**6th July. 2024.**

**Joint Standing Committee on The National Disability Insurance Scheme.**

**General Issues - Annual Report Number 2 of the 47th Parliament**

Dear Committee Members,

I write to give you an idea of the depth of concern we have as Parents and Carers for our NDIS Participant, in regards to possible changes being discussed as a result of the NDIS Review.

We Self-Manage The NDIS Plan on our Participant's behalf and have done so since 2016. We also hire our own high quality staff, both who are UnRegistered Providers, although one is Registered with their Professional Association.

Our Participant, until very recently was also using a Registered Provider and had done so for 15 years but we removed our Participant because he was no longer achieving anything in that Placement and quite frankly they were only going through the motions.

**Overview of our Family Situation and Participant.**

Our Participant is a 34 year old male and is a much loved and valued family member and it is our intention to honor and support his wish to remain in our family home for as long as we are able to.
Our Participant requires daily support. He has a diagnosis of Intellectual Disability, Autism, Severe Anxiety, Depression, Impulse Control Disorder and a rare genetic disorder called Cowden's Syndrome.

We take responsibility for many everyday tasks such as helping him to shower, helping him with his oral hygiene, and food preparation and helping him with money management . We also need to ensure he is dressed in an appropriate manner, monitor his medication that has been prescribed by both his Psychiatrist and G.P. We also try to manage our Participant's behavior by following his Behaviour Support Plan. Our Participant's behavior can quite often be inflexible, particularly when he can't get what he wants immediately and there have been previous incidents of violent outbursts both at his Day Service and at home directed mostly at his mother.

Both Parents have serious health issues which often severely impede our capacity to support our Participant at times. His Mother has had major heart surgery and needs a hip replacement and has problems with osteoarthritis. She also has a Brain Tumor which affects her balance which is why she uses a walking frame. His Mother also has Cowden's Syndrome and has previous bouts of cancer. His mother also has been diagnosed with Epilepsy due to her Brain Tumor.
It has recently been discovered after an MRI that the Brain Tumor is actually starting to increase in size so His mother is facing probable Brain Surgery.

His Father has had a three level spinal fusion which required a major surgical Procedure. He also requires both hips to be replaced, and suffers from osteoarthritis. His Father also has a serious Heart condition as well as Diabetes and significant depression. There also have been investigations by a neurologist that have determined that his Father has also developed Parkinson’s Disease.
These days, he depends on prescribed medications for substantial pain relief. With the help of this medication, he is able to walk short distances.

It should also be noted that His Mother is actually the Primary Carer for both her husband as well as the Participant.

**Concerns**

We have finally found quality supports after 8 years of trying for our son and these supports are starting to make a difference.

As previously mentioned, we are Self-Managers and we have hired our own staff. Both are unregistered providers although one is registered with their professional association and the other is a highly qualified disability support worker of over 20 years duration.

We are very much aware of the fact that it is our Responsibility to ensure funds are spent correctly and appropriately and as Self- Managers we have done just that over the 8 years our son has been on the scheme.

We are very concerned that we will be forced to use only registered providers by the NDIS thus losing the quality people we have and losing any hard won gains we have made for our son. Our current providers are Sole Providers and have both said that due to the complicated and costly procedures they will not sign up to be Registered Providers.

If that were to happen that is the removal of Choice and Control that the Participant currently has and from memory was one of the building blocks of the NDIS.

It is also taking out Quality Staff from the Disability System should this occur.

Another concern is upon looking at this Review Report it appears that Participants could lose their rights to Reasonable and Necessary Support as it is stated in the NDIS Act.

This looks to me as the Government cutting people with Disabilities out when it comes to being the decision maker about how they wish to live their lives.

As Dougie Herd so eloquently put it when he appeared before the Joint Standing Committee on Independent Assessments if it's Reasonable and it's Necessary then Fund It! If Support is Reasonable and Necessary in order for Participants to be part of their community and live life on their own terms then Fund It!. If supports are Reasonable and Necessary to enable Participants to gain skills needed to help them to gain possible supported employment then Fund It! They may well be paying taxes in future.

Speaking of Assessments, the Review Report proposes that Participants may be forced to undergo Assessments to prove their needs. We have been down this road before with the Previous Government and "Independent Assessments" At this point we have no idea how these assessments will be used nor the type of Assessment tools that they plan on using.

When is the Government and NDIS going to understand that People with Disabilities are different, have different needs even if they have the same disabilities and they should not be put in a box just to please some bean counter.

People could be pushed off the NDIS and left with NO support until the States get it together and establish the “Foundational” support systems as recommended by the NDIS Review Report. How is the Government going to ensure that these proposed supports are of a quality standard and the State Governments are not going to use a piecemeal approach to these supports?

Another major concern upon reading this Review Report, is that it will be much harder or near impossible to appeal a totally inadequate plan. How is that fair and evenhanded? There is an easy fix for that, make sure all Participants/Nominees/Carers have the opportunity to check the written plan before it is signed off by a Delegate.

Another major concern is that Co-Design does not appear to be written into the Legislation. How can that be? Is this the view that we the Government will decide how things will be done and going back to the bad old days?

The NDIS was about Participants giving them the right to decide for themselves what they want to do with their lives and how they want to live; that is where Co-Design can and must come in.

**What we would like to see from the Committee**

1. To ensure that people who Self-Manage their own or a Participant’s plan will still have the ability to use either UnRegistered or Registered Providers. Thus, maintaining their ability to maintain their Choice and Control of their lives which is actually their right. They have the right to choose who they want to interact with and who they let into their home and lives. Additionally, as a Carer of a Participant who lives at home,

Mandatory use of only Registered Providers will also be taking away my rights as to who I let into my home and who I have to deal with.

2. Build up Participants/Carers ability to Self-Manage their Plan. Fund Capacity Building Programs that can guide them to manage their Plans in an appropriate manner and so they can recognise dodgy providers of services.
3. Put people with Disabilities, their families/Carers at the forefront of the decision making process instead of talking at us start talking to **ALL** of us. If we have a process where we can work together, we may be able to get the NDIS on track.
4. Make it easier and cost effective for Providers especially Sole Providers to become Registered Providers.

While we fully agree that the Government has to crack down on dodgy Providers, something the Quality and Safeguards Commission is failing to do.

What we cannot and will not support is the Government and the NDIS taking away the rights of people like our Son who just wants a good life to learn and be part of their community.

Thank you for your time,

Yours Sincerely,