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The Royal Australasian College of Physicians

# **Health and the National Disability Insurance Scheme**

Position Statement

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## Acknowledgements

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### The NDIS Working Group members:

Dr Robyn Horsley (Chair) OAM  
Clinical Associate Professor Robyn A Wallace (Chair and Member from July 2015 to June 2017)  
Dr Stephen de Graaff  
Dr Anne Kynaston  
Dr Katherine Langdon  
Dr Robert Leitner  
Dr Jacqueline Small  
Dr Elizabeth Thompson  
Professor Graham Vimpani

### Supported by:

Alex Lynch, Senior Policy Officer  
Yvonne Gritschneider, Policy Officer  
Louise Hardy, Manager, Policy and Advocacy

## 1. Executive Summary

The Royal Australasian College of Physicians (RACP) strongly supports the National Disability Insurance Scheme (NDIS), its underlying values and principles, including individual autonomy, non-discrimination, and full and effective participation and inclusion in society. NDIS efforts to build supports for people living with disability to participate in society are underpinned by the ethical foundations expressed by the United Nations Convention of the Rights of People with Disability (the Convention).

The NDIS is transforming the delivery of support services to many Australians living with disability. It will enable thousands of adults and children living with a significant and permanent disability to obtain the support they need to fully participate in society through a sustainable, family and child- or person-centred approach that offers them choice and control.

This position statement specifically addresses the NDIS and its relevance for the health of people living with disabilities. Its recommendations are intended for a broad audience, including physicians and the broader health sector, the National Disability Insurance Agency (NDIA), governments, disability service providers, and people living with disability and their families and carers. This position statement focuses on several key areas, including:

- Support for the importance of the underlying principles of the NDIS, such as individual autonomy, non-discrimination, and full and effective participation and inclusion in society;
- Recognition that living with disability can have a significant impact on an individual's health and wellbeing, and can affect the delivery of health care and health promotion;
- The NDIS, and related changes in mainstream sectors such as health, provides an opportunity for improved health outcomes for people living with disability, particularly through improved access to mainstream services, and the upskilling of carers and support workers; and
- Collaboration between the health sector, including paediatricians and physicians, and the disability sector, including the NDIA and disability service providers, to make reasonable adjustments to health care systems that improve health outcomes for people living with disability.

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 NDIS does not fund or replace mainstream services such as healthcare. The health sector and health professionals do, however, have a 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 RACP recognises that health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity.<sup>1</sup> Being healthy allows a person to actively participate in their day-to-day life and community. Health is a resource for everyday life, not the object of living, and is a positive concept emphasising social and personal resources as well as physical capabilities. Furthermore, the biopsychosocial model of health recognises the complex interplay of biological factors, psychological factors and socioeconomic factors in determining health outcomes. This holistic approach to health care is particularly relevant for people living with disability and complements the person-centred focus of the NDIS.

Even though many people living with disability may be healthy, people living with disability do have more health problems as a group than those who do not live with disability. This has implications for the NDIS and its interaction with the health sector. Adults with intellectual disability experience significantly reduced life expectancies, with more than a third of premature deaths potentially avoidable through appropriate healthcare interventions. However, negative health and wellbeing outcomes are not inevitable. These unacceptable health disparities must be a driver in both the disability and health sectors for substantial change in models of care.

Paediatricians are often engaged during, or even prior to, the period in which concerns about the child's development arise. The comprehensive assessment typically conducted by a paediatrician can assist families, doctors, educators and disability support providers in developing management plans and reviewing their effectiveness.

Collaboration across sectors, especially health and disability, is a critical foundation for successful implementation of the NDIS. This position statement aims to highlight some of the ways in which health professionals and the health sector are working with the NDIA and the disability sector to support the rollout of the NDIS and the health and wellbeing of people living with disability. It also raises some of the challenges that exist for inter-sectoral collaboration and explores opportunities to improve outcomes for people living with disability, particularly in the following areas:

- Early childhood intervention - especially where there may be conditions that raise the likelihood of disability emerging when the child is older.
- Early and timely intervention for children and adults with acquired disability, once acute management in the health sector has been completed.
- The health sector's responsibility to make reasonable adjustments to ensure optimal delivery of health services for NDIS participants.
- Inclusion of measures in the NDIS plan, especially within the health and wellbeing domain, that support the maintenance of good health, important for full participation in society.
- Enabling employment access as a key aim of the NDIS. Health practitioners may play an important role in assessing work capacity and facilitating appropriate work.
- Supporting and educating family carers to ensure that they remain physically and psychologically able to care for the person living with disability.
- The challenges in supporting people with very high and complex needs where there may be multiple carers, additional vulnerabilities and difficulties with service integration.

Under the NDIS framework, participants are responsible for determining their goals and the kinds of supports they need to achieve those goals. 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.

In addition to this position statement, the RACP has developed *NDIS Guides for Physicians and Paediatricians* to assist medical specialists to work with the NDIS and support and advocate for their patients who may be eligible for, or are already participants in, the scheme. For more information on the history of the NDIS, please see the NDIA website <https://www.ndis.gov.au/about-us>. To access the RACP's *NDIS Guides for Physicians and Paediatricians*, go to <https://www.racp.edu.au/ndis-guide-for-physicians>.

## 2. Recommendations

### The RACP calls on the NDIA to:

1. 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 backgrounds
  - who are refugees and other recent arrivals
  - children with developmental delay or disability
  - who are in out-of-home care or under a public guardianship;
2. 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";
3. 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:
  - a. developmental delay and other developmental disabilities
  - b. participants with a life-limiting condition who may require access to specialist palliative care;
4. 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;
5. ensure that practices and therapies funded by the NDIS are evidence based, explicitly goal-directed, and accountable to meaningful, measurable outcomes over set timeframes;
6. ensure that registration requirements for service providers include training and development of staff skills and practices so that they are equipped to support the health and wellbeing of people with disabilities;
7. ensure the review process delivers people with a timely response that captures their complex needs and provides adequate funding through the NDIS plan, especially where loss of community placement or risk of harm to the person or other members of the community exist. This 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;
8. support people with deteriorating or fluctuating conditions, whose level of support needs may vary over time;

9. 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;
10. continue to advocate for improved safeguards and reporting of child abuse of NDIS participants;
11. ensure that NDIS plans and their implementation are delivered in a timely way, including during the roll-out of the NDIS; and
12. 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 health services to:**

13. commit to supporting the goals and underlying principles of the NDIS, and emulate its person-centred approach;
14. review policies and procedures to improve access to health services and health outcomes, including reasonable adjustments to service delivery, such as:
  - a. working with the NDIS and NDIS providers in their area to ensure the provision of support during hospital attendances/admissions and that discharge plans are appropriate
  - b. coordinating with NDIS providers on health care needs of people living with disability in supported accommodation
  - c. comprehensive support for NDIS participants, especially those transitioning from early intervention to school or from paediatric to adult services, in collaboration with early intervention services, schools and other education providers and disability service providers. More frequent than annual reviews of NDIS plans throughout the transition period may be necessary
  - d. strategies such as longer appointment times and plain English health literature.
15. have a strategy for addressing the care needs of people living with disability who are socioeconomically disadvantaged;
16. improve data collection and evaluation of the experiences and health outcomes of people living with disabilities in their service, including those who are NDIS participants, and review policies and processes to improve outcomes; and
17. ensure that children at risk of developmental problems who may be eligible for the Early Childhood Early Intervention (ECEI) scheme have priority access to personnel trained in disability and early intervention.

**The RACP calls on NDIS registered service providers to:**

18. recognise their role in improving and maintaining health and wellbeing of NDIS participants, including facilitating their access to health services such as annual GP health assessments available under Medicare, and supporting them to implement treatment advice;

19. provide staff with training to support their participants' goals under the NDIS's Health and Wellbeing outcome domain; and
20. improve data collection on the health outcomes of NDIS participants in their services, and use that data to improve service provision.

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

21. fully implement the National Framework for Quality and Safeguards in order to protect NDIS participants from potential abuse by service providers;
22. ensure that users of existing disability programs, who do not fulfil the criteria for inclusion as NDIS participants, are not disadvantaged once the NDIS has rolled out;
23. 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;
24. 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;
25. recognise the critical importance of the health and wellbeing of carers and family members and ensure they are addressed;
26. closely monitor and address challenges faced by Aboriginal and Torres Strait Islander peoples in accessing the NDIS;
27. grant New Zealand citizens living in Australia and their children access to the NDIS, in accordance with reciprocal arrangements with New Zealand;
28. ensure the maintenance of the functions of health services that have, to date, been provided or funded by disability agencies; and
29. 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.

**The RACP calls on its members and other health professionals to:**

30. gain an understanding of the NDIS and its eligibility requirements, and provide information to people living with disability who may be eligible for the NDIS;
31. where appropriate to their specialty, offer:
  - a. full biopsychosocial and functional assessments of people living with disability who may be eligible for the NDIS
  - b. regular reviews of work capacity of NDIS participants and identification of forms of 'good' work that will be beneficial to their health, and assist with referral for education, training and vocational assistance

- c. documentation of assessments and comprehensive recommendations to NDIS applicants in a format which will support their application and assist the NDIS planner to understand the person's health support needs
  - d. early intervention standardised tools to identify children who may be eligible for the NDIS ECEI program, with measurement and validation of outcomes
  - e. timely reviews of potentially treatable, reversible, or life threatening conditions that may present as developmental delays in children living with disability; and
32. highlight co-existing conditions such as mental health disorders that may contribute to impaired functioning or challenging behaviour for people living with disability in any reports for the NDIS, including considering whether mental health disorders give rise to a disability that is relevant to NDIS eligibility.

**The RACP is committed to:**

- 33. incorporating the person-centred principles of the NDIS when developing relevant policies and clinician resources relevant to the health care needs of people living with disability;
- 34. working to improve our members' understanding of the NDIS and its impact on their patients, in part through the creation of NDIS Guides for Physicians and Paediatricians;
- 35. continuing to advocate for health care models that support people with disability to identify and participate in 'good work,' identified in our 'What is good work?' and 'Realising the health benefits of work' position statements;
- 36. continuing to advocate for NDIS, disability, health and education services to work collaboratively to develop effective care for young people living with disability and who are in transition from paediatric to adult services;
- 37. continuing to advocate for improved safeguards and reporting of abuse of NDIS participants; and
- 38. continuing to advocate for strengthening of accountability systems of health and disability service providers of the NDIS.



### **3. NDIS – individual autonomy and effective participation in society**

The NDIS represents a fundamental transformation of the delivery of support services to Australians living with disability. As an insurance scheme, the NDIS invests in people living with disability early, to improve their outcomes through life. Unlike previous models of service delivery, the NDIS provides a person-centred approach (PCA) with individualised funding arrangements. This approach aims to improve individual autonomy, which can deliver significant health benefits.<sup>2</sup>

With a lifetime approach, the NDIS supports people living with disability, their families and carers, to focus on what they can and want to do, including identifying what supports and services they need to achieve these goals. The NDIS has two parts: NDIS plans (sometimes known as individually funded packages) for eligible people with a disability, and information, linkages and capacity building (ILC). Both parts contribute to the overall goal of the NDIS to enable people with disability to live an ordinary life.

For those people eligible for a funded package, NDIA planners will assist in identifying goals and support needs and determine a funding package for those services and activities - an NDIS plan. Once a person has an NDIS plan with funding for specific goals, they are able to choose who will provide their support services and where, when and how. This part of the process may be supported by an NDIA partner in the community, e.g. Local Area Coordinator.

Health professionals can support people living with disability to identify their goals and needs, especially those relating to health and wellbeing and, where relevant, provide advice and recommendations about intervention and therapies. In the health and wellbeing domain, an individual's NDIS funding package could include coordination of supports, assistance with daily personal activities, decision making support, scheduling appointments and providing support for those with complex communication needs while accessing health services including hospitals. Importantly, living a healthy life, such as getting enough physical activity and eating a nutritious diet, is relevant for many aspects of a person's life.

Physicians and paediatricians may be asked to provide supporting documentation of a person's functional impairment and confirmation of disability to assist with completion of NDIS application forms.

Physicians, paediatricians and other health professionals can find more information on the NDIS in the RACP's NDIS Guides for Physicians and Paediatricians located on the [RACP website](#).

### **4. The impact of living with a disability on health, wellbeing and health care**

Good health is important for people of all ages, especially those living with disability. Poor health can reduce a person's participation in everyday life and lead to significant functional impairment or limitations. A person's health is influenced by socioeconomic factors, that is, those conditions in which people are born, grow, live, work and age. These influences are collectively known as the social determinants of health (SDoH).<sup>3</sup> Children and adults living with disability often experience additional socioeconomic disadvantage compared with other people in the community, such as financial and housing stress, living a long way from services and having transport difficulties.

The biopsychosocial model of health recognises the complex interplay of biological factors, psychological factors, disability and socioeconomic factors in determining health outcomes. It

represents a person-centred approach to health and wellbeing, and a means to equip health professionals to assist their patients with disability.

### **The impact of living with a disability on health – children**

*“Some people have a view of what is the ‘best option’ for us as a family and for Thomas. This was most apparent when he was taken to the doctor. It makes me feel more confident and relaxed if the health professional acknowledges Thomas in some way as a person, know his name and talks to him ... recognise him as a person and be enquiring about how he manages things. He is a loved person.”*

*– May and Thomas<sup>4</sup>*

Children with developmental disabilities can lead rich and rewarding lives, especially if they receive help and support to be included in their community. However, children with disabilities may experience difficulties such as higher rates of health problems and need for health services, early emergence of conditions such as obesity, additional behaviours that are challenging and mental health problems. The importance of supporting families, especially those experiencing significant stress from early in the child’s life, cannot be emphasised too strongly.

Early intervention and disability services can promote healthy living for children with developmental disabilities. This can include incorporating physical activity into programs and providing healthy food and nutrition. This can assist in laying the foundation for longer term health and wellbeing.<sup>5</sup> This is important in light of the health differences in children with developmental disabilities that are apparent from the early years, including a tendency to be more overweight and experience more hospitalisations than other children.<sup>6 7 8</sup>

The NDIA needs to recognise that carers of children with a disability often have a role that is far in excess of usual parenting responsibilities.<sup>9</sup> Constant care demands can be exhausting for carers, and specific characteristics associated with the disability, such as communication difficulties or challenging behaviours, are important predictors of parent stress.<sup>10</sup> Disability and health services working with NDIS participants should ensure that determined efforts to identify and address these problems are made, to reduce the risk of stress for carers and families.

### **The impact of living with a disability on health – adults**

*“We really need to have someone to be an ‘umbrella’ for all these services. There needs to be one main doctor who arranges for everyone involved to speak together once a year. To sit around a table together and to review what progress has been made, what issues there are and what we now need to do.”<sup>11</sup> - NSW Agency for Clinical Innovation-Intellectual Disability Network Patient Journeys*

There are many factors that have a significant impact on health of adults living with disability including:

- reduced employment opportunities;
- reduced social networks;
- inappropriate housing;
- lower educational standards;
- sustained economic hardship; and
- increased risk of social, physical, financial and sexual abuse.

Limited co-ordination of care for adults living with disability continues to frustrate carers as well as health professionals. NDIS planning for the individual can include provision of reasonable and

necessary supports to achieve employment if appropriate, adequate housing, and opportunities for social engagement.

### **The impact of living with a disability on health - intellectual disability**

While carers of adults with intellectual disability (ID) remain important when accessing health services, it is important for people with ID to be active participants in their own care. This may involve the provision of plain English information or other alternative communication tools to address difficulties understanding medical terminology, likely processes, and risks and benefits of treatment. Adults with intellectual disability are higher users of inpatient and outpatient health services<sup>12 13 14</sup> and experience higher rates of preventable in-hospital mortality and morbidity.<sup>15 16</sup> Some of the specific issues include:

- physical, policy, procedural and attitudinal barriers in hospital;<sup>17</sup>
- more often provided with palliative care status for conditions that would be treated in their peers;<sup>18</sup>
- diagnostic overshadowing - changes in a person's behaviour or functional abilities due to unrecognised physical or mental health conditions;
- negative experiences in the hospital setting including poor communication between staff and patient, over sedation, insufficient pain management and poor discharge preparations,<sup>19</sup> and some hospital staff displaying a lack of knowledge about intellectual disability<sup>20</sup>.
- limited health literacy - difficulties with learning and applying health knowledge, and in health decision making, and especially with communication, managing emotions and relating to other people;<sup>21</sup>
- difficulties providing health information, or with understanding what will happen during a physical examination or other procedure such as CT scan; and
- low degrees of health literacy amongst support workers, carers and family members.

Compared to their peers, adults with intellectual disability tend to have more health problems (on average 5 to 6 each) which may not be diagnosed or treated. Even though some may be related to the underlying aetiology of the disability, many are preventable health conditions. Different types of health conditions may be seen in people, depending on the severity of the disability, with more complex health needs requiring specialist input.<sup>22 23 24 25 26 27 28</sup>

A recently published study confirms that substantial health inequities remain for people with ID. In a large population-based cohort study in NSW that included 42,204 people with ID, median age of death of people with ID was 54 years, compared to 81 years in the general population, with 38 per cent due to potentially treatable conditions. Respiratory and neurological causes of death were particularly common, with an overall mortality figure of 1.3.<sup>29</sup>

This study is ground-breaking in Australia given its size, and that it systematically examines mortality in a large population of people with ID who use disability services. Although there are limitations to the study, the policy implications for health and disability services are significant. Whole of system responses are urgently required to address existing barriers to prevention, early detection and treatment of health conditions experienced by people with ID.

## **5. An opportunity to improve health outcomes for people living with disability, through improved access to mainstream services**

One of the key domains of an NDIS plan is health and wellbeing. This is a key opportunity to ensure that relevant disability supports required to achieve personal health goals are provided. The NDIS can achieve these aims by providing improved access to:

- early intervention in early childhood;
- timely and early intervention for children and adults with acquired disability, once acute management in the health sector has been completed;
- the provision of disability supports for accessing health care;
- assistance in accessing allied health care, equipment and consumables as required, to support the participant to undertake activities of daily life that are impacted by their disability; and
- education of support workers and family carers on the provision of health and wellbeing support.

### **Intersection of health and the NDIS**

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.

While the NDIS does not provide funding for mainstream services such as healthcare, it does have a role in funding some supports and services needed to maximise functioning in daily life. The NDIS will fund supports that assist people living with disability to undertake activities of daily living impacted by the person's disability. These may include wheelchairs, hearing aids, adjustable beds and prosthetics.

Allied health therapies such as physiotherapy, speech therapy or occupational therapy will be funded by the NDIS where these services are required to maintain function. However, the health system is responsible if these supports and services are required as part of rehabilitation post-accident or injury, or as part of treatment for a medical condition. The health system is also responsible for providing health services such as diagnosis and assessment of health conditions, clinical services and treatment of health conditions, medications and pharmaceuticals.

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.

The NDIA has developed review processes to address concerns about an NDIS plan as well as complaints procedures. There are circumstances in which a physician or paediatrician may feel that a participant's NDIS plan is not providing them with reasonable supports, or that a specific disability services provider is not provisioning these services appropriately. In these cases, a mechanism is available for a health professional to work with the NDIS participant to make a complaint where a problem exists, and seek an acceptable solution. This information is provided to participants by their planners - a practice the RACP supports.

### **Early childhood early intervention**

Early intervention programs are best delivered in a coordinated, planned, family-centred manner that reflects a life-course approach to health and wellbeing outcomes.<sup>30</sup> Timely review by an experienced paediatrician or other medical specialist is critical in identifying potentially treatable, reversible or life

threatening conditions that may present with developmental delay. Intervention provided as early as possible will improve outcomes for children with developmental delay, or at risk of delay, as a result of another condition, such as epilepsy or hearing impairment.

Parents and carers of children with developmental delay often express concerns about their child's progress prior to this being confirmed by professionals. There is evidence that providing support and services for infants and young children with early developmental impairments, and their families, can alter the child's longer term developmental trajectory and reduce the risk of secondary health and psychosocial complications.<sup>31</sup>

The NDIS has adopted an Early Childhood Early Intervention approach as part of its framework, to address the specific needs of children identified with, or at risk of, developmental delay or disability, aged six years and under. The aim of ECEI is to ensure that the child is included in their community and that parents or primary caregivers are able to provide young children who have developmental delay or disability with experiences and opportunities that help children gain and use the functional skills they need to participate meaningfully in the key environments of their lives (<https://www.ndis.gov.au/ecei>).

The ECEI model of care offers contact by an access partner, who then commences a conversation with the family in relation to concerns and goals they may have for their child. For children who are eligible for individual NDIS funding, this forms the basis of their NDIS plan.

The NDIS should consider the comprehensive assessments provided by paediatricians and multidisciplinary teams as part of the NDIS planning process. Health services should engage with the NDIA and NDIS service providers to conduct and communicate the results of assessments and provide education around assessment interpretation and significance.

NDIS and the health sector should collaborate to develop processes that allow the sharing of standardised assessments of function and need, and development of clear recommendations that are helpful to individuals and families. This can then be delivered in language that meets the requirements of the disability, health and education sectors.

Paediatricians bring expertise in understanding the evidence for effectiveness of various supports and interventions, and can help families make informed decisions about how best to spend their time and funding.

Other important elements of early intervention for the NDIS to encompass include:

- Ensuring expert advice is used to regularly review policies, procedures and approved interventions for children with neurodevelopmental and behavioural disabilities;
- Education of parents and carers and support workers, explaining why evidence-based supports are preferred, and the need to review the effectiveness of supports and interventions offered;
- Increasing use of standardised tools for detection and assessment of development and cognition; and
- Measurement and evaluation of the outcomes of children in the program.

#### **Other specific issues experienced by children with disability and their families.**

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 care 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>32,33</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 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>34</sup>

Health care access issues, placement instability and information sharing are ongoing challenges, with the risk of fragmentation of care. There is a collective responsibility amongst care providers, paediatricians and health care professionals, child protection case workers and NDIS planners, to work collaboratively. This will help to ensure that NDIS eligible participants in this highly vulnerable group are not disadvantaged. Training and support for care providers will need to include education around working within the NDIS.

Transition from paediatric to adult services can increase stress for the young person living with disability and the family, and may be associated with deterioration of function and wellbeing.<sup>35</sup> Different models of care tend to exist in adult and paediatric health care sectors, with varying levels of engagement with primary health care and other sectors. The NDIS, disability, health and education services must work together to develop effective care for young people during this period, with strong communication amongst services. Person-centred interviews and planning can be useful tools to support transition planning<sup>36</sup> and have been shown to be an effective mechanism to hear carer/family concerns and elicit instructive suggestions on improving transitional care.<sup>37</sup> Throughout the period of transition, provision needs to be made for NDIS plans to be reviewed more frequently than once per year, in order to facilitate a successful transition to adulthood, as well as to adult health and disability services. The RACP is aware that the NDIS is moving to set dates for plan reviews based on the likelihood that some NDIS participants will need their support arrangements changed. However, participants are able to request an unscheduled plan review, if their circumstances or support needs change, before the review date.

### **Adults living with disability**

The NDIS is an opportunity for health services to make reasonable and necessary adjustments to enhance disability support and access for NDIS participants and other people living with disability. 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<sup>1</sup>. 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.

Physicians can provide important assistance and information in NDIS plan development by:

- providing documentation about a patient's health diagnoses and the functional impact;
- assisting NDIS participants by discussing the types and levels of disability supports required to manage their health care issues; and
- providing advice around family and carer's needs in supporting the health and well-being of NDIS participants.

Health care and the provision of reports and information should be approached in ways that will be most useful to the NDIS participant through:

- providing reports and information in formats that will be most useful to the participant and NDIS planner;
- providing advocacy and negotiations with the hospital funding body and the disability service provider, if required supports are not NDIS funded in the hospital setting;
- assisting in the development of reasonable adjustments of health service delivery;
- using a biopsychosocial approach which provides the best opportunity to develop individualised adjustments to the patient's standard disease management plans, and recommendations for the most appropriate disability supports, taking into consideration their disability, personal attributes, social and economic circumstances;<sup>38</sup>
- including NDIS patients' disability support workers and families in the patient's healthcare management, listening to them and sharing understandable information about diagnosis and treatments as well as discussing the potential role of disability supports in the context of their NDIS plan; and
- making reasonable adjustments to ensure their services are as accessible and effective for people living with disability as for those who are not.<sup>39</sup> These may include:
  - longer and more accessible appointments;
  - accessible information;
  - earlier identification of disability;
  - addressing health equity issues;
  - printed discharge letters; and
  - handover notes for disability service providers.

Health assessments that include the functional needs of the person living with disability may be required to ensure that a full understanding of care, services and resource needs is provided for the participant in their discussion with the NDIA planner.

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<sup>1</sup> At present, whether or not reasonable and necessary support for inpatients are funded by the NDIS is unclear. Until the grey area is clarified, adult participants, their families and advocates should discuss with service providers what their own approach is in this situation and plan in advance for hospital admittances. This has implications for disability service providers in terms of their roles and responsibilities of support in the health facility setting. Clarification of this issue is urgent and requires resolution between NDIA and health service providers.

Health services should work with NDIS service providers in their geographical area to support development of health literacy amongst disability support workers and carers – to a degree sufficient to support the NDIS participant's health needs. In some instances, proposed reasonable adjustments to facilitate access to mainstream services and ideal models of service delivery have not been implemented across adult disability services.<sup>40 41 42</sup>

People living with disability in the residential sector face specific challenges in accessing health care. Support workers in these settings may not have had effective training in health care. Additionally, discharge planning post-admission, for individual patients living in a group home situation, can be complex. Health services should coordinate with the group home and NDIS service provider of a person living with disability where appropriate, to share health updates in accessible language formats.

Disability that fluctuates and emerges over time, such as motor neurone disease, multiple sclerosis and psychosocial disability, may prove complex for a system where established disability with more consistent life course is more common. There will need to be flexibility in plans to accommodate fluctuations in care support needs over time.

### **Adults with acquired disability**

For NDIS clients with an acquired disability, physicians can assist through diagnosis of the clinical condition and associated disability, allowing for a tailored management plan to ensure maintenance of function and quality of life.

Disability assessors and providers should work with health services at key intersection points to allow planning for those with acquired disability to begin as soon as possible. These access points include acute and sub-acute hospitals, ambulatory services and community health centres. Better communication between care providers and allied health services will allow earlier assessment of functional needs and ensure correct determination of equipment needs under an individual's NDIS plan. Key performance indicators for carers and support providers must be in place to ensure maintenance of the individual's optimal level of function.

Case managers and reviewers must recognise the differences between maintenance of function (disability services) and functional recovery (rehabilitation/health services) in the knowledge that client status and needs can change over time. This may be reflected in a need for more consistent reviews of plans for an NDIS recipient living with a recently-acquired disability.

Adults living with developmental, intellectual and acquired neurological disability may not be able to verbally express symptoms that indicate significant pathology. It can take longer to develop rapport and obtain an accurate medical history. Physicians need to gather information, often from family, carers or service providers, about the patient's personality, biopsychosocial setting, communication style and supports.

Disability services that should be considered in NDIS planning to enhance access to health services include:

- transport access and requirements;
- educational needs and support;
- vocational needs and support;
- relationship/family counselling including sexuality counselling;
- behavioural and adjustment counselling;
- home and vehicle modifications;



- worksite assessment and modification; and
- recreational and avocational supports.

Areas where potential under-utilisation and poor delivery of services are particularly prevalent include:

- acquired brain injury, stroke, multiple sclerosis, chronic neurological conditions beyond the physical deficits including cognitive and language deficits, behavioural issues;
- spinal cord injury;
- amputee prosthetics;
- arthritis and chronic pain syndromes;
- chronic cardiac, respiratory and renal conditions; and
- childhood neurological conditions transitioning into adulthood.

### Employment access

The NDIS can assist and enable people living with disability to develop skills and undertake training to prepare for work and to reap the health, social and economic benefits of training and employment. Evidence shows that work in general maximises health outcomes, financial security, self-esteem and independence.<sup>43</sup> It is anticipated that once fully implemented the NDIS will support 25,000 to 40,000 people living with disability to find work, and enable 34,000 carers back into the workforce, thus contributing to a significant increase in participation in Australia's economy.

Employment can provide increased income and, with this, higher living standards and financial independence. Employment can contribute to a sense of identity and self-worth and have positive impacts. The RACP Position Statements of 'Realising the Health Benefits of Work' and 'What is Good Work' have summarised other health benefits to employment, and the Productivity Commission has noted NDIS support for people living with disability to engage in healthy employment will have economic benefits for Australia.<sup>44 45 46</sup>

Physicians can work with the NDIA to conduct timely and regular reviews of work capacity. Work capacity status is not static. As general health improves and other non-disability related issues are addressed, work capacity increases.

Physicians, particularly occupational physicians, can work with people living with disability from a strengths-based perspective to establish what work they are able to do. They can provide advice to their NDIS planner on:

- the nature of workplace modifications and appropriate equipment that would support individuals living with disability within the workplace;
- referral to disability employment services for assistance with work preparation including vocational counselling, upskilling and identification of suitable training options;
- transportation costs to and from the workplace;
- equipment to facilitate workplace integration; and
- social skills training and cognitive training.

Separately, the RACP supports improved access to flexible working arrangements which assists those with caring responsibilities to remain connected with the workplace, to facilitate leave as required and then entry back into the workforce. This benefits the family carer's own health and wellbeing, which in turn will optimise the care that they can provide to the person living with disability.

Where possible, the NDIS should work with employers to ensure that flexible work practices for people living with disability and their family carers become mainstream. Making job design and work environments flexible for all employees should be a priority. Managers require information, support and training in the nature and impact of discrimination, and the important skills and contribution people living with disability can bring to their business.

### **Carers of people living with a disability**

The welfare of the family carer and/or NDIS support worker is an occupational health and safety issue. The family's wellbeing can directly affect the person living with disability. Supporting people living with complex disabilities can have a significant impact on carer energy, mental health, general health and welfare, employment opportunities and the ability to perform family responsibilities. It is important for family carers of people with high needs to be financially supported with time to rest and participate in activities that improve their own general wellbeing.

Family carers' capacity to manage the complex needs of people living with disability may vary. Factors such as English language fluency, health and computer literacy, as well as their own psychological wellbeing can be important.

NDIS providers should ensure adequate education and support of family carers to deliver optimum care for the person living with disability within the carer's capacity. Support and education around preventative strategies to manage the carer's physical and mental health is essential. Failure to meet these necessary supports can risk family breakdown. Family carers require training in skills such as manual handling, managing challenging behaviours and specific health based advice around optimum care of the person living with disability. The NDIS does not provide direct support to carers.

## **6. Maximising health outcomes for people living with a disability**

Health services and professionals, including physicians and paediatricians, need a working knowledge of the NDIS including its underpinning principles, eligibility requirements and planning process. Successful NDIS implementation requires collaboration and engagement between the NDIA, the disability sector, mainstream health services and the education sector.

The NDIA has committed to broad consultation as it rolls out across Australia, though anecdotally there is scope for improved consultation with health stakeholders. Key health stakeholders include consumers, clinicians, NDIS-registered allied health providers, hospital administrators, disability and health government agencies, primary healthcare networks, private hospitals, disability service providers, early childhood educators, professional organisations and societies and representatives from communities facing additional challenges.

Areas where collaboration could bring benefits include:

- promoting a person-centred approach in hospital services, especially within adult medicine;
- improving knowledge of the NDIS among physicians and other health workers;
- clarifying the role of disability supports in hospital settings;
- better understanding the implications for NDIS participants of non-standard models of healthcare for adults with intellectual disability;<sup>47 48</sup>
- mutual sharing of health and disability sector knowledge;
- exploring opportunities for people living with disability to engage in or return to work in a way that acknowledges their strengths and capabilities;
- production of practical guidance and supporting documents for both health and disability workers; and
- consideration of end of life care for people living with disability.

It is important that there is engagement at many levels, from hospital departments and health services, to state and territory and national government. The RACP recognises that diverse and innovative models of engagement and collaboration are being developed, and encourages its members to participate in such groups and share information.

## Specific Groups Facing Challenges

This position statement does not comprehensively explore the specific challenges faced by some groups in the community accessing health care. Health professionals and health services will need to work with the NDIA to ensure that any groups facing these challenges are well accommodated. They include:

- rural and remote people living with disability:
  - Rural and regional areas can experience a confluence of health and disability services workforce shortages that can impact upon the type, variety and, potentially, the quality of disability services available.
  - Where personnel do exist in remote and rural areas, their workloads are often large and diverse, which limits time available for the provision of early intervention for young children.
  - An opportunity exists to supplement these services in rural and remote areas of Australia with innovative use of telehealth, parent coaching and therapy assistance to supplement the service provided by existing allied health staff.
- people from culturally and linguistically diverse backgrounds (CALD):
  - The person-centred focus of the NDIS allows CALD people living with disability, their families and carers, to choose support services from culturally appropriate multicultural service providers.
  - Participation of people from CALD backgrounds in the NDIS trial sites was less than 2 per cent in both Victoria and NSW, suggesting access is a significant issue for this population group.<sup>49</sup>
  - The NDIS does not include funding for language services which has implications for all people with low English proficiency making information inaccessible.
- children and young people at risk of maltreatment, or who have experienced systems abuse:
  - Children living with disability are at higher risk of harm inflicted by others or neglect of their material needs and wellbeing. This issue requires ongoing attention, noting that the Commonwealth Government has taken the positive step of funding an independent commission to implement the NDIS quality and safeguards framework.
- refugees and new arrivals:
  - The ability to obtain a diagnostic clinical assessment to satisfy eligibility criteria to gain access to the NDIS is an issue for many new arrivals.
  - At this stage, it appears people seeking asylum will not have access to the NDIS, whereas children of asylum seekers have previously had access to early intervention programs. The RACP is concerned about children of asylum seekers potentially missing out on vital early intervention being unable to access the NDIS ECEI.
- Aboriginal and Torres Strait Islanders:
  - The First People's Disability Network has a [10 point plan](#)<sup>50</sup> for the roll-out of the NDIS as it pertains to Aboriginal and Torres Strait Islanders.

- people living with disability in the justice system:
  - People with intellectual disability are often hidden in mainstream criminal justice systems, and can experience poor general health and psychiatric morbidity.
  - Time in custody provides an opportunity for a comprehensive health assessment, and potentially establishing eligibility for access to the NDIS.
- out-of-home care:
  - The physical, mental and social health needs of children and young people in out-of-home care are well recognised, with a high prevalence of chronic medical conditions, disability and developmental delay.
  - Children in out-of-home care need to be identified. The NDIA should work with the responsible States and Territories to develop a system to identify and track children in out-of-home care, and participants of other disability services, to facilitate access to the NDIS as it becomes appropriate to their circumstances.
  - Training and support for care providers will need to be included in NDIS planning.
- children with neurodevelopmental and behavioural disabilities:
  - This group is at high risk of poor mental health, educational and economic outcomes, and their families and carers are more likely to experience high levels of emotional and financial stress.
  - It is essential that care and services provided through the disability, health and education sectors work seamlessly and coherently to provide appropriate intervention and care to allow these children to participate fully in all aspects of their lives.
  - Provision of these services needs to be considered through a developmental lens as children transition through preschool, school and into adulthood.
  - Access to appropriate evidence-based interventions at the right time can have a significant influence on their prospects for becoming happy, contributing adult members of Australian society, as well as on the level of disability support required in later life.
- mental health concerns:
  - The Australian Institute of Health and Welfare (AIHW) found that in 2011-2012, half of people aged under 65 with severe or profound core activity limitation had mental health conditions.
  - As a consequence of symptoms associated with their disability, mental health issues in a person living with disability may not be recognised (referred to as diagnostic overshadowing). In conducting health assessments for people living with disability, physicians and other health professionals should be alert to indicators of mental health conditions.
- citizens of New Zealand living in Australia:
  - New Zealanders face restrictions on their ability to access the NDIS, and these restrictions should be removed.

## Current challenges faced by the NDIS

Any major reform on the scale of the NDIS is likely to face setbacks and challenges during implementation, some of which may be difficult to foresee. National Disability Services (NDS) recently

released a list of proposals and ideas to improve the current rollout of the NDIS.<sup>51</sup> The list cited the most pressing challenges facing the NDIS rollout as:

- Speed: the pace of the rollout is being maintained to meet inter-governmental agreements.
- Funding: debate about the means by which to fully fund the NDIS (noting that it is projected to deliver significant economic and social benefits).
- Systems: citing independent reports, NDS notes that there are some inefficiencies with the NDIS MyPlace Portal and the systems that process registration requests. There are concerns these systems may not cope with the weight of a full roll-out.
- Supply: concerns around whether the market can support the high support requirements of NDIS participants once the roll-out has reached a larger scale. The Productivity Commission released a draft position statement in June 2017 for feedback from Stakeholders which will inform their final report. The Commission raises similar concerns around the pace of scheme roll-out, rapid expansion of the disability workforce, transition for current disability sector consumers into /not into the NDIS, the need for tracking outcomes and the need for data collection on who is in the scheme, what services they are likely to require and their costs to ensure financial sustainability of the scheme.
- NDS has proposed a range of measures to mitigate these challenges in its report, [How to get the NDIS on track](#)<sup>52</sup>. Amidst ongoing discussion at a State and Commonwealth level about funding and eligibility, it is important that there are systems in place to regularly review progress and address issues, and to ensure that any changes are in the best interests of NDIS participants.

## 7. Conclusion

The NDIS presents a transformative opportunity to support people living with disability to achieve lifespan goals. It is a chance to improve the participation and quality of life of adults and children living with disability who access the Scheme, and their carers. There are many areas where health services and the NDIS should work in partnership alongside other stakeholders. Physicians, paediatricians and healthcare providers in child development, paediatric disability, adult disability and mental health are eager to support the NDIS delivering its promised outcomes to Australians living with disability.

The RACP welcomes the NDIS as a bold step forward in recognising Australia's responsibility to support people living with disability to be fully engaged participants in our society. We look forward to the health sector adapting to maximise the positive impacts of the NDIS for the health of all its participants.

The RACP recognises that the NDIS is evolving and as such this position statement may be updated as the NDIS roll-out progresses.

## 8. List of abbreviations used in this document

NDIS – National Disability Insurance Scheme

NDIA – National Disability Insurance Agency

RACP – Royal Australasian College of Physicians

ECEI – Early Childhood Early Intervention – the approach NDIA uses to work with Early Childhood Providers to deliver early childhood intervention for children aged 0-6 years

PCA – Person-centred approach

SDoH – Social Determinants of Health

ACI – Agency for Clinical Innovation

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