## Submission to the NDIS Productivity Commission

I am the mother of a 13 year old boy with Autism and intellectual disability. From the day he was born (12 weeks premature) his many medical problems were diagnosed and addressed to more than satisfactory account. But his disabilities were ignored, brushed over, evaded and simply not dealt with in an appropriate manner. A common theme when I asked about any particular issue was ‘we will have to wait and see’. This approach cost us precious early intervention time. We spent a small fortune of our own money and time taking him to various specialists, speech, physiotherapy, occupational therapy and psychologists trying to get answers and help. Much of this ‘therapy time’ was spent explaining our situation and assessing our son. It took 11 years to get a correct diagnosis. The opportunity to express what I want for our country to progress in disability sectors is very much welcomed. I thank you for this and I apologise for any bitterness in my voice that years of not being listened to has brought about!

- I believe there is desperate need for a centralised hub with regional offices, where carers and patients can be directed as soon as disability is suspected or diagnosed. Each family needs a case manager who can guide people through the maze of options available. ***We are in shock when we are first confronted with disability. We are not thinking clearly. We need clear appropriate guidance to all possible services we may require.***

- Money into research in all areas of disability and mental heath is urgently needed. That’s a no brainer.

- Medical professionals and therapists need constant training in new advances in diagnosis and treatment of disabilities. The lack of knowledge of disability in the medical and educational sectors astounds me. Misinformation and misjudgment is rife. I would expect regular professional development days would be compulsory for all practicing therapists, doctors and teachers. A system of constant updating is imperative. This is particularly important in conditions where diagnosis is increasing, for example: Autism Spectrum Disorder. *No bias shown from this writer of course!*

- Media attention and advertising alerting the general public to the plight of the disabled and their carers is paramount. ***And put a positive spin on it please, we don’t want sympathy, we want action.*** If the political parties can spend money on an election campaign, they can spend money on pushing our cause.

- There is a great need for respite services, sitter services and after school care services for older students. At present these services, if offered at all, are managed by local councils and a few schools and the cost and services offered varies considerably. These services need to be streamlined and greatly expanded AND NOT MEANS TESTED. I’m sorry, but if I work (and I am grateful to have a flexible employer) to afford small extras for my son, I shouldn't be punished for it.

- Help for the Carer families with reasonably priced counseling and access to support groups should be provided. Presently most support groups are organised by carers on an adhoc basis. Counseling in particular is a service most carers probably need but won't ask for; it needs to be available, affordable and discreetly offered.

- For my husband and me our greatest concern is what happens to our child when we can no longer take care of him. Placing him in a nursing home (even if there is one available) is not an acceptable option. More money put into residential homes helping people become independent while looking after them with respect is what we demand of our community. I don't think that is too much to expect.

- Filling out forms regularly to prove my son is disabled is insulting to me and the specialist who diagnosed him, not to mention a huge time waster. Believe me, if it was possible for him to 'recover' from his disability, they would hear me shouting it from Melbourne to Kakadu.

- Disabled people and Carers need respect and we need to have our needs met in the same way we all expect to have our medical needs met through Medicare. This should be a right in a wealthy country such as ours, not a privilege we have to beg for.

- I guess to the outside world, the face of disability is ugly. Take a closer look, it's unique, it's challenging and it's different and yes often it is very ugly. But its purpose is to change world, to make it a better place. Hopefully this is happening now. I would like to say I am happy and comfortable having a son with a disability, but the truth is it is a long difficult depressing road. If the community just eases the burden a small amount, it will make a huge difference to every Carer and disabled persons life.

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