

Submission
No 307

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

Organisation: Intellectual Disability Rights Service

Date Received: 22 August 2018

22nd August 2018

The Director, Portfolio Committee Number 2

Health and Community Services,

Parliament House, Macquarie Street, Sydney, NSW 2000

And by email: portfoliocommittee2@parliament.nsw.gov.au

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

(We thank Mr Stedman for granting us an extension of time until the 22nd August 2018 to make submissions).

About IDRS.

The Intellectual Disability Rights Service (IDRS) is a community legal centre that provides legal services to persons with intellectual disability throughout NSW. IDRS's services include the provision of legal advice and legal representation in select matters. IDRS engages in policy and law reform work and community legal education with a view to advancing the rights of people with intellectual disability.

We have copied your terms of reference below, and we have made submissions in relation to the terms of reference that are most relevant to our clients.

Terms of Reference

That Portfolio Committee No.2 – Health and Community Services inquire into and report on the provision of disability services across New South Wales, and in particular

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

Firstly, the NSW government needs to expand and guarantee advocacy funding, and legal centre funding, in order to assist participants with understanding and negotiating service agreements generally, and to assist with negotiations or legal action when these agreements are breached.

Group homes are called specialist disability accommodation under the NDIS.

There are around 8,000 people with disability living in supported group accommodation in NSW, (see page 2 of the data from the NSW Official Community Visitor Scheme). Under the NDIS, service providers now require them to enter into contracts. In many cases, residents do not know their rights, or receive support to enforce their rights. There are also issues about finding a responsible person to sign on their behalf. For each group home resident an accommodation agreement and a services agreement is required. Each of these agreements typically includes more than four pages of conditions and extra pages of attachments. These agreements are usually prepared by the service providers. We are aware of cases where the service providers refuse to make changes to these agreements when they should be changed to cater for the individual needs of the group home resident.

Also under the NDIS separate agreements may be required for any other services provided, such as having a co-ordinator of supports, community access services, day-programmes, etc.

Two of the assumptions under the NDIS are that all participants will know their consumer rights, and that they have legal capacity to enforce those rights. Unfortunately, both assumptions are not true for many participants. The NDIS will not fund legal services, and government funding of advocacy is uncertain. Without access to free advocacy, and free legal services, many residents of group homes, and other people with disabilities, will not know their rights, nor will they be able to enforce them.

Secondly, there is a need for the NSW Government to legislate to provide residential rights for residents of group homes similar to residential tenants and boarding house occupants.

Group home residents do not have rights under the *Residential Tenancies Act 2010*, nor under the *Boarding Houses Act 2012*. Their rights depend on the accommodation agreement they have with the service provider. In many cases residents are unable to understand or sign the accommodation agreement and they have no-one to help them.

The NDIA has published Terms of Business for service providers that provide for terms that must be included in a Specialist Disability Accommodation service agreement. These refer to matters including the maximum rent, the maximum board, the duration of the agreement, notices of termination, a minimum 90 day notice before the resident can be evicted, etc. Service providers may use their own service agreements. If service providers do not comply with the NDIA Terms of Business they risk losing their registration as a service provider, but there is no other penalty. (Please refer to the following source for the **NDIS Terms of Business for Registered Providers** and for the **Specialist Disability Accommodation-**

Addendum to the Terms or Business for Registered Providers):

ndis.gov.au/providers/provider toolkit/key resources/important documents/terms of business

Unfortunately, despite the NDIA terms that must be included, these agreements do not protect group home residents against

- Eviction,
- The conflict of interest that arises when the accommodation provider is the same as the service provider,
- The strict enforcement of the terms of the agreement by the accommodation service provider without the resident being able to negotiate the terms because of the shortage of group home accommodation, the stated supports that the NDIA has put in place for the resident, and the disability and vulnerability of the resident.

In March this year, the NSW Department of Family and Community Services was involved in a consultation process relating to the Protection for Residents of Long Term Supported Group Accommodation in NSW. We are not aware of the outcome of that consultation.

We submit that whilst it is possible for a group home resident in NSW to take legal action on the grounds that a service agreement is unjust, or not fair and equitable, (for example under legislation including the *Contracts Review Act 1980*, *The Fair Trading Act 1987*, and the *Australian Consumer Laws*), never the less, these laws have not been drawn up to cater for group home living arrangements, and as far as we are aware, they have not been applied to them.

The *National Disability Insurance Scheme Act, 2013, Clth*, does not prevent the NSW government from legislating to provide residential rights for residents of group homes.

Thirdly, there is a need for the NSW government to make some changes to the NSW Civil and Administrative Tribunal, (NCAT), to provide a suitable forum for dealing with all service agreements, including group home accommodation agreements.

Our clients usually have no funds, and therefore they are denied access to justice in civil matters in the courts. NCAT is their only practical way of enforcing their rights.

We submit that the following changes need to be made to NCAT:

- More resources are needed to work with our clients because they often have to rely on support workers, carers, advocates, and community legal centres to help them apply to the Tribunal, provide evidence, and appear at hearings, and
- The jurisdictional limit of \$40,000.00, should not be used to deny our clients access to the Tribunal, and

- It should be made clear that the Tribunal has powers to make orders resembling specific performance, and injunctions, because in many cases damages will not be a suitable remedy, and
 - It should be made clear whether NCAT orders need to be registered with the Local Court to be enforceable.
- b. The experience of people with complex care and support needs in developing, enacting, and reviewing NDIS plans,

We submit the NSW government should fund more supports because the NDIA does not give people with learning disabilities extra help to implement their plans, and because the NDIA does not investigate accurately whether people with learning disabilities have a support person.

One clear error in delivery of plans to many people with cognitive impairment is the lack of provision of any support to implement those plans. There seems to be no understanding that a person who has learning disabilities as their primary disability would also need to have lots of help to implement their plans. We have seen many people who either have had no idea how to enact their plans or how to engage the services they want to engage to reach their goals. We have met people who have not spent a dollar of their plan and it is about to expire – meanwhile they are homeless, lack support or any constructive goals in their lives. For these people the transition was not at all well managed and there should be ongoing careful consideration that people with cognitive impairment should be given the opportunity to have support coordination until such time as they no longer need it.

Also, the fact that an advocate/friend/neighbour turns up to an initial planning meeting doesn't mean that person is "the" informal support or mainstream support for that person ongoing. This assumption has on some occasions to our knowledge been actively discouraged by the actual support person yet they are still mentioned by name as the informal support in the plan and no other support has been provided in the plan to help implement it.

- c. The accessibility of early intervention supports for children,

Firstly, we submit that the NSW government should provide more resources for occupational therapy and speech therapy, and also fund therapy for children with learning disabilities whilst they are waiting for the NDIA to make a decision about their therapy.

There is a large demand that is not being met to access occupational therapists, (OT). OT waiting lists in NSW we are told are extremely long and it takes months for an OT to assess children for their needs if they do not already have an OT they can access through the health sector due to their health related disability. Speech therapy access also has long delays in getting through to services in some areas but this is not as bad as OT.

Also, the barrier, to families accessing timely therapy for their child with a cognitive disability, is the time the NDIA takes to respond to any request for therapy that is beyond the NDIA internal proscribed

amounts. When a family lets the planner know that they want to have their child engaged in therapy for anything from speech to intensive behaviour therapy even if that family has extensive evidence of the success of the therapy the support will not be granted at the planning stage. The planning stage is simply not equipped to cope with investigations in to the s34 criteria of “reasonable and necessary.” Families are left having to embark on the lengthy internal review process to examine the evidence they have of therapy success. This internal review process takes months (at least 3 months and more likely somewhere between 6 months or until the end of plan). In the meantime the child receives reduced therapy levels and this can see either the family paying for the supports out of pocket or children dropping further behind in their supports.

The NDIA has, in a number of cases we have seen, referred families to a Commonwealth Service that supports families in crisis as an appropriate support to be used for day to day family support for children with ongoing exceptionally high needs. Not only does this show their lack of knowledge of the problem, it also does not help the child and it causes more stress for the family supporting the child.

The NDIA has also inappropriately told families they should be accessing services under the National In Home Care program where the principle of that program is to provide short term support for children with challenging behaviour. Again it shows the lack of knowledge of the NDIA because this service is completely at odds with the need for the ongoing consistent personal care needed to shower, bath, be fed etc to meet the needs of a child due to their specific disability.

Secondly, we submit that the NSW government should provide more information to the NDIA about the community services that are not available in NSW for people with disabilities.

There is a lack of knowledge within the NDIA about the access principles of alternative government schemes that may or may not exist in NSW for people with disabilities. In our experience some people are refused NDIS funding based on the reason that they can access a service in the community and then when they apply for that service they find it is not available for them.

The NSW government has entered an agreement with the Commonwealth about what “interface” services are State responsibility but the State services do not exist! The NSW government must act to fill these State gaps.

- d. The effectiveness and impact of privatising government run disability services,

Firstly, there is a need for the NSW Government to be an accommodation provider of last resort for people who cannot find group home accommodation.

We have a case at present where the same service provider manages the group home and supplies the accommodation and independent living services to residents, and that service provider has given our client a notice of eviction and withdrawal of services. Our client has done nothing wrong. The client’s family are not able to provide care. No alternative suitable accommodation has been found. The NDIS (Quality and Safeguards) Commission has said that they have no powers to stop the eviction and withdrawal of services, and legal action would

involve significant time and costs to all involved. If the eviction proceeds our highly vulnerable client will be left in the street posing grave risks to their safety.

Our clients often have high needs requiring 24/7 care. Also they often have behavioural problems related to their disability. These conditions can be challenging for staff and other group home residents. Therefore, our clients may easily become homeless because the service provider does not want to care for them, or they assault the staff or other residents and an apprehended violence order is made restricting them from returning to the group home when there is no suitable group home accommodation available for them.

The NDIA does not fund emergency group home accommodation, as far as we are aware. Nor does it restrict service providers from evicting residents, even where there is no alternative suitable accommodation available for them.

Before the NDIS, Aging Disability and Home Care, (ADHC), was the accommodation provider of last resort with a portfolio of group homes and with connections to other NSW departments that provided accommodation. Now that ADHC has gone, there is an urgent need for the NSW Government to provide emergency group home accommodation for our people with cognitive disability.

Secondly, there is a need for the NSW government to retain ownership of its remaining stock of group homes in NSW because there is a shortage of group home accommodation.

Before the NDIS there was a shortage of group homes under ADHC. We believe it has sold some of its group homes. The shortage continues.

The NDIA does not build group homes. Instead it relies on private service providers to supply them. Its approach to overcoming the shortage is to offer financial incentives for the private sector to build more group homes, however the final outcome of this approach is unknown. For example, in August 2017, the Summer Foundation and PricewaterhouseCoopers released a joint report on specialist disability accommodation under the NDIS which stated that "at the moment there is so much demand that people don't have any choice...When we talk about a mature market it's having the supply meeting demand in the 10 year time frame."

We understand the NSW government still owns a number of group homes and some of them are leased to private service providers. We know from our clients and from community forums that many of the NSW government's group homes had to be AAA rated purpose built homes with ramps, wider doorways, height adjusted bathroom fittings, and height adjusted kitchen fittings, etc. These homes should remain in NSW government ownership, or if sold, in future, there should be a covenant requiring the private service provider to use them as group homes for 50 years. If in future, the supply of group homes exceeds the demand, the need for the NSW government to keep its stock of quality group homes can be reviewed.

We request that the government does not sell its remaining stock of group homes.

- e. The provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme

We repeat the two matters referred to in response to paragraph d.

We also submit that the NSW government should fund emergency supports for people with disabilities.

We note that before the NDIS, when a person with a disability was accepted by ADHC, there was a willingness to properly provide for any urgent changes to their reasonable needs, and there were case-workers to help them. Under the NDIS, the ground rules have changed, because the onus is on the person with a disability to apply to the NDIA for any changes in their plans, and until their application is approved, the NDIA makes no changes, and provides no funds. As stated, many people with disability are incapable of applying to the NDIA without help. Nor does the NDIA fund case-workers to help them, (although the NDIA does fund co-ordinators of supports, and local area co-ordinators, however these positions do not have the personal involvement that case-workers used to have with the person with a disability). Therefore when there are changes in circumstances people with disabilities should be supported by having their urgent needs provided whilst they await a review of their plan by the NDIA.

- f. The adequacy of current regulations and oversight mechanisms in relation to disability service providers

In NSW the NDIS Quality and Safeguards Commission commenced on the 1st July 2018. Although it is too early for us to be aware of the workings of the Commission we note the following:

Firstly, we understand that the NSW Ombudsman, Official Community Visitor Scheme, will continue, which is welcome, however, we fear that its ability to protect our clients has been weakened with the demise of ADHC, and because it is not directly connected with the NDIS Quality and Safeguards Commission.

Secondly, the NDIS Quality and Safeguards Commission has a complaints procedure based on conciliation with the service provider. This depends on the goodwill of the service provider. As stated above, there are clients with complex behaviours that will be difficult. There are no time limits for resolving complaints, and the commissioner does not have powers that can help people with disabilities enforce their rights under their service agreements. (For example, we refer again to the group home eviction case above). Therefore, when difficult problems cannot be resolved with the service provider, it is left to the person with disability to take their own legal action, which is

often problematic for them. We are concerned that the power imbalance has shifted further in favour of the service providers.

- g. Workforce issues impacting on the delivery of disability services,
- h. Challenges facing disability service providers and their sustainability,
- i. Incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services,

We had one case where it was very clear that the NDIA should have provided funding for the child to be cared for safely in the home, however no funding was received from the NDIA, and fortunately the NSW health services provided the funding. We had another case where the mother of the child with complex needs received no funding from either the NDIA or NSW Health or from anywhere else, for two years for the provision of some appropriate respite care whilst she was ill or he was ill.

- j. Policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales, and
- k. Any other related matter.

Issues for people with disability in the criminal justice system: They are,

Issues around the funding of assessment or support plans for people with disabilities that are needed for court appearances to achieve diversion orders.

Issues around having a supported independent living (SIL) assessment done in order to get bail, because these cannot be done while the person is in custody.

Issues around not being able to have a NDIA plan done until there is a release date. This poses a problem for those who spend a long time on remand.

In our experience people with cognitive disability are more frequently being remanded in correctional centres and for longer periods because there is no effective system in place to facilitate access to the NDIS, planning or access to support services when a person with disability is in prison.

For further information or to discuss our submission please contact the undersigned.

Thank you.

Janene Cootes, CEO, IDRS.

Tim Chate, solicitor, IDRS