Submission to The Productivity Commission 2017, National Disability Insurance Scheme (NDIS) Costs, Position Paper

NB: The Productivity Commission 2017, National Disability Insurance Scheme (NDIS) Costs, Position Paper, Canberra, will be referred to from here on as ‘NDIS Costs PP’.

I have an ABI. I preface the following with this: I have only been able to assemble these few thoughts in the two weeks available to me since receiving NDIS Costs PP, so have listed thoughts, rather than assembled a cohesive response. Thoughts are listed here in no order of priority, or particular order. I have dipped into the NDIS Costs PP and seen the draft code of conduct paper, but understand there are a number of other relevant documents on the roll-out/effectiveness, etc., of NDIS. Any following comment is so limited.

The NDIS Costs PP (p.v) states that: ‘The scope of the study is to include: (3) whether there are any issues with the scheme’s design, including the application of market and insurance principles, in ensuring the best possible outcomes for people with severe and profound disability.’

NDIS constraints of system: one example is that market and insurance principles cannot take account of the people transiting from prison and long term hospital stays, especially if released/discharged without the correct paperwork, etc. I have witnessed two separate occasions in Centrelink offices, where the young man has vented to staff about being released without proper paperwork, money and scripts. One young man: ‘What do I have to do to go straight? Rob someone else and go back inside to get my medication?’

With all the support workers factored in to facilitate access to systems, etc., will NDIS increase the dependency of disabled people by having other people do things for them instead of them learning to do it themselves – and providing the technology to allow this? Will the disabled have to learn helplessness to be helped?

With its scattering of resources, apparent choice and seeming fragmentation of services, NDIS does not even have the dignity of anarchy, as anarchy has a major self-responsibility component. NDIS seems to undermine this, as it is based on the market principles of caveat emptor (buyer beware) - the law of the jungle/social Darwinism - and is an adversarial system. It is impossible to be properly self-responsible for many because of the severity of the disablilty.

NDIS Costs PP, p28, raises the issues of the use of trustees and substitute decision makers. While these may be employed staff, NDIS also pre-supposes the disabled person has a trusted carer/supporter. In reality, who is there to be trusted and who can be relied on? Repeated studies indicate the levels of family, worker and carer abuse of the disabled. From personal experience, I had an employer pay for an income insurance policy for me, only to keep the proceeds when I became ill and they found out I was eligible for Centrelink payments.

Apparently, some 44-47% of Australians are functionally illiterate and NDIS is predicated on a high literacy level and access to technology. It is essentially city-centric, as evidenced by the reference to ‘thinning markets’ (NDIS Costs PP, p228).

There is also the separate issue of even literate, ‘normal’ people reading screens differently to pages and how this can affect comprehension and accessibility.

Issues about technology include the effectiveness of the coming access system. There was a report that ‘planning is already underway on future upgrades to the nbn, before the first rollout of the service is even complete… it’s a dud’. [*Herald Sun* (10/7/17, p9)] For those that have transitioned to nbn, a number still have access problems and are left without services for months on end. [*The Age*, 11/7/17]. There are also financial matters involved with access: the cost of the service and sorting through the paperwork to ascertain what coverage, etc.

There are repeated reports of hacking of confidential information. What will be the security measures in place for protection of personal information? There’s the openness of the system, resulting in the recent Medicare leaks with people’s information for sale on the web. There is also the absurdity of a situation in which I was involved earlier this year. I was sent a secure email from the Department of Human Services. Even though I eventually registered, I still could not access it. Repeated emails requesting assistance were ignored. NDIS claimed that they hadn’t sent it, so it must have been Medicare or Centrelink. This was dismissed by Centrelink when I visited. They checked their and what they could of the Medicare system and claimed they had not sent it. The mystery remains.

In the current NDIS design, there is nothing holistic, as a baseline, or as a safety net. Everything is fragmented and casualised and continuity of care, particularly in urgent circumstances, will be even more difficult.

There is the casualisation of staff: finding someone to do the job when wanted/needed, when staff work 3-4 days a week and are booked out for weeks is even now problematic.

There has been an increasing disparity in the public-private patient divide and this will probably be exacerbated by NDIS.

There is the question of professional standards, when the documents explicitly state that any ‘protection’ is only under consumer law.

To repeat: the present format of the NDIS is an adversarial system, that is loaded for institutions and those with private wealth. A participant cannot rely on Legal Aid, because Legal Aid’s priority is criminal matters and they are constantly overwhelmed by demand.

Forget about access to advocates to assist. For example, there is one advocate for the Ballarat region. She is so overwhelmed by demand, that she now deals only with people she knows. What happens to the rest of us?

There is also the issue of already clogged courts and tribunals. How much more so will they be with the NDIS cases? Also, how many cases will go unheard, not brought, not tried or tested in court because the disabled person does not have the capacity, funds or inclination to pursue such a process, especially if they have already gone through WorkCover, TAC or VetAffairs, etc? They know only too well how the ‘insurance principles’ work.

There is also the question, in any contract law: what would the ‘reasonable person’ presume/do/know? The definition of ‘reasonable person’ in this disability context may take years to determine and people will be in a state of flux in the meantime, while it is sorted out in the courts. Will there be scales of ‘reasonableness’ depending on the severity and type of the disability, etc?

The question of ‘reasonable and necessary supports’ is separate.

With the NDIS adversarial system, all these must ultimately be tried in the courts.

This is a completely separate issue to disclosure of conflict of interest, let alone how/when this must be done and ensuring participant understanding.

Will the recent Fair Work decision about casuals and part-timers being able to ask to go full-time after 12 months apply to NDIS?

Research has demonstrated that the more choice people have, the less they can come to a decision, so they take nothing. An example is the 1995 jam study (*Too many choices*, New York Times, 2010, Alima Tugend, [www.nytimes.com/2010/02/27/your-morg/27shortats.html?mab2+mab2](http://www.nytimes.com/2010/02/27/your-morg/27shortats.html?mab2+mab2)) by Professor Iyengar and his research assistants. While this study has been criticized because of the difficulty in separating choice overload from information overload, whichever one it is applies to NDIS, with its base of choice and the volume of information to be gone through. How many will walk away because of this? How many may walk away because they feel the disabled are being used as guinea pigs for the full privatization of the health system and they do not want to participate in such a system?

The NDIS Costs PP, p281, criticizes the lack of fit for purpose information that means confusion for participants. This is important to address, as is the necessity of explaining the NDIS pathways and procedures. I still haven’t had this done and I am up to the planning stage.

[wishing for more time]

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