



JOINT STANDING COMMITTEE

TRANSITIONAL ARRANGEMENTS

FOR THE NDIS

ACT Government submission

ACT GOVERNMENT SUBMISSION

AUGUST 2017

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INTRODUCTION

Since October 2012, the ACT has been preparing for the implementation of the National Disability Insurance Scheme (NDIS). The ACT was the first jurisdiction to accept all eligible residents into the Scheme, and this was largely achieved by the end of the second quarter in 2016-17.

There are many lessons to be learned from the transition of an entire jurisdiction:

- almost all block funded and government-provided services have been cashed out;
- the market was supported to reform and expand through access to \$12 million of NDIS sector development funding;
- people with disabilities were given support and training using those funds to exercise control and choice in preparing their plans;
- more than 500 government staff were successfully supported with training and redundancy payments to transition into new employment, many with NDIS providers or in their own NDIS registered businesses;
- quality and safeguards for people with disabilities were improved through ACT legislative changes to accommodate the fact that there were no longer Government block funded contracts to require national standards to be met;
- clients living in government group homes and their families interviewed and selected their new service providers and tenancy managers; and

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- Housing ACT transferred management of assets and houses valued at over \$35 million to registered housing providers to support the separation of support and tenancy management.

During the transition period, the ACT Government never lost sight of the fact that the implementation of the NDIS will transform the way people living with disabilities are supported to live their lives in the way they choose.

During this fundamental reform the ACT Government has retained a focus on supporting not only NDIS participants but the estimated 59,200 Canberrans with disabilities living in the ACT through the National Disability Strategy and the ACT's own implementation plan *Involve*.

The transition to the NDIS has been a collaborative process, as improving the lives of people with disabilities is the responsibility of all members of an inclusive society – families, carers, support workers, employers, community organisations, non-government organisations, community members and government.

The ACT Government has shared responsibility with the Commonwealth and disability service providers, people with disabilities, carers, guardians and mainstream providers to ensure the ACT was ready to provide a transition to the NDIS that was as seamless as possible.

The ACT is now well placed to share information and, where possible, data about its approach to NDIS implementation. The ACT is also well placed to highlight the systemic challenges that the Government, participants and providers are currently experiencing. These challenges include unexpected cost pressures on mainstream services due to the movement in responsibilities between the NDIS and other services once the final Interface Principles were

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established after the NDIS Trials had started. The full costs of continuity of support are unknown, but as the whole ACT system has transitioned, ACT Government is well placed to gather this data and help assess the impact and cost on the Commonwealth as well as the states and territories.

The ACT Government's concerns include the potential for cost shifting as supports such as personal care in schools and special needs transport transition from in-kind to cash and issues of scope are negotiated; the impact on participants resulting from the changes in the NDIA planning process; and the impact of pricing on the disability sector.

The ACT Government is concerned about the potential for further cost shifting as issues of scope are negotiated, particularly in the health and education systems, but also across the full range of state and territory services.

In the education sector this would place additional pressure on schools in a climate where new Commonwealth funding arrangements have created resourcing uncertainty for schools and there are increasing parent/carers expectations in relation to the supports provided to their children behind the school gate.

BOUNDARIES AND INTERFACE ISSUES

HEALTH

ACT Health note that the terms *reasonable and necessary* supports are ambiguous, contextual and very loosely, if at all, correlated with evidence-based care and principles of equity. Many groups, for example people from culturally and linguistically diverse backgrounds and individuals with mental

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illness struggle to articulate what they consider to be *reasonable and necessary* needs under a choice and control approach. The process fundamentally favours those with the greatest health literacy, self-advocacy skills and, possibly, personal resources. This clearly has implications for public perceptions as to the overall fairness and financial sustainability of the scheme.

Over time the ACT has experienced a cost pressure associated with the fact that what is “in scope” for the NDIS has moved. There are also cost pressures associated with the provision of services recognised to be the remit of the NDIS however, for a range of reasons, people have not transitioned.

In relation to children, the NDIS environment is complex, involving multiple agencies. The child may often receive services under NDIS packages and from community support agencies (as well as Health and Education).

Communication is not always as effective as it needs to be, nor are the pathways clear.

The providers who take a “key worker” approach may, in some cases, not be serving the family appropriately. The Community Paediatric and Child Health Service has experience of children with severe language delay having an Occupational Therapist visit under the “key worker” model to provide speech development exercises to the parent – not direct speech therapy to the child. Children coming to the end of their package at age 7 are often in difficulty because they are not NDIS-eligible but have ongoing functional difficulties and need continuing support. These children potentially ‘fall through the gaps’ as most cannot afford private providers.

There is an acknowledged gap in the area of paediatric rehabilitation for children whose condition is still stabilising. NDIS will only fund services when

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there is 'permanent and ongoing disability' that is stable. Thus children who may, for example, be post-accident or surgery and who will not have an ongoing disability cannot access services through NDIS. This gap is currently being met in the ACT on the basis of an individually brokered response, funded by ACT Health.

Families of children with disabilities have expressed concern to Healthcare Access at Schools staff, regarding their interaction with NDIS. Comments have included: difficulty with using the portal; lack of communication from NDIS; lack of consideration for access – for example asking carers to attend evening information sessions even though they are full time carers; lost paperwork requiring repeat applications; early intervention not occurring due to time delays or not meeting eligibility criteria; and significant time delays to access services.

One parent stated that "In the past when my child needed a service we were referred and able to access without cost. Now, we are waiting for months for services to deliver care, and we have the added burden of paperwork. NDIS has meant I can choose the service, but it has made it more complicated and harder for me as a carer to access the supports for my child."

EQUIPMENT

Work continues at a national level with respect to assistive technology including prosthetics and orthotics. ACT Health's equipment policies have been modified to reflect the introduction of the NDIS. As with other states and territories, ACT Health has been asked by the NDIA to develop a 'Working

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Arrangement for Assistive Technology’. This arrangement is being suggested to cover the next two to three years and will be a fee for service arrangement.

This is still being negotiated. ACT Health has cashed out their permanent equipment scheme (ACTES) and transferred ownership of equipment to the individual. The repairs and maintenance of equipment has remained as an in-kind service.

It is a concern that a national approach for the provision of assistive technology has not been developed, and the ACT sees this as a systemic issue, given that up to 50 per cent of NDIS participants require some form of equipment or assistive technology.

The anticipated decrease in demand for equipment through the ACT Equipment Scheme (ACTES), which has been cashed out for NDIS purposes, has occurred. However, ACTES funding for NDIS eligible individuals has fluctuated during this period for a range of reasons, including: people waiting for their plans to be approved; plans not including the full suite of supports; and/or individuals may not have transitioned in yet.

ACT Health continues to fill the gap for clients whose equipment needs should be met by the NDIA. As a result of concerns relating to the planning, combined with extended delays in the approval process for assistive technology and equipment supports in NDIS plans, there is some cost shifting to ACT Health. Frontline staff have suggested people are seeking support from NGO’S to fill the gap while they wait for their plans to be approved. There are examples where equipment is either provided as an ‘extended’ loan from the short-term Equipment Loan Scheme (ELS) and/or is purchased outright. ELS support is not specific to NDIS clients. However, due to the extended period of assessment

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and approval, a number of NDIS participants have required access to ELS equipment beyond the ELS maximum three-month loan period. This has resulted in AT resources not being available when required and some increased administrative burden associated with the extension of the loan periods while clients wait for their NDIS funded equipment.

There have been limited savings due to ACTES being cashed out, due to the requirement to supply items not provided by NDIS (such as compression garments), custom footwear and items for people over 65). There is also substantial work to progress the working arrangement established at the request of the NDIA, as referred to previously.

During the early phases of the trial ACT Health offered, and on occasions this was accepted, education and training for NDIA assessors. This training was provided at no cost to the NDIA. ACT Health has also met \$150,000 per annum staff costs from the period March 2014 to December 2016 to assist with the transition.

NDIS participants needing equipment are often already clients of the health system and well known in the system. ACT Health is working with the NDIA to provide a quality, seamless service. With prostheses for example, ACT Health is responsible for the provision of the interim device while the NDIA is responsible for the definitive prosthesis, and any subsequent replacements. While the replacement of prosthesis should be anticipated and straightforward, participants are reporting delays and/or mistakes associated with the replacement of such devices.

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If the cost of an assistive technology item is identified as being above benchmark then it needs to be forwarded to the NDIA Technical Advisory Team (TAT) for consideration. ACT Health views the benchmarks as quite low for many items that are already supplied to clients by Health.

So far the NDIA has been unable to provide, in advance, the benchmark amounts for assistive technology for each client. Lack of information has become a challenge for Health's in-kind providers, who spend considerable time and effort clarifying the cost of services. Even when ACT Health has provided advice in advance of expected client needs before planning occurs, the information appears not to be reflected in prices on a client plan.

Additionally, items which are referred to the TAT for approval or review can result in extensive delays for a decision. There are examples where an urgent review was required and has taken over four and a half months for fairly straightforward equipment. The NDIA does not fund supports until they are included in approved plans. When individuals are at risk, ACT Health has chosen to fund the supports - these impacts have not yet been costed.

In relation to equipment, it should be noted that the non-government sector is also facing challenges. Existing small organisations are facing significant administrative costs in getting invoices approved and paid. This burden is magnified for equipment because each item is provided on a one-off basis, rather than being part of an ongoing relationship with a participant.

ACT Health Divisions of Women, Youth and Children, and Rehabilitation, Aged and Community Care (RACC) are continuing to fund supports for individuals (including children) who are eligible for in-scope services but where the time they would need to wait for support creates a clinical risk to their well-being

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and/or would result in their condition deteriorating significantly. ACT Health has also had to fund services for non-eligible children who may have accessed support from Therapy ACT prior to the transition to the NDIS.

There have been a number of patients aged under 65 in Canberra Hospital who have extended lengths of stay and complex needs who are dependent upon support from the NDIS to be discharged into the community. The NDIA has made it clear they will not provide 24 hours' support. For the small number of people who require 24-hour support, identifying and securing suitable and appropriate accommodation is incredibly challenging. ACT Health has supported these individuals to access the NDIS.

MENTAL HEALTH

The ACT's experience is that successful engagement of people with psychosocial disability depends upon strong clinical engagement and advocacy from the clinician who is working with the client. This engagement includes clients who may be subject to Mental Health Orders who are unwilling to engage or those unable to engage meaningfully in terms of making an application to NDIS.

As a result of client difficulty engaging with the NDIS, support that should be provided by the NDIS package is being cost shifted to ACT funded and provided services, such as Mental Health, Justice Health and Alcohol and Drug Services Recovery Support Officers (for example, transport to appointments, assistance with activities of daily living such as shopping, cleaning, etc). ACT Health has also provided approximately \$500,000 to community organisations during the NDIS transition to support eligible mental health consumers whose transition

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to the NDIS was delayed.

A specific gap that has emerged in NDIS supports is support for people with forensic disability where their behaviour manifests as a public safety issue. The NDIA has been insistent and consistent that support to address public safety is the responsibility of mainstream services. It is estimated this will cost the ACT a minimum of \$250,000 to \$300,000 per case. This includes costs required to manage individuals on Community Care and Forensic Community Orders, their support package, remuneration for a delegate, as well as administrative and quality/regulation requirements. The ACT Government did not anticipate it would be required to meet such costs, given that they relate directly to the participant's ability to live in the community and, in our view, do not fall into the category of reasonable adjustment to a mainstream service.

ACT Health Mental Health Services believe definitional clarification is required for certain supports not currently identified as separate billable items under the NDIS. For example, medication 'prompting' (as opposed to medication dispensing or administration) for people with psychosocial disability is currently not a billable item. Medication prompting could, however, be considered as a critical service for such people with forensic disability to maintain their independence and participate in the community and in employment.

SPECIALISED STUDENT TRANSPORT

The ACT experience working with the NDIA to address the issue of scope for Specialised Student Transport demonstrates the difficulty of operationalising the concept of reasonable and necessary.

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There is a clear tension between the intent for the reasonable and necessary concept to be malleable and provide flexibility to exercise choice and control, and the need for greater clarity in guiding planners on determining whether a support is reasonable and necessary to achieve fairness and consistency in decision-making.

The lack of clarity about what is reasonable and necessary in the context of specialised student transport is a potential barrier to transition of responsibility for specialised student transport from in-kind provision by states and territories to cashed out arrangements under the NDIS.

This is due to the lack of consistency of existing program eligibility across states and territories and differing perspectives on what is reasonable and necessary for the NDIS to fund.

If the NDIA seek to limit scope of funding for student transport by restricting eligibility there could be a service gap for students already receiving specialised transport and/or a cost shift to states and territories.

Transport services are required to make capital investment in fleet and other infrastructure such as communication systems. Therefore industry will be seeking longer term contractual arrangements and/or consideration for capital expenditure (such as the user cost of capital in the housing context) to ensure that appropriate transport services are available in order for clients to exercise choice and control. A transport sub-working group of the COAG Senior Officials' Working Group, including representation from all states and territories and the NDIA, is currently grappling with the issue.

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The NDIA has developed an approach to what is reasonable and necessary, for consultation with the sub-working group, based on the considerations outlined in the NDIS Act s.34(1).

States and territories are likely to have differing views of what is reasonable and necessary in transport and this could impact on the feasibility of cash out.

The absence of clear and publicly available guidelines on what is reasonable and necessary creates uncertainty for students and their families and can impact on their school enrolment decisions. It also creates uncertainty for transport providers who need to plan their service offer (transport routes) around knowledge of which students will be approved for transport funding.

When states and territories bundle contracts and/or service delivery arrangements for special needs transport with other demand responsive transport services in order to achieve market viability and cost efficiencies, it is imperative to consider the definition of what is reasonable and necessary.

EDUCATION

PERSONAL CARE IN SCHOOLS (PCIS)

There are still issues to be resolved at a national level in relation to the scope of the NDIS funding responsibility for PCIS, and how this responsibility will be operationalised in terms of assessment, funding and service delivery arrangements.

The Applied Principles specify the NDIS is responsible for funding PCIS 'additional to reasonable adjustment' obligations under the *Disability Discrimination Act 1992*. A key challenge arises in determining NDIS responsibility to fund PCIS supports in the school system where all personal care supports have traditionally been deemed as 'reasonable adjustments'.

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The meaning of ‘reasonable adjustment’ and its application to personal care in the context of the NDIS has not been definitively clarified in case law.

The Applied Principles note that further work must be undertaken on how a student’s personal care needs will be assessed, calculation of the level of funded supports for personal care, and how these funds will be managed/administered; this work is currently being undertaken by the Victorian Department of Education.

Key issues for consideration include:

- how to measure and cost the provision of PCIS;
- whether it is viable for PCIS to be delivered through individualised NDIS funding packages; and
- how might NDIS funding of PCIS impact on school operations – will there be an expectation for families to exercise choice and control over who provides PCIS for their child? Will this mean external providers delivering PCIS? How does this affect a school’s legal responsibility for duty of care for students?

In the absence of clarity around the scope of PCIS in the Applied Principles, the ACT’s in-kind contribution for PCIS has been costed on the basis of all levels of personal care being included within scope (from low levels of PCIS through to very high levels of PCIS).

Any change to the Applied Principles that restricts the NDIS funding responsibility for PCIS will result in a cost shift from the Commonwealth to the ACT.

PLANNING

While there are many stories of participants and families who have found great support through the NDIS, there are also a significant proportion of participants and families who don't know how to activate plans, especially as they have to find providers themselves. Families who are either used to being "in the system" or have never accessed support before may have an expectation that the NDIA will do this for them, or at least make recommendations.

The ACT Government has been informed that the level of information given to participants by the NDIA continues to be a problem. Examples continue of participants not being aware their plans have been approved and have been ready to be used for weeks, at times even months.

During the ACT trial, disability providers and the ACT Government were active in supporting participants to enter the scheme. They brought with them an extensive understanding of participant needs and were able to support and facilitate good planning outcomes. Support was particularly evident in people with psychosocial disability where providers were able to supplement the lack of NDIA planner knowledge of this disability. With the introduction of the first plan process this became less evident and participant outcomes were negatively impacted. The ACT is pleased that the NDIA has now acknowledged the flaws in the first plan process and is seeking to improve participant pathways.

Mainstream services note that frequently, in the administration of a plan, adjustments may need to be made. As establishing and reviewing plans by phone has been the most common method over recent months, assurance is required that people with limited English proficiency will have access to free

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accredited interpreter services at least for the planning phase (noting that the NDIS may provide funds within a plan under the 'consumables' category for interpreting and translation services).

There are frequent instances where a plan has been mislaid within the process, causing further delays. Consideration could be given to expanding online services to include the planning process.

Clients have difficulty engaging with NDIS. These difficulties include:

- extended delays in approval of Assistive Technology and equipment;
- delays in plans approval, as well as additional administrative burden for providers spent clarifying services/plans;
- payment delays faced by the non government sector;
- lengthy wait times on phones and failure to return calls; and
- providers not being told that plan review had been undertaken.

MENTAL HEALTH

The episodic nature of mental illness means that plans often need to be modified quite rapidly to support someone who is becoming unwell, but instead the process can take several months. At the same time, NDIS plan reviews for mental health clients have been conducted over the phone by NDIA ringing the consumer without the knowledge of the person's support co-ordinator (this has occurred for residents of Brian Hennessy Rehabilitation Centre, for example). Not involving the support co-ordinator runs the risk of inadequate supports being included in the new plan and discharge staff having to submit a request for a new review. Health is also aware that some plans have been 'auto-renewed' removing any possibility of the participant changing

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the goals articulated in their plan, and this is of concern if there has been a change in function.

In mental health inpatient units, it is very challenging to obtain visibility of the plans, and therefore to link or craft them with a view to discharge. It is also unclear what supports are considered clinical, and what can be in a plan. For example, despite general agreement at the ACT Operational Working Group that it should fall under NDIS service provision, Mental Health ACT has struggled to get 'medication prompting' for patients into a plan, as opposed to medication administration and prescription, which are clearly clinical functions.

PLANNING DELAYS

The time it takes to get an NDIS plan from the time of application lodgement (generally four to six months) is of concern. Almost all areas of ACT Health are reporting considerable delays with assessment processes that impact on length of stay in or support by mainstream health services, particularly inpatient services.

Mainstream services are having difficulty escalating these concerns within the NDIA. Agencies report it seems as if the NDIA is overwhelmed with the need to transition people into the scheme across the country and NDIA resources in the ACT have suffered as a result.

The NDIA is currently unable to identify time frames between clients being found eligible, for planning to commence, and when a plan will be in place. The only timeframe identified is related to the determination of eligibility. There continue to be long wait times for children with disabilities to be assessed as eligible, have a plan developed and then implemented. During this process

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eligible children have no access to NDIS funded disability services. The NDIA has insistently and consistently stated that unless the plan is approved, it is the responsibility of ACT Health to provide such a service while people are on the waitlist. Health estimates additional costs of approximately \$2000 per child with children generally having access to six sessions of support while they wait.

PLAN REVIEWS

The ACT Government was approached by a number of participants whose plans are being cut. In some occasions plans are being cut by up to 80%. The ACT has also been informed that participants are unwilling to ask for a plan review as they are concerned their plans will be cut.

WORKING WITH COMPLEXITY AND PROVIDER OF LAST RESORT

It has become increasingly apparent that a number of clients who have extensive needs or whose lives touch multiple areas of the service system are not getting the outcomes the scheme was meant to deliver. Concerns have been expressed by both disability providers and the mainstream system that “cherry picking” is occurring and that participant plans are not sufficient to meet needs.

The NDIA approach to working with these clients has been on an individual by individual basis and there has been no consistent systemic approach.

INFORMATION LINKAGES AND CAPACITY BUILDING

ACT Government funding for Information Linkages and Capacity Building (ILC) ceased on 1 July 2016 as it transitioned to the NDIS. Because the NDIA had not completed the ILC commissioning framework and was therefore unable to implement the ILC in time for the end of ACT responsibility, \$1.3 million was provided by the Commonwealth in 2016-17 for transitional grants to organisations that had previously been funded by ACT Government to deliver ILC type services.

Initially, 14 organisations were assessed as eligible for ILC transitional funding. Two of these organisations were funded at 50 % of their original contract and the remainder at 100 %. Subsequently, an additional organisation was funded for transitional support at a later date, while one organisation transferred its funding to another organisation.

The NDIA's ILC Grant application round opened on 24 January 2017 and applications closed on 8 March 2017. As the ILC grant round happened later in the year than originally intended the ACT Government negotiated a two month extension to organisations' transitional funding from the Commonwealth. The extension, until 31 August 2017, provided certainty and stability while the outcome of the ILC grants was finalised.

The NDIA notified all applicants of the outcome of its ILC Commissioning process after close of business on Thursday 20 April 2017. Unfortunately a

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small number of organisations were not successful in their application for ILC grants.

The ACT Government negotiated a further six months funding for four of those providers who were not successful. The NDIA agreed to this further assistance on the basis:

- that the activities the four organisations deliver align with ILC and have the potential to contribute to ILC in future; and/or
- there is a risk to their viability and a flow-on risk that valuable sector capacity could be lost.

The ACT Government is committed to ensuring organisations impacted by ILC were supported during this difficult period and made available some small grants via the Commonwealth Government sector development fund that impacted ILC organisations were able to apply for. These grants are available to help organisations with non recurrent costs associated with continuing, adjusting or winding up programs. These costs may be equipment, including information communication technology; marketing and communication material, for example rebranding; or costs associated with engaging financial or legal advice.

The ACT Council on Social Services (ACTCOSS) recently released *Choice and Control: Strengthening human rights, power and inclusion for people with disability*, which identifies a number of concerns regarding the way ILC is currently being implemented in the ACT. ACTCOSS is concerned about the current resourcing for ILC, especially in the context of the majority of ILC

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funding sitting with the LAC provider. ACTCOSS is also concerned that the focus of the LAC provider has shifted to planning targets, thus limiting their ability to undertake ILC work. There are also concerns about the framing of ILC funding as project funding, and the implications this may have for organisational sustainability and their ability to plan for the future.

As ILC develops there is a potential loss of social capital developed by those organisations which will not have access to NDIS funding, via either individual funding packages (IFPs) or ILC funding, but which provide services and connections of value to people with disability and the community as whole.

Many providers expressed concerns regarding the bureaucratic impost of the ILC grant program, including the onerous administrative burden, the process delays and allocation of only one year agreements to successful providers.

Whilst the Commonwealth investment of \$2.9 million into ILC brings a new mix of programs that build capacity of people with disability across the board, further work is required to develop the ILC “market” to ensure that the aims of ILC policy can be realised.

The ACT Government is working closely with the ILC team in the NDIA however feels that this area has been neglected in the push for transition and would be happy to work with the NDIA to develop this approach.



ACT Community Services Directorate

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