Commission. If I tried I think I would fail spectacularly, instead I will write what I know, my experience of disability and recovery and the supports that I have received and those that were not available to me and my family but that may have made a difference to my experience of mental illness and to my journey of recovery had they been available. This is my contribution.

My experience as a person with a mental illness and the system that supports me:

I was first diagnosed with a mental illness when I was 18 I am now 31. I consider myself fortunate to have insight into my illness and understand that not everyone has this experience of mental illness. Over time I and my family have through necessity become experts at navigating the mental health system and the social security system. I have experienced health care and support both in the public and private sector. My experience and what I have watched others experience in the public mental health system has been about people being 'done to', people having their dignity and respect stripped from them at the very time they need compassion, to be treated as people and shown dignity. Some consumers refuse to use the word consumer feeling that instead they have survived a system of psychiatry. After recently reading the story of Anne Deveson and her son Jonathon in "Tell me I'm here" I was reminded of how often the system fails people with a mental illness and their families and how both individuals and their families are survivors. I often wonder if individuals would still consider themselves survivors (and let me borrow someone else's words here in the disability sector) 'if a scaffolding of supports had been built around them'. When I think about these supports I often imagine a nest of tightly woven twigs and branches with no gaps the sort a mother bird might build for her babies.

My first experience of psychosis ended in my first hospital admission which was extremely traumatic. I was hospitalised for about 3 weeks in which time I received a diagnosis and medications to stabilise my mood. Although follow up outpatient appointments were made I found the experience of having to be admitted to hospital was the most traumatic experience of my life. I was not the only one traumatised, my family were also traumatised both by my unusual behaviour and trying to 'come to terms' with someone they love having a mental illness. They were never offered any support and each family member dealt with my illness in different ways. This placed enormous stress on my family, how does a father come to terms that he is helpless to fix this for his daughter to make the pain go away?

After each brief hospitalisation I was discharged into the care of my family. After having been placed in such an unusual environment as a psychiatric institution, I found it extremely difficult to re-orient myself back into everyday life. I received no support at first to do so. It took three hospital admissions before I was considered for a case manager, (I had a family and the hospital system held the view that case managers were only for people who had little or no family supports readily available to them), a lady who was an OT who tried to provide support. I was not yet ready however to come to terms with my illness and the baggage of stigma associated with mental illness.

Each time after a hospitalisation I threw myself back into work wanting life to get back to normal so to speak as quickly as possible. Each time I would crash and become unwell again. My family and I decided that we would see if I was eligible for social security support. My mum came with me to Centrelink to see if I could receive support from the government in the form of job assistance or a disability pension. We were offered the advice you are not unwell enough to apply for a disability support pension, you wouldn't receive one if you applied, you should not apply. We went home disheartened, wondering what support I could receive. I decided not to give up and made an appointment with the disability officer at the Centrelink office some time later. She was extremely helpful and assisted us with filling out the forms and gaining the necessary documentation from psychiatrists, psychologists and doctors to see if I was eligible for financial support.

I received support in the form of a disability support pension which still supports me even now years later albeit at a reduced level (worked out based on my fortnightly income). What has the pension allowed me to do? Receiving the pension has allowed me to study part-time at university and gain a bachelors degree, which has led to me gaining part-time work which I have now held for nearly three years. This financial support took pressure off me to try to work, manage my illness, manage my studies, etc. I think it is important to realise that this entitlement has contributed significantly to the stability of all aspects of my life and reduced the stress that can contribute to and exacerbate anxiety and depression.

I have also received support under the Medicare scheme from Occupational Therapists and psychologists where required, although this was piecemeal never offered without a long wait list in the public system.

Thoughts for a future system of support:

I envision a system that is respectful and based on need not my disability. I have found that I am the expert in my own recovery and understand my needs best. It has taken a very long time to find a psychiatrist who shares this core belief with me and works with me and not against me to ensure that we work together to minimise the impact of my illness on my everyday life.

What do I think would have made a difference for myself and my family:

- In my experience, when people with disability are in charge of their recovery whether that be through designing a support plan and working through that plan of recovery over time together with a so called expert whether that be a psychiatrist, psychologist or occupational therapist, they can commence the journey of owning their recovery and not until.
- Continuity of support – without the support of a psychiatrist who has come to know me the person as well as my mental health needs and mental illness and how that interacts with my everyday life I would not be where I am now. I cannot express enough how the continuity of medical and professional support benefits me, after all how many of us have a family GP and dentist who know us and our families well and are not making decisions about our health based on meeting us for the first time.
- Support for the family who supported me. My family would have benefited from a range of family supports. Supports such as family therapy, practical support to take me to appointments and pick me up, a navigator to help us as a family to navigate the hospital setting and home life. (I have a large family and everything was focused on me when I became unwell which meant less time for the needs of my brothers and sisters. They also suffered while I was in hospital and post-hospital).
- Co-ordinated and responsive support in the community post hospitalisation. My family and I have always felt that I would have benefited from the support of a psychology. Since the introduction to Medicare of 6 appointments a year for psychology or occupational therapist sessions, I have received both psychology and occupational therapist support not received in the public system due

to long waiting lists for both professionals. These supports have been invaluable in assisting me to become job ready and to teach me strategies and skills to manage anxiety and everyday living skills.

- Being able to choose your health professional is something most of us expect, and for me having a psychiatrist that knows me and my illness well is important. Under the public system I had a different psychiatrist appointed every six months. Of these 6 or so psychiatrists that came into and went out of my life like a revolving door, only one read my entire patient file. Many I'm sure had good intentions but lacked the time to really provide the necessary long term support required to assist in stabilising my moods.
- Peer support and mentoring – when I was first diagnosed I looked to identify with people who understood what I was going through, people with an experience of mental illness. I think something that would have really assisted me post hospitalisation would have been a really good peer mentor a person who could understand and identify with my experience and could give me hope to know that I would always be in this awful space inside my head, to help me understand that the stigma and re-building of relationships with family and friends are possible. To sometimes just stand beside me as someone who has also been there before, strengthening me. I have since found this through friendships with peers and natural relationships, but it was not something on offer at the time I was first hospitalised, I remember looking for it and only found ARAFMI (an association of relatives and friends of people experiencing mental illness).
- Employers who make workplace accommodations for mental illness should be encouraged and supported. I have found an employer who is very supportive of my needs. I am able to freely express my needs and feel that I am listened to and they will be taken into consideration in the workplace. Considerations such as starting later in the morning, and the flexibility to be able to have an extended period of time off without the threat of losing my job, if I have a particularly bad episode of mania or depression. This contributes to feeling nurtured and well supported in the workplace.
- Having someone to assist us to navigate the social security system and hospital system over the long term would have also assisted me. As my hospital appointed Case Manager assisted me for a 6 -12 month period of time, I would have benefited from longer term support. A person who is on a journey of recovery is not going to be ready to find a house, fill out social security systems, attend courses, become job ready and learn new skills in managing their illness all in the space of 6 – 12 months. This support needs to provided as and when the person is ready not the system.

I look forward to reading and thinking about submissions that are received by the Productivity Commission and the personal statements made by individuals with disability. I have hope that Australia will work very hard to create a flexible, creative, dynamic service system that responds to the needs of people with disability no matter how or when they encounter it.