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**RACP Submission - Joint Standing
Committee on the National Disability
Insurance Scheme Inquiry into NDIS
Planning**

September 2019

Overview

The Royal Australasian College of Physicians (RACP) is grateful for the opportunity to provide feedback to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS).

The Royal Australasian College of Physicians (RACP), represents over 17,000 fellows and 8,000 trainees across over 30 specialties in Australia and New Zealand. This includes rehabilitation medicine physicians, paediatricians and occupational and environmental medicine physicians who 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. Rehabilitation 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 physician and paediatrician 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, 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 supports they need to achieve those goals. This has the benefit of allowing participants to decide what they want from their support.

The RACP recognises that physicians and paediatricians can play an important role in providing people living with disability with information about the NDIS, about information, 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.

The College appreciates that the provision of a more comprehensive set of services for Australians living with disability is a complex undertaking, which is made more complex by the variations in service provision (other than what is provided under the NDIS) across jurisdictions and even within individual states and territories.

The NDIS does not replace mainstream health services however, under its health and wellbeing domain, it is integral to ensuring that health care plans are carried out, and that participants have access to sufficient and appropriate health care. The health sector and health professionals have a key role to play in the successful implementation of the NDIS for children, young people and adults living with disability. This includes providing the right information to NDIS participants, their families, carers and planners, to assist them to make decisions in relation to individual NDIS plans and their implementation.

The submission responds to select Terms of Reference that the RACP is able to provide comment on, based on responses received from RACP Fellows.

Executive summary and recommendations

While the RACP supports the underlying principles of the NDIS, RACP Fellows have identified a range of issues with the current planning processes.

It is broadly apparent that the backgrounds and expertise of NDIS planners vary considerably depending on location and the health condition being considered. It is vital that this is improved, and that NDIS planners and service providers have sufficient expertise and training to understand the types of supports required for vulnerable cohorts who struggle to navigate the system. This includes people from culturally and linguistically diverse backgrounds, who our Fellows have reported may struggle to access appropriate information about the NDIS.

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, particularly for those with developmental disabilities such as intellectual disability or autism, and challenging behaviours. In the case of paediatric care, some RACP Fellows have reported that 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.

NDIS participants must be sufficiently supported to engage adequately in goal setting and the review and planning processes. This is particularly important in the case of families with young children, who may be under immense stress and, without support, unable to engage sufficiently in these processes.

RACP Fellows have identified a range of gaps which occur at various points throughout the planning process for NDIS participants. Specific areas include: access request forms, outsourcing of service provision and gaps in services for vulnerable populations.

With regard to rural and regional participants, access to rural and regional health workers is a challenge across the health system, and the NDIS is no different. RACP Fellows have described a range of challenges specific to the NDIS and NDIS participants in a range of rural and regional areas.

The RACP recommends that:

- 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
- health professionals are able to refer patients directly to the Senior NDIS planner service
- 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 interpreters is improved

In addition, we reiterate the recommendations made in our [2017 NDIS position statement](#) which are relevant to the current inquiry.

The RACP calls on the NDIA to:

- provide planners with information and training to support NDIS participants' goals under the NDIS's 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 child's paediatrician in developing and reviewing support plans. This includes disseminating plans and other information with the person's or carer's consent.

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

- 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 over again; effectively coordinate intervention, especially for those people with complex needs or vulnerabilities.

Response to selected Terms of Reference

a) the experience, expertise and qualifications of planners; b) the ability of planners to understand and address complex needs; c) the ongoing training and professional development of planners;

The Productivity Commission has noted that “*good planning processes are essential for the long-term sustainability of the NDIS.*”ⁱ 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.

The experience, expertise and qualifications of planners can vary greatly depending on location. Some RACP Fellows report that the level of understanding of a client’s impairments tends to vary greatly 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. Anecdotal evidence from Fellows indicates that planners who have previously been health professionals appear to have a better general understanding of complex needs, however our members report that many planners have indicated that they are not allowed adequate time to understand the disability health support needs of participants.

It is vital that NDIS planners have an understanding of their client’s needs and how this can be supported through plan funding and access to necessary disability supports. It is important to ensure that NDIS planners and service providers 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. It is essential that planners are supported by appropriate guidelines or other resources such as an evidence-based framework developed by appropriate clinicians and could benefit from the support of a panel of appropriately trained persons to assist with the assessment process.

Diagnosis does not function across all conditions for many individuals seeking to access the NDIS. In the case of neurodevelopmental and behavioural diagnoses, these often overlap and interact and for many children an accurate diagnosis may not be clear or may not be possible early in their life-course. These conditions would benefit more from a function and care needs-based approach. 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 at one end of the spectrum may need no support or minimal supports to reach their potential while another child, with the same condition, may have complex problems that require lifelong care.

As such, NDIS planners need to develop awareness of the nuances associated with developmental disabilities, to ensure that support and care 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.

It is also the case that children may experience disability, but not have a diagnosis. For example conditions that require genetic testing and analysis can progress through a number of stages of genetic testing that can take many months. Some patients who undergo genetic testing may never reach a conclusive diagnosis, due to the current limits of understanding of the genetics of the conditions. Thus a system in which assessment relies heavily on completion of a diagnosis may disadvantage people with a disability where there is currently no definitive diagnostic protocol.

Some RACP Fellows indicate that planners would benefit from a greater understanding of quality of life goals for children with severe disability, and the individual needs associated with certain types of physical or neurodevelopmental disabilities in children. Many NDIS participants experience issues with organisation and planning skills, and thus require the support of a coordinator to assist with locating the best service provider, and to help them liaise with the service provider to achieve the best outcome. Some RACP Fellows have found that often participants are not funded for a coordinator or funds are only for a short time, and when issues occur, the service stops and allocated funds are not used or are not further funded for the following year.

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.

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, particularly for those with developmental disabilities such as intellectual disability or autism, and challenging behaviours. For example, anecdotal evidence from NSW-based RACP Fellows suggests that the decision to transfer current disability services from Ageing, Disability and Home Care NSW (ADAHN) to the non-government sector to support delivery of the NDIS has created some access issues for these cohorts. Particularly in communities where there may not be sufficient eligible clients for the NDIS, service providers may not be able to continue operating, which will disproportionately affect regional, rural and remote communities.

In the case of paediatric care, some RACP Fellows have reported that 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. These behaviours can also indicate unmet needs which require a response from multiple agencies. With the introduction of the NDIS, there are insufficient funds to employ specific counsellors and family support workers to maintain family unity and to help parents enhance parenting skills and resolve problemsⁱⁱ.

It is important that planners are equipped with the appropriate information and training to support NDIS participants' goals, including a working knowledge of the health system, to ensure appropriate and consistent planning across states and territories. Some planners have expertise in the health sector, but participants or health professionals are unable to request continued services from particular planners, 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. 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 care being provided.

We must ensure that families do not relinquish care, or see their services suspended. Planners should assist participants to consider their health in their plan, including 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; 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; and supports to increase the person living with disability's capacity to manage their own health as much as possible.

We welcome the changes announced in June 2019 by the COAG Disability Reform Council to fund disability related health supports under the NDIS.ⁱⁱⁱ We look forward to seeing the progress of this reform, as it may lead to increased and beneficial access to services.

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. Health professionals would be able to provide an improved standard of care if enabled 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 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 reduce any unwarranted variation 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.

e) participant involvement in planning processes and the efficacy of introducing draft plans;

From their first contact with the NDIS, participants are encouraged to be involved in goal setting and are engaged in the planning and review processes. The information provided by participants is used to formulate their next plan. There still exists some gaps around participant knowledge about the NDIS system and how to construct a plan, particularly for new participants and families of very young children. In the area of paediatrics, some RACP Fellows have reported that families are already under immense stress due to the demands of managing a child with additional needs. These families typically do not have the resources (both time, financial and understanding of NDIS processes) to go through the NDIS appeal processes which may be required to achieve good plan outcomes for their children.

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.

f) the incidence, severity and impact of plan gaps;

Although it is impossible to attribute a precise measure of the incidences and severity of plan gaps, RACP Fellows have reported a variety of gaps which occur at various points throughout the planning process for NDIS participants:

Access Request Forms:

Some RACP Fellows have noted that the Access Request Form doesn't appropriately reflect/explain NDIS eligibility requirements to participants, who subsequently fill out the form without key details for consideration. The subsequent result is that patients that should be eligible for NDIS are deemed not eligible as a result of 'poor' applications. There is great variability in the quality and relevance of information in the Access Request forms depending upon who completes the forms – 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. It is unclear how the NDIA assesses the supporting evidence that is provided, 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.

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 best 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 ADAHC 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:

Service gaps still exist for certain groups in the community who are currently experiencing difficulties accessing the NDIS or who are at risk of falling through the cracks.

Those with limited access to the NDIS include:

- Aboriginal and Torres Strait Islander communities;
- People from CALD communities; and
- Regional, rural and remote communities.

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 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.

Ultimately, plan gaps produce significant negative effects for NDIS participants and for mainstream health services, as individual participants often require ongoing support from health professionals to manage these gaps.

As mentioned above, the RACP welcomes the recent decision by the Disability Reform Council that the NDIA will be responsible for the provision of disability-related health supports^{iv}. We hope that this will improve the resolution of service gaps under the NDIS, but there are many areas where service provision and support can be vastly improved.

g) the reassessment process, including the incidence and impact of funding changes; h) the review process and means to streamline it; i) the incidence of appeals to the AAT and possible measures to reduce the number;

Some RACP Fellows have expressed concerns that health professionals may be burdened with the responsibility for providing extensive supporting documentation to support NDIS applications; this is no different at the annual plan review stage. 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 supports. 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.

In relation to requests to “review a reviewable decision” (for example, if the NDIA deems someone ineligible and they request a review of the access decision) this process can take up to 6 months. Anecdotal evidence suggests that in some cases, the process can be so slow that the NDIA has advised some participants that they may be better off re-submitting a new request. Subsequently, the review process is avoided by submitting new Access Request Forms.

In terms of the AAT appeals 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).

I) the adequacy of the planning process for rural and regional participants;

It is important that the rollout of the NDIS examines ways of providing more tailored planning and supports in rural and remote communities to ensure access to health care, including local training and provision of culturally appropriate supports. Evidence shows that there are barriers to greater access, delivery of therapy supports and choice in rural and remote areas⁹, particularly in allied health services (e.g. medical, paediatric and mental health services). Access in rural and regional areas to health workers who understand the systems and services required by people with disability is important.

This has been evidenced in areas such as:

Victoria

RACP Fellows based in northern Victoria have noted areas where the NDIS has not been fully rolled out, which has produced experiences of disadvantage for many regional and rural clients in these areas.

New South Wales

RACP Fellows have reported that in NSW, the gap in allied health services has led to significantly longer wait lists compared to those in metropolitan areas. Nonetheless, wait lists in metropolitan areas can stretch up to 18 months. RACP Fellows note that in rural and remote areas, some people must travel up to 700 km to access much needed services in capital cities.

Queensland

Some RACP Fellows report that delays in appointment times and access to planners is a barrier for many patients in northern regional, rural and remote QLD.

The Northern Territory

RACP Fellows based in the Northern Territory have expressed concerns that government run allied health services are being diminished, while private providers are not willing or able to provide services to remote communities. There are also concerns that the patient driven application process means that the most marginalised members of the population (e.g. remote Indigenous populations) do not necessarily have the means to negotiate the application process and are thus missing out on much needed support.

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 less 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. Location of services and colocation of medical and allied health services is vital in these areas.

m) any other related matters;

The RACP would like to draw attention to the following additional matters:

Eligibility Criteria – Psychosocial Disability

It has been reported that the complexity of collecting evidence to prove permanent, functional disability inhibits many people from meeting the Scheme's eligibility criteria, which particularly affects individuals with psychosocial disability.

Evidence is particularly hard to obtain for people who are often disconnected from services and supports or don't have access to services and supports (such as people in rural, regional and remote areas), are transient and/or homeless, or face difficulties in accessing services and information such as with people with language barriers^{vi}. Some RACP Fellows have reported that clinicians have sometimes elected to provide a service prior to eligibility assessment in order to support the patient; however, this can result in no payment for the service which has been provided.

Concerns have been raised about the definition of 'permanency' for this disability. This is incompatible with clinical practice for psychosocial disability, which uses recovery models in supporting people living with psychosocial disability. The recovery model of mental health is focused on building capacity; however, periods of severe disability may still occur.

The eligibility criteria should be flexible enough to support 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 eligibility 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.

Eligibility for Early Childhood Early Intervention (ECEI):

The RACP would also like to draw attention to concerns raised regarding the eligibility of children and families for the NDIS. Eligibility for early childhood intervention individually funded support plans under the NDIS for children age 0-6 in sections 25(1) of the NDIS Act 2013 requires that a child meet the developmental delay requirements set out in section 9 of the NDIS Act 2013^{vii}. The definition effectively excludes those children who have mild developmental delays.

The College is concerned about ineligible children who may not qualify for the NDIS and may have difficulty accessing other relevant services, including children with disruptive behaviours and complex developmental trauma. For example, children with milder disabilities are less able to access early intervention services as a result of the NDIS - children on the milder end of the autism spectrum (level 1 on ADOS – autism diagnostic observational scale) are not eligible for early intervention services and thus experience difficulties in accessing much needed support. Although the recent changes to the NDIS (introduction of the ECEI approach from 1 July 2018 and the standardised 6-month interim plans for children who will experience significant wait times) may help address these concerns, children not eligible for the NDIS require a coordinated response.

The NDIA projections indicate by the Financial Year 2019–2020 that 47,000 of the 460,000 total NDIS Participants with approved Plans will be children aged 0-6 and that a further 59,000 children age 0–6 may identify as having a developmental delay or disability but are not expected to be eligible for an individualised funded support package^{viii}. To accommodate these significant numbers of children, the Australian Government must ensure that ineligible children and their families are supported to access mainstream services including health 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 clients.

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.

Rehabilitation Medicine and the NDIS:

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. This is particularly important for rehabilitation services dealing with people with newly acquired disability and includes those in and recently discharged from inpatient rehabilitation units, and must acknowledge the differing needs of this group compared to people living with disability who are well-established and living in the community.

A closer examination of the intersection between the NDIS and rehabilitation medicine health services may lead 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.

Links between NDIS and Vocational Rehabilitation Services and the role of employment:

One of the stated aims of the NDIS is to support people living with disability to fully participate in their societies, including through employment. However, in practice RACP Fellows have found that there is an unstated assumption that everyone accessing the NDIS is incapable of employment. One way in which this has been demonstrated is that at this stage the linkages between the NDIS and agencies with expertise in returning those with disabilities to appropriate work are unclear. These links need to be strengthened to ensure that those NDIS participants who are able and willing to return to work are able to.

As well as vocational rehabilitation services provided by the health sector, improving the links with personal injury and income protection insurance schemes would be beneficial. Clearer communication is required to illustrate how the NDIS will intersect with vocational rehabilitation services and participants living with disability, to ensure that the NDIS can successfully facilitate access and support employment and transitions to work for participants.

Unsupported conditions:

Respiratory physicians have also been experiencing difficulties related to the lack of acknowledgement of dyspnoea as a chronic disability and thus excluded from NDIS support. Ensuring consistent coverage of this condition will help to achieve an enhanced quality of life for many individuals and assist caregivers as well.

The NDIS and children with neurodevelopmental and behavioural challenges:

The current NDIS system would benefit from stronger connections between the NDIS and related agencies. This is particularly the case when providing care for children with neurodevelopmental and behavioural challenges who have disabilities arising from complex, brain-based medical conditions. These conditions can change rapidly as a child develops, and consequently their support needs can change significantly as they travel through various stages of learning and development.

These complex interactions and constant changes present unique challenges for the child and their families, clinicians, educators and disability planners. However, the current policy environment does not allow for consistent engagement between experts across health, education and disability to share their expertise, collect common data or evaluate and measure common intervention strategies. These silos put further pressure on carers, children and their families.

The RACP is concerned that the key worker model can present limitations when a child requires profession specific assessment, advice and therapy. Our Fellows have noted some instances where families may be directed to external, private therapists. This imposes a burden 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.

Very limited amounts of funding are provided within the individuals therapy budget. Families are then forced to choose between physiotherapy, occupational therapy, speech pathology, and psychology as the funds are usually not adequate to meet to needs. The other typical scenario is that there is funding for one therapy session per month. This means that children are not able to access the therapy they require, or which has been recommended by their medical professionals.

The NDIS and children with both significant medical conditions and developmental delays:

Children with co-morbid significant medical conditions and developmental delays experience barriers and challenges, which in some cases are not being adequately addressed by the NDIS.

An example of this provided by an RACP Fellow is a child who may have Type 1 diabetes mellitus and autistic spectrum disorder or ADHD. When they have high or low blood glucose levels their behaviour is usually more difficult to control, and they often require a much greater deal of time in one on one support, both for their diabetes and their behaviour, at home and at school.

A further example is children with pituitary disease and central diabetes insipidus and adrenal insufficiency as the result of brain tumours who also have had strokes because of their surgery and may have limitations in their ability to communicate when they are unwell. These children risk death when they become unwell with fever/ diarrhoea or vomiting, and they can be subtly unwell but still require urgent stress doses of corticosteroid or additional fluid if their medication wears off.

These situations reinforce the need for health professionals to be able to refer patients directly to the Senior NDIS planner service, who may be better placed to differentiate between what should be provided by the NDIS and what should be provided by health services. We understand that these planners have more training and understanding of the broader health system.

Conclusion

The rollout of the NDIS must ensure that NDIS 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 particular condition. Patients considered to be ineligible for NDIS support must be referred to the appropriate avenues for their health 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.

The NDIS, as a needs-based system, requires the certainty of support for people with disability. It is crucial that this is delivered through quality planning processes, underpinned by timely and accurate support. Quality planning will support quality outcomes.

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