

Submission
No 35

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Name: Mr Stephen Cox
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Partially
Confidential

My name is Stephen Cox and I am a single dad (have been since the 90s) with 3 now grown children, one of whom is paranoid schizophrenic and in theory covered by NDIS. I will cover some background purely to put our current circumstances in context so please bear with me.

In the early 90s although I was employed in a well paid and senior position in Sydney, it became clear that my wife's pattern of behaviour (constantly leaving, talking to dead Indians, communing with Shirley McLean to discuss my eldest sons imaginary friend etc.) was getting worse and that it was impossible to continue to work in my time intensive job and ensure everything was OK at home.

As a result, I resigned and moved the family to be near hers as my mother-in-law had always been very supportive. Whilst this helped for awhile, after her mother died, she finally left, luckily not making any attempt to take the kids. I set up my own business as a computer consultant working from home so I could be home when the kids got back from school and if they were sick. Whilst things were often difficult, the kids and I went along OK, not making a fortune but not destitute either. However behaviour worsened and I realised that his ability to work and look after himself financially was decreasing and I needed to find a larger income so I could ensure he was at least financially provided for in the long term. All 3 kids had grown and left home so I took a job in Angola, paying better money than I could make in Australia. As returns to Australia were very time consuming and because it was more exciting, I bought the kids to Europe for holidays whilst there and eventually bought a cheap run down flat in France that I have gradually done up.

However 2 things happened:

1. As a result of my stopping an employee from stealing just on \$50m, I was arrested, jailed (only 2 days luckily) and deported from Angola. I was fired and flown to France (where at least I had somewhere to live) but suffered two heart attacks along the way and ended up in Toulouse Hospital for heart surgery
2. behaviour had deteriorated and I needed to be home. On my arrival back in Australia, I found that had been thrown out of a number of group homes (he is either unaware of or happy to live in squalor of his own making) so bought him home even though my first intention was to try to see if he could survive by himself in the outside world.

I also became aware of a new mechanism called NDIS to which he was apparently entitled. Frankly I didn't understand the history or processes involved in NDIS but a very helpful lady from NDIA helped me put together first plan and this was approved in December 2016.

Unbeknownst to me (or at least not understood by me- NDIS's major success has been the obfuscation and confusion its processes and acronyms bring), an organisation called PIR were appointed to be either the LAC or Support co-ordinator. They did nothing for at least 6 months and we had no contact. However later in the year (whilst I was away - see later) they organized for another organisation to take shopping once a week and to the doctor on alternate weeks for his fortnightly shot and another to take him for a drive 1 hour per week. These people were nice but when I tried to get them to do more than just be an expensive taxi service, this failed. In hindsight because of no co-ordination by PIR. Note. Rightly or wrongly, I had decided I need to be away for some periods.

Initially this was just to have a break as my health means I have limited time left but also to train/test how would survive once I am dead and to try to put in place appropriate support including covering any gaps identified by my absence. Frankly it didn't go well as far as support in my absence.

- Initially PIR spent just on half annual budget under NDIS through not organizing any support but that described above i.e. car rides. This meant that his budget was cut significantly this year under NDIS denied but obvious use it or lose it process.
- If support transport didn't turn up, there was no monitoring by PIR nor follow up plan. If as a result he missed his medication, there was no notification or follow up.

- PIR were to prepare an annual report on status including gains and losses and future plans. This had not been written at the time/of his plan renewal and I have still not seen any evidence of it.
- There was no co-ordination with me for the next years plan and I organized this with NDIA myself. I had asked PIR to participate via phone in as their presence in the house was too stressful for both and myself but this didn't happen
- Frequent requests by me for information, status or reports were ignored and despite the fact that I was nominated on his NDIS plan as his carer, PIR ignored my requests for information, citing privacy issues. Yes I have been his sole carer for almost 25 years . When I asked for assistance in being formally recognized as his carer (a request made 6 times so far) I was ignored.
- In desperation, I had sign a limited Power of Attorney giving me the right to obtain information and take actions on his behalf as regards NDIS PIR initially seemed to accept this and on my request, made an appointment with the mental health Psychologist to help to determine plans for his mental stimulation in the future so we could develop an associated plan. I was happy to sit in the waiting room whilst this happened so could feel free to talk but I have been precluded from any information or guidance on his future coming out of that meeting.
- In a meeting in May 2018, it was agreed that once PIR had provided a report of what they had done for the last 6 months and planned for the next 6, I would sign the annual agreement with them on behalf. I felt this was the only way to get them to do anything. I am now being told they waited till I left and coerced into signing this document. knows he signed something he probably shouldn't have but isn't sure what it was for or who it was with and is enormously upset he may have done the wrong thing.
- PIR committed they would check on once per week, by alternating phone call or visit and email me on the results. No emails for the last month
- PIR waited until I left and have now challenged the validity of the Power of Attorney that I gave them early in the year to try to convince them to give me information and keep me involved.

Why would an organisation seek to repudiate the role of father, sole carer and someone they acknowledged was what they wished more of their client family were like. I have been unable to find out how much they charge for co-ordinating Support, but if it is greater than zero, they are milking the system as they provide no support or co-ordination. Surely they cant be lying and underhanded for the \$200 per hour they can charge

Current Status:

I have found and am managing a local support worker to take to Taekwondo, shopping, library and doctors as well as helping him to shower more often and clean his accommodation. A mental health nurse has been very helpful in trying to get moving forward medically and intellectually. PIR do nothing and I and would like to remove them but we have been told we cant till next year and it may ruin our budget If we do so

Bottom line.

NDIS is a wonderful idea , incredibly badly implemented. Made worse by the fact that the commercial sharks have realized what a golden goose it could be for them and are in a feeding frenzy. Control and Choice are its catch cry. Yes Control by others who ignore the disabled or their carer and Choice of their way or the highway. They have accidentally created another stolen generation: a well intentioned idea hijacked by others I had hoped it would make my shuffling off this mortal coil easier, knowing my son was in good hands and had the support he needed. It is the opposite but I think we all know nothing will be done.

I had actually looked at trying to set up a respite care process on 18 acres of Crown Land next to me but given I cant even get my son looked after by a process designed to do exactly that, I despair. I am not looking for sympathy as there are always others worse off but given I have been lucky enough to be able to work for a good education and am reasonably erudite, I despair even more for those unable to stick up for themselves For gods sake help us