

NSW Health

Interim evaluation of the impacts of the National Disability Insurance Scheme on the NSW health system

FINAL REPORT

June 2018

Disclaimer

Inherent Limitations

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The findings in this report have been formed on the above basis.

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Glossary

| | |
|----------|---|
| ADHC | Ageing, Disability and Home Care, a Division within FACS |
| ALOS | Average Length of Stay |
| APDC | Admitted Patient Data Collection |
| APTOS | National Disability Insurance Scheme Applied Principles and Tables of Support |
| BHI | NSW Bureau of Health Information |
| CCSP | Community Care Support Program |
| CEC | NSW Clinical Excellence Commission |
| DNR | District Network Return data set |
| DSS | Department of Social Services |
| ECEI | Early Childhood Early Intervention |
| ED | Emergency Department |
| DPC | NSW Department of Premier and Cabinet |
| EDDC | Emergency Department Data Collection |
| FACS | NSW Department of Family and Community Services |
| HETI | NSW Health Education and Training Institute |
| HNE | Hunter New England |
| ILC | Information, Linkages and Capacity-building |
| LAC | Local Area Coordination / Coordinator |
| LHD | Local Health District |
| LOS | Length of stay |
| MH-AMB | Mental Health Ambulatory data collection |
| Ministry | Ministry of Health |
| NAPDC | Non-Admitted Patient Data Collection |

Glossary

| | |
|-------|--|
| NDIA | National Disability Insurance Agency |
| NDIS | National Disability Insurance Scheme |
| NMEOF | NSW Health's <i>National Disability Insurance Scheme Monitoring and Evaluation Operational Framework</i> |
| PMO | Project Management Office, a team within the Government Relations Branch of the Ministry of Health |
| RBDM | Registry of Births, Deaths and Marriages |
| ROWG | Regional Operational Working Group |
| SDA | Specialist Disability Accommodation |
| SHN | Speciality Health Network |
| SIL | Supported Independent Living |
| WFW | Patient Flow Portal 'Waiting For What' data |

Summary of findings

Summary of findings



The interim evaluation

The National Disability Insurance Scheme (NDIS) is the largest social reform since the introduction of Medicare. Launched in 2013 in a number of trial sites, the NDIS is intended to improve the economic and community participation of people with disability in Australia.

For people with significant and permanent disability the NDIS funds reasonable and necessary supports to enable them to meet their goals and needs. NDIS participants have an individual plan that includes targeted supports to assist them to undertake activities of daily living, live and participate in their community, and participate in social, educational and economic activity. At full Scheme, the NDIS is expected to support approximately 475,000 people at an estimated cost of \$22 billion per annum nationally.

The NDIS was developed to operate in conjunction with mainstream service systems which will continue to offer universal access to their services. The health system has and will continue to be responsible for meeting the health needs of NDIS participants – through the NSW health system as well as private and Commonwealth-funded health services – and people with disability may access both health and disability services at the same time.

The NSW Ministry of Health engaged KPMG in late 2017 to conduct an evidence-based qualitative and quantitative assessment of the impact of the NDIS on the NSW health system to date. The evaluation focussed on six questions:

1. What impact has the NDIS design had on the NSW Health system?
2. How has (or should) NSW Health developed the capabilities of NGO providers to effectively support NDIS participants and prevent unnecessary health service utilisation?
3. How have (or should) NSW Health services changed to accommodate the NDIS, or as a result of the transition to the NDIS?
4. How has (or should) NSW Health supported people to access and participate in the NDIS?
5. How adequate are safeguards used within the health system that protect people with disability participating in the NDIS?
6. How has NSW Health service provision been affected by the NDIS?



Key findings

All governments and agencies involved in the design and implementation of the NDIS expected there to be challenges given the size and complexity of the reform. As expected, the Scheme remains relatively immature with a number of aspects requiring further development, in particular the growth and maturity of the support provider market as well as within the NDIS workforce for support planning and coordination. Further, in the rapid launch and transition to full Scheme, the necessary focus on access for participants and change to existing programs, has meant that not all stakeholders have fully understood processes and roles and responsibilities.

The interim evaluation identified a number of challenges and issues for the NSW Health system resulting from the transition to the NDIS which were either contributing to immediate, negative impacts for the health system or generating significant risks for the health system. These are primarily related to:

- *Clarity* – there remains a lack of clarity on the boundaries for decision making and associated delivery responsibilities between the NDIS and NSW Health. This is particularly impacting on the consistency and timeliness of NDIA decision making (including eligibility and funding decisions).
- *Consistency* – the evaluation identified numerous examples where the NDIA has been inconsistent in their decision making regarding access and funding of supports, which has resulted in an impact to both participants and NSW Health. Again, these decisions predominantly relate to eligibility and funding of particular services.
- *Communication* – there is a need for more effective communication at all levels of the system, both within NSW Health, across NSW Government and between NSW government and the NDIA and the Commonwealth.
- *Culture* – whilst a range of positive and constructive relationships are being developed between the NDIS workforce and the NSW Health workforce, these are relatively dependent on individuals and there is yet to be achieved a strong culture of mutual respect and partnership.

Key findings of the interim evaluation are structured into three key themes: health system policy and operating environment, NDIS access and participant pathway, and disability sector readiness and development.

Summary of findings



Findings: Health system policy and operating environment

These findings relate to the effectiveness of external intergovernmental governance arrangements in place to support and oversight NSW's transition to the NDIS, and NSW Health's internal operating model used to manage the implementation of the NDIS across the NSW health system. Main findings are:

1. The introduction of the NDIS and changing role of ADHC has fundamentally changed relationships between the health and disability sectors and how they work together, and the NSW health system is taking some time to adjust to these changes.
2. The health system has established local, internal escalation processes to manage operational issues related to the NDIS. However, intergovernmental governance arrangements are not always effective for resolution of matters with regard to NDIS operations and effectiveness.
3. While the COAG APTOS outline the role and responsibilities of NDIS and mainstream agencies, the consistency and variability of NDIA decisions is contributing to a lack of clarity at an operational level.
4. Changes to Community Care Support Program (CCSP) funding arrangements have impacted on community nursing/allied health services budgets, and there are a number of CCSP clients who remain with LHDs/SHNs due to being ineligible for the NDIS.
5. There are relatively few safeguards within the NSW health system specifically relating to supporting and protecting people with disability, over and above safeguards which apply for all patients.



Findings: NDIS access and the participant pathway

These findings relate to the NSW health system's role and activities across the NDIS participant pathway, including supporting participants to access to the NDIS. Main findings are:

1. The health system has a role in supporting NSW participants to access the NDIS – including supporting participants to connect with the NDIS and providing information and evidence. However, LHDs/SHNs report additional burden (in terms of time) for clinicians, in part due to a lack of clarity on interface boundaries and information required to support funding decisions regarding 'reasonable and necessary' supports.
2. Health clinicians contribute to various aspects of the participant pathway. However, there is a perception that health professional input is not always valued or recognised by NDIS assessors and planners.
3. Inefficiency and timeliness of NDIS processes are reported to be increasing the burden on NSW Health clinicians and services.
4. NDIS support coordinators are not seen to be adequately connecting or coordinating health and disability supports for participants.
5. There are conflicting views on the respective role of the health system and the NDIS in facilitating hospital discharge for NDIS participants.
6. LHDs/SHNs consistently raised issues relating to delays in discharge in some circumstances and for specific NDIS participant cohorts. At this stage of implementation however, there is limited population-level quantitative evidence of change in average lengths of stay for NDIS participants.
7. Health clinicians report significant waiting times to access the ECEI pathway, with associated risks that children's development may be adversely impacted and there may be some potential long-term consequences for health and other mainstream service systems. This is also contributing to increasing utilisation of paediatric health services for children with disability or developmental delay aged 0-6 years.
8. There have been some benefits for some mental health patients and mental health services resulting from the inclusion of people with psychosocial disability needs in the NDIS.

Summary of findings



Findings: Sector readiness and development

These findings relate to the changes occurring in the disability market, the readiness of disability support providers for the NDIS, and the associated implications for the NSW health system. Main findings are:

1. Gaps in the disability market and market immaturity are contributing to pressures experienced by the health system.
2. LHDs/SHNs have expressed concerns relating to the capability of some disability providers and the capacity to grow the required disability workforce leading to impacts on the NSW health system.
3. The health system has to date had a limited role in building disability provider capability.
4. There have been some changes in disability support provider behaviour that impact what the disability provider will and will not provide, and this is further contributing to additional demands on the health system.



Immediate issues, strategies and actions

There are a number of key issues highlighted in this interim evaluation which are contributing to impacts and risks for the NSW health system during transition, and which are critical for NSW Government and the Ministry to resolve in the short-term. The table on the following page outlines the four most significant issues, and suggests a number of strategies and actions to minimize impacts and risks.

Summary of findings



Short-term strategies and actions

| Issue | Strategies and actions for consideration |
|--|---|
| <p>Roles, responsibilities and consistency of decision-making by the NDIA: There is inconsistency and variability in applying the APTOS by the NDIA. This is contributing to a lack of clarity at an operational level relating to the NSW health system's role, and risks that the health system will continue to provide "disability-related" supports to NDIS participants unnecessarily.</p> | <p>As a priority, NSW Government should seek to raise issues (through existing inter-governmental governance structures) relating to inconsistent and variable decision-making through existing escalation pathways and governance structures.</p> <p>The Ministry should continue and strengthen efforts to document and raise decisions that have been made by the NDIA which, in the Ministry's view, are inconsistent with the APTOS, and seek to agree with the NDIA a process for resolving issues relating to NDIA decisions.</p> <p>The Ministry should also work with the NDIA to determine how new NDIA decisions can be effectively communicated through the Ministry to health services.</p> |
| <p>Timeliness and inefficiency of NDIS processes and delays in discharge: LHDs/SHNs are experiencing delays in discharge for some NDIS participants attributable to timeliness and efficiency of NDIS processes and decision-making and gaps in the disability support market. These delays are creating unnecessary pressure on inpatient and rehabilitation services, and have flow-on effects in terms of access to services for other patients.</p> | <p>NSW Government should seek to agree with the NDIA, and clearly document, the role of health services (including discharge planners) and the NDIS workforce (NDIS support coordinators, support providers and the NDIA) in facilitating timely discharge.</p> <p>The Ministry should continue to gather robust quantitative evidence of delays in discharge, including working with LHDs/SHNs to ensure that the Waiting for What (WFW) data collection is fully implemented by LHDs/SHNs to elicit robust data over time, and undertake analyses to estimate the cost to the health system of delays in discharge for NDIS participants.</p> <p>NSW Government and the Ministry should work through existing intergovernmental processes to understand how the additional cost to the health system of delays in discharge for NDIS participants could be funded/reimbursed.</p> |
| <p>Inadequate collaboration and coordination: There is inadequate collaboration between the health and disability systems, a fundamental difference in expectations and understanding of the NDIS support coordinator role between the health system and NDIA. This was further exacerbated by issues relating to the capability and visibility of NDIS support coordinators.</p> | <p>NSW Government should work with the NDIA and other jurisdictional governments to agree on the expectations for support coordinators with respect to their role in coordinating health and disability supports and working with health services (including prior to and at the point of discharge).</p> |
| <p>Delays in accessing NDIS early childhood early intervention (ECEI): There are significant delays in children accessing the ECEI pathway for children aged 0-6 years. This is contributing to increased utilisation of paediatric allied health services in the short term, potential negative consequences for children in the long-term, and long-term risks for the health system in terms of additional demand for health services.</p> | <p>As a priority, NSW Government should continue to raise issues relating to ECEI delays and resourcing, and the potential long-term consequences for children, the health system, and the NDIS, through existing escalation pathways and governance structures.</p> <p>The Ministry should continue to monitor the quantum and cost of additional children's therapy service provision for children with disability or developmental delay who would otherwise access these supports through ECEI or the NDIS, monitor waiting times for children's therapy services, and utilise this data to inform intergovernmental discussions.</p> |

Summary of findings



Longer term considerations

The fundamental shift to a new, nationally consistent, person-centred approach to disability support is complex and will need time to evolve and mature. Other service systems also need time to adjust to the NDIS, and to broader changes in community expectations and government accountability.

The NSW Government's focus is turning to preparing for full Scheme implementation from 1 July 2018. This includes the development of a NSW NDIS Full Scheme Delivery Plan which will confirm the anticipated social and economic benefits, outline a program of work and benefits realisation strategy for NSW agencies to optimise these benefits, with associated performance management and governance arrangements. This plan is being developed by the Department of Premier and Cabinet (DPC) together with cluster agencies (including Health). In addition, each cluster agency will also have a NDIS Delivery Plan for full Scheme implementation.

The findings of this interim evaluation will inform NSW Health's input into the Full Scheme Delivery Plan, and the future considerations outlined below will be considered in the development of the plan. There are four strategic areas for further consideration:

1. Resolving policy boundaries relating to eligibility and funding.
2. Improving communication channels and access to enable earlier identification and resolution of operational challenges.
3. Aligning performance analysis to realise benefits and ensure intended outcomes for people with disability are being achieved.
4. Continuing to evolve and improve analysis and monitoring of impacts and benefits through data analysis.

These strategic areas may also be relevant for other NSW mainstream agencies, and hence may also inform NSW Government's full Scheme negotiations.

Section 1:
Introduction and
context

1.1 The National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is the largest social reform since the introduction of Medicare. Launched in 2013 in a number of trial sites, the NDIS is intended to improve the economic and community participation of people with disability in Australia.

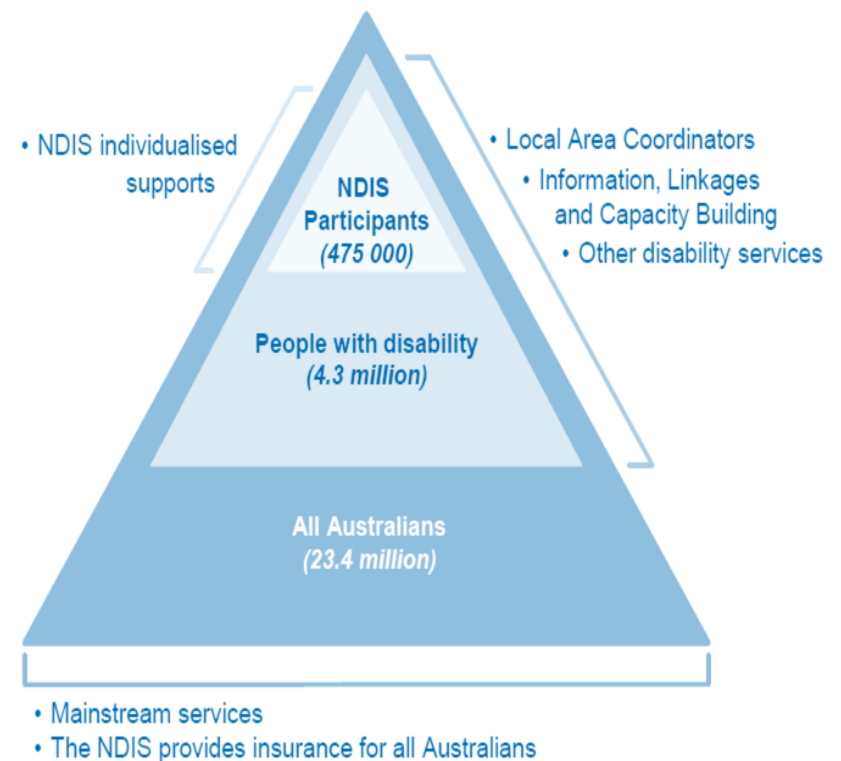
Through increased investment in life-time disability support, the Scheme will be a significant contributor to achieving better health, wellbeing and employment outcomes for people with disability; will contribute to increased employment for people with disability and carers; and will provide new industry and workforce opportunities.

In addition to providing insurance for all Australians, the NDIS funds reasonable and necessary supports for people with significant disability-related needs, and seeks to build community capacity and inclusion for all people with disability.

For people with significant and permanent disability aged under 65 years, the NDIS funds reasonable and necessary supports to enable them to meet their goals and needs. NDIS participants have an individual plan that includes targeted supports to assist them to undertake activities of daily living, live and participate in their community, and participate in social, educational and economic activity. At full Scheme, the NDIS is expected to support approximately 475,000 people at an estimated cost of \$22 billion per annum nationally.

In addition, the NDIS also supports a much larger cohort of people with disability (approximately 4.3 million nationally) who do not require formal disability supports. The NDIS funds Local Area Coordinators (LACs) and a range of Information, Linkages and Capacity building (ILC) initiatives which seek to build the capacity of the community mainstream services (such as health services) to be inclusive for people with disability, and to ensure that people with disability can access community-based and mainstream services and infrastructure in the same way as people without disability. LACs and ILC initiatives also seek to build the capacity of individuals with disability to be more independent and able to make decisions about their lives. These NDIS tiers are illustrated in Figure 1 below.

Figure 1: The NDIS and tiers of support



This introduction provides further information about the development and implementation of the NDIS, the changing role of NSW government and the interface between the NDIS and health system.

1.2 Development of the NDIS

Findings and agreements

Authority

Why real change was needed

In 2010 the Australian Government asked the Productivity Commission to carry out a public inquiry into a long-term disability care and support scheme. The Productivity Commission held 23 days of public hearings, listened to 237 presentations and received over 1,000 submissions including from people with disability and the disability sector. The message was clear – **the old disability system did not work**. The Productivity Commission recognised there were some pockets of success but found that, overall, **no arrangements in any jurisdiction were working well in all areas where real change was needed**. The Productivity Commission found that:

- Most families and **individuals could not adequately prepare for the risk and financial impact of a significant disability**. The costs of lifetime care can be so substantial that the risks and costs need to be pooled.
- The **old disability support system was underfunded, unfair, fragmented, and inefficient**, and gave people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system were growing, with rising costs for all governments. A new national scheme was needed to provide insurance cover for all Australians in the event of a significant disability. Funding of the scheme should be a core function of government, just like Medicare.
- The **benefits of the scheme would significantly outweigh the costs**. People would know that, if they or a member of their family acquired a significant disability, there would be a properly financed, comprehensive, cohesive system to support them. The NDIS would only have to produce an annual gain of \$3,800 per participant to meet a cost-benefit test. Given the scope of benefits, that test would be passed easily. This new system would require real change from all levels of government to provide the intended benefits.

- Productivity Commission Inquiry Report into Disability Care and Support (31 July 2011)

Benefits of the reform for NSW

NSW Government was extensively involved in the Productivity Commission's inquiry and made two written submissions including about the value and benefits from the NDIS for NSW and all people living with a disability:

- **Expected demand for specialist disability supports would reach unsustainable levels within government resources**, with real growth rates of 8-10% projected. Over the medium- to long-term, funding structures under the old disability system would not be able to meet the cost. Additional revenue was needed to ensure sustainability.
- **Social and economic benefits** would include meeting support needs, providing equity and certainty to people with a disability, system integration, eliminating service gaps / duplication, minimising administration, and eliminating cost shifting between governments.

- NSW Government Submissions to the Productivity Commission Inquiry into Disability Care and Support (August 2010 and May 2011)

1.2 Development of the NDIS

Findings and agreements

Recognition of the need to reform disability services

The Council of Australian Governments (COAG) welcomed the release of the Productivity Commission's final report and agreed on the need for major reform of disability services in Australia through the NDIS.

All governments recognised that addressing the challenges in disability services would require shared and coordinated effort. COAG agreed to develop high-level principles to guide consideration of the Productivity Commission's recommendations for the NDIS, including for foundation reforms, funding and governance. At the 13 April 2012 meeting, COAG released the high-level principles and stated the NDIS reform should *promote an efficient allocation of resources based on managing the long-term costs of supporting people with disabilities and their carers while maximising the economic and social benefits.*

Historic agreement to establish the NDIs in NSW

The Commonwealth and NSW Governments committed to the NDIS in NSW to:

- **Provide all eligible NSW residents with access to a scheme based on insurance principles** that guarantees lifetime coverage for participants for the cost of reasonable and necessary disability care and support.
- **Provide people with disability the choice and control** over their disability supports, including specialist, mainstream and community supports.
- **Guarantee a sustainable funding model** for the provision of disability supports into the future.

NSW agreed to contribute its existing funding for specialist and other disability services and supports, and funding for some in-kind services, to pay for the NDIS. NSW agreed to contribute \$3.2 billion in 2018-19 to pay for the NDIS. The Commonwealth agreed to contribute \$3.32 billion to the NDIS in 2018-19.

Shared framework to progress the NDIS in NSW

The Commonwealth and NSW Governments agreed that:

- Development and **implementation of the NDIS will be a shared responsibility** of the Commonwealth and States and Territories.
- The NDIS is a substantial and important reform that will fundamentally change the nature of disability care and support.
- Work on implementing the first stage of the NDIS should start immediately.
- The **NDIS should be refined and further developed over time**, which will require a careful and considered approach by all levels of government.
- Commonwealth and NSW Governments have respective objectives, roles and responsibilities for the first stage of the NDIS in NSW, a launch site in the Hunter area.

Authority

- COAG Meeting Communique (19 August 2011)
- COAG Meeting Communique (13 April 2012)
- COAG High-level Principles for a NDIS (13 April 2012)
- Heads of Agreement between the Commonwealth and NSW Governments on the National Disability Insurance Scheme (6 December 2012)
- Intergovernmental Agreement for the NDIS Launch (7 December 2012)
- Bilateral Agreement for NDIS Launch between the Commonwealth and NSW Governments (7 December 2012)

1.2 Development of the NDIS

Findings and agreements

NSW commitment to transition to the full Scheme

The Commonwealth and NSW Governments committed to implement the NDIS in NSW and agreed to:

- **Roles and responsibilities for the transition to full coverage** of a NDIS in NSW, building on the lessons learned in trials conducted in NSW, Victoria, Western Australia, South Australia, Tasmania, the Australian Capital Territory and the Northern Territory.
- Work through the Council of Australian Governments (COAG) Disability Reform Council, or equivalent **multilateral forum, to refine and further develop the NDIS over time.**
- A program of work and responsibilities between the Commonwealth and NSW Governments to **transition to the full Scheme** and operationalise the Bilateral Agreement.

Plan to optimise benefits from full Scheme NDIS

Currently in development

The Commonwealth and NSW Governments have signed the full Scheme Bilateral Agreement for the NDIS in NSW. The NSW Government is also **developing a whole-of-government Delivery Plan to optimise benefits from the NDIS for all people with disability.** The Delivery Plan will set the shared aspiration for the NDIS in NSW, alongside complementary commitments to promote inclusion for all people with disability in NSW; the role of NSW Government agencies in optimising the social and economic benefits of the NDIS; and the role of NSW Government agencies to identify and manage risks associated with full Scheme delivery. The whole-of-government Delivery Plan will be supported by Cluster agency-specific Delivery Plans.

Authority

- Bilateral Agreement Between the Commonwealth and NSW to Transition to a NDIS (16 September 2015)
- NSW Operational Plan to transition to full implementation of the NDIS
- NSW Government and Cluster agency Transition Plans
- Full Scheme Bilateral Agreement between the Commonwealth and NSW (25 May 2018)
- NSW Government and Cluster agency Full Scheme Delivery Plans

1.3 Implementation of NDIS in NSW

The NDIS is being implemented systematically across Australia and will be fully operational by 2020. In NSW, implementation of the Scheme is occurring over a two-year period, with transition to the Scheme from State-based arrangements occurring over the period July 2016 to June 2018.

Prior to full implementation, the NDIS was trialed in a number of locations around Australia over the period July 2013 to June 2016, including in the Hunter region of NSW. On 1 July 2015, Nepean Blue Mountains (NBM) commenced as an early launch site for people with disability aged 0-17 years.

At the time of this interim evaluation was undertaken, the NDIS was operational in seven Local Health Districts (LHDs) (Year 1 LHDs) and three Specialty Health Networks (SHNs), and being implemented in the remaining eight LHDs during 2017-18 (Year 2 LHDs). The NSW NDIS implementation schedule, by LHD, as set out in the Bilateral Agreement is outlined in Table 1.

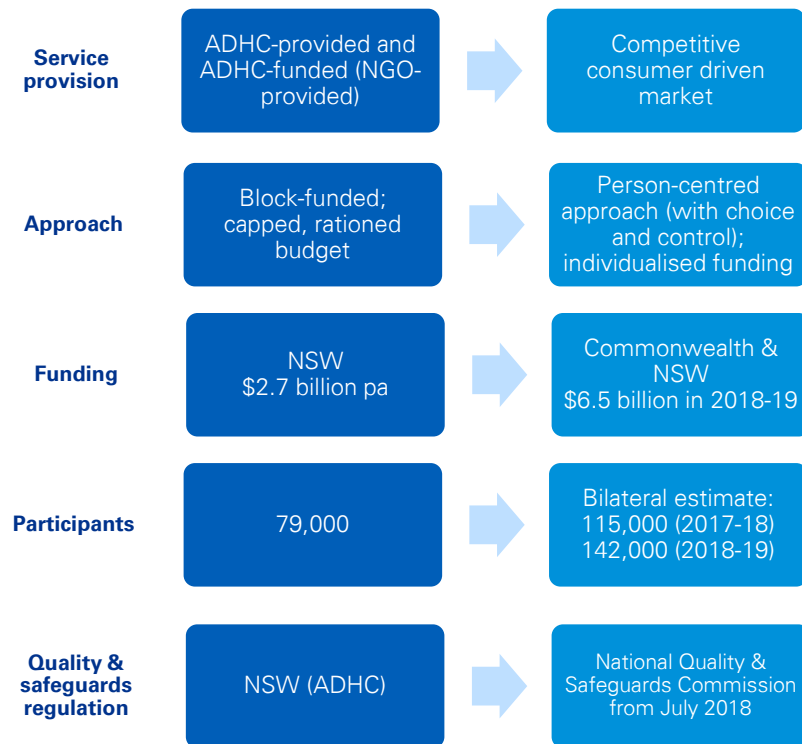
Table 1: NSW NDIS implementation schedule

| Year | Local Health District |
|--------------------------------|---|
| From 1 July 2013 | Hunter New England (Hunter NDIS trial site encompassing Local Government Areas (LGAs) of Newcastle, Lake Macquarie, and Maitland) |
| From 1 July 2015 | Nepean Blue Mountains (early launch site for 0-17 year olds) |
| From 1 July 2016 (Year 1 LHDs) | Hunter New England (remaining LGAs) Nepean Blue Mountains (remaining age groups) Central Coast Northern Sydney South Western Sydney Western Sydney Southern NSW |
| From July 2017 (Year 2 LHDs) | Illawarra-Shoalhaven Mid North Coast Murrumbidgee Northern NSW South Eastern Sydney Sydney Western NSW Far Western NSW |

1.4 Changing role of NSW Government

The implementation of the NDIS has fundamentally changed the role of the NSW Government in relation to specialist disability services. Overall, the implementation of the NDIS has resulted in key changes in the provision of support, the available funding for disability supports, number of people who are able to access supports and the regulation of the market for disability support. Key impacts are illustrated in Figure 2 below.

Figure 2: Impact of the NDIS



In full Scheme, NSW Government will move towards a role largely focused on oversight, reporting and integration of mainstream services, and will also retain a role in facilitating inclusion for all NSW residents with disability (including those not eligible for the NDIS). NSW Health will continue to focus on health service delivery, and will be a mainstream agency that will continue to provide health services to people with disability, their families and carers.

Future Role of ADHC

With the introduction of the NDIS, Ageing, Disability and Home Care (ADHC), an agency of the NSW Department of Family and Community Services, (FACS) has wound down – both from a policy and funding perspective and from a service delivery perspective. It will no longer be in place as a Division of FACS post June 2018.

ADHC was the primary funder of disability supports in NSW and had a significant role in providing specialist disability services. The NSW Government announced in 2014 that it would transfer the delivery of all of its direct specialist disability services to the non-government sector, and this transfer is currently being implemented.

ADHC was the primary agency responsible for disability policy, planning and quality improvement and sector and provider monitoring. ADHC also had a critical role in working with other mainstream government agencies and services, including the NSW health system, and in connecting disability and mainstream services. ADHC had relationships with these agencies and services at multiple levels, including at the policy/strategic level, district/LHD management level, and individual clinician/practitioner/service level. Through these relationships, ADHC was able to work with the health system to negotiate and resolve issues, including by providing disability supports directly or by using its funder role and knowledge of services system capacity and vacancies to direct non-government providers to provide services.

1.4 Changing role of NSW Government

The transfer will mean the NSW Government will have no direct role in providing specialist disability services under the NDIS, other than where LHDs/SHNs or other NSW Government agencies have elected to be a registered NDIS support provider.

Services being transferred encompass:

- the majority of specialist disability accommodation, specialist supported living and centre-based respite (transfer partially completed)
- in-home support (partially completed)
- clinical and allied health services (completed)
- services for people with complex support needs (in progress).

FACS, similar to other mainstream agencies, will maintain functions in relation to responsibilities under the Disability Inclusion Act for those people within NSW who have a disability but are not eligible for the NDIS.

Future role of NSW Health

The NDIS exists within the principles of universal access to health services (that is, non-discriminatory access to existing health services) and the responsibilities of mainstream service systems. The health system has and will continue to be responsible for meeting the health needs of NDIS participants – through the NSW health system as well as private and Commonwealth-funded health services – and people with disability may access both health and disability services at the same time.

NSW Health will continue to interact with the NDIS in a number of ways, though as NSW moves to full Scheme, the role of NSW Health will change, as was anticipated by the APTOS. In full Scheme, NSW Health will have a role in:

- Information and assistance to individuals accessing the NDIS or ILC supports
- Providing clarity on available health services and responsibilities
- Delivering health services to people with disability (both participants and the wider non-eligible population)
- Contributing to data and reporting on participant and Scheme outcomes

- Delivering targeted disability services in the NDIS as an in-kind or registered provider of supports
- Undertaking monitoring, reporting and benchmarking in areas such as quality and safeguards.

NSW Health will need to adjust operational processes to gather information, monitor and deliver services appropriately as required. The NDIS interface will have a substantial impact on the ongoing activity of NSW Health. While the NDIS aims to deliver improved health and wellbeing in the long-term, adjustments are required by all agencies to ensure NSW Government can realise the intended benefits for people with disability, their families and NSW Health.

Section 2:
NDIS legislation and
governance
arrangements

2.1 NDIS legislation and intergovernmental agreements

Commonwealth and NSW Government Agreements

Arrangements relating to the transition to the NDIS in NSW were formally outlined in Bilateral Agreements between the NSW Government and the Commonwealth, developed prior to the transition commencing.

The NSW Government and the Commonwealth signed two Bilateral Agreements – for launch and for transition:

- *Launch* – the Bilateral agreement confirmed the operational and funding details for the roll-out of the NDIS in each launch site. In preparation for launch in July 2013, details on the planned intake of participants and the balance of cash and in-kind contributions to the Scheme during launch were agreed bilaterally between the Commonwealth and New South Wales (and other jurisdictions).
- *Transition* - The Bilateral agreement sets out the arrangements for the NSW transition period from 1 July 2016 to 30 June 2018, including governance, participant transition, financial contributions (both cash and in-kind), continuity of supports, sector and system readiness, quality and safeguards, performance reporting, workforce, mainstream interfaces, supports for specialist disability housing, and the early transition of additional sites in 2015.

Bilateral arrangements for full Scheme were currently under negotiation at the time this interim evaluation was undertaken.

NSW Operational Plan

The NSW NDIS Operational Plan is a separate document between the Commonwealth, NSW Government and the NDIA setting out the key deliverables to support transition. As part of the clearly defined roles and responsibilities of the Commonwealth and NSW Governments, an emphasis is placed on cooperation for risk mitigation and effective implementation of the NDIS in NSW.

NDIS legislation

NDIS Act 2013

The Commonwealth *National Disability Insurance Scheme Act 2013 (NDIS Act)* established the NDIS. The Act describes the objects and principles of the Scheme, Ministerial Governance arrangements, the assistance available for people with disability who are eligible for the Scheme, as well as a number of other administrative, reporting and Scheme governance matters.

The NDIS Act Rules and Operational Guidelines provide more specific, additional information about the Scheme and Scheme operation. This includes rules relating to:

- becoming a Participant
- supports for children
- nominees
- plan management
- protection and disclosure of information
- registered providers of supports
- supports for participants, including consideration of what is appropriately funded by the NDIS.

Interoperability

The NDIS works in conjunction with the following NSW legislation:

- *National Disability Insurance Scheme (NSW Enabling) Act 2013*
- *Disability Inclusion Act 2014*
- *Guardianship Act 1987*
- *Children and Young Persons (Care and Protection) Act 1998*
- *Community Services (Complaints, Reviews and Monitoring) Act 1993*
- *Privacy and Personal Information Protection Act 1998*
- *Health Records and Information Privacy Act 2002.*

2.1 Legislation and intergovernmental agreements

NDIS-mainstream interface

In addition to agreements and legislation that govern the transition to and operation of the Scheme, there are two formal documents which outline the respective roles of the NDIS and mainstream services in supporting people with disability, including NSW Health. These are:

Principles to Determine the Responsibilities of the NDIS and other service systems

The criteria for supports that are funded by the NDIS are set out in the NDIS Act and NDIS (Supports for Participants) Rules 2013.¹ As part of the NDIS implementation, Governments agreed the *Principles to Determine the Responsibilities of the NDIS and Other Service Systems*² (otherwise referred to as the Applied Principles and Tables of Support (APTOS)). These principles underpin the agreement that people with disability have the skills, resources and confidence to access other service systems, in line with an inclusion agenda and the National Disability Strategy.

Governments agreed on principles that are intended to be used to determine the funding and delivery responsibilities of the NDIS in achieving this vision. The NDIS launch sites provided governments with an opportunity to review interactions between the NDIS and other service systems and consider the lessons arising from launch of the Scheme.

Operational Guidance for NSW Mainstream Services

The *Operational Guidance for NSW Mainstream Services on the Interface with the NDIS (the Mainstream Interface Operational Guidance)* was developed by the NSW Government as part of its commitment under the Operational Plan. It was developed to ensure consistency in pathways between the NDIS and mainstream services. The *Mainstream Interface Operational Guidance* sets out the respective roles and responsibilities of the NDIS and mainstream service systems in supporting people with disability, assisting people to request access to the NDIS and responsibility for provision of services once a participant's plan is implemented.

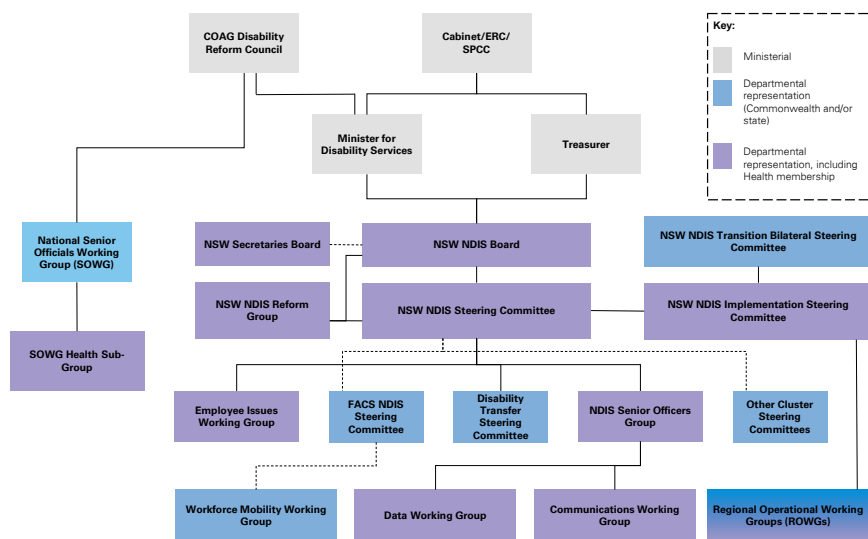
¹<https://www.legislation.gov.au/Details/F2013L01063>

²<https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf>

2.2 NSW NDIS governance structures

There are a range of NSW intergovernmental structures and arrangements that have been established to provide oversight and governance of the transition to the NDIS in NSW. These are illustrated in Figure 3 below.

Figure 3: NSW NDIS governance



Source: Ministry of Health

The main governance structures established for the implementation of the NDIS in NSW are:

NSW NDIS Board oversees the delivery of the Scheme in NSW. It provides high level oversight, decision making and strategic direction of key aspects of the NSW transition. This is to ensure that NSW delivers on full implementation of the NDIS and meets its commitments under the Bilateral Agreement, Intergovernmental Agreement and Heads of Agreement.

NSW NDIS Steering Committee reports to the NDIS Board. The Committee provides strategic oversight of NSW's NDIS planning and drives state readiness for full Scheme. It ensures that the efforts of NSW Government clusters and NDIS work streams are coordinated to a shared purpose and outcome so NSW meets its commitments under the Bilateral Agreement.

NSW NDIS Senior Officers' Group (SOG) supports the NDIS Steering Committee and Board. It provides a mechanism for coordinated cluster planning, escalation and resolution of issues, and monitoring performance; and embeds cross-government accountability for the NDIS. The SOG leads and facilitates NSW NDIS transition planning, work streams and activities.

NSW NDIS Transition Bilateral Steering Committee (also known as the Tripartite) includes key members from the Commonwealth Government and NSW Government. Matters relating to the terms of the Bilateral Agreement or NDIS funding or that cannot be resolved at the NSW NDIS Implementation Steering Committee are directed to this Committee.

NSW NDIS Implementation Steering Committee consists of officials from the NSW and Commonwealth Governments and the NDIA. The Committee has an assurance role in the move to full Scheme in NSW, giving effect to the operational aspects of the Bilateral Agreement and schedules. It continually monitors and reviews risks escalated from the Regional Operational Working Groups (ROWGs) – including participant, market, sector, and system readiness – and has line of sight to the NSW Government service delivery transfer arrangements throughout the transition.

2.2 NSW NDIS governance structures

Senior Officials Working Group (SOWG) is a sub-group of the COAG Disability Reform Council (DRC). It is chaired by the Department of Social Services (DSS), comprised of officials from relevant Commonwealth, State and Territory Disability departments and central agencies, and is responsible for providing advice to the DRC and addressing issues that have a broader national policy implication.

SOWG Health Sub-Group comprises representatives from each jurisdiction, the Commonwealth and the NDIA, as well as line agency representatives with health subject matter expertise and/or responsibility for health programs. The Group, chaired by NSW (through NDIS Reform Group Branch in DPC), provides advice to SOWG on the application of the Applied Principles and Tables of Support (APTOS) in relation to a range of NDIS-health interface issues including the application of the APTOS. The Group also provides regular updates to the Australian Health Ministers' Advisory Council. This is a time limited group, and the SOWG will be asked to determine if there is an ongoing need in October 2018.

Formal governance structures for NSW enable all agencies with an interest in the NDIS to have a voice and share their respective views. This in turn supports the Minister for Disability Services in representing a NSW position at DRC. DPC and FACS led intergovernmental relations on behalf of the NSW Government, particularly with the NDIA, and DPC is the key relationship manager for DSS. As a result of these arrangements, NSW Health engages DPC for support in issue escalation and resolution.

NSW Health governance arrangements

NSW Health has a range of internal governance mechanisms to support implementation and oversight of its functions in relation to the NDIS – including a comprehensive Transition Plan and specific, multi-level governance, oversight and monitoring arrangements.

1. Transition planning

The Ministry developed the *NSW Health NDIS Transition Plan 2015-16* and associated guidance material to support the health system in adapting to the NDIS. The purpose of the Plan was to:

- support and contribute to the successful state-wide implementation of the NDIS
- support the provision of integrated health care to people with disability while supporting their access to the NDIS
- maximise opportunities, mitigate risks and minimise impacts from the NDIS on the NSW health system
- support the provision of improved preventive care and in the longer term reduce hospitalisations and other acute episodes as a result of better, integrated NSW Health/NDIS supports for people with disability in the community.

The Transition Plan provides guidance to NSW Health system stakeholders regarding the tasks and activities that need to be undertaken to effectively deliver on NSW Health's responsibilities in relation to the NDIS. This includes key deliverables, opportunities, resources and monitoring and evaluation for each health service, organisation and pillar.

2.2 NSW NDIS governance structures

2. Internal governance and accountability

Two key internal governance mechanisms have been established within the NSW health system to prepare for the implementation of the NDIS; the NDIS Working Group and the Social Policy implementation Unit Program Management Office (PMO).

The NDIS Working Group plans and coordinates NSW Health’s response to operating in a NDIS environment, and supporting the service delivery sectors of NSW Health impacted by the NDIS. Working group representatives are drawn from across the Ministry, and include representatives from Aboriginal health, EnableNSW, allied health, child and family health, clinical networks, communications, community health, disability policy, information management and mental health. Meetings are chaired by the Ministry’s Government Relations Branch, and are held monthly.

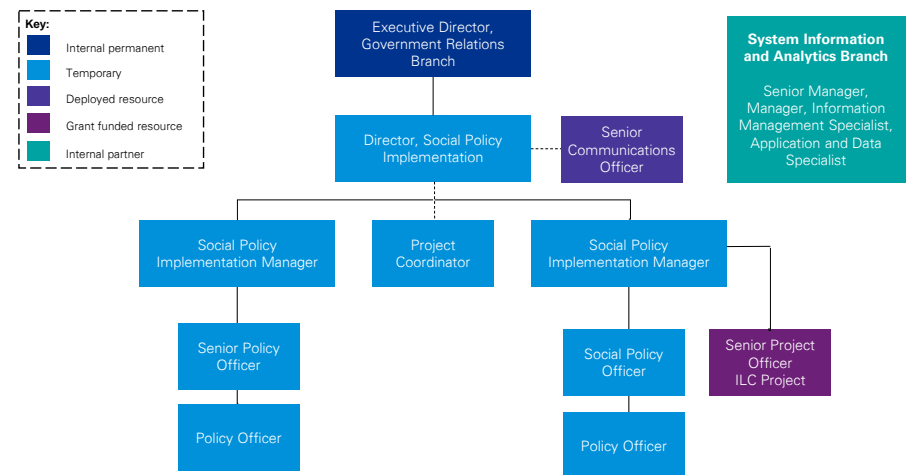
A time-limited (three-year) PMO was established within the Ministry's Government Relations Branch to assist with NSW Health’s transition to the NDIS. The PMO has two main functions:

1. To work directly with LHDs/SHNs to educate and respond to the NDIS.
2. To support policy design, governance, information management, monitoring and evaluation.

The PMO structure is described in Figure 4.

The Ministry has also established an NDIS Community of Interest (COI) involving representatives from all LHDs and SHNs. The COI provides a forum for sharing information about the NDIS, coordinating and collaborating on NDIS-related initiatives, managing NDIS-related risks and facilitating NDIS-related reporting within NSW Health. Meetings are held fortnightly, and are coordinated by the Ministry’s Government Relations Branch.

Figure 4: Social Policy Implementation Unit PMO structure



Source: NSW Ministry of Health

Section 3:
Interim evaluation
approach

3.1 Interim evaluation approach

Purpose

The NSW Ministry of Health (the Ministry) engaged KPMG to conduct an evidence-based qualitative and quantitative assessment of the impact of the NDIS on NSW Health services to date (that is, for the first 18 months of transition from 1 July 2016). The results of the interim evaluation will be used to inform how NSW Health can respond to and intersect with the Scheme once it is fully operational, as well as provide an evidence base for discussions with key stakeholders relating to the NDIS/Health interface.

NDIS Monitoring and Evaluation Operational Framework

The approach to this interim evaluation was based on NSW Health's *National Disability Insurance Scheme Monitoring and Evaluation Operational Framework (NMEOF)*. The NMEOF sets out the conceptual framework for monitoring and evaluating the transition of people with disability to the NDIS.

In particular, the NMEOF establishes the basis for identifying and measuring the inputs, activities and outputs of the health system, and interaction points with the disability system as they relate to the NDIS. It also provides the basis for identifying and measuring the impacts or outcomes on the health system resulting from implementation of the NDIS. In terms of impacts or outcomes on the NSW health system, the NMEOF categorises these impacts into five broad areas which have been used as the basis for this interim evaluation. The five broad impact areas are:

1. **Health service delivery and pathways** which encompass impacts on the type and nature of health services accessed by people with disability (and NDIS participants in particular), how people with disability interact with both the health system and disability system (including referral pathways), and how the health system and disability system work together to meet the health and disability needs of individuals.
2. **Service usage and cost** which encompass impacts on demand, utilisation, and cost of health services for people with disability.
3. **Workforce** which encompasses impacts on the availability and turnover of health system staff, skills and capabilities of the health service workforce, and skills and capabilities of the non-government workforce supporting people with disability.
4. **Financing** which encompasses impacts on funding available for health services (and changes in funding as a result of the NDIS), health system revenues for disability services provided through the health system, and expenditure on health services for people with disability.
5. **Planning and governance** which relates to the activities undertaken by the health system to prepare for the NDIS, to effectively manage change and participate in cross-Government planning processes.

The NMEOF also contains a series of high-level and specific evaluation questions which correspond to one or more of these categories of impact, along with indicators, data sources and responsibilities for collecting these data elements. This interim evaluation focused on a sub-set of NMEOF questions outlined below.

Six key evaluation questions from the NMEOF were identified as the focus of this interim evaluation. These six evaluation questions and the specific aspects that were considered in exploring each question are detailed below.

2.2 Evaluation questions

| Evaluation question | Aspects considered |
|--|---|
| 1. What impact has the NDIS design had on the NSW Health system? | <ul style="list-style-type: none"> • NSW health system inputs and activities and changes to accommodate, facilitate or respond to NDIS principles and structures – e.g. <i>insurance approach, choice and control, early intervention focus (including Early Childhood Early Interventions (ECEI), individual and community capacity building (including local area coordinators (LACs) and Information, Linkages and capacity building (ILC))</i>. • NSW health system inputs, activities and changes to accommodate, facilitate or respond to the NDIS participant pathway – <i>access, eligibility, planning, plan implementation, coordination, plan review</i>. |
| 2. How has (or should) NSW Health developed the capabilities of NGO providers to effectively support NDIS participants and prevent unnecessary health service utilisation? | <ul style="list-style-type: none"> • Types and nature of activities undertaken by different parts of the health system to build capabilities, skills and competencies of NGOs to effectively support NDIS participants' health • Coverage of capability building activities (practitioners and organisations covered/targeted) • Effectiveness of capability-building activities • Health system resources used to undertake capability building activities |
| 3. How have (or should) NSW Health services change to accommodate the NDIS, or as a result of the transition to the NDIS? | <ul style="list-style-type: none"> • Identification of health services impacted by NDIS or NDIS transition • Services that are directly impacted – e.g. assistive technology (EnableNSW), mental health services, community/allied health services • Services that are indirectly impacted – e.g. use of emergency departments, inpatient services (length of stay) • Changes or modifications made by health services in response to the NDIS • Identification of pathways between the health and disability systems for NDIS participants, and changes in pathways • Effectiveness and appropriateness of pathways (e.g. in terms of ability to access the health and disability services, navigation, issues, blockages and pressure points) |

Evaluation questions

| Evaluation question | Aspects considered |
|---|--|
| 4. How has (or should) NSW Health supported people to access and participate in the NDIS? | <ul style="list-style-type: none">• Role of health system in facilitating access to the NDIS, and scope, nature, and type of activities and support(s) provided• Differential role/supports during NDIS transition compared with full Scheme operation, and for specific cohort groups (for example, children with disability or developmental delay, people with complex support needs, people with psychosocial disability)• Health system resources used to support NDIS participant processes |
| 5. How adequate are safeguards used within the health system that protect people with disability participating in the NDIS? | <ul style="list-style-type: none">• Scope and nature of safeguarding mechanisms in place in the health system that seek to protect the rights of people with disability and protect them from harm, and adequacy of these mechanisms• Changes to health system safeguarding mechanisms made as a result of the NDIS• Nature and level of health system involvement in NDIS safeguarding |
| 6. How has NSW Health service provision been affected by the NDIS? | <ul style="list-style-type: none">• Identification of health services impacted by NDIS or NDIS transition – directly and indirectly – by service area• Nature and quantum of impact (e.g. volume and cost)• Consideration of differential impacts of NDIS transition compared with full Scheme operation, and for different cohort groups• Changes in discharge patterns, Average Length of Stay (ALOS) and types of admissions• Impact of transfer of NSW Government disability services to the non-government sector |

Key features of the evaluation approach

Data collection activities

The evaluation included both qualitative and quantitative methods. Given the early stages of Scheme implementation and the immaturity in formal associated data collection processes, a significant proportion of the evaluation data collection activities was qualitative in nature. Qualitative data collection included data from interviews with senior management across the NSW Health system and with key stakeholders, as well as a desktop document review. In addition case studies were developed and analysed based on information provided by NSW Health practitioners. Where possible, quantitative data analysis was undertaken to determine whether there was any evidence of change in health service utilisation since the NDIS commenced in NSW, and to examine any association between qualitative and quantitative findings.

Qualitative evaluation data collection

Qualitative evaluation data collection activities included interviews with a range of stakeholders:

- NSW Health services and organisations: LHDs and Speciality Health Networks (SHNs); Ambulance NSW; EnableNSW
- Other Health sector stakeholders (system managers, Pillars, system enablers and broader networks of providers): Ministry of Health; Agency of Clinical Innovation; Health Education and Training Institute and Bureau of Health Information; Primary Health Care Network.
- NSW Government agencies: Department of Family and Community Services (FACS), Department of Premier and Cabinet (DPC).
- Disability sector stakeholders: National Disability Insurance Agency (NDIA); non-government disability service providers; Local Area Coordination providers; disability consumer peak bodies.

Interviews were conducted in-person or by telephone and were based on semi-structured consultation guides tailored to each stakeholder group. A full list of consulted organisations can be found at Appendix A.

Table 2: Number of consultations

| Stakeholder group | Interviews completed |
|--|----------------------|
| NSW Health services and organisations | 26 |
| Health system managers, Pillars, system enablers and broader networks of providers | 11 |
| NSW Government agencies | 2 |
| Disability sector stakeholders | 10 |
| Total | 49 |

Quantitative evaluation data collection and analysis

The quantitative data analysis utilised a number of different data sets, including:

- Linked NDIS participant and NSW Health (APDC and EDDC) data sets – summary hospital use data for NDIS participants provided by the Ministry
- Waiting For What (WFW) data – summary data extracted from the Patient Flow Portal WFW system for NDIS-related waits. Data were extracted and tabulated by the Ministry
- LHD collected data – a number of LHDs/SHNs have provided data sets drawn from local collections and analyses carried out during NDIS implementation.

The Ministry initiated the NSW Health Data Linkage Project to enable the creation of a data set for monitoring and evaluation of changes in health service utilisation for NDIS participants over time. The Data Linkage Project extends the linkage of de-identified data from FACS and the NDIA with NSW Health data sets, including the EnableNSW client data collection, the Admitted Patient Data Collection (APDC), the Emergency Department Data Collection (EDDC), the Mental Health Ambulatory (MH-AMB) data collection, the Non-Admitted Patient Data Collection (NAPDC) and the District Network Return (DNR), Registry of Births, Deaths and Marriages (RBDM) death registrations, and the Ambulance data collection (and will be extended to additional data sets over time).

Key features of the evaluation approach

While data from the Data Linkage Project were made available for this report, the Project itself is in its early stages. Further, given the timing of the interim evaluation, available data was limited to a sub-group of NDIS participants who transitioned into the Scheme relatively early, and for whom health service utilisation data was available up to 12 months following their NDIS plan approval date. There are a number of limitations associated with use of this data, and results of analysis of this data and reflected in this report should, therefore, be interpreted with these caveats in mind.

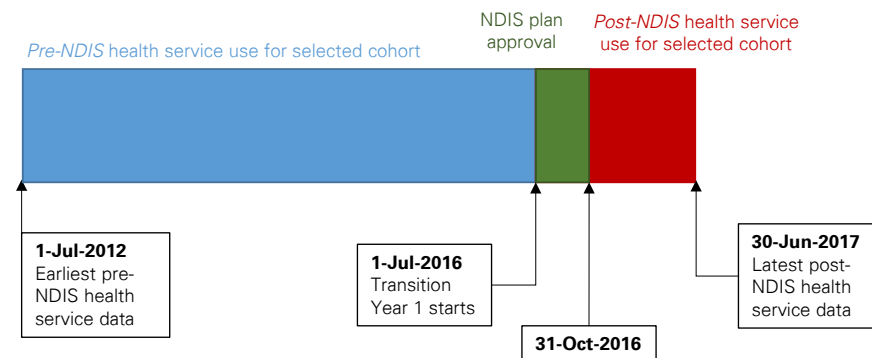
Limitations

Interim nature of the evaluation

This evaluation was completed during the NDIS transition phase, and impacts of the NDIS on the NSW health system are unlikely to be fully evident in the linked data sets available at this point in time. Evidence of impact will likely become more evident in the medium to long-term.

In particular, linked hospital utilisation data was available only for NDIS participants in Year 1 LHDs who transitioned to the NDIS early (and had a plan approval date between 1 July and 31 October 2016), and for whom health utilisation data was available for at least eight months post NDIS plan approval date. This meant that the number of NDIS participants in the linked data set was small, and that the participants included in the linked data was not necessarily representative of the full NDIS participant cohort. This is because the NDIS transition arrangements in Year 1 meant that a number of people with higher support needs transitioned into the Scheme early, and this group is likely to be over-represented in the linked data set. The linked data utilized in this interim evaluation is illustrated in figure 5.

Figure 5: Linked health service use data available for analysis



Linked data for Year 2 LHDs, who at the time the interim evaluation was being undertaken were also in the process of transition, included less than eight months health utilisation data post NDIS plan approval date, and so could not be included in this review.

Further, available health services utilisation data covered the period up to 30 June 2017. This meant that less than 12 months of post NDIS health services utilisation data was available for some NDIS participants included in the linked data set. Again, health service utilisation during this period (and for a small group of NDIS participants) may not be representative of health service utilisation for the whole NDIS participant cohort, across a longer time period.

Key features of the evaluation approach

Availability of robust quantitative data

There were additional factors which limited the availability of robust qualitative data to inform the interim evaluation, including:

- The absence of an NDIA data dictionary, business rules and data governance framework for NDIA data. At present, the Ministry does not have relevant documentation that defines the fields contained in the linked NDIA dataset and associated business rules, nor does the Ministry have access to the NDIA data custodians to seek clarification of business rules underlying specific fields. This means that there may not be a common understanding of the information used by all parties, and limits the use of the data to well understood fields. A data dictionary and governance framework would also provide some assurance that data interpretation and decision-making is sound and based on firm evidence.
- Variable practices in the use of NDIS categories and Patient Flow Portal 'Waiting for What' (WFW) system data across LHDs/SHNs, and incomplete implementation of the WFW data system within and across LHDs/SHNs during the period under analysis.

Reliance on qualitative data

Due to these limitations related to the availability of quantitative data, much of the evidence presented in this interim evaluation report is qualitative in nature, collected during consultations with a broad range of stakeholders within and external to the NSW Health System, as described in Appendix A. These stakeholders had different levels of experience and interaction with the NDIS and awareness of its impacts. Further, the qualitative data collection relied on a sample of stakeholders selected by the Ministry and KPMG. This created a potential for bias in the selection of interviewees within the health system and disability sector, and may not necessarily be representative of the entire group of stakeholders who engage with, or operate within both systems.

Previous work relevant to the evaluation

Prior to this interim evaluation being undertaken, the Ministry commissioned three separate reports from external evaluators relating to the potential impacts of the NDIS on the NSW health system, including:

[Impact Assessment: Introduction of the NDIS, Impact Assessment Report \(June 2014\)](#)

In 2014, NSW Health commissioned Doll Martin Associates to undertake an independent investigation and business analysis of the impact of NDIS on NSW Health information systems. The report identified NSW Health's current gaps in information systems data and workflow/processes in relation to meeting NDIS information management, billing and reporting requirements. It also describes a series of potential solutions, along with guidance as to the anticipated costs and resource implications of each for the NSW health system.

[Transition and Implementation of the National Disability Insurance Scheme in NSW – Formative Evaluation of the Hunter New England Trial](#)

The Ministry commissioned Ernst & Young to conduct a review of the impact of the transition from the existing disability support system to the NDIS for Hunter New England LHD.

The formative evaluation found that many of the actions taken by Hunter New England LHD during the trial period should be used to inform the ongoing NSW NDIS transition. In particular, the program management structure established by Hunter New England LHD was integral to enabling and supporting the internal change required to effectively manage the trial. This included "the establishment of a governance structure to support the ongoing review and discussion of any issues that arose or matters requiring resolution".

[NDIS Year 1 Implementation - NSW Health Lessons Learnt \(August 2017\)](#)

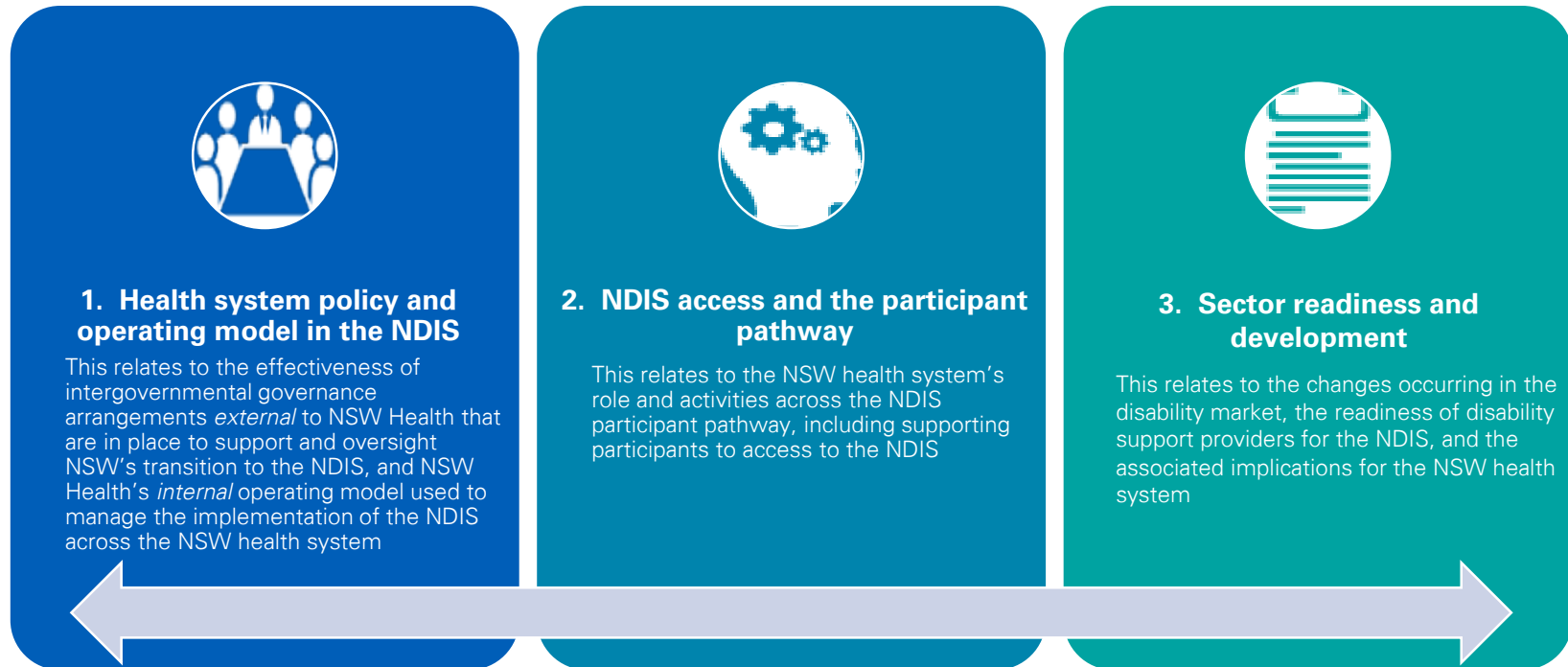
Released in August 2017, the Ministry developed this document to assist LHDs and SHNs in areas where the NDIS was due to be introduced during Year 2. It presents lessons learnt from LHDs that were in Year 1 areas and provides practical suggestions for dealing with common issues. Lessons included:

- Identifying which stakeholders are most important and building relationships with them to assist navigating the evolving environment.
- Understanding the local LHDs/SHNs provider landscape will provide a strong foundation for responding to the NDIS.
- Strong executive sponsorship, governance structures, and tools and processes (including escalation processes) are key features of successful responses.
- Education and up-skilling of the workforce is a cornerstone for successfully responding to the NDIS, as well as staff communication at regular intervals.

Section 4:
Key themes and
findings

4. Main themes and findings

The themes and findings from the interim evaluation are grouped into **three key themes**:



4.1 Health system policy and operating model in the NDIS

Key findings – Health system policy and operating model in the NDIS

1. The introduction of the NDIS and changing role of ADHC has fundamentally changed relationships between the health and disability sectors and how they work together, and the NSW health system is taking some time to adjust to these changes.
2. The health system has established local, internal escalation processes to manage operational issues related to the NDIS. However, intergovernmental governance arrangements are not always an effective mechanism for resolution of matters with regard to NDIS operations and effectiveness.
3. While the COAG APTOS outline the role and responsibilities of NDIS and other entities (including mainstream agencies), the lack of consistency and variability of NDIA decisions is contributing to a lack of clarity at an operational level.
4. Changes to Community Care Support Program (CCSP) funding arrangements have impacted on community nursing/allied health services budgets, and there are a number of CCSP clients who have been unable to gain access to the NDIS (for a variety of reasons) and have subsequently sought assistance from LHDs/SHNs
5. There are relatively few safeguards within the NSW health system specifically relating to supporting and protecting people with disability, over and above safeguards which apply for all patients.

4.1 Health system policy and operating model in the NDIS

Findings and supporting evidence

The introduction of the NDIS and changing role of ADHC has fundamentally changed relationships between the health and disability sectors and how they work together, and the NSW health system is taking some time to adjust to these changes

The introduction of the NDIS represents a fundamental shift in the way specialist disability supports are funded and provided, and represents a shift from multiple State/Territory-based “service systems” to a single, national “scheme”.

In addition, the roles and functions of government disability agencies are also changing. Prior to the transition to the NDIS in NSW, ADHC had responsibility for disability policy and funding, and had a role in both direct disability support provision and commissioning services from non-government service providers. With the transition to the NDIS, it is anticipated that most ADHC operations will cease in full Scheme implementation. The NDIA, as the administrator of the Scheme and funder of all specialist disability supports nationally, has a fundamentally different role to ADHC, and hence the health system cannot work with or rely on the NDIA in the same way. This represents a significant adjustment for the health system, and means that:

- health services are unable to work with the NDIA in the same way as ADHC to coordinate health and disability supports, and to negotiate and resolve issues at an operational and individual level (e.g. to facilitate timely discharge from hospital)
- existing relationships with ADHC at a strategic/policy level, operational level and individual clinician/practitioner level are no longer relevant
- relationships with multiple other parts of the Scheme become much more important for health services – including the range of support providers and support coordinators who support participants within their catchments – as well as with NDIA staff and NDIS partners such as Local Area Coordination / Coordinator (LACs)

- health services are being compelled to be much more proactive in resolving issues for NDIS participants who are accessing the health system, and compelled to work more closely with a range of different stakeholders.

These changes are taking LHDs/SHNs some time to adjust to. However, there is some evidence that LHD clinicians and managers are moving away from seeing the NDIA as a direct replacement for ADHC. Further, there is evidence that LHDs/SHNs are forming new relationships with a broader range of Scheme stakeholders, including disability support providers and the NDIA. In many instances, NDIS Transition Managers/Leads have taken ownership of this role, facilitating collaboration with local stakeholders and the NDIA through local working groups and regular meetings. Some LHD Transition Managers meet regularly with NDIA contacts to facilitate ongoing resolution of operational challenges, including within specialty clinical areas such as brain injury and spinal cord injury, mental health and family and children. Further, one LHD noted significant success working directly with disability support providers, resulting in complex mental health inpatients being more readily discharged from hospital into supported accommodation.

Nevertheless, relationships with the NDIA were variable. Some LHDs/SHNs expressed frustration that the NDIA was not doing more to foster these relationships and that support providers (and support coordinators) similarly were not seeing relationships with the health system as important or as beneficial for them. A few LHDs were more negative, and held the view that the NDIA was deliberately trying to be inaccessible to the health system and had no interest in working with the health system (though these views were held by LHDs who saw the NDIA being more of a direct replacement for ADHC).

A number of LHDs noted that they needed to continue to develop their relationship with the NDIA and support providers as they move towards full Scheme, recognising that closer relationships with multiple stakeholders was important and beneficial for the health system. However, many LHDs highlighted the challenges in building relationships in an evolving marketplace, and working with a wide range of stakeholders with whom they had little or no relationship previously, and no contractual connection.

4.1 Health system policy and operating model in the NDIS

The health system has established local, internal escalation processes to manage operational issues related to the NDIS. However, intergovernmental governance arrangements are not always effective for resolution of matters with regard to NDIS operations and effectiveness.

As part of the Ministry-established *Escalation and Management Protocol*³, LHDs/SHNs have established formal local escalation processes to manage operational issues related to the NDIS. The shape and scope of structures vary across LHDs/SHNs, with some using existing clinical escalation pathways, and others forming NDIS-specific escalation and governance arrangements. Many LHDs/SHNs have also established NDIS Transition Managers/Leads to support managers and clinicians during transition, to contribute to resolving issues locally, and to act as an escalation point for issues which cannot be resolved at the clinician/support provider/local NDIA level.

Where an issue is unable to be resolved at a local level directly with the NDIA, issues are escalated to the Ministry for resolution in LHD forums or with one of the Regional Operational Working Group (ROWGs).

Further, most LHDs/SHNs reported that the current escalation processes through the Ministry and ROWGs are not always effective in resolving issues in a timely manner, and that feedback on the nature of discussions and resolutions are variable. For speciality networks with a state-wide remit, issues are required to go through the Ministry to all four ROWGs, which can be challenging when each ROWG interprets documents/issues differently.

It was also noted that NSW Health does not have direct, formal relationships with the NDIA at the operational level. While there are some relationships forming between LHD Transition Managers and regional NDIA staff, there are no formal regional/LHD structures for escalating and resolving issues directly with the NDIA, and all issues are raised and resolved via the Ministry at multi-agency ROWGs. Further, the Ministry does not have a direct relationship with the NDIA's NSW State Office or National Office, which has limited its ability to resolve more significant or systemic issues in a timely and efficient manner.

³ *NDIS NSW Health Internal Issues Escalation and Management Protocol*, internal NSW Health document, provided to KPMG in November 2017

Intergovernmental governance arrangements in NSW were established for NDIS transition and will likely require some adjustment for full Scheme implementation arrangements. As NSW tracks closer to full Scheme, the nature of issues requiring resolution for NSW Health have become more operational and reflect concerns with regard to clarity of roles and responsibilities, consistency of NDIA decision making and the impact this is having on the NSW Health system. Given the dual role of NSW Health in full Scheme, as both a service provider and key mainstream interface agency, it is likely that NSW Health will require the capacity to deal directly with the NDIA with regard to key operational matters to enable direct and timely identification and resolution.

At the NSW Health cluster agency level, it is likely that governance arrangements will also require adjustment to reflect full Scheme requirements. It will be important that NSW Health continues to:

- Contribute to NSW practice and the national disability policy agenda.
- Contribute to the development of the NSW Full Scheme Delivery Plan and then drive the development of a NSW Health Full Scheme Cluster Delivery Plan.
- Ensure governance delivers a united approach to communications.
- Support the benefits of the NDIS and contributes to the NSW Government's benefits realisation strategy, in particular those of most relevance for NSW Health and in ensuring delivery of health outcomes for people with a disability.
- Develop and refine the performance monitoring framework to reflect full Scheme knowledge and ensure that the experience of participants is front and centre of policy and operational decision making.

4.1 Health system policy and operating model in the NDIS

While the COAG APTOS outline the roles and responsibilities of NDIS and mainstream agencies, the consistency and variability of NDIA decisions is contributing to a lack of clarity at an operational level

Whilst the COAG APTOS outline the respective role and responsibilities of NDIS and other entities (including mainstream agencies), there remains a lack of clarity at the operational level around the respective roles and responsibilities of the NSW health system and NDIS in supporting NDIS participants.

There are several factors that have contributed to this lack of clarity:

1. *Variable understanding of the NDIS:* LHDs/SHNs are adjusting to the new Scheme and while knowledge and understanding is increasing, there is some variability in understanding across clinicians and managers, and in some cases, a reluctance to move away from established practices. However, LHDs/SHNs are being proactive in providing information about the NDIS to clinicians and managers within their LHD, and the role of Transition Manager/Lead is seen as a critical enabler to increasing understanding.
2. *Variable understanding of the APTOS:* There is also variable understanding and awareness of the APTOS by LHD clinicians and managers. Understandably, those clinicians and managers with more experience in communicating with LACs and NDIS planners have a greater level of understanding, though there remains significant variability. This variable understanding is caused, in part, by the lack of consistent information about the expectations that LHDs/SHNs can have of the NDIA, and is contributing to frustration with the Scheme among some clinicians, and impacting on their ability to negotiate and work with LACS and planners.
3. *Inconsistent application of the APTOS by the NDIA:* While the APTOS are relatively clear, LHDs/SHNs raised numerous examples of decisions by LACs and NDIA planners which are not consistent with the Principles, and different delegated decisions/interpretations of the Principles across

participant plans. Under the NDIS, LACs and planners play an important role in identifying current and future “reasonable and necessary” supports that a participant may need. Further, planners have the authority to determine which supports will be included in participant plans. LHDs/SHNs noted that in some cases, LACs or planners stated that a participant must access specific services (mainly allied health services) through the health system even where they are disability-related (for example, where a participant was already accessing therapy services through mainstream health services, including those formerly funded by ADHC, an LAC stating that these services should continue to be provided by mainstream health services). In other cases, supports were included in participants’ plans and excluded from others’ plans, despite the participants having similar disability types, goals and needs.

4. *Poor communication relating to NDIA decisions:* NDIA decisions and determinations relating to what the Scheme will and will not fund are inconsistently communicated to the NSW Government (and the Ministry) – both formally (for example, through formal governance structures and communication channels), and informally. As a result, it is difficult for the Ministry to keep LHDs/SHNs reliably informed and fully up-to-date.

This lack of clarity at the operational level is having a number of immediate and short-term consequences for the health system:

- LHDs/SHNs do not have explicit authority to negotiate with the NDIA or challenge NDIA decisions at a participant level – for example, challenge NDIS planner expectations relating to what the health system should provide for a participant.
- In some cases, LHDs/SHNs are continuing to provide services – particularly allied health services – to some NDIS participants which can be seen as “disability-related”, where these supports have not been included in a participant’s plan, or where LHDs/SHNs are unaware that they have been funded through a participant’s plan. Under current information sharing arrangements, NDIS participants are under no obligation to inform NSW Health of their NDIS participant status or the nature or extent of funded supports included in their NDIS Plan.

4.1 Health system policy and operating model in the NDIS

- LHDs/SHNs are being required to provide specific services and interventions for people with disability for the first time (where they had previously been provided by ADHC or non-government disability service providers), and in some cases, where they do not have the resources or capability to provide these services in the medium to long term. These are predominantly allied health and community nursing services, including meal time management, swallowing assessments, casting where it is combined with botox and catheter care.

Changes to Community Care Support Program (CCSP) funding arrangements have impacted on community nursing/allied health services budgets, and there are a number of CCSP clients who remain with LHDs/SHNs due to being ineligible for the NDIS

LHDs/SHNs collectively received \$20.3 million in 2015-16 in CCSP funding from ADHC to provide a range of specialist disability services for people with moderate levels of disability living in the community. This included \$14.1 million for clinical (community nursing and allied health services) and \$6.2 million for non-clinical services, such as respite, meals, domestic assistance and other services.

With the transition to the NDIS, LHD CCSP funding has been withdrawn from LHDs/SHNs. For a variety of reasons (including differences in eligibility criteria), many existing CCSP clients have not transitioned to the NDIS, which has had a direct impact on LHD budgets, where:

- LHDs/SHNs have not experienced a proportional reduction in demand for CCSP-type services
- LHDs/SHNs have not been able to proportionally reduce allied health or community nursing staffing or costs.

At this point in time, there is no robust data on the number of LHD CCSP clients who have been deemed ineligible for the NDIS (or choose not to transition to the NDIS), or how many CCSP clients LHDs/SHNs continue to support. Advice from the Ministry indicates that up to two-thirds of LHDs/SHNs' CCSP client base has either been determined ineligible for the NDIS or have not otherwise transitioned. Further, NSW Health stakeholders indicated that in their view a

further proportion of existing CCSP clients who have been determined eligible for the NDIS have not had their required supports included, or sufficiently funded, within their NDIS Plan.

In response, many LHDs/SHNs are continuing to provide CCSP-type supports to clients who are ineligible for the NDIS, particularly where clients have a clinical need, and where withdrawal of services would put their health at risk (with flow-on consequences for other parts of the health system). These costs were unexpected, and at this point in time unfunded. However, some LHDs/SHNs are choosing *not* to provide unfunded non-clinical supports (such as meals, domestic assistance) in an attempt to reduce ongoing costs, though are continuing allied health and community nursing services to NDIS ineligible patients.

Additional pressure on allied health and community nursing services and budgets are being created by:

- NDIA decisions relating to supports which they consider are more appropriately provided by the health system— for example, recent NDIA determinations that catheter care, wound care, continence support, meal time management and swallowing assessments are not disability-related and should be provided by the health system.
- A level of ongoing demand from NDIS participants seeking supports which have not been included in their plan or where their support allocation has been exhausted (predominantly therapy/allied health services).

4.1 Health system policy and operating model in the NDIS

There are relatively few safeguards within the NSW health system specifically relating to supporting and protecting people with disability, over and above general safeguards for all patients

Safeguards refer to a range of supports and mechanisms that ensure NDIS participants (and people with disability more broadly) remain safe and well. Safeguards include natural safeguards such as personal relationships and community connections, and formal safeguards such as service standards, regulations and quality assurance systems that apply to individuals and organisations providing supports.

During transition to the NDIS, quality and safeguarding arrangements for NDIS participants is the responsibility of NSW Government (ADHC), though new national arrangements will be implemented when the NDIS Quality and Safeguarding Commission (QSC) becomes operational for NSW on 1 July 2018.

While quality and safeguarding arrangements apply to NDIS participants and organisations providing NDIS-funded support, safeguarding for vulnerable groups is also important in other mainstream service systems – including for people with disability accessing the NSW health system. In the context of the NSW health system, safeguarding can encompass:

- General safeguards relating to all patients, such as health service standards, patient care standards, quality assurance and monitoring processes, and complaints mechanisms.
- Specific policies, procedures or guidelines relating to patients with disability – to ensure their safety and wellbeing while accessing health services, and to maximise patient outcomes for this group.
- Capability and capacity to provide effective and appropriate health care to patients with disability, including understanding of the health needs of people with disability, skills and capabilities to communicate and support people with disability, and skills and capabilities to provide general and specialised health services and interventions across the diversity of disability cohorts.

These safeguarding arrangements were important prior to the transition to the NDIS, and will remain important throughout transition and at full Scheme.

In conducting the interim evaluation, it was evident that while general safeguards were in place for all patients, there were relatively few specific safeguards for patients with disability. In particular, there were few specific policies, procedures and guidelines relating to patients with disability, other than *Responding to the Needs of People with Disability during Hospitalisation (PD2017_001)*, and *EnableNSW - Assistive Technology for Communication, Mobility, Respiratory Function & Self-Care (PD2011_027)* – currently being revised).

However, it was noted that there was a range of clinical expertise in areas focusing on the delivery of health services to people with disability, such as diagnosis and assessment services, intellectual disability health teams, EnableNSW, seating and prostheses services, and allied health services. Further, there are some initiatives in place which seek to increase the capacity of a broader range of NSW Health clinicians to work with people with disability, such as:

- some online training modules provided by the Health Education and Training Institute (HETI) relating to building clinicians' awareness, skills and capabilities in working with people with disability.
- some initiatives which aimed to increase the health system's capacity to work with people with disability (in particular people with intellectual disability), such as the Specialised Intellectual Disability Health Teams (in three LHDs), Agency for Clinical Innovation's Intellectual Disability Clinical Network, and some Registered Nurse and Clinical Nurse Consultant positions which were disability-focused (including intellectual disability, psychosocial disability/mental health)
- NDIS Transition Managers/Leads provided a central point of information and advice for clinicians and managers relating to the NDIS and broader disability matters.

4.1 Health system policy and operating model in the NDIS

LHDs/SHNs and other health sector stakeholders did not see the relative lack of specific safeguards as a significant issue for the health system at this point in time.

However, the lack of specific safeguards remains an area of risk for the NSW health system particularly once ADHC has been wound down and is not able to support the health system to provide health care to patients with disability. Both health and disability stakeholders recognised that there is room for improvement – particularly with respect to building health system capacity and capability to provide effective and appropriate health care to patients with disability. This included specific capacity and capability with respect to supporting people with intellectual disability and psychosocial disability in the health system (as noted above), as well as people with disability and complex health needs and/or multiple comorbidities. There was also a need to build capacity and capability within NSW to deliver some specialised services for people with disability which have been previously provided by ADHC or ADHC-funded NGOs (such as casting combined with botox for children with cerebral palsy, specialist sub-acute care following a surgical intervention for people with specific physical disabilities such as spina bifida).

4.1 Health system policy and operating model in the NDIS

Issues, risks and strategies for consideration

| Issue | Risks to be managed | Strategies and actions for consideration | Responsibility | Priority |
|--|--|---|---|---------------------------------|
| Application of the APTOS by the NDIA is inconsistent, and decisions relating to what the NDIA will and will not fund are not adequately communicated | Continued lack of clarity at the operational level about the NSW health system's role, and risk that the health system will continue to provide 'disability-related' supports to NDIS participants that are, or should be, funded by NDIS, at some cost to the health system | <p>As a priority, raise issues relating to inconsistent and variable decision-making through existing escalation pathways and governance structures, including NSW Government and cross-jurisdictional governance structures.</p> <p>Continue and strengthen efforts to document and raise decisions that have been made by the NDIA which, in the Ministry's view, are inconsistent with the APTOS, and seek to agree with the NDIA a process for resolving issues relating to NDIA decisions</p> <p>Work with the NDIA to determine how new NDIA policies can be effectively communicated through the Ministry to health services</p> | <p><i>NDIA has primary responsibility</i></p> <p>NSW Government to raise through existing inter-governmental governance structures</p> <p>Ministry of Health to raise through SOWG Health sub-group or directly with NDIA</p> | 1 – Immediate/ high priority |

4.1 Health system policy and operating model in the NDIS

| Issue | Risks to be managed | Strategies and actions for consideration | Responsibility | Priority |
|---|--|--|---|----------------------------|
| <p>Current governance arrangements need adjustment for full Scheme implementation to ensure they are fit for purpose</p> <p>NSW Health has no direct relationship with the NDIA which has impacted its ability to achieve timely resolution of operational issues</p> | <ul style="list-style-type: none"> Governance arrangements are not fit for purpose for full Scheme performance, and do not enable a change in focus from 'design and build' to 'monitor and sustain' Governance arrangements do not provide a consistent platform for communication on Scheme related activity to the NDIA and the Commonwealth, and vice versa NSW Health does not collect or share information at an operational level, resulting in reduced collaboration and quality of support | <ul style="list-style-type: none"> NSW Health to adjust internal governance structures where required to focus on full Scheme implementation, including engagement of LHDs and SHNs at ROWGs NSW Health to work with DPC to establish appropriate governance levers to enable a more direct operational relationship with the NDIA and the NDIS Quality and Safeguards Commission (QSC) NSW Health to continue to monitor and report on health outcomes, economic benefits and efficiencies delivered through the NDIS for people with disability living in NSW NSW Health to continue to monitor and report on its mainstream service activities that support people with disability to promote access to the NDIS and reduce system inefficiencies | <p><i>NSW health system and NSW Government have primary responsibility (through Ministry and DPC)</i></p> | <p>2 – Medium priority</p> |

4.1 Health system policy and operating model in the NDIS

Issues, risks and strategies for consideration

| Issue | Risks to be managed | Strategies and actions for consideration | Responsibility | Priority |
|---|--|--|---|---------------------|
| The introduction of the NDIS has fundamentally changed relationships between the health and disability sectors and how they work together, with new relationship development taking time | Health system stakeholders are unable to form or deepen relationships with the disability sector in an evolving marketplace, and are not able to effectively operate within the Scheme | <p>Ministry and LHDs/SHNs can work together to assist each other to form and deepen relationships:</p> <ul style="list-style-type: none"> with the NDIA at the local and regional level, utilising existing relationships with NDIA, e.g. through ROWGs with large or strategically important disability support providers, support coordination agencies and ECEI partners in their catchments, utilising available information on existing LHD/clinician relationships <p>LHDs/SHNs could support this work through continuing NDIS transition lead positions. Assistance from the Ministry could include compiling information from public sources relating to large/significant providers or agencies, provision of guidance on “relationship mapping” and collation of relationship information, and guidance on how to best target their efforts</p> | <i>NSW health system has primary responsibility (Ministry of Health and LHDs)</i> | 2 – Medium priority |
| Current LHD escalation processes to resolve issues through the Ministry and ROWGs are not always effective in resolving issues in a timely manner, and resolutions are not always communicated effectively to LHDs/SHNs | Resolution of LHD issues with NDIA regional officers continues to be inadequate or untimely, further extending confusion and misunderstanding of NDIS processes and decisions | <p>Investigate whether the process for escalating issues to the Ministry and ROWGs can be improved, whether the right matters are being escalated, and whether documentation of discussions and decisions can be more effectively communicated by the Ministry to LHDs/SHNs, and vice versa</p> <p>Consider whether the ROWGs are the most effective mechanism for resolving regional issues, or whether a dedicated regional NSW Health/NDIA governance group (one per NDIS region, attended by NDIA, relevant LHDs/SHNs and Ministry) may be more appropriate, at least until the Scheme matures and LHDs/SHNs’ own relationships with the NDIA develop further</p> | <i>Joint responsibility</i> Ministry of Health and DPC, working with NDIA (directly or through existing governance structures) | 2 – Medium priority |

4.1 Health system policy and operating model in the NDIS

Issues, risks and strategies for consideration

| Issue | Risks to be managed | Strategies and actions for consideration | Responsibility | Priority |
|--|---|---|---|---------------------|
| There are few disability-specific safeguards in the health system, and health system capacity to support and protect patients with disability is unclear | Patients with disability in the health system are inadequately protected, and are unable to access high quality health services appropriate for their needs and circumstances | <p>Government Relations Branch to work collectively with the Health and Social Policy Branch (lead Branch responsible for disability inclusion), as well as Agency for Clinical Innovation, EnableNSW and areas of the health system which provide specialised health services to people with disability (such as diagnostic and assessment services, intellectual disability health teams) to better understand the capability and capacity of the health system to provide effective and appropriate health care to patients with disability</p> <p>As part of this, it is suggested that these stakeholders also examine whether additional targeted learning, development and capacity building is required for NSW health clinicians to better address the needs of patients with disability. This includes patients with disability and complex health needs and/or multiple comorbidities, and patients within specific disability cohorts such as intellectual or psychosocial disability who may have specific health needs.</p> | <i>NSW health system has primary responsibility (through Ministry of Health, with EnableNSW, ACI and LHDs/SHNs)</i> | 2 – Medium priority |

4.2 NDIS access and the participant pathway

Key findings - NDIS access and the participant pathway

1. The health system has a role in supporting NSW participants to access the NDIS – including supporting participants to connect with the NDIS and providing information and evidence. However, the role of NSW Health has been more burdensome than expected (in terms of time), in relation to both access and planning stages, and particularly during the transition period. This is in part due to a lack of clarity on interface boundaries and information required to support funding decisions regarding ‘reasonable and necessary’ supports.
2. Health clinicians contribute to various aspects of the participant pathway. However, there is a perception that health professional input is not always valued or recognised by NDIS assessors and planners, and that decisions which may impact patient care are being made without consideration of clinical advice.
3. Inefficiency and timeliness of NDIS processes are reported to be increasing the burden on NSW Health clinicians and services.
4. NDIS support coordinators are not seen to be adequately connecting or coordinating health and disability supports for participants.
5. There are conflicting views on the respective role of the health system and the NDIS in facilitating hospital discharge for NDIS participants. A commonly cited example is the role of NSW Health staff and NDIS support coordinators in securing accommodation for participants.
6. LHDs/SHNs consistently raised issues relating to delays in discharge in some circumstances and for specific NDIS participant cohorts. At this stage of implementation however, there is limited population-level quantitative evidence of change in average lengths of stay for NDIS participants.
7. Health clinicians report significant waiting times to access the ECEI pathway, during which time, the children and their families are not being provided with required early intervention supports. There are associated risks that children’s development may be adversely impacted and there may be some potential long-term consequences for health and other mainstream service systems. This is also contributing to increasing utilisation of paediatric health services for children with disability or developmental delay aged 0-6 years.
8. There have been some benefits for some mental health patients and mental health services resulting from the inclusion of people with psychosocial disability needs in the NDIS.

4.2 NDIS access and the participant pathway

Findings and supporting evidence

The health system has a role in supporting NSW participants to access the NDIS – including supporting participants to connect with the NDIS and providing information and evidence. However, the role of LHDs/SHNs have been more burdensome than expected (in terms of time) for clinicians, particularly during the transition period.

The *Operational Guidance for NSW Mainstream Services* states that all NSW Government agencies have a role in assisting people with disability to access the NDIS. For the health system, this can include (*where requested, or with the patient's consent*):

- determining the current supports a patient receives
- providing advice on patient eligibility for the NDIS
- acting as an representative of the patient, with a single health professional potentially being a 'lead' for supporting the person to access the NDIS and lodge their access request
- providing documentation to support a patient's application for access to the Scheme or planning discussions, including copies of existing reports/letters/assessments and other information on the impact of the impairment on the person's functional capacity, where this will assist with their access request application or planning conversation.

Focus during transition has been on supporting new participants to access the Scheme (that is, people who had not accessed disability supports prior to the NDIS being implemented²), and supporting people who accessed CCSP and selected other programs to access the Scheme. For existing clients of 'defined' programs funded or provided by ADHC under State-based arrangements, a more streamlined process was in place to confirm eligibility for the Scheme.^{4, 5, 6}

There was substantial qualitative evidence from LHDs/SHNs and other stakeholders that the health system is fulfilling its role in supporting people to access the NDIS. The Ministry of Health and LHDs/SHNs adopted a number of different strategies to support clinicians, including providing specific training for clinicians on NDIS processes, developing information sheets, guidelines, tools or templates to assist clinicians, and utilising centralised models where all access

request forms are reviewed, refined and submitted by an LHD NDIS Transition Manager.

However, all LHDs/SHNs highlighted the additional administrative burden associated with supporting people to access the NDIS during the transition period. While LHDs/SHNs recognised that this was a core responsibility, they noted that their contribution was much more time-intensive than expected, and that NDIS requirements were creating additional administrative burden which included:

- providing or creating specific evidence and assessment report requirements
- requests for additional evidence beyond what clinicians considered reasonable or necessary
- rejection of initial evidence provided, with or without explanation
- need to present evidence using specific language and terminology (not typically used in the health system), and in a different format than that held by health services
- need to have a formal diagnosis of a disabling condition or impairment from a health professional, and/or evidence of functional impact or need.

LHDs/SHNs stated that this additional administrative effort means there is less time available for health service delivery and direct patient care, which creates or exacerbates delays in accessing health services for other patients and may present risks to patient safety and patient outcomes.

At this point in time, the additional administrative burden and associated impact on health service provision could not be quantified. It was however raised as a key concern by all LHDs/SHNs.

⁴ These groups include people with newly acquired disability, people with increasing disability needs who require support for the first time, people who were unable to access disability supports previously due to service availability or waiting times, and people with psychosocial disability who were accessing Commonwealth or State-funded mental health supports. As at 30 September 2017, 22,261 additional people who had not previously received disability supports were deemed NDIS eligible (82 per cent of new applicants).

⁵ Defined programs for which the streamlined process was in place are listed here: <https://www.ndis.gov.au/operational-guideline/access/list-c.html>; and National Disability Insurance Scheme (Prescribed Programs—New South Wales) Rules 2016 are listed here: <https://www.legislation.gov.au/Details/F2016L00792>

⁶ As at 30 September 2017, 46,277 people who previously received disability supports were deemed NDIS eligible – more than 96 per cent of individuals were receiving ADHC-funded or provided disability supports.

4.2 NDIS access and the participant pathway

It should be noted that, potentially, the additional burden of supporting access to the NDIS is to some extent temporary. While numbers of new participants accessing the NDIS in the first year of full Scheme operation are expected to remain high, numbers in future years are expected to be lower.

Health clinicians contribute to various aspects of the participant pathway. However, there is a perception that health professional input is not always valued or recognised by NDIS assessors and planners.

The design of the NDIS participant pathway allows for providers and practitioners (including health professionals) to provide input to participants accessing the Scheme, including plan creation, plan implementation and plan review. While the planning process is driven by the participant, for some people, particularly those with more complex support needs, additional professional input, information and specialist advice can be valuable in informing the development of a participant's plan and contributing to participant outcomes.

There was a common view among LHDs/SHNs that health professionals are not contributing to NDIS planning and plan implementation processes in any systematic way, and that health professional input is often not sought by LACs or planners. Further, there was a widespread perception among LHDs/SHNs that the NDIA does not want, or recognise the value of, health professional input into planning, plan implementation, or plan review processes.

There is however limited quantitative evidence of the impact on the health system at this point in time. Rather, LHDs/SHNs noted that the lack of recognition of the benefits of clinical information and/or opinion by LACs and planners led to numerous risks for participants and the health system:

- Necessary supports may not be included and/or inadequately funded in a participant plan, particularly where an LAC/planner is unaware that the participant currently accesses these supports, does not identify the supports as 'reasonable and necessary', and/or does not appreciate the interconnectedness of supports in ensuring participant safety and wellbeing
- NSW Health may be required to step in to provide additional health services (e.g. allied health services) as a consequence of inadequate NDIS funding and supports.

- NSW Health may be required to provide health services where inappropriate NDIS supports or lack of supports have had health consequences (for example, injuries as a result of inappropriate assistive technology provision or poor disability provider practice relating to positioning and prevention of pressure injuries).

Inefficiency and timeliness of NDIS processes are reported to be increasing the burden on NSW Health clinicians and services.

LHDs/SHNs consistently raised two issues relating to the efficiency and timeliness of NDIS processes which were having an unexpected impact on the health system.

1. Waiting times for NDIS access and planning decisions

An access decision should be received from the NDIA within 21 days from the receipt of an access request (unless the NDIA CEO seeks additional information under s26(1) of the NDIS Act). However, the experience of LHDs/SHNs suggest that this benchmark is not being met, and for some participants receiving an access decision is taking significantly longer.

While some LHDs/SHNs were aware of the phasing and prioritisation rules available to NDIA delegates set out under sections 32 and 32A of the NDIS Act, there was a view among some LHDs that the NDIA was not appropriately prioritising participant applications and not adequately considering the urgency of their access request in processing applications.

LHDs/SHNs stated that delays in NDIS access decisions are impacting most on people without informal supports or other services, and on people with progressive or degenerative conditions, such as motor neurone disease, muscular dystrophy and multiple sclerosis (particularly where support needs are increasing over a relatively short period of time).

LHDs/SHNs provided numerous examples where delays in NDIS processes were impacting on health service utilisation – in particular where a person seeks to utilise allied and other outpatient health services while they wait for a

4.2 NDIS access and the participant pathway

NDIS access decision or implementation of an approved NDIS Plan, and where a person needs access to the NDIS in order to be discharged from hospital (resulting in delays in discharge). At this stage of implementation however, there is limited available population-level quantitative evidence to support these statements.

2. Difficulties in communicating with the NDIA

LHDs/SHNs expressed frustration with the single point of access to the NDIA through its central national phone number, and in particular:

- clinicians contacting the NDIA typically experienced long delays in connecting with an NDIS call centre operator
- clinicians being unable to communicate directly with NDIS Planners or other NDIA representative to resolve issues, although a number of LHDs stated that relationships with local NDIA representatives were developing.

LHDs/SHNs stated that communication issues add to the administrative burden for clinicians, and limit the ability for the health system and NDIA to resolve issues locally.

NDIS support coordinators are not seen to be adequately connecting or coordinating health and disability supports for participants, which leads to fragmentation of services

Based on discussions with multiple stakeholders (including the NDIA and LHDs/SHNs), it was evident that there is a fundamental difference in expectations and understanding of the support coordinator role between the health system, NDIA, and support coordinators, and there are issues with the capability, consistency and visibility of support coordinators.

LHDs/SHNs consistently raised the following issues:

- Clinicians were often unaware that a NDIS participant had a support coordinator, and where they did have a support coordinator, they were unaware of how to contact them when they needed to.

- Support coordinators were often not visible to health services, and the level of contact with health services varied between coordinators. This made it difficult for clinicians to be fully aware of the disability supports a participant was accessing, and how health and disability supports could be coordinated.
- Support coordinators' willingness to support a participant while they accessed health services (for example, presented to ED, were admitted to hospital), or liaise with health services themselves, varied between coordinators.
- Support coordinators' role in working with LHD clinicians and discharge planners to facilitate discharge for NDIS participants varied between coordinators and was often limited (discussed further below).

There were also some concerns that the quality of support coordinators and the knowledge of the health system, and health system processes, varied substantially.

There are conflicting views on the respective role of the health system and the NDIA in facilitating hospital discharge for NDIS participants

LHDs/SHNs consistently raised issues relating to the role of the NDIA and NDIS support coordinators at, and before, the point of discharge – particularly where a participant required new support arrangements to be put in place.

Prior to the NDIS, discharge planners worked with ADHC and non-government disability providers to facilitate discharge for people with disability. This was underpinned by the NSW Health & Ageing and Disability and Home Care (ADHC) Joint Guideline.⁷ Where a person required additional supports or a supported accommodation placement, discharge planners would contact ADHC to establish these support arrangements. ADHC would utilise its knowledge of disability support capacity and vacancies across the disability support system, and had the ability to access ADHC direct service capacity or use its funding relationship with NGOs to facilitate access to NGO-provided services. Under the NDIS, ADHC no longer performs this role.

⁷ Ministry of Health (2013), NSW Health & Ageing and Disability and Home Care (ADHC) Joint Guideline, http://www1.health.nsw.gov.au/pds/ActivePDS/Documents/GL2013_001.pdf

4.2 NDIS access and the participant pathway

The NDIA asserts that the health system should facilitate discharge for NDIS participants in the same way as for the general population, and that this includes ensuring that appropriate disability, informal and other supports are in place prior to discharge. The NDIS considers that the Health system (through discharge planners) should:

- facilitate access to the NDIS where a patient does not have a plan, or work with the NDIA to initiate a plan review for existing NDIS participants where required – as early as possible in the inpatient period.
- work with a NDIS participant’s support coordinator (should they have one) or LAC to ensure supports are in place prior to a participant’s discharge, working with a NDIS participant’s family or informal support network, or arranging for supports to be put in place themselves.

LHDs/SHNs accept that it is a core part of their role to facilitate access to the NDIS. Further, in terms of guidance provided to LHDs/SHNs, the *Mainstream Interface Operational Guidance* provided by the NSW Government and best practice advice contained in Ministry policy guidelines, supports these assertions and make clear that LHDs/SHNs should liaise with all appropriate providers that the patient currently receives services from and make referrals to service providers for any additional needs identified.⁸

However, LHDs/SHNs do not consider that it is their role to *establish* disability support arrangements - that is, have a role beyond simply making referrals to appropriate services. They stated that many discharge planners do not have the knowledge of, or connections with, the disability market or provider capacity/vacancies to do this at this early stage, nor do they have the same degree of influence or levers that ADHC had prior to NDIS transition. In relation to support coordinators, LHDs/SHNs expected a participant’s coordinator to play an active role in discharge, communicating with support providers, initiating a plan review where required, and establishing new support arrangements in a timely way where these were necessary to facilitate discharge, and consistently expressed frustration that this was not occurring.

Further, LHDs/SHNs expressed additional frustration where a participant did not have a support coordinator, and in particular that establishing support coordination arrangements was not able to be achieved in a timely way.

LHDs/SHNs viewed this disconnect as contributing to additional delays in discharge for some participants compared with previous State-based arrangements (discussed further below). In addition, discharge planners are also spending more time on facilitating discharge for NDIS participants in these circumstances. These additional time pressures were being exacerbated by the fact that discharge planners were performing these additional tasks with incomplete knowledge of, or connections with, local disability support providers, and limited visibility of where vacancies or spare capacity exists in the system (with no central source to access this information).

LHDs/SHNs consistently raised issues relating to delays in discharge in some circumstances and for specific NDIS participant cohorts. However, early quantitative evidence of change illustrate an average decrease in occupied bed days and average lengths of stay for NDIS participants

LHDs/SHNs consistently highlighted issues relating to delays in discharge for some NDIS participant groups compared with previous State-based arrangements – across both inpatient and sub-acute/rehabilitation services, and for some NDIS participant cohort groups – in particular:

- People with newly acquired disability who require access to the NDIS and a NDIS package for the first time, and prior to discharge.
- NDIS participants with significantly greater support needs than before they were admitted, and who require a NDIS plan review to access greater levels of NDIS supports post-discharge.
- NDIS participants who require Specialist Disability Accommodation (SDA) for the first time, or who require a different SDA placement to be arranged prior to discharge.
- NDIS participants who require home modifications to be completed prior to discharge.

⁸ Ministry of Health (2011), Care Coordination: Planning from Admission to Transfer of Care in NSW Public Hospitals, http://www1.health.nsw.gov.au/pds/ActivePDS/Documents/PD2011_015.pdf

4.2 NDIS access and the participant pathway

Where delays have occurred, participants are occupying inpatient or rehabilitation beds unnecessarily (that is, where there is no clinical need), and preventing other patients from utilising those beds. This creates blockages in other parts of the health system, including planned admissions, movement of patients from ED to inpatient beds, and movement of patients from inpatient to rehabilitation beds.

Continuation of NSW Health's data analysis and monitoring activities will assist in quantifying the actual contribution of NDIS implementation to delays in discharge, particularly of long stay patients with disability requiring a supported accommodation placement.

LHDs/SHNs and disability sector stakeholders raised additional issues relating to the rehabilitation discharge pathway for people with newly acquired disability (for example, acquired brain injury or spinal cord injury) who require access to the NDIS for the first time.

Stakeholders stated that there is some uncertainty relating to when the rehabilitation phase ends and the provision of ongoing supports to maintain function in the community commences (e.g. in supported independent living or at home). Disability sector stakeholders in particular highlighted the example of 'step-down' accommodation, which for some people may be beneficial as part of their rehabilitation and adjustment, and noted that this type of accommodation is not typically funded by the health system or the NDIS.

In addition, LHDs/SHNs considered that there is a lack of clarity on the period of time that is considered 'post-operative rehabilitation' for a NDIS participant following surgery, particularly where this surgery relates specifically to a person's function or disability. For example, children with a physical disability, such as cerebral palsy or spinal bifida, sometimes require surgical intervention to improve their mobility and functional capacity and prevent functional declines, and require rehabilitation post-surgery. Prior to the NDIS, once a person with a disability had been discharged from hospital, community-based rehabilitation was generally provided by ADHC or a non-government disability service provider rather than the health system. However, under the NDIS, there is lack of clarity at the policy level as to the point at which the health system's responsibility for post-surgical rehabilitation stops, and when NDIS' responsibility starts, and LHDs highlighted examples where the NDIA did not fund these post-surgical interventions.

To illustrate, in one LHD the spinal injury rehabilitation unit discharged eight NDIS participants between October and December 2017. All eight of these patients were admitted to the rehabilitation unit after the NDIS transition commenced in the LHD catchment. Their lengths of stay in the unit varied from 50 days to 479 days. All but one experienced delays in discharge while awaiting NDIS plan approval or plan review. Further delays were experienced while the participants awaited home modifications to be completed or an appropriate SDA placement found. Two patients had to access health insurance or personal funds to access the services they needed.

Table 5 illustrates the number of NDIS participants who were awaiting discharge from the LHD by reason of the delay in discharge. The table also shows the average lengths of stay (and ranges) for these participants, and the maximum cost to the health system of these delays in discharge.

Table 5: Most recent discharges of NDIS participants from Spinal Cord Unit, metropolitan LHD, October to December 2018

| Reason for delay | Patients | LOS range | ALOS | Max additional cost of delayed discharge** |
|-------------------------------------|----------|-----------------|--------------|--|
| Waiting for plan approval or review | 7 | 50 - 479 | 219.4 | \$1.4m |
| Waiting for alternate accommodation | 5 | 230 - 479 | 338.6 | \$1.7m |
| Waiting for home modification | 4 | 50 - 479 | 243.8 | \$0.6m |
| Total unique patients* | 8 | 50 - 479 | 236.3 | \$1.8m |

* May not equal sum of cells above because a patient may have more than one reason for delay

** Assuming all long stay outlier days of stay were due to NDIS related delay.

NDIS related delays in discharge – early evidence

Reasons for delays in discharge attributed to the NDIS – early evidence

The Patient Flow Portal ‘The Waiting for What’ (WFW) data system records patients who experienced a wait for some reason during their admitted patient stay. It captures each type of wait, its start and end dates, as well as dates of admission and discharge, specialty and the reason for the wait.

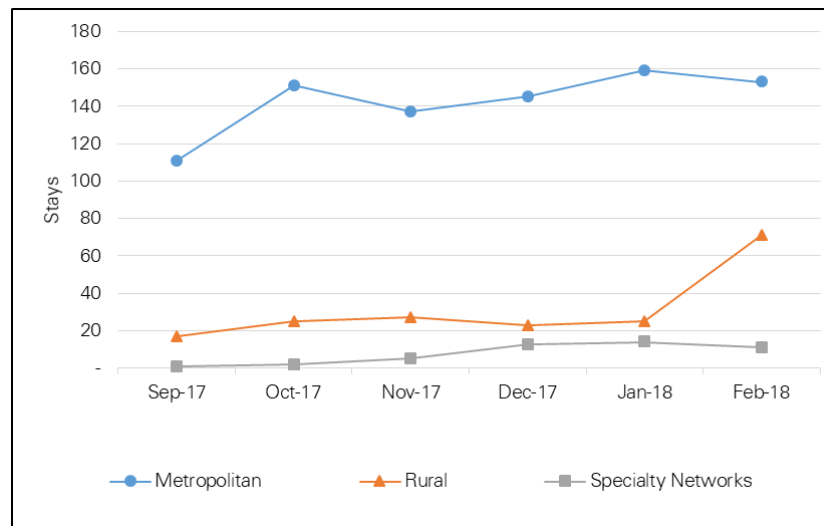
It is important to note that a ‘wait’ does not necessarily mean a ‘delay’. A wait refers to an entry in the WFW system that indicates the hospital is awaiting something to occur in relation to the patient. ‘Delay in discharge’ means that the wait has led to the patient being discharged later than expected (i.e. based on clinical assessment of Estimated Date of Discharge (EDD)). It is possible for a patient to have a ‘wait’ without experiencing a delay in discharge.

Monthly snapshots were available for analysis and included data for each month between September 2017 and February 2018. Data was available for each of the five NDIS WFW categories in the WFW system: awaiting access request form (ARF) submission, awaiting eligibility determination, awaiting plan approval, awaiting supports implementation, and awaiting plan review.

It should be noted that the quality of NDIS-related data is variable given the relatively recent introduction and variable use of NDIS data fields across the State. The number of hospitals reporting NDIS related waits through WFW varies from month to month (ranging from 29 hospitals reporting in September 2017 to 51 in February 2018).

Based on available data in LHD/SHN data collection systems, there are consistently more than 120 patients experiencing some sort of NDIS-related wait from month to month across LHDs. The actual number of waits recorded for these patients varied from 163 (Sep-17) to 267 (Feb-18). The number of stays with a recorded NDIS-related wait by LHD geography is illustrated in Figure 6 below.

Figure 6: Number of stays with at least one NDIS related wait, by LHD geography# and month, September 2017 to February 2018



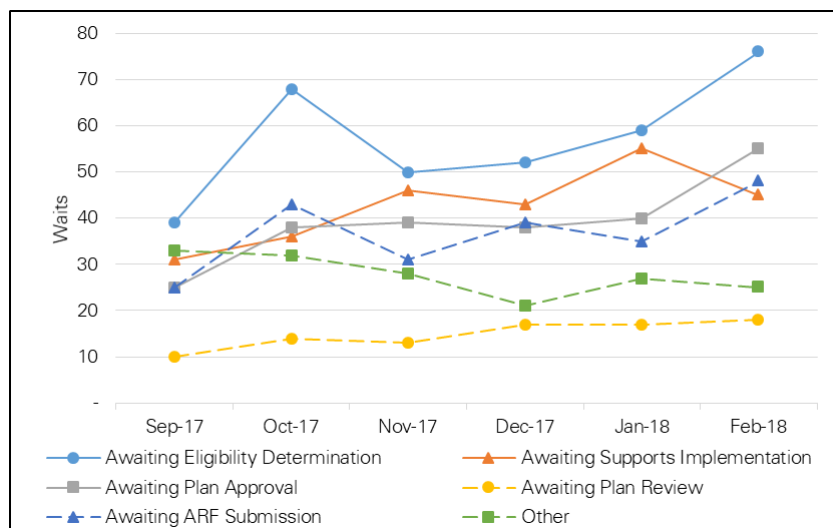
Metropolitan LHDs include Northern Sydney, South Eastern Sydney, Western Sydney, Sydney, South Western Sydney, Central Coast, Illawarra Shoalhaven, and Nepean Blue Mountains. Rural LHDs include Hunter New England, Mid North Coast, Murrumbidgee, Northern NSW, Southern NSW, Western NSW and Far West. Specialty Networks include St Vincents Health, Sydney Children’s Hospitals Network, and Justice and Forensic Mental Health Network

Source: NSW Ministry of Health, Waiting For What data.

NDIS related delays in discharge – early evidence

The most common reasons for NDIS related waits were 'Awaiting Eligibility Determination', 'Awaiting ARF Submission', 'Awaiting Plan Approval', and 'Awaiting Supports Implementation'. The number of episodes (patients) experiencing a NDIS-related wait by reason for wait is illustrated in Figure 7 below.

Figure 7: Number of NDIS related waits, by NDIS wait category and month, all LHDs, September 2017 to February 2018



Source: NSW Ministry of Health, Waiting For What data.

While there have been consistently more than 100 patients experiencing an NDIS related wait in any given month, around 60-70 patients per month are experiencing a delay in discharge due to NDIS related reasons. This is illustrated in Table 3 below. The majority of delays in discharge due to the NDIS are experienced by patients in South Western Sydney, Northern Sydney and Western NSW. However, it should be noted that the number of patients with an NDIS related delay in discharge is likely to be an underestimation of actual numbers given the variable (though increasing) coverage of the WFW system, as well as variable interpretation and assessment of EDD across hospitals and LHDs/SHNs.

Table 3: Stays with NDIS related delay in discharge*, all LHDs by month, September 2017 to February 2018

| LHD | Sep-17 | Oct-17 | Nov-17 | Dec-17 | Jan-18 | Feb-18 |
|-----------------------|-----------|-----------|-----------|-----------|-----------|-----------|
| Central Coast | 2 | 1 | 2 | 2 | 1 | - |
| Illawarra Shoalhaven | 2 | 3 | 6 | 4 | 5 | 8 |
| Nepean Blue Mount. | 2 | 2 | - | - | - | - |
| Northern Sydney | 15 | 18 | 14 | 11 | 12 | 8 |
| South Eastern Sydney | 6 | 7 | 2 | 2 | 2 | 3 |
| South Western Sydney | 18 | 16 | 17 | 16 | 24 | 19 |
| Sydney | 3 | 6 | 4 | 2 | 2 | 2 |
| Western Sydney | 3 | 4 | 2 | 3 | 7 | 5 |
| Hunter New England | 2 | 3 | 4 | 2 | 3 | 4 |
| Mid North Coast | - | - | - | - | - | 1 |
| Murrumbidgee | - | - | - | - | - | 2 |
| Northern NSW | 1 | - | - | 2 | 3 | 3 |
| Southern NSW | 2 | 1 | 1 | - | 1 | 1 |
| Western NSW | - | - | 1 | 1 | 1 | 11 |
| Far West | - | - | - | - | - | - |
| St Vincent's Health | - | - | 3 | 5 | 2 | 2 |
| Sydney Children's | - | - | - | - | - | - |
| Justice & Forensic MH | - | - | - | - | - | - |
| Grand Total | 56 | 61 | 56 | 50 | 63 | 69 |

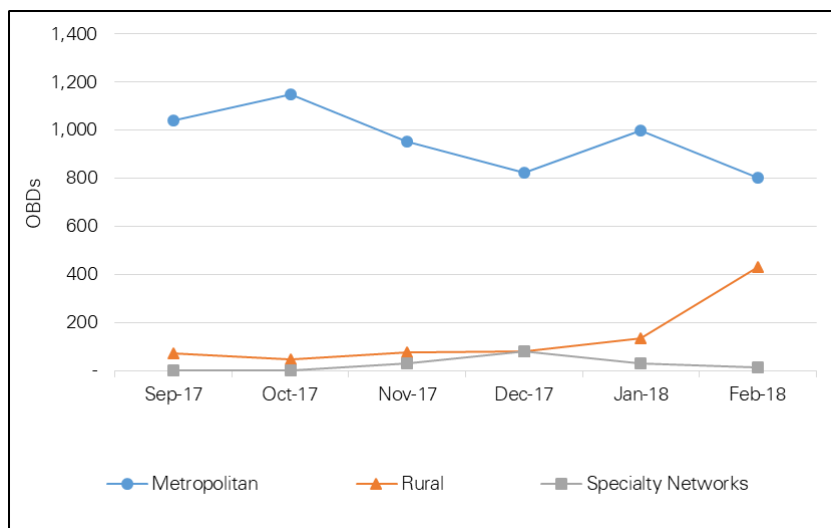
* Episode has an expected date of discharge (EDD) and an NDIS related wait that exceeded that EDD.

Source: NSW Ministry of Health, Waiting For What data

NDIS related delays in discharge – early evidence

The number of additional days of stay due to NDIS-related reasons, by LHD, is illustrated in Figure 8 below. The 1,246 additional days across all LHDs in February 2018 is equivalent to 44.5 full occupied beds for that month.

Figure 8: Additional days of stay in the month due to NDIS related delay in discharge, by LHD geography# and month, September 2017 to February 2018



Metropolitan LHDs include Northern Sydney, South Eastern Sydney, Western Sydney, Sydney, South Western Sydney, Central Coast, Illawarra Shoalhaven, and Nepean Blue Mountains. Rural LHDs include Hunter New England, Mid North Coast, Murrumbidgee, Northern NSW, Southern NSW, Western NSW and Far West. Specialty Networks include St Vincents Health, Sydney Children's Hospitals Network, and Justice and Forensic Mental Health Network

Source: NSW Ministry of Health, Waiting For What data.

Throughout the period, the specialty impacted by delays in discharge is rehabilitation. NDIS delays in discharge are also materially impacting on General Medicine and Mental Health.

The WFW system allocates waits to the specialty of the patient as at the end of the month concerned. This means that all days associated with a wait are associated with that specialty, even though they may have impacted multiple specialties during the patient's treatment journey. This is likely to be partly responsible for the relatively high proportion of days waiting associated with the Rehabilitation specialty. This is illustrated in Table 4 below.

Table 4: Cumulative additional days of stay due to NDIS related delay in discharge, by Specialty and month for all LHDs, September 2017 to February 2018

| Specialty | Sep-17 | Oct-17 | Nov-17 | Dec-17 | Jan-18 | Feb-18 |
|--------------------|--------------|--------------|--------------|--------------|--------------|--------------|
| Endocrinology | - | - | 8 | 65 | 73 | 104 |
| General Medicine | 1,101 | 1,125 | 580 | 778 | 1,006 | 1,040 |
| Mental Health | 690 | 818 | 142 | 36 | 164 | 923 |
| Orthopaedics | - | - | - | - | 19 | 25 |
| Rehabilitation | 1,600 | 1,881 | 1,962 | 1,825 | 1,462 | 1,185 |
| Other | 228 | 242 | 238 | 128 | 260 | 325 |
| Grand Total | 3,619 | 4,066 | 2,930 | 2,832 | 2,984 | 3,602 |

Source: NSW Ministry of Health, Waiting For What data

Changes in health service utilisation – early evidence

Analysis of linked admitted patient utilisation data for NDIS participants in Year 1 LHDs was undertaken to determine whether there was any change in admitted patient service utilisation pre and post NDIS implementation. The data set encompassed 8,984 NDIS participants, all of whom transitioned to the NDIS relatively early (i.e. had an approved plan in place between 1 July and 31 October 2016 inclusive), and who have at least 8 months of post NDIS hospital use data available for analysis. High-level results include:

- On average, approximately 23 per cent of the 8,984 participants in the data set were admitted at least once for each of the four years leading up to their NDIS plan approval. This statistic was stable over the pre NDIS period.
- For the post NDIS period, 18 per cent of the cohort had been admitted at least once
- For those who were admitted, their average hospital stays per year increased from 2.5 to 2.9 over the four years pre NDIS, and up to 3.9 stays per year post NDIS.
- The average cost per episode varied over the pre NDIS period from \$6,395 to \$8,140. The post NDIS average cost per episode was \$5,154.

Overall, the number of admitted episodes post NDIS increased slightly from pre NDIS levels. The increase is, however, largely consistent with pre NDIS trends. Conversely, there was a *decrease* in the number of overnight stay OBDs associated with these admitted episodes in the post NDIS period (see Figure 9). As a result, ALOS has decreased materially for overnight stay episodes, post NDIS.

The Ministry undertook further analysis of OBD trends for unplanned, acute, overnight stay episodes, including statistical testing of the changes from year to year. That analysis found a statistically significant reduction in unplanned, acute OBDs in the eight to twelve month period following plan approval for NDIS participants with plans approved between 1 July and 31 October 2016 inclusive. This reduction is, however, largely consistent with pre NDIS trends and as such, is not possible to determine whether the post NDIS change is attributable to the transition to NDIS or to a continuation of the pre NDIS trend.

Table 5: Number of overnight stay OBDs for NDIS participants, by 12 month period relative to NDIS plan approval date

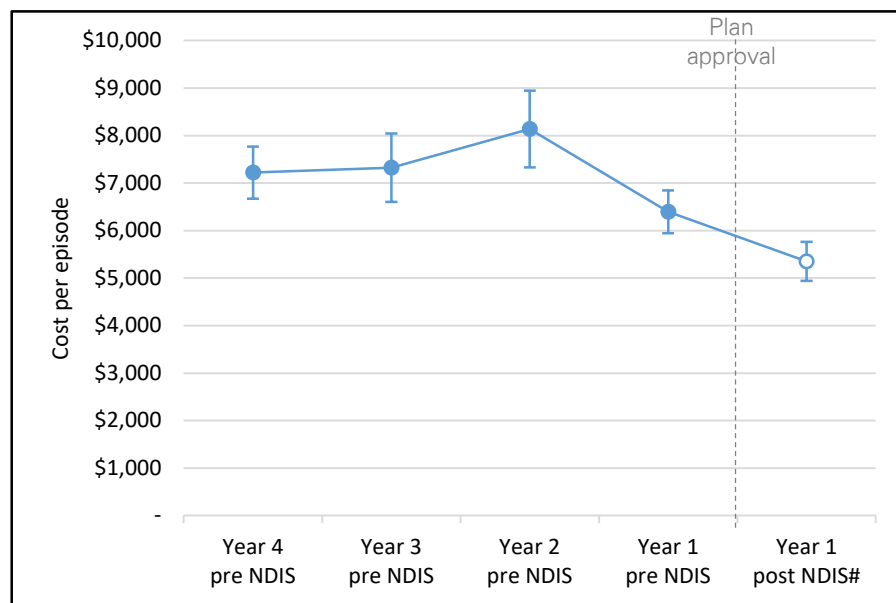
| | Year 4 pre NDIS | Year 3 pre NDIS | Year 2 pre NDIS | Year 1 pre NDIS | Year 1 post NDIS* |
|-------------|--------------------|--------------------|--------------------|--------------------|----------------------|
| Year 1 LHDs | 30,265 | 30,598 | 32,277 | 25,919 | 18,819 |

*Number of OBDs scaled pro rata to a full year for participants with less than 12 months of available data. Source: NSW Ministry of Health linked data.

Changes in health service utilisation - early evidence

The average cost per episode decreased in the post NDIS period, as shown in Figure 9 below. This finding is, however, largely consistent with the pre NDIS trend and therefore is not possible to attribute to the introduction of the NDIS.

Figure 9: Cost per acute* hospital episode for NDIS participants, by 12 month period relative to NDIS plan approval date



* Includes episodes with either acute or mental health care type.

Year 1 post NDIS data have not been scaled to a full 12 month period.

Source: NSW Ministry of Health linked data. Cost data were obtained from linked District Network Return (DNR) data. Costs have not been adjusted for inflation

Case Study - Access to the NDIS

Background

John* is a 58 year old male living in social housing, with no informal supports. He has limited mobility and nerve damage from an injury incurred a number of years ago, and his impairment significantly reduces his functional capacity and ability to complete activities of daily living. He is regularly unable to access the community due to his functional impairment, and becomes malnourished and experiences suicidal ideation due to his circumstances.

John was hospitalised three times during December 2017 and January 2018 due to chronic pain resulting from his disability and inability to cope independently at home.

The participant submitted an NDIS access request form, with support from his General Practitioner in mid 2017 and was deemed ineligible for the NDIS due to insufficient evidence provided to support his functional impairment. Following John's admission, the LHD collated new evidence of his disability and the LHD submitted a new access request form on his behalf in late 2017. A new report was also developed to provide evidence of his disability, its permanency and its substantial impact on functional ability.

In January 2018, John received notification that he was eligible for the NDIS, and a planning meeting was subsequently held with John. A plan with support coordination and in excess of \$100,000 was provided. The LHD has been required to continue to liaise with the participant and support coordinator to ensure the support plan is implemented.

* Name and other details have been changed and that the detail provided in the case study is third party reported.

Impact

The delay in accessing supports due to the participant's initial ineligibility determination resulted in the participant being admitted to hospital three times over the course of a two month period.

The LHD also had to provide significant support in producing evidence and developing a second access request form required before the patient was deemed eligible for the NDIS.

Following eligibility determination, the LHD has had to actively and extensively liaise with the participant to link him in with his support coordinator and the NDIA to ensure the plan is implemented.

This case study highlights some of the challenges experienced in supporting patients to access the NDIS. In particular, the resource investment to support appropriate and timely decision-making in relation to patient access and funding requests.

Case Study – Specialist Disability Accommodation

Background

Peter* is a young man with intellectual disability, autism, and behaviours of concern. He requires one-to-one support 24 hours each day. Peter has a history of moving in and out of transitional respite housing, supported accommodation placements, and his parent's respective homes. He was previously living with his mother and receiving support services from a supported accommodation provider until his mother withdrew Peter from the service due to the perceived quality of care issues.

Peter is a NDIS participant and has a NDIS plan. He also has a NDIS Support Coordinator. Prior to his admission to hospital, Peter and his mother were working with the coordinator to find a suitable Specialist Disability Accommodation (SDA) placement.

Peter was admitted to hospital following a behavioural disturbance at home, and given safety concerns, he was unable to remain at home.

During Peter's stay in hospital, his Support Coordinator arranged discharge into a short term respite placement. However Peter was returned to hospital following a further behavioural disturbance. Despite continued efforts to find a SDA placement, the Support Coordinator has been unable to find a provider who is willing to support him.

The Support Coordinator has also been unable to source appropriate social housing or a rental subsidy as Housing NSW indicated that NDIS participants approved for SDA were not eligible for social housing, priority housing status or rental subsidies, and that the participant was too "high risk" for temporary crisis accommodation.

* Name and other details have been changed and the detail provided in the case study is third party reported.

Impact

As a result of a lack of appropriate SDA vacancies and inability to place the participant in social housing, the participant remained in hospital as an inpatient for 90 days, despite being medically stable and ready for discharge to the community.

The cost of this participant's delay in discharge (estimated to be in excess of 50 days) is more than \$40,000, with each additional day spent waiting for SDA costing at least a further \$857 (based on the average cost per bed day for maintenance care, taken from the NSW Activity Based Management portal, estimated based on actual costs of care for 2016-17).

The case study highlights inpatient discharge delay and bed blockage, and the challenges experienced by the participant, his family, the Support Coordinator and the LHD when no appropriate SDA placement is available to meet the participant's behavioural and other support needs, or when the participant is rejected by SDA providers. In addition, in this case, the NSW Social Housing Eligibility and Allocations Policy Supplement prevents the participant from accessing any form of social housing.

Case Study – Newly Acquired Disability

Background

Paul* is a homeless male with a newly acquired spinal cord injury and hypoxic brain injury. Following his injury and significant period as an inpatient, he was moved to an LHD inpatient rehabilitation facility.

Paul suffers from significant motor and sensory paralysis in both his upper and lower limbs. He requires support for all personal care tasks, a hoist with two people to assist for all functional transfers, an electric bed to assist with transferring, appropriate pressure injury prevention mattresses, and a power wheelchair for all indoor and outdoor activities.

He does not have any informal supports and requires assistance with daily living activities.

The LHD submitted a NDIS Access Request Form on Paul's behalf on 1 November 2017. On 20 December 2017, the NDIA responded to the application confirming that he is eligible for NDIS supports, and a planning discussion was subsequently arranged.

Paul's plan did not, however, contain funding for supported independent living. Given Paul was homeless prior to his admission to hospital, he had no other accommodation to return to, hence remained in the inpatient rehabilitation facility.

In January 2018, an LHD social worker contacted the NDIA to discuss funding for the supported independent living Paul required in order to be discharged. The NDIA requested the details of Paul's circumstances so it could be escalated. The social worker was also referred to the NDIS Technical Advisory Team as part of this process, but was required to leave a number of messages.

The LHD continues to liaise with the NDIA to secure supported independent living funding.

* Name and other details have been changed and information within the case study is third party reported.

Impact

As at March 2018 Paul has been unable to be discharged and remains in the LHD rehabilitation facility, and funding for supported independent living accommodation has yet to be included in his NDIS plan.

Paul has been in the rehabilitation facility for more than 120 days, of which approximately 90 days were deemed clinically unnecessary. The approximate cost of these additional 90 days is more than \$85,000, with each additional day spent waiting for supports at a cost of approximately \$961 per day (based on the average cost per bed day for rehabilitation care, taken from the NSW Activity Based Management portal, and based on actual costs of care for 2016-17).

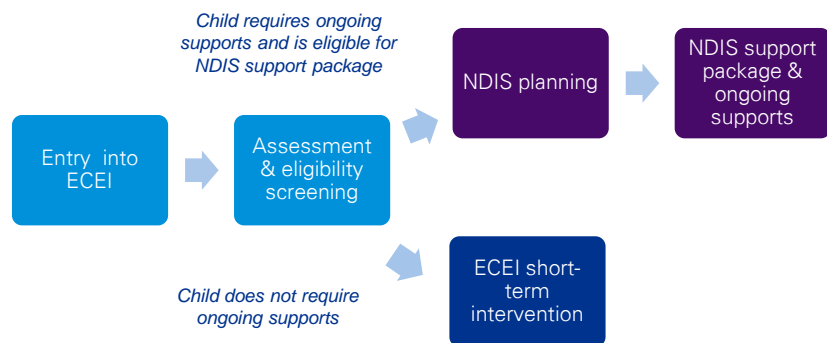
The same LHD has seven other patients awaiting transfer from the acute setting to the rehabilitation facility, and the delay in Paul's discharge contributed to 'bed block' which has flow on operational and financial impacts for other parts of the LHD and to other patients.

4.2 NDIS access and the participant pathway

Health clinicians report significant waiting times to access the ECEI pathway, with associated risks that children's development may be adversely impacted and some potential long-term consequences for the health and other mainstream service systems. This is also contributing to increasing utilisation of paediatric health services for children with disability or developmental delay aged 0-6 years.

ECEI is the pathway into the NDIS for children aged 0 to 6 years with significant disability or developmental delay who require ongoing supports. ECEI is also a source of short-term, time-limited therapy and early intervention support for these children, as well as for those children with one or more developmental delays who do not need ongoing NDIS supports. A high-level overview of the ECEI pathway is provided in Figure 10 below.

Figure 10: High-level ECEI pathway



Timely access to ECEI and NDIS early intervention supports is especially important for young children. There is a range of evidence which demonstrates that early therapy and other supports can significantly improve a child's development and functional abilities, reduce the impact of any disability, delay or deficits and decrease the need for formal supports over a person's lifetime.

All Year 1 LHDs and some Year 2 LHDs reported that there were waiting times for children with disability or developmental delay in accessing the ECEI pathway and in receiving early intervention supports. While there is no comprehensive ECEI waiting time data available, LHDs/SHNs reported wait times of between six and nine months as typical, and up to 12 months in extreme cases (as at December 2017). While LHDs/SHNs recognised that the ECEI pathway and services are relatively new and need time to be fully established and reach full capacity, there was a common concern that the ECEI pathway has not been resourced sufficiently by the NDIA, and/or that the current ECEI processes are not otherwise working effectively. The Ministry also noted that there potential for conflict of interest between ECEI partners' role between their ECEI role and their role as an NDIS registered provider (where they are permitted by the NDIA to have both roles), and this may be exacerbating delays – particularly where providers are diverting staff to provide NDIS supports to children who already have an approved NDIS Plan.⁹

The requirement for all children to utilise the ECEI gateway created additional and unnecessary delays. A number of LHDs/SHNs noted that children with diagnosed disabling conditions recognised by the NDIA as providing automatic entry to the NDIS ('List D' conditions¹⁰) still have to go through the ECEI pathway, and considered these types of delays unnecessary and inconsistent with the NDIA's streamlined 'List D' access process.

Most LHDs/SHNs also highlighted the risks and potential long-term consequences for children and the health system resulting from ECEI delays. ECEI delays may mean key developmental windows are missed with potential for long-term developmental implications for children, increased disability and disability support needs, and greater lifetime costs of disability. This may have long-term impacts on the health system in terms of greater demand for health services (particularly where there are increased health needs associated with disability), and increased requirements for other mainstream services, such as supports in education settings. Delays in accessing ECEI and NDIS early

⁹ This potential for conflict of interest was also recognised in the Report of the Joint Standing Committee on the NDIS, *Provision of services under the NDIS Early Childhood Early Intervention Approach*, they raised the matter as a matter of conflict of interest: https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/EarlyChildhood/-/media/Committees/ndis_ctte/EarlyChildhood/report.pdf

¹⁰ <https://www.ndis.gov.au/operational-guideline/access/list-d>

4.2 NDIS access and the participant pathway

intervention supports directly also contradicts the Scheme's stated intent of intervening early to reduce lifetime costs of disability. There was some evidence of short-term impacts for the health system associated with ECEI delays, particularly in Year 1 LHDs. LHDs/SHNs consistently stated that delays in access to the ECEI pathway, and variability in access to interim ECEI supports during ECEI assessment, is placing greater pressure on paediatric health services, particularly allied health services. As a result:

- LHDs/SHNs are providing paediatric health services to children while they wait for access to ECEI and then NDIS supports to meet immediate needs, including occupational therapy, speech pathology, physiotherapy and dietetics. While there is no comprehensive data available across all LHDs/SHNs, one LHD noted that in early 2018, its speech pathology department was providing services to 88 children at various stages of the NDIS access process. The same LHD was also providing physiotherapy services to approximately 50 children through its outpatient clinics who were expected to be eligible for the NDIS.
- Decisions made by LHDs/SHNs to provide services to children waiting for access to ECEI and/or NDIS supports has increased waiting times for allied health services. As an example, one LHD reported the waiting times for community allied health services had increased substantially, varying anywhere between two weeks for psychology, to 34 weeks for dietetics and a maximum of 56 weeks for occupational therapy. Others have limited their paediatric health services to only supporting children below school age.

In addition, specialised interventions previously provided by specialist allied health staff are no longer available through ADHC's Community Support Teams or ADHC-funded NGOs, and are not funded by the NDIA. Examples include children with cerebral palsy who require casting combined with botox, and children with physical disabilities (such as spina bifida) requiring sub-acute care following a surgical intervention. LHDs/SHNs had not expected that they would need to provide these (and other) specialised interventions related to children's functional impairment, and indicated that they do not have the safeguards, resources or specialised clinical skills to provide these services.

It was noted that at the time this interim evaluation was being undertaken, the NDIA had just released details of a new NDIS pathway, designed to significantly improve the experience that people and organisations have with the NDIS. This new pathway specifically considered and addressed some of the issues being experienced by children and families accessing the ECEI pathway. The new pathway is now being progressively piloted and tested before being rolled out nationally, and the NDIA is engaging with stakeholders on the testing and implementation of the new pathway. Further, NSW ECEI Partners for the full Scheme are expected to be confirmed shortly, and they will provide ECEI supports from 1 July 2018.

Case Study - Access to ECEI

Background

Brittany* is a four year old child, living at home, who has Global Developmental Delay likely related to her genetic translocation.

Brittany's physiotherapist made calls to three ECEI partners, none of whom were able to accept a referral due to long waitlists. Calls were made to the same partners every one to two months, each time being informed by the individual provider that they were working through a defined list of children (previously known to FACS) and could not accept new referrals.

After seven months, the physiotherapist faxed a referral to two different ECEI partners but did not receive a response.

As the ECEI referral pathway was not progressing, the physiotherapist assisted Brittany's mother with a NDIS application. The following month, the NDIA verbally informed the physiotherapist that Brittany met the access criteria for the NDIS.

Two months after approval, the physiotherapist called the NDIA and was advised Brittany still needed to go through the ECEI pathway despite being identified as eligible for the NDIS. The NDIA advised that the ECEI partner would assist with the initial planning meeting which could be expected within the next two to six months.

*name and other details have been changed and information in the case study is third party reported.

Impact

Brittany's family is still waiting for an initial planning meeting to take place with a local ECEI partner. The family report that they have waited over 12 months to access services through the ECEI pathway.

This delay has resulted in Brittany being left without supports during an intense period of child development, with potential long-term adverse consequences.

The lack of clarity around the ECEI pathway has resulted in mixed messaging from ECEI partners and the NDIA. This has caused confusion for Brittany's family, who thought that being granted access to the NDIS would mean Brittany would be able to access the interventions she needed.

Brittany's family is now seeking interim assistance from the LHD to provide occupational therapy and speech pathology services. Under activity based funding, Speech Pathology services are priced at \$196 per service event and Occupational Therapy at \$185. If Brittany received weekly therapy for each, this would cost the health system \$1,524 per month for the duration of the interim assistance.

4.2 NDIS access and the participant pathway

There have been benefits for mental health patients and services as a result of the inclusion of people with psychosocial disability needs in the scope of the NDIS

The NSW health system continues to have responsibility for funding or providing a range of services to support people with mental health conditions, including inpatient mental health services and community-based services (such as such as Housing and Accommodation Support Initiative (HASI) and Community Living Supports).^{11, 12}

People with long-term and significant psychosocial disability needs who are accessing NSW health funded or provided mental health services are now able to access community-based disability supports through the NDIS. As a result, many LHDs/SHNs reported seeing positive outcomes for some individuals in this cohort, and for the health system. A number of long-stay patients who had previously been supported in acute mental health facilities are now being supported to live in the community through the NDIS.

At this point in time, there is limited data on the impact of the NDIS on mental health services. However, early data provided by the Ministry indicates that a number of long-stay mental health patients (that is, patients with lengths of stay over 365 days) in Year 1 LHDs have been able to access the NDIS. Table 6 below illustrates that of the 91 long-stay mental health patients in Year 1 LHDs as at 1 July 2016 who applied for access to the NDIS, more than half (53%) were deemed eligible and had an NDIS approved plan after 1 July 2016.

Table 6: Number of participants who were long-stay mental health patients as at 1 July 2016 and who had an NDIS plan approved in the period following 1 July 2016, Year 1 LHDs*

| | Number of long stay MH* inpatients as at 1 July 2016 | Number with an approved NDIS plan from 1 July 2016 | % |
|---------------------|--|--|-----|
| Year 1 LHDs# | 91 | 48 | 53% |

* Mental Health inpatients are defined as those with an episode of care type = 'M' or days in psychiatric unit > 0

Includes data from Central Coast, Nepean Blue Mountains, Northern Sydney, South Western Sydney, Southern NSW, Western Sydney

Source: Ministry of Health linked data

It was noted that some LHDs/SHNs and the Ministry's Mental Health Branch raised concerns relating to the consistency of decisions relating to NDIS eligibility for people with psychosocial disability – in particular relating to the interpretation of “permanency” of psychosocial disabling conditions, and the potential for recovery. Further, LHDs/SHNs highlighted examples of delays in discharge for some mental health long-stay patients because of a lack of suitable supported accommodation or social housing. Whilst this is not a NDIS-specific issue, it impacts on the participants’ ability to return to the community, and exercise choice and control over the use of their NDIS funded supports.

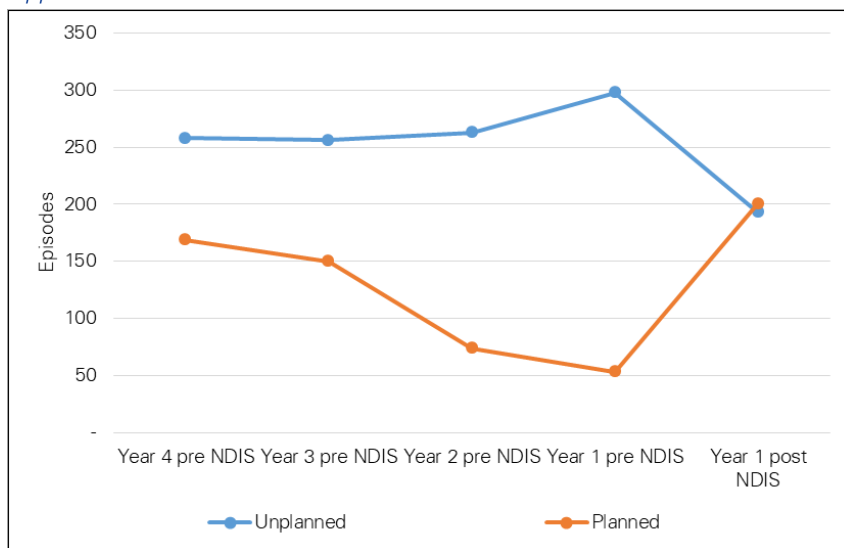
¹¹ <https://www.facs.nsw.gov.au/about/reforms/future-directions/reforms/partnerships/chapters/housing-mental-health>;

¹² <http://www.health.nsw.gov.au/mentalhealth/reform/Factsheets/mh-community-supports.pdf>

4.2 NDIS access and the participant pathway

Analysis of linked data relating to mental health admitted patient service utilisation by NDIS participants in Year 1 did not indicate any material change in mental health admitted patient episodes overall. However, analysis indicated that there was a decrease in unplanned mental health episodes one year post NDIS compared with the pre NDIS period, and an increase in planned admissions. This is illustrated in Figure 11 below.

Figure 11: Number of mental health admitted episodes for NDIS participants, by unplanned flag and 12 month period# relative to NDIS plan approval date*



* Mental health admitted episodes are defined as episodes where days in psych are > 0 or episode of care type = "M"

Number of episodes scaled pro rata to a full year for participants with less than 12 months of available data.

Source: NSW Ministry of Health linked data.

4.2 NDIS access and the participant pathway

Issues, risks and strategies for consideration

| Issue | Risks to be managed | Strategies and actions for consideration | Responsibility | Priority |
|--|---|--|---|---|
| LHDs/SHNs are experiencing delays in discharge attributable to timeliness and efficiency of NDIS processes, and there were numerous examples of inadequate collaboration between the health and disability sectors at the point of discharge | <p>Delays in discharge continue for some NDIS participants, creating unnecessary pressure on inpatient and rehabilitation services, and avoidable increases in health service costs.</p> <p>NSW Health is not fully aware of the quantum or impact of delays in discharge over time, and is not able to realise the benefits of more timely discharge for NDIS participants</p> | <p>Seek to agree with the NDIA, and clearly document, the role of health services (including discharge planners) and the NDIS workforce (NDIS support coordinators, support providers and the NDIA) in facilitating timely discharge¹³</p> <p>Work through NSW intergovernmental processes to understand how the additional cost to the health system of delays in discharge could be funded/reimbursed where additional time spent in hospital is clinically unnecessary and the delay in discharge is caused by delays outside the health system's control (e.g. delays in NDIA processes, lack of NDIS market capacity)</p> <p>Continue to gather robust quantitative evidence of delays in discharge, including working with LHDs/SHNs to ensure that the Waiting for What (WFW) data collection is fully implemented by LHDs/SHNs to elicit robust data over time, and undertake analyses to estimate the cost to the health system of delays in discharge for NDIS participants (where these delays are due to non-clinical factors).</p> <p>Continue to request access to additional NDIA data elements for inclusion in the NDIS Data Linkage, to supplement the WFW data collection (for example, 'date Access Request form was requested by the client', 'date Access Request Form was submitted to the NDIA').</p> | <p><i>NDIA has primary responsibility</i></p> <p>NSW Government to raise through existing inter-governmental governance structures</p> <p>Ministry of Health to raise through SOWG Health sub-group or directly with NDIA</p> <p><i>NSW health system has primary responsibility (through Ministry of Health, working with LHDs/SHNs)</i></p> | <p>1 – Immediate/ high priority</p> <p>1 – Immediate/ high priority</p> |

¹³ It is noted that there is a current project being undertaken by the Summer Foundation and funded by the NDIA (through Information, Linkages and Capacity building funding) which is examining how the discharge process for NDIS participants can be improved.

4.2 NDIS access and the participant pathway

Issues, risks and strategies for consideration

| Issue | Risks to be managed | Strategies and actions for consideration | Responsibility | Priority |
|--|--|---|---|---------------------------------|
| There are significant delays in children accessing the ECEI pathway and receiving required early intervention supports | Sustained ECEI delays may lead to poor outcomes for children, additional demand for health services and additional costs (and fewer benefits) for the long-term | As a priority, continue to raise issues relating to ECEI delays and resourcing, and the potential long-term consequences for children, the health system, and the NDIS, through existing escalation pathways and governance structures. This should build on the recent high-level meeting (in March 2018) between DSS, NDIA, NSW Health and FACS where a series of issues were raised and priorities for NSW Government identified (shortening ECEI gateway timeframes, expediting children with significant disability, and improving NDIS plan utilisation for children) | <i>NDIA has primary responsibility</i> NSW Government to raise through existing inter-governmental governance structures | 1 – Immediate/ high priority |
| | Additional demand for children’s therapy services in the health system in the short-term leads to delays in service access for other children (with health needs) | Monitor the quantum and cost to the health system of additional children’s therapy service provision for children with disability or developmental delay who would otherwise access these supports through ECEI or the NDIS, monitor waiting times for children’s therapy services, and utilise this data to inform intergovernmental discussions | <i>NSW health system has primary responsibility (Ministry of Health, working with LHDs/SHNs)</i> | |
| Unexpected utilisation of paediatric allied health services is creating additional pressures on allied health services | Utilisation of allied health services for non-clinical purposes by NDIS participants as a substitute for specialist disability support continues, impacting on availability of services for other patients | Work with LHDs/SHNs to assist them to identify the specific circumstances where children waiting for access to ECEI should be able to access paediatric allied health services as an interim measure, and how access should be prioritized. Collect data on the additional services provided and associated estimates of cost, and work through NSW intergovernmental processes to identify how any additional cost to the health system could be funded/reimbursed through the NDIS. | <i>NSW health system has primary responsibility (Ministry of Health, working with LHDs/SHNs)</i> | 1 – Immediate/ high priority |

4.2 NDIS access and the participant pathway

Issues, risks and strategies for consideration

| Issue | Risks to be managed | Strategies and actions for consideration | Responsibility | Priority |
|--|--|--|--|--|
| Unexpected utilisation of paediatric allied health services is creating additional pressures on allied health services <i>(continued)</i> | Utilisation of allied health services for non-clinical purposes by NDIS participants as a substitute for specialist disability support continues, impacting on availability of services for other patients <i>(continued)</i> | Continue to request access to additional NDIA data elements for ECEI participants (e.g. to identify the number of children experiences delays in accessing ECEI and/or early intervention supports), supported by an NDIA data dictionary and appropriate business rules. | <i>NSW health system has primary responsibility (Ministry of Health, working with LHDs/SHNs)</i> | 1 – Immediate/high priority |
| Inefficiency and delays in NDIS processes are impacting on health professionals and services | NDIS process issues continue to create additional administrative burden on health professionals at full Scheme, and continue to cause delays in discharge | Continue to raise issues relating to operational performance with the NDIA and through appropriate governance structures Continue to support and strengthen the implementation of the Patient Flow Portal WFW data collection as a way of documenting the impact of delays in discharge which can be attributed to NDIS processes | <i>NDIA has primary responsibility</i> NSW Government to raise through existing inter-governmental governance structures Ministry of Health to raise through SOWG Health sub-group or directly with NDIA <i>NSW health system has primary responsibility (Ministry of Health, with LHDs/SHNs)</i> | 2 – Medium priority 2 – Medium priority |

4.2 NDIS access and the participant pathway

Issues, risks and strategies for consideration

| Issue | Risks to be managed | Strategies and actions for consideration | Responsibility | Priority |
|---|---|---|---|---------------------|
| Health professional input is not sought or recognised as important in informing NDIS participant planning processes | Inadequate NDIS planning and funding decisions and inadequate NDIS supports lead to safety increased demand for health services, quality and safety risks and poorer participant outcomes | Work with the NDIA and other jurisdictional governments to develop protocols and guidance materials for LACs and planners relating to when health professional input should inform or enhance the planning process, and the nature of health professional input | <i>Joint NDIA/health responsibility</i> Ministry of Health to work directly with NDIA | 2 – Medium priority |
| There is variability in the quality and capability of NDIS support coordinators | Health and disability supports are not well-coordinated Health system continues to experience delays in discharge where participants require new support arrangements to be put in place NSW Health is required to absorb increased costs for NDIS participants in relation to discharge planning and delays in discharge | Work with the NDIA and other jurisdictional governments to agree on the expectations for support coordinators with respect to their role in coordinating health and disability supports and working with health services including prior to and at the point of discharge | <i>NDIA has primary responsibility</i> Ministry of Health to raise through SOWG Health sub-group or directly with NDIA | 2 – Medium priority |

4.2 NDIS access and the participant pathway

Issues, risks and strategies for consideration

| Issue | Risks to be managed | Strategies and actions for consideration | Responsibility | Priority |
|---|---|--|--|---------------------|
| Supporting access to the NDIS is a responsibility for the health system, though it is creating administrative burden in excess of what was expected | NDIS access and evidence processes continue to increase administrative burden beyond what was expected, impacting on time available for patient care leading to risks to patient safety | Continue to work with the NDIA and other jurisdictional governments to achieve greater clarity on the health input and evidence required to facilitate participant access to the NDIS, including the range of acceptable evidence, assessments, and language and terminology, and to discuss options for streamlining the evidence process and forms | <i>NSW health system has primary responsibility (Ministry of Health, working with NDIA)</i> | 2 – Medium priority |
| Supporting access to the NDIS is a responsibility for the health system, though it is creating administrative burden in excess of what was expected | NDIS access and evidence processes continue to increase administrative burden beyond what was expected, impacting on time available for patient care leading to risks to patient safety | Collate the range of tools and resources developed by LHDs/SHNs to inform a 'good practice guide' for all clinicians involved in facilitating access to the NDIS, building on existing guidance materials already developed by the Ministry. This could be combined with targeted training, online or in-person and run periodically (e.g. through HETI) | <i>NSW health system has primary responsibility (Ministry of Health, working with LHDs/SHNs)</i> | 3 – Lower priority |

4.3 Sector readiness and development

Key findings – Sector readiness and development

1. Gaps in the disability market and market immaturity are contributing to pressures experienced by the health system.
2. LHDs/SHNs have expressed concerns relating to the capability of some disability providers and the capacity to grow the required disability workforce leading to impacts on the NSW health system.
3. The health system has, to date, had a limited role in building disability provider capability.
4. There have been some changes in disability support provider behaviour that impact what the disability provider will and will not provide (and the participants they choose to support) and this is further contributing to additional demands on the health system.

4.3 Sector readiness and development

Findings and supporting evidence

Gaps in the disability market immaturity are contributing to pressures experienced by the health system

The disability market is changing rapidly as a result of the introduction of the NDIS, with a number of new market entrants, opportunities for growth in support provision and greater ability for market participants to determine the support types they will provide, to whom, and the locations in which they provide them. These market changes were expected, and market growth is essential for the success of the Scheme and its ability to deliver outcomes for participants.

Some growth in supply in disability supports has been evident in NSW since the NDIS commenced:

- There has been an increase in the number of organisations registered to provide a range of NDIS support categories, and many existing support providers have increased their capacity to provide additional supports to NDIS participants.
- There has been a significant number of new allied health (therapeutic support) providers and individual practitioners (sole traders) registering as NDIS providers.
- There has been an increase in supply of Specialist Disability Accommodation (SDA).
- There has also been some reduction in supply, with some existing support providers reducing the provision of some support types (such as respite and some group-based community participation), and smaller organisations exiting the market completely or being acquired by larger providers.

Growth in market supply has the potential to provide benefits for the health system in terms of increasing the levels of support for participants and contributing to better outcomes, thus reducing issues and blockages in the health system where disability supports are not available (for example, at discharge). However, quantitative evidence of these types of benefits are not evident at this stage.

The table below outlines the number of registered providers by selected NDIS support categories over the period January to December 2017.

Table 7: Number of registered NDIS providers by Registration Group and Quarter, New South Wales, December 2016 to December 2017

| Registration Group | Jan-Mar 2017 | Apr-Jun 2017 | Jul-Sep 2017 | Oct-Dec 2017 |
|--|--------------|--------------|--------------|--------------|
| Early Childhood Supports | 583 | 715 | 850 | 937 |
| Specialised Disability Accommodation# | 15 | 102 | 168 | 205 |
| Support Coordination | 335 | 414 | 465 | 510 |
| Therapeutic Supports | 1,753 | 2,215 | 2,642 | 3,061 |

Registration for SDA only possible from March 2017.

Source: NDIA Quarterly Reports for New South Wales

Disability market gaps have always been an issue in the disability sector and, despite some recent increases in supply, some shortfalls still exist:

- Support types which require substantial financial investment, including SDA.
- Supported Independent Living (SIL) supports for people with complex behavioural needs, and supports that require a highly skilled/specialised workforce such as behaviour support and intervention.
- Significant market gaps in rural and remote areas of NSW, where supply has traditionally been limited and where increases in supply have been less evident.
- Constraints on supply (and potential impacts on quality) due to workforce challenges associated with attracting and retaining skilled and experienced support staff.
- Supports to particular cohorts of participants that require service providers to have additional skills and experience.

4.3 Sector readiness and development

The full impact of disability market supply gaps and challenges on the health system are unknown. There is limited available quantitative evidence that current market gaps have increased pressures on the health system, and LHDs/SHNs noted that the same issues and blockages that were present before the introduction of the NDIS largely remain (particularly relating to supported independent living and supports for people with complex needs).

LHDs/SHNs have expressed concerns relating to the capability of some disability providers and the capacity to grow the required disability workforce, leading to impacts on the NSW health system.

A majority of LHDs/SHNs raised concerns about the capability of some new and existing disability support providers, including:

- concerns about the capability and experience of new allied health providers and practitioners, and reliance on new graduates (particularly in rural and remote locations), with some examples of poor practice
- concerns about the quality of a growing disability workforce to effectively support NDIS participants with complex support needs, and participants in SIL.

Capability and experience of new allied health providers and practitioners

LHDs/SHNs were aware of a number of NDIS registered practitioners who were either new graduates or had little clinical experience, or who were more experienced practitioners in clinical areas not generally relevant for disability support (for example, physiotherapists experienced in working with people with musculoskeletal issues working with NDIS participants with complex neurological conditions). There was concern that these practitioners did not have the depth of clinical experience necessary to work with specific NDIS participant cohorts. Further, there was concern that this lack of capability posed risks for participants in the short-term and potentially long-term (risk of injuries and poor functional outcomes leading to future health system and NDIS costs).

Actual evidence of impact on the health system was limited. LHDs/SHNs did, however, raise some examples of poor practice:

- inappropriate equipment/assistive technology prescription (to some extent mitigated by EnableNSW's role in advising the NDIA on participants' equipment prescriptions and quotes)
- poor positioning practices, resulting in pressure care injuries requiring treatment
- poor wound management practices resulting in avoidable admission to hospital.

There were also concerns raised that new allied health practitioners may not be receiving the depth of clinical training and experience necessary to work with a range of people with disability, including people with relatively complex needs, early in their careers (such as with a large disability support organisation or in the health system where they can learn from experienced practitioners). Again, although there was no evidence of actual impact on the health system or aggregated patient outcomes at this point in time, it remains an area of risk for the health system in the long-term.

Concerns about the quality of the growing disability workforce

There were some concerns about the quality of the growing disability workforce to effectively support NDIS participants – particularly those with complex support needs and participants in SIL – which pose additional risks to the health system in terms of increased health service utilisation. These concerns and risks were associated with:

- potential decline in quality and standards of care over time
- providers recruiting less experienced/skilled support workers, as competition for experienced workers increases in an already challenging workforce environment and fixed pricing structure.

4.3 Sector readiness and development

There is no quantitative evidence at this stage of impacts on the health system of inadequate disability provider capacity or capability, such as impacts on emergency department usage

One of the potential consequences of inadequate disability provider and workforce capability and capacity is an increase in incidents and injuries for NDIS participants. For the health system, this could be experienced as increasing presentations to emergency departments (ED), increased admissions and an increase in admitted patient bed days.

At this point in time, there is no quantitative evidence to support this:

- as noted in 4.2 above, there is very little quantitative evidence of changes in admitted patients episodes or OBDs by NDIS participants
- there is no quantitative evidence of changes in emergency department utilisation by NDIS participants since the NDIS commenced. This is discussed below.

Analysis of emergency department utilisation

Analysis of linked emergency department utilisation data for NDIS participants in Year 1 LHDs was undertaken to determine whether there was any change in ED utilisation pre and post NDIS implementation. The data set encompassed NDIS participants who transitioned to the NDIS relatively early (and had an approved plan in place between 1 July and 31 October 2016 inclusive), and who have at least 8 months of post NDIS hospital use data available for analysis.

At a population (cohort) level, there were 8,984 NDIS participants in the data set, and they experienced between 6,517 and 7,056 ED presentations per year over the four year pre NDIS period. They experienced approximately 7,356 ED presentations in the year post NDIS (scaled to full year for participants with less than 12 months of available data) – as shown in Figure 15 below.

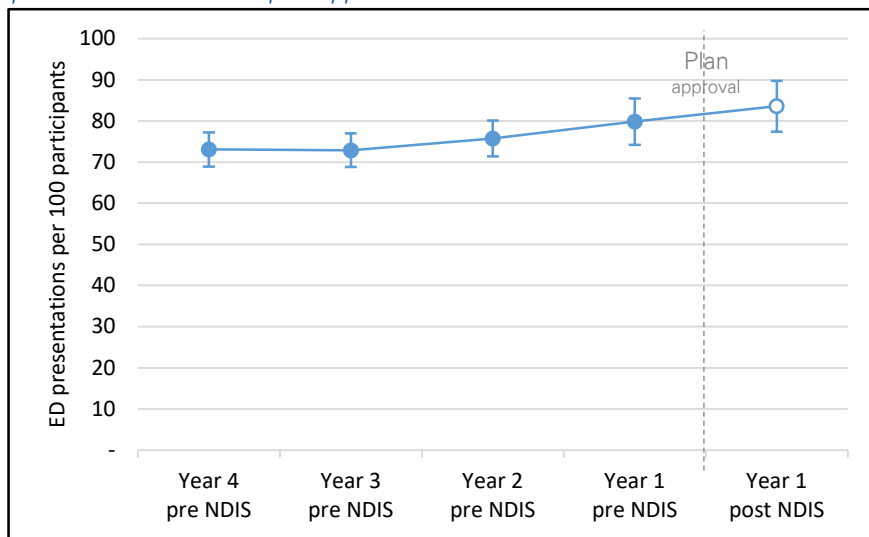
Additional points to note are:

- On average, about 30 per cent of participants presented to an ED at least once for each of the four years leading up to their NDIS plan approval. This statistic was very stable over the pre NDIS period.
- For the post NDIS period, 25 per cent of the cohort had presented at least once to an ED (however, this proportion underestimates the full 12 month use rate due to the available a full year of post NDIS data).
- For those who presented to ED, they averaged between 2.4 and 2.6 presentations per year pre NDIS, and 3.3 presentations per year post NDIS.
- The average cost per ED presentation over the pre NDIS period varied from \$721 to \$724. The post NDIS average cost per presentation was \$713.
- The estimated total cost to the health system of ED use by these NDIS participants varied from \$4.7m to \$5.1m per year during the pre NDIS period and rose to \$5.2m in the first year post NDIS.

It is important to note, however, that the Ministry's analysis found post NDIS changes in ED presentations were not statistically significant for any of the Year 1 LHDs other than Western Sydney. Specific sub-cohort analysis was also not undertaken given the limitations with the available data. Further investigation and ongoing monitoring of ED presentations, for NDIS participants overall and for sub-cohorts, will be explored in subsequent data analysis by Ministry of Health once the sample sizes are sufficient

4.3 Sector readiness and development

Figure 14: Number of ED presentations per 100 NDIS participants, by 12 month period# relative to NDIS plan approval date



*Number of presentations scaled pro rata to a full year for participants with less than 12 months of available data.

Source: NSW Ministry of Health linked data.

4.3 Sector readiness and development

The health system has had a limited role in building disability provider capability

The NSW health system has traditionally had a restricted role in working with disability support providers to build and maintain their capability to support people with disability – generally or specifically related to ‘health’ matters – and this has not changed since the NDIS commenced.

All NDIS registered providers in NSW are required to meet the NSW Disability Standards, and will be required to comply with a new nationally consistent NDIS Quality and Safeguarding Framework when it is introduced for NSW-based providers from July 2018. Providers will be required to demonstrate that they can meet the six current Standards, including demonstrating that they can support people with disability effectively, keep them safe and protect them from harm. The Disability Standards, and new Quality and Safeguarding Framework, provide for a minimum level of quality and capability required to support NDIS participants.

Providers also have more specific responsibilities with respect to monitoring and maintaining the health and wellbeing of the participants that they support. For some providers, this requires more specific capability in individual health care planning and monitoring. Providers may also be responsible for providing health related activities (such as administering regular or pro re nata (PRN) medication, percutaneous endoscopic gastrostomy (PEG) feeding and maintenance, monitoring blood glucose levels and administering insulin for participants with diabetes etc.), and it is important that they have qualified staff to undertake health-related activities safely and consistent with their areas of responsibility. These activities complement more complex supports provided by health professionals.

LHDs/SHNs and other health system stakeholders recognised that providers’ general capability to support participants, and their ‘health capability’, were important factors in keeping participants healthy and well, reducing the risk of unnecessary illnesses, injuries or incidents impacting on a person’s health, and in preventing unnecessary health service utilisation. However, despite some concerns relating to provider capability and risks for the health system, LHDs/SHNs largely did not see it as their role to build disability support provider capability, other than through clinician-to-clinician/service provider

relationships (e.g. as part of handover of care; shared care/support arrangements), and in the past had relied on ADHC to do this. Further, capability building was not seen as a priority for LHDs/SHNs, and would be difficult to provide within existing LHD resources. LHDs/SHNs noted that even if it were a priority, the number of non-government providers and the variability in expertise would mean capability building activities would be challenging and costly, not the best use of health resources, and may not be able to be offered to all providers.

LHDs/SHNs considered that providers themselves had primary responsibility for ensuring that they had the capacity and capability to support participants effectively, that they meet the required standards, and provided opportunities for their staff for relevant learning and development. Further, LHDs/SHNs highlighted other organisations who were better placed to work with providers to build their health and other capability (though there is no agreed position on respective responsibilities):

- In the broader health sector: Primary Health Networks (PHNs), individual primary care providers and clinicians, and Commonwealth Department of Health.
- Disability sector: primarily disability providers themselves, but also disability industry bodies (such as National Disability Services, NDS), the NDIA, and the NDIS QSC.

There have been some changes in disability support provider behaviour that impact what the disability provider will and will not provide, and this is further contributing to additional demands on the health system.

LHDs/SHNs highlighted examples of disability support providers changing their behaviour as a result of the introduction of the NDIS – in terms of the supports and activities that they are willing and not willing to provide, the participants they choose to support, and how they work with the health system in supporting participants.

A number of LHDs/SHNs raised numerous examples of provider behaviour changes which were having an impact on the NSW health system. These included:

4.3 Sector readiness and development

- Providers being more selective on who they will support and under what conditions, for example:
 - some SIL providers are less willing to accept a new SIL client (in a group home) without confirmation that the NDIA would adequately fund the SIL placement
 - SIL providers not being willing to accept a new SIL client where they were seen as complex or too costly to support (within available NDIS funding)
 - where there has been an incident with a client which results in utilising the ED and/or hospital admission, some SIL providers being less willing to take clients back into their care.
- Providers being less willing to provide 'additional' support beyond what they have been funded for, for example:
 - SIL providers being less willing to support a client (and hospital nursing staff) while the client is in hospital (as the NDIA will not pay for services provided while the participant is in hospital)
 - providers being less willing to participate in coordination activities, (e.g. case conference meetings with health and other providers).
- Providers no longer undertaking specific activities which are considered by the NDIA to be health-related (and which are not funded by the NDIS, e.g. catheter care, mealtime management, swallowing assessments).
- Providers being less willing to provide extra supports or 'go the extra mile', given concerns around the adequacy of some NDIS prices, concerns about occupational health and safety risks, their inability to move funding between participants to meet additional needs, and increased focus on the efficiency of their service provision.

It is difficult to determine or quantify the size or scale of impact on the health system of these behavior changes. From a qualitative perspective, LHDs/SHNs highlighted three main impacts on the health system:

1. Where providers are being more selective about who they will support and under what conditions, this was contributing to delays in discharge for some participants (and additional bed days), and can require additional clinician or discharge planner time in liaising with service providers to secure placements.
2. Where providers are less willing to provide 'additional' support beyond what they have been funded for, this was increasing demands on clinicians (particularly nursing staff in hospital, community nursing and allied health staff) to undertake these activities.
3. The withdrawal of specific health-related capacity and services previously provided by ADHC or ADHC-funded NGOs directly impacts on the health system in terms of additional demand on health services and resources. In some cases, this is also challenging health system capability where it does not have the required specialist staff or skills to provide these supports and activities (for example, mealtime management supports).

4.3 Sector readiness and development

| Issue | Risks to be managed | Strategies and actions for consideration | Responsibility | Priority |
|--|--|--|---|----------------------------|
| <p>The health system has concerns relating to the capability of some disability providers and the capacity to grow the required disability workforce</p> | <p>Inadequate disability market capability and workforce issues lead to poor practice and inadequate quality of supports for NDIS participants, which contribute to increased demand for health services</p> | <p>LHDs/SHNs and the Ministry continue to keep a 'watching brief' on disability market capability issues and emerging impacts on the health system (as per NMEOF), and document specific examples of preventable incidents and injuries with participants which have resulted in an avoidable NSW health system intervention. These matters could then be raised with the QSC (note that this would be over and above the existing mandatory reporting requirements relating to serious incidents)</p> <p>Ministry to continue to seek access to more detailed market and provider data from the NDIA than is currently available</p> <p>Provide guidance to LHDs/SHNs on how they can build their knowledge of the disability market, monitor and collect information on actual or emerging disability market capability issues and gaps and resulting health system impacts</p> <p>Where there are emerging issues that are LHD specific, seek to work with the regional NDIA office, local disability providers, local PHNs, HETI and the Ministry, to determine the types of health capability training or support that may be required, and how issues can be addressed jointly at a local level</p> <p>Explore options for LHDs/SHNs to extend LHD-focussed professional development and training opportunities held for health sector clinicians to disability practitioners where relevant, and where there is no additional cost for LHDs/SHNs (or where there are opportunities to recoup costs from external attendees)</p> | <p><i>NSW health system has primary responsibility (Ministry of Health, working with LHDs/SHNs and health system pillars such as HETI, ACI)</i></p> | <p>2 – Medium priority</p> |

4.4 Summary of findings – evaluation questions

The key themes and findings outlined in the previous sections can be aligned to the six evaluation questions which were the focus for this evaluation. Table 8 below links the key findings to each evaluation question:

Table 8: Summary of key findings for each evaluation question

| Evaluation question | Summary of key findings |
|--|--|
| <p>Question 1: What impact has the NDIS design had on the NSW Health system?</p> | <ul style="list-style-type: none"> • The introduction of the NDIS and changing role of ADHC has fundamentally changed relationships between the health and disability sectors and how they work together, and the NSW health system is taking some time to adjust to these changes. • While the APTOS outline the role and responsibilities of NDIS and mainstream agencies, there remains a lack of clarity around the respective roles and responsibilities of the health and disability systems at the operational level. • NSW Health is a member of NSW intergovernmental governance structures and arrangements and have had an active role in supporting the coordinated disability policy agenda. However, current governance arrangements are not always effective for timely resolution of matters with regard to NDIS operations and effectiveness. • NSW Health does not have a direct relationship with the NDIA State and National Offices which has impacted its ability to achieve timely resolution of operational issues. |
| <p>Question 2: How has (or should) NSW Health developed the capabilities of NGO providers to effectively support NDIS participants and prevent unnecessary health service utilisation?</p> | <ul style="list-style-type: none"> • The NSW health system has had to date a limited role in building disability provider capability. • There have been changes in the disability market since NDIS implementation, including a large number of new registered NDIS providers, particularly for allied health/therapy services. LHDs/SHNs have expressed concerns relating to the capability of some disability providers and the capacity to grow the required disability workforce and resulting risks for participants and the health sector. • There have been some changes in disability support provider behaviour that impact what the disability provider will and will not provide, and this is further contributing to additional demands on the health system. • Availability of a number of disability support types are contributing to pressures experienced by the health system – including availability of Specialist Disability Accommodation (SDA) (contributing to delays in discharge from hospital), and ECEI (contributing to pressures on paediatric health services). |

4.4 Summary of findings – evaluation questions

| Evaluation question | Summary of key findings |
|--|---|
| <p>Question 3: How have (or should) NSW Health services changed to accommodate the NDIS, or as a result of the transition to the NDIS?</p> | <ul style="list-style-type: none"> • The introduction of the NDIS represents a significant cultural change for the health system, and the health system continues to adjust to the new NDIS philosophy and approach and the changes resulting from the withdrawal of ADHC from direct service provision. • The health system has established internal governance structures, including a PMO and NDIS Working Group, to manage NSW Health’s transition to the NDIS. • The health system has established internal escalation processes to manage operational issues related to the NDIS. However, intergovernmental governance arrangements are not always effective for resolution of matters with regard to NDIS operations and effectiveness. • Changes to Community Care Support Program (CCSP) funding arrangements have impacted on community nursing/allied health services budgets, and there are a number of CCSP clients who remain with LHDs/SHNs due to being ineligible for the NDIS • Most LHDs/SHNs have a NDIS Transition Lead (either created from existing resources, or recruited specifically for the role) to facilitate the transition to the NDIS and adjustments at a local level. • Inefficiency and timeliness of NDIS processes are reported to be increasing the burden on NSW Health clinicians and services. • There are conflicting views on the respective role of the health system and the NDIS in facilitating hospital discharge for NDIS participants. |
| <p>Question 4: How has (or should) NSW Health supported people to access and participate in the NDIS?</p> | <ul style="list-style-type: none"> • The health system has a role in supporting NSW participants to access the NDIS – including supporting participants to connect with the NDIS and providing information and evidence. However, the role of NSW Health in this process has not been as expected and LHDs/SHNs report additional burden (in terms of time) for clinicians, particularly during the transition period. • Health clinicians contribute to various aspects of the participant pathway. However, there is a perception that health professional input is not always valued or recognised by NDIS assessors and planners. • NDIS support coordinators are not seen to be adequately connecting or coordinating health and disability supports for participants, and there is a difference in expectations and understanding of the support coordinator role between the health system, NDIA, and support coordinators. |

4.4 Summary of findings – evaluation questions

| Evaluation question | Summary of key findings |
|---|---|
| <p>Question 5: How adequate are safeguards used within the health system that protect people with disability participating in the NDIS?</p> | <ul style="list-style-type: none"> • There are relatively few safeguards within the health system specifically relating to supporting and protecting people with disability, over and above general patient safeguards. • There were some initiatives in place which sought to increase the capacity of a broader range of NSW Health clinicians to work with people with disability, including online training modules provided by HETI, specialized services and expertise (such as the Specialised Intellectual Disability Health Teams in three LHDs/SHNs, Agency for Clinical Innovation’s Intellectual Disability Clinical Network, and some Registered Nurse and Clinical Nurse Consultant positions which were disability-focused). • NDIS Transition Managers/Leads provide a central point of information and advice for clinicians and managers relating to the NDIS and broader disability matters. |
| <p>Question 6: How has NSW Health service provision been affected by the NDIS?</p> | <ul style="list-style-type: none"> • LHDs/SHNs consistently raised issues relating to delays in discharge in some circumstances and for specific NDIS participant cohorts: <ul style="list-style-type: none"> ○ People with newly acquired disability who require access to the NDIS and an NDIS package for the first time, and prior to discharge ○ NDIS participants with significantly greater support needs than before they were admitted, and who require a NDIS plan review to access greater levels of NDIS supports post-discharge ○ NDIS participants who require Specialist Disability Accommodation (SDA) for the first time, or who require a different SDA placement to be arranged prior to discharge. ○ NDIS participants who require home modifications to be completed prior to discharge • Health clinicians report significant waiting times to access the ECEI pathway, and increasing utilisation of paediatric health services for children with disability or developmental delay aged 0-6 years as a result. • At this point in time, there was some early quantitative evidence of a <i>decrease</i> in admitted patient OBDs and average lengths of stay for NDIS participants in Year 1 LHDs, in the post NDIS period. • There is no quantitative evidence of meaningful change in ED presentations for NDIS participants for Year 1 LHDs, though there are some changes for specific cohort groups. • There have been some benefits for some mental health patients and mental health services resulting from the inclusion of people with psychosocial disability needs in the NDIS. |

Section 5:
Future
considerations

5. Future considerations

Key outcomes of the evaluation

All governments and agencies involved in the design and implementation of the Scheme expected there to be challenges given the size and complexity of the reform. As expected, the Scheme remains relatively immature with a number of aspects requiring further development, in particular the growth and maturity of the support provider market and the NDIS workforce with regard to support planning and coordination. Further, in the rapid launch and transition to full Scheme, the necessary focus on access for participants and change to existing programs has meant that not all stakeholders have fully understood processes and roles and responsibilities.

The findings of the Interim Evaluation suggest, however, that NSW Health did not expect this degree of challenge or impact on the health system, and at this early stage of Scheme implementation this is resulting in some negative impacts on the health system. This is primarily related to:

1. Clarity – there remains a lack of clarity on the boundaries for decision making and associated delivery responsibilities between the NDIS and NSW Health. This is particularly impacting on NDIS eligibility and funding decisions.
2. Consistency – the evaluation identified numerous examples where the NDIA has been inconsistent in application of decisions which has resulted in an impact to both participants and NSW Health. Again, these decisions predominantly relate to eligibility and funding of particular services.
3. Communication – there is a need for more effective communication at all levels of the system, both within NSW Health, across NSW Government and between NSW government and the NDIA and the Commonwealth.
4. Culture – whilst a range of positive and constructive relationships are being developed between the NDIS workforce and the NSW Health workforce, these are relatively dependent on individuals and there is yet to be achieved a strong culture of mutual respect and partnership.

Future considerations

While the transition to the NDIS has been relatively complex and has given rise to a number of issues, there have also been substantial achievements for both the Commonwealth and NSW Governments. By the end of the transition period, 115,000 new and existing participants¹⁴ will have successfully transitioned to the NDIS in NSW, and NSW Government will have mostly transferred its direct specialist disability services to non-government organisations. Almost 37,000 new participants will be able to access disability supports through the NDIS who did not access supports under State-based arrangements, and some participants will be able to access a greater level and intensity of supports to better meet their needs.

The fundamental shift to a new, nationally consistent, person-centred approach to disability support will need time to evolve and mature. Other service systems also need time to adjust to the NDIS, and to broader changes in community expectations and government accountability.

NSW Government remains committed to a nationally consistent disability scheme that has the potential to achieve great value, both economic and social, for people with a disability. The NSW Government's focus is turning to preparing for full Scheme implementation from 1 July 2018. This includes the development of a NSW NDIS Full Scheme Delivery Plan which will confirm the anticipated social and economic benefits, outline a program of work and benefits realisation strategy for NSW agencies to optimise these benefits, with associated performance management and governance arrangements. This Delivery Plan is being developed by DPC together with cluster agencies (including Health). In addition, each cluster agency will also have a NDIS Delivery Plan for full Scheme implementation.

The findings of this interim evaluation will inform NSW Health's input into its NDIS Delivery Plan for full Scheme, and future considerations resulting from this evaluation will therefore be considered in the development of the Delivery Plan. There are a range of strategies identified in the key findings that look to address many of the associated impacts.

¹⁴ 115,000 was based on bilateral estimates. Based on experience of transition to date, the actual number of participants is likely to be fewer than 95,000

5. Future considerations

The key considerations below relate to those matters of more strategic purpose and urgency and include:

- Resolving policy boundaries relating to eligibility and funding.
- Improving communication channels and access to enable earlier identification and resolution of operational challenges.
- Aligning performance monitoring and analysis to benefits realisation and participant outcomes measurement.
- Continuing to evolve and improve analysis and monitoring of impacts and benefits through robust data analysis.

Resolving policy boundaries relating to eligibility and funding

The NDIS operates under a range of legislative and regulatory arrangements and agreements. Specifically, these arrangements seek to set out the differing roles, responsibilities and obligations of the NDIA, the Commonwealth and State and Territory Governments. The Interim Evaluation findings suggest that there remains further work to be undertaken to ensure clarity and consistency in understanding and decision making with regard to eligibility and funding boundaries. The Interim Evaluation findings suggest that the APTOS have, in some circumstances, not been consistently applied by the NDIA. This is impacting on the health system's understanding of its roles and responsibilities with respect to people with disability, particularly at the operational level, with risks that the health system will continue to provide 'disability-related' supports to NDIS participants, that should be funded through the NDIS, unnecessarily and at some cost. In the short term the following should be undertaken:

- As a priority, raise issues relating to inconsistent and variable decision-making through existing escalation pathways and governance structures, including NSW Government and cross-jurisdictional governance structures.

- Document, discuss and where necessary escalate issues relating to decisions made by the NDIA which, in the Ministry's view, are inconsistent with the APTOS.
- Seek to agree with the NDIA a process for discussing decisions which impact on the health system before they are finalised.
- Work with NDIA to determine how NDIA decisions on access and funding of supports (including the policies and/or rationale which underpin these decisions) can be more effectively communicated through the Ministry to health services.

In the longer term:

- Consider whether there is a need for a legislative change with the APTOS being made part of the NDIS rules, clearly articulating the distinct boundaries between the NDIA and mainstream agencies and who is responsible for funding what services and supports.

With clear boundaries, NSW Health can then realign its service offering to adapt to the NDIS conditions and requirements.

Improving communication and relationships

The governance arrangements in NSW were established for NDIS transition and will likely require some adjustment for full Scheme implementation arrangements. Given the dual role of NSW Health in full Scheme as both a service provider (recognising this is not, at present, a significant role) and key mainstream interface agency, it is likely that NSW Health will require some capacity to deal directly with the NDIA with regard to key operational matters to enable direct and timely identification and resolution.

It will be important for NSW Health to work with DPC and other jurisdictions' health agencies to design governance structures which are appropriate for full Scheme, and which provide for communication and engagement on full Scheme operations. This direct relationship should exist:

5. Future considerations

- at a strategic level, with senior NSW Health, NDIA and DSS officials
- at the operational/regional level, with senior LHD officials and NDIA Region Managers.

As these communication channels develop, it will be important to examine how existing relationships can be 'reset', moving towards relationships which are cooperative, collaborative, and based on mutual understanding and adherence to agreed roles and responsibilities.

Benefits realisation

There are a range of anticipated benefits for NSW Government and NSW Health resulting from the NDIS, both for NSW participants and for the health system. These include:

- increased social and economic participation for people with disability, their families and carers
- greater inclusion for people with disability
- savings for NSW Government from more efficient use of mainstream services, reductions in the lifetime costs of disability, better health and functional outcomes for NSW residents and more efficient health expenditures.

The NSW Government's NDIS Full Scheme Delivery Plan (currently under development) will establish a benefits realisation strategy for tracking and monitoring the achievement of intended NDIS benefits to NSW participants, NSW Government and the NSW community.

For NSW Health, benefits realisation will include:

- Being clear on the intended *benefits and outcomes* for NSW NDIS participants and the NSW health system from the NDIS (rather than a focus on costs and issues).
- Being clear on how benefits and outcomes can be measured and monitored over time, and how this measurement and monitoring can fully capture the value of the NDIS for participants and the health system.

- Developing a program of work for the health system to achieve benefits (consistent with and building on the broader NSW Government Program of Work).
- Embedding robust data analysis and measurement processes (for example, continuing and enhancing NSW Health's NDIS Data Linkage project).
- Working with other NSW mainstream agencies and other jurisdictions to maximise the collection and analysis of linked data to understand, measure and monitor the benefits and impacts of the scheme and to inform future planning.
- Identify and mitigate risks for both participants and the health system in the short-term and long-term.

Data and performance monitoring

Robust data and analysis will continue to play an important role in measuring the impacts, benefits and outcomes of the NDIS for the NSW health system over time, and also to monitor the issues, risks and costs for the health system in the short-term as the NDIS continues to evolve and mature.

The Ministry's existing NMEOF already provides a solid basis for this data analysis and monitoring, and it remains a valuable base on which to continue and improve data analysis and monitoring activities. Considerable work has also been undertaken by the Ministry in developing new data collections, progressing with further data linkage with NDIS data and including new NSW Health data sets in the data linkage, and incorporating an NDIS flag in health data systems. Results of initial data analysis conducted by the Ministry (and reflected in this report) is demonstrating some useful early findings.

In the short-term, continuing the Ministry's program of data linkage and analysis will mean that much larger and richer data sets will be available to identify post NDIS impacts and benefits. More powerful statistical analyses will be possible, allowing greater confidence in quantitative estimates of NDIS impacts on admitted episodes. In addition, access to activity based funding fields will allow those activity impacts to be reliably converted into cost estimates.

5. Future considerations

Further, and as noted earlier in this report, gaining access to the NDIA's data governance framework and data dictionary, and pursuing opportunities to work more closely with the NDIA on data issues, will also improve the quality and robustness of the data linkage and analysis.

In addition, it is noted that the NDIA has a legislative basis for allowing others to use NDIS data, and the recent Productivity Commission report recommends the establishment of national policies for data sharing. National data sharing policies and mechanisms will provide more consistent and comparable information across mainstream services and jurisdictions, and across administrative data collections, and allow for more robust monitoring and evaluation activities to be undertaken

Appendix A:
Stakeholder
consultations

Stakeholder consultations

| Category | Organisation | Stakeholders consulted |
|------------------|---|--|
| Year 1 LHDs/SHNs | Central Coast | Chief Executive Officer (CEO); Executive Director of Strategy and Innovation; Acting Executive Manager of Central Coast Integrated Care Program; Physiotherapy Manager; Health Service Manager of Ongoing and Complex Care |
| | Hunter New England | Directors of Operations, Mental Health, Workforce Allied Health, and Greater Metro Services |
| | Justice Health and Forensic Mental Health Network | Executive Director of Clinical Operations; Acting Co-Director of Forensic Mental Health; Coordinator of Cognitive Disability Services, Forensic Health; Network Director of Nursing & Midwifery Services; Acting Co-Director of Services & Programs |
| | Nepean Blue Mountains | Director of Allied Health & Community Programs; General Manager of Primary Care & Community Health; Lead Clinician of Occupational Therapy; NDIS Coordinator Manager of Allied Health |
| | Northern Sydney | Head of Primary Health; Directors of Allied Health, Nursing and Midwifery, Operations, Mental Health; Manager of Health Services Planning; NDIS Transition Manager |
| | South Western Sydney | CEO; Directors of Allied Health, Mental Health, Operations, Finance, Brain Injury Unit; General Manager of Hospital; Service Manager of Aged Care & Rehabilitation; Clinical Director of Aged Care & Rehabilitation; Pathways to Community Living Initiative (PCLI) Project Manager; Nurse Manager; NDIS Project Officer |
| | Southern NSW | Executive Director of Clinical Governance; Directors of Mental Health, Finance, and Nursing and Midwifery; General Manager of Integrated Care; Manager of Women's Health |
| | St Vincent's Health Network | Director of Allied Health and Community Services; Manager of Nursing; NDIS Transition Manager |

Stakeholder consultations

| Category | Organisation | Stakeholders consulted |
|------------------|------------------------------------|--|
| Year 1 LHDs/SHNs | Sydney Children's Hospital Network | CEO; Clinical Program Directors of the Children's Hospitals at Westmead and Randwick; NDIS Transition Manager; Area Director of Mental Health |
| | Western Sydney | Executive Directors of Mental Health, Nursing & Midwifery, Integrated & Community Health; Director of Strategic Business Development and Commercial Services; General Manager of Hospital; |
| Year 2 LHDs/SHNs | Far West NSW | CEO |
| | Illawarra Shoalhaven | Executive Director, Integrated Care, Mental Health, Planning, Information and Performance; Director of Allied Health; Mental Health Services; Co-directors of Physiotherapy, Occupational therapy, Speech pathology, Primary health care; Project Lead of Ambulatory and Primary health care |
| | Mid North Coast | CEO; NDIS Transition Lead; Directors of Mental Health, Finance, and Nursing; Discharge planner; Head dietician; Occupational therapist in charge; Speech pathologist |
| | Murrumbidgee | CEO; Director of Allied Health, Subacute and Aged Care; Director of Operations; NDIS Project Manager; |
| | Northern NSW | NDIS Transition Manager; Director of Integrated Care and Allied Health; Manager for Community and Allied Health; Representative of Grafton Hospital; Manager for Lismore Base Hospital |
| | South Eastern Sydney | Clinical Coordinator of Intellectual Disability, Director of Child, Youth and Family Services, Manager of Disability Strategy, Manager of Aged Care |

Stakeholder consultations

| Category | Organisation | Stakeholders consulted |
|--------------------------|--|---|
| Year 2 LHDs/SHNs | Sydney | Chief Executive; NDIS Transition Managers |
| | Western NSW | Executive Director of Allied Health & Innovation; NDIS Transition Manager |
| Ministry of Health | Aboriginal Health | Director, Centre for Aboriginal Health; Manager, Centre for Aboriginal Health |
| | Communications | Executive Director, Strategic Communications and Engagement |
| | Health and Social Policy | Executive Director, Health and Social Policy; Director, Priority Programs; Director, Maternity, Child, Youth and Paediatrics; Clinical Lead, Child and Family Health; Manager, Aged Care Team; Manager, Primary and Community Care Team |
| | Health System Information, Performance and Reporting | Executive Director, Health System Information, Performance and Reporting; Director, Information Management and Quality; A/Director, Systems Integration Monitoring and Evaluation; Senior Project Manager |
| | Mental Health | Director, Community Partnerships; Principal Policy Officer, Mental Health |
| | Workforce and Planning | Executive Director, Workforce Planning and Development; Director, Workforce Policy and Development; Clinical Lead, Allied Health |
| PHNs | Central and Eastern Sydney | General Manager; Manager of NDIS Transition |
| | North Coast | CEO |
| NSW Health organisations | Ambulance NSW | Executive Director, Business Innovation & Planning; Director of Clinical Innovation; Health Service Manager |
| | EnableNSW | Manager, EnableNSW; Clinical Advisor; NDIS Transition Lead; NDIS Transition Manager |

Stakeholder consultations

| Category | Organisation | Stakeholders consulted |
|---------------------------|---|--|
| NSW health system pillars | Agency for Clinical Innovation | Director, Primary Care and Chronic Services; various Network Managers (Burn Injury Network, Intellectual Disability Network, Rehabilitation Network, Spinal Cord Injury Network, Respiratory Network, Mental Health Network, Stroke Network) |
| | Bureau of Health Information | Director, Surveys |
| | Health Education and Training Institute | Senior Program Officer of Allied Health, Professional Practice & Interprofessional Collaboration |
| Consumer peak bodies | Being | Policy representative |
| | Carers NSW | Policy representative |
| | Council for Intellectual Disability | CEO |
| | First People's Disability Network | Policy representative |
| | People with Disability Australia | Policy representative |
| NDIA | National Office | General Manager of Operations; Expert Advisor - Mainstream Interfaces; Special Advisor |
| | Service delivery | State Director NSW/ACT; Selection of planners |
| LAC providers | Social Futures | CEO |
| | St Vincent de Paul | Community Engagement Coordinator of Local Area Coordination Program |
| | Uniting | Director |

Stakeholder consultations

| Category | Organisation | Stakeholders consulted |
|------------------------------|-----------------------|--|
| Disability service providers | Disability Trust | CEO |
| | Flourish | CEO |
| | Life Without Barriers | Business Partner, Disability Reform |
| | Lifestart | CEO |
| | Northcott | CEO; Executive manager |
| NSW Government | DPC | Executive Director - NDIS Reform Group |
| | FACS | Executive Director - NDIS Transition |



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