

# **Individual Submission to the Productivity Commission: Enquiry into the NDIS and its costs March 2017 (Kirsty Magarey)**

My experience with the NDIS started when my son became the holder of an individually funded package and, in due course so did I. I was eligible to apply at the same time as he was accepted, but it took me another six months to summon my organisational skills, and make my application, whereupon I was also accepted in.

I have to confess at the outset that I have for some time had the gravest reservations about the NDIS model of funding. It seems to me to prioritise a privatised form of care which, while it does create greater choice, also introduces all the inefficiencies of a market based model. So, for instance, discovering information about who and what service providers are available is in itself a dizzyingly confusing task, and then there's the ferocious costs and efforts involved with organising funding for those services. Furthermore it's likely that in the longer run service providers, as competitors in a market, will have to sink funds into advertising and self-promotion, which will in turn increase the costs for consumers and doesn't seem to offer the best prospects of cheap and sustainable services. Creating a 'market' in disability care also does not seem the most economically efficient approach to a sector that has long depended on charitable contributions by those who are generous enough to contribute. Introducing market principles and norms into this sector seems likely to damage the voluntary nature of this support (and this has already occurred, see below).

The NDIS model does increase choice, but it's also likely to undermine pre-existing structures and choices, so that, by decreasing the pre-existing options, this 'choice' could be a sleight of hand which removes the opportunity to choose services that previously existed. It also decreases choice by forcing disabled people to participate in a competitive market with all the negative elements of that marketplace. While everyone wants choice for people with a disability they don't want the organisations that have supported them for so long to be defunded and destroyed.

## **Continue Block Funding**

Despite these fears and hesitations about the model I have to accept that the NDIS has been implemented(!), and I am now simply hoping, for the sake of the disability sector, that action can be taken to save what we have left of the structures that were, in the end, prior to the NDIS' introduction, quite effective at guiding and supporting people with a disability, however inadequately funded they were.

I believe that public support for the NDIS was premised on the idea that the increases in funding would augment pre-existing structures and organisations rather than destroying or removing them. The costs to the community of ending previously block funded programs are significant.

Quite apart from the disappointments and damages that result from these defunding arrangements, another feature that is lost are the cost efficiencies in block funding programs. These efficiencies are lost when there is a sole reliance on individually funded plans without the benefits of block funded broad coverage programmes. The two approaches need to complement each other and create positive 'synergies' rather than competing for funds destructively.

The solution would seem to be to continue giving block funding to disability organisations because they do so much more than simply providing the supports people have available to them under the NDIS. They can guide a person through a familiarisation process and identify their probable future needs even before they have worked out what is happening to them. This is not a paternalistic approach, just a recognition of the realities of expertise and the supportive, useful role it can play.

I, for example, have MS, and the MS Society was able to offer enormous support on diagnosis, when I was lost in the medical system and its unfamiliarity. They were then able to act for me to organise support and to assist me in my quest to manage the condition effectively. They contributed to my capacity to stay in the workforce for a good 10 years beyond when most people might have bowed out. They were also able to organise efficiently funded services that were available across the community of people with MS. In that instance the service was not a 'choice', but actually it so happened that many in the community did want those services and so benefitted from the economies of scale involved. Examples of these services have been in-house masseurs, meditation and yoga, exercise classes & etc. They have had a clear therapeutic benefit for those who have utilised the services and by being offered more broadly they have been able to be offered more cheaply.

Furthermore, by having these services pre-arranged (so to speak) I did not have to carry the burden of initiating their provision or of developing the analysis and understanding that these were the services which would benefit me. The Society had taken these onerous burdens off my shoulders and provided a no-choice service! Big bonus for someone struggling to keep their head above water, with no inclination or capacity to be making 'choices', let alone well-informed choices. I just needed help.

The MS Society has lost significant amounts of government funding over time, in particular as the NDIS has commenced. Another element in their decreased levels of funding has been that there's been a significant slowing of their private donations – while not being in a position to speak for them I believe the Society thinks

this has been because of the popular perception that the NDIS will support people, so charitable donations to the Society are no longer so important. This couldn't be further from the truth. The NDIS leaves people out – including aged people, people who are newly diagnosed and indeed its primary effect seems likely to atomise the MS community between those that have an individually funded package under the NDIS and those who don't. A most unfortunate outcome, including an outcome with cost implications.

The agencies that have long supported those with a disability have developed an in-depth understanding of the relevant conditions and the needs and interests of people with that disability. Losing those in-depth and specific understandings will be a costly exercise for people with those particular forms of disability.

There are a few agencies that I mention here as having (had) an important role in supporting people with a disability – and whose discontinuance will have a direct cost impact on people with a disability (and their families).

SHOUT (Self-help Organisations United Together) is in financial difficulties due to a lack of funding, and if ever there was a crucial organisation to support people with a disability (both NDIS funded and not), it is this one. If such organisations are to go under then the cost of supporting those with a disability will inevitably go up because disasters and difficulties will happen unsupported and end up back with the medical system or doing great damage (and creating great costs) to the community. This is a classic example of the need to continue block funding. No funding can effectively flow from an individually funded package to SHOUT and yet IFP individuals and others in the disability community benefit from such services.

Another significant agency in the ACT which supported my son when he was experiencing difficulties was Therapy ACT. This crucial organisation has shut its doors since the NDIS commenced. Therapy ACT was able to triage and direct families to the appropriate services, either within Therapy ACT or elsewhere. The agency functioned as a 'guide' for both my family and others, with the additional benefit of offering an in-house broad cross section of therapists and services who we could trust because they had been selected and relevantly expert by the Government. Many of those therapists have gone in to private practice and the NDIS will accordingly have increased costs to support the select number of plan funded children who can access those services. If my son was still a child we would have the significant difficulties of having to select the appropriate therapists with insufficient information to help us in our selection. Furthermore, I am aware that children whose difficulties do not constitute a permanent disability may not be able to access or identify the services at all. Many of these destructive outcomes could have been avoided if sufficient block funding was maintained.

Your discussion paper asked about the under-utilisation of plans. I am a classic case in point, having had a plan whereby I used about 15% of the available funds. This is because I am struggling to keep my head above water

and am so stressed that I can't even contemplate making changes to our problematic life arrangements, let alone actually making them. What's more I'm not the best at organising my paperwork (the tax office have just written to harass me about undone tax returns, and I regularly lose significant amounts of unclaimed services from my health fund just because my life is so chaotic and I don't find time to do my paperwork).

Similarly as a self-managed NDIS participant I found it impossible to keep my papers together and do the appropriate claiming. As a now plan-managed NDIS participant I find it even harder, if anything, to manage that additional layer of administrative burden and all I really want to do is to go back to the good old days when the MS Society told me what I want and needed and provided it at a reasonable cost. Nothing like a bit of benevolent paternalism. In fact there are many benefits to it, including being able to shrug off the burden of managing your costs and choices with a reasonably low level of bureaucratic rigidity. In the meantime my credit cards and mortgage are groaning and I am an 'under-utilisation' risk to the NDIS, with the immediate threat of having my unused funding cut back – not because I don't want and need the features these choices provide, but because I can't get organised to utilise the promised benefits and it's easier to blow my budget RIGHT OUT than navigate the NDIS' portal & etc.

## The Portal

The portal is where all the difficult process issues with the NDIS coalesce. I was initially self-managed and the only reason I have had to go to a plan managed status is the inadequate design of the portal.

(Incidentally I am aware the Commonwealth Bank have offered to work with the NDIA in administering funds, and the fact the NDIA have rejected these offers seems to be symptomatic of the process that has led the portal to be so comprehensively inefficient.)

### *Access to Records*

Participants need to be able to call up a list of funds that have been applied for and that have either been accepted and paid, or refused. Ideally there would also be some identifying feature of the applications so that we are not left with the absurdity that the only feature distinguishing various applications for funds is the date on which the service was received and the date on which the application for payment is made.

A history, with as much detail as possible, is something most institutions involving financial transactions provide as a matter of course. It's just a basic service. Thus, for instance, my bank can tell me the transactions that have taken place over the last year and can also let me sort them in various ways and search through them for particular records. The Portal cannot do this. It is this incapacity that means I have had to turn to a plan manager who can supply this data. So, at a cost of just under \$2000 a year, for presumably a very large

number of participants, a whole business model has had to be created simply because the portal is so badly designed. Presuming self-managed plans are cheaper to run, by using the labour and organisation of the individuals concerned, it is not cost effective to be relying on the plan managers to perform that basic function of elementary financial management, and record keeping.

Just to provide more information on the abysmal nature of the service offered by the Portal (I am leaving the fact the portal is so often 'down' to be covered by others, because in a sense that failure is too obvious to warrant further discussion): At the moment to discover a service payment online you need to not only know the date of the service (a requirement that doesn't make sense because the portal allows you to lodge a 'block request' for funding which covers multiple dates and a lengthy timeline), but also the date that the funds were applied for: something that only the most strenuous or obsessive record keeper will have recorded. This means that effectively you need to ask for a print out of services claimed to be sent to you by hardcopy. This is not efficient. The Portal needs to be modified so you can view all your records without having to nominate the date on which you utilised a service (AND THE DATE ON WHICH YOU LODGED A CLAIM FOR THE MONEY FROM THE NDIA). This is just such a basic service that it's embarrassing to be having to point it out. When I set out to explain this inefficiency to non-NDIS participants they can't even begin to believe how absurd it is.

#### *Inadequate Data Collection*

Medicare should have been seen as offering an effective and experienced model for managing the portal. There is a distinction between Medicare and the NDIS in that Medicare requires services provided to be associated with a registered provider. For plan-managed and self-managed participants in the NDIS there is no comparable need for users to rely on registered providers. Despite this difference in the data collection requirements, the Medicare model of: service date, service provider, cost, could still have been usefully utilised. Participants could either have chosen to identify their service provider or type of payment within their own categories – as in via a name they choose to give the provider or nature of a service, or the NDIA might have come up with a slightly more helpful categorisation of services to choose from – as in was it cleaning services or physio services & etc. If these categorisations were too threatening for participants then they could have been provided with the facility to create their own categories.

If a little more data were collected about the services that have been used, as people input their requests for funds, this would help in future analyses about whether plans are being 'cost effective', or effectively utilised. It would also help the NDIA provide some statistical analysis of the use to which the funds are being put. At the moment, with the current level of data collection, the question as to whether the NDIS costs can be minimised has to be addressed abstractly, with no concrete meaningful data on the use of funds.

To make more efficient use of NDIS money the first thing must be to redesign the portal, and hopefully this process will involve employing people who can maintain the system and keep it running while they transition to a more logical, cost effective arrangement.

### The Terms of Reference

Incidentally, I was confused by the Terms of Reference, which several times refer to those with 'severe and profound disabilities'. It's unclear whether that's a term of art which distinguishes between NDIS participants, or whether it's a misunderstanding of the criteria for inclusion in the NDIS:

- you have an impairment or condition that is likely to be permanent (i.e. it is likely to be life long) and
- your impairment substantially reduces your ability to participate effectively in activities, or perform tasks or actions unless you have:
  - assistance from other people or
  - you have assistive technology or equipment (other than common items such as glasses) or
  - you can't participate effectively even with assistance or aides and equipment **and**
- your impairment affects your capacity for social and economic participation **and**
- you are likely to require support under the NDIS for your lifetime.

An impairment that varies in intensity e.g. because the impairment is of a chronic episodic nature may still be permanent, and you may require support under the NDIS for your lifetime, despite the variation.

This definition doesn't seem to equate to a 'severe and profound' disability. My disability 'substantially reduces my ability to participate effectively in activities' and has caused me to stop working, but it's not a 'severe and profound' disability. If the Productivity Commission is able to clarify the meaning of that distinct definition used by the Minister in his reference that might be helpful.