

**Submission
No 148**

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

Organisation: NSW Council for Intellectual Disability

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Submission to inquiry into the NDIS in NSW

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Who we are

NSW Council for Intellectual Disability (CID) works to ensure all people with intellectual disability are valued members of the community. CID has been a leader in disability rights for more than 60 years.

People with disability are at the front and centre of everything we do – they are decision-makers, staff members, Board Members and spokespeople. We work to build a community that protects rights, includes everyone and supports people well. We focus on issues that people with disability tell us are important, such as the NDIS, health, jobs, education, transport and safety.

CID promotes human rights. We help people with disability to be heard, we speak up on the big issues and campaign for change. We advise organisations on how to be more inclusive so that our society is equal and accessible.

We believe people with disability should have the same opportunities as everyone else. Through CID all people with disability their families and supporters can learn and build skills, and actively participate in the community. We provide information, hold workshops and develop useful resources. We go to community events, share our stories and connect with peers.

This submission complements that of our Advocacy Group

CID has an Advocacy Group of people with intellectual disability which has made its own submission to the inquiry. CID supports the points raised by our Advocacy Group and provides the following submission which complements that of the Advocacy Group.

Problems with NDIS implementation in NSW

CID is a strong supporter of the NDIS and its underlying concepts of equity of access to disability support and choice and control by people with disability. The NDIS has benefited many people. However, there have been fundamental problems with its implementation which need to be fixed if the scheme is to fulfil its potential.

Particularly in the first year of NDIS implementation in NSW, but continuing to a substantial degree to date, CID has been receiving numerous complaints about the process and outcomes of NDIS plans in NSW. These concerns have come from a wide range of sources including people with intellectual disability, parents, service providers and other advocacy groups.

These problems have included:

1. The lack of any concerted strategy for outreach and engagement with people with intellectual disability who lead isolated lives and who would be unlikely to be aware of or seek out the NDIS.
2. Lead up to planning meeting
 - a. Lots of confusion about engagement with the Scheme, the initial phone calls from National Access Team, and the planning meeting itself.
 - b. Anxiety about not being ready and not knowing what to ask for.
 - c. Need for individual advocacy services to support people through planning meetings, particularly for people who are marginalised and don't have close informal supports.
 - d. Lack of adequate supply of individual advocacy.
 - e. Reports that the NDIA is unreasonably requesting people to get assessments for their intellectual disability
3. Skills and experience of planners and LACs who often have very little experience with intellectual disability.
4. Role of current service providers in planning meetings – Inconsistent practice from service providers being the main/only participants through to not being involved at all with resultant anxiety for families.

5. Self management - Discouragement of families from pursuing self-management, including families who have been successfully self managing in NSW.
6. The plan
 - a. Disconnects between discussions in plan meetings and plans received.
 - b. Very wide disparities of funding for people with similar needs.
 - c. Very reduced and inadequate funds for professional supports including behaviour support.
 - d. Inadequate funding allocated to people in contact with the criminal justice system, including clients of the ADHC Community Justice Program.
 - e. Wide variation in the degree to which plans acknowledge and address individual goals and needs.
 - f. Plans very difficult to understand and action if a person does not have a skilled support coordinator.
 - g. Major concerns about the mobility allowance, especially in regional areas.
2. Support coordination
 - a. Planners and LACS inconsistency in funding of support coordination.
 - b. Very limited market of support coordinators.
 - c. Service providers being made the support coordinator without choice and despite conflict of interest.
3. Demarcation issues between the NDIS and State mainstream services leaving individuals without necessary support that they had previously been getting from State disability services.
4. Very hard to contact NDIA with concerns
5. Unwieldy and slow review and appeal processes

This experience has left CID with major concerns about:

- The participant pathway - The NDIA has recognised major problems with its planning pathway and a new pathway has been trialed but not yet implemented beyond trial areas. The trials have not been in NSW.
- The speed of the transition process in NSW with 72,000 people transitioning into the NDIS in two years. This speed has made it extremely difficult to maintain plan quality.
- The skills, experience, training and caseloads of LACs and planners.
- The methodology being used to finalise plans including whether reference/typical support packages for people with intellectual disability:
 - Have carried much greater weight in individual outcomes than they were intended for.
 - Are an accurate reflection of participant needs.
- There being major compromises on the NDIS foundational principles of choice and control both generally and in relation to self management.

- Conflicts of interest between participants and direct support providers not being adequately addressed.

My Choice Matters

The NSW Government did seek to build the capacity of people with disability in NSW to exercise choice and control including through funding CID to run the My Choice Matters project. www.mychoicematters.org.au/

Since 2014, MCM has delivered workshops to over 13,000 people with disabilities and their families and carers in 174 towns and cities across NSW aimed to build confidence and understanding as the NDIS has been rolled out. Over 60 resources have been developed including some designed to strengthen the ability of mainstream services such as health and education to engage in conversations about the NDIS. Other programs have included a Become a Leader face to face program and online platform, a schools program for Year 10 students, peer group training in mentoring and facilitation, training for residents/staff and families in supported accommodation as well as grant applications to run peer groups and community projects.

However, the reach of this program was inherently limited and the ability of people to actually exercise choice and control was very much constrained by the above problems with NDIS planning and the limitations on choice imposed by the NSW Government process for tendering out of its disability services. See below.

Problems with NSW Government tender out of its disability services

Rather than being focused on individual choice and control, the NSW Government process for exiting from service provision was based on tendering out of Ageing, Disability and Home Care (ADHC) services to the non-government sector in large service groups.

1. Choice and control is central to Government disability policy but was not reflected in the Government's process to transfer its services to NGOs

The NDIS and NSW Government disability policy have been founded on people with disability having choice and control over their lives and their support services.

The objects of the Disability Inclusion Act 2014 NSW include:

- (c) to enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports and services.

The NSW Government process for transfer of its services to the non-Government sector did not reflect choice and control. It was rather based on a tender process where ADHC services were put to the market in large groups of services, including

ADHC's 352 group and respite houses being put to the market in 18 geographic based groups, that is an average of about 20 houses in each group.

One negative effect of this approach and the long leases of group homes given to successful tenderers was to entrench the group home model despite its limitations on individualised lifestyles and choice of whether to live in a congregate environment and, if so, with whom.

2. There was no consultation process with people with disability and their families and advocates about the proposal to tender services out rather than allow people to choose what service they wanted and from which providers.

This lack of consultation contrasted markedly with long established practice in NSW and the expectations in the Carers (Recognition) Act 2010. (Section 7(2) and Carers Charter)

There was some subsequent consultation but this was only after the key decisions had been made by the Government:

- Consultation with families about what qualities they would look for in new providers and some inclusion of community nominees in panels inputting to shortlisting of service providers.
- ADHC ran local forums where group home residents and families could hear from shortlisted service providers and express a preference for a provider. However, this preference would carry very limited weight given the large groupings of services that were to be allocated to successful tenderers and due to final decisions being made by Government.

The influence of these local forums was ultimately further eroded by shortlists of only one provider being offered for consideration in most ADHC regions. Many parents reported to us their anger about this whole process, in some cases reporting a history of negative dealings with the one provider that had been shortlisted for their area.

Even if all of the people living in a particular group home were opposed to the provider ADHC chose, they will not be able to change their provider for two years. The Government pointed out that, in the meantime, people with disability could leave their home to seek a different provider. But, where are the homes with vacancies that people could move to? And why should people have to leave their homes because the Government has imposed on them a service provider they don't want?

This NSW process was markedly inferior to that in the ACT where residents of each group home could choose which of a range of service providers would take over their specific group home.

3. There was considerable opposition amongst families/carers to the Government's decision to cease being a service provider.

This opposition was particularly strong and understandable amongst families of people with complex behavioural needs due to:

- ADHC always having been the predominant provider of services to people with complex needs. See KPMG (2015), *Market analysis and consultations to inform the safe transition of people with complex support needs to the NDIS*.
- ADHC's longstanding role as provider of last resort for people with complex needs.
- Many families' experiences of NGO services not being able to meet a person's needs and the NGO then withdrawing its services and ADHC needing to take over.
- The NDIA not having developed any clear plan for how it would meet the needs of people with complex needs, including supported accommodation provider of last resort and crisis arrangements. This remains the case at the time of this submission despite work by the NDIA towards develop a complex needs planning pathway and provider of last resort arrangements.
- The Government was tendering out the complex behavioural needs roles played by ADHC but there was no clear plan for how the NDIA would continue funding these roles past June 2018. This issue remains unresolved.
- ADHC provided or funded a range of very important mental and physical health services which would not be maintained by the NDIA. There was no plan for whether or how these services would be maintained. See below.

4. The Government was committed to fully exiting disability service provision by June 2018.

There was community concern that this deadline could lead to

- Tenders being accepted that would not lead to a reasonable quality of service provision, in particular for people with complex needs.
- An undue advantage for large service providers and large consortiums so that the Government could transfer services to a comparatively small number of providers.

These factors created a conflict between the interests of Government and the interests of people with disability.

5. Whilst the NDIS would allow people with disability to change support arrangements and providers after the Government's tendering out process, in fact the tender decisions made by the Government could considerably constrain this choice.

Tender decisions gave successful providers a market advantage related to the size of the market share they acquired and the 5-10 year leases (plus options to renew) given to successful tenderers for supported accommodation.

Recommendations

- The inquiry should squarely acknowledge the flawed process by which the NSW Government exited from service provision and transitioned people with disability into the NDIS, in particular highlighting how that process was inconsistent with the Government's own commitment to choice and control by people with disability.
- The NSW Government should work with the NDIS to make certain that there are adequate disability services for people in crises and with complex needs, including the State reinstating community based provider of last resort arrangements until and unless the NDIA fills this gap.

The latter of the above recommendations is further supported by:

Inadequate disability supports leading to strain on other services such as justice and health services

The lack of any current NDIS system to ensure crisis and last resort service provision, in particular for people with complex needs, is likely to result in inappropriate use of general and psychiatric hospitals and gaols as supported accommodation.

At our complex support needs Roundtable in 2017, a table group of people with expertise on the NDIS interface with the justice system reported that, with NDIS implementation and ADHC exit from service provision, the following problems have arisen:

- Greater difficulty and delay in getting disability support services which are essential to put together a support plan to get a diversionary order from the court.
- Increased difficulty and delay in getting disability support when a person with cognitive disability has been charged with a crime has resulted in some people being unnecessarily remanded in custody.
- If person is in prison and does not have an NDIS plan or needs a plan review to set up an adequate disability support plan, there is no clear system to get this done quickly and the person can spend a long time in prison.
- Many people with intellectual disability do not know they have a disability until they come into contact with the justice system.
- Some people with complex needs are not taken up by services – the market is not responding to their needs.

www.nswcid.org.au/images/Resources/A_Pathway_Through_Complexity_CID.pdf

Gaps in services

Under its agreement with the Commonwealth, the NSW Government agreed to hand over its whole disability budget for NDIS participant plans.

It soon became apparent however that there was a range of very important services funded by ADHC that would not continue to be funded by the NDIA.

Health services funded by ADHC

ADHC provided or funded a range of very important mental and physical health services which would not be maintained by the NDIA. There was no plan for whether or how these services would be maintained. The Ombudsman highlighted the need for prompt resolution of the future arrangements for these services www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/reviewable-deaths-vol-1/report-of-reviewable-deaths-in-2012-and-2013-volume-2-deaths-of-people-with-disabilities-in-care page 64 and Recommendation 9. CID has advocated very strongly on this issue, with some success. The current status of these services is in the attachment to this submission.

On a very positive note, NSW Health has allocated a new \$4.7 million a year for intellectual disability health services. This will extend the services provided by three pilot intellectual disability health teams. There will be six intellectual disability health teams located in Local Health Districts. In other LHDs, there will be an outreach nurse or allied health professional who will be able to link people to some assistance from the intellectual disability health teams. These services will fill some of the gaps left by the ADHC health services.

Recommendation - NSW Health should audit and fill any gaps in health care left by the cessation of ADHC funding for intellectual disability health services.

Assessment and management of dysphagia

Like its counterparts in other States, ADHC has a long history of providing or funding speech pathology and other allied health professionals for assessment of swallowing problems and preparation and implementation of mealtime management plans.

Until some time in 2017, the NDIA accepted responsibility for funding these services. Then, it decided that assessment of swallowing problems and preparation of eating and drinking plans were not its responsibility but the responsibility of health services. CID and, we understand, the NSW Government see the NDIA stance as incorrect on this and we understand that this issue will be ultimately considered by the Disability Reform Council. This issue needs urgent resolution as, in the meantime, people with disability and swallowing problems may be at grave risk of limited lifestyles, choking and death.

Recommendation - The NSW Government should vigorously pursue the NDIA accepting responsibility for assessment of swallowing problems and preparation of eating and drinking plans. If the Government is unable to promptly resolve this issue with the NDIA, it should

provide a funding stream to allow specialist disability speech pathologists and other relevant professionals to do this work.

Interface with justice services

The Community Justice Program (CJP) is a long-standing and highly successful program of ADHC that provided tailored community disability support to over 300 people with intellectual disability and very serious histories of offending. General ADHC services also provided a range of assistance to people with less serious histories of offending.

The NDIA has taken a narrower view of its role than ADHC seeking to distinguish supports needed because of 'offending behaviour' as opposed to supports needed because of 'challenging behaviour'. This is a false distinction. When a person with intellectual disability is labelled as having offending behaviour, this is because the justice system has become involved rather than because the behaviour does not relate to the disability.

Also, the NDIA has tended to argue that the justice system has responsibilities for offenders with intellectual disability that it is never had in any systematic way for offenders with or without disability.

In view of this problem, the NSW Government has allocated money in the 2018 budget to maintain the CJP.

Recommendations

- The NSW Government should continue to fund the Community Justice Program as a hub of expertise in the casework and behaviour support needs of people with intellectual disability and serious problems with the justice system.
- To the extent that there is an ongoing shortfall between NDIS funding for offenders with intellectual disability and what ADHC has previously provided, the NSW Government should continue to meet the shortfall.

Advocacy services

The role of advocacy organisations within a robust civil society is well understood. As well as being an important accountability for governments, advocacy organisations are a critical and effective means of involving people with disability in service design. They bring together different parts of the system and ensure that people with disability can have their voices heard within a complex scheme.

Having agreed to hand over its whole disability budget to the NDIS, the NSW Government intended to stop funding disability advocacy services in June 2018. This would have amounted to a flagrant downgrading of the vital supply of individual and systemic advocacy for people with disability in NSW. The Government softened its position in 2018 and has agreed to continue funding advocacy services until June 2020. The need for these services is ongoing and the NSW Government needs to plan now for the long term funding of disability advocacy organisations in NSW.

Recommendation - The NSW Government should continue at a minimum to maintain its 2017-2018 advocacy service funding on a permanent basis.

Workforce issues impacting on the delivery of disability services

There has never been an adequate supply of skilled workers in the disability service sphere.

This problem has been the greater in relation to people with complex behaviour support needs. The supply of a skilled workforce to work with this group has arguably been declining when it needs to increase with the implementation of the NDIS. Factors leading to a decline in the workforce have included the tender out of ADHC services and many experienced workers then choosing to leave the disability services sphere.

For a detailed discussion of these issues, see A Pathway Through Complexity, the report from our Roundtable on Meeting Complex Behaviour Support Needs in the NDIS 2017. www.nswcid.org.au/images/Resources/A_Pathway_Through_Complexity_CID.pdf

Recommendation - With the NDIA and Australian Department of Social Services, the NSW Government should take urgent action to develop the disability service workforce including through enhancing the role of TAFE colleges in training of disability service workers.

Housing

There is a range of concerns about the availability of appropriate housing for people with intellectual disability. The housing stock previously used for ADHC group homes has now been let to accommodation providers on long leases and would seldom have any vacancies. The NDIS Supported Disability Accommodation program is limited to people with very high support needs and is skewed towards congregate living in group homes.

Recommendation - The NSW government should develop a comprehensive housing strategy to provide a flexible and appropriate range of affordable housing for people with disability.

Regulation and oversight mechanisms

The role of the Ombudsman

The Community and Disability Services Division of the Ombudsman has played vital roles in relation to complaints, monitoring and review of disability service provision. These roles will largely be taken over by the NDIS Quality and Safeguards Commission. However, there are important gaps in the role of the new Commission and it will be very important that the role of the Ombudsman is maintained in relation to these:

- Review of deaths of people with disability - The Ombudsman has had a role of reviewing the deaths of people with disability who die in supported accommodation. This role is particularly important in view of the strong evidence of inadequate health care experienced by people with disability including that 38% of deaths of

disability service clients in NSW are potentially avoidable.

<https://bmjopen.bmj.com/content/7/2/e013489> The Quality and Safeguards Commission will have a role in this area in that deaths will have to be reported by service providers to the Commission. We do trust that the Commission will take at least as robust a role as has the Ombudsman in relation to reviewing these deaths in relation to the role of service providers. However, unlike the Ombudsman, the Commission will have no authority to investigate the role of health services. It is vital that this role be maintained by partnership between the Ombudsman and the Quality and Safeguards Commission.

- Community visitors - Attached to the Ombudsman are community visitors who regularly visit supported accommodation, assist residents with grievances and monitor and seek to resolve problems in service provision. This is an important monitoring mechanism for people who are often very vulnerable and have impaired capacity to recognise and speak out about infringements of their rights. At least at this stage, the national Quality and Safeguards Framework does not include a role for community visitors. The NSW Government should fully maintain the existing community visitor role and ensure it is well linked to the Commonwealth Commission.

Recommendation - The NSW Government should:

- Maintain the Ombudsman's responsibility to review the role of health services in relation to deaths of people with disability.
- Maintain the existing community visitor scheme unless it is replicated in the the national Quality and Safeguards Framework.

Security of tenure in supported accommodation – model contracts prepared by ADHC

Historically, people living in disability supported accommodation have not had legal security of tenure. This has sometimes been a major practical problem, especially where a non-government provider has found it challenging to meet a person's needs and then insisted that the person move.

People living in ADHC accommodation also have not had any legal security of tenure. However, ADHC's public service and political obligations have meant that it has accepted a role as provider of last resort and has very seldom if ever evicted a person with intellectual disability without providing alternative accommodation.

With the tender out of ADHC services to non-government organisations, ADHC prepared model contracts for NGOs to use which would have allowed service providers to evict people for any reason with 90 days notice or 30 days if a resident is posing serious risk of harm. There were strong objection to these contracts from us and many families.

ADHC responded with a blog at <http://ndis.nsw.gov.au/2017/08/agreements-for-residents-in-group-homes/> Whilst ADHC denied there was a problem, it provided new sample contracts, which addressed some of the problems we had highlighted.

In particular, the new contracts narrowed the range of situations where accommodation and service providers can terminate residency or services. During the first two years, providers may only terminate in specific situations, in particular where there is a serious risk of harm to the resident or other people. Also, termination requires the approval of the National Disability Insurance Agency.

However, we pointed out to ADHC that the new sample contracts did not cover some of the important protections that were detailed in the Department's fact sheet. See our blog at www.nswcid.org.au/blog/update-on-adhc-transfer-of-accommodation-services-to-the-ngo-sector.html

We remain concerned that some residents with complex needs may face eviction by NGOs in circumstances where ADHC would have felt obliged to hang in there and try harder to meet the residents' needs.

Proposed legislation on 'resident rights' in supported accommodation

ADHC has now consulted on proposals for legislation to regulate the relationship between service providers and residents of supported accommodation.

www.facs.nsw.gov.au/about/reforms/future-directions/resident-rights-consultation

The consultation paper proposed that:

- An accommodation provider be allowed to evict a resident for any reason at the end of the term of a residency agreement or, during a continuous lease period, by giving 90 days notice.
- A provider be allowed to evict on 30 days notice if a person "cannot be supported at the property without causing serious risk to staff or other occupants" or has breached other requirements of the accommodation agreement.

These proposals could leave a person open to eviction where the problem is not any fault of theirs but a lack of adequate behaviour support to avoid serious risk to other people.

The paper proposed that residents could appeal termination orders to the NSW Civil and Administrative Tribunal but:

- A person with intellectual disability may not have the support that they need to understand and exercise their appeal rights.
- A danger is that the Tribunal will just be bound to approve the eviction because the person has breached the agreement.
- The accommodation provider will generally be in a much stronger position to provide evidence to the Tribunal than will the person with disability.

The paper did speak about the Tribunal taking due consideration of the complex needs of residents but did not make it clear what this would allow the Tribunal to do apart from ordering that support be provided by relevant agencies to assist the person to find alternate accommodation. This mistakenly assumed that alternate accommodation will be available.

The paper raised a range of proposals and considerations without putting forward a clear and comprehensive regime. The proposals could lead to a major reduction of the security of tenure that people with disability in practical terms have had to date.

In our submission on this consultation, we proposed as follows and request the inquiry to endorse our view.

Recommendation

For a legislative eviction regime to be fair to residents with intellectual disability, it needs to include a range of elements including:

- a. In accordance with historical practice, having a starting point that accommodation is a person's home for as long as the person wants.
- b. Independent support and advocacy for a person who is in danger of eviction so that the person's rights are protected and the person is aware of accommodation options.
- c. That any eviction requires the approval of the NSW Civil and Administrative Tribunal rather than only where the resident challenges an eviction.
- d. That the Tribunal have broad discretion so that it can take a problem-solving approach and refuse eviction in unfair circumstances, for example if eviction is based on a person's behaviour but the person is not receiving good practice behaviour support.
- e. That an NDIS coordinator of support and planner be involved in Tribunal hearings.
- f. That the resident be represented at the Tribunal by an advocate or lawyer who not only attends the hearing but also has the capacity to independently explore the case to put to the Tribunal.
- g. That, as for guardianship applications, the Tribunal for all such hearings consist of three members bringing expertise in disability as well as law.
- h. That the Tribunal have input from the NDIS Quality and Safeguards Commission in relation to information it holds concerning the residence in question, including in relation to reportable incidents and use of restrictive practices.

Looking to the future - the place of disability strategy in the NSW government

NDIS implementation and the Government's exit from service provision has seen the establishment of an NDIS Implementation Unit in the Department of Premier and Cabinet. It has been increasingly valuable to have this unit placed in a central agency and responsible to the Premier.

With NSW having now transitioned out of service provision and into the NDIS, there remains a range of major challenging issues to be addressed including the continued development of interfaces in responsibility between the NDIS and NSW government agencies, and gaps in the adequacy of the NDIS compared with what was previously provided or funded by ADHC.

More fundamentally, the NSW Government has ongoing responsibility for a fully inclusive life for people with disability and fully inclusive mainstream services in accordance with the UN Convention on the Rights of People with Disability, the COAG National Disability Strategy and the Disability Inclusion Act NSW.

If these challenges are to be adequately addressed, it will be vital that leadership on disability strategy and reform continue to occur within the Department of Premier and Cabinet. It would be inherently much more difficult for strategy and reform to be led by a small section in a comparatively junior portfolio like Family and Community Services. The leadership of a central agency and senior minister is vital. See *Getting Around To Inclusion*, the report from our Roundtable on making mainstream services accessible and responsive to people with disability 2017.

www.nswcid.org.au/blog/update-on-adhc-transfer-of-accommodation-services-to-the-ngo-sector.html

Recommendation - The NSW Government should create a permanent Disability Inclusion Unit in the Department of Premier and Cabinet with responsibilities for:

- Inclusion of people with disability in the NSW community
- NSW implementation of the National Disability Strategy
- Disability inclusion plans under the Disability Inclusion Act
- Issues arising from NDIS implementation including mainstream interface issues
- The Disability Council of NSW
- Funding of disability advocacy

The Premier or another very senior minister should be Minister for Disability Inclusion.