



RACGP

Royal Australian College of General Practitioners

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RACGP submission

Review of the NDIS Act and the new NDIS Participant Service Guarantee

November 2019

1. Introduction

The Royal Australian College of General Practitioners (RACGP) welcomes the opportunity to provide a submission to the review of the National Disability Insurance Scheme (NDIS) Act and the new NDIS Participant Service Guarantee.

The RACGP is Australia's largest professional general practice organisation, representing over 40,000 members working in or toward a career in general practice.

The RACGP is responsible for:

- defining the nature and scope of the discipline
- setting the standards and curricula for training
- maintaining the standards for quality general practice
- supporting specialist general practitioners (GPs) in their pursuit of excellence in patient and community service.

2. Recommendations

The recommendations below have been developed based on member feedback on the current operation of the NDIS, and GPs' involvement with and experience of the NDIS as it has been rolled out across Australia.

Relevant background and rationale relating to each recommendation is outlined in section 3 of this submission.

2.1. Improving the NDIS access process

To make it quicker and easier for patients to access the NDIS, the RACGP recommends that the review consider:

Staffing

- ensuring that staffing levels are adequate to respond to the large number of people seeking access to NDIS services. Our members are concerned that the NDIS staffing cap has slowed the rollout of supports
- ensuring staff are appropriately qualified and trained to undertake their role, supporting people to navigate the scheme while also improving the timeliness of service delivery.

Standardising forms and processes

- introducing standardised processes to guide decision-making in the NDIS and to improve consistency between participants' experiences, supports and funding
- introducing standardised GP functional assessment forms for both adults and children that are more comprehensive than the current Access Request Form
- allowing people with disability to review assessment reports before being submitted to the National Disability Insurance Agency (NDIA) to ensure their concerns have been correctly represented
- making decisions within reasonable timeframes.

Communication

- sending NDIS applicants a confirmation letter or email with a reference number when a matter has been discussed or is pending approval
- increasing engagement between planners and GPs to resolve any questions about a patient's diagnosis or the impact of their functional impairment.

2.2. Enhancing the role of GPs in the NDIS planning process

As raised in our [submission](#) to the Joint Standing Committee on the National Disability Insurance Scheme – In order to enhance the role of GPs in the NDIS planning process, and therefore improve the quality and effectiveness of NDIS plans, the RACGP recommends that:

- GPs have the opportunity to view and discuss a draft of a patient's NDIS plan with the patient, and provide feedback and advice to NDIS planners for consideration when finalising the plan
- there be an option for GPs to automatically receive a copy of a patient's NDIS plan (with patient consent) to allow them to keep a complete record of their patients' health and social journey (supporting continuity of care)
- notifications be sent to a patient's usual GP to update them on the patient's NDIS status and provide information relevant for the provision of ongoing, holistic care by the GP
- GPs be able to make direct contact with NDIS planners (with patient consent) to advise of issues being experienced by a patient or the need to amend their plan.

2.3. Other recommendations to improve the planning process

To further improve the planning process and prevent delays in accessing key supports, the RACGP recommends that:

- plan reviews are completed within set timeframes (ie three weeks) and, when required, be accelerated to ensure the participant continues or starts receiving necessary supports
- more flexible options for attending planning meetings be made available, such as Skype
- comprehensive records of planning discussions be maintained to prevent the duplication of information.

2.4. Legislative framework

To strengthen the legislative framework (NDIS Act and Rules), the RACGP recommends that:

- the term 'review' be clarified, as it currently has multiple meanings
- section 24 of the Act be amended to clearly outline the disability requirements to gain entry to the NDIS.

2.5. Recognition of the GP role in supporting applicants to the NDIS

The RACGP recommends that the review consider how GPs can be reimbursed for time spent preparing reports and other relevant documentation to support NDIS applications. This includes circumstances where their patient is not physically present in the consultation room.

2.6. NDIS Participant Service Guarantee – additional principles

The RACGP recommends that the following principles be included in the new NDIS Participant Service Guarantee along with those listed in the discussion paper:

- Consistent – consistency in decision-making and funding across all jurisdictions.
- Quality – ensuring that the NDIS provides high-quality services to people with disability and meets their support needs.

3. Discussion

The RACGP sought feedback from all members to inform this response to the review of the National Disability Insurance Scheme (NDIS) Act and the new NDIS Participant Service Guarantee. The below summarises the feedback received from our members, as well as drawing on previous RACGP policy advice and advocacy activity regarding the NDIS.

3.1. Improving the quality of information provided about the NDIS

Our members have advised that their patients are:

- given insufficient or inconsistent information when they apply for access to the NDIS, including both the process and timeframes. Step by step information with clear service timeframes for patients and their families is required
- often unaware of available services and therefore do not ask for these at planning meetings. This leads to inequity as those with greater knowledge of services (through an advocate or assistance) will usually receive a more comprehensive plan.

3.2. Recognising the role of GPs in supporting people with disability

Increased awareness and recognition of the role that GPs and general practice have in the care of people with disability is needed, including support to access and understand the NDIS.

3.2.1 Continuity of care

GPs are most often a patient's first point of contact in the health system and provide ongoing care for their patients, whether or not they are accepted as an NDIS participant. NDIS processes should support this existing therapeutic relationship, and not lead to fragmented care.

Even when other health professionals are providing support to a person with disability, many people with disability often have other health issues which require care from GPs and their teams. Therefore, GPs are intrinsically involved in disability work and often have a strong and ongoing relationship with people who have a disability.

3.2.2 Supporting their patients to access the NDIS

GPs play an important role in assisting their patients to access the NDIS. When a person is applying to become an NDIS participant, they (or an NDIA representative) will ask a GP to provide evidence of disability and functional impact. The GP may provide this evidence by completing the supporting evidence section of the NDIS Access Request Form, but will most commonly provide copies of relevant assessments or reports outlining the extent of the functional impact of a disability. This can be particularly helpful for patients and families who do not feel confident articulating the impact of a disability themselves.

If a patient's NDIS request is denied, they have the right to appeal the decision. Their GP may play a role in supporting them to do so, including alerting them to the possibility of appeal. If the original decision is upheld, the GP will often try to provide or find appropriate support services for them.

3.2.3 Helping patients to understand how the NDIS works

People with disability frequently seek help from their GP to understand NDIS fact sheets, letters and emails, as well as their plan once this has been developed. This is especially true of people who:

- have English as a second language
- have a disability affecting their language comprehension level
- are overwhelmed with a new diagnosis of a disabling condition.

To assist patients who have an upcoming planning meeting, GPs may run through the NDIS process with them and prepare a list of services and items of equipment that they think would be beneficial for the patient's needs. The patient can then use this at their planning meeting. During this consultation, the GP may also discuss goal setting with the patient and explain how funding is allocated. Member feedback indicates that patients generally find these face-to-face meetings more helpful than being directed to a website that is difficult to navigate.

Members also report that patients and families may seek their help to interpret the recommendations of multidisciplinary diagnostic assessments and functional capacity assessments performed by other health professionals as part of the access process. This further emphasises the need for the NDIS to formally recognise the role of GPs in providing ongoing care and ensuring that they are appropriately communicated with regarding their patients' NDIS interactions.

3.3. Issues with the NDIS planning process

3.3.1 GPs should be integral to planning conversations

The RACGP provided a [submission](#) to the Joint Standing Committee on the National Disability Insurance Scheme inquiry into NDIS planning in September 2019. This submission outlined the RACGP's concerns in relation to the lack of involvement of GPs in the planning process.

3.3.2 Some people with disability are unable to participate in planning discussions

RACGP members have noted that patients with cognitive difficulties may need active support to be involved in planning discussions.

A participant's ability to advocate often determines what is included in their plan. Members report that some parents or carers of people with a cognitive disability are able to advocate on their behalf and therefore can assist in securing appropriate funding. However, not all participants have access to a skilled advocate with the knowledge and awareness to speak on their behalf.

3.3.3 Funding variability is not well understood or explained

The level of funding allocated to participants can differ depending on the planner's understanding of their particular needs. For example, GPs have reported significant discrepancies (ie thousands of dollars) between funding packages provided to children with autism. This includes children who are non-verbal being given a fraction of the amount of other children with less severe forms of the condition.

3.3.4 Participants need more support to understand how to use allocated funding

Members report that some participants are being allocated funding but are unsure how this should be spent, even if they have access to support coordination services. Subsequently, participants are allocated less funding when their plan is reviewed as a result of the unspent funds, despite genuinely needing the funds to cover their support needs.

3.4. Ways to improve the planning process

3.4.1 Involve GPs in plan development

The RACGP's [submission](#) to the inquiry into NDIS planning includes a number of recommendations to enhance the role of GPs in the NDIS planning process, and therefore improve the quality and effectiveness of NDIS plans.

Implementation of the RACGP's recommendations by increasing the involvement of GPs in the NDIS planning process would:

- speed up the planning process by ensuring planners are provided with comprehensive information about the functional impact of a person's disability
- reduce patient stress as the patient is more supported to advocate for their support needs
- allow for more equitable distribution of limited NDIS funds, with realistic expectations prior to the formulation of a plan as to how much therapy a participant requires per given year
- ensure the GP can maintain referrals and improve the flow of communication between the participant's care team
- reduce costs by minimising the volume of enquiries being submitted to the NDIA

- potentially reduce requests for plan reviews due to establishing a clear expectation for care, ongoing continuity of care and a clear pathway for review when indicated.

3.4.2 Introduce a process to accelerate plan reviews where needed

Participants often experience delays in having their plan reviewed. GPs have recommended that there should be a mechanism in place to accelerate a review when there is an obvious problem with a plan, including an issue identified by a participant's GP.

As with initial applications and plan approvals, the time taken to complete plan reviews can vary considerably between participants. Members have stated that reviews should not take more than three weeks to ensure that participants are not left waiting for access to vital supports.

3.4.3 Introduce more flexible options for planning meetings

NDIS participants require more flexible non-face to face options to attend planning discussions, particularly if their disability limits their capacity to travel to face-to-face meetings.

3.4.4 Keep records of planning discussions

All interactions between participants and the NDIA, planners and Local Area Coordinators should be documented so that participants are not required to provide the same information repeatedly.

3.5. Specific concerns in relation to the NDIS Act and Rules

3.5.1 Use of the term 'review'

As noted in the discussion paper, the term 'review' is used in two different ways in the NDIS Act, which is a source of confusion for stakeholders and the NDIA. The RACGP agrees that the Act should be amended to clearly articulate the difference between a plan review and a review of a decision.

3.5.2 Section 24 of the Act – Disability requirements

Section 24 of the NDIS Act outlines the disability requirements a person must meet to be eligible to access the scheme.

This part of the legislation has been the subject of mixed and confused interpretations, and has had a significant adverse impact on children with disabilities who are transitioning from the Early Childhood Early Intervention approach to the full NDIS.

Our members have reported cases of different interpretations of the legislation affecting children who entered the NDIS via the Early Childhood Early Intervention approach with one diagnosis (eg global developmental delay), before being diagnosed with another condition (eg level 2 autism). These children attend a GP consultation to gather the necessary documentation to justify their ongoing disability under this section of the Act. However, interpretations of what sort of documentation meets the requirements of this part of the legislation can vary considerably. Confusion around what exactly is required can lead to lengthy delays in accessing therapies.

For example, two children who were both diagnosed with level 2 autism were required to produce substantially different documentation to prove they met the disability requirements. One child only needed a letter from their paediatrician, while the other was not accepted until they underwent an expensive and time-consuming Adaptive Behaviour Assessment System-3 (ABAS-3) assessment.

Our members note that other key stakeholders have also expressed concern about the value of the Early Childhood Early Intervention approach, with calls for children who are likely to be long-term NDIS participants to progress straight to an NDIS package.¹

3.6. Other issues

3.6.1 Patients and GPs do not receive financial support for some requests related to patient access to the NDIS

The Department of Health has confirmed that patients are eligible to access Medicare Benefits Schedule (MBS) rebates for consultations with their GP when the GP is assisting them to apply for the NDIS (eg assisting with an Access Request). However, MBS rules for GP consultations stipulate that they can only be billed if the patient is present in the consultation room.

Our members have advised that the NDIA requests extensive reports supplying a patient's medical history, letters from other non-GP specialists, discharge summaries and more. The NDIA may request this information separately from or subsequent to an Access Request. Where similar reports are prepared for other insurers (who might request the information in the same way the NDIA does), a GP will charge the insurer for the time and effort involved.

A GP is unlikely to request that a patient attend a consultation for paperwork that the GP can complete in the patient's absence, particularly if the patient's disability prevents them from easily accessing the practice. In such cases, because the patient is not present while the request is completed, MBS rebates are not available and there is no other facility that currently exists for the NDIA to reimburse the GP for their time and expertise completing such requests.

Without the support from the MBS, a financially vulnerable patient seeking access to the NDIS may be unable to afford their GP's fee for this service.

The RACGP recommends that the review consider how GPs can be reimbursed for time spent preparing reports and other relevant documentation to support NDIS applications. This includes circumstances where their patient is not physically present in the consultation room.

3.6.2 Assessment tools for children with autism

Another issue raised by our members is the use of the generic Paediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT) for children who already have a diagnosis of autism instead of the version specifically designed to assess the performance of children with the condition. This has resulted in children being assessed as having higher functional capacity than they actually have. Concerns have also been raised that the PEDI-CAT is being administered by people without suitable qualifications.

3.6.3 Seeking a review of a decision

GPs report that the advice their patients are given when seeking to review a decision can be confusing. Some participants are hesitant to request a review for fear they will be left with less funding. The availability of evidence and expertise to support a review may also be limited.

3.7. Principles to be included in the new NDIS Participant Service Guarantee

The RACGP supports the inclusion of the principles outlined in the discussion paper and recommends the following principles also be included in the Participant Service Guarantee:

- Consistent
 - There should be consistency in decision-making and funding across all jurisdictions.
- Quality
 - The NDIS should be capable of providing high-quality services to people with disability and meeting their support needs.
 - Reviews of NDIS plans should involve collecting outcome data that is used for continuous quality improvement purposes, both in terms of the quality of the plan and the suitability of the services provided to the participant.
 - Ongoing research should also be done to ensure the scheme remains fit for purpose now and into the future.

3.8. Reflections on current fulfilment of principles

RACGP members report that, although improvements have been made, NDIS processes have proven challenging and the NDIA has largely not fulfilled the principles listed in the discussion paper.

Below outlines some concerns reported by our members in relation to the principles recommended for inclusion in the Participant Service Guarantee.

3.8.1 Timely

The RACGP notes that it can take significant time for NDIS applications and plans to be approved and in some cases those with the most complex needs are being left waiting for support. Additionally, GPs report that children who were already receiving disability services (as part of another disability support service) prior to transitioning to the NDIS have had their applications delayed because of IT issues.

Members have also advised that their patients have resorted to buying their own assistive equipment due to the long wait times to be approved (eg a participant purchasing their own specialised bed for pressure sore prevention and respiratory care). Delays in being approved for equipment upgrades can prevent participants from engaging in activities, as their current item of equipment, such as a wheelchair, may not be suitable for that purpose.

Members have reported that their patients have experienced delays in the scheduling of planning meetings. This can result in a great deal of stress for participants and their families due to being unable to access key supports.

3.8.2 Engaged

All NDIS applicants are required to undergo a functional assessment to demonstrate the impact of their disability on their everyday life. Members have advised that the quality of these assessments can differ greatly. This is largely due to the lack of guidance provided by the NDIA around what should be covered.

The current Access Request Form has a number of limitations and does not allow for GPs and other health professionals to fully detail the functional impact of a person's disability. The form provides insufficient space to respond and is not available electronically.

The RACGP has [previously highlighted](#) the need for more efficient and reliable disability assessment tools for GPs. We recommend that, to streamline the NDIS access process, standardised GP functional assessment forms for both adults and children be developed. There are various functional assessments currently used to support patients accessing the NDIS. The development of two standardised and comprehensive assessment forms, one for adults and one for children, would support GPs in highlighting the differing support needs of these cohorts. It has been proposed that such forms could include tick boxes so that GPs can provide as much information as possible in the shortest length of time. This would also make it easier for the GP to complete the assessment without the patient being present in the room.

In line with the service standard for the 'Engaged' principle proposed in the discussion paper, all application and assessment forms must be able to be understood by people with different abilities and needs.

3.8.3 Expert

Expertise varies considerably amongst planners and Local Area Coordinators. While there are NDIA staff who are highly competent and have a sound understanding of disability, GPs have found that others do not have the requisite knowledge or expertise to engage effectively with all those involved in the NDIS process.

GP experience has found that although NDIA staff may have undergone the same or similar training, their ability to analyse a situation and provide advice on appropriate supports can differ. As a result, different patients can have a different experience and outcome depending on the staff member they engage with.

NDIS participants require access to planners and Local Area Coordinators who understand their needs and can respond to any questions or concerns that the participant and their family may have.

Fulfilment of this principle is complicated by the number of staff needed to ensure the scheme operates effectively. The RACGP understands that a lack of appropriate follow through on key actions is resulting in people with disability missing out on key supports.

There also seems to be a lack of communication between the NDIA and Local Area Coordinators, with both parties unsure of their roles and responsibilities.

3.8.4 Connected

Dialogue between the NDIA and the health sector has been limited and needs to be improved. Achieving this principle should involve connections between all those providing care to the participant and their family members or carers, including GPs.

Members report that it would be beneficial for patients if their GPs were supported to liaise with disability service providers to advise of issues being experienced by their patients. GPs have also reported being unable to make contact with Early Childhood Early Intervention partner organisations to discuss particular systemic issues (eg phone calls not being returned).

The NDIS must also be capable of responding to emergencies involving people with disability – such as someone presenting to a hospital emergency department in urgent need of accommodation because their parents are no longer able to cope. Being more connected to the wider health sector (including the hospital system) would support this.

3.8.5 Decisions are made on merit

The RACGP believes that national standards to guide decision-making in the NDIS would be beneficial. Standards would help to prevent inconsistencies with regard to applications being accepted or declined and funding amounts. Members have identified this as a significant issue, with differences in what is approved even being evident between siblings who have the same condition and level of impairment.

Members also report that people with disability whose application has been rejected are often not provided with an adequate explanation as to why this has happened.

3.8.6 Accessible

It is essential that the NDIS is accessible for all people with disability and can deliver culturally appropriate services. Research has concluded that the NDIS can entrench health inequalities because it does not take into account social determinants of health at the individual level as a barrier to exercising choice and control.² This could disproportionately affect some groups, such as Aboriginal and Torres Strait Islander people, who are more likely to experience disability and be adversely impacted by social determinants of health.

4. Conclusion

The RACGP looks forward to contributing to further discussions around the NDIS and the new Participant Service Guarantee.

5. References

¹ Royal Australasian College of Physicians. Provision of services under the NDIS Early Childhood Early Intervention Approach – written submission. Sydney: RACP, 2017.

² Malbon E, Carey G, Meltzer A. Personalisation schemes in social care: are they growing social and health inequalities? BMC Public Health 2019 Jun 24;19(1):805.