

Letter re NDIS

I am the mother of a 28 year old son with Borderline Personality Disorder and Bipolar Disorder. He has attempted suicide several times and experiences periods of being extremely unwell where he is unable to get out of bed, sleep, organise his life appointments, feed himself and generally he does not have any social interactions apart from myself most of the time.

I have been caring for my son since he was 12 years old and more so 15 years old when he became severely depressed and suicidal.

He has been on a Disability Support Pension for around 5 years and this has been a life saver for him and for me.

He has also been allocated NDIS funding for the past 2 ½ years. My experience trying to assist him to navigate and manage his NDIS Plan has been horrific I have to say and I want to put it into words.

I am a health professional and have worked in health for 30 years and I know a good system from a severely faulty one. An overview of my experience trying to help my son is given below:

During the first year of the plan we engaged a company as coordinator (Wellways) – the only service organised for my son was a weekly cleaner visit. While he did benefit a lot from this service, he asked consistently, and I requested on his behalf, for someone to visit to help him with transport to appointments, social engagement, help in managing his daily living – this was a service WW did not provide and even though a coordinator is supposed to source this from outside their own organisation, they do not like to and this did not happen for the whole year that my son was under their coordination.

Year 2 (2018-2019) we changed to another coordinator – Mindworks – same issue that the coordination money has been used up (in 6 months the total for the year) and the only service provided was one person visiting to take my son to a coffee meeting every few weeks that was arranged by this organisation. They were repeatedly asked to arrange a cleaner and domestic help, transport help etc. and did not arrange this so after 4 months of repeated phone calls and emails at the end of 2018, I stopped coordination with them and I am currently trying to find a coordinator who would actually provide the services my son wants and asks for. Organisations do not even ring me back, or just tell me they cannot help because the funds for coordination have been used up. The new plan is not meant to be submitted until after June so why does the years coordination funding run out 6 months into the year?

He has also had his case closed by the [REDACTED] Mental Health team in January this year due to ... not sure really. He did not agree with his case worker that all he needed to do was follow the day plan she had written for him and all would be well. I argued that when he is unwell he is not able to follow plans like this and this is when he needs the case management most, but this is when the CHS chose to close his case.

Therefore I am again managing my son myself and I work at [REDACTED] 9 days a fortnight and am looking at having to reduce my days there just to have enough time to make the phone calls to try and get someone to provide the services to my son that he wants and needs. His funding is unused for actual services, all the coordination and financial mediation money may be gone but they have not provided the services he needs – something wrong there!

I still do not know how to use the "Portal" that they say is 'easy' to use because you need ++ time to work it out and the password expires after 24 hours if you don't access it!! This has happened twice to me.

What it needs from my perspective:

Coordination money needs to be much greater to allow for actual case management otherwise who does this?

Service providers need to be clearly listed **for the local area** (ie. not available at all for Geelong) and information given to the NDIS participant or carer or organisations that do the coordination. Where is the local list of NDIS providers?

Each carer and / or participant needs a thorough introduction meeting to learn how to use the Portal when they start a plan. The Local Area Coordinators could do this but are there enough coordinators employed? Are there enough NDIS staff employed to help participants?

The assumption is that people who have NDIS funding can manage this themselves. People with mental illness cannot manage this. I would argue no-one, even with a PHD in education, can manage this in a reasonable amount of time. Carers are also working and the system needs to be much more user friendly.

I doubt that NDIS can work at all as the theory is flawed. How can an organisation employ enough workers to provide enough services for all the potential participants, if they don't know how many participants they will have and this is where their income comes from? It seems there are nowhere near enough service providers in Geelong.

Also service providers that are on the lists eg. [REDACTED] are almost all very low levels of training, particularly in mental health. How can these people help the participant with mental illness without training? Very unsafe for participants and service providers. Actual mental health professionals do not provide services through NDIS as, I guess, the organisations cannot work with this system?

I am afraid I have to say go back to the old system where we had organisations like [REDACTED] for example. [REDACTED] had to close down when NDIS came in. With the old ways for mental health support, the client was referred to the organisation and the organisation provided case management from mental health trained workers and organised or linked in the participants with whatever programs and services were required to help them to get well. There seems to be a complete lack of organisations who are able to do this now. I have tried everyone around [REDACTED] and I am exhausted and losing hope.

It is no wonder the NDIS funding is \$4 Billion underspent! It is too hard to access appropriate and safe supports for the participants. NDIS needs a major overhaul or get rid of it and go back to the old ways. I supported the original idea that the participant could chose their providers rather than the funding going direct to organisations, but there are so many flaws in the current system that participants can't have choice about anything and are completely missing out on any supports at all.

Hoping though that someone in the system may be brave enough to try to fix it before it is too late for the people with mental illness in the Geelong region.

[REDACTED] [REDACTED]