

Good morning,

My eldest child is 33 years old. He has suffered from chronic mental health problems (he has been diagnosed with schizophrenia) since he was 16. I feel an urgent need to express my frustrations surrounding the entire Mental Health system and what appears to be a non-existent NDIS scheme and how I feel the system has been negligent in ensuring his needs are being met. His story is a very long and difficult ongoing journey and I would have to write a book to express the entirety of it but I hope I can shed some light on how I feel the ACT Government, along with the NDIS, could improve on the services provided to those people who suffer from Mental health / psychological issues.

I feel like I am always having to fight and battle to gain the assistance he needs to live a happy and healthy life. I think it's great that these days people with conditions such as his can live independently. For this to be truly successful though, much more thought and compassion needs to come from the Mental Health Services that have been, at times, non-existent when he has needed them the most. He has tried living in shared accommodation many years ago but he found it difficult to adjust to that way of living and has since only wanted to live on his own unless he was living with his family. Sadly, aspects of the illness he suffers from have made it very difficult for us to live with him for long periods of time. This is partly due to his condition and partly due to the Mental Health services he has received over the years, or lack of!

A recent example of the lack of services he has received occurred late last year. I had written a letter to the Minister for Housing earlier in the year as a last ditch effort to find somewhere safe and stable for him to live, something no parent or carer should have to do as it should be automatic for vulnerable people like him to be offered suitable housing. After around 6 months he was finally placed on the Priority Housing list and immediately was offered a lovely unit in Dunlop in late November. Around the same time he was transitioning onto a new medication (I have no idea why as he was coping very well on the medication he was taking previous to this - I felt like he was just being used as a guinea pig to be honest) and although he was very excited and happy to finally have a place he could call home, these changes all at once caused him to become unstable. This happened just prior to Christmas and when I tried to call Belconnen Mental Health to discuss his situation they said he was still being looked after by Gungahlin Mental Health. I was then transferred over to Gungahlin Mental Health and was told by the receptionist there that they were no longer looking after him as he had been transferred over to Belconnen! How can this happen? After a few days I received a call from a really understanding and compassionate Case Officer from the Belconnen team who was going to become his new case worker from what I could tell. I finally felt like someone understood my frustrations by showing empathy and fully understanding where I was coming from. I tried to call her back the following week to be told she had suddenly left. Once again, I was left feeling like no one really cares about my son, especially when he really needs services to provide him with assistance and support. I am so frustrated to find there are still massive communication problems between the different mental health and related services in general - a silo system of separated services will never work. There needs to be much greater unification, empathy, compassion and sharing of information so each of the service providers are on the same page and know exactly what they need to do to effectively help people suffering these illnesses.

Sadly, due to little to no services being in place when he moved into his new home, his health rapidly declined and he was taken to hospital twice within weeks and unfortunately for us all he was there over the Christmas period. During a lunch break while at work one day I returned a call from a 'Social worker' from the Canberra Hospital Mental Health ward to try to organise a meeting with her to discuss his situation and when expressing my frustrations about the lack of services I was told I would be offended by her if I tried to explain issues with the services provided and was told that nothing would change and that in the past she had dealt with a 90 year old women who was still writing letters to the Government to try and help her relative. I was so shocked and disgusted to hear this. It just seems that all around hardly anyone truly really cares or has any fight in them to change the way things are. I feel so sick when all the positive news the government wants to talk about these days is how well they are doing financially. What has happened to human decency and community first. We are real people with feelings out here, many of whom are struggling with all kinds of difficult and straining situations, mentally, emotionally, financially, etc. Why has everything become so money focused?

I just want to be his Mum, to be there to support and love him as do his two sisters. We are not trained in how to deal with and manage the illness itself apart from what we have been forced to learn over the years due to no one else being there to help him.

I also must mention that hiring Contractors who constantly come and go is definitely not the answer to successfully managing and assisting those suffering chronic mental health illnesses. He needs to build a rapport with people who help him as he finds it difficult in any social situation. He currently has one person who goes to see him once a week for a few hours but this just isn't enough.

I have not seen any evidence of my son receiving appropriate service from the NDIS. He has said he is receiving a certain amount of money from the scheme but where is the actual physical support such as maybe a house cleaner or someone to help him with his yard work. I try and help as much as I can but there is only so much I can do when trying to hold down a full time job, take care of my own home, help my elderly Mum as much as I can along with wanting to still be available as a good Mum to my two other children.

Hopefully I will never be placed in this position again where I have to write yet another letter to gain the critical supports he needs and deserves. He is a vulnerable person who deserves to live just as happy a life as the next person. People with these horrible conditions go through enough every single day of their lives and sadly many don't possess the resources to enable them to fight for their own rights.

My request is for the ACT Government and the NDIS to really look at the Mental Health Services currently provided, right down to ensuring the right kind of people are employed in this field, even possibly hiring people who have first hand experience with mental health experiences so they can really get close to and understand those they are assisting and give them a sense of security and being cared for and supported.

I know this letter isn't completely aimed at the NDIS scheme as requested and I do apologise for its length, however, mental health is a difficult and complicated subject and I need to express my thoughts and feelings as much as I can due to a desire to help all suffering such chronic and life changing illnesses. There are many much worse off than my son who have no one to back them up and speak out for them so I feel it's important for someone to speak out to try and help them all.

Kind regards,

Exhausted parent