

Submission to the Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT

March 2018

My experience with the scheme is as the carer of a 35 year-old son with both intellectual disability and mental illness. My son is a participant in the NDIS which on paper is able to provide much more support than he has previously been offered. We have not been able to realise much of the promise. The difficulties are as follows:

Initial planning

The planning process incorporated a face to face meeting with my son. However the subsequent approach was largely based on a report (unseen by me) from a doctor who only took responsibility for my son for mental health, not disability issues, and gave a 'main diagnosis' which was of no use in trying to determine disability supports. Given my son has a complex array of symptoms, the value for him of a 'main diagnosis' of any kind is questionable. The planning process did not provide for me to view a draft to correct the many errors of fact, there being only a process of review of a decision, which was not what I needed as I was not at this early stage questioning the money or its groupings.

The point was the records need to be corrected. Subsequent contact with NDIA about my son showed this was not done and I had to explain in detail again what the real situation is.

The process of implementing the plan was fraught and took three months to engage a Support Coordinator and more time to engage potential other supports. There were not appropriate services available for much of the money.

Review process

The review process outsourced to Feros Care was a whole new system for which we were not prepared. The questions were largely irrelevant. The questioner was frustrated and the process was stressful, as I was expecting money to be taken away. I had to argue strongly to retain a Support Coordinator for my son even though this was part of the system on initiation and we had barely nine months to implement the plan at that stage. The new Plan was acceptable for the moment but the problem of my son's unmet needs remained.

Emergency situations

There is no agility built into the system to provide for the situation I found myself in after the 2017 review. There is also only conflicting advice available. My son's circumstances had changed in November 2017 and he need Supported Independent Living (SIL), not in his original plan. Feros Care as Local Area Coordinator earlier promised that they were there to help but when it came to needing help to apply for a review of the plan to include SIL, I was told it had no advice. Even after calling NDIA to ask about the process and being directed to a form on the website, I apparently used the wrong process and it was only by luck that several weeks later, someone worked out what I was really trying to do and undertook a review. The result was only a six month plan from January 2018 still with no SIL.

The reliance on finding a care organisation to submit a proposal before SIL is possible, gives a Catch 22 situation for my son trying to be discharged from hospital. Because he has no SIL in his plan already, some places will not even consider him, so the options are limited. While we wait for those

anticipating taking him, even for applications noted as urgent, the places can be lost, and the cost of keeping him in hospital; is born by the health budget.

24/7 care accommodation

The effort to move my son from hospital to community care is proving next to impossible. There are insufficient care organisations in the ACT to provide 24/7 supported independent living and almost none able to take those with dual disability such as my son. There is poor communication and liaison between the health sector and the disability support providers. The health sector seems to think they are engaging with the equivalent of the previous ACT government disability department rather than private businesses who only get paid according to set rates and allowances in Plans.

Resolution not within grasp

As this inquiry draws to a close, I do not see any way forward. I have applied for another review of my son's plan, eventually coaxing a proposal from the care organisation that agreed to take my son, only to find that this organisation belatedly thinks the target house unsuitable, so that I have to start all over again after three months of looking and expect I will have to start the review process again with a new proposal even if I obtain another theoretical place for my son. All of this is compounded by the emergent challenging behaviours of my son which are not seen by the hospital as a health problem to be addressed by them, and yet which make it a huge challenge for arranging staff to care for him in the community. In an already limited market, my son is readily rejected.

The funded hours for accommodation searching provided to my son's Support Coordinator from the January 2018 Plan are almost expired so I now have to pick up the job of searching. With the NDIA process the way they are, asking for more of this funding now would take until next year.

Recommendations

In relation to these difficulties further work is required on:

1. Models of housing care for those with challenging behaviours, analysis of the effect of the NDIS on the market in which organisations are competing for suburban housing to be used as care homes when not purpose built, and consideration of additional support for care organisations to expand and training for their staff to cope with challenging behaviours.
2. Resourcing NDIA review processes.
3. Improving health-disability liaison.
4. Alleviating the cost shifting and responsibility wars caused by the competition between health areas funded solely by territory government funding versus NDIS with its large Commonwealth funding component.