

24 March 2017

Review of NDIS Costs
Productivity Commission
GPO Box 1428
BARTON ACT 2600

Dear Commissioners

Re: National Disability Insurance Scheme (NDIS) Costs

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) is pleased to provide a written submission to the Productivity Commission's study into the costs associated with the National Disability Insurance Scheme (NDIS).

The RANZCP has almost 6000 members including more than 4000 fully qualified psychiatrists, many of whom have specific interest and expertise relevant to this study. As such, the RANZCP is well positioned to provide assistance and advice about this issue due to the breadth of clinical, academic and service delivery expertise it represents.

The RANZCP supports the purpose of this study and welcomes the opportunity to contribute. We strongly support efforts to ensure the financial sustainability of the NDIS to ensure that people with psychosocial disability can be provided with adequate goods and services to improve their well-being, independent living and participation in the community, both now and into the future.

However, the RANZCP continues to have concerns about the financial sustainability of the NDIS with regard to people with psychosocial disability. These concerns largely relate to the interface between the NDIS and mental health services as well as the readiness of people living with mental illness, eligibility criteria, the scope and availability of funded supports, and aspects of the planning and assessment processes.

Please see the attached submission for detailed responses to questions raised in the issues paper.

If you would like to discuss any of the issues raised in the submission, please contact Rosie Forster, Senior Department Manager, Practice, Policy and Partnerships via

[REDACTED]

Yours sincerely

[REDACTED]

Professor Malcolm Hopwood
President

Ref: 0663o



The Royal
Australian &
New Zealand
College of
Psychiatrists

Productivity Commission
National Disability Insurance Scheme Costs

March 2017

advocating for
equitable access to
services

Royal Australian and New Zealand College of Psychiatrists submission

National Disability Insurance Scheme Costs

About the Royal Australian and New Zealand College of Psychiatrists

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) is a membership organisation that prepares doctors to be medical specialists in the field of psychiatry, supports and enhances clinical practice, advocates for people affected by mental illness and advises government on mental health care. The RANZCP is the peak body representing psychiatrists in Australia and New Zealand and as a bi-national college has strong ties with associations in the Asia-Pacific region.

The RANZCP has almost 6000 members including more than 4000 fully qualified psychiatrists and nearly 1400 members who are training to qualify as psychiatrists. Psychiatrists are clinical leaders in the provision of mental healthcare in the community and use a range of evidence-based treatments to support a person in their journey of recovery.

Introduction

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) is pleased to provide a written submission for the Productivity Commission's study into the costs associated with the National Disability Insurance Scheme (NDIS). We value the ongoing consultative approach taken by the National Disability Insurance Agency (NDIA) and other stakeholders and we are pleased that concerns voiced by the RANZCP and others in the mental health sector are being increasingly heard.

The RANZCP has been closely monitoring the design and implementation of the NDIS and has contributed to numerous consultations with the NDIA, including the following:

- [Senate Inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition](#), February 2017
- [NDIA Personal care and community participation](#), April 2016
- [NDIS Information, Linkages and Capacity Building Commissioning Framework](#), April 2016
- [Independent review of the NDIS Act 2013](#), October 2015
- [NDIS Quality and safeguarding framework](#), April 2015
- [NDIS Information, Linkages and Capacity Building](#), March 2015.

The RANZCP strongly supports efforts to ensure the financial sustainability of the NDIS to ensure that people with psychosocial disability can be provided with adequate services to improve their well-being and participation in the community, both now and into the future. This is particularly important considering that 18.5% of all people with any type of disability have a psychological disability (as defined by the 2012 Survey of Disability, Ageing and Carers; ABS, 2015) and that current funding for mental health is seriously inadequate with mental health representing 13% of the burden of disease but 7% of government funding (NMHC, 2014).

However, in order for this potential to be realised, the experiences and support needs of consumers with mental illness and their families and carers must be addressed. NDIS funding and design must be guided by the principle of equitable access of all people with a disability. The *Convention on the Rights of Persons with Disabilities* (UN General Assembly, 2007) clearly includes consumers with mental ill health under the definition of disability and emphasises that access to services must be equitable and not on the basis of disability type.

The RANZCP therefore urges serious consideration of the NDIS' capacity to support people with psychosocial disability in recognition of the broad concerns of the mental health sector that there is a disconnect between the NDIS and the experiences of consumers and practitioners within the sector.

Scheme boundaries

Other aspects of the eligibility criteria of the NDIS that are affecting participation in the scheme

The RANZCP believes that there needs to be more flexibility within the NDIS eligibility criteria to encompass the lived experiences of consumers with mental illness and the language used in best-practice approaches to mental health. Otherwise people with psychosocial disability may require additional supports to apply for the NDIS as their understanding of their disability, and the language which they use to describe it, may disadvantage them in this process.

The RANZCP is concerned about the centrality of disability 'permanence' in the eligibility criteria for the NDIS as the language of 'permanence' does not fit with the recovery-oriented approach of the mental health sector. Access to full supports under the NDIS depends on an applicant's ability to show that their disability is permanent but the permanence of one's disability is not something that a significant proportion of people living mental illness would want or be able to acknowledge. Eligibility criteria that relies on permanence may therefore contribute to many individuals not seeking, or opting out of, treatment if that treatment is predicated upon their acceptance of the lifelong nature of their illness. Consumers with significant mental or intellectual impairments risk exclusion from the NDIS because of the way they understand and describe their situation, despite having high support needs. On the other hand, as individuals come to accept the 'permanence' of their disability, they may seek to (re)engage with the NDIS which may have unforeseen effects on participation rates.

Best-practice mental health care aims to support consumers to arrive at their own definition of well-being using language and definitions that are meaningful to them. The language of empowerment, recovery and ability is emphasised over that of disability, impairment and illness. This approach, which complements the NDIS focus on enabling consumer choice, independence and participation, empowers consumers to work towards aims that are meaningful and achievable for them. In order to apply for NDIS supports, consumers with mental illness will have to straddle these two conflicting philosophies and vocabularies related to their impairment.

The RANZCP would suggest an approach to eligibility that focuses more on functional impairment. For people with psychiatric disability, functional impairment is often a better measure than diagnosis when determining disability permanence. This is because diagnosing mental disorders is often less straightforward than for physical conditions. Mental health diagnoses are also more likely to change over time as the clinician learns more about the consumer, how they respond to various treatments, and the historical and environmental factors that impact upon them. It is unclear how the NDIA will accommodate this complexity or whether a change in diagnosis may change the consumer's access to support.

Recommendations

- **Eligibility criteria which focus on functional impairment over a diagnosis of 'permanent' disability, accompanied by a clear understanding of what functional impairment means with regard to mental illness.**
- **Clarification regarding how changes in diagnoses may impact upon eligibility.**

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Other early intervention programs

The RANZCP believes that early intervention programs will be essential for people with psychosocial disability as managing mental health issues early improves long-term health outcomes and can decrease the need for acute or crisis care later in life. This can be challenging, however, due to the lack of insight exhibited by many individuals with severe mental illness. Even where people with psychosocial disability are able to recognise their conditions, they may approach their diagnosis with ambivalence for a variety of reasons. It is unclear how this cohort will access the supports they need under the NDIS, especially if the language of 'disability' and 'permanence' are not meaningful to them.

The RANZCP would welcome clarification regarding how the NDIS will accommodate consumers with high support needs but who do not recognise their eligibility for the NDIS. Outreach services will be essential in this regard and consideration should also be given to allowing health providers to refer consumers to the NDIS in instances where this is the most realistic way to link them with supports. Currently, there are limited options for health providers to directly refer eligible participants to the NDIA.

Furthermore, while the NDIS continues to maintain a focus that could lead to the exclusion of many with psychosocial disability from an individually funded package (IFP), the Information, Linkages and Capacity Building (ILC) framework will be the only way for many consumers to access supports under the NDIS. Due to the complex nature of quantifying impairment linked to mental illness, some consumers may begin receiving supports under the ILC and then be moved across to an IFP once the full extent of their support needs are understood. The RANZCP would like to see a mechanism for identifying and responding to unmet support needs in a systemic manner. This is particularly important for consumers who are initially found to be ineligible for an IFP due to the incongruence between eligibility criteria and the realities of psychosocial disability.

Recommendations

- **Referral pathways to the NDIS from health professionals.**
- **Outreach services to identify people with psychosocial disability who may be eligible for NDIS supports.**
- **Policies that provide support to consumers to reapply to the NDIS, or have their eligibility reassessed, under more suitable conditions.**

Service gaps

It is well established that the mental health sector is chronically underfunded and unable to meet current demand. Boundary disputes are common as are gaps where no services are available to meet consumer needs. There is a considerable risk that existing services will simply lack the capacity to respond to the increasing demand facilitated through the NDIS. In addition, housing, education, employment, health, accessibility and transport services are almost universally at capacity and facing funding cuts. Services must be resourced so that they are able to be responsive and to minimise wait times. This will ensure that the increase in referrals via the NDIS does not lead to a bottle-necking scenario where demand outstrips supply even more than it already does.

Feedback from RANZCP members who work in NDIS trial sites has indicated that there is a lack of clarity regarding the roles and responsibilities of NDIS providers which may exacerbate these issues. For

example, the RANZCP has been informed of an instance where an agency had received NDIS funding to provide accommodation services. The agency was reliant on the private market, however, and was unable to secure anything appropriate for a consumer with severe mental illness. At the same time, pre-existing disability accommodation had ceased to be available, leaving the consumer without secure housing, further impacting on their mental health. In this example, it was unclear to the practitioner and consumer involved as to whether the agency was funded only to provide linkages to existing, mainstream housing, or if the organisation should have had access to direct resources such as housing stock. It is therefore essential that the registration process for providers ensures clarity of role and responsibility and transparency in communicating this to other stakeholders.

Recommendations

- **Clear definitions of the roles of different service providers and mechanisms to communicate these to participants and stakeholders.**
- **Interim supports for consumers who are linked in with services that are at capacity.**

How the rollout of the NDIS will affect mental health services provision

Governments must ensure that the transition to the NDIS does not create service gaps for vulnerable people who fall outside the NDIS scope but who nevertheless rely on existing community programs. Currently, there is a serious risk that people living with mental illness who are not eligible for NDIS services are going to be left with less support than they have now. This is because NDIS funding agreements between the Commonwealth Government and most jurisdictions commit the majority of funding for existing non-clinical support services to the NDIS. As a result, many community mental health support programs will transition into the NDIS without equivalent programs being offered for those who fall outside its scope, whether this be due to their age, residency status or the nature of their disability. For example, New Zealanders living in Australia are granted Special Category Visas and are therefore not eligible for NDIS services. The transition to the NDIS is therefore likely to deprive many people of access to services to which they have previously had access. This is likely to have both public health and economic implications with respect to the functioning of the Australian economy and health system.

The same concerns hold for federal services like the Partners in Recovery programs and Personal Helpers and Mentors services which currently cater for a wide range of consumers including people who are likely to fall outside the scope of the NDIS. After the transition, these people will still require supports and governments will still be responsible for providing them. Yet there is already evidence of people losing access to these supports due to their transition into the NDIS (Whiting, 2017).

The RANZCP would note here that levels of impairment among people with psychosocial disability can change regularly, sometimes dramatically and without warning. Under these circumstances, the importance of pre-existing supports and linkages cannot be overemphasised. Existing networks can enable early intervention, decrease the need for crisis intervention and lower the risks of hospital admission, housing breakdown, job loss and increasing isolation.

The RANZCP is particularly concerned regarding the impact of the NDIS on the future well-being of people with intellectual and developmental disabilities (IDD). The health system is badly set up for people with IDD and mental health issues. The mental health sector is not funded, nor does it have the expertise, to work with people with IDD, except where they have serious mental illness. Neither is the

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NDIS geared for consumers with complex and severe disability linked to IDD, nor is it disposed to residential respite which is an essential specialist service necessary to support families at risk of burnout.

There are already reports of services experiencing unprecedented levels of inpatient admissions for children and adolescents with IDD and/or autism spectrum disorder. Without enough beds, young people may be admitted to adult mental health services or general paediatric services, neither of which are likely to be able to manage the symptoms of the often-distressed young person. In these circumstances, young people may become stuck in emergency departments which are even more inappropriate. This can often lead to the young person reaching crisis point and being institutionalised. In contrast, when psychiatrists with expertise in IDD are able to collaborate with the disability service team, the young person can usually be stabilised and returned to their family.

Therefore, the closures of state-run disability services which currently provide most of the mental health input for people with IDD is concerning. For example, the NSW Department of Ageing, Disability and Home Care has been the primary investor in developing mental health skills in services for people with IDD but as these are increasingly closing, the subspecialty of mental health care for people with intellectual disability is increasingly at risk of being lost. The RANZCP is concerned that the implementation of the NDIS may lead to the privatisation of disability services in some states which is likely to compound these risks. There are also particular fears that the resources for multidisciplinary positive behaviour supports will be lost with the potential consequence that families may be unable to care for their family members. This will only increase the strain on emergency departments.

Specific attention also needs to be given to people whose symptoms are well managed. There is a real concern that these people may no longer be able to receive support from the services they are currently accessing if they do not receive an IFP. Although the support they receive may only be occasional, many would struggle to maintain their current levels of well-being without it.

Recommendation

- **Policies to guarantee that consumers who are not eligible for the NDIS will maintain access to pre-existing supports, both during and after the transition.**

The intersection between the NDIS and mental health services

It is widely acknowledged that the health system, particularly the mental health sector, is fragmented and confusing. Many of the new private service providers under the NDIS lack the experience and networks to make effective linkages for their participants. In many cases, initial planning and coordination is falling to NGOs who are poorly remunerated for the considerable amount of paperwork, goal setting and relationship building that is required.

Care coordination could be greatly improved with the increased involvement of health professionals. RANZCP members have indicated that there have been issues with a lack of communicated information regarding pilot sites, how services will be provided to clients following the wider rollout of the NDIS, and how existing services will be impacted upon. RANZCP members have also reported that NDIA staff turnover and other issues have resulted in inconsistent responses to their feedback and there is currently no mechanism for a treating specialist to be informed of NDIS registration nor to provide feedback. It is essential that communication channels with treating specialists be kept open, given their

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core role in consumer management and the importance of their expertise and 'on-the-ground' experiences for continuous improvement processes.

There is also scope for greater involvement of mental health social workers, particularly in the private sector, to do more of the practical work currently done by 'agency case managers' with no mental health experience, particularly where consumers do not meet conditions for public case manager allocations.

Recommendations

- **Capacity building in primary health networks and local health districts including:**
 - **mapping service availability across primary, hospital, specialist and tertiary services**
 - **building resources to support GPs (e.g. the development of clinical pathways in GP software and/or competency frameworks and toolkits).**
- **Greater involvement of health professionals in care coordination.**

Planning processes

Planning process

The unpredictability of mental illness means that it is often difficult to develop a complete understanding of the level of impairment experienced without extended interactions. The model of the NDIS, whereby the consumer is assessed by a person unknown to them, and within a very specific framework, does not lend itself to this. The NDIS should be able to accommodate the inherent complexities of mental illness by ensuring that accurate assessments are gauged over a period of time and with input from treating clinicians. Incorporating more flexibility and nuance into this process would make the NDIS more applicable and relevant to the mental health sector and enable consumers with mental illness to feel secure in the capacity of the NDIS to support them over their lifetime.

Assessments, plans and reviews need to be flexible to accommodate the often rapidly changing support needs of people with mental illness. Psychiatric conditions can be exceedingly unpredictable in how and when symptoms manifest, how the consumer responds to treatment, and the associated level of impairment. Diagnoses may require regular review as the treating clinician learns more about the consumer, how they respond to treatment and other factors that may be at play. While the RANZCP recognises that plans will specify the time and circumstances under which they will be reviewed, it will also be important to establish how quickly an IFP can be reviewed to ensure that administrative delays do not compromise the provision of care in times of increased, and unexpected, need.

Recommendations

- **Assessments to be gauged over a period of time and with input from treating clinicians.**
- **Policies to ensure a support package can be reviewed quickly in times of unexpected need.**

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Assessment tools

Feedback from RANZCP members working in NDIS pilot sites indicates that some consumers with severe mental illness such as schizophrenia, severe personality disorder or autism spectrum disorder face difficulty accessing supports because of a lack of understanding of, and/or effective assessment tools for, their impairment and needs. Other people whose diagnoses complicate their assessments include children and adolescents diagnosed with childhood disorders such as severe dyslexia who encounter difficulties with their eligibility once they turn 18 years of age and their needs change.

Assessment tools may also not be effective in gauging the support needs of people with comorbidities – for example, someone with mild to moderate physical and psychosocial disabilities may experience significant, lifelong impairment due to the combined and compounding effects of their conditions. While they may have very high support needs due to the combination of impairments, the diagnoses may not be considered severe enough for an IFP when considered individually. In NDIS pilot sites, this has reportedly led to very vulnerable people not being able to access the supports they need.

Recommendations

- **Accounting for the impact of comorbidities in the assessment process.**
- **Evaluation of the suitability of assessment tools for the identification of support needs for:**
 - **people with severe mental illness**
 - **young adults who have been diagnosed with childhood disorders.**

Participant supports

Consumers with psychosocial disability often have very different support needs to those with other forms of disability which often relate to majorly disabling issues not adequately covered under the NDIS. For example, substance abuse disorders are a common comorbidity among people living with mental illness but it is unclear how this will be addressed under the NDIS. The RANZCP is also aware of one consumer with severe mental illness who would greatly benefit from additional psychotherapy sessions which she cannot afford. Though currently receiving an IFP which includes various classes, no specific therapeutic supports are provided for her mental illness. This is despite the Productivity Commission's assertion in the issues paper that 'the NDIS may fund... therapeutic supports' (p. 20).

The RANZCP also understands that NDIS funding will not be provided to prisoners and young people in detention. This appears to be predicated on the assumption that appropriate services will be provided within custodial settings, funded by state and territory governments. Considering the significant and ongoing underinvestment in prison and youth detention health services, the RANZCP is concerned that individuals whose disabilities render them eligible for NDIS services will lose access to those services while in custody. The RANZCP urges the Commonwealth Government to ensure NDIS funding for people in receipt of forensic disability services.

For individuals transitioning back into the community from custodial settings, NDIS funding will only be provided within 3 months of their date of discharge, yet release is often only granted contingent upon supports being in place. If such supports can only be guaranteed within 3 months of the date of discharge, and the date of discharge can only be set when supports are in place, this is likely to result in a catch-22 scenario wherein release dates cannot be set without supports, and supports cannot be

arranged without release dates. In reality, the period of transition often takes much longer than 3 months so this policy is likely to prevent the release and care of individuals seeking release from custody. There are already significant challenges faced by those attempting to reintegrate into the community after very long periods of time in custody and it is therefore essential that their needs are adequately met for the full period of transition, not only to facilitate their release, but also to support their well-being and recovery, and to decrease recidivism rates which will have flow-on benefits for the entire community.

Recommendations

- **Policies to ensure that an appropriate range of supports is provided for people with psychosocial disability.**
- **Provision of supports for people requiring disability services in custodial settings.**
- **Delinking of supports from discharge dates for individuals leaving custodial settings.**

Market readiness

Participant readiness

Getting the balance right between consumer-driven care and meeting the needs of consumers with mental illness can be complex. Consumers with psychosocial disability may have difficulty in identifying their support needs for a number of reasons including the experience of stigmatisation leading to a desire to avoid association with a particular label, a lack of insight into their needs which may be a symptom of the illness itself, or the experience of having a diagnosis change over time which can lead to a lack of faith in the capacity of labels to adequately represent lived experience. Unlike other disability sectors, self-managed care plans have not been introduced in the mental health sector and so additional supports will be required to help consumers accurately identify their needs, including education and training.

Once support needs have been identified, families and carers often ask for a list of recommendations from NDIS providers but this is not available. The RANZCP does not believe that one NDIS provider should be recommended over another. Rather, information about the services should be available to health professionals so that they can assist their patients to make their own decisions. The RANZCP supports a ratings system, used by participants and other authorised parties, to provide a simple and democratic snapshot of feedback on service providers.

People with psychosocial disability generally have much lower than average incomes and lower rates of schooling and employment. Furthermore, the majority of NDIS communication is online while the proportion of consumers with severe mental illness who have an internet connection at home is thought to be quite low. People with psychosocial disability therefore face the double barriers of low literacy and lack of access to information technology. Consumers with prolonged and severe mental illness are also more likely to lack contact with family, carers and other support networks who could assist them.

The RANZCP therefore supports the development of a range of information platforms that are accessible and user-friendly. The Purple Orange project is a good example of how an online platform can be used to empower participants to manage their own care, share information and engage with the NDIS meaningfully. The RANZCP also encourages the trial of 'expos', described in the NDIS Quality and Safeguarding consultation paper, as a way to reach individuals without internet access.

Recommendations

- **Supports for people with psychosocial disability when developing plans, including education and training.**
- **More work to ensure the accessibility of information platforms including:**
 - **consultation to identify preferred ways of accessing and sharing information**
 - **consideration of telephone lines, outreach workers at community centres, literacy classes and purchase of computer devices.**

Assistance for informal carers

The RANZCP believes that the needs of informal carers should be more fully integrated into the NDIS model to ensure that they receive targeted supports to meet their specific needs. Carers provide approximately 1.3 billion hours of care per year with an estimated replacement value of \$40.9 million annually (Carers Australia, 2014). Yet while informal carers play an essential role in the support of people with psychosocial disability, services for carers are often inaccessible, under resourced and of such poor quality as to be of little benefit.

It is common for carers to experience mental ill health related to their caring duties. Although it is likely that carers' support needs will lessen as their care recipient receives more comprehensive supports externally, their own health issues may or may not resolve naturally. The RANZCP believes that the financial sustainability of the NDIS would be more secure with the provision of additional supports for informal carers, including the option of a separate carer assessment. This would ensure that informal carers are well supported to continue whatever unofficial functions they may be fulfilling in support of their loved ones.

The RANZCP is concerned that within a consumer's IFP, there is no guarantee that their carer's support needs will be catered for. IFPs are consumer driven and therefore will only factor in carers insofar as the consumer perceives they require support. Consumers may not have a full understanding of their carer's support needs, however, and the carer may not wish to disclose the full extent of these to their care recipient.

In these instances personalised assessment, treatment and care may be advantageous so that the access of carers to necessary supports is not contingent on their capacity to convey these to the consumer. Unless this is addressed, there will be increasing pressures on the ILC to support carers whose needs are not adequately gauged and provided for via the IFP process.

Recommendation

- **Separate carer assessments during the planning process.**

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