Submission to the Productivity Commission into the costs of the NDIS

Background

I am the primary carer of a profoundly disabled non-verbal 27 year old son. My son was abused in 2012/2013 whilst a resident in a supported accommodation facility managed by a Victorian NGO.

My son was offered and accepted early transition to NDIS. We live in East Gippsland, Victoria.

Draft Plan/Backlog of Reviews

By not allowing participants to see a draft plan, it appears that there is now a huge backlog of reviews. In our situation, my son's plan was built on the planner's incorrect comprehension and apparent "translation" of the goals and other assessment documents. This could perhaps have been dealt with at draft stage instead of the planner telling me as soon as she was describing the plan – that I should review it – even before it was approved.

Payment of Family Members

A massive issue for my son is that the NDIS does not have the same rules around payment of family members as the Victorian DHHS has. After my son was abused, my two older sons stepped in and each provided some support using ISP funds. As they both live in Melbourne and travelled to Gippsland to provide support, this was allowed under the Victorian DHHS rules. I self-manage the ISP funding and directly employ workers and have done since 2013.

The NDIS does not allow payment of family members unless there are exceptional circumstances. We applied for exceptional circumstances and it was granted by the Technical Advisory Team. However, they restricted payments to family members to a period of three months.

My disabled son is severely autistic, has a profound intellectual disability, has complex medical needs and requires 24/7 support. It is impossible to put a team in place in 3 months to replace the support currently provided by the three family members (myself and my two sons). So we have requested a review of this decision and asked for an extension to 12 months to ensure the transition to external staff is successful and does not cause my son extreme distress/anxiety – which in turn would lead to behaviours of concern and require more intervention, more funds and higher rate for support workers.

In my opinion, the cost benefit of using family members would, in fact, save the NDIS a great deal of money. We do not expect to be paid agency rates. For example, with my son's ISP of approximately $65K-$70K for the last few years, my son was provided with 33 hours per week of one-to-one support. I am on the carer's pension and provided the rest of the one-to-one support. As well as the 33 hours/week, the ISP amount of $65-$70K allowed for all equipment and consumables purchases and 13,000 kms for travel (we live in an outer regional area and my son is unable to use the meager public transport that is available).

I estimated that we could provide my son's full support for approximately $180K – that's one-on-one support. The equivalent in agency rates would be over $300K per year.

Yes, the family wants to transition away from full time paid support by family members – especially myself as I am 57 with a back injury and am exhausted. But, the major criterion here is and has been, the safety, health and happiness of my son.

It has been proven by the last four service providers used, that unless a family member is present, at the very least, my son was taken advantage of – and at the very worst, he was abused and was consistently put at risk of seizure, coma and sudden death.

Lead Tenant
My son's primary goal is to transition away from the family home and live in an independent safe, healthy and happy environment. The family considers a "lead tenant" concept would be successful to provide some of his support.

A "lead tenant" arrangement is where a co-tenant of the house has their rent/utilities paid in return for providing some support. So for example, we envisaged a lead tenant providing 3-4 overnights including breakfast for my son in return for free rent and utilities.

Agency costs for this would be approximately $1200 per week, whereas the rent/utilities would be around $300 per week. Again, this would save the NDIS money, but is not allowed under the scheme.

Therapy costs
Anecdotally, it appears that by setting maximum rates for therapists, once it is known that a client is on the NDIS, it automatically means that maximum rate is charged. I have seen examples where the same therapist charges $80 per hour for non-NDIS clients and $175 per hour for NDIS clients. Their justification seems to be that the NDIS requires more paperwork. I don't understand that justification – why not just charge more hours for the paperwork at $80 per hour.

Secondly, therapists are now charging maximum rates for producing assessments. This has (again anecdotally) resulted in, for example, a quote of nearly $1500 to provide an assessment for a piece of equipment, which will cost around $600.

Final Comments
For the last 5 years our family has ensured my disabled son has been safe, healthy and happy. The NDIS is threatening that security, which is terrible considering the NDIS was designed specifically for people like my son. It needs to be implemented with more flexibility especially where that would reduce costs. Why not trial some of these things for participants for 12 months and see if they are successful?

Apart from the issues noted above, I have found the whole NDIS plan/review cycle extremely stressful and deleterious to my own mental health. It has now been over 7 months since the first plan meeting

Oh – and as an aside – when my son was abused, I gave up my career in IT to support him. I am now 57. When I am successful in transitioning my son to live independently of me (which is required because I'm not immortal), I will actually place myself into enormous financial jeopardy. I will not be able to get a job (my previous one has gone to India) – and I will have no way to pay my mortgage. I understand the NDIS is about my son – and that hopefully, I will be the last generation to be in the dire situation I am in – but it would be helpful if carers in the situation such as myself could be at least considered by someone - even if it isn't the NDIA.