General issues around the implementation and performance of the NDIS Submission 9

Good Morning

I would like to make a submission to the Committee for the General issues around the implementation and performance of the NDIS.

In October 2016 my (then) five year old child was formally diagnosed with Autism Spectrum Disorder. 12 months prior to this I had no suspicions that my son had this condition.

Given South Australia is a trial site for the NDIS, the diagnosis, while upsetting, was tempered with hope that my son could receive early support and with therapy this condition would not impact his life as severely as I feared.

I am now 8 months into the process of getting my son onto the NDIs and have received no funding or assistance from NDIS. To date I feel that NDIS has made our lives worse as I grapple with dealing with the NDIS and the loss of hope that my son will ever receive assistance. All staff I have interacted in with NDIs have been helpful, empathetic and kind. This criticism is not one of them, it is the process that I am critical of.

In October 2016 I lodged my son's claim, I received his eligibility approx. December 2016 and had a planning meeting late January 2017. His planner thanked me for providing a comprehensive and easy to understand submission with therapist's reports. There was no guidance provided on what to take to that meeting. Since then I have had no progress.

I am proactive and have called the 1800 number approximately ten times since March 2017. Through this repeated phone calls I have had my son's plan approved by the central team. It has been referred to my local office to action, this is yet to happen. The plan was approved by central 1/5/17 and, as of 8/6/17, the local office has not approved it. The central team has emailed and phoned the local office (St Mary's) repeatedly and now they advise me to physically visit the local office "make myself a pest and force them into action". When I told them I had some dignity left and couldn't bring myself to this level of begging, the call centre staff (kindly) advised me to "leave my dignity at home and get my son his plan". I did this yesterday. The front desk staff member was kind and helpful and has emailed the appropriate staff member (as they weren't in the office) to get the plan actioned.

To be brutally honest I have no hope of this resulting in any action. I have resigned myself that I will have to visit the office weekly and cry and beg for assistance. I will be embarrassed and ashamed of myself but my son needs help, my family needs help and they deserve better than this. I am ashamed that our country forces people to this level of desperation.

In addition to direct dealings with NDIS I have asked my local MP, the SA Dignity for Disability MP, Autism SA, my son's GP, my son's paediatrician, my son's psychologist, my son's Occupational Therapist and my son's school and to intervene on our behalf with NDIS. This has had no impact. I have lodged a formal complaint with NDIS, this has had no impact.

I feel that I am fighting a war to get my son's NDIS planned actioned.

Already I am dealing with my son's disability and the impact this has on our daily lives and then this pressure has been heaped onto my shoulders. It is difficult, the time and emotional stress is enormous and this is a process being put on vulnerable families.

Is this what you intended for the NDIS? I hope not.

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I am a professional and have skills in report writing and dealing with stakeholders I am finding the NDIs challenging and depressing. It is negatively impacting on me and my family's life. I fear that person's without my skills would find this process even more difficult and challenging. How do you expect a person with a disability to manage this by themselves? I don't think they could. It would not surprise me if this process pushes people to severe anxiety and depression or worse.

I am happy to discuss any of this further with you

Thank you

Catherine Naylor