

To Whom It May Concern:

I'm not sure if what I have to say actually addresses any of the Terms of Reference but I would like to make a comment in regards to the NDIS and the process of application.

My son has a very rare genetic muscle disease. There is no actual treatment and no cure. The best that can be done is exercise and diet modifications. He has constant muscle weakness and pain all the time - there is never a moment when he is not in pain. For many years I was his unofficial carer but as I have aged, I have had some major health issues and so we decided in 2023, to make an application for NDIS.

We gathered as much "evidence" as we could from specialists that we'd seen when he was first diagnosed, as well as his GP, his psychologist, and a geneticist and submitted it all. That application was rejected on the basis that "all available treatment options to relieve or cure your impairment have not been explored." When I spoke to someone at NDIS it was also very obvious that they had never heard of Glycogen Storage Diseases and it clearly did not fit any of their drop down boxes, but I was told that this decision was based on the secondary disability that we listed which was anxiety.

In 2024 we tried again, this time with extra "evidence" from an exercise physiologist as well as some of the evidence from the previous application. This time we did not list any other disabilities, just his Glycogen Storage Disease. Another rejection, but the person who made the decision had applied the new evidence to the old application! When we tried to explain that, they did a review and but it was rejected again with a comment that my son had not done enough to cure his incurable degenerative genetic muscle disease.

I also found out that when you make a subsequent application - all of the details from the first rejected application are taken into consideration - I would like to know why that happens? Why do you not just start completely fresh with a whole new application - even the file number is used again - so no matter what you submit, whoever makes these decisions just goes back to why there was a rejection in the first place.

And I would also like to know whether the people making the decisions are actually medical people - or are they insurance people? They should have medical knowledge.

I am sure there must be more stories like ours, my son is preparing to try again, but is not hopeful of getting any other result.