Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100 Parliament House
Canberra ACT 2600

Re: NDIS General Issues Enquiry

## **Summary:**

This submission outlines my experience in dealing with the NDIS on behalf of my grandson and in my role as a Volunteer at the Casey North Crisis and Information Support Service.

- Lack of information and support for new participants
- Unqualified Support Workers
- Too easy for Support Workers to register with providers (insufficient "vetting" of qualifications)
- Plan Managers able to approve invoices without confirming service provided.
- Concerns for clients when family support no longer available (due to age, illness, etc)

Good afternoon, thank you for the opportunity to address the Committee.

I am here today, not as a professional, or representing any organisation with a vested interest in receiving revenue from the NDIS but as a grandmother who wants safety and security for my 23-year-old grandson, who I have been supporting since his mother died 2.5 years ago. He has been diagnosed with high functioning autism, ADHD, Anxiety, he has Erb's (Brachial plexus) Palsy in his left shoulder and an eating disorder.

My grandson has been receiving support from the NDIS for approx. 2 years, my biggest shock when we started on this journey was that we were given a plan, which initially I thought was a large amount of funds, until I became aware of the rates charged by Support Workers and was basically told to "go spend it".

I had no idea where to start and was told by the Local Area Co-Ordinator that he was unable to make any recommendations, as it could be seen as a "conflict of interest". He did direct me to a list of providers. It soon became obvious that some of the "major" providers require limited or no qualifications from their workers. Workers profiles openly state "need to make some additional money". I was able to draw on the experiences of a friend who has a lot of experience with NDIS who was able to assist me, not everyone has this support. A recent question on a Facebook Page asked the following question "Hi, could anyone please tell me what you can get to use the consumables part of funding? I only just noticed it and have no idea what we could use it on. Thanks." How does this happen? Is NDIS just handing out money without supporting information?

I would love to see all initial Plans include the provision of a "Support Coordinator/Advisor" (or similar) for a minimum of six (6) weeks to assist in navigating the complex and very important area of choosing support workers.

I volunteer at a Community Crisis Centre and the number of parents (particularly single mothers) who are trying to cope with children/family members who have been either refused NDIS or who are receiving insufficient funding is heart breaking. I interviewed a young single mother the other day who obviously has a cognitive disability (which impacts her ability to keep a job) and she "thinks her daughter is autistic" but she cannot afford the specialist fees to get a diagnosis, surely we can do better that this? This is just one example, there must be some way of assisting these extremely vulnerable people to get the support they need and deserve, or has the scheme evolved into "support for the rich"? We are far from "rich" but my daughter always prioritised private health insurance and recognised that C needed assistance from a very early age, this meant he had access to the required specialists and I was able to access the necessary reports to support the NDIS application.

I now find it is a full-time job to monitor and supervise workers who, to my mind, bring very little value to my grandson's life. Taking him shopping and allowing him to buy a kilo of apples when he only needs 3-4 per week, not getting him to check what is in freezer, cupboard before leaving the house. Deciding that the vacuuming in his room doesn't need to be done weekly, just every 2-3 weeks, he needs structure and routine, giving him vague options like this mean it is likely to never get done. These are only examples and small

things, but they are vital in teaching him independence and life skills, and thus (hopefully) reducing his reliance on NDIS.

It seems that some agencies make the "Worker Orientation Module called 'Quality, Safety and You' designed to assist all NDIS workers to better support people with disability" mandatory, however the NDIS Commission website indicates it is optional? Why optional? It was apparently developed to "to promote a safe and skilled workforce within the NDIS. Providing quality supports for people with disability involves not only the right capabilities but also the right attitudes. NDIS providers and the people they engage need to be familiar with the principles underpinning the NDIS, respect the rights of people with disability, aim to prevent harm and respond appropriately if harm occurs"

- After personally completing the module, my belief is it can only improve
  the quality of the Support Workers and the Certificate should be
  mandatory for all Support Workers before they can work in the sector, and
  the need to complete the module may eliminate the "wrongly motivated".
- From what I can see most of the major providers only require a Police
   Check and Working with Children check, which should be mandatory, but
   neither of these attest to the person's ability to provide appropriate
   support to a disabled/special needs person,.

I have read the written submissions made to the Committee and the arguments of registered vs non registered workers, whilst I may not be qualified to join that argument I am surprised that it was not compulsory for workers to be registered with the NDIS as recommended by the NDIA? Again would this requirement eliminate the "wrongly motivated"?

Supposed benefits to not being registered -

- Starting up is quicker and easier = no qualifications needed
- Less costs as there are no licensing or audit fees = encourages inappropriate workers
- Able to work directly with participants (instead of through the NDIA), making it easier to build relationships = I do not see the logic in this statement
- Able to offer more competitive prices as it is not subjected to the NDIS price guide= Never happens in my experience
- One of the largest providers of non-registered workers threatened me
  with a \$5000 penalty after I contacted a couple of their workers but did
  not go ahead and engage any of them but used an alternative provider,
  this threat did not affect me but had it been made to my grandson he
  would have been extremely upset and anxious. Needless to say we have
  never gone near their website since.
- Another provider told me she chooses her workers "on a gut feel"

C has Dual Diplomas in Digital Media Technologies and Digital and Interactive Games. Following the death of his mother, he was lucky enough to find a job in an E-Waste recycling plant (without any Government assistance or funding), I saw this job as a stepping stone into the workplace, after about 9 months I started approaching Disability Employment Services only to find that he was "locked out of the system" because he has a job!! So some of the most vulnerable people in our society are discriminated against and once the "has a job" box is "ticked" they are ignored?? Quoting from the NDIS "recognising people with a disability as "equal and valued members of our society with the same dreams, desires and ambitions to succeed as anyone else" but they are discriminated against in the job arena?

An enquiry regarding this situation submitted to the Hon Bill Shorten and was referred to the Minister for Social Services and the response from the Minister was an insult to my intelligence, it did not respond to my question and referred to "my son" instead of my grandson. I am only mentioning this because thanks to our Support Coordinator we have been able to get NDIS support for my grandson to be mentored and assisted to find a job more suited to his skills. This all just adds to the NDIS costs, and I would think that the DES would be more appropriate to the deliver these services at a cheaper cost.

We chose to work with a Plan Manager, with all claims requiring to be approved by myself prior to payment. In the very early stages, I delayed approving an invoice due to errors the Plan Manager paid the invoice I then found out that invoices not approved within a set period are automatically paid.

Automatic payment by Plan Managers should not be allowed, all invoices should have to be approved by the Participant or their Carer. The Plan Manager has no knowledge of what services have or have not been provided.

I am now 77 my concern is what happens to my grandson when I am no longer able to support him? When my daughter was alive her boys were her life and I owe it to her and my grandson to do everything I possibly can to secure his future. I do not profess to have all the answers I am just asking for the scheme to be "fixed" and operate in accordance with the United Nations Conventions of the Rights of the Persons with a Disability – this states that Persons with a Disability have the same rights as all other people – this includes people have the right to realise their potential, and have access to supports throughout their lives.

To sum up I would like to`see -

- Temporary Support Co-Ordinator to assist in first 6 months of `NDIS
- Training/Registration of Support Workers
- Plan Managers to confirm service prior to paying invoices
- Teamwork between DES and NDIS

Thank you for listening, I would also like to thank the Hon Jason Wood and his staff (particularly Tom Ellis) for also listening to me and their guidance in getting me here today.