

My name is Debra and listed below is some feedback on the NDIS and my experiences navigating the plan reviews, accessing services, and working with providers, on behalf of my son Billy.

Billy has severe complex needs. He requires high level support in all daily tasks which I am responsible for just over 70% of Billy's care. The remaining time he is supported by his support worker Haylee and since finishing school last year, attends a day program with Advanced Disability. My daughter, Sienna is also significantly involved in Billy's care needs.

Billy is 19 yrs old, therefore working towards developing some independence for Billy is extremely important.

Billy has several disabilities that impact him profoundly and overlap. Billy's diagnosis are:

- Craniosynostosis
- Hydrocephalus
- Severe ID
- Level 3 Autism
- Sensory Processing Disorder

Additionally, Billy has diagnosis of:

- Choanal Atresia
- Underdeveloped left eye
- Blocked Tear ducts
- Narrow Jaw (dental issues)
- Ridged palette
- Patella Ulta (left knee)
- Hip Dysplasia
- Knee contractor
- External Tibial Torsion (right leg)

Due to Billy's extensive medical history, he is completely dependent on his current support network, as described above, for high levels of support for all daily living activities, his safety and care, and accessing the community.

I have had mostly satisfactory experiences with the NDIS. This year was a little different. This is Billy's first year out of high school. This is something I believe the NDIS should understand. I have listed below in bullet points things you may consider:

- First year after leaving high school for people who are unable to work or stay at home independently, should be managed by a specialist team, as funding will likely significantly increase if informal carers are employed or unable to provide care during the times the NDIS participant would have been at school.
- Better training for NDIS employees. They seem to be either told to focus on the amount rather than supports. I had a NDIS employee call me in response to a plan review as I felt the plan was not in line with Billy's goals and the first words she spoke was, "you are asking for a lot".
- Self-managed plans should be governed better. The only management from the NDIS regarding self-managed plans is random audits. Many people are making purchases that are not in accordance with reasonable and necessary or value for money. They can do this as there is no governing of this group.
- Providers almost always change the maximum up to the cap when the service does not give the perceived value.
- Providers are taking advantage of packages by charging excessive amounts of money for cancellations even when a person becomes ill. There is no way to predict illness and therefore cancellation shouldn't be charged.

- Support coordinators should be accountable to a governing body. Many support coordinators are falling short in providing a value for money service.
- Providers should be required to be trained with a minimum qualification around disability support or trained in their role to provide the service. This would eliminate people who have decided to take a piece of the money pie by starting a support worker business with no qualifications.
- Disability or impairment should be limited to participants that have lifelong conditions due to self-inflicted lifestyle choices such as drugs and alcohol abuse.
- In person NDIS plan reviews should be made available as I believe the plan reviews are far too open for interpretation by the planning person.
- Parts of each plan should be means tested. This means if a person has significant financial security, they may be able to purchase certain supports themselves rather than have the NDIS pay for everything and everyone.
- During the plan reviews, NDIS should consider other reports as evidence as school networks, day programs and other non-allied health professionals often know the participant well and add a lot of value.