

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

Name: Name suppressed
Date Received: 8 August 2018

Partially
Confidential

Submission to the Joint Parliamentary Committee on general issues and
The implementation of the National Disability Insurance Scheme and provision
of
Disability services in New South Wales

By

J M and F B

Parents

26 July 2018

Note: Please use initials only if published.

Background:

We are the parents of a son who is 48 years old.

He has profound intellectual and physical disabilities and for the past 28 years has been a resident (one of five residents; four non-ambulant and one ambulant and all non-verbal) in a Sydney area government group home supported in all his needs 24/7.

To address the Terms of Reference:

- a) **the implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability.**

The principle and spirit of the NDIS is the perfect vehicle for people with a disability; the initiative commendable.

Let us not lose this major initiative once again by learning from hindsight.

Many attempts in the past have been made by the government to tender its disability services to the non-government sector; it did not succeed due to many factors that are arising within the NDIS scheme now.

Is this once again the cart before the horse? Where are all the safety nets for those who may fall through the gaps? What is the future for people with disability?

Any person with a disability has the right to live inclusively within society; however, many need numerous supports to do just that.

Who would not want to be fully supported to achieve their dreams and goals and have the funding provided to do so? I know I would.

But in all practicality the NDIS, after all the hype and advertising of being able to provide all those supports does not fully deliver, particularly for those with high support, complex and medical needs.

Those who may have variable needs and have had very little funding, if any, should benefit very well under the scheme if managed very carefully.

This is the point from where, in our opinion, the NDIS should have started. The scheme needed to commence more simply and move forward in many stages; it is decidedly more complicated in catering for those with higher support and complex needs.

One ongoing issue with the NDIS scheme is not defining what disability is according to their criteria and who may apply.

There is no real advertising about this fact.

Discerning these criteria appears to be left up to planners who are not adequately trained and are certainly not familiar with the many forms and issues associated with particular disabilities.

For instance: When required to contact the NDIA, for our son, after his and our details were submitted to the NDIA by the government, without consent; I was then questioned by the NDIA representative to confirm those details.

The information provided by the Department gave our son's prognosis as having an intellectual disability only. The details did not state the full picture of our son's condition as needing 24 hour care; he has limited capacity.

The NDIS representative was taken aback when told what care was required.

I was then told that a planner would be appointed (no control) to ring me and via phone would work out a plan.

I said 'no' to the phone call and requested a face-to-face meeting at the group home with our son present, as well as a staff member (Team Leader), so that the planner could actually see why I had made that request.

Is it really any wonder why those with limited capacity, with informal family supports, and perhaps those with very little in the way of advocacy except for staff providing information are encountering difficulties with the implementation and subsequent choice or control within the NDIS framework.

The NDIS is rolling out to a TIME FRAME directive and not to ensuring that people are adequately equipped to handle the full implementation of the scheme.

NDIS Plan: No choice or control

Our son's NDIS plan has now been reviewed for a fifth time: the initial Plan #1 with the majority of his needs being addressed; then Plan #s 2; 3; 4 and 5; all within the period of eight months; adjustments to the funding, decreases moreso, made in each review.

No consultation or notice was given prior to the reviews (as stated one would be notified according to the NDIS plan) with either ourselves, as his plan nominees, or the support co-ordinator (whose funding has been dramatically cut back in those reviews).

When the NDIA was queried about those reviews the response was that the plans were reviewed by an internal audit.

We are also not privy to the recent SIL quote given on the group home; it is our understanding that the participant/representatives should be consulted before these figures are given.

No prior consultation or notice given.

b) the experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans

Government Transition of group homes:

Recently the government transferred its specialist disability services including accommodation and respite services to the non-government sector.

The government was considered the provider of last resort. It is no longer.

The transition of the group homes has a direct impact on the success, or otherwise, to the implementation of the NDIS scheme for those with complex, medical and higher needs.

Our journey thus far:

We came into the government system when services were very limited; respite virtually nil, little contact with any social workers, no counselling, and very few other options.

It was the era.

Not like it is now with Early Intervention programs for families of young children with disabilities, which is a most necessary and welcomed service.

We were advised by the first social worker we saw to get our son into the government system should anything happen to us and because we had limited family or other supports available to us.

We have encountered many issues along that journey. Lastly, and not the least of those, was the furore raised in the late 80s when the only available placement for our son was in a nursing home; not the ideal situation, but because of his age, was the only alternative other than institutional care in Newcastle; too far from us.

This was not an option for us and we fought hard with many parties to have the current group home set up; this has been his home, along with two other of his friends from that time, for the past 28 years.

Now ... what are we all going through yet another upheaval and lack of security for his future?

Our son was guaranteed, by the then government, a permanent place within the current group home.

This is a 'home and family' made and not simply a house.

Informal Supports:

I make mention of this issue because it affects the implementation of the NDIS plan for those with limited capacity.

Due to our son's limited capacity we have always been able to work with the government, as the previous service provider, as informal supports for our son's medical and financial needs.

This has always worked well; however, under the NDIS we are now encountering obstacles with other services, let alone within the current group home, as not being his 'legal guardians' even though we were encouraged by the NDIA planner to be our son's plan nominees and I have, as his mother, been asked to set up his MyGov account; Centrelink; the signing of service provider agreements and other requirements on his behalf.

These informal arrangements, as I am certain for many families in similar circumstances, need to be recognised and respected; we are his parents, persons responsible and plan nominees. We have always been by his side.

Group Home Setting:

The complexity of residing (for those with limited capacity) in the group home setting is that no-one, Team Leader or Upper Management under the new service provider agreements, appear to know who should be managing what.

For us to be told prior to the transition that nothing would change within the group home setting could not be farther from the truth.

It is overwhelmingly stressful for all concerned.

Why? Because many government managers and staff also transitioned at the same time as the group homes and became the same management under new service providers - to our knowledge, very little training or education in the management of the group homes under the new NDIS arrangements has been given and from our perspective this has resulted in nothing but chaos.

We need to work with so many different people; sign and re-sign contracts with all service providers (according to how many changes to plan dates we need to notify them about); if one service provider is deemed unsuitable then we do it all again – sign and re-sign.

There has been much contention between staff and allied service providers who have been engaged (on an individual basis) and, at present, is not working to the full and idealistic expectations of the NDIS initiative.

In the group home situation, or any other co-housing arrangements, that requires high support management, one can only imagine for example: 5 residents needing, and have the right to under the NDIS scheme their own OT; speech pathologist; dietitian; physio or any other allied health service/ and or services?

Aside from us needing to engage these services on our son's behalf, these individual services are all being managed by the one Team Leader, and in our opinion, with little administration time being allocated; staffing levels insufficient to manage all the appointments and needing to be present to support the participant; let alone needing to take individuals to their various day programs; prepare all the meals; do all the household duties in between; and the participant's keyworkers (should they be fortunate enough to have a keyworker) attending to all the necessary paperwork and filing; and provide total personal care of the individual and their possessions.

Full time, consistent and qualified staff is paramount to the success of the NDIS implementation within the group home setting.

The necessity of fully training and educating group home staff prior to the government transition to the non-government sector was decidedly insufficient and time poor.

Medical Needs/Community Nurse:

Community based nursing provides a much needed and necessary service. Our son requires the community RN to provide an ongoing invasive procedure regularly on the same days each week to ensure the timely and consistent care for a chronic condition.

Other methods of care for this condition have been trialled in the past without success.

This qualified care has been given to our son since the late 90s after an incident occurred within the group home

It appears uncertain that this nursing service is going to be provided for under his NDIS package; the funding only allows for an RN to train un-qualified carers to provide this service.

This same suggestion of discontinuance of service has been encountered on a few occasions in the past and we have objected to this service being withdrawn for these many reasons; it has been recommended by GP referral.

When there is the need for group home staff to take leave or are ill and need to be replaced by casual, agency or other staff unknown to the home or residents, then there is more opportunity for this type of personal care to be given ad hoc.

How many carers would need to be trained to give continuity of care and be accountable for the procedure?

Community nursing care is a service to those in the community and for the community.

d) the effectiveness and impact of privatising government-run disability services

We do not see how the non-government sector can support the prolific release of the government-run group homes and its specialist disability services in such a 'holus bolus' manner.

We see this as simply an economic exercise; relinquishing all responsibility to the most vulnerable people in its care; and closing its doors to any recourse one may have should the NDIS scheme fail for whatever reason.

There is no turning back.

All safety nets have been removed for those participants and the new service providers.

g) workforce issues impacting on the delivery of disability services

We cannot stress enough the importance and dependence our son has on group home staff to be qualified; dedicated and consistent.

Quite a few staff have been associated with our son's group home for many years and need the incentive to continue and be valued for the care they provide.

With the possibility of new contracts being undertaken after the 2 years transition period of government group home staff, we see the probability of losing those staff due to renegotiations of their conditions under new service provision.

The lessening of those conditions and entitlements cannot be allowed to happen.

This can only encourage the use (and with all due respect to those people and the back-up service they fulfil); more casual staff, agency staff or volunteers; all due to the higher costs of employing more qualified and permanent staff.

Under the NDIS each individual has the right to know, and choose, who they engage to look after them and support all their needs.

We also have a right, on our son's behalf, to know any new staff and what their qualifications are when employed by the new service providers and provide daily personal care.

Safety issues:

What mechanisms are in place for the protection of very vulnerable people in care (with limited capacity to speak up) after the many recent stories arising around the abuse, neglect and exploitation of people with disability?

We are solely dependent upon the many good service providers providing best practice care.

Under the NDIS one has the choice to choose another service provider if unsuitable but, the waiting lists for the best service providers is often years long. What then?

One cannot jump the cue ... there is no real choice.

Re: Day Program staffing issue

Our son had been attending a day program, one day per week for 4 to 5 hours. At this point he was attending on a 1:2 ratio – one staff to two clients.

The service then notified us that there was an issue with his eating and drinking, in so far, as it was taking quite a long time to feed him and they could not get on with the remainder of the program.

It was suggested by the service that they would prefer he attend at a 1:1 ratio.

His support co-ordinator checked that the funds were available in his NDIS package for this to be done, sought our consent, and it was agreed that this would be fine.

However, right up until the afternoon of the day before he was to return, and we had signed the new service agreement with the provider, all was confirmed.

The following morning I was contacted via email and told that they could not provide the 1:1 position as they did not have the staff available on a consistent basis.

We now need to wait on the return of the program coordinator for us to see what options are available for him to remain with their service.

It is a local service and transport to and from his group home is manageable within the routine of the home; he cannot travel on his own (non-mobile and non-verbal).

Workforce issues are numerous in trying to encourage and maintain reliable, appropriately qualified, trained and permanent staff in order for services to deliver what they are actually offering.

How can the best standards be maintained if the many issues are not addressed; service providers will not have any choice but to close their doors; or those with much higher support needs will not be able to access these services.

Where is the choice and control in this situation?

This only proves to us the necessity for a service provider to use a transient workforce.

h) challenges facing disability service providers and their sustainability

For any service to function fully, and to the highest quality standard, they need a qualified, dedicated, permanent workforce and the funding to do so.

We do not see the NDIS scheme working unless there is appropriately qualified staff doing the correct assessments; appropriating the funding necessary; good monitoring of the participants progress; and the need for timely reviews.

Where is the funding going to come from in the future to guarantee the sustainability of the NDIS scheme for all of the above?

We are grateful for the group home he is in; the group home staff; and are seeing encouraging signs that he has a good new service provider in these early days of transition.

We are in our 70s now and with all the emotional turmoil and uncertainty for his care and future we find it is taking its toll.

The NDIS states: 'The NDIS will provide all Australians under the age of 65 who have a permanent and significant disability with the reasonable and necessary supports they need to enjoy an ordinary life'.

Our son's aspirations and goals are limited; however, his support needs are many in order to simply live 'an ordinary life' in safety, security, and peace, now and in the future.

We appreciate the opportunity to present this submission for your consideration.

Sincerely

(Parents of a person with limited capacity)

