Submission
No 198

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

Name:	Mr Peter Bennett
Date Received:	8 August 2018

Hi,

My name is Peter Bennett, I am a self funded retiree & do not receive any Centrelink benefits. I am a quadriplegic, I am 68 years old & have been living with my disability for 30 years in my own home. Please note, I am happy for my submission to be public.

Since my accident in 1988, I have received homecare from the state funded HomeCare NSW, my last package in this system was called CSP (Community Support Package). Since 2016, a private company, Australian Unity, receives my funding & provides my services, my funding now comes from the CoS (the Continuity of Support scheme) for people aged over 65 when the NDIS rolled out in their area.

Extremely Poor Communication for the over 65's who missed out on the NDIS

Before the NDIS rolled out in my area, I was receiving excellent communication via post from Family Community Services, Ageing, Disability & Home Care. I received plenty of positive advice about the NDIS & how great it was going to be & how it was going to change lives & help people with disabilities get out into the community etc. It was stated that, I didn't have to do anything, that it was all automatic because I was already receiving services. In 2014 I had an assessment done by Assessments Australia & was told it was for the NDIS, & I asked for a support person to help me. I had needed more hours approved for my Homecare package since 2010 (after having a stroke in 2008) & was still waiting, so I was really looking forward to the NDIS being rolled out. Letters kept arriving about the NDIS & that I would be notified when it was coming to my area. **Then all communication stopped**. In 2016, people I knew, were receiving NDIS support & I wondered when I was going to be contacted. I continually asked my service provider, Australian Unity, when I was going to be in the NDIS but they had no information either. I really needed somebody to advocate on my behalf, who new the system, but I had no idea who to contact despite trying Google.

I rang & emailed the NDIA & NDIS multiple times, but I wasn't in their system at all. I asked them multiple times, to send me something in writing, to say if I was in or out of the NDIS but received nothing. I started to assume that I had missed out & wondered if I should have filled in an application form. After ringing the NDIA/NDIS again & again (& waiting on hold for more than 40 mins each time, very difficult with a major disability) eventually they told me I could have filled an application form in prior to me turning 65 & prior to the the NDIS rolling out in my area which was 1/7/16, by then it was too late & this was extremely disappointing. I felt & still feel I never received all the facts.

I accepted I wasn't in the NDIS, & kept asking Australian Unity where my funding was coming from. Eventually they gave me a copy of a generic letter, given to service providers stating that the CoS (Continuity of Support program) would fund the over 65's who missed out on the NDIS. The CoS would be no different to before & that I should notice no difference. I receive 26 hours/week & that hasn't changed, but there is little capacity for extra funding in the CoS with changing needs.

Loss of Respite for Unpaid Carers

However, my partner lost her 5 hours respite a week, which I had been using for personal care to put me to bed, because I didn't have enough hours since 2010. My partner lost her respite because these hours were in her name, not mine, & there is no appeal & no way of getting her respite hours back. This seemed to coincide with the NDIS rolling out. This was a shock for unpaid carers & my partner received only 1 months warning beforehand, unpaid carers are obviously very under appreciated in the system. There seems to be no capacity in the CoS for respite in my name either (there is respite available in Aged Care, but this is unsuitable for me, due to not enough personal care hours provided in the Aged Care system) This loss of hours has lead to me having to decrease the number of showers per week I have, I now have only 3 showers per week & the other 4 days I have to have a bed bath, this was necessary to free time up for my night service which was previously funded by my partner's respite. **I am now much worse off than before the NDIS/CoS rollout.** If I had continued on as before, in the state funded CSP, my growing needs would have been catered for as I got older, but now there is a limit to how much the CoS will fund in the future. This has put untold extra stress on my partner & I don't dare to think what life would be like without her.

No Contact or Support for people in the CoS

There is no phone contact for the CoS, just an email address where they get back to you in about 5 weeks & they only give you generic advice, so nothing specific on your situation. I have received no paperwork or statement to where my funding is coming from, it is just left to the service provider & they have provided nothing in writing. The lack of information has been infuriating, stressful & harder to deal with than my disability at times.

I was never provided with a support person or advocate who knows the system, this would have been invaluable. I am not sure if any person knows the system anyway, it is totally disjointed & impossible to navigate. Why do people in the NDIS get advocacy & support but the over 65's in CoS get no support at all?

It is worth noting that the NDIA/NDIS staff have not even heard of the CoS, even though it's on their own website, so there is a severe lack of knowledge of the whole system which is of great concern.

Age Discrimination for over 65's & the NDIS

I regard the NDIS as been discriminatory against the over 65 year olds with a disability, we are a very small group of vulnerable people without a voice. My disability is still the same, before or after age 65, & if anything, I will need more support as I grow older, not less. The CoS does not have enough capacity to cater for changing needs of someone with a major disability. The Aged Care system is not suitable for someone with a major disability either, is it designed for the increasingly frail, but more able bodied. Over 65 year olds with a disability are getting treated differently to under 65 year olds with a disability, & this contrary to the Anti Discrimination Act. We are a minority of a minority & we have no voice.

Lack of Care Workers after NDIS Rollout & Funding

Since the rollout of the NDIS, care workers are becoming increasingly scarce. I believe this is due to more people getting services now with the NDIS, & therefore, there are less care workers to go around. My service provider hasn't been able to provide some my night services to put me to bed, due to lack of care workers, nine of my services have been missed in the last 2 months, this has never happened before, ever. Other Agencies have been asked to provide my service, but they have the same problem & can't provide anyone for me. I believe if the pay rates were increased for night work, this would attract more care workers to the job. I think federal funding needs to be increased so Agencies can pay their staff appropriately, especially for the more experienced Grade 3 or 4 Care workers as is needed in my case. I believe this should be a top listed occupation during immigration processes as well.

It should also be noted, that my service provider has told me that the government is underfunding them for my service, & this is due to the rate of pay per hour being severely outdated, the funding has stayed the same but rates of pay have gone up, therefore funding needs to go up too. There is a serious flaw in the system to allow this to occur. I sometimes wonder how some of the smaller agencies will survive & if all of my services will continue into the future.

Increasing the Medicare Levy

I believe most people in Australia wouldn't mind paying a little extra to provide for the NDIS or for people with disabilities, as they imagine themselves in that situation & would want to be looked after. I was astounded when the Government announced it wouldn't be increasing the medicare levy for the NDIS as they had planned, as the NDIS had plenty of money! An increased Medicare Levy could be used to fund the NDIS for the small number of over 65 year olds with a disability & stop the age discrimination. An increased Medicare Levy could also be used for increasing funding to agencies to pay for more experienced care workers for those with major disabilities & provide incentive for these people to work at night with a much higher rate of pay. Extra funding could also be used for other disability services left out of the NDIS, like CoS, Advocacy & Enable NSW

More Funding for Enable NSW after NDIS Rollout

Until fairly recently, I had self funded all my equipment like wheelchairs, car & home modifications, electric bed, hoist, catheters & other continence products etc. It basically costs me about $100,000 a year to have my disability. For a few years now, I have been getting Band 3 funding from Enable NSW for some equipment, it is a means tested system which pays for a percentage of eligible equipment. This hasn't really changed with the NDIS rollout, but it is a timely & laborious process that doesn't work all that well when you need equipment in a hurry. I am getting $600 worth of catheters per year through Enable NSW, & about $600 through CAPS, however I use approximately $3,500 worth a year, which is quite a shortfall. If Enable NSW had extra funds, they could supply more catheters for Band 3 consumers as they are a basic necessity for someone with a disability.

My overall experience since the NDIS rollout has been:

* In waiting for the NDIS rollout, the old state system was put on hold for years with no extra funding allocated for existing packages
* Lack of any information of my NDIS status & current funding package by a government office, it is left to the service provider which biased & lacks knowledge & information
* Age discrimination for over 65 year olds with a disability been left out of the NDIS
* Lack of any advocacy & support person through the whole process of change
* Complete loss of my partner's respite leading to 5 hours less personal care for me, which is a worse outcome for me
* Limited scope for extra funding for changing needs with the new CoS package, which is a worse outcome for me
* Less Care Workers available to do my service, leading to multiple missed services, which is a worse outcome for me
* NDIS/NDIA staff have little, if any knowledge of the CoS even though it's on their website
* No central office or website where you can access all information & contacts on disability services & advocacy
* Increased stress on unpaid carers & service recipients
* No information on how I can make a complaint or appeal the situation
* Lack of enough funding for disability services other than the NDIS, like CoS, Enable NSW & Advocacy

It should be noted, I only found about this Inquiry by pure luck, hence my late submission. It has not been widely publicised or promoted, which is extremely unfortunate & I imagine many stories will not be told. However, thank you for the opportunity to have my say about my experience with the NDIS rollout, I hope it gives a good insight to some of the unforeseen effects of the NDIS & CoS. I only hope this will help change things for the better.

Kindly, please acknowledge your receipt of this email.

Best Regards,

Peter Bennett