

19/6/2017

RE: General issues around the implementation and performance of the NDIS

Dear members of the Joint Standing Committee on the National Disability Insurance Scheme,

I appreciate the opportunity to submit information on our experience on the implementation and operation of the NDIS.

My 12-year-old son has Cerebral Palsy, Autism Spectrum Disorder and Cortical Vision Impairment. He is non-verbal, incontinent, has high anxiety, sensory issues and oral aversion. He has a gastrostomy and is fed Nutrini formula via his Peg.

As a family we are educated, professional and capable of dealing with government agencies, however, our experience in dealing with the NDIA for our son's NDIS plan has been a disaster.

We were exceptionally prepared for our initial planning meeting with the NDIA in October 2016. We had prepared extensive information about our son's disabilities (including all the required proof), functional considerations, what is important in his life, family life, extensive goals (including how they can be measured), a typical week in his life and an itemised list of required consumables (nappies, gastrostomy care etc.). Next to each of his goals we identified what we were hoping would be provided by the NDIS to help him meet these goals.

The initial planning meeting was in our home, face to face with an NDIA Planner. Our son was also present (in and out of the room) for the planning meeting so the NDIA Planner had a first hand experience of his extensive needs. The Planning meeting went for 3.75 hours. The NDIA Planner was thorough as he worked through the extensive NDIS questionnaire with us. He took the time to read all of the information we had provided. He indicated we were better prepared than most with the extensive information we provided. He acknowledged the goals we had set and services we had requested were reasonable and necessary and linked to measurable outcomes.

We received our son's first approved NDIS Plan on 13/11/16. The support budgets allocated appeared to be fair to us at the time. The plan did not provide for 100% of what we had asked for, but we thought it was a good start for our son's first plan. We were not satisfied though that Support Coordination has been refused. We requested a review of this decision and received a new approved NDIS Plan with Support Coordination on 7/12/2016. I called the NDIA Planner to ask him about the Support Budgets in our son's plan. I just wanted some clarification as to what services were available from which budget. He was helpful and broke it down for us. Please note we were provided with a Core Supports budget of \$17,197.50, which had an extensive list of what this could be spent on. This is important, as I will refer to it again in the following paragraphs. The NDIA Planner said this Core Supports budget could be used for Consumables and Support Workers to help our son meet his goals.

After logging into the NDIA portal we realised there were major discrepancies in the support budgets between the printed plan we had been provided and the portal version of the supports budget. We began the process of seeking information from the NDIA about having this fixed. We were advised this was an error with the Portal and many people had the same issue. We were advised to complete an online form. After 2 weeks I followed up with the NDIA and was told no one knows where this online form goes and I should go to the NDIS desk at Centrelink. I did this multiple times over the following month. Each time the NDIS person we dealt with was helpful and logged requests into the system. After a month without action they logged a complaint. For the first time we were contacted by a Regional Complaints Officer who was knowledgeable and helpful. Within 3 days the portal issue was fixed. This was on 22/1/17.

After the Portal issues were fixed we began using the budgets provided for in the approved NDIS Plan. Aside from the fact that actually finding and engaging Support Workers was not easy, we were glad to be starting to implement the plan. Things started off okay until invoices for the Support Worker we had engaged were rejected by the NDIA. Fortunately we had been provided with Support Coordination in the second plan (7/12/16) and she began the process of liaising with the NDIA to work through this issue.

It was at this point that the NDIA advised that there was no Support Budget provided to engage any Support Workers for our son. We were told that \$6,500 of the \$17,197.50 Core Support budget was for consumables (nappies etc.) and the remaining \$10,697.50 of this budget was for In Kind Support for the Department of Education and therefore there was zero dollars provided for any Support Workers. Our Support Coordinator instigated a review with the NDIA without our knowledge. She said she did this without talking to us as she knew how distressed we were that our Support Worker (a sole trader) was not being paid and there were outstanding invoices over 90 days old and was still providing services to our son.

As a result of this review we received another new plan on 8/6/17, which included new money - \$7,800 to be used for Support Workers for Social and Community Participation. For our son to achieve his goals (that were considered reasonable and necessary by the NDIA) we would require \$21,300. We have instigated a Review of a Reviewable Decision on 22/6/17. We have been advised this process could take many months.

After receiving the new plan on 8/6/17 I have again been in touch with the Regional Complaints Officer who helped us in December 2016 regarding the Portal issues. My main reason for contacting her was to find out how our Support Worker could get paid the outstanding invoices (approximately \$800) for the work she had already provided our son. This has been through a process with the NDIA and they have advised these invoices can not be paid (ever) due to there not being any funds in the support budget for Support Workers at the time we engaged her. I have asked the NDIA to explain to us how we were supposed to know that this budget wasn't in the approved plan considering the original plan did not specify In Kind Support for the Department of Education for 250 hours of Daily activities totalling \$10,697.50. Not only didn't our plan specify In Kind Support, but the version of the plan provided to our Support Coordinator also did not specify this. The only place this was specified was the NDIA version of the plan. I have also asked what the \$10,697.50 for In Kind Support for the Dept. of Education for 250 hours was supposed to cover. The Regional Complaints Officer has forwarded these requests to the appropriate teams in the NDIA and has advised there will be a written response. It has now been over 3 weeks and still no response. I have received a call from an NDIA person from Vic North on a separate matter (changing primary contact from my son's mother to myself due to the stress this has put on her she is unable to deal with these issues any more) and he said he has never seen 250 hours for daily activities as In Kind Support to the Dept. of Education and is going to try and find out what it's for. I would also like to point out here that I sit on my son's School Council (Specialist School for children with a physical disability) and I have spoken to other parents (their children have more extensive disabilities than my son) and this In Kind Support budget is not included in their plan. The school Principal also has no idea what this budget is for.

Not only has this process been extremely distressing to us from an emotional point of view, it has now impacted us financially as we have had to pay our Support Worker for the outstanding invoices from our own funds. This had to be done with a credit card cash advance and at this stage I have no idea how much the \$800 will eventually cost us, including interest, by the time we are able to pay off this debt.

Over this past 6 weeks I have had six totally sleepless nights worrying about these issues. My son's mother's mental health has been so affected since we found out there was no budget for support workers and we have been left out of pocket she had to take a week off work. We should be using sick leave to care for our son when he is sick, not for ourselves due to the stresses created by the NDIA.

My final point is that the number 1 goal identified by the NDIA in my son's Plan is 'During this plan: To learn to become more independent from my parents'. This was deemed reasonable and necessary by the NDIS. How is he supposed to become more independent from his parents if there were not any funds provided for anyone to be able to accompany him to social and community participation opportunities? The only people who can accompany him without a budget for Support Workers is his parents! This would be a joke if it weren't so serious!

I also run an Autism Support Group in our local area, with 25 members. I have seen all 25 NDIS plans along with 5 shared by parents on the School Council at my son's school for children with a physical disability. The inconsistencies between plans are unbelievable. Children like my son with multiple disabilities (Cerebral Palsy, Autism, Vision impairment, non-verbal, peg fed, high anxiety, wheel chair bound) who cannot even do the most basic functions on their own have received less money in their plans than more able children with lesser disabilities (Asperger's) who go to a mainstream school without an aide, are verbal and can do a lot (eating, dressing, brushing teeth, bath, public transport, handle money, operate a computer, play sport) on their own. How is this fair? Surely this shows the system is failing those most in need.

While we are grateful for the NDIS and hope that it will eventually make a difference for our son, at this point it has only resulted in enormous emotional distress, anxiety and us being out of pocket financially.

The majority of the NDIA people we have been dealing with are not knowledgeable and although empathetic they are not trained or equipped to deal with the many issues that the NDIS is currently creating for vulnerable families who are already under extreme pressure of caring for someone with a disability.

Yours sincerely

(Father of child with multiple disabilities accessing the NDIS)