Submission No 104

INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

Name: Ms Alisa Coleman

Date Received: 16 July 2018

Hon Greg Donnelly MLC,
Chair,
Portfolio Committee No 2 -
Health and Community Services,
NSW Parliament,
Macquarie Street,
SYDNEY NSW 2000

Attention: Mr Alexander Stedman
Director, Committees

16 July, 2018.

Dear Sir,

Re: Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

My name is Alisa Coleman. My submission to this Inquiry is written and presented from two perspectives. The first, from the perspective of an individual National Disability Insurance Scheme (NDIS) participant. The second, from the perspective of a former NSW Public Servant (from 1985 to 2000 inclusive), who wrote across-portfolio policy advice on disability specific issues, for the NSW Government.

Like the majority of people with significant disabilities, the roll-out of the NDIS with its implied promise of increased independence, participation through respected decision making and greater choice through, were necessary, controlled risk taking, was a policy shift that I cautiously welcomed.

From a policy perspective, I had misgivings over how well a government initiative reliant on private sector delivery would play out.

After 16 months of NDIS participation, I am now two NDIS Plans into the Scheme. On the face of it, the NDIS has delivered on its promise, to me. I have ongoing access to core services such as homecare and continence aids. I receive a transport subsidy. Allocated funds cover essential equipment maintenance as well as future equipment upgrades. I also have access to funds covering additional services provided by allied health professionals.

Dig a little deeper into the workings of the NDIS, however, and there are significant problems with Scheme implementation. The “risk taking” part of the NDIS promise has, for me and presumably other Scheme Participants, taken on a form that I, for one, did not fully anticipate.

A plethora of legislative instruments, declarations, standards and terms of business all require NDIS Registered Service Providers (NRSP’s) to respect and give priority to the needs of people with disabilities. In practice, however, there is no legislative obligation on NRSP’s to conduct business, post Registration, in a manner that places the operational practices of the NDIS consistently ahead of the NRSP’s private business operational considerations.

Effectively, NRSP's are continuing to operate as private businesses while receiving publically acquired NDIS dollars to deliver services to NDIS participants without being compelled to conform on a day-to day basis, post Registration, with any specific NDIS practice requirements.

From the perspective of an NDIS Participant, an unmonitored NDIS environment free from authoritatively binding accountability measures is enabling Private Service Providers to conduct business irrespective of the requirements of the NDIS, if they so choose.

To help to illustrate my concerns, all further comments are offered in the context of my most negative personal experience of the NDIS in practice and broadly cover three areas of the Terms of Reference for the Inquiry, as follows:

(a) The implementation of the NDIS and its success or otherwise in providing choice and control for people with disability;

(d) the effectiveness and impact of privatizing government-run disability services;

(f) the adequacy of current regulations and oversight mechanisms in relation to disability service providers.

The overall premise of my position is that the capacity to have choice and control in service delivery for people with disabilities is dependent upon all NDIS Registered Service Providers, whether private or public, being compelled to conform to effectively binding regulatory requirements and oversight mechanisms. Conformity is essential if NDIS directed public funds are to purchase and provide high quality, safe and consistently administered services to NDIS Participants, in accordance with Scheme aims and objectives.

At the present time, NDIS implementation and service delivery does not meet the requirements of my premised position.

The Problem – Personal and Systemic

In March 2017, two events occurred to me that have had an ongoing impact on my life. One event was anticipated the other unexpected. The first event was the approval of my initial NDIS Plan. The second event, in all probability linked to the first, was that my Homecare Service Provider, referred to herein as AUH, changed without notice, how my daily morning homecare services were to be delivered to me (and potentially all other AUH NDIS Participants who found themselves in a similar position to myself - mobility restricted and living independently and alone in private homes).

Effectively, AUH overturned a "reasonable accommodation" arrangement that had been put into place, on my behalf under the auspices of the Home and Community Care Program (HACC), by the then government-run Homecare Service of NSW, in 1996. The arrangement, which had continued, unbroken, until March 2017 (and some 13 months after the government hand-over of the Homecare Service of NSW

to AUH), permitted my morning care staff, to enter my home independently, by using sets of my door keys.

On the face of it, the change was a small one. All that was being required of me was that I answer my own intercom and front door to let my morning care staff into my home. The reality of the change was then and remains today, a far more significant issue….it reduced my level of personal independence and subjected me to a general requirement that does not accommodate my specific disabilities or living conditions.

I live alone in a large, strata managed, secure apartment building. I permanently use a motorized wheelchair for mobility. I am unable to access either my intercom or front door from my bed or my bedroom. Transferring from my bed to my wheelchair unassisted and unsupervised places me at a significantly higher risk of a fall and of potential injury.

In theory, the issue that I have described above should have been an easy complaint to resolve. In reality, it was then and still is now, unresolvable.

As the NSW Ombudsman's Office would later confirm, in March 2017, AUH had not developed a coherently documented complaint process, despite having received Registration through the National Disability Insurance Agency (NDIA). As a result, my internal complaint had rapidly escalated to become an external one, in the absence of a viable solution to the issue (including leaving AUH and receiving Homecare Services from another Service Provider).

I take the view that a forced decision to leave one arrangement for another is not a controlled choice and therefore not one that I am prepared to make. I share a long work history with my current care staff (one person for 18 years, others for 10+ years). We came together initially through the Homecare Service of NSW (the Service) and later transferred together to AUH.

The public Homecare Service trained care staff in ways that NDIS Service Providers are not currently compelled to do. The lack of face-to-face and general training under the NDIS, is of concern to me. No person with disabilities has exactly the same care needs as any other person with disabilities. For me to leave familiar care arrangements for the unknown, is not a controlled choice.

In the absence of acceptable choices, I have, over the last 16 months, sought and received advice and assistance from the NSW Ombudsman's Office (OO), the Australian Centre for Disability Law (ACDL) and currently the Australian Human Rights Commission (AHRC).

With the imminent termination of my AHRC action from 18/7/18, for failure to reach a conciliated settlement, my only remaining course of action, should I choose to accept it, will be to take my complaint onto either the Federal Court or the Federal Circuit Court.

As my case of indirect discrimination on the grounds of physical disability in the provision of goods and services, does not qualify for Legal Aid, the costs, financial, physical and emotional, will be mine alone.

How I have come to be in this position is still not entirely clear to me but is, upon reflection and with the benefit of both hindsight and additional research, becoming clearer.

In short, since March 2017, I have been threatened with a loss of service for failing to comply with an AUH "key policy" that did not and still does not exist. I had a formal complaint to the NSW Ombudsman's Office discontinued on the stand alone advice of the Respondent (AUH), without my knowledge or concurrence. I have been advised by the Australian Centre for Disability Law that they could make a case of indirect discrimination on the grounds of physical disability against AUH but for a lack of staff and other resources and I have taken part in an AHRC Conciliation Conference that, if it had been successful, would have given the Respondent (AUH) an authority over me that a swag of NDIS legislative instruments, declarations, standards and terms of business do not, at least on paper, permit.

Assumptions

The longer explanation is far more complex. I had, from the outset of my complaint assumed that all NDIS Participants (including me) and all NDIS Service Providers (including AUH), were contracted together as parties, under the auspices of the NDIA.

I had reasoned that as s118 of the *National Disability Insurance Scheme Act* 2013 (the *NDIA* Act), prescribes multiple functions to the NDIA, in order to assist the Agency to deliver the NDIS, it followed that the NDIS *Individual Service Agreement* had a contractual function.

My Agreement, in keeping with my reasoning, cited the NDIA on the front page of the document as the "Participant's (ie my) Plan Nominee or Plan Management Provider", together with me as the NDIS Participant and AUH as the NDIS Service Provider.

However, according to advice that I have recently received from the NDIA, via emails from the AHRC on three successive occasions (19/6, 21/6 and 11/7/18 respectively), the Agreement merely "outlines a personalized and self-directed support arrangement between the Participant and the Registered Service Provider." The fact that the Service Agreement template appears on NDIS letterhead is, according to the NDIA, of no consequence.

Apparently, no formalized relationship exists between NDIS Participants, NDIS Service Providers and the NDIA. This is despite the facts that the NDIA is responsible for approving the following:
Participant access to the NDIS, Participant Plan assessments, Plan contents, Plan reviews and amendments and, ultimately, Participant removal from the Scheme, in some circumstances.

The NDIA also has responsibility for registering all NDIS Service Providers. The Registration Process requires that each prospective Service Provider must formally acknowledge, in writing, through the *Declaration of Suitability,* an awareness of and

or agreement with, key documents relevant to the NDIS and obtain Third Party Verification (TPV), of suitability for registration.

Amongst the documents deemed to be most relevant for Registration in NSW are:

- The *Provider Guide to Suitability* - Section 9.6 of the Guide details the "Requirements for Specialist Disability Providers in New South Wales" (at page 74);
- The *NDIA Terms of Business* (NTB) is cited in the Guide above, as requiring, as an imperative, "…. agreement by all providers seeking Registration"; and
- The *NSW Disability Service Standards*, Disability Inclusion Regulation 2014, Schedule 1

There is, however, no compulsion, on the part of Service Providers to incorporate, implement or rely upon any of the elements of the NDIS documents into daily practice, post Registration.

The NDIA does not monitor NDIS document compliance. Nor does the NDIA hold Service Providers accountable, on a day to day basis for non-compliance. It is left to individual Service Providers to decide which documents, if any, from the Registration Process, they choose to incorporate into their core operations in order to provide services to NDIS Participants.

As a case on point, the *Declaration of Suitability* explicitly states, at point 13 that "the provider agrees to notify the NDIA as soon as possible after becoming aware of any of the following events (including):
13.1 a complaint has been made…..(about) effectiveness or safety of the provision of supports by the Provider…."

As this provision requires that Service Providers self-report safety concerns, I am confident, in hindsight, that AUH did not report my complaint to the NDIA in March 2017. To my knowledge, the NDIA first became aware of my complaint only recently when the AHRC contacted them, on my behalf.

Nor did AUH rely on other measures, including the *NSW Disability Service Standards*, in my case. The Standards require under the *Disability Inclusion Regulation* 2014, Schedule1, "(that providers)…..make sure the person's views are respected, that the person is informed as the complaint is dealt with, and that the person has the opportunity to be involved in the resolution process."

Instead of being made subject to the requirement of the Standards, on 15/5/17, I received an email from the Executive General Manager, Home and Disability Services, AUH, threatening to discontinue my homecare services, for "policy" non-compliance.

What role does the NDIA have in disputes involving individual NDIS Participants? Answer, none. This is despite the fact that the NDIA can revoke Provider Registration under s72 of the *NDIA* Act for non-compliance with the NDIS Terms of Business.

The decision to revoke Registration does not, however, extend to matters involving individual NDIS Participants in practice, despite the NDIS Terms of Business appearing to permit involvement.

Specifically, the NDIS Terms of Business (NTB) permits under the heading of "Provision of Services" (at pages 3 and 4) that:
"The Agency (meaning either the NDIA or the NDIA Launch Transition Agency -see Interpretations page 6, NTB), may issue from time to time, specific policies on how Registered Providers are to manage conflicts of interest in cases where there is a heightened risk to the Participant or the scope and magnitude of supports……These steps will be proportionate to the risk of the Participant and their ability to exercise informed and empowered choice and control."

In my case, post the threat to my services, I ceased dealing directly with AUH on matters relating to my complaint.

Despite the lack of Service Provider compliance with the documents of Provider Registration, the NDIA appears to place considerable value on the Registration Process, for reasons that remain unclear to me.

There is, arguably, no point in conducting a process that has no ongoing function or purpose, post process. Ensuring short-term awareness of aims, objectives, legislative instruments and principles is one thing but transforming written words into positive, long-term, measurable actions, practices and procedures, is a significantly different and far more complex, other thing.

Without some means of compelling Registered Service Providers to incorporate and implement the documents listed in the *Declaration of Suitability*, the Declaration is little more than a check-list in the process of Registration. The result, in my view, is the degradation of the fundamental intent behind the NDIS.

By way of explanation, two examples of what I view as lost NDIS intent follow:

1. For Providers, agreement with the *NDIA Terms of Business* involves, at page 3, (engaging in) "actions to manage actual or perceived conflicts (sufficiently to) ensure its (ie a Providers') organisational or ethical values DO NOT IMPEDE (caps added) a participant's right to choice and control."

   Had, AUH (as a Registered Service Provider) been compelled to comply with the stated requirement, my complaint would not have arisen. AUH have effectively argued over the last 16 months, that the door key issue, is not a matter over which I can responsibly exercise choice and control because it is an AUH operational matter.

   Despite AUH's assertion, choice and control remains a fundamental principle of the NDIS and is also a primary component of NDIA statutory function: s118 (1)(a)(ii), *National Disability Insurance Scheme* Act (2013);

2. Despite the NDIA's Registration Process requiring that Providers work through, then sign the Declaration of Suitability, the Sydney Morning Herald (June 30-July 1, 2018) reported on the fraudulent and unsafe practices of some NDIA Registered Family Day Care Service Providers.

   The point is that the Registration process is itself flawed. It is not rigorous enough to prevent the registration of suspect Service Providers, who once registered will operate in an unmonitored, unaccountable NDIS environment.

What value is the current NDIA registration process in light of the above examples?

During my first 16 months as an NDIS participant I have had no choice or control over the following significant issues:

- whether or not the former government-run Homecare Service of NSW should have been privatized;
- whether or not AUH was an appropriate private sector alternative (despite its long history as an aged-care Service Provider) to replace the Homecare Service of NSW given its lack of prior experience in the provision of disability-specific homecare;
- the introduction of a key "policy" change to my personal homecare arrangement (and the apparent unwillingness on the part of AUH to practice any form of policy flexibility in the delivery of its services to NDIS Participants);
- the complexities and limitations of both internal and external complaint processes (including the apparent inability or unwillingness to intercede on disputes involving safety concerns between individual NDIS Participants and Registered Private Providers); and
- an apparent lack of monitored Service Provider accountability in respect of NDIS implementation.

The NDIS is a scheme that is intended to operate in accordance with aims and objectives that place an emphasis on service access, individual needs, participation, integration, values, standards and service management through choice and control in dignity and with respect for people with disabilities. Without an effective way of delivering and monitoring the NDIS, however, the Scheme can never fully fulfil in practice the benefits of the NDIS promise.

Should the Committee require a more detailed explanation of the issues raised in my submission, I may be contacted at the address provided above. Alternatively, I may be contacted by email on or by telephone on

I wish the Committee of Inquiry success in its deliberations and look forward to any future outcomes from the Inquiry, with interest.

A. Coleman

Alisa Coleman
LLB (Hons); LLM (Hons)
NDIS Participant