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**RACP Submission to the National  
Disability Insurance Scheme (NDIS) Act  
Review and Participant Service Guarantee  
(Tune Review)**

October 2019

## Overview

The RACP trains, educates and advocates on behalf of over 17,000 physicians and 8,000 trainee physicians, across Australia and New Zealand. The College represents a broad range of medical specialties including general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine, and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients, including the role the NDIS will have in supporting the health and access to health care of people living with disability. Rehabilitation medicine 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 RACP has contributed physicians' perspectives and expertise at various stages of the NDIS roll-out across Australia, also assisting to equip physicians and paediatricians with the skills and knowledge to work effectively within the new NDIS model and support the delivery of high-quality care to their patients with disabilities. To achieve this aim, in 2017 the RACP launched a comprehensive online resource for medical specialists, available at [www.racp.edu.au/ndisguides](http://www.racp.edu.au/ndisguides), to provide practical, user-friendly information on topics including eligibility, planning and funded supports. The RACP also has a specific position statement on [Health and the National Disability Insurance Scheme](#).

The RACP strongly supports the NDIS, its underlying values and principles, including individual autonomy, non-discrimination, and full and effective participation and inclusion in society. We recognise and support the principle that the NDIS is a patient-centred framework where participants are responsible for determining their goals and the kinds of support they need to achieve those goals. This has the benefit of allowing participants to decide what they want from this support.

The RACP recognises that physicians can play an important role in providing people living with disability with information about the NDIS, linkages and capacity building (ILC), and about the types of therapies, interventions and supports that will assist them in meeting their goals and maximising their participation in their community. We also recognise that the health sector has an important role to play in providing care to NDIS participants and people with a disability, and that currently there are occasions of poor provision of care. People with intellectual disability in particular experience higher rates of preventable in-hospital mortality and morbidity. We recognise that this is totally unacceptable, and that the health sector must do more to address this.

This submission responds to select questions from the discussion paper that the RACP can provide comment on, based on responses received from RACP Fellows.

## Executive summary and recommendations

While the RACP supports the underlying principles and objectives of the NDIS, RACP Fellows have identified a range of issues emerging in the scheme.

The NDIS is complex, hard to navigate and access is highly variable, particularly for vulnerable groups. Participants must be sufficiently supported to engage adequately throughout the process, from access application, to goal setting, planning and the review and appeals processes. RACP Fellows have identified a range of gaps and complexities which occur throughout these stages.

The RACP calls on Commonwealth, State and Territories Governments to:

- clarify the roles and responsibilities of health and disability services in identifying adults and children in need of diagnostic or care needs assessment, particularly in remote and rural areas;
- provide a health care provider initiated entry pathway into the NDIS to improve the timeliness of the application process and ensure that participants and their families, who are often under time and financial pressure dealing with the disability, have support in navigating a complex system. Invest in the development of integrated, interagency models of care that will ensure that people and their families don't need to retell their stories repeatedly; effectively coordinate intervention, especially for those people with complex needs or vulnerabilities.
- ensure that vulnerable groups, for example children in out-of-home care, who were given priority access under previous schemes, do not experience undue delays in accessing NDIS funded services;
- fully implement the National Framework for Quality and Safeguards in order to protect NDIS participants from potential abuse by service providers;
- ensure that planners and service providers are supported to develop sufficient expertise so that they may provide adequate support for participants with high or complex needs, particularly those with developmental or intellectual disabilities or children with challenging behaviours

The RACP calls on the National Disability Insurance Agency (NDIA) to:

- work with health system clinicians to clarify definitions that relate to the interface between health services and the NDIS for participants with ongoing disability, particularly around eligibility - for example "at risk";
- support prospective and current NDIS participants to obtain advice from physicians and paediatricians on diagnosis and management of disability and any health concerns. Examples include:
  - developmental delay and other developmental disabilities
  - participants with a life-limiting condition who may require access to specialist palliative care;
- provide planners with information and training to support NDIS participants' goals under the NDIS' Health and Wellbeing outcome domain, including an understanding of what it means to live a healthy life, and a working knowledge of the health system;
- incorporate processes into the NDIS system that ensure NDIS planners and access partners consult and, when appropriate, work with the patient's physician(s) in developing and reviewing support plans to ensure that plans are comprehensive and address every area of impairment where support is required. This includes disseminating plans and other information with the person's or carer's consent.
- support people with deteriorating or fluctuating conditions, whose level of support needs may vary over time;
- provide clear and up-to-date information for health professionals on the operation of the NDIS, to inform the support that those professionals may give to NDIS participants and carers attempting to access services
- ensure fair, equitable and timely access to the NDIS for eligible people living with disability and with increased vulnerability or additional challenges. Processes should respond to an individual's level of need, including those:
  - in the criminal justice system
  - at risk of maltreatment and abuse
  - in remote and rural areas
  - who are parents and also live with disability
  - who have family carers with coexisting mental health problems
  - from Aboriginal and Torres Strait Islander communities
  - from culturally and linguistically diverse (CALD) backgrounds
  - who are refugees and other recent arrivals

- children with developmental delay or disability
- adolescents and young adults in the transition period from children’s to adult services
- who are in out-of-home care or under a public guardianship
- ensure that practices and therapies funded by the NDIS are evidence based, explicitly goal-directed, and accountable to meaningful, measurable outcomes over set timeframes;
- improve the provision of plain English information or alternative communication tools to address difficulties understanding medical terminology, likely processes and risks and benefits of treatment, including access to interpreters when required.

## Possible principles for NDIA service standards

The RACP supports the development of principles to guide the standards of service that the NDIA provides. We believe these standards need to specifically address reducing barriers to being assessed as an eligible participant in the NDIS. These barriers are broader than timeliness, and include:

- limited understanding of the role of health professionals in supporting access applications (for example, knowing what information is required in letters of support, and which clinicians and allied health professionals are responsible for providing this);
- lack of transparency for patients and clinicians in how the NDIS access applications are assessed by the NDIA
- confusion over eligibility requirements, for example whether a diagnosis is required
- lack of clarity about what information is required and from whom.

On the proposed ‘Expert’ principle, the RACP agrees that NDIA staff should have a high level of disability training, and a level of knowledge of the impact of disabilities and the supports required to help manage them. However, it is unrealistic to expect that NDIS planners and other staff will have a comprehensive clinical knowledge of the range of disabilities participants face and it is important to also acknowledge and make provision to engage with suitably qualified medical practitioners to ensure that planners are making evidence-based decisions on the best possible advice. The NDIS should explicitly articulate the role of medical specialists and other health professionals in providing expert advice on their patients’ conditions, and there should be an appropriate pathway for NDIS staff to engage independent medical expertise if necessary to support decision making.

The principles outlined have overlooked what is arguably the most important service principle – that support is patient, or participant, centred. One of the objectives of the NDIS as outlined in the NDIS Act is *“enabling people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports”*. This can only be achieved if there is a team-based approach that takes into consideration all aspects of the participant’s goals and needs. This is more focused than the description of the ‘Connected’ principle, which talks about coordination between government departments and with non-government organisations.

## Participant pathway

### Access to the NDIS is highly variable

Every Australian deserves equitable access to services, regardless of their circumstances or where they live. Anecdotal information indicates that an excessive focus on meeting intergovernmental-agreed timelines for participant intakes has come at the expense of quality in individual NDIS plans.

Groups with limited access to the NDIS include: Aboriginal and Torres Strait Islander communities; people from CALD communities and regional, rural and remote communities.

Aboriginal and Torres Strait Islander people have higher rates of disability than non-Indigenous people across all age groups<sup>1</sup>. Indigenous Australians with a disability have a very distinct age, geographic and health profile compared to the rest of the population. The RACP is in favour of tailored, culturally appropriate services which are community informed and community led where possible, to support the provision of services to Aboriginal

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<sup>1</sup> Australian Bureau of Statistics (ABS), Aboriginal and Torres Strait Islander People with a Disability, 2015, analysis based on Surveys of Disability, Ageing and Carers, 2009, 2012 and 2015

and Torres Strait Islander people with disability. An example of this is the work of the First Peoples Disability Network Australia (FPDN), a national organisation governed by First Peoples with lived experience of disability who support Australia's First Peoples with disability, their families and communities.

While RACP Fellows acknowledge the power of a client/carer driven application process, it is apparent that vulnerable families who need NDIS support most often struggle to gain an understanding of the system or simply can't find the time to fill out the forms. It is therefore strongly recommended that the Government provide a Health Care Provider initiated entry into the NDIS.

RACP Fellows recommend that mechanisms be established which expedite access to the NDIS for more vulnerable children, such as "immediate response" policies and procedures in health and hospital settings. This would ensure that support is provided for children diagnosed with significant changes or deterioration in skills, functionality or behaviour, and prevent loss of placements. 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.

Feedback from RACP Fellows indicates that the literature provided to participants is not easy to read. The NDIS does not currently include funding for language services, which has implications for all people with low English proficiency or communication difficulties. The RACP recommends improved provision of plain English information or other alternative communication tools to address difficulties understanding medical terminology, likely processes, and risks and benefits of treatment, including interpreters.

In rural and remote areas, some people must travel long distances to access much needed services in capital cities. Anecdotal evidence from RACP Fellows describe patients with NDIS plans that are under or even unspent due to lack of availability of services in rural and remote areas. These patients would previously have received support through government run services for which they are now ineligible. In remote areas, patients cannot rely on privately funded services because even with NDIS funding, they are not economically viable to operate. It would be more beneficial to NDIS participants to identify different agencies to cover grouped areas of services such as allied health services, housing support services, respite and social participation and education issues to concentrate skilled staff within fewer agencies. In regional and remote areas this could improve professional support and continuing education of NDIS service providers, ultimately improving the standard of service provided, as well as avoiding duplication of services and inefficient expenditure.

### **Participant knowledge of NDIS processes**

The NDIS is complex and hard to navigate, particularly when participants are new to experiencing a disability (of either themselves or their family). This results in gaps around participant knowledge of the NDIS system and how to construct a plan.

For example, families who are managing a child with additional needs are likely to be experiencing immense stress. These families typically do not have the time, financial resources or understanding of NDIS processes required to go through the NDIS appeal processes that may be required to achieve good plan outcomes for their children. It can also be challenging for parents and clinicians to know what are realistic goals for their children as they may not understand the full extent of their disability until later in life. It may be more realistic to trial strategies and supports to see what works for the individual child, with regular review.

With regard to draft plans, anecdotal evidence from RACP Fellows suggests that draft plans occur on an ad-hoc basis or only in rare circumstances. There is always the risk of excess administrative burden being placed on planners and participants to develop draft plans, however they may also prevent the development of inaccurate and unsuitable plans and subsequent reviews.

### **Service provision for ineligible children**

Governments must ensure that ineligible children and their families are supported to access mainstream services including health care and assist them in obtaining effective intervention and support. Concurrently to this, health providers and services must work to ensure that the services they provide are accessible and appropriate for NDIS participants. The RACP is concerned that children with milder disabilities are less able to access early intervention services as a result of the NDIS. For example, children on the milder end of the autism spectrum<sup>2</sup> are not eligible for early intervention services and thus experience difficulties in accessing

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<sup>2</sup> Level 1 on ADOS – autism diagnostic observational scale

much needed support. Although the recent changes to the NDIS<sup>3</sup> may help address these concerns, children not eligible for the NDIS require a coordinated response.

The current definition of developmental delay requirements set out in section 9 of the NDIS Act 2013<sup>4</sup>, states developmental delay is determined if a child is under 6 years and the developmental delay:

- is attributable to a mental or physical impairment or a combination of mental and physical impairments; and
- results in substantial reduction in functional capacity in one or more of the areas of major life activity, for example self-care, language, cognitive development, and
- results in the need for a combination and sequence of special interdisciplinary treatment or other services that are of extended duration and are individually planned and coordinated.

These conditions must be met to qualify for early childhood intervention individually funded support plans, which effectively excludes those children who have mild developmental delays. The RACP is concerned about this cohort, particularly because they may have difficulty accessing other relevant services.

The 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. It is important that children known to be at risk of developmental delay on the basis of biological or other factors are able to receive early intervention to increase opportunity to reach developmental potential, educate and support parents to promote their child's development and inclusion.

### **Eligibility criteria for people living with a psychosocial disability and for adult onset physical health conditions associated with fluctuations and progressive decline**

The definition of 'permanency' used for people living with psychosocial disability in the current eligibility criteria is incompatible with the current, best practice, recovery models. Under the recovery model, health practitioners and patients focus on building capacity, but periods of severe disability may still occur.

To accommodate this model and encourage recovery, the NDIS should allow people to enter and exit and access ongoing support during and to prevent further periods of impairment. 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. It has been reported that the complexity of collecting evidence to prove permanent, functional disability inhibits many people from meeting the NDIS' eligibility criteria. This is problematic for people who may not have access to or are disconnected from services and supports, such as:

- people in rural, regional and remote areas
- people who are transient and/or homeless
- people who face difficulties in accessing services and information such as with people with language barriers

## **Planning process 1: Creating your plan**

### **Variation in the expertise of NDIS planners**

RACP Fellows report significant variance between planners about the appropriate level of support for a particular condition, which can lead to different funding levels for similar clients, both in terms of core supports and capacity-building supports.

Planners have also been reported to act independently in deciding which requests will be funded but lack the training and experience of clinicians working in disability and do not necessarily accept the recommendations of clinicians. RACP Fellows have expressed concern over NDIS planners disseminating information to carers

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<sup>3</sup> Introduction of the ECEI approach from 1 July 2018 and the standardised 6-month interim plans for children who will experience significant wait times

<sup>4</sup> Productivity Commission (2017). Productivity Commission Study Report: National Disability Insurance Scheme (NDIS) Costs, Canberra. <https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf>

about therapies which have no or minimal evidence base. The uptake of such therapies is potentially linked to the poor availability of more conventional therapies.

Anecdotal evidence from RACP Fellows indicates that planners who have previously been health professionals appear to have a better general understanding of complex needs, however it is also reported that many planners have indicated that they are not allowed adequate time to understand the disability or health support needs of participants.

It is vital that NDIS planners have an understanding of their client's needs and how they can be supported through plan funding and access to necessary disability supports. NDIS planners and service providers must have sufficient expertise and training to understand the types of supports required for vulnerable cohorts who struggle to navigate the system, including but not limited to:

- individuals with significant impairment;
- individuals with psychosocial disability;
- non-residents;
- individuals from culturally and linguistically diverse (CALD) communities;
- Aboriginal and Torres Strait Islander communities; and
- children with high or complex needs, particularly those with developmental disabilities or challenging behaviours.

Some RACP Fellows have reported families being asked at review meetings whether their child's condition has improved, even in cases where:

- the condition has been listed as palliative;
- it has been clearly stated by the child's medical specialist that the disability is permanent and will have lifelong impacts requiring therapy and care; or
- the disability is listed as degenerative.

Some patients have also reported inappropriate questions being asked by planners and Local Area Coordinators, including a patient with Down Syndrome who was asked how long they have had Down Syndrome. This indicates a gap in knowledge and understanding of particular conditions on the part of NDIS planners and Local Area Coordinators (LACs). It is essential that planners are supported by appropriate guidelines or other resources such as an evidence-based framework developed by expert clinicians. Planners could benefit from the support of a panel of appropriately trained persons to assist with the assessment process.

Diagnosis is different across conditions for many individuals seeking to access the NDIS. Currently, a diagnosis of Autism Spectrum Disorder (ASD) acts as a gateway to the NDIS. It is typical that neurodevelopmental and behavioural conditions, such as ASD, lie on a spectrum. A child, adolescent or adult at one end of the spectrum may need no support or minimal support to reach their potential while another person with the same condition may have complex problems that require lifelong care. NDIS planners need to develop awareness of the nuances associated with developmental disabilities, to ensure that support of children with broader neurodevelopmental challenges can be planned, including situations where the diagnosis is uncertain or yet to be determined. Any assessment of autism concerns must be undertaken within the context of a broader neurodevelopmental, behavioural and functional assessment.

Anecdotal evidence suggests that planners do not account for growth of children and need for equipment to be updated as a result. Inadequate allocation of funding for orthotics, for example, has been a major issue across many states and territories. This has resulted in significant delays in children being able to obtain appropriate orthotics, which has been detrimental to their functional abilities. Delays in approval or reviews of plans caused by appeals of plans has also delayed replacement of outgrown orthotics in children.

Participants are unable to request continued services from particular planners, who may have particular expertise in the health sector, as they are randomly allocated. Most participants are not able to maintain contact with a single planner and at the time of a plan review, many participants are often allocated a different planner. The issue of continuity of care is one which has been addressed in many settings in the health system, including maternity care models that allow for a patient to see a shared care team. The NDIS could learn from these experiences in order to provide better continuity of support. Some RACP Fellows have reported that few planners are available on a consistent basis, as planners and LAC's are regularly rotated. This can influence the quality of support being provided.

Planners should provide information to participants about how to access mainstream health services and disability supports (both NDIS and non-NDIS funded supports) to assist in the management of their acute, emergency and chronic medical conditions across settings, including at home, with their general practitioner and at outpatient or inpatient settings and disability supports in case of unexpected hospital admissions. This information should explicitly cover the roles of disability supports in emergency department presentation, admission, daily ward rounds or updates and discharge planning - this increases the person living with disability's capacity to manage their own health as much as possible.

The NDIA have made a commitment to enhancing the skills of their staff in the area of psychosocial disability, and some of the issues experienced in this area have been marginally improved through the introduction of the Complex Support Needs Pathway, where some NDIS participants are assessed as requiring targeted assistance from a Senior NDIS planner due to complex support needs. However, health professionals are unable to refer to this service – it is only an internal referral process. NDIS participant experience could be improved if health professionals were able to refer patients directly to this service for assessment. Examples of work which could complement this could include the introduction of expert resource teams to support psychosocial disability services where the needs of participants are highly complex. Another option could be the development of a transparent set of standards, competencies and frameworks in order to provide greater consistency of approach amongst planners and to allow for accurate evaluation of outcomes.

The Australian Government must ensure that planners and service providers are supported to develop sufficient expertise so that they may provide adequate support for participants with high or complex needs, particularly those with developmental disabilities or children with challenging behaviours. The Government may need to reconsider the scope, qualifications, and experience required by the position descriptions, noting that planners play a crucial and pivotal role in the smooth functioning of the NDIS.

### Access Request Forms

RACP Fellows have reported that the Access Request Form does not currently appropriately reflect/explain NDIS eligibility requirements to participants and because of this, key details are not included by them. As a result, people miss out on the NDIS because of a 'poor' application, not because they are ineligible.

It is unclear how the NDIA assesses the supporting evidence that is provided in Access Request Forms and what information is needed. Clinicians are unsure of what, or how much, information is needed to support an application, and there is widespread uncertainty about whether a diagnosis is needed. For example, some RACP Fellows have noted that attaching diagnostic letters from specialists is considered to be insufficient evidence of functional impairment and identified areas of need.

The Access Request Form is itself unclear about whether it needs to be completed by a participant or treating health professional, and if it is not completed by a professional, what supporting information is needed.

Anecdotal evidence suggests there is a lack of communication of the current processes and systems used for assessments with families. There is also a lack of feedback to families and health professionals about where they are in the assessment process. Throughout the assessment process, some families are referred to local services (such as playgroups) which are already stretched.

Once plans are approved, some NDIS participants struggle to link in with appropriate services as a result of:

- Minimal intervention provided by Local Area Coordinators
- Lack of funding for Support Coordination
- Inconsistent quality of Support Coordination – meaning more vulnerable NDIS Participants, particularly with challenging behaviours, are not appropriately supported

There have also been anecdotal reports that there is insufficient time available for general practitioners (GPs) to adequately complete the access paperwork for families. Some RACP Fellows have reported that reviews of the Access Request Forms should include feedback from the health sector (including PHNs), as these stakeholders have significant involvement in the completion of applications and are thus well equipped to provide valuable feedback and improve on the current processes.

### Outsourcing of service provision

Outsourcing of the planning process in some cases has compromised the quality of care being provided to families. Anecdotal reports from RACP Fellows indicates that outsourcing of planning to non-government

organisations (NGOs) has resulted in some cases where a planner has no understanding of a child or young person's disability. In this case, planners are unable to give families answers to any questions at these initial or review planning meetings.

This has also impacted on the provision of 'last-resort' services. For example, in NSW, services of this nature were previously provided through Ageing, Disability and Home Care (ADHC) or NSW Health. All therapy services are now provided by funded services, which creates barriers for children and young people with challenging behaviours or other difficult presentations attempting to access services.

### **Service gaps for vulnerable populations**

As mentioned earlier, feedback from RACP Fellows indicates that NDIS language is complex, and many participants and families often struggle to understand it. The literature provided to participants throughout the planning process is not easy to read, and there is currently no funding through the NDIS for language services, which has implications for all people with low English proficiency or communication difficulties. The RACP acknowledges the introduction of the Cultural and Linguistic Diversity Strategy 2018 but recommends improved provision of plain English information or other alternative communication tools to address difficulties understanding medical terminology, likely processes, and risks and benefits of treatment, including interpreters.

## **Planning process 2: Using and reviewing plans**

### **The role of the health and disability sectors**

Improved collaboration between health and disability sectors can help to deliver supports to enable people living with disability to lead healthier lives. It is imperative that the points at which people living with disability access health services are accessible and easy to navigate.

The RACP recommends clarification by both health services and the NDIS of key clinical terminology relevant for both sectors. Health system clinicians can help to clarify definitions that relate to the interface between health services and the NDIS for participants with ongoing disability, particularly around eligibility, for example "at risk". This is also important for appropriately identifying the need for specific assistive technology and vehicle/home modifications.

### **Challenges faced by NDIS participants in having their plan reviewed**

Anecdotal evidence from RACP Fellows shows that families face difficulties locating suitable allied health specialists and often, long waiting times for appointments to commence and continue therapy. It is understood that it may take weeks to months for families to find or change service providers and find suitable support workers to work with their child at home or in the community. These delays in uptake impact the rate of use of plan budgets and hence families face added stresses at the time of plan review with unspent funds, needing to justify the ongoing provision of funding at the same level. The NDIA should take into account delays in participants commencing plans resulting in underspent budgets at the time of plan reviews, so that participants with the same or greater level of support needs are not in any way disadvantaged.

It would be useful for the NDIA to continue to provide updated face to face information sessions as well as online information for new participants to understand their support needs and how to prepare for planning meetings. Participants need to be provided with information about eligibility for Support Coordination and how Local Area Coordination (LAC) services and ECEI partners can advise and help participants access suitable supports and resources.

## **Appealing a decision by the NDIA**

### **Timeliness of reviews and engagement of health professionals**

The current NDIS review process is not timely enough, and frequently does not capture the complex needs of participants. This needs to be rectified by the NDIA, especially where loss of community placement or risk of harm to the person or other members of the community exist. This change should include the ability for health professionals to assist NDIS participants in making a complaint if essential supports - including under the health and wellbeing domain - are not included in their NDIS plan, or an NDIS provider is not properly implementing those supports.

Some RACP Fellows have expressed concerns that health professionals may be burdened with the responsibility for providing extensive documentation to support plan reviews. For an unscheduled review (due to a change of circumstances) an NDIS participant requires strong evidence.

Unscheduled plan review requests can take a long time unless they are escalated as urgent, with reported wait times reaching up to 3 months. This can have major implications for participants who require urgent support. Some RACP Fellows feel that the current review process can be very time consuming and patients often feel that it is not worth it, as it is a similar timeline to waiting for a new plan to be reviewed. Requests to “review a reviewable decision” (for example, if the NDIA deems someone ineligible and they request a review of the decision) can take up to 6 months. Anecdotal evidence suggests that in some cases, the process can be so slow that the NDIA has advised participants that they may be better off re-submitting a new request. Consequently, the review process is avoided by submitting new Access Request Forms.

### **The Administrative Appeals Tribunal (AAT) Process**

Some RACP Fellows have noted that they have found the AAT to be thorough and very reasonable in understanding individual needs, but the process is slow and very expensive. The appeals process can be stressful and time consuming for patients and those who support them. RACP Fellows have noted that, as far as they are aware, very few appeals have been upheld. Some RACP Fellows support longer time frames for funding, for example 2 to 3 years for core and capacity building funding to allow for planning goals that take longer than a year (such as further education, skills training, transition to work etc).

## **Removing red tape from the NDIS**

### **Responsiveness of plans to the changing needs of children and adolescents**

As children enter school, cognitive, learning and executive functioning problems can be exposed for the first time. Access issues emerge for children with physical disabilities at school and in leisure pursuits. Emotional and mental health problems can impact on the quality of life of children living with disability and their families. Educators may identify these problems and will need to work with families, health services and the NDIS to address the issues so that effective support is provided.

Goal setting may change as the child begins to express their autonomy and develop their identity. Goal directed therapy aimed at maintaining physical and emotional function and well-being is conceptually important in these years, with ongoing skill development and functional improvement sought wherever possible.<sup>5 6</sup> The NDIS should provide services to address barriers to the full participation of the child in the activities that he or she wishes to pursue. Achievement of this goal may also require access to health and psychological services. The transition of adolescents from school and children’s care to adult services is another key period of changing functional needs that require developmentally-appropriate support.

The increased physical, mental and social health needs of children and young people living in out-of-home care settings are well recognised, with a high prevalence of chronic medical conditions, disability and developmental delay.<sup>7</sup>

## **Conclusion**

The NDIS must ensure that participants are able to access the necessary supports at the right amount and the right time through their NDIS package, without being subject to constrictions based on their location or condition. People considered to be ineligible for NDIS support must be referred to the appropriate avenues for their needs and be supported appropriately.

Paediatricians and other medical specialists remain keen to work closely with the Australian Government to improve care, health and wellbeing for people with disabilities and health conditions. The RACP recognises that close and effective collaboration across sectors is in the best interests of vulnerable individuals and their families.

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<sup>5</sup> Rosenbaum, P. and Gorter, J. W. (2012), The ‘F-words’ in childhood disability: I swear this is how we should think!. *Child: Care, Health and Development*, 38: 457–463. doi:10.1111/j.1365-2214.2011.01338.x

<sup>6</sup> WHO (2002): Towards a Common Language for Functioning, Disability and Health. International Classification of Functioning, Disability and Health (ICF). Available at <http://apps.who.int/classifications/icfbrowser/> (Accessed 15 September 2017)

<sup>7</sup> RACP. 2008. Health of Children in Out-of-Home-Care

The NDIS, as a needs-based system, requires the certainty of support for people with disability. It is crucial that this is delivered through a fair, equitable access system, quality planning processes, with adequate support from informed planners and service providers.