

28 August 2017

To whom it may concern

I write with some concerns about the NDIS and its associated bureaucratic burden in the context of my older brother who has Downs Syndrome.

While my concerns may simply represent 'teething issues' or a one-off form information gathering exercise associated with the changed funding arrangements, they might also be sign of the problems of applying a 'one size fits all' framework (which is designed to give individuals 'greater choice and control') inappropriately to some people with an intellectual disability who don't want or need this framework applied to them.

But first, let me give you some background about my brother (let's call him 'N') and his circumstances and then I'll explain how the new NDIS arrangements have impacted his sense of wellbeing and created an extra burden on my mother (let's call her 'J').

### **N's background and circumstances**

From the age of 6 years, much of N's daily care needs and living arrangements have been greatly assisted and supported by Minda Inc. — an Adelaide-based disability services organisation with a 119 year history.

Now aged in his 50s, for over 30 years N has been living in a 'share house' arrangement supported by Minda Inc. This has enabled him to live (together with other Downs syndrome mates) in a house in their local community, supported by regular visits by their carers (employed by Minda Inc.). These typically wonderful carers support N and his house mates in their daily lives and, importantly, manage their finances. Minda Inc. also support N's employment, providing transport to his job as a nursery assistant at the farm in the Adelaide hills.

The ongoing care and services provided by Minda Inc., alongside my parent's emotional support, have generally given my brother (N) the capability and freedom to experience a good, happy and (much longer than anticipated) life.

In other words, N's personal wellbeing has (for the most part) been very well served by Minda Inc., who now work in partnership with my elderly and increasingly frail mother (J, now aged 85 years). (My father passed away in 2011, and my younger brother and myself both live in other cities and/or states.)

### **How NDIS pre-planning and planning meetings have negatively affected the wellbeing of my older brother and my elderly mother**

Recently, when discussing N, my mother described him as being overwhelmed and intimidated by his upcoming pre-NDIA planning meeting with Minda Inc. N does not handle change very well. He likes routine. Having NDIA pre-planning and planning meetings to discuss his 'goals' is something that he finds confronting and uncomfortable (as he possibly doesn't understand what the term means), and definitely 'out of routine'.

In a recent conversation with my mother where we discussed the upcoming pre-planning meeting, my mother was under the impression that Minda Inc. would be acting as an agent for N in the actual planning meeting with the NDIA. From her perspective, she had assumed that as Minda Inc. would

be acting as an agent that that would mean that neither she nor N would not need to have to go through meeting. But I'm not sure that's the correct assumption.

Nonetheless, the pre-planning meeting with Minda Inc. still requires my mother to complete some paper work on behalf of my brother and to spend time continuing to cajole N to attend that meeting.

I also jotted down the following quotes when discussing her views on the NDIS and associated need for pre-planning and planning meetings:

- 'they could do it a lot cheaper the way they did it before'
- 'it's more burdensome and hassle for everybody'
- 'many can't fathom what it's all about'.

My mother is also unclear whether these type of planning meetings need to occur annually. At the age of 85, she (and I) are naturally worried about the continued burden of paper work (and associated cajoling) for her own wellbeing at a time in her life when she needs to concentrate more on her own health and welfare.

Thank you for the opportunity to provide input to the study.

Yours sincerely

Canberra, ACT.