

Submission to the Productivity Commission Inquiry into the
National Disability Insurance Scheme (Costs)

By

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My submission is based my personal experience of having been excluded from the NDIS due to the failure of the transition arrangements and the rigid application of an administrative technicality.

I was diagnosed with Multiple Sclerosis, a neuro-degenerative disease in 1998. I have suffered from a significant, permanent and worsening mobility disability since 2010. I am unable to walk without bilateral support. I also suffer from other disabilities caused by the progressive nature of this disease.

My submission has regard to the following issues and observations stated in the Commission's Issues Paper released on February 22, 2017.

- The governance and administrative arrangements of the NDIS. (p7)
- Whether there are any issues with scheme design. (p7)
- Ensuring the best outcomes for people with profound or severe permanent disability. (p7)
- "To streamline the process of accessing the NDIS, people receiving support under specified state and territory disability programs are generally assumed to meet the disability requirements specified in the Act." (p13)
- "early intervention support is likely to benefit the person by reducing the person's future needs for supports in relation to disability."(p14)
- "Preventing the deterioration of such functional capacity."(p14)
- "The NDIS is intended to meet people's disability support needs, not to replace other mainstream services."(p15)
- "Poorly defined boundaries between the NDIS and mainstream services can raise the risk of gaps in services...and cost shifting (between agencies or governments.)". (p15)
- Is the way the NDIS refers people who do not qualify for support under the scheme back to mainstream services effective? (p17)
- The rationale behind the concept of "reasonable and necessary supports" as set out on p20.
- The rationale behind the objective of reducing the burden on informal carers as set out on p 22.
- The assertion that "State and Territory Governments provide mainstream services and offer support to those unable to access the NDIS". (p28)
- Issues with the scheme's design, ...in ensuring the best possible outcomes for people with severe and profound disability

I have detailed my experience with the transition to the NDIS in the ACT at Attachment A.

I have also attached correspondence that I received from the then Minister for Disability in the ACT Government at Attachment B.

On 24 February 2017 the NDIA issued a statement in response to criticism of the transition arrangements stating that :

"The NDIA is committed to working with people with disability, their families and carers to resolve any issues during this period of transition."

My experience provides no support for the assertion that the NDIA is willing to work with people with disability to resolve any issues during this period of transition. The reverse has been the case to date.

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Issues with Scheme Design and Transition Arrangements.

My experience demonstrates that :

- There was a failure of communication between the ACT administration and the NDIS at the time of the launch of the NDIS in the ACT.
- The ACT administration issued no communication whatsoever to at least some of its existing disabled clients who were already in receipt of ACT Government disability support regarding their likely eligibility for the NDIS and the procedure required to be followed. (I suggest one could safely assume that I am not the only victim of this failure of communication.)
- The eligibility criteria specified on the ACT NDIS internet portal on 7 January 2016 were incorrect and misleading.
- The transition procedure described on the NDIS website is wrong and misleading.
- There is no definition of a “current Service provider” on the NDIS website.
- There is no mechanism to inform people with a disability who for any reason, such as lack of information, unwillingness to ask for help, remote location, socio –economic isolation, or intellectual disability, have no history of accessing external service providers, and no information about their eligibility for the NDIS or how to go about applying for admission to the scheme.
- **There is no redress available for any individual who becomes the victim of these administrative failures and legislative rigidity.**

Issues with the Scheme Legislation

The failure of the legislation to allow any discretion to the decision maker whatsoever and the lack of any scope whatsoever for an “Act of Grace” or the capacity to admit an eligible person retrospectively who has through no fault of their own failed to comply with the correct application procedure for any reason including cognitive impairment, lack of information or misinformation.

In particular, if the age restriction cuts in before the administrative failure is identified, the otherwise eligible person with a disability is permanently and irreversibly excluded from the NDIS. This constitutes a major injustice.

Whatever the rationale for the rigid age criterion for admission to the NDIS, it is evident that it is not intended to exclude people who have a significant, long-standing and non-age-related disability that predates the launch of the scheme by many years and who failed to make an application before turning 65 as a result of a failure of communication, wherever the fault for that may lie.

The fact that the scheme has different start dates in different regions and States underlines the arbitrary nature of the age-based cut-off for eligibility. This means that among eligible applicants of identical age, a proportion will have access to the NDIS and many others won't, depending on where they live.

Applicants affected by the above inequities will be advised that they may still be able to access support from the Commonwealth Aged Care system. The support under Aged Care legislation is far from equivalent and is not appropriate. Aged care support is designed to address ageing, not disability. The kind of supports that a disabled person requires to assist them in managing their non-age-related disability and to remain an active and independent member of the community are not available under the Aged Care system. (for example, vehicle modification, and specialist physiotherapy and occupational therapy services that target their particular disabling condition(s) or illness-related deficits. Furthermore the aged care supports are viewed as "welfare" and are means tested. By contrast the NDIS is explicitly designed to operate as an **insurance scheme** and as such, there was a conscious policy decision that it was inappropriate and discriminatory to means test measures designed to enable people with a disability to work, to be educated, to participate in the community and to lead as full a life as possible despite their disadvantage.

Proposed Cost Savings Measures

Legislation is currently under consideration to roll a variety of payments currently available to people with a disability into the NDIS. This will mean that if individuals who are not admitted to the NDIS will not be able to access payments for which they are currently eligible. If this were to be enacted it would arbitrarily exclude people aged over the age of 65 from accessing payments such as the Mobility Allowance. Such blatant age discrimination is particularly extraordinary in light of the Government's decision to progressively increase the retirement age beyond 65 and the apparently bipartisan support of the principle that people over the age of 65 can and should continue to undertake both paid and voluntary work, undertake vital caring roles, undertake further education, continue to live in their own homes and continue to participate actively in society. All research shows that healthy ageing requires such participation in the economy and the community and results in net savings to Government outlays. It would be inequitable, short-sighted and counter-productive to eliminate the scarce supports that remain available to a limited number of people with a disability over the age of 65. If enacted the new measures would increase marginalization, isolation and disadvantages experienced by older people with a non-age-related disability.

Comments on observations and statements contained in the Issues Paper

"To streamline the process of accessing the NDIS, people receiving support under specified state and territory disability programs are generally assumed to meet the disability requirements specified in the Act."(p13)

Although I was in receipt of a disability grant and disability services from the ACT Government prior to the launch of the NDIS in the ACT, the ACT did not make my details available to the NDIS, nor did they advise me that this was something that I needed to do. The then Minister for Disability in the ACT, the Hon Chris Bourke, however did support my “out of time” application for consideration and I attach his letters to me which demonstrate that he also considered the transition process to have been flawed and that “the rigidity of the Act was not enabling the NDIS to operate consistently with the intended principles.” (Attachment B)

“early intervention support is likely to benefit the person by reducing the person’s future needs for supports in relation to disability.”(p14)

“Preventing the deterioration of such functional capacity.”(p14)

Whilst I already have a significant mobility disability there is ample evidence to support the view that with specialized allied health professional therapy and the use of various mobility devices such as the WalkAide, the Musmate and the Hip Flexion Assist Device designed to assist and improve walking, that it is possible to prevent or significantly slow the rate of further deterioration of mobility and even to improve it. Funding support for the relevant specialized therapy (neurological physiotherapy) and devices is available under the NDIS. It is not available in aged care packages. The latter focus their support on devices for people who are no longer ambulatory.

It should also be noted that many younger people with MS are currently being found ineligible for the NDIS on the grounds that they do not exhibit a sufficient degree of “permanent and ongoing” disability. Given that MS is a progressive, degenerative disease this attitude makes a nonsense of the purported adherence to “early intervention.”

“Poorly defined boundaries between the NDIS and mainstream services can raise the risk of gaps in services...and cost shifting (between agencies or governments.)”.
(p15)

Indeed! This is exactly what is happening and individuals with disability are bearing the cost.

Is the way the NDIS refers people who do not qualify for support under the scheme back to mainstream services effective? (p17)

“State and Territory Governments provide mainstream services and offer support to those unable to access the NDIS”. (p28)

Equivalent support to that available under the NDIS for people with a non-age-related disability who have been excluded from the NDIS is simply not available under state and territory schemes. The ACT Government has essentially closed down its Disability Agency.

Attachment A

My Experience with the transition to the NDIS in the ACT

On the 8th of November 2013 I applied for a grant from the ACT Government under the auspices of the Enhanced Service Offer Grants Round 2 Offer. At the time I filled out a 23 page application form detailing the nature of my disabilities and my requirement for assistance. I understood that this program was part of a trial for the introduction of the NDIS and that it was important to register at this time to ensure that I would receive continuing support under the auspices of the NDIS. I understood that my details would be made available to the NDIS when it became fully operational on an ongoing basis.

I was successful in my application and received a grant for a WalkAide device which was paid on 17 April 2014 and which I acquitted on 27 May 2014. The letter that I received from the ACT Community Services Directorate stated that, **“we hope this allocation enables you to achieve some of your goals prior to the launch of the National Disability Insurance scheme in the ACT from July 2014.”**

I did not make further contact with the ACT agency as I assumed on the basis of this correspondence that I was “in the system” and that my details would be retained and made available to the NDIS.

In January 2016, I became aware that other people with MS in the ACT were starting to be contacted by NDIS planners to assist them in formulating a care plan. I contacted the NDIS by email to ask them what I needed to do to initiate a consultation to arrange ongoing support. To my great distress, I was advised that the NDIS had no record of my prior application or grant and that because in January 2016 I was then over the age of 65 that I was ineligible to register for the NDIS.

On 7 January 2016, the ACT Government NDIS website stated specifically that to be eligible for the NDIS a person must have

- “A significant and permanent disability
- Be a resident of the ACT
- Be under the age of 65 on 1 July 2014”

This can no doubt be verified by accessing the ACT Agency’s internal records.

I met all of these criteria on 1 July 2014 (my birthdate is 29 November 1949) and I met all the criteria stated on the ACT Government NDIS web portal on 7 January 2015, the date that I formally wrote to the Minister responsible for the NDIA and the Minister for Disability in the ACT. Following receipt of my representations the ACT Government altered the wording on its website.

I was advised by an official of the Department of Human Services, who had been delegated to respond to me, that in order to obtain a formal determination on my eligibility for admission to the NDIS, I should submit an Application for Admission to the NDIS.

This proved to be nearly impossible as:

- It is not possible to download an application form from the internet site
- It is not possible to obtain an application form by going in to the shopfront and
- The only way you can obtain an application form is by submitting to a telephone interview in which the first question is your date of birth. If you are over 65 it is not possible to obtain an application form no matter what your age and eligibility was on the launch date.

I was advised by the NDIS that my application had been rejected on 11 May 2016 on the grounds of my age. I immediately applied to the CEO of the NDIA for an Internal Review of that decision. On 24 June, 2016, I was advised that the Internal Review had upheld the original decision. I then explored the possibility of seeking a further review of my case through the Administrative Appeals Tribunal. After reviewing the legislation, I formed the view that such an appeal was unlikely to succeed given the lack of discretion accorded to the Delegate.

In further researching my options to find an equitable resolution to the situation in which I found myself, I revisited the information on the NDIS website regarding access to the scheme. The website contains the following information in its section on FAQs.

How will I be able to access the National Disability Insurance Scheme administered by the National Disability Insurance Agency?

You will receive an information pack from your current disability support provider.

This will contain a consent form which will ask your permission for the NDIA to contact you about having eligibility and support needs considered by NDIA. You will need to complete the form and mail it to NDIA or give it to your provider.

When we receive your consent form we will ring you in the month before you are scheduled to come into the Scheme. We will ask you to complete the [Access Request Form](#) and to provide information we need to confirm your eligibility to participate in the scheme. We will also ask for some information so that we can confirm who you are (like a birth certificate) – and where you live.

Finally, we will ask you about information you have on your support needs relating to your disability. This might include any current assessment you might have about your support needs, or your current Individualised Support Package plan.

You can then choose to give all of this information directly to us or ask us to collect it from other people so that we have the information available before we meet with you.

There appears to be no definition on the NDIS site of a “current disability support provider.” However I do have the letters I received from the Community Services Directorate. A letter dated 18 February, 2014 from the Executive Director, Disability ACT, stated “*Should you have an queries or require assistance in obtaining quotations, please contact the ESO Individual Planning Team...*” A further letter dated 1 April, 2014 from the Senior Manager, Contracts and Grants Unit, CSD, stated that “*...we hope this allocation enables you to achieve some of your goals prior to the launch of the National Disability Insurance Scheme in the ACT from July 2014...If you need any assistance with accepting this offer or putting your supports or services in place, and do not have a service provider who can assist you, please contact the ESO Individual Planning Team.*” These letters, together with emailed advice from the “*Clinical Consultant, Disability ACT*” clearly state that I was being offered personal access to an Individual Planning Team in the CSD and led me to believe that the CSD was my Current Service Provider. Furthermore this correspondence took place only a few weeks before the launch of the NDIS in the ACT.

The ACT CSD’s failure to contact me or advise me of how I needed to proceed given, that I was a very recent recipient of an ACT Government grant intended for disabled clients who were, in the words of the then Minister for Disability, Joy Burch, “in priority need” remains unexplained. Equally, I have had no satisfactory explanation of why the CSD not request my permission to provide my information to the NDIS, nor why, given that I was a person *in priority need*, no further contact was made with me? The transitional access procedure outlined on the NDIS website was not followed.

The then ACT Minister for Disability was sympathetic to my situation and made representations to the Federal Minister and the Chair of the NDIA on my behalf. I am not privy to the content of those representations but the facts are that:

- I was a legitimate and eligible applicant at the time of the launch of the NDIS scheme in the ACT,
- I was in receipt of support from ACT Disability prior to and at the time of the launch date of the NDIS,
- the information that the CSD held regarding my requirement for disability support which documented my eligibility, and/or my contact details should have been provided to the NDIA during the transition period.
- I was under 65 at the launch date.

Eventually, the ACT Government took the view that it was unfortunate that I had thought that I was already “in the system” but that there was nothing that could be done to redress the situation.

In turn the NDIA took the view that it was too bad that I didn’t apply for admission to the NDIS using the proper form at the proper time but that the Act allowed the Decision Maker no discretion to consider my circumstances.