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**RACP Submission - Implementation of the
National Disability Insurance Scheme and
the provision of disability services in New
South Wales
August 2018**

Overview

Thank you for the opportunity to provide feedback to the Legislative Council's Health and Community Services Committee's Inquiry into the Implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in New South Wales (NSW).

The Royal Australasian College of Physicians (RACP), represents over 17,000 fellows and 7,500 trainees across over 30 specialties in Australia and New Zealand. This includes rehabilitation medicine physicians and paediatricians 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, 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. The College appreciates that the provision of a more comprehensive set of services for Australians living with disability is a complex undertaking, and is made more complex by the variation in service offerings (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 will be integral to ensuring that health care plans are carried out, and that participants have access to sufficient and appropriate health care. Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity.ⁱ Good health is fundamental to wellbeing for all people, including those living with disability. It helps them to participate in their community, to cope with life's adversities, and to set and achieve their goals. 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.

More broadly, it is important to recognise that the NDIS will not cover large numbers of NSW residents who are living with disability. It is imperative that services that provide them with support are not shut down or scaled back under the false assumption that the NDIS will provide them with an appropriate substitute package.

Key recommendations

1. The rollout of the NDIS should be undertaken at an appropriate pace to ensure that each new and existing participant can undergo effective and comprehensive planning, and have access to necessary interventions throughout this process.

The Productivity Commission has noted that "*Good planning processes are essential for the long-term sustainability of the NDIS.*"ⁱⁱ 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. Adjusting these timeframes requires consent from individual States, and is an option the NSW Government should consider to preserve the quality of the rollout. The latest NDIA Quarterly report for NSW indicates that the current rate of participation in the NDIS is at 81% of the agreed bilateral target.ⁱⁱⁱ Whilst this is not a poor performance, it demonstrates that more work must be

done to ensure that participants both current and new are able to effectively access the NDIS according to their particular needs and circumstances.

Examples of issues arising 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.

2. Fully fund Information, Linkages and Capacity (ILC) services during the NDIS rollout transition period

The College agrees with the Commonwealth Productivity Commission's recommendation to increase ILC funding during the NDIS transition period to the full amount (approximately \$131 million per year, inflation-adjusted) immediately. This is currently planned for 2019/20 – we are concerned that in the likely event the full roll out is not achieved by this date, full ILC funding will be delayed. 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.

3. Provide more tailored supports to those with difficulties accessing the NDIS, including people with limited English and communication difficulties, and intellectual disability

Every Australian deserves equitable access to services, regardless of their circumstances or where they live. It is important to recognise that there are still 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.

Settlement Services International estimates that, with the Scheme fully operational in 2019-20, 20% of the NDIS packages nationally will be used by people from CALD backgrounds. The national participation rate is currently at 7.2%, with 9% in NSW^{iv}.

Feedback from RACP Fellows indicates that the literature provided to participants is not easy to read; the NDIS also does not currently include funding 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.

Aboriginal and Torres Strait Islander people have higher rates of disability than non-Indigenous people across all age groups, and Aboriginal and Torres Strait Islander people aged 35–54 are 2.7 times as likely to have a disability as non-Indigenous people of the same age^v. 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 and Torres Strait Islander people with disability. The Department of Social Services also recommends improved data collection and increased community driven research with respect to disability and Aboriginal and Torres Strait Islander people^{vi}.

It is important that the rollout of the NDIS in NSW examines ways of providing more tailored 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 areas^{vii}. Access in rural and regional areas to health workers who understand the systems and services required by people with disability is important. There are currently gaps in allied health services (e.g. medical, paediatric and mental health services) in

remote, rural and regional areas. RACP Fellows have reported that 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.

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.

4. Develop a better understanding and communication of the intersection between the NDIS and mainstream health services to improve outcomes and avoid cost shifting

There is a lack of clarity about how some intersections between the NDIS and other mainstream health 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.

Some RACP Fellows have also noted that the decision to transfer current disability services from Ageing, Disability and Home Care NSW to the non-government sector to support delivery of the NDIS has created some access problems. Particularly in communities where there may not be sufficient eligible clients for the NDIS, service providers may not be able to continue operating. This will disproportionately affect regional, rural and remote communities. The NSW Government must ensure continuity of support to ensure that participants are not left without appropriate services.

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. The NSW Government must set clear boundaries at the operational level around 'who supplies what' to people with disability, and only withdraw when continuity of service is assured.

5. Undertake a specific review of the intersection between the NDIS and rehabilitation medicine health services

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.

6. Improve communication around the linkages between the NDIS and vocational rehabilitation services to clarify some of the Scheme's benefits

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, at this stage the linkages between the NDIS and agencies with expertise in returning those with disabilities to appropriate work are unclear. 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.

7. Enable access to the Early Childhood Early Intervention (ECEI) approach for children recognised to be at risk of developmental delay/disability, and inclusive of therapeutic intervention for children who require it

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. The RACP recognises the recent appointment of organisations to deliver the NDIA's ECEI approach across NSW at full scheme from July 1 2018. This approach will provide much needed supports including functional assessments, short-term, targeted speech and occupational therapy, and information about local community and mainstream health services.

However, 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.

Early Childhood Intervention Australia (ECIA) NSW/ACT has also identified a number of issues currently being experienced by NSW ECEI Transition Providers while working with other government funded services during the NDIS transition, such as:

- Long waiting lists for Community Health and Family Support services;
- Lack of clarity as to responsibility of the NDIS and other government systems;
- Responsiveness of general community services to the needs of children with developmental delay and disability;
- Lack of a coordinated approach for families experiencing vulnerability with children with developmental delay and disability; and
- Long waiting lists for developmental assessments^{viii}.

8. Introduce “immediate response” policies and procedures to ensure support for children with significant changes or deterioration in skills or behaviour

The College recommends that mechanisms be established which expedite access to the NDIS and NDIS ECEI 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.

9. Ensure that NDIS planners and service providers have sufficient expertise to understand the types of supports needed for children with high or complex needs, particularly those with developmental disabilities or challenging behaviours

ECIA NSW/ACT estimates that by 2019/20 there are likely to be 9,037 to 12,065 children with delays in NSW that are not likely to receive an individualised funding support package under the NDIS but still require some degree of support from other government systems and the community^{ix}. 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.

Often referred to as “hidden disabilities”, planners may not understand the type of supports that are suitable to address these challenges and include insufficient funds to properly meet a child's 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. 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 problems^x. The NDIS must ensure that families do not relinquish care, see their services suspended or get abandoned to mainstream services such as health.

The NSW Government must ensure that planners and service providers are supported to develop sufficient expertise so that they may provide adequate support for children with high or complex needs, particularly those with developmental disabilities or challenging behaviours. One such example could be the introduction of expert resource teams to support services where the needs of children are highly complex.

On eligibility criteria:

10. Undertake a review of the current eligibility criteria for people living with a psychosocial disability and for adult onset physical health conditions associated with fluctuations and progressive decline

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. 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^{xi}. Some RACP Fellows have reported that in some cases, it is easier and more efficient to provide a service and review eligibility at a later time, which 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 recovery models used 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 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.

11. Provide a more coordinated response regarding service provision for ineligible children

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 NDIS Act 2013^{xii}. 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 introduction of the NDIA's ECEI approach from July 1 2018 will help to link those not eligible for an NDIS plan to other government services and the community, children not eligible for the NDIS require a coordinated response from the NSW Government. The NSW Government must ensure that ineligible children and their families are supported to access mainstream health services and assist them in obtaining effective intervention and support.

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^{xiii}. ECIA NSW/ACT has projected that 21,043 children age 0-6 will seek access to the NDIS NSW by 2019-20 and that 12,625 children in NSW are not likely to receive an individualised funding support package under the NDIS but will still require some degree of support from other government systems and the community^{xiv}.

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

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