

Hon Kevin Andrews MP
Chair of Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6022
House of Representatives
Parliament House
Canberra ACT 2600

11th October 2019

Dear Mr Andrews,

My 36 year old son was a client of the National Disability Insurance Scheme. He had schizophrenia. He committed suicide in July 2019. The introduction of the NDIS contributed to this.

While the NDIS is a great initiative for people with disabilities, it has had mental health tacked on, and frankly that is not fit for purpose.

This is not a complaint – it is of course too late for that. Hopefully feedback should enable support services for people with mental illness through NDIS to become effective, as promised.

My son was being seen by a psychiatrist for about ten years. Prior to the NDIS my son also received mental health support services from organisations like Mission Australia. He was seen by some wonderful qualified professionals whom he met regularly, they were in a position to understand him and his condition and they provided considerable help to him. With the introduction of the NDIS, these services all had to be withdrawn and to be replaced by NDIS where nothing was actually in place for him.

My son had an NDIS plan set by a delegate who had no knowledge or experience with mental health issues, his plan funding was fine, but it was heavily skewed to “Increased social or community participation” (85%) for services that can cost around \$40 to \$60 per hour from a list of a handful of items. The balance was for “Improved daily living” with the majority of the services available also limited to around \$60 per hour. That is to say, these services would exclude individual professional help. His “go to” person was now a services coordinator, an administrator. As you can image this was disastrous. He became very dejected.

For a client with a physical disability the services coordinator role makes sense, they would ask the client what services they required, and organise them, such as a new wheelchair, modifications to a bathroom, and someone to take them to the supermarket.

The services coordinator asked my son what services he wanted. He said dancing lessons, among other things. All of his requests were rejected. I asked for psychological help for him, which was also rejected, as it was “mainstream”. So nothing happened, except he became more dejected. He had high hopes of the NDIS and was very excited when he was accepted onto the scheme.

A methodology where an administrator asks a client with severe mental health issues what services he wants, when the client is in no position to understand his condition, let alone what he needs, and his requests are then rejected by his Capacity Building Choice and Control provider because they are not on the list, is not a system that is likely to help anyone with mental illness.

After eight months of his plan, NDIS had arranged for an unqualified outreach worker to see my son a couple of times a week for a coffee or a walk, and just recently a cleaner to help him with his flat, as he'd lost the ability to look after himself. These were fine, but hardly enough. We did eventually get the NDIS Capacity Building Choice and Control provider to agree to pay for a gestalt therapist that we had previously engaged privately before the NDIS.

My son's new service coordinator, an intelligent, dedicated and resourceful person, but in an administrative role, was going beyond his duty and trying to "work the system" to provide additional services for my son when he died.

My son spent many hours on the phone to the NDIS to try to determine what services he could get and which he could not. For example, could he attend a seminar, or meditation? He was repeatedly given conflicting advice by NDIS staff, or advice that was then rejected by his Capacity Building Choice and Control provider. This frustration increased his disenchantment with the NDIS. A friend of mine's daughter recently started working for the NDIS and advised that virtually everyone in her office was on a twelve month contract like her. So lack of expertise and knowledge by NDIS staff is hardly surprising.

In my opinion, and what I had said to NDIS on numerous occasions, my son needed to work with a qualified person, probably a psychologist or a professional such as he had previously seen, to develop a plan, with objectives and strategies to enable him to live better with his condition, and then to engage with services to help him achieve his objectives. This role would be, in effect, a case-manager, who would provide the "business case" for those services. Such a role does not exist within the NDIS structure I was advised.

My son had extreme anxiety when with people and in crowds. So possibly dancing lessons could have been an excellent way for him to meet with people he did not know in a safe and controlled environment, to enable him to reduce this anxiety. But understandably there would need to be a justification for such a service, from the case-manager.

I would have thought that a structured approach like this would be appropriate for many people with mental illness. But this is not done in NDIS it seems.

My comments above relate to the NDIS system and the processes, based on my observations of my son's experiences. Some of the people that he dealt with were kind, considerate people; some did far more for him than they were supposed to do. I thank these people from the bottom of my heart for their help. Nonetheless, the National Disability Insurance Scheme failed my son catastrophically.

Yours faithfully,