



Family &
Community
Services

Report on the Trial of the National Disability Insurance Scheme in the Hunter, NSW

July 2013 - December 2014



Document approval

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- NDIA Scheme Actuary monthly extract – December 2014
- Department of Family and Community Services, Ageing, Disability and Home Care (ADHC) Minimum Data Set (MDS) 2012-13
- Department of Family and Community Services, Ageing, Disability and Home Care (ADHC) Minimum Data Set (MDS) 2013-14

This Report has been prepared by Ageing, Disability and Home Care (ADHC), part of the Department of Family & Community Services (FACS).

The information, statements, statistics and commentary (together the “Information”) contained in this report have been prepared by ADHC from information supplied by the National Disability Insurance Agency (NDIA) and PricewaterhouseCoopers (PwC). ADHC may in their absolute discretion, but without being under any obligation to do so, update, amend or supplement this document. ADHC has based this report on information received or obtained, on the basis that such information is accurate. The Information contained in this report has not been subject to an Audit.

It should be noted that trial site experience is limited. Participants that have entered the NDIS to date will not be representative of all participants likely to enter the NDIS due to bilateral phasing arrangements (by geographic area/Local Government Area). Hence, the analyses contained in this report should not be extrapolated to make assumptions for the full scheme in NSW.

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1 Executive Summary

The National Disability Insurance Scheme (NDIS) launched in July 2013 in a number of locations across Australia, including the Hunter in NSW. It is expected that approximately 10,000 people with disability in NSW will transition to the NDIS over the three years of the trial, including over 6,600 existing NSW disability clients and approximately 3,400 new participants. This report contains data relating to the first 18 months of the Hunter trial site (July 2013 – December 2014), including eligibility outcomes, participant characteristics, and participant supports and related costs. The trends described in this report relate to a small proportion of the total number of expected NDIS participants in NSW, and trends may shift as the number of participants increases. Once phasing is complete in all three trial site LGAs (Newcastle, Lake Macquarie and Maitland), a final report will be published.

Access requests and eligibility decisions:

- Almost 4,500 people made an access request in the first 18 months of the Hunter trial. The number of access requests peaked in February and March 2014, and averaged between 200-250 requests per month.
- 78% of people who made an access request were found eligible for the NDIS. Over three-quarters of these eligible participants accessed the NDIS through the disability requirements (76%), while the remaining 24% accessed the NDIS for early intervention.

NDIS participants:

- By 31 December 2014, 2,979 eligible participants had an approved support plan, which is approximately one-third of the estimated capacity for the Hunter trial. Over 500 additional people were eligible participants but yet to receive an approved support plan.
- 71% of these participants with a support plan were previously receiving a NSW disability service (existing clients), while the remaining 29% were new participants.
- There was an average of 66 days between lodging an access request and an approved support plan.

Costs of support:

- The average annualised cost of participants' current plans was \$54,350 at 31 December 2014, including over 200 residents of Stockton large residential centre. Excluding Stockton residents, NSW's average cost was \$40,059.
- Although NSW's average cost was higher than the actuarial estimate of \$36,750, more than three-quarters of participants' plans were below this estimate.
- NSW participant costs are influenced by the number of high-cost existing clients phasing in trial, including from large residential centres and group homes, and the lower than expected allocation of low value plans.
- The cost of NSW's participants remains within the agreed funding envelope, due to the lower than expected number of participants.

Ability Links NSW:

- Ability Links NSW officially launched in the Central Coast and Hunter New England Districts on 1 July 2013, and has since expanded across NSW. In the Hunter, Linkers assisted almost 1,000 people by providing information or referrals, and made over 25,000 community connections.

2 The Hunter trial site

2.1 The Bilateral Agreement

The Bilateral Agreement between NSW and the Commonwealth provides the foundation for the Hunter trial site, including the expected population and the process for their progressive transition to the NDIS. The Hunter trial site has the capacity for 10,000 people with disability to transition to the NDIS over the three years of the trial (Table 2.1.1).

2.1.1 Expected NDIS Hunter trial population

	2013-14	2014-15	2015-16
Existing clients	2,673	1,200	2,748
New participants	327	830	2,333
Total	3,000	2,030	5,081
<i>Cumulative total</i>	<i>3,000</i>	<i>5,030</i>	<i>10,111</i>

The expected population of the Hunter trial includes people previously receiving a NSW disability service (existing clients), as well as new participants. The number of new participants will reflect previously unmet need as well as new incidence of disability, which is expected to grow each year. New participants may also be people who have sporadically received disability services in the past, for example, a one-off service or multiple services in non-consecutive periods of time, but were not receiving a service at the time of their access request. Depending on their needs, these sporadic clients may or may not enter the NDIS during the three-year trial.

Broadly, existing clients transition in order of their LGA of residence based on a sequence of service providers agreed between NSW and the Commonwealth governments. The transition of existing clients from Newcastle LGA was completed in 2013-14. The transition of existing clients from Lake Macquarie began in Q4 2013-14, continues in 2014-15 and will be completed in 2015-16, when Maitland existing clients will commence transition. New participants can present to NDIA from any of the three trial site LGAs at any point in the three year trial, which is particularly likely for new incidence of disability or sporadic users.

In early 2014, NSW and the Commonwealth governments updated the phasing arrangements to ensure that the phasing of clients in 2014-15 reflected lessons learnt in the first year of the Hunter trial and balanced the needs of clients and providers, as well as NDIA's operational capacity. The revised arrangements identified how people with disability in Lake Macquarie and their providers would transition to the NDIS during 2014-15. NSW will continue to work with the Commonwealth and NDIA to ensure appropriate phasing arrangements are in place for the final year of the Hunter trial.

3 Access requests and eligibility decisions

3.1 Access requests

An access request is a formal request by an individual to become an NDIS participant. It provides the NDIA with the information required to assess a person's eligibility for the NDIS under the authority of the *National Disability Insurance Scheme Act 2013* (NDIS Act). Once a person is deemed eligible for the NDIS, they are a participant of the NDIS and will generally remain so for life.

NSW is supporting both existing clients and new participants to access the NDIS through the Hunter Community Pathways team. This team has centralised and simplified intake processes to support more streamlined referrals to the NDIA, ensuring that people with disability can access the NDIS as soon as possible. NSW is also working with service providers, both directly and through National Disability Services (NDS), their national peak body, to ensure they have the knowledge and capacity to support their clients through the transition process.

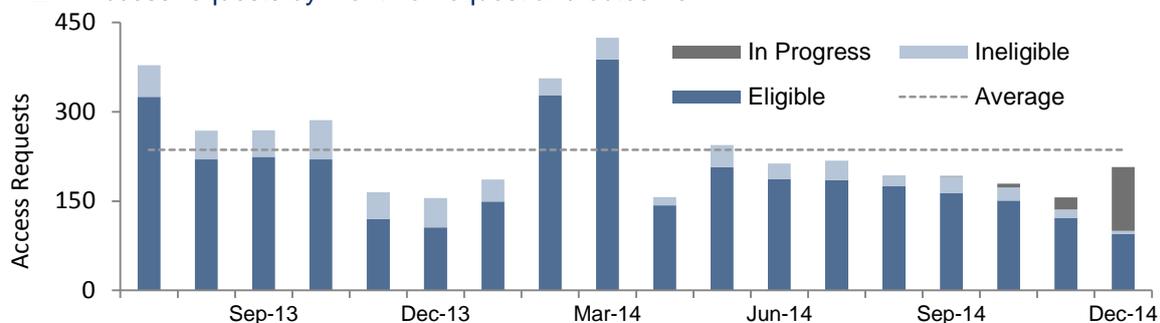
In the first 18 months of the Hunter trial, 4,495 people lodged an access request. Of these 4,495 people 78% were found eligible, 13% were found ineligible, a further 2% were assessed but then revoked or closed, and 3% were withdrawn¹ (Table 3.1.1). As at 31 December 2014, 134 access requests were being assessed.

3.1.1 Access requests by decision outcome

	Eligible	Ineligible	Revoked/closed	Withdrawn	In Progress	Total
No.	3,507	605	99	150	134	4,495
%	78%	13%	2%	3%	3%	100%

The number of access requests averaged between 200-250 per month between July 2013 and December 2014. The number peaked in February and March 2014 when almost one-fifth of all requests were lodged (Figure 3.1.2). This was driven by improved processes for the regular collection of client information from service providers, as well as streamlined eligibility and planning processes for existing clients in specific programs. The number of access requests declined from June to November 2014, before increasing towards the overall average in December 2014.

3.1.2 Access requests by month of request and outcome



¹ An access request is: *closed* by participant requests or death; *revoked* by the NDIA when an individual no longer meets the access requirements; or *withdrawn* by a participant prior to the eligibility assessment.

3.2 Eligibility

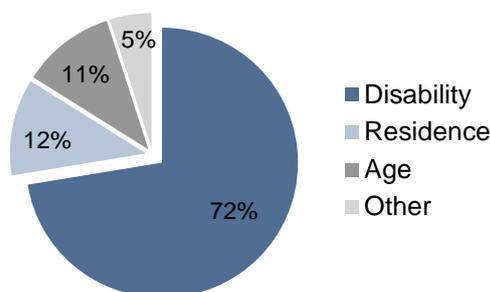
Following the submission of an access request, the NDIA assesses whether a person can become an NDIS participant based on multiple eligibility criteria. To be eligible for the Hunter trial, a person must qualify under the disability or early intervention requirements and be living in Newcastle, Lake Macquarie or Maitland LGAs. Participants must also be under the age of 65 years at the time of their access request, and meet requirements relating to their residency status in Australia.

The number of people eligible for the NDIS in the first 18 months of the trial period peaked in March 2014, with nearly 400 eligible participants, or 10% of the yearly total. This reflects the large number of access requests made in February and March 2014.

At 31 December 2014, 605 people were assessed by the NDIA as ineligible for the NDIS in the Hunter trial site. Ineligibility means that an individual is unable to become a participant in the NDIS as they do not meet the access requirements at a particular point in time. If a person's circumstances later change, they can make another access request to become a participant at any time.

The majority of ineligibility decisions (72%) related to the disability or early intervention requirements of the NDIS (Figure 3.2.1), most commonly because the applicant did not meet the impairment criteria. The age and residence requirements accounted for 11% and 12% of ineligible decisions respectively. The remaining 5% were found ineligible for other reasons, for example, an applicant not providing requested information in order for their eligibility to be determined.

3.2.1 Ineligibility decisions by reason



Of the 605 people found ineligible, more than half were existing clients (56%). Existing clients had a lower rate of disability related ineligibility compared to other applicants (65% compared to 82%), and were more likely to be found ineligible due to age (16%) than other applicants (5%).

The NDIS Act makes provisions for people who have been found ineligible for the NDIS to request a review of this decision. In addition to these reviews triggered by individuals, the NDIA undertook a review of people found ineligible in the Hunter trial to ensure the access criteria are applied appropriately and consistently by planners. This ensures consistency in decision-making, improves operational

guidance for NDIA planners when applying the eligibility criteria, and helps the NDIA in its capacity building and learning from the trial sites.

Continuity of support is provided during the trial to existing clients who were found ineligible. They will continue to receive support consistent with their current arrangements for the extent of the trial to ensure they are not disadvantaged in the transition to the NDIS. Beyond the period of the trial, people found ineligible for an individually funded package will continue to be supported with information and access to community and mainstream services to support them to fully participate in their community. In particular, people aged 65 years or over at the time of their access request can be supported through the aged-care system.

3.3 Ability Links NSW

Information, linkages and capacity building targets people with disability, their families and carers to provide information and referral to informal, community and mainstream supports. The NSW contribution to the Hunter trial includes Ability Links NSW, which helps people access services and supports in their local communities. This is particularly important for people with disability who do not receive an individually funded package but will benefit from additional support.

Ability Links NSW officially launched in the Central Coast and Hunter New England Districts on 1 July 2013, with St Vincent de Paul Society appointed as the provider for the generalist Linker positions. Barkuma Neighbourhood Centre was appointed as the provider of a number of specific Aboriginal identified Linker positions.

Ability Links has since expanded throughout NSW, so that families in every part of NSW have access to a Linker. There are now 16 providers and joint working arrangements in place across NSW. Of these, 12 are Aboriginal non government organisations and joint working arrangements that have Aboriginal identified Linker positions. In addition, ADHC has asked that the generalist or mainstream providers have a broad range of diversity in their Linker teams to help reach all people in community. All Linkers are available to work with both Aboriginal and non-Aboriginal people. Linkers will meet with people in their homes, in the community or in a range of office and community based locations across NSW.

To December 2014, Linkers assisted over 7,400 people across NSW, including 966 in the Hunter trial site, by providing people with information or referral and providing facilitated support to link with the community. Over this period Linkers also made almost 90,000 community connections at expos, community events and interagency meetings, and through local community groups, businesses and mainstream service providers, including 25,162 in the Hunter trial site.

4 NDIS participants

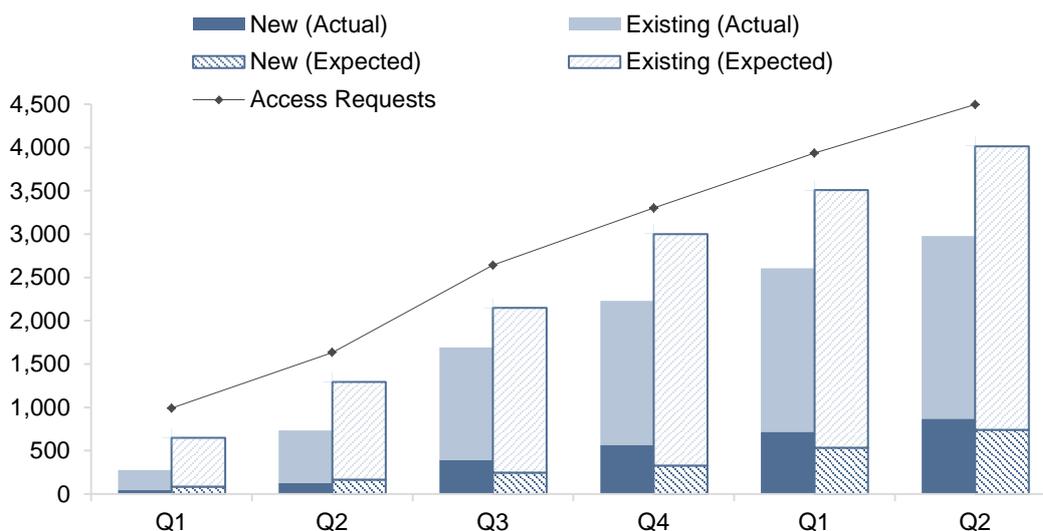
4.1 Participants with approved support plans

To 31 December 2014, 2,979 participants had an approved support plan (Figure 4.1.1)², three-quarters of the expected number (4,014) for this time period. In only two months, March and February 2014, did the actual number of approved participant plans exceed the expected number per month. At 31 December 2014, there were 528 eligible participants with support plans in progress (3,507; 87% of expected participants).

Seventy one per cent of participants with a support plan were existing clients and 29% were new participants, compared to expected proportions of 82% and 18% respectively. The smaller number of participants and higher proportion of new participants may have been due to:

- Sporadic clients - some existing sporadic clients may not have required services in the first 18 months of the Hunter trial, but will access the scheme at a later date. Sporadic clients who did become NDIS participants may have entered as a new participant rather than an existing client if they were not receiving a service at that point in time.
- Existing unmet need - people from the three trial site LGAs who were not receiving any disability services could enter the NDIS as new participants from July 2013. It is likely that people with an existing unmet need would enter the NDIS as early as possible, which would temporarily shift the balance of new participants and existing clients. Future new participants would be limited to new incidence of disability or sporadic users.

4.1.1 Plans by approval quarter (cumulative)

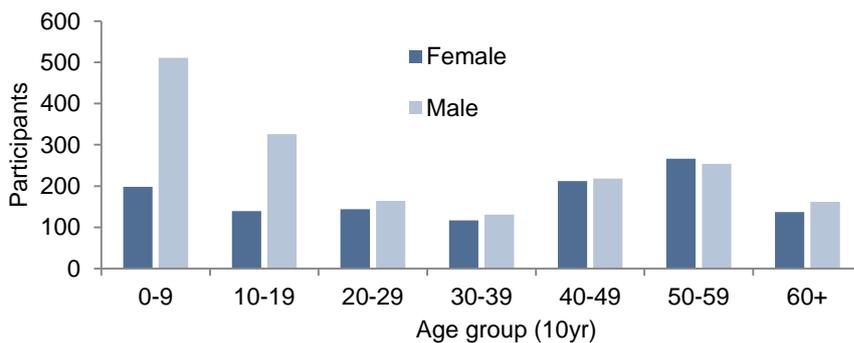


² Includes participants who are currently eligible, are not deceased and have a client status of “active”

4.2 Demographics

More than half the participants with a support plan in the Hunter trial site are male (59%) compared to 41% who are female. The gender gap is driven by large differences in participants under the age of 20, where males outnumber females more than 2:1 (Figure 4.2.1). The median age of male participants is 22 years, compared to 40 years for female participants. Participants range in age from 0 to 66 years³ with a median age of 30. New participants have a median age of 18 years, almost half that of existing clients (33 years).

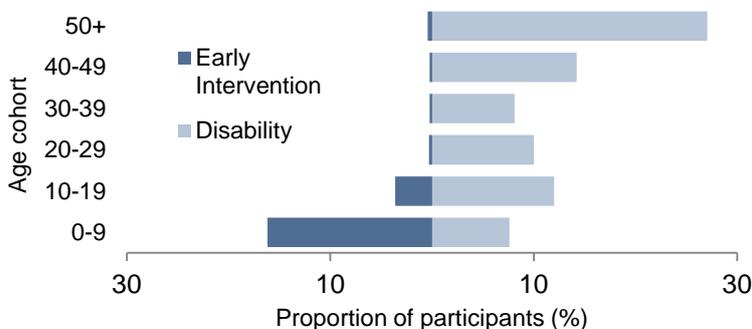
4.2.1 Participants by age and gender



The vast majority of participants with a support plan accessed the NDIS through the disability requirements (79%). A person meets the disability requirements if, among other conditions, they have a permanent impairment that requires lifetime support and substantially reduces their ability to take part in activities, as well as their social and economic participation.

Early intervention aims to reduce the impact of a disability and future needs, or improve or prevent deterioration of a person’s functional capacity. It can be appropriate not only when it is first identified or appears, often in childhood, but also when there is a change in the disability. Proportionally, more new participants accessed the NDIS through early intervention (30%) than existing clients (12%), and people accessing the NDIS through early intervention were overwhelmingly male (75%). More than 90% of early intervention participants were under the age of 15 (Figure 4.2.2).

4.2.2 Participants by age and access type



³ Participants who turn 65 can choose to remain in the NDIS or receive services from the aged-care system

A small proportion of NSW participants with a support plan were Aboriginal or Torres Strait Islander (ATSI) (4%) or from a culturally and linguistically diverse (CALD) background (1%). This compares to 8% and 3%, respectively, of existing clients in the trial site in 2012-13⁴. These comparisons should be used with care, given high not-stated rates (43% for ATSI variable) and inconsistent CALD definitions between the NDIS and existing NSW data. The NDIA acknowledges that these variables are not well collected, and detailed exception reporting is underway to ensure these data are collected⁵. NSW has a higher proportion of ATSI participants than the national total (3%) but a lower proportion of CALD participants (4%).

NSW recognises the need to engage specifically with these communities to ensure the NDIS can be accessed by all who need it, and will work with the NDIA, Commonwealth and other jurisdictions to ensure that specific access strategies are developed for the full scheme NDIS, drawing on the lessons learned from the national trials.

Ability Links NSW includes specific Aboriginal-identified positions to work with both Aboriginal and non-Aboriginal communities. The December 2013 release of *Ready Together* was available in Braille, easy English and large print and in nine community languages for people from a CALD background to promote understanding of the NDIS. The nine languages were identified based on the largest population groups and newly arrived residents in NSW. Further engagement will occur to ensure communities across NSW are aware of the NDIS and people are supported to make an access request

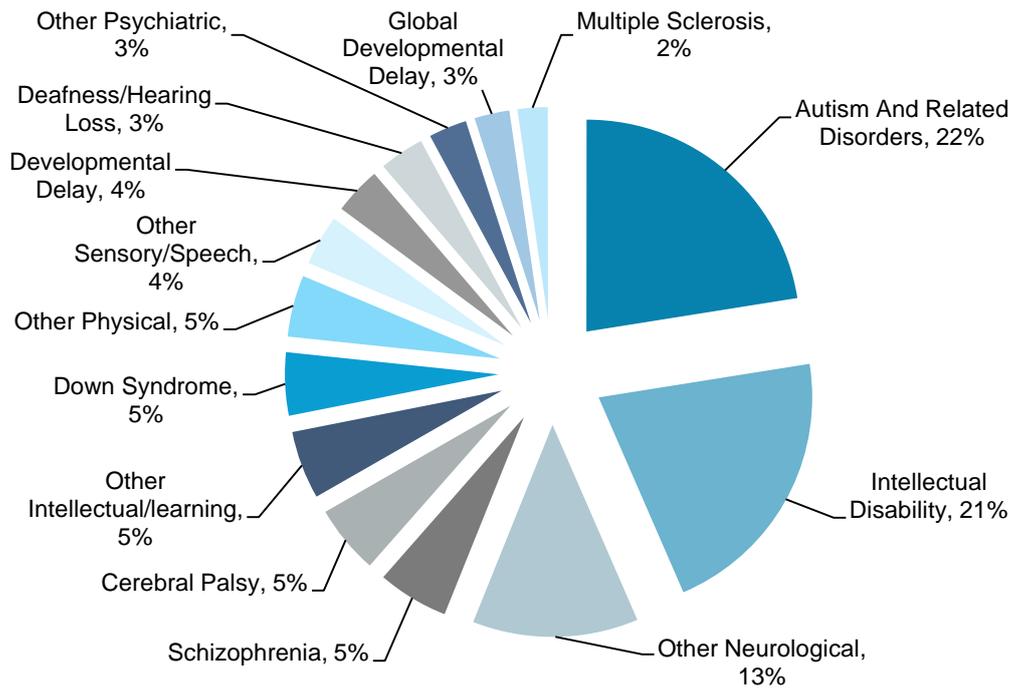
4.3 Primary disability category

The most commonly reported primary disability was *autism and related disorders* (22%) followed by *intellectual disability* (21%) and *other neurological* (13%) (Figure 4.3.1). While these categories were the three most common across both existing clients and new participants, *autism and related disorders* was more common in the latter (32% to 19%) and *intellectual disability* was more common in existing clients (24% to 13%). The vast majority of participants with *autism and related disorders* are under the age of 15 years, whereas participants with an *intellectual disability* are distributed evenly across age groups: about half are over and under 40 years. Other disability types with young age profiles include *development delay*, *global development delay*, and *other sensory/speech*. *Multiple sclerosis* has the oldest age profile, with two-thirds of participants over the age of 50 years.

⁴ Includes clients from Newcastle, Lake Macquarie or Maitland LGAs in the HACC and Disability Minimum Data Sets 2012-13.

⁵ Quarterly Report to COAG Disability Reform Council, 31 December 2014, National Disability Insurance Agency.

4.3.1 Participants by primary disability category



5 Participant plans

5.1 Planning process for participants

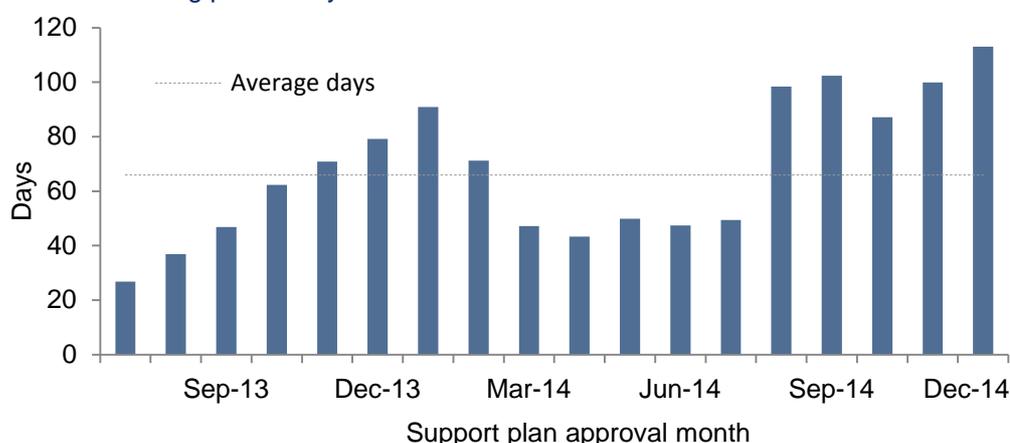
Under the NDIS Act, the NDIA is required to assess access requests within 21 days, unless further information is required. Once found eligible, a support plan is developed with an NDIA planner who identifies the participant's needs, goals and aspirations, as well as the current and potential future supports required. The planning process can be affected by a number of factors including the NDIA's planning resources, availability of participant information, and participants' expectations and willingness to engage.

In the first 18 months of the trial, there was an average of 66 days between lodging an access request and an approved support plan. Planning times varied across the trial period - after steadily increasing for the first six months of the trial, planning times were significantly shorter from March to July 2014 (Figure 5.1.1). This was due to a number of operational changes in the trial site:

- In January 2014, the NDIA implemented significant improvements to its assessment and planning processes, including better data collection and recruitment of additional planning staff.
- In February and March 2014, the NDIA further streamlined the eligibility and planning process for existing clients in specific programs. These clients received a support plan based on their current support arrangements, with a view to reviewing that plan to develop longer term support arrangements within a six-month period.

The increase in planning times from August to December 2014 coincided with the demand for plan reviews. The NDIA is required to regularly review participant plans to ensure they remain relevant and continue to meet participants' support needs. Reviews will vary in complexity depending on participants' circumstances, and may not result in any change. The majority of plan reviews (over 80%) occurred in the August to December 2014 period, which placed additional burden on NDIA's planning resources.

5.1.1 Planning process by month

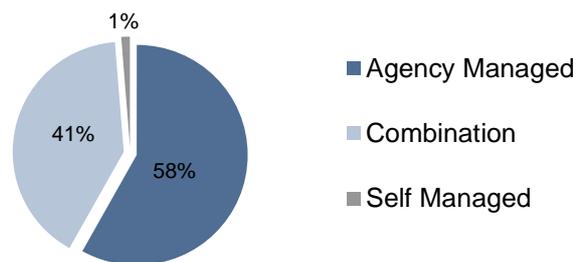


5.2 Plan management

Participants can choose to self-manage the financial and administrative processes relating to their plan such as finding and organising supports, making payments to providers, managing plan expenditure and keeping records of all plan purchases. Alternatives to self-management include management by the NDIA or a registered plan management provider. A participant may also choose a combination of these categories, for example, they self-manage some supports in their plan and have the Agency manage the rest.

Only a very small proportion of participants chose to self-manage their support plan (1%), though approximately one-third used a combination of self and agency management (41%) (Figure 5.2.1). The majority of participants chose agency management only (58%), though this proportion decreased over time. In addition, the proportion of agency-managed plans is lower for participants' subsequent plans (48%), compared to their initial plan (60%), suggesting that participants may choose to manage more supports as they become more familiar with the NDIS.

5.2.1 Participants by plan management



5.3 Plan supports

Each participant's individualised plan sets out their goals and aspirations and the supports they need to achieve them, including informal, community, mainstream and NDIS funded supports. Participants engage support providers in accordance with their plan. Support can relate to personal supports and training or assistive products and equipment, depending on the need. Over a third of all support provided to participants are related to providing them with opportunities to participate in the community and a further 18% are assisting participants with their personal activities.

Participants who access the NDIS through the disability requirements receive, on average, twice as many supports as early intervention participants. Similarly, existing clients receive twice as many supports as new participants. Participants with disability type *cerebral palsy* receive, on average, 19 support items in their plan. The next highest categories are *other neurological* (15), *down syndrome* (14) and *intellectual disability* (14).

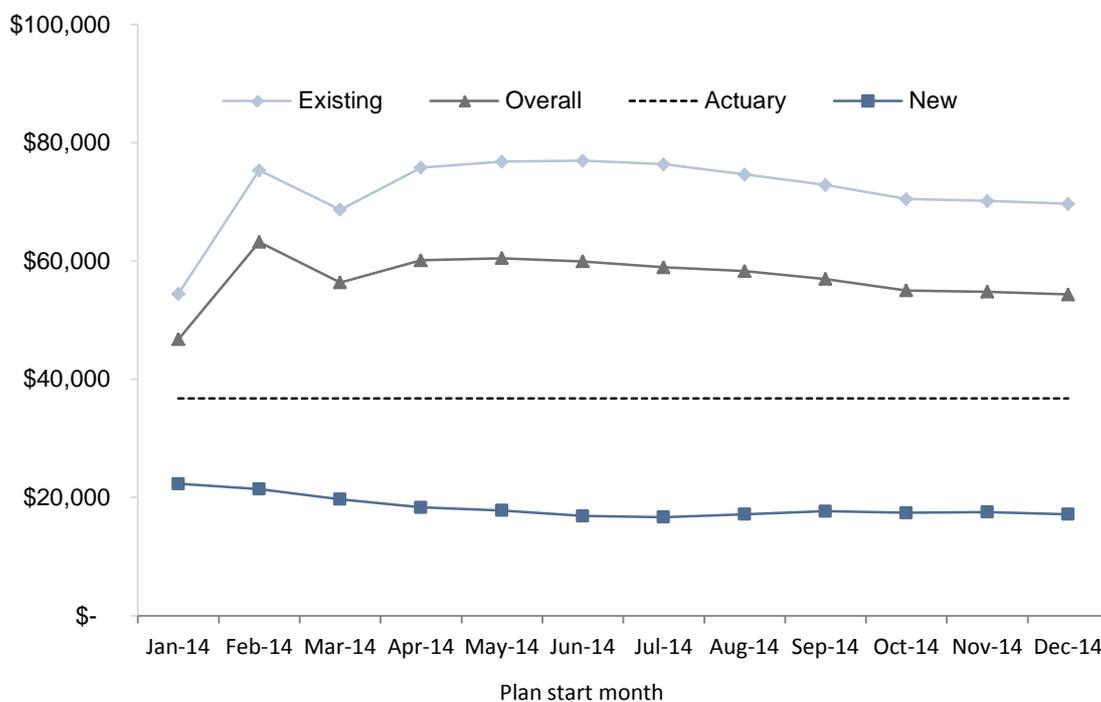
6 Costs of support

6.1 Average annualised cost of support plans

The average annualised cost of an individual support package was modelled in the design phase of the NDIS at \$36,750 (2014-15 dollars). In the first 18 months of the Hunter trial, the overall average cost of NSW participant plans was consistently higher than this estimate. At 31 December, the average annualised cost for participants' current plans was \$54,350 (Figure 6.1.1). There was a significant difference in costs associated with existing clients and new participants, with average costs of \$69,685 and \$17,177 respectively. Although the average cost of participants is substantially higher than the actuarial model of \$36,750, more than three-quarters of participants in the Hunter trial have an annualised cost lower than this figure.

The high cost for existing clients is due to the transition of more than 200 residents of Stockton large residential centre over the first 18 months of the trial. Residents in large residential centres are generally the highest need clients, and therefore have the highest cost plans. The average cost of existing clients is likely to remain high with the transition of the remaining Stockton residents by the end of Q3 2014-15, followed by the transition of residents from the Kanangra large residential centre from Q4 2014-15. NSW's agreement with the Commonwealth does not include an expected average cost of participants and NSW remains committed to transitioning all existing clients in accordance with the agreement.

6.1.1 Average annualised costs of support plans (year-to-date)

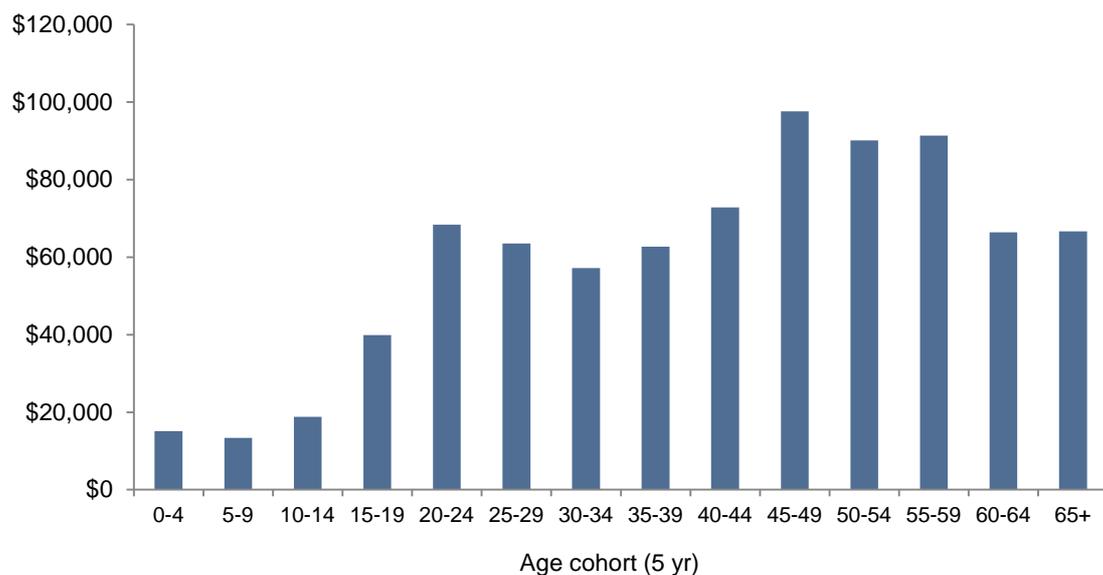


The NDIA's ability to meet the costs of the NDIS for NSW participants is influenced by both the number of plans and the distribution of plan costs. To 31 December 2014, there were fewer low cost participants (<\$10,000) than expected, which drove the average participant cost higher. This was mitigated by the number of participants overall, which was also lower than expected and meant that the committed support for the first 18 months of trial was within the agreed funding envelope.

6.2 Demographic trends

Figure 6.2.1 shows that younger participants, particularly children aged 0-14, have the smallest average plan costs (<\$20,000). Plan costs generally increase with age and the most expensive participants are those aged 45-49 years, at an average of almost \$100,000. The relationship between age and plan costs is a function of the type of participants in younger age categories: younger participants are more likely to be new and early intervention participants, who require lower levels of support. This is reflected in their annualised support plan costs of approximately \$17,000 and \$14,000 respectively.

6.2.1 Average annualised costs of support plans by age



Average support plan costs range from \$100,253 for participants with *cerebral palsy* to \$15,477 for participants with *deafness/hearing loss*. Participants with an *intellectual disability*, which is the second most prevalent disability type, have the second highest average cost at \$90,481. The most prevalent disability group, *autism and related disorders*, has an average annualised package cost of \$27,592.

6.3 High cost participants

Over 12% of NSW participants have an annualised package cost of over \$150,000 and 3% over \$250,000. Higher cost participants tend to be older and more likely to have an *intellectual disability, other neurological or cerebral palsy* disability type compared to participants with lower plan costs. The vast majority of this high cost cohort receive support to participate in the community (98%) and support with tasks of daily life in a shared living arrangement (94%). Other common supports include aids and equipment for personal care or safety (72%) and assistance with travel or transport (66%).

Over half of these high cost clients are residents of Stockton large residential centre. The Hunter trial site includes two large residential centres (LRCs), Stockton and Kanangra, which are undergoing a redevelopment program initiated by NSW to provide contemporary accommodation for residents of these centres. This contemporary accommodation will provide a more home-like environment where people can have more choice and control over the way they live and who they live with. After redevelopment, residents will be housed in purpose built homes with 24-hour support and more access to the community.

From February to December 2014, over 200 Stockton residents transitioned to the NDIS. This will continue into Q3 2014-15, after which Kanangra LRC residents will transition from Q4 2014-15. Under the NDIS, Stockton residents are receiving annualised support plans that are significantly higher than the average cost of support plans. The average Stockton plan includes 15 support items, of which 10 are personal supports and training, and 5 assistive products and equipment items.

Excluding Stockton residents, the average cost of NSW NDIS participants was \$40,059. The proportion of NSW participants that are Stockton residents will be much lower when the NDIS is fully operational across NSW, reducing the impact of these high cost residents on overall average costs.