



Submission:

**Productivity Commission Study on
National Disability Insurance Scheme Costs**

March 2017

About ACTCOSS

ACTCOSS acknowledges Canberra has been built on the land of the Ngunnawal people. We pay respects to their Elders and recognise the strength and resilience of Aboriginal and Torres Strait Islander peoples. We celebrate Aboriginal and Torres Strait Islander cultures and ongoing contribution to the ACT community.

The ACT Council of Social Service Inc. (ACTCOSS) is the peak representative body for not-for-profit community organisations, people living with disadvantage and low-income citizens of the Territory.

ACTCOSS is a member of the nationwide COSS network, made up of each of the state and territory Councils and the national body, the Australian Council of Social Service (ACOSS).

ACTCOSS' vision is to live in a fair and equitable community that respects and values diversity, human rights and sustainability and promotes justice, equity, reconciliation and social inclusion.

The membership of the Council includes the majority of community based service providers in the social welfare area, a range of community associations and networks, self-help and consumer groups and interested individuals.

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Acronyms

ACT	Australian Capital Territory
ACTCOSS	ACT Council of Social Service Inc.
CALD	culturally and linguistically diverse
DPO	Disabled Peoples Organisations
ILC	Information, Linkages and Capacity Building
LAC	Local Area Coordination
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
PSD	psychosocial disability
TIS	telephone interpreter service

Introduction

One of the key objectives of the National Disability Insurance Scheme (NDIS), the landmark social policy reform of this generation, is to 'enable people with disability to exercise choice and control in pursuit of their goals and the planning and delivery of their supports'.¹

There is evidence that where people have clear plans, relatively straight forward asks and a good alignment between their goals and the items in the plans, that the NDIS is having a positive impact in the lives of people with disability and is providing people with supports they did not have before.

However, there is a growing disconnect between this objective of the NDIS and the experience for some individuals in entering and being a participant in the scheme. The ability of the National Disability Insurance Agency (NDIA) to fulfil the purpose of the NDIS is fast losing credibility, through its disempowering processes that restrict rather than enhance people with disability's exercise of choice and control over their services and supports.

While there has been significant investment in the ACT in service provider readiness, we have not seen adequate investment in peer support and advocacy that will empower consumers to adapt and gain the most out of the NDIS.

The ACT was the only whole jurisdiction trial site for the NDIS and is the first jurisdiction to complete full rollout. Some of the issues related to implementation of the NDIS and related costs are more visible here than in other trial sites or jurisdictions.

This includes:

1. The impact of planning processes on outcomes and related long term costs of the scheme
2. Reasons for difficulties in implementing plans
3. The impact of communication failures on administration, evaluation and costs of NDIS
4. The impact of ILC implementation on the provision of vital community infrastructure and long term financial sustainability of the NDIS
5. The intersections and gaps between the NDIS and mainstream services.

¹ Australian Government, *National Disability Insurance Scheme Act 2013*, Australian Government, 2013, p.4.

1. The impact of planning processes on outcomes and related long term costs

Disempowering planning processes reduce positive outcomes for participants of the NDIS and will potentially increase long term costs of the NDIS. The insurance approach that was actively implemented during trial phase, valuing higher investment early on the package to reduce costs in the long term, now seems to have been lost in some plans, and this coincides with national rollout. Now the focus is purely on containing costs in the short term, ignoring that this will lead to higher costs over the whole life of a package.

Issues in the ACT:

- Limiting person centred planning including:
 - the advent of the 'my first plan', during which planning processes exclude or severely restrict the development of an individual's vision and goals for their life, frequently reducing the process to a half hour conversation over the phone. Planning by phone increases communication difficulties and reduces the ability to clearly present participant goals and needs, and compromises accurate assessment by the planner. This approach is not appropriate and will not ensure lifelong supports adequately reflect the goals and needs of people with complex needs.
 - the starting point for planning being a standardised reference package, rather than an individual's circumstances and their goals
- Rationing and reduction of services following the formal review of an annual NDIS plan. There are reports of underlying assumptions by the NDIA that one year into a package the need for disability supports may be reduced. This is not necessarily the case beyond specific early intervention items
- Information about the participant, through the development of their plan, is primarily controlled by the agency. There is no opportunity for the participant to be consulted about the plan before it is finalised to ensure it properly reflects their goals and needs
- The requirement that a full review is required for any amendments to plans, including where the plan bears little resemblance to the planning conversation or contains even small mistakes. This leads to high numbers of participants having a review, extending the timeframes for completion of the review (some have taken many months) and leaves participants without supports while they are waiting for the review to be completed.

This imposes a personal cost high for individuals having to fight for what they need in their plan, and living in fear of loss of supports and delays or gaps in receiving supports. It is a key example of inefficient administration of the NDIS. If NDIA practice changed so that participants were given a draft of their plan, could access any support needed to have it clearly explained, and could negotiate amendments before being made final, this would improve the experience for participants, reduce administration costs and improve efficiency. And service providers are being put in the invidious position of having to either carry the cash flow risk of continuing service provision or denying services to people during the period of the review

- At annual reviews, there are reports of participants being required to justify that they've improved their life as a result of what has been provided via the NDIS. There is an implied failure on the part of the participant if they report this hasn't occurred
- Information being inaccessible and compromising choice and control. For example, confusing formats of plans, material not being written in plain English, inability to access planning sessions that include the telephone interpreter service (TIS), inability to access plans because of technology decisions taken by the NDIA, unreliability of access to the participant portal and inability to exercise control over the information held about them
- Barriers to self-management. Reported examples include:
 - As part of a review process the NDIA themselves decide they will manage the plan, without the participant being consulted, when they had previously been self-managing
 - An apparent presumption by some NDIA staff against self-management even where a person is interested in self-management.

As a result of these planning issues, there is **reduced equity of outcomes for participants**. Those with good self-advocacy, system navigation skills and/or access to skilled advocates get plans that better reflect their goals and needs, have higher funding levels and experience a better implementation process. Participants without these skills or access to skilled advocates don't. Improved funding of independent advocacy, fully funded peer navigators who can support self-advocacy, as well as ensuring all participants going through planning are offered these supports, would improve consistency and equity for participants.

The ACT is only now engaging Local Area Coordination (LAC). The successful organisation is currently based outside the ACT and will take time to set up

locally. Ideally, this LAC role should have been in place prior to plans even being started and progressed to support people to identify and consider good local services.

In addition to improved processes, more adequately trained and properly resourced planners would improve equity of outcomes for participants.

In the trial phase in the ACT, the NDIA only employed planners under short term contracts, which led to a **high turnover and expertise continually being lost**. One of the positive strategies implemented in the ACT trial phase amongst these challenges was appointment of specialist teams/positions for particular disabilities, to ensure planners had specialist knowledge, thus improving the planning process. Since national rollout, this no longer occurs. Our stakeholders have reported reduced quality of the experience of engaging with the NDIS, less accurate and useful plans, and poorer outcomes for participants.

The NDIA and its **planners lack the skills and knowledge to support ongoing capacity building** for participants. At plan review time, there are reports that if a specific capacity building goal is met, there doesn't seem to be a pro-active approach by planners to investigate where further capacity building is needed for the next plan. Learning is ongoing and lifelong, not just one off. Constraining costs in the short term seems to be the key goal, so inclusion of support for capacity building in plans is reduced at review. What is needed is continual investing in the person, which will save money over the life of the package. These savings should not be expected to be realised within the first year of plan implementation.

Since national rollout, **unrealistic planning timeframes** have been a significant cause of many of the above poor processes. These include the NDIA being required to complete as many new plans in the first six months since the official launch of the scheme, as in the entire three year trial phase. These pressures will only increase, with the NDIA needing to approve 850 plans per day and review 1100 plans per day in 2018-19, and review 2000 plans per day in 2019-20.²

Bruce Bonyhady, previous chair of the NDIA Board, described these pressures as potentially compromising quality of plans. He said, 'Consideration should be given to including quality as well as quantity measures in the monitoring of bilateral targets.'³ He also states:

Many plans have been extended and plan reviews have been deferred and Local Area Coordinators have not been able to engage in essential work on

2 B Bonyhady, Letter to Minister Christian Porter, 22 December 2016, pp.3-4.

3 *ibid.*, p.4.

community inclusion. This is not sustainable and so administrative cost targets should be reviewed periodically, based on the emerging evidence during the transition period.⁴

The **prioritising of quantitative over qualitative outcomes** in the administration of the NDIS will need to change if it is to realise its objectives regarding improved choice and control.

The NDIS independent evaluation Intermediate Report of September 2016 included findings that since becoming NDIS participants, **30% of participants are exercising the same choice and control and 15% are exercising less choice and control.**⁵ Those who are exercising less choice and control over their supports since becoming NDIS participants include people:

- with psychosocial disability (PSD)
- with vulnerable families
- unable to navigate what services are available
- less able to articulate their support needs
- living in non-metropolitan areas, with fewer services.⁶

It also found that those whose exercise of choice and control had decreased, are more likely to **experience a decrease not an increase in support**, such as fewer supports than previously received.⁷ Lastly, it finds that choice and control is restricted because of the **limitations in the number or capacity of services.**⁸

Recommendation

There needs to be a review of the NDIS legislation and all NDIA operations, and amendments to policies and processes in response to the findings of this review, to ensure the outcome of the key NDIS objective to 'enable people with disability to exercise choice and control in pursuit of their goals and the planning and delivery of their supports',⁹ is effectively implemented. This in turn, will assess costs over the life of a participant's package rather than containing costs only in the short term.

4 *ibid.*, p.6.

5 K Mavromaras, M Moskos & S Mahuteau, *Evaluation of the NDIS: Intermediate Report*, National Institute of Labour Studies, Flinders University, 2016, p.xiii.

6 *ibid.*

7 *ibid.*

8 *ibid.*

9 Australian Government, *National Disability Insurance Scheme Act 2013*, *op. cit.*, p.4.

2. Reasons for difficulties implementing plans

Reported reasons for difficulties implementing plans include:

- There was no dedicated Local Area Coordination for the trial period in the ACT, greatly contributing to lower than expected rates of plan implementation. There has not been a service dedicated to assisting participants to interpret very complex plans. Reasons cited by stakeholders we consulted include:
 - plans being difficult to understand because they are in a confusing format
 - not being in plain English
 - lack of clarity of how much funding is available for what type of supports

With a new system, there are also difficulties navigating the system without support. Even those who are experts have difficulty navigating, as information changes so quickly

- Funding for LAC has only just been announced in the ACT in March 2017, after the NDIS started nearly three years ago
- Lists of registered service providers are not reflective of reality. Many either don't have capacity to offer services to participants or have stopped providing that service type, with lists not being updated in a timely way
- The amounts being given for support coordination are inadequate. In many plans the allocation is under \$1000. We are advised that allocations are consistently too low to purchase adequate (and in some circumstances any) support coordination. Some organisations are declining to manage plans because the support coordination is too low
- The amounts set aside for financial and service intermediary supports to assist with plan management are also too low and some providers are withdrawing from plan management because of this
- Portal issues have been significant barriers to implementing plans, with services not being able to provide a service until new plans are authorised on the portal, often a significant time delay of up to 6 weeks after the person has been told their plan is approved. Again, this puts a provider in the position of having to either carry the cash flow risk of continuing service provision or denying services to people during the gap between existing and new plan approval

- There has been almost no forward investment in the capacity of consumers to engage with the NDIS in the ACT. Much of the investment for NDIS readiness has been targeted towards provider readiness and while this is welcome it has not been matched by supporting people with disability to develop their readiness to exercise choice and control in the scheme. When the Productivity Commission recommended an NDIS in 2010 they envisaged a layer of disability support organisations that would be consumer governed and would support people to realise choice and control. In some other jurisdictions we have seen good intersectional work to support people to access the scheme and get peer support as they move to individualised funding but there has been very little of this in the ACT
- Coordination of supports is a key service type to assist a person to implement their plan, yet it is often not accessible, either due to lack of capacity or it not being viable if the person only has a small amount of hours in their plan for it. There is a need for higher investment early on to help set up appropriate supports. This item needs to be priced realistically
- Cultural and language barriers are also an issue, with very few translated plans, and there being no standard practice in offering to utilise TIS during planning processes or to translate plans for all CALD participants
- Plans are often wrong. Information about the participant, through the development of their plan, is primarily controlled by the agency, with no opportunity for the participant to be consulted about the plan before it is finalised to ensure it properly reflects their goals and needs. This is compounded by the requirement that all amendments to plans, even small mistakes, require a full review at a national level. This leads many participants to having a review, which takes many months to occur, during which time supports are not able to be implemented
- There is a misalignment between the supports provided in the community, the supports people have asked for and the way supports are described in plans. The prescribed support area definitions are hampering the scheme's flexibility and ability to realise choice and control. Some people are getting funding for assistance to engage support from allied health professionals for skill development, training, assessment and therapy, when what they really require and asked for at the plan interview is equipment. Registered providers and plan managers are then spending time trying to 'fit' these supports to peoples actual needs

- There is a lack of advocacy and consumer feedback mechanisms which, if resourced adequately and used effectively, could be system savers for the NDIS and ensure the scheme succeeds
- The NDIA here in the ACT lacks a regular grassroots feedback mechanism for participants to provide feedback on the scheme. While the NDIA does engage with peaks and attend some forums, there would be real advantages in a local consumer committee of people with NDIS plans providing regular feedback on the way they experience the transition from block funded services. This level of feedback has been suggested many times by local advocacy organisations including by People with Disabilities ACT; the ACT Disability Expert Reference Group; and at community meetings such as the Chronic Illness Seminar held on 16 March 2017. These local mechanisms need to directly feed into national policy decision making, given local NDIA offices have little authority to change policy or practice
- Good advocacy and information is a system saver for the NDIS and there is a developing body of evidence that sustainable NDIS plans are those that have drawn on individual advocacy support at an early stage. Yet funding for advocacy has not grown under the National Disability Advocacy Program for local organisations since the NDIS started despite the demands for services, support and advice having grown exponentially. There has been investment in service provider capacity but no investment in consumer advocacy capacity. This is a concern shared by Advocacy For Inclusion, ACT Disability, Aged and Carer Advocacy Service, and People with Disabilities ACT
- Both individual and systemic advocacy are important to meet the obligations of the ACT under the United Nations Convention on the Rights of People with Disability and to overcome ingrained systemic discrimination and barriers experienced by people with disability
- Disabled Peoples Organisations (DPO) also provide an important voice for people with disability on a range of issues in the ACT. The NDIS has recognised that access to independent advocacy and information is essential to enabling people with disability to make informed choices and achieve positive outcomes. Organisations must be funded to a level that will enable them to provide this support to all people with disability including marginalised communities such as Aboriginal and/or Torres Strait Islander peoples; people living in group houses; people who are in contact with the criminal justice system; or people from CALD backgrounds. DPO funding has not increased since the NDIS began and

the oldest cross disability DPO in the ACT has barely enough funding to maintain one full time equivalent position.

3. Communication failures impact on administration, evaluation and costs of NDIS

The NDIS communication strategy and processes require urgent improvements. Serious communication concerns increase delays and make the eligibility, planning and review processes more difficult for participants and providers. They include:

- Lack of access to local NDIA offices via telephone, with the national call centre being the only phone number available to participants. This is particularly difficult for:
 - participants who have started the planning process, who experience long delays speaking to the appropriate person, consistent with other national government call centres
 - Service providers trying to resolve issues regarding plan, portal, payment and other service issues
- Many extended email system failures over the time of the ACT Trial, where no one in the local offices could receive emails
- Email security protocols that mean participants can't respond directly to emails from the NDIA
- Changes in policy or practice take months after they've come into effect to be released in writing from the national office of the NDIA, with local offices not allowed to give any information in writing until this formal release. This communication delay increases frustration, misinformation and misunderstanding for participants and service providers. Information should be provided in writing and loaded up for online access prior to changes occurring
- Even when changes are finally in writing, the current system is dependent on an individual checking the NDIA website. Regular service provider specific email systems need to be established, as occur in other national government programs such as the Commonwealth Aged Care Programs administered by the Department of Health. These systems automatically email web-links to information about new and/or changed policy and practice, to improve timely dissemination of information. These automated

systems also allow forwarding on advice across multiple consumer and provider mailing lists to extend the distribution of information.

4. How ILC is being implemented and its impact on the long term financial sustainability of the NDIS

The purpose of the NDIS Information, Linkages and Capacity Building (ILC) program is to enable greater access to the social and economic life of the community for people with disability, their families and carers.¹⁰ ILC is a core foundation of the NDIS. The ILC policy framework states:

ILC is a key component of the NDIS insurance model and will contribute to the sustainability of the NDIS by building the capacity of the community, people with disability, their families and carers which in turn will reduce the need for funding of supports for people with disability through Individualised Funding Packages.¹¹

This objective can only be achieved if people living with disabilities, their families and carers are supported to participate in and communities are enabled to create more inclusive mainstream services and infrastructure.¹² The ILC will also contribute to the long term sustainability of the NDIS by encouraging the provision of more inclusive and accessible market.¹³

ILC funded infrastructure and services will need to support potentially nearly 500,000 people with disability who need assistance with activities of daily living at least weekly, but won't be eligible as NDIS participants.¹⁴ The ILC is trying to achieve this with insufficient funding. The majority of ILC funding is going to Local Area Coordination (\$550m compared to \$132m for the rest of ILC). The NDIA previously stated that LACs would be the largest single investment by the NDIA in delivering ILC outcomes.

The role of the LAC was initially to:

- Link people with disability to the NDIS, providing assistance with the NDIS planning process and planning implementation

10 Australian Government, *A Framework for Information, Linkages and Capacity Building*, Australian Government, 2015, p.3.

11 *ibid.*, p.2.

12 R Naufal, *ILC: Kneecapping the NDIS*, Disability Services Consulting, January 2017, viewed 28 February 2017, <<http://www.disabilityservicesconsulting.com.au/resources/ilc-kneecapping-the-ndis>>.

13 *ibid.*

14 Australian Government, *A Framework for Information, Linkages and Capacity Building*, op. cit., p.7.

- Link people with disability to information and support in the community, connecting to and building informal/natural supports
- Work with the local community to make sure it is more welcoming and inclusive.¹⁵

The LAC role has expanded to now undertake planning, including reviews, for 70% of NDIS participants. Processing such a large number of individual plans will mean the community inclusion aspects of LACs are displaced and potentially overridden as priorities. This was demonstrated during the ACT trial, where planning and LAC was combined, with only planning occurring and not the other LAC roles.

With the majority of ILC funding going to LAC, and planning being the main channel through which LACs deliver ILC outcomes, inclusion objectives are both deprioritised and under-resourced. Therefore, growing community and mainstream inclusion, on which the NDIS sustainability relies, will effectively not occur.

ILC funding is also almost exclusively being framed as project funding, which means there are challenges in driving either organisational or operational reform, building continuity and sustainability of programs and growing capacity over time. Block funded service provision that is not appropriate to be funded through individual funding plans, is also an emerging gap, with a lot of focus of ILC being on information provision not on social engagement or recovery support (especially for people with psychosocial disability).

Bruce Bonyhady, former chair of the NDIA board, said, 'Currently only \$132 million (excluding LAC support) has been allocated to the ILC. This is not sufficient and means that one of the key foundations on which the NDIS is being built is weak.'¹⁶

If the ILC does not enable greater access for people with disability to the social and economic life of the community, more people with disability will need individual funding plans, which will greatly increase the costs of the NDIS and put its financial sustainability at risk.

The Commonwealth has not done work to transition and maintain individual information services that could have been useful in the rollout. For instance, it defunded its main specialist disability information and referral service provided by Nican, an ACT based information service that provided a menu of more than 5000 disability services in the sports, recreation, and education and arts areas

15 National Disability Insurance Agency, *Local Area Coordination*, NDIS, viewed 28 February 2017, <<https://www.ndis.gov.au/communities/local-area-coordination>>.

16 B Bonyhady, op. cit., p.6.

and also had a sizeable ACT footprint. It defunded that program without managing the transition of that service or ensuring a service was in place in the lead up to ILC.

The ACT in 2017 actually has less ILC capacity than it had before the NDIS.

5. The intersection between the NDIS and mainstream services

The experience of people with PSD and/or mental health conditions is one of the main areas of concern in the ACT regarding the NDIS.

ACTCOSS supports Community Mental Health Australia's position that the recovery focus of community managed mental health services should not be lost with the rollout of the NDIS. The NDIS was designed prior to people with PSD being part of the target group. Therefore, many elements are inadequate regarding eligibility criteria, access to the scheme, planning processes, and lack of consideration of the rehabilitation supports that are central to the recovery approach for people with psychosocial disability and/or mental health conditions.

Eligibility for the NDIS requires a permanent and lifelong disability, where people with PSD may have difficulty acknowledging their diagnosis, find it disempowering to their recovery to acknowledge it as permanent and often have episodic needs. This is leading to many people with PSD not being accepted into the NDIS, with the emerging gap of no block funded specialist supports to ensure adequate support.

Poor communication together with disempowering planning processes outlined above, are particularly difficult for people PSD. Long waiting times, poor communication, unclear information and interaction only by phone exacerbate anxiety and other mental health symptoms.

Inadequate pricing levels of the NDIS mean funding levels don't cover employment costs for qualified mental health staff. It is vital that supporting people with complex PSD needs is adequately funded in the NDIS, to ensure effective and quality supports.

NDIS perception of supports as primarily generalist disability supports, and not recovery focused psychosocial rehabilitation supports. It is these recovery focused support that have been critical to the community mental health system successfully supporting people with PSD. The removal of these supports from

the service system is an unintended and dangerous outcome from the implementation of the NDIS.

For example, effective and highly valued psychosocial rehabilitation supports were provided through the Commonwealth funded Partners in Recovery (PIR) program, Day to Day Living (D2DL) and Personal Helpers and Mentors (PhAMs) which are ending in the ACT, with the funding being rolled into the NDIS. However, with the NDIS not providing psychosocial rehabilitation, it effectively means that that this proven support for people with PSD will no longer exist. This is a huge gap that will occur across Australia at full implementation and must be remedied. The guarantee in the bilateral agreements for continuity of support backs the need for this to be altered.

There must continue to be an adequately funded community mental health service system outside the NDIS.

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