ACT GOVERNMENT SUBMISSION TO THE PRODUCTIVITY COMMISSION REVIEW OF THE FINANCIAL SUSTAINABILITY OF THE NDIS

2017



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1. Overview

Since October 2012, the ACT has been preparing for the implementation of the NDIS. The ACT will be 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;
- the NDIA is co-located with the ACT Government human services gateway to facilitate access to a range of support services for people with disabilities and their families, including housing and supports for children and young people;
- 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
- Housing ACT transferred management of assets and houses valued at over \$35million 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*.

This 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 had a 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.

In March 2014 the ACT Government agreed to report to the ACT Legislative Assembly every six months on the progress of the implementation of the NDIS. There have been six reports, with the final report being tabled during the March 2017 Sitting Period.

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 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 established after the NDIS Trials had started. We do not yet know the full costs of continuity of support, but as the whole ACT system has transitioned we are best 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 further 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. This submission provides detail on a number of current and potential financial pressures for the ACT resulting from decisions on what is in scope for NDIS, delays in planning and delivery, and intersection issues with mainstream services.

The submission also describes the issues arising in market development, despite considerable investment in provider reform and building business efficiency and capacity, including NDIS pricing issues and the impact of ICT and Portal problems on cash flow for NDIS providers.

With many ACT participants undergoing plan reviews, we are also able to reflect on the risk to control and choice and quality life experiences and outcomes for participants as plans appear to be increasingly based on an off-the-shelf reference package rather than a serious consideration of the participant's own aspirations and goals.

In developing this submission, the Community Services Directorate sought input from all relevant ACT Government agencies, as well as drawing on feedback from participants and providers and seeking specific input from the ACT Disability Reference Group.

2. The ACT Transition

Roles and responsibilities are set out in the Intergovernmental Agreement and the Heads of Agreement signed by the Commonwealth and ACT Governments in December 2012. The ACT Bilateral Agreement is Schedule E.

2.1 Commonwealth and State Funding and Governance Arrangements for the NDIS Including Financial Contributions and Risk-sharing

Under the COAG Intergovernmental Agreement on the NDIS, (IGA) and the ACT Bilateral Agreement, the ACT is currently contributing 59.1 per cent of the costs, based on an estimate of 5,075 participants in the Scheme. This is around \$120 million per year. Finalisation of negotiations for cross billing between the ACT and the Commonwealth have indicated an increase of ACT payments by \$0.5 million per year is required, largely to take account of the costs of people with disabilities aged under 65 in nursing homes.

The coming financial year, 2017-18, will be the first full year in which all ACT participants will be in the Scheme.

By full Scheme in 2019-20, the ACT will provide around 49 per cent of scheme costs or \$167 million. Total investment in the ACT grows to \$342 million by 2019-20 when the NDIS is expected to be at full scheme nationally. This reflects the expected ACT population share of participants at 7,000.

In this context, we note that the ACT is currently owed \$42.5 million from the Disability Care Australia Fund income over the last 3 financial years, as per the following table (see ACT Estimate for 2014-15 to 2016-17).

Estimated Disbursements from DCAF	2014-15 <i>Trial</i> \$'000	2015-16 <i>Trial</i> \$'000	2016-17 <i>Trial</i> \$'000	2017-18 <i>Trans</i> \$'000	2018-19 <i>Trans</i> \$'000	Total \$'000 \$'000
ACT Estimate of Commonwealth						
revenue from DCAF for ACT	13,600	14,200	14,700	15,200	15,715	73,415
2015-16 Commonwealth	0	1,417	12,490	43,817	15,715	73,439
Budget						

Future Risk Sharing

The ACT Government has significant concerns regarding the future risk sharing arrangements. Under the original *Heads of Agreement between the Commonwealth and the Australian Capital Territory Government on the National Disability Insurance Scheme*, the risk sharing arrangements from 2019-20 are subject to this review, noting that the ACT may be required to assume up to 25 per cent of the risk. However, the ACT has little ability to control the parameters of the NDIS. It is possible that average package costs could increase significantly due to decisions that the ACT is unable to influence and this would negatively impact the ACT, particularly if a share of the risk has been assumed.

It is also possible that such decisions could result in more people with disabilities requiring emergency or ongoing support outside the NDIS. The ACT therefore strongly urges the Commission to consider the risks assumed by states and territories in their role as providers of last resort. This role has high potential costs and risks, and this significant impost should be recognised through the Commonwealth assuming ongoing risks for the NDIS.

2.2 What Programs have been cashed out and transitioned to NDIS

The ACT Government announced in April 2014 that it would gradually transition out of specialist disability and therapy services that it delivered.

Disability ACT and Therapy ACT worked one-on-one with residents and their families to support them to make decisions about their future support arrangements as the ACT transitioned individuals and group homes to non-government service providers as part of the NDIS.

Therapy ACT transitioned all clients to non-government providers by August 2016, five months ahead of the planned closure.

Disability ACT and the National Disability Insurance Agency worked together to ensure a smooth transition of group homes, in partnership with the residents, their guardians and their chosen non-government provider. A structured transition process was in place to share individual residents' information and household operations, with the residents' chosen non-government provider.

Disability ACT transitioned its last group home client to the non-government sector in January 2017, six months ahead of schedule. The feedback from residents, families and providers has been overwhelmingly positive.

Most programs that are in scope for the NDIS have been cashed out by the ACT and Commonwealth Governments, including:

- supported accommodation, including ACT Government services;
- most allied health services, including ACT Government services;
- community access programs;
- school readiness early intervention programs, including ACT Government services;
- · mental health community supports including group programs; and
- support for the ACT Equipment Scheme but not the maintenance of such equipment.

ACT Government programs that have not been cashed out to date are:

- personal care in schools;
- special needs school transport;
- taxi subsidy scheme;
- prosthetics and orthotics (noting that this is not consistent across the country); and
- embedded supports for children in Out of Home Care;
- some ACT Health nursing and allied health services (i.e. some occupational therapy, podiatry and dietetics services); and
- ACT Health support for a small number of complex clients living in the community.

2.3 Cash and In Kind

In 2016-17 \$100 million in cash will be provided to NDIA. This was higher than expected due to the early wind up of Therapy ACT and Disability ACT supported accommodation.

Only \$20 million of in kind services will be provided in 2016-2017:

- \$2.3 million disability (related to the last few group home clients to transition);
- \$6.6 million personal care in schools;
- \$5.4 million special needs transport;
- \$2.6 million health, inclusive of Rehabilitation, Aged and Community Care \$2,420,937, which comprises:
 - prosthetics and orthotics and clinical technology services;
 - Community Allied Health services e.g. podiatry, occupational therapy;
 - o community nursing and domestic assistance/nursing (with the majority of this contribution (\$1,062,285) related to support for two community clients); and
 - healthcare access at school, considered as in kind to a value of \$229,000;
- \$0.47 million taxi subsidy; and
- \$0.82 million child protection.

The final cash and in kind mix for 2017-2018 is being determined, including looking again at whether some ACT costs might be counted as an in kind contribution.

The operation of in kind arrangements is difficult due to the NDIA's extensive administrative requirements. In addition, in kind bills have been provided to the NDIA however there has been a lack of acknowledgement by the NDIA of the receipt of in kind invoicing from both Education and Health Directorates for the whole period of the ACT Trial and transition since 1 July 2014. Most ACT plans do not appear to explicitly recognise 'in kind' arrangements and where in kind supports have been visible in plans this has created confusion for participants and providers.

3. ACT Cost Pressures Outside of ACT NDIS Contributions

The ACT has experienced a cost pressure associated with the fact that what is "in scope" for the NDIS has moved over time.

3.1 Community Services Directorate Cost Pressures

The ACT had expected most of Therapy ACT services to be in scope for the NDIS. However, a gap in the NDIS scope meant the ACT Government had to establish a Child Development Service with Therapy ACT funds for clinical diagnosis of children (\$4.3 million) and the Therapy Assistants programs (\$1.5 million) and these funds were not in scope.

Early Intervention (EI) services funded and provided by the ACT were designed based on a clear delineation of responsibility as set out in the NDIA's Operational Guidelines. The Guidelines state that children with delays in one or more developmental areas are eligible for an EI package. Children with delays of more than twelve months in one area of development (for example, significantly delayed communication) are eligible for a package of targeted therapy.

Many children previously provided with services through Therapy ACT received packages for one area of significant delay when the NDIS commenced. However, the NDIA has recently changed the operational guidelines relating to eligibility to the scheme for developmental delay. Specifically, the 'need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated' is being interpreted to mean children with only one area of delayed development are not eligible. As a result, the NDIA access team deems children with one area of delay not eligible for the scheme because they do not require interdisciplinary care and these children are no longer receiving (or renewing) packages or early intervention supports. This pushes the cost back on the ACT funded services in the absence of the EI partner to provide further evidence of need or to provide therapy supports.

The ACT Child Development Service has found that providing evidence of functional impact in two areas of delay is more likely to support eligibility to the Scheme. Examples of children not deemed eligible for the NDIS since the new guidelines were implemented are detailed below.

Case Study One: Three year old girl with family history of Autism

A three year old girl has a strong family history of Autism Spectrum Disorder and learning difficulties. The child has severely delayed expressive and receptive language, but due to being so young formal assessments do not capture this very well. For example, the Clinical Evaluation of Language Fundamentals Preschool showed only a moderate delay when her scores were scaled, even though she could not complete any of the tests. As she did not have concerns in other areas of development, she was not deemed eligible for the scheme or for early intervention supports.

Case Study Two: Two and a half year old boys with delayed language skills

Two boys aged two to two and a half years are attending an ACT Child Development Service language group. After five sessions of language stimulation they have made no progress. They continue to have zero words and poor play skills. These children require Augmentative & Alternative Communications (AAC)/visual supports before learning language. To implement this they require longer term intervention. However as they have only one area of concern they are not currently eligible for the NDIS.

Overall, the NDIA national access team has variable responses to eligibility for EI and developmental delay, with some clients referred by the ACT Child Development Service being told that they are not eligible for the NDIS and either sent back to the Child Development Service or referred to the NDIA portal to find the new Early Childhood Early Intervention (ECEI) partner, which is not yet established in the ACT.

Children who were deemed eligible for the scheme and have not implemented plans (due to difficulties in finding providers, issues with transport, etc) are being reviewed by the NDIA and referred back to mainstream services for evidence of need and further assessment.

The Children's and Young People Equipment Loan Service (CAYPELS) was part of Therapy ACT but is not in scope for the NDIS and continues to provide equipment to children, young people and their families that is specialised and used to assist in the areas of mobility, communication and daily living. CAYPELS provides short term assessment loans to private providers (allied health professionals) in the sector and also offers a three month trial loan to clients. This service costs \$700,000 per annum.

The cost of regulating NDIS providers had been met by the ACT since 2014. The ACT has amended the *Disability Services Act 1991* to regulate NDIS providers until the national scheme commences in 2019. Costs of the Human Services Registrar will be around \$2 million from 2014 to 2019.

As of 31 December 2016, there were 106 requests from 24 providers requiring shortfall funding for 441 clients who phased into NDIS late. Currently \$1,791,033 worth of shortfall payments have been paid by the ACT Government to providers. It is anticipated a further 11 claims may be submitted for January 2017 with an estimated value of \$152,000. The ACT will continue to work with organisations as clients transition through the final stages of the NDIS trial to ensure they continue to be supported and organisations are funded until they phase.

There are also unexpected costs and an administrative burden associated with the cumbersome in kind reporting process required by the NDIA, and challenges associated with reliance on the quality and integrity of provider data reports from the NDIA.

Finally, the \$22 million cost of redundancy and retraining of Disability ACT and Therapy ACT staff has been met by the ACT Government.

3.2 Information, Linkages and Capacity Building (ILC)

ACT Government funding for 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 per cent of their original contract (Pegasus and Technical Aid to the Disabled (TADACT) and the remainder at 100 per cent. Subsequently, an additional organisation was funded for transitional support at a later date (1RPH), while one organisation transferred its funding to another organisation (Autism Aspergers ACT to Marymead).

The NDIA's ILC Grant application round opened on 24 January 2017 and applications closed on 8 March 2017. Successful grant recipients should receive funding from the NDIA from 1 July 2017. The ILC grant round has happened later in the year than originally intended and current funded services have indicated concern at the timing of the round in relation to planning for their organisations' ongoing business and viability into the next financial year.

The ACT Government has negotiated a two month extension to organisations' transitional funding from the Commonwealth. The extension, until 31 August 2017, will provide certainty and stability while the outcome of the ICL grants are finalised (expected to be announced in May 2017). However, this represents a considerable risk for the ACT in both service capacity and financial risk if local organisations are unsuccessful in the tender process. To date local ACT organisations have not been successful in the Local Area Coordination or Early Childhood Early Intervention Centre tenders.

Although \$3 million is available in ILC grants, should the NDIA take a "bigger is better" approach to assessing service providers, well known community-based organisations in the ACT could be faced with the need to wind up or scale back service provision at short notice. Providers coming in from other markets may take time to set up in the ACT and may not, in any case, fill the gaps created by the loss of local services.

This would place both political and financial pressure on the ACT Government as providers seek additional transitional funding and mainstream ACT Government services (particularly Health, Education and Community Services) are required to fill gaps in service delivery.

3.3 Education Directorate Cost Pressures

Specialised Student Transport

The ACT has sought to drive planning and discussions with the NDIA since 2014 in relation to transition of responsibility of specialised student transport from the ACT to the NDIS. These efforts have been frustrated by an ongoing lack of engagement from the NDIA which, in turn, has created ongoing uncertainty for students, their families and service providers.

In June 2016 the NDIA proposed a timeline to transition responsibility for specialised transport from states and territories to the NDIA, with the objective of achieving cash out in the year following completion of phasing in each jurisdiction. This positioned the ACT as being the first jurisdiction to cash out in January 2017. However, this timeline was revised through mutual agreement to January 2018 due to the complexities in achieving transition. These complexities include the fact that specialised student transport does not fit neatly within an individualised funding model and lack of clarity in relation to both scope (eligibility criteria for accessing transport assistance) and the NDIA's willingness to contract service provision.

The NDIA's lack of readiness to take on responsibility for student transport has become increasingly apparent, as has the need for a multilateral approach to addressing the relevant policy issues. Therefore we now consider it unlikely that cash out will be achieved by the beginning of 2018.

Year-on-year extensions of current in kind arrangements are problematic for the ACT Government and its agencies. The ACT is therefore seeking a multi-year funding arrangement to allow for forward planning, including fleet management, and as a prerequisite to stimulating a suitable market response. Negotiations with the NDIA are ongoing.

The issue of scope is a particular concern, noting there are significant differences in eligibility across jurisdictions. There remains a lack of clarity around what the NDIA considers parental responsibility and what is reasonable and necessary to fund in relation to student transport.

Should the NDIA seek to restrict the scope of funding for student transport by restricting eligibility, this could result in a service gap for students already receiving specialised transport and/or a cost shift to states and territories.

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'. 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.

School Readiness Early Intervention Services

Following the ACT Government withdrawal from school readiness early intervention services at the end of 2014, anecdotal feedback suggests there are young children requiring early intervention that are not getting the right supports or not connecting with providers. This has significant implications for school readiness and longer term cost impacts for the Education Directorate.

To maximise the opportunity for all potentially NDIS eligible Aboriginal and Torres Strait Islander students to engage with the NDIS, the Education Directorate in cooperation with schools referred a significant proportion of these students and their families to the Gugan Gulwan NDIS Outreach Support program.

Therapy

A lack of clarity around funding and service delivery boundaries for the NDIS and education systems in relation to provision of therapy support has created gaps in service delivery as well as some duplication. This is putting financial pressure on the ACT Education system, which is providing services to cover the service gaps for children.

Key issues include:

- Families may choose not to use NDIS funds for specific therapy services, even when schools identify a need for the student to have support in this area. This frequently occurs in situations where students have limited functional communication at school but the family does not see the need for Augmentative and Alternative Communication (AAC) devices.
- When the family has engaged an NDIS provider but the provider's scope of practice or service arrangements do not cover issues identified at school, such as mealtime management, equipment maintenance/ growth, safety on specialised transport to and from school.
- The Applied Principles specify the NDIS is responsible for specialised transition support. However, it is unclear what this will look like and the role of NDIS therapists as opposed to educational services (e.g. in relation to environmental modifications).
- Lack of clarity on responsibility for training of school staff around student's specific equipment where it is used across home and school, including manual handling and/or use of specialised equipment, and use of AAC devices.
- Lack of clarity around whether it is an NDIS or education system responsibility to provide ongoing support for school staff with use of equipment that is provided through an NDIS package (especially around AAC).
- Potential duplication of services with regard to manual handling the creation of manual handling protocols, prescription of manual handling aids and training of staff.
- Access delays for new applicants to the NDIS are in some cases requiring the
 Directorate to provide individualised therapy support for students to cover the service
 gap and need for intervention where families cannot afford to pay for a private
 therapist.

Other Costs

The Education Directorate has needed to re-establish some services which were cashed out in anticipation they would be in scope for Information, Linkage and Capacity Building. This includes, for example, capacity building for school staff to support the sexual health and social safety needs of students with disabilities.

In addition, at the commencement of trial the ACT Government cashed out therapy services for school age children (six years or older) who were previously supported by Therapy ACT. The Education Directorate has engaged 26 full time equivalent allied health professionals at a cost of approximately \$3 million per annum to meet the needs of students with disabilities within schools. Allied health professionals assist in making adjustments to environment and curriculum, one to one supports and professional learning for the 2,290 public school students identified as having disabilities.

3.4 Health Directorate

Some Commonwealth mental health programs have been cashed out and many clients are not eligible for NDIS, so people go to ACT services for support. In addition some ACT funded group mental health programs and other community programs have not been able to transition to the individualised environment, leaving clients unable to choose those programs because providers have simply closed them down.

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 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 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 annum. 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 that 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.

The Health Directorate 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 and/or would result in their condition deteriorating significantly. The Health Directorate 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. ACT Health has supported these individuals to access the NDIS. Where the patient is not yet eligible to phase to the NDIS, ACT Health is supporting the individual to access appropriate services.

The NDIA has established a Co-ordinated Response Team (CRT) to facilitate timely access for participants into the scheme and a more co-ordinated planning process. The CRT has worked with clinicians to develop a pathway to assist with streamlining the processes for in-patients of Canberra Hospital. While the finalised pathway outlines the various steps, the only timeframe the NDIA has been willing to commit to is the first step whereby the NDIA is legislated to consider eligibility upon receipt of all relevant information within a three-week period.

There are ongoing discussions at a national level through the Senior Officers Working Group, which supports the work of the COAG Disability Reform Council, about mainstream interface issues. The focus for the next eight months will include the health interface. This is particularly contentious when it comes to the provision of respiratory support.

Equipment

Work continues at a National Level with respect to assistive technology. ACT Health's equipment policies have been modified to reflect the introduction of the NDIS. ACT Health has, like each state and territory, been asked by the NDIA to develop a 'Working 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. We believe that ACT Health is the only jurisdiction to cash out this service; we understand that the agreements with other states are an extension of in kind funding arrangements.

It is a concern that a national approach 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.

Extended delays in the approval process for assistive technology and equipment supports in NDIS plans are causing considerable costs to ACT Health, which continues to fill the gap for clients who need such equipment. Equipment is either provided as an 'extended' loan from the short-term Equipment Loan Scheme (ELS) and/or is purchased outright. ELS supports the general community as well as NDIS clients. However, due to the extended period of assessment and approval, a number of NDIS participants have required access to ELS equipment far beyond the ELS maximum three-month loan period. There is also an increased administrative burden associated with the extension of the loan periods while clients wait for their NDIS funded equipment.

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: 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.

Anticipated administrative savings associated with ACTES being cashed out have not eventuated because there continues to be a significant body of work required surrounding the provision of items not provided by NDIS (such as compression garments), custom footwear and items for people over 65 – and now to progress the working arrangement established at the request of the NDIA, as referred to above.

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

The starting place should be the needs of the client. NDIS participants needing equipment are often already clients of the health system and well known to the health system. ACT Health is trying to work with the NDIA to provide a quality, seamless service. With prosthesis, 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.

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. The benchmarks seem to ACT Health to be quite low for many items that Health is already supplying to clients.

So far the NDIA has been unable to provide, in advance, the benchmark amounts for assistive technology for each client. This becomes a challenge for Health's in kind providers, who are spending 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, this information appears not to be reflected in prices on a client plan.

Additionally, when a case is referred to the TAT for approval or review there can be extensive delays for a decision. There are examples where cases that require an urgent review have taken over four and a half months for fairly straightforward equipment. The NDIA has refused to fund supports until they have been 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 — particularly TADACT — 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.

3.5 Implications for risk sharing and governance

From the discussion above, it is clear that the impacts of the NDIS on state and territory funded services is already extending the risks of the NDIS beyond the Commonwealth risks. Until full scheme states and territories contribute 60 per cent of scheme costs and even at full scheme, 50 per cent of scheme costs, as well as the ongoing responsibility for mainstream services.

It will not be acceptable or reasonable to change the governance arrangements, as demanded by the Commonwealth in return for access to Disability Care Australia Fund, and to reduce the level of control states and territories have over the scheme.

All jurisdictions have the same interest in ensuring that the scheme is financially sustainable as costs are shared 50/50, and the old system is effectively being dismantled (as has been almost fully completed in the ACT).

4. ACT NDIS Client Phasing Arrangements during the NDIS Trial

4.1 Participants

The ACT Bilateral target (Schedule E to the IGA) is 5,075 participants phased in gradually across nine quarters from 1 July 2014 to 30 September 2016.

4.2 Phasing

In 2014, adults aged 63-64 years transitioned, along with newborns to school age children.

In 2015, those who transitioned to the NDIS included:

- all school-age children;
- 49-62 year olds; and
- people living in group homes where the youngest resident aged between 26 and 36 years.

In 2016, people aged 20-48 years transitioned as well as the remainder of group homes.

4.3 ACT Client Numbers Issues

In early October 2016, when participant plan numbers reached the bilateral target of 5,075, the NDIA made a unilateral decision to cease accepting ACT residents with disabilities into the NDIS, without prior consultation with or advice to ACT Government.

As soon as the ACT Government was alerted to the problem, senior executives engaged in discussions with the NDIA and the Commonwealth Department of Social Services to rectify the situation.

On 19 October 2016 the NDIA issued a statement advising that:

- the NDIA is continuing planning in the ACT;
- all eligible participants will continue to receive access to the NDIA in line with agreed priority intake plans;
- the NDIS is not a capped program; and
- priority will be given to participants who have already been found eligible for the scheme.

The ACT Bilateral Agreement (Schedule E of the IGA) clearly states that any cost associated with ACT participant numbers above the estimated 5,075 is a Commonwealth responsibility. In any case, the ACT Community Services Directorate has alerted the Commonwealth to a number of data issues that have affected the estimated number of likely participants in the ACT.

4.4 Current ACT Participant Numbers

The number of participants with plans as at March 2017 is still under investigation by the NDIA Scheme Actuary. Current figures have the number at around 5,800, with 300 eligible participants yet to have a plan approved.

Approximately 1,700 children under 18 years have plans that are currently under review. Of these, 682 are 0-6 and these plans are considered to be early intervention plans. Based on an analysis of the level of disability, there may be as many as 1,000 children who will be transitioned out of the scheme when their plans are reviewed.

Prior to the NDIS, 300 people with mental illness received community based supports in addition to clinical support. The ACT anticipated this number would rise, with to up to 900 participants with psychosocial disability transitioning in to the NDIS. The December 2016 NDIA report to COAG stated that 680 ACT participants have psychosocial disability as their primary diagnosis. In transition, engagement with new services and providers continues to be a concern for people with psychosocial disability, particularly where the person is explicitly unwilling to engage with services. As previously noted, successful engagement depends upon strong clinical engagement and clinician advocacy.

5. Development of the Market and Sector Development

As the first jurisdiction to fully transition to the NDIS, the ACT has been leading the nation in its investment in the community and sector to make this transition. This means the Government has had the opportunity to intensively support the ACT community, individuals and providers. This section outlines the support provided and the ACT's assessment of its effectiveness.

According to the NDIA, at 31 December 2016 there were 535 providers registered with the NDIS to deliver services in scope for the NDIS in the ACT (although it is clear that many of these are currently active in the market). When the ACT Government made the commitment to introduce the NDIS in December 2012, it funded 64 community providers to deliver disability and in scope mental health services.

Over the past three years the ACT Government has implemented a Commonwealth funded \$12 million sector development program to support community organisations, government services and people with disabilities, their families and carers to prepare for the NDIS.

In addition, \$7 million worth of individualised grants to people with disabilities over 18 months from mid 2013, mostly before the NDIS Trial began, assisted people with disabilities to get ready for the new environment of a fee-for-service market and control and choice in selecting service providers.

Below is outlined the full range of programs which have been funded across the last four years. While none of the programs have been formally evaluated, there are other indicators of the success of the programs in terms of

- what people with a disability have said about their readiness to develop a participant plan;
- families' views on their readiness and ability to support their family member to develop a plan; and

 The smooth transition from government group homes to other providers of support and accommodation, without government going to tender for supported accommodation as an interim step on the way to control and individualised choices about supported accommodation.

In every other jurisdiction where government has moved out of service provision, even in NDIS trial sites and now in the transition to full scheme, governments have transferred their service provision to other providers as an interim step to cashing it out and participants then being able to make their own choices about who provides them a service.

In the ACT, Government invested in advice and support to people living in government group homes to understand the NDIS, and choose an alternative provider of housing as well as support. The investment extended to the document preparation associated with that transfer so that whole households could transfer to new arrangements seamlessly. The full transfer of government supported accommodation occurred over just 30 months, six months ahead of the target date, which is a strong indicator of the success of the approach taken. This approach could be used by other jurisdictions as model of how to make this crucial change.

Two significant measures in participant preparation which the ACT Government and the sector think were particularly useful were the pre-planning sessions undertaken by the NDIA for participants and the grants of up to \$1,000 provided by the ACT Government to individuals to seek assistance and advice about transition to the NDIS. The former provided a helpful framing of the overall scheme and entry into it, while the latter enabled many people to seek and pay for assistance directly with those they trusted (including service providers).

If the Local Area Coordination funding does not provide pre-planning sessions and does not enable or provide direct grants for participants to pre-plan, we anticipate that outcomes will be poorer and transaction costs considerably higher, resulting in a negative market impact.

5.1 Programs Funded

In 2014, \$1,471,000 was allocated in NDIS assistance grants to ACT providers. Through 2015 and 2016 a further 39 Business Investment Packages were allocated valued at \$1,712,170.

A list of successful applicants and what they were funded for is available on the Community Service Directorate's NDIS web page at http://www.communityservices.act.gov.au/

ACT community sector providers have been assisted to refine and redesign their service offers and to develop their governance structures, financial management processes and ICT systems.

A wide variety of resources and supports have also been available to support people with disabilities to prepare for and transition to the NDIS. This has included grants and workshops to support plan development.

The program called *Your Voice Your Choice, Good Life Planning* was launched in September 2015 to support people with disabilities to prepare for the NDIS. The program was delivered by Mental Illness Fellowship Victoria with Imagine More and Community Connections. It was community based and used co-designed, strengths based strategies that were informed, and where possible led, by people with disabilities. The program developed and delivered events, tools and resources focused on people who have not traditionally engaged with disability

services. Sector Development Funding of \$727,000 was allocated to this program, which ran to December 2016.

Programs have also worked with Aboriginal controlled organisations and members of the Aboriginal and Torres Strait Islander community to assist them to become NDIS participants. *Opening Doors,* led by the Nous Group partnering with Lifestyle Solutions and First People's Disability Network, has provided an intensive targeted response to:

- Aboriginal organisations looking to build their capacity to enter disability provision in the ACT; and
- mainstream disability providers looking to deliver more culturally sensitive services.

The program received \$440,000 in funding and is currently winding up.

Other programs supported disability providers to operate in the NDIS environment, such as:

- Ready4, led by National Disability Service partnering with ACTCOSS and RSM Australia, provided a central point of information and delivered one-on-one and small group support for the development of NDIS service offers, and business, system and governance models. The program was funded \$600,000 and ran to December 2016.
- Values in Action, which has seen Julia Farr Association Purple Orange provide intensive
 assistance to five disability providers committed to developing a sustainable highperforming person-centred workforce. The program received funding of \$360,000 and
 will be completed in the first half of 2017.
- The NDIS Workforce Awareness Program provides plain English advice to ACT workers and organisations about the NDIS, what people need to know and where they can go for more information.

5.2 Support for Psychosocial Disability

Through the transition support programs, the ACT Government provided specific support for people with mental illness and providers of mental health services. In addition to the *Your Voice Your Choice, Good Life Planning* program described above, the following initiatives were funded:

- Mental Health Funding 2013-14 (\$160,000). Three projects were funded: supported decision making for people with a psychosocial disability; connecting communities; and peer workforce development.
- Three mental health providers were each successful in obtaining a \$50,000 NDIS Business Investment Package in the 2015 round of funding. The NDIS Taskforce mental health officer worked closely with these organisations to support them in this work. The organisations supported were:
 - St Vincent de Paul to develop organisational readiness.
 - Mental Health Foundation to develop organisational readiness.
 - Richmond Fellowship to support a staff member to develop a new supported accommodation service.

6. General Workforce Development

With the introduction of the NDIS and the ageing of the general population, national and local workforce modelling forecasts an increasing demand for workers in a range of professional and non-professional occupations related to the disability sector. In the ACT, the disability sector was projected to need approximately 500 new workers each year from 2015 to 2018. Of these, 170 would be direct support workers.

The existing workforce is also older, more likely to be female and from an Anglo-Australian or English-speaking background, and less likely to be Aboriginal or Torres Strait Islander than the people it supports. It is appropriate for the disability workforce to reflect the diversity of the ACT community it serves.

The ACT is about to start a major project to build the workforce needed to deliver the NDIS in the ACT. National Disability Service (NDS) was recently selected through an open tender to work with the ACT Government on this project over the next two years. The project will commence when contract negotiations are finalised in April 2017. Funding of \$1.27 million was made available to the ACT through the Commonwealth's NDIS Sector Development Fund.

6.1 Government Workforce Issues

A case management approach to all staff was implemented for the 523 staff supported across both Therapy ACT and Disability ACT. There are now only 27 remaining staff at Disability ACT, who are engaged in finalising arrangements for the closure of Disability ACT.

Of all staff affected by this process, 333 requested training support. Training included Certificate III and Certificate IV and diploma and double diploma level of study. The qualifications and training have resulted in staff being highly sought after within the sector and has enabled many staff to establish private practices or businesses. The majority of staff have remained within the sector.

6.2 Workforce Shortages: Allied Health and Therapy Capacity in the ACT

With the closure of Therapy ACT by December 2016, the allied health workforce has been a risk and a concern. In March 2016, the ACT NDIS Taskforce contacted all NDIS registered providers of allied health and therapy services in the ACT; 51 organisations provided data which showed there were 151 FTE in the sector across all allied health specialties. These providers were able to access resources like *Ready4* to assist them to operate effectively under the NDIS.

In November 2016, the ACT Government invited Expression of Interests from three local organisations to undertake a short term project to assist the ACT allied health sector to thrive under the NDIS and meet the needs of participants, using \$50,000 from the Commonwealth's NDIS Sector Development Fund. NDS was selected to deliver this project from March to August 2017 to improve the capacity of the allied health sector in the ACT to respond to the opportunities and demand for services under the NDIS, and to establish an appropriate host agency to continue this work and sustainably support the allied health sector beyond this project.

7. Quality and Safeguards under the NDIS

The Territory, like other jurisdictions, agreed as part of the IGA to maintain existing safeguards during the NDIS trial until the transition to a nationally consistent approach.

As a human rights jurisdiction, the ACT Government is committed to ensuring people with disabilities are empowered to exercise their rights and live fulfilling lives. This required amendments to the *Disability Services Act 1991* and regulations to require compliance with the national disability standards, and the establishment of a MOU with the NDIA to require organisations to be assessed by the ACT Human Services Registrar prior to being registered as a provider by the NDIA. The Human Services Registrar function sits within the Community Services Directorate and also has responsibility for regulation of out of home care and community housing providers, which has been of interest to all jurisdictions – particularly with the development of the Specialist Disability Accommodation Rules.

During the NDIS trial, and until the transition to a nationally consistent risk-based quality assurance approach, the ACT is maintaining (and seeks to extend) existing quality assurances for specialist disability services.

Other existing safeguards in the ACT include the Working with Vulnerable People Checks, the Disability and Community Services Commissioner, the Official Visitor for Disability Services and self-advocacy and capacity building supports and strategies. Specialist disability service providers in the ACT also have a legal obligation to report critical incidents, including allegations of abuse against clients.

The ACT endorsed the *National Framework for Reducing and Eliminating the Use of Restrictive Practices* in March 2014. The Government is also consulting about the establishment of a Senior Practitioner and a Restrictive Practices Framework in the ACT. Reducing and seeking to eliminate the use of restrictive practices is consistent with commitments under the *United Nations Convention on the Rights of Persons with Disability*. The ACT is also implementing the National Plan to Reduce Violence Against Women and their Children, and is concerned that the NDIA does not have emergency response protocols in place to immediately cover the increased personal care and other costs, in the absence of a formal plan review, when a woman's partner is removed from a household due to domestic/family violence.

Supported accommodation is a complex issue. The sector's and NDIA's ability to identify and successfully and sustainably co-habit people together is challenging, across all forms of supported accommodation, not just Specialist Disability Accommodation.

The NDIA is putting pressure on participants and providers to share accommodation by providing package costs based on shared accommodation with the number of people living in the house based on the bedrooms in the house, not the number of people sharing. We have been advised that the NDIA is also refusing to allow for the provision of a bedroom for overnight staff by reducing participant package costs based on the number of bedrooms in the house, as if another participant was living in the bedroom. If this is correct, it is not only inappropriate in relation to enabling participant choice and control, but is asking providers to ignore the requirements of relevant awards and their work health and safety responsibilities.

8. The Sustainability of Scheme Costs

In the ACT Government's view, sustainability of NDIS costs depends on a range of variables, some of which interact. These include:

- participant eligibility;
- the income for the scheme from government contributions;
- the level of the Medicare levy;
- overall participant package costs;
- what is determined to be a "reasonable and necessary support" under the NDIS and what should be provided by a "reasonable adjustment" to a mainstream service;
- costs to state, territory and Commonwealth mainstream services as a result of NDIS implementation (including gaps and delays in access to necessary supports);
- costs to states, territories and the Commonwealth from continuity of support requirements, particularly where the line has moved for what is in scope and out of scope for the NDIS;
- effectiveness and efficiency of Information, Linkages and Capacity Building and Local Area Coordination providers in assisting participants and non-participants to get what they need outside individualised packages; and
- establishment of an effective and efficient market that provides a choice of services for participants at an efficient price.

The ACT does not support a "drive to the bottom" where individualised supports determined during detailed planning for participants are replaced by "reference packages" that do not reflect individual needs. The ACT Government has already seen this process underway as first plans have been reviewed and replaced with new plans set at "benchmark costs". Participants and providers are telling us that they have not received an explanation of why changes have been made, other than that the first plan costs were too high and the NDIA had been "very generous" in the ACT.

While we understand the reasoning behind the reference package approach, inappropriate use of this methodology in plan reviews, combined with poor communication, creates a risk that providers will see NDIS as unpredictable and unreliable and withdraw from services that offer narrow margins. Specific provider risks are discussed further below.

As outlined above, the ACT Government is facing cost pressures from demand for mainstream services and from continuity of service for people both eligible and ineligible for the NDIS.

We have also outlined above the time, effort and resources devoted in the ACT to growing and developing a robust market, underpinned by an appropriately trained and skilled workforce. However, the ACT is concerned that the wage level underpinning the current pricing structure at the Social, Community Home Care and Disability Services Industry Award 2010 (SCHCADS) Level 2.3 is very low, and too low for the ACT labour market, with an unemployment rate of only 3.5 per cent. In addition, the main classification used by the community sector in the ACT is SCHCADS 4 or 5, so it will be difficult to recruit and retain an NDIS workforce paid at a much lower level.

The ACT was able to get NDIA agreement to prices 8 per cent higher than NSW in the first year of NDIS Trial 2014-2015 to take account of the ACT market, but this higher price is being absorbed over time, even though the differential still exists.

9. Jurisdictional Capacity

9.1 NDIA Capacity

The ACT is very concerned about an apparent lack of operational capability within the NDIA when the ACT has no residual disability services and has been transitioning clients and cashing out services, including ACT run services, expecting the NDIA would have the capacity to pick up the service coordination previously provided by ACT Government. This is of most concern in relation to the NDIA's inability to provide an emergency response. The ACT is still using Disability ACT staff to do this when Disability ACT will close its doors on 30 June 2017.

Fundamentally, where the NDIA does not see a solution to a problem as part of an individualised package, it simply tries to push the responsibility for the response back on to the ACT Government. For example:

- children with challenging behaviours who may not be able to live with their parents all
 of the time have been pushed back as a child protection issue;
- participants being discharged from a psychiatric inpatient unit have been pushed back as a health, homelessness or public housing issue; and
- participants unable to leave hospital without a modified or supported accommodation option have been pushed back as a health problem, and remain in hospital.

In the ACT, as is no doubt the case in other jurisdictions, we have always needed to work across government on these sorts of cases to find a solution. However, the NDIA is not working in this way and does not seem to be taking steps to enable it to do so. This issue has been raised with the NDIA.

The ACT Government also has concerns regarding the capacity and capability of the NDIA to provide good quality, consistent and timely assessments, plans and plan reviews. An example of inconsistency is the differential engagement of parents with the NDIA in the interests of a child. It seems the most articulate families are more successful in negotiating beneficial NDIA packages than vulnerable families. Another example is inconsistency in financial package support, which has been noted to have occurred across the sector by participants, providers and governments.

There is obviously a middle ground to be struck between highly subjective packages and the prescriptive use of "reference" packages. In our view, the NDIA is yet to strike a balance that delivers consistency and fairness, while recognising and supporting the diversity of individuals' goals and aspirations.

The quality of planning is a concern to both clinicians in the Health system and individuals. Examples include key supports being missed during the planning process, causing issues for providers who are already providing supports that the NDIA may not fund, while individuals are missing out on the supports they need. Missed supports in plans cannot simply be identified as an error and corrected, they require a plan review, which is time consuming, and often dependent upon strong advocacy. For example, Residents of Brian Henessy Rehabilitation Centre, which is being closed as clients transition to community accommodation settings, have a plan that reflects their needs while in a 24 hour supported facility, but will not support the move to community-based accommodation.

The episodic nature of mental illness means that plans often need to be modified quite rapidly to support someone who is becoming unwell, however the process is taking 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 (as we are aware because it has occurred for residents of Brian Hennessy Rehabilitation Centre). This 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 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 them 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.

9.2 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, and the impact on people with disabilities and costs to the ACT has been covered in other sections. As noted previously, 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 that 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 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 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.

9.3 ACT Capacity

The ACT largely funded its disability policy, government and Ministerial support capacity through the administrative overhead contribution to the Community Services Directorate from Disability ACT and Therapy ACT service delivery arms. As this service delivery has been gradually cashed out and funds sent to the NDIA since 1 July 2014, the administrative contribution has also been reduced to the point where there is a small amount now for residual regulatory responsibilities until the national quality and safeguards system is operational in 2019, and a small amount of policy support. Not only have funds moved from the ACT to the NDIA, but experienced staff have also moved out of the ACT to positions in the new NDIS

world. This includes policy staff. The ACT has needed to rebuild its policy and government support capacity adding additional costs.

However, the ACT Government is committed to retaining disability policy capacity, both to continue to support the transition to the NDIS and to address the many other issues that affect the lives of people with disability. The Government committed at the 2016 election to the establishment of an Office for Disability and this is now in place.

10. Examine the Most Appropriate Levers to Manage Any Potential Cost Overruns

The ACT sees a number of levers to manage costs, as follows.

10.1 Local Area Coordination (LAC)

LAC is a new role in the ACT. During the Trial the ACT theoretically had a combined planner/ LAC role, but in reality the role only undertook planning and there was no local area coordination. The ACT opposed the combination of roles and we believe that our concerns were justified and that this approach has led to higher costs.

The use of LACs in setting participant plans that are a more balanced combination of mainstream services and individualised package costs should reduce scheme costs. The successful LAC provider for the ACT was announced in late February 2017 and is an aged care provider from Queensland, Feros Care, which will take some time to establish its credentials with the local community and learn about ACT services.

Establishing plans that are more balanced will be enhanced over time by the use of ILC services to build the capacity of mainstream organisations to provide services in a more inclusive way that meet the needs of people with a disability, their families and carers. Until Information, Linkages and Capacity Building can build this capacity, which will take time and will also require significant cultural change, the ACT believes participants and families will look for specialist disability services as providing the most appropriate support. This higher demand for specialist disability services will keep costs higher.

10.2 Early Childhood Early Intervention (ECEI) Centres

It is not known how many children 0-6 during the past two and a half years of Trial and Transition should have been diverted away from a participant plan to a light touch service at an ECEI Centre. The new ECEI Partner for the ACT is EACH. The establishment of this Centre should substantially reduce the costs for this group of children going forward. Had the ECEI Centre been operational in the ACT earlier, this may also have reduced participant numbers.

The ACT is negotiating for co-location of EACH with the Child Development Service, and for outreach visits to the ACT Child and Family Centres. As outlined above, 682 children aged 0-6 are currently having plan reviews. To date, one third of these children have had their plans reviewed, and 20 per cent of those will transition out of their early intervention packages.

A further 700 children are aged 6-12 years of age and are yet to have their plans reviewed. Based on the experience to date, it is not clear that the NDIA's estimate of 1,000 children transitioning out of the NDIS within the next three months is supported. The ACT Government's priority is to ensure that those children who are eligible for ongoing

participation in NDIS continue to have access, and that those who transition out are supported to access any mainstream services they may require.

Women with Disability ACT supports the ECEI model as giving the best flexibility, most liberal entry points, and most autonomy for users, for children with disabilities or developmental delay to get assessment and direction to appropriate services. The referral pathway seems to be efficient for parents, and is cost effective and ensures that those who are then not deemed eligible to become NDIS participants have still accessed appropriate supports. As women are often the parent who is organising the interaction with the health and disability systems, this is a positive framework.

10.3 Appropriate Plan Reviews

In the ACT, at the time of writing, approximately 1,700 children under 18 years of age have plans that are under review, inclusive of the two cohorts of children discussed above. Based on an analysis of the level of disability by the NDIA, there should be as many as 1,000 children under 18 years of age who will be transitioned out of the scheme.

Successfully transitioning significant numbers is dependent on mainstream organisations being able to include children with disabilities into their services and activities. This in turn is dependent on better networking and coordination, which will be supported by the LAC and ILC providers commencing operations. Managing this transition however will likely increase operational costs of both sets of providers.

11. Whether there are any issues with the scheme's design, including the application of market and insurance principles, in ensuring the best possible outcomes for people with severe and profound disability

At the moment, providers advise that there is a risk of market failure for service types where prices are too low, and for accommodation supports. People with severe and profound disability are at risk here. For example, the ACT Government has been told that packages for a group of such people were reduced without consultation or communication with the provider, after plan review by up to \$70,000 per person. These services are labour intensive, and current prices are already based on low wage costs, as noted above. The risk of substantial reductions in package levels puts pressure on the ability of organisations to provide safe and appropriate – let alone high quality – services for the prices on offer from the NDIA.

12. Participants and Advocates

Participants and Advocates have formed the Disability Advocacy Network with representatives from the Mental Health Community Coalition, Women with Disabilities ACT, People with Disabilities ACT, ACT Disability, Aged and Carer Advocacy Service, Advocacy for Inclusion, YWCA and ACT Council of Social Services. This group has met regularly with the NDIA for at least the last 12 months. Agenda items have included:

- overlong wait times to get a call to the 1800 number answered;
- inability of frontline 1800 call staff to direct queries properly;
- manners of frontline staff on calls;
- invoicing; and

loss of influence of ACT NDIA as the regional headquarters shifts to Wollongong.

Participants see a general lack of decision making or problem solving capacity by the NDIA without directive from the national office.

Participants and advocates in this group have expressed concern that the "My First Plan" process imposes an off-the-shelf reference package, meaning that the vision of the NDIS of control and choice driving life planning is being lost. They are concerned that this approach will continue to be adopted until full rollout in 2019-20.

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. According to the most recent report from the NDIA, one in four ACT participants is not utilising their plan.

Community feedback also talks about plan reviews started without notification to the participant, items 'cut' from plans when still needed and without explanation, and payments of current invoices frozen while plan reviews are taking place. There is also some ongoing frustration with aspects of the website and payment portal.

Issues that the ACT Education Directorate has identified as affecting participants include:

- families not knowing how to activate plans, which is supported by anecdotal feedback that plans for children with EI packages are not being drawn down and that Aboriginal and Torres Strait Islander children are not getting the right supports for their plans;
- significant delays in receiving a response from the NDIA when a participant/carer has requested an internal review of an NDIA decision (up to 3 months);
- plans being difficult to understand and interpret; and
- callers to the NDIA not being given a reference number, making it difficult to track and follow up issues.

The Education Directorate, as both a mainstream and in kind service provider, has highlighted a noticeable decline in NDIA responsiveness and engagement with issues raised in relation to the interface or advocacy for students and their families.

12.1 Women with Disability

The ACT Government is proud that it appointed a Gender Adviser to the ACT NDIS Taskforce in 2014, and has continued to take a gendered look at the NDIS. Some important issues raised by Women with Disabilities ACT (WWDACT) include that there appears to be a lower uptake of the NDIS by ACT women with disabilities, possibly due to self-censorship, which is gender-related, with women believing that there are people with greater need who should get priority access to the funds. Even when eligible, women tend to be more conservative in asking for funding for various activities. This points to a need for some gender disaggregation of the data on utilisation rates.

Feedback to WWDACT from community consultation in 2015 (Contributing our Voices report) is that women are unsure of how to implement some aspects (or sometimes, all) of their plans. There is a lack of linkages between the services that are being used, meaning women have to

repeatedly tell their stories. Women identified that there is also a lack of medical specialists in Canberra, necessitating trips interstate (usually to Sydney) for required NDIS clinical diagnosis. Even if funding is available, the logistics of arranging the trip can present difficulties for someone who has responsibility for running a household.

WWDACT is aware of a number of women in the ACT who had not previously accessed services, even though they had significant disabilities, with similar reasoning to that above – that others had a greater need, or that they were not in need of additional funds. With persuasion, they have then decided to enter the scheme. These are women in the 30-55 age group and are often caregivers within a family.

WWDACT also provided feedback that the criteria for participant supports are too often neither clear nor effective, affecting both participants and planners. In addition, planners do not show evidence of having a trauma-informed approach, nor any training in awareness of domestic violence, sexual assault, abuse or neglect. This means that they are not able to effectively assess the needs of participants who have experienced trauma. This lack of awareness coupled with unconscious bias is likely to result in sub-optimal allocation of funding amount or type.

NDIS Planners need to be aware that women with disabilities are disproportionately represented in the lowest income quintile, compared to non-disabled men, and often have higher living costs because of their caregiver roles. Therefore there is great value in enabling them to self-manage packages to achieve cost-effectiveness and maximise flexibility. In recognition of this, the addition of funding for financial management as a component is valuable for women with disabilities. WWDACT has self-funded one forum on self-management. NDIS-run information forums on self-management would assist all participants.

12.2 Aboriginal and Torres Strait Providers and Participants

Winnunga Nimmityjah and Gugan Gulwan are Aboriginal controlled organisations that support people to access the NDIS. Currently, less than half the plans of Aboriginal and Torres Strait Islander participants are activated. According to Winnunga and Gugan, the most important thing for Aboriginal and Torres Strait Islander participants is to have a trusted place to go to in order to access services. Gugan and Winnunga are such places. Winnunga has recommended block funding of some service provision, including plan activation, to achieve the provision of services at a trusted place. The NDIA Chief Operating Officer has agreed to consider this.

13. Providers

As noted in section 11 above, specifically in relation to services for participants with high support needs, providers have reported a number of issues to the ACT Government. We are concerned that some of these matters threaten the viability of the market and may place vulnerable people with severe and profound disability at risk.

While acknowledging the significant work underway to address ICT issues within the NDIA, providers continue to report that they are having difficulty getting payments from the portal. In line with the advice from participants and advocates, providers have told us that the 1800 number provides a poor service, with very long waiting times and failure to return calls if the operator cannot address the issue. Operators will not give a name and number, so the provider has to go back through the 1800 number, with the same problems occurring again.

Providers have said they are finding that if there are changes to a plan – or even if it is under review – payments to providers under the old plan are frozen. Communication challenges between the NDIA, participants (or their families) and providers results in providers not being told there has been a plan review and a new plan. As a result, providers keep providing services under the old plan and then cannot get paid for those services. This has caused significant cash flow problems for a number of ACT providers.

Our understanding is that the problem tends to arise particularly when plans are reviewed by phone, but participants and families don't realise that a phone call from the NDIA is actually a plan review. Once this becomes apparent, they then have to lodge a review request if supports are inappropriately reduced. As noted above, this was also reported by ACT Mental Health in relation to clients in mental health inpatient facilities. While ACT Disability, Aged and Carer Advocacy Service is funded to support participants in seeking reviews, other advocacy services are also experiencing increased demand. Meanwhile, providers cannot be paid for the level of service previously included in a plan while the new review is underway. In areas of intensive support needs, this may result in a "skeleton" staffing arrangement that significantly affects participants' quality of life and increases the risk of adverse outcomes for both participants and staff.

Local providers have told the ACT Government that the explanation of how prices are set is not transparent to or accepted by them. If plan hours are reduced, providers say it is often not worthwhile providing the service. Providers have also reported "cherry picking" of service types which are better paid and have "easier" clients, which opens up market gaps for other services.

These pricing issues are very serious, in the ACT Government's view – particularly in the areas of supported accommodation, intensive personal support and support for participants with complex needs. The NDIA has identified a range of market risks in relation to insufficient or uneven supply in these areas, which it notes are magnified where the government has withdrawn as a service provider. The risk to participants in the ACT from providers who currently support people with complex needs withdrawing from the market is high.

14. Conclusion

The ACT Government welcomes the opportunity to provide this submission and is keen to engage with the Productivity Commission as the review proceeds. We would be happy to host a visit and/or appear at a public hearing, and encourage the Commission to continue to engage directly with ACT-based participants, carers, advocates and providers.