

National Disability Insurance Scheme (NDIS) Costs, Productivity Commission Position Paper

RACP Submission

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Introduction

The Royal Australasian College of Physicians (RACP) is supportive of the NDIS and its aims. We welcome the *Productivity Commission's* review of the Scheme's costs as an important step in ensuring sustainability and providing certainty to Australian's living with disability.

Physicians and paediatricians have a strong interest in promoting the health and wellbeing needs of NDIS participants, and the role the NDIS will have in supporting the health and access to health care of people living with disability. Physicians and paediatricians are well placed to provide assessment, recommendations and advice to patients and their parents around the types of NDIS supports that are important in improving or maintaining their health.

The NDIS does not replace mainstream health services however, under its health and wellbeing domain, it will be integral to ensuring that health care plans are carried out, and that participants have access to sufficient and appropriate health care.

The *Position Paper* identifies many of the challenges facing the scheme in its rollout, effectiveness and sustainability. The *Commission* has correctly identified that a greater focus on market development, planning processes and supporting infrastructure is required to ensure the success of the NDIS.

Recommendations

The RACP makes the following recommendations for the Productivity Commission to consider in its final report on the NDIS:

On the roll out of the NDIS:

- The rollout should be slowed as necessary to ensure that each new and existing participant can undergo effective and comprehensive planning, and receive necessary interventions throughout this process;
- Planners should be educated in the principles of co-design to ensure that plans are truly person-centred and reflect their needs;
- Information, Linkages and Capacity (ILC) services should be fully funded during the NDIS rollout transition period;
- Ensure that people who have limited English are provided with interpreters and that people with communication difficulties, including intellectual disability, are provided with communication supports such as easy-read literature; and
- Procedures must be in place to protect NDIS participants from abuse, and effectively address abuse where it has occurred.

On the intersection of the NDIS and mainstream services:

- A better developed and communicated understanding of the intersection between the NDIS and mainstream services to improve outcomes and avoid cost shifting is needed;
- Governments must work with the NDIS to ensure that clear boundaries exist around who provides disability services, and that non-NDIS services are only withdrawn once an NDIS plan is fully implemented;
- A specific examination of the intersection between the NDIS and rehabilitation medicine health services should be undertaken; and

- Better communication around the linkages between the NDIS and vocational rehabilitation services would help crystalize some of the Scheme's benefits.

On the intersection between the NDIS and aged care services:

- The NDIA must work with aged care services and their funding bodies to ensure a two-tiered system of care standards for people living with disability over the age of 65 does not emerge; and
- Clarification of the NDIS eligibility status for people living with early-onset dementia is important.

On the disability services workforce and evidence-based interventions:

- Ensure that the growing disability services workforce reach minimum standards of knowledge and qualification in helping those they care for to maintain and improve their health:
- Regular assessment of the implementation of the NDIS, and the performance of service providers:
- A consistent and regularly-reviewed focus on funding only evidence-based supports; and
- The inclusion of outcomes measures in baseline assessments, before plan implementation, and at annual reviews:

On Early Childhood Early Intervention (ECEI):

- The Early Childhood Early Intervention (ECEI) approach should be made available for children recognised to be at risk for developmental delay/disability, and inclusive of therapeutic intervention for children who require it;
- Introduction of "immediate response" policies and procedures will ensure support for children with significant changes or deterioration in skills or behavior is provided to prevent loss of placements;
- Introduction of expert resource teams to support services where the needs of children are highly complex will ensure providers can meet a child's support needs; and
- Ensuring planners have sufficient expertise to understand the types of supports needed to support children with high or complex needs, particularly those with developmental disabilities or challenging behaviours.

On eligibility criteria:

- To provide clarity to people living with disability, we recommend a review of the eligibility criteria for people living with a psychosocial disability; and
- A review of the eligibility criteria for adult onset physical health conditions associated with fluctuations and progressive decline.

The NDIS Rollout

The Commission has noted that "Good planning processes are essential for the long-term sustainability of the NDIS." Anecdotal information indicates that an excessive focus on meeting intergovernmental-agreed timelines on participant intakes has come at the expense of quality in individual NDIS plans. Issues have included phone contact with little or no warning or pre-planning, no in-person assessment of a participant's living arrangements and use of language that implies to a participant the conversation's purpose is to gather information, but is used to make key decisions about their plan. Further, the brevity of some calls is particularly problematic for participants with language, speech or cognitive issues. The Commission's Position Statement' has appropriately identified many of these issues.

At present there appears to be an unequal balance of power between the planner and the participant and their carers in the development of plans. There is also inconsistency across plans for those with similar disabilities, indicating that people living with disability who are or have effective advocates are likely to receive more comprehensive plans. Planners should be educated in the principles of co-design to ensure that plans are truly person-centred and reflect their needs. There are other concerns around the planning process, such as a lack of awareness of the right to a face-to-face planning meeting, and an overreliance on phone meetings. Participants should have the option to discuss their plans with their health professionals offered by default, to ensure their health and wellbeing needs are being met by their plan.

As the *Commission* notes, Information, Linkages and Capacity services that direct NDIS participants and those living with disability who are not eligible for the NDIS to mainstream services like health are critical. We agree with the *Commission's* recommendation to increase ILC funding during the NDIS transition period to the full \$131 million per year, an amount not currently planned until 2019/20. It is important that the suggestion to divert these funds from the National Disability Insurance Agency's (NDIA) program delivery budget does not result in inadequate funds being available to other parts of the Scheme.

The intersection of the NDIS and other mainstream services

There is still confusion as to how some intersections between the NDIS and other mainstream services will function. This is key to the financial sustainability of the NDIS, but also to the outcomes of its participants, who are at risk of falling between cracks in care systems. This will require the NDIS and NDIS providers to have a comprehensive understanding of the health, housing and other social services available in their area. It will further require NDIS providers to be aware of admission and discharge procedures to services including hospitals – in turn other services will need to make reasonable adjustments to ensure smooth procedures and communication between themselves and NDIS providers. The improved understanding of the intersection between the NDIS and other services should lead to a reduction in cost-shifting.

The interface between the NDIS and other disability services is critical for participant outcomes and the financial sustainability of the scheme. Some disability supports are not being provided because of unclear boundaries about the responsibilities of the different levels of government. Governments must set clearer boundaries at the operational level around 'who supplies what' to people with disability, and only withdraw when continuity of service is assured.

This collaborative approach at the coalface to improve health outcomes is important for rehabilitation services dealing with people with newly acquired disability. That includes those in and recently discharged from inpatient rehabilitation units, and acknowledging the differing needs of this group compared to people living with disability who are well-established and living in the community. It may be that this collaboration leads to NDIS planning processes and timelines being adjusted to ensure that people with newly acquired disability have a seamless and efficient transition from

health and rehabilitation services to the community and NDIS participation. Rehabilitation is integral to many people living with acquired disability, and it is important that collaboration between the NDIS and rehabilitation medicine services is comprehensive.

Another related point of intersection will be between the NDIS, participants living with disability, and vocational rehabilitation services. One of the stated aims of the NDIS is to support people living with disability to fully participate in their societies, including through employment. Returning to the workforce is important, but the position statement does not fully address linkages with agencies with expertise in returning those with disabilities to appropriate work.

The intersection between the NDIS and aged care services

The NDIS is anticipated to provide the option to transition adults living with a disability into aged-care services from the age of 65. The Position Paper notes that the NDIS provides participants with flexibility to continue as an NDIS participant after 65, though not once they enter an aged care facility or permanent home-care arrangement. It should be clarified whether Aboriginal and Torres Strait Islander people living with a disability have this option from the age of 50, as they do with Commonwealth Continuity of Service arrangements.

The largest population living with disability in Australia (those over 65) are excluded from joining the NDIS. It is important to note that disability over the age of 65 is very real, and not simply a normal component of the ageing process. The NDIA needs to work with aged care services to ensure that a two-tiered system does not emerge, whereby some people living with disability over 65 receive needs-based services under the NDIS, and others receive aged care services that are sometimes capped or means-tested.

Anecdotally, our Members have found there is confusion amongst patients living with disability as to their options upon turning 65. There is also conflicting messages as to the opportunity for people with young-onset dementia to access the NDIS (though they appear to be technically eligible).

The disability services workforce and evidence-based interventions

It is important that expectations around the growth of the Australian disability workforce are realistic – it is estimated that one in five new jobs created in Australia in the next few years, will be in the disability care sector. This workforce will need qualifications, knowledge and understanding of specific medical and health issues of individual clients of sufficient level to deliver services that maintain and improve their health. The emerging workforce will need to be monitored and regulated to ensure that baseline standards of competency are established and maintained. It is also important to ensure that the disability services workforce does not simply cannibalize the workforce of related industries, such as aged care.

We are concerned by the lack of focus on the importance of all NDIS-funded services being evidence-based. Whilst alluded to, it is important the *Position Statement* clearly and persuasively argue that all treatments funded by taxpayers have a compelling, peer-reviewed evidence base supporting them. Individuals living with disability should be free to select those services that most suit their needs, however both they and the NDIS' limited funding pool should be protected from therapies that can:

- Negatively impact outcomes;
- o Take the place of evidence-based treatments; and
- Lead to cost blowouts.

Even in the best case scenario, funding supports that are not evidence-based will result in participants failing to reach the full potential offered by the NDIS.

We do support the *Position Statement's* focus on the need for the NDIS to be consistently reviewed to ensure quality in service delivery, outcomes measurements, and cost-effectiveness. Outcomes measures should be an integral part of baseline assessments, before plan implementation and annually at each plan review. Data collection on who is in the scheme and what services they are receiving and their costs should be a key priority, and is critical to sustainability. Programs to assess the implementation of the NDIS and outcomes for participants should be robust. For example, requirements for service providers are not always consistent. These should be readily available and accessible for providers, and NDIS participants, to help ensure all providers and service providers that employ them are fully qualified and accredited.

Early Childhood Early Intervention

ECEI has led to a more accessible first point of contact for families and young children showing signs of developmental delay and in need of disability supports. There are concerns that the key worker model can present limitations when a child requires professional specific assessment, advice and therapy. Anecdotally, some of our Fellows have seen instances where families are directed to external, private therapists. This is becoming burdensome for families who need to engage multiple service providers in order to meet their child's needs. It is important that NDIS providers offering the key worker service also be in a position to provide these specific therapeutic services as part of the ECEI package.

Introduction of "immediate response" policies and procedures to ensure support for children with significant changes or deterioration in skills or behavior is provided to prevent loss of placements and to address circumstances such as an unanticipated and significant deterioration in skills or functionality. This is also relevant for young people and adults with disability. It is important that children living with disability and their families have a clear understanding of their eligibility for the NDIS, and their pathway to participation.

There are substantial risks that those with high or complex support needs will not be met by the NDIS under its current models of service. This is especially the case for those with developmental disabilities, such as intellectual disability or autism, and challenging behaviours. As a "hidden disability" planners may not understand the type of supports needed and include insufficient funds to properly meet needs. Some non-government organisations do not have sufficient experience to address aggressive or violent behaviours, complex behaviour presentations, coexisting issues in the family such as stress, mental health problems, or instability in family membership. The NDIS must ensure that families do not relinquish care, see their services suspended or get abandoned to mainstream services such as health.

Eligibility for the NDIS

At this stage, 6 per cent of NDIS participants fulfil eligibility criteria in the area of psychosocial disability. Concerns have been raised about the definition of 'permanency 'for this disability. This is incompatible with recovery models used in supporting people living with psychosocial disability. The recovery model of mental health is focused on building capacity. Periods of severe disability may still occur. The eligibility criteria need review if the intention is for people living with psychosocial disability to be able to enter and exit the scheme, with ongoing support during and prevention of periods of impairment. The current criteria limit this ability.

Adult onset physical health conditions associated with fluctuations and progressive decline that are likely to lead to significant functional impairment and increased support needs should also be considered. Examples include motor neurone and Huntington's disease.

Other comments

Beyond the above issues, we would like to note our appreciation that the Productivity Commission has highlighted the following:

- Recognition that in some circumstances people living with disability and their families are paying more for certain supports through the NDIS than under their previous arrangements;
- The importance of setting maximum prices for some supports, noting that some of these prices remain high;
- Greater than expected variability in package costs for similar conditions, potentially reflecting a lack of consistency in planners' decisions; and
- Significant dissatisfaction with phone planning, as well as a lack of awareness of participants' rights such as the right to a face-to-face planning meeting.