



The Royal Children's Hospital submission for to the NDIS Joint Standing Committee inquiry into Transitional arrangements for the NDIS

The Royal Children's Hospital has been actively reviewing its response to the rollout of the National Disability Insurance Scheme (NDIS) and has established a project to investigate and manage the transition of services which may be impacted by the implementation of the NDIS. During the course of the project a consistent range of issues have been identified and discussed and The Royal Children's Hospital (RCH) welcomes the opportunity to make this submission to the Joint Standing Committee on the NDIS.

Input during the transition has provided by leaders in the areas of:

- Early Intervention
- Neurodevelopment
- Rehabilitation
- Continence
- Nutrition
- Allied Health
- Finance
- Business Management
- Service Improvement

Professionals with training in the following disciplines have been actively involved:

- Physiotherapy
- Speech Pathology
- Nursing
- Dietetics
- Paediatrics
- Public Health
- Rehabilitation
- Prosthetics

The boundaries and interface of NDIS service provision, and other non-NDIS service provision, with particular reference to health, education and transport services

It is suggested that the National Disability Insurance Agency (NDIA) establish a framework around the services and categories that are covered by the NDIS. This would help inform plan discussions, provide clarity for providers as they develop evidence-based supports that are eligible for consideration within a plan, and prepare to be ready to meet the needs of NDIS participants.

The differences between what the NDIS deems covered under health and what is eligible under disability is unclear. Areas identified by the RCH as needing clarity include:

- Rehabilitation – at what point does acute rehabilitation cease and longer-term rehabilitation begin?

- Patients with complex care require differentiation between the impact of chronic disability and acute care requirements. This has a bearing for the NDIS in discerning what areas of care are funded under ongoing disability as opposed to immediate health related issues.
- Patients with nutritional needs e.g. what is to be covered for NDIS participants with a requirement for enteral feeds to meet their nutritional needs.
- Whether the impact of chronic illness is considered a disability, e.g. if the condition is not primarily one that impacts the neuromuscular system but has a major impact on ability to engage in activities, education and participate in the community.

The current lack of clarity on the differentiation between health and disability results in inconsistencies in participant plans. For providers uncertainty surrounding funding for services makes strategic planning difficult.

The RCH and Murdoch Children's Research Institute (MCRI) have expertise in all of the areas listed above, as they pertain to children and young people, and also a clear understanding of current Victorian funding pathways. Both the RCH and MCRI would welcome the opportunity to provide further input to develop the clarity that will be of benefit to participants and providers alike.

The consistency of NDIS plans and delivery of NDIS and other services for people with disabilities across Australia

While not including providers in planning meetings may avoid conflicts of interest, this approach can have consequences for NDIS participants who may not be skilled at advocating for themselves. Additionally, inconsistencies in levels of planner knowledge regarding clinical issues, can lead to widely varied judgements of need and/or capacity. By allowing providers the opportunity to participate in planning meetings inconsistent judgments could be mitigated. An alternative or additional measure might be for planners to seek answers to specific queries from providers. This could assist in the construction of plans which are both clinically appropriate and cost effective.

Plan consistency

The RCH has seen examples of plan inconsistency, with some plans providing in excess of a child and family's needs and others failing to make adequate provision. Four possible causes for the inconsistency are:

- Lack of detailed knowledge of the disabilities planners are seeing and how the needs of a participant may vary based on their age and ability.
- Lack of clarity about what is provided by the NDIS, versus from other sources including health and education (as described above).
- Insufficient planner knowledge or NDIS direction regarding evidence-based strategies and supports to address participant needs.
- Variation in parent/carer ability to articulate their child's needs in a way that is relevant to NDIS planning.

We understand that not all planners can have an in-depth understanding of the full range of disabilities, functional variation within them and the way needs change with varying severity, ability and age. However, a clear decision-making model that is available for planners, participants and those providing information to the NDIS would reduce inconsistency and create plans that meet the needs of participants. We are keen to contribute to development of a decision model for infants, children and young people to improve this process.

For example functional assessment components required for eligibility and planning are not currently part of diagnostic assessments as funded by health, but could efficiently be included in diagnostic assessments with a small increment of funding. By making an additional investment, existing services can be leveraged to create a more thorough assessment plan that could be linked through a decision model to an NDIS plan and pathway which will assist the NDIS in being able to

deliver appropriate cost effective interventions and supports for participants. This would in essence provide the 'missing link' of information.

Delivery of NDIS services

We have experience with some plans listing interventions and support services that are not evidence-based e.g. animal-assisted therapy has been provided as part of plans for children with autism. If non-evidence-based therapies are provided at the expense of evidence-based interventions, this may create a perception of the misuse of public funding could arise. Participants could also miss opportunities for effective interventions.

We are concerned about the provision of non-evidence-based therapies because there is the potential for an 'opportunity cost' to be incurred by the NDIS both financially and in terms of the effectiveness of the program.

The rollout of the Information, Linkages and Capacity Building Program

There is a need for information to participants and professionals to be 'fit for purpose' to allow for informed decision making. Currently much of the visible material that is available is positioned at a basic level (e.g. the explanation of service agreements) which, while useful for participants who may struggle intellectually, is of low utility for providers and professionals.

Materials for Cultural and Linguistically Diverse (CALD) participants also need to be created and be readily available for participants and providers. Failure to have such material available risks disadvantaging participants from CALD backgrounds.

Further development of smartphone applications to enable participant accessibility to information is strongly encouraged. Many lower income RCH patient families do not have access to a desktop or laptop to access online material. Developing smartphone applications would go a long way to further enabling participants to manage their use of the scheme more effectively, exercise greater autonomy, and reduce inadvertent widening of the disadvantage gap.

The level of interaction and transparency between State and Commonwealth appears to be suboptimal and at times opaque. Data sharing and linkages need additional work to allow for better communication between State and Commonwealth counterparts. Currently the lack of data sharing between the various branches of State and Commonwealth government agencies creates a substantial workload (with further cost implications) for providers.

The level of 'whole of government' engagement is suboptimal, as described above in the section about boundaries between health and disability. For many children and young people with an eligible disability, and for their families, their opportunities and productivity will be maximised when services are provided in a seamless way between relevant government portfolios (health, education, disability and community services). Identification of the ages, stages and types of children and young people that would benefit the most from a 'whole of government' approach would be an excellent next step for NDIS to initiate, on the path to minimising duplication of services and maximising delivery of cost-effective interventions and supports.

Access requirements to the NDIS MyPlace portal and the ensuing administrative processes are confusing and do not take into consideration the needs of larger scale organisations with increased levels of internal bureaucracy. A review of the portal and the needs of larger scale organisations should be prioritised.

Other related matters

While the NDIS is attempting to shift thinking and practice toward functionally based services, the eligibility criteria as listed in current NDIS documents are very diagnosis focussed. The mixed message this provides is slowing progress towards a model that is informed by diagnostic

knowledge of predicted life course, and optimises interventions and supports based on functional needs.

The presence of some diagnoses and not others could also be perceived as discriminatory. An opportunity to prevent disability by including infants who are at high risk of a disability is also missed with the current eligibility approach. More specifically, we have noted that some of the tests cited in the eligibility questionnaires currently being used are out of date (e.g. references are made to DSM 4 which is no longer current, now replaced by DSM 5). We would be happy to be consulted about eligibility criteria that might be suitable for NDIS for infants, children and young people.

Large health care providers are well placed to deliver interventions and supports that will be part of the plans for NDIS participants in a cost effective way. They are also well placed to provide seamless care that is required between health and disability for the participants who will need both. Many of the interventions and supports now to be provided by NDIS funding have been provided by large health care providers, with funding streams from state disability services or education, for many years.

Currently, however, the path towards becoming an NDIS provider is fraught with complexity. As organisations struggle with various financial, organisational and clinical issues there is an increased risk that public health care providers may choose not to provide services.

Making funding available to large healthcare providers to support data analysis and the development of the systems necessary to service NDIS participants will help leverage existing services and ensure continuity of care. Failure to make funding available to large scale public healthcare providers increases the risk that providers will not be able to make informed strategic decisions regarding participation within the NDIS.

This would result in substantial negative impacts for NDIS implementation, a loss of expertise in service provision, further divisions being developed between health and disability, and a missed opportunity to increase well-coordinated care. These will in turn increase costs for NDIS and other government departments. We would be happy to provide further insights and to participate in the development of processes relevant to large public healthcare providers.

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