

Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape

Submission to the Department of Social Services

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The position of Public Advocate is established under the *Guardianship and Administration Act 2000* (Qld). The primary role of the Public Advocate is to promote and protect the rights and interests of Queensland adults with impaired decision-making capacity. More specifically, the Public Advocate has the following functions:

- promoting and protecting the rights of adults with impaired capacity (the adults) for a matter;
- promoting the protection of the adults from neglect, exploitation or abuse;
- encouraging the development of programs to help the adults reach the greatest practicable degree of autonomy;
- promoting the provision of services and facilities for the adults; and
- monitoring and reviewing the delivery of services and facilities to the adults.¹

As the Public Advocate, I welcome the opportunity to contribute to the consultation process associated with improving the National Disability Insurance Scheme (NDIS) experience for service participants. Initiatives such as the development of a Service Guarantee for NDIS participants, will assist in fine-tuning features of the NDIS to improve its accessibility, operation and outcomes.

I acknowledge and support the development of an NDIS Participant Service Guarantee that will set new standards for shorter timeframes for people with disability to obtain their NDIS plans and have their plans reviewed. The principles outlined in the Discussion Paper are all relevant to the development of the service guarantee. Together, they should provide a strong foundation for the provision of service levels commensurate with and expected of a scheme of this nature.

Participant Service Guarantee

The connected principle

A number of issues associated with the roll out of the NDIS in Queensland related to the 'connected' principle:

The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services.²

The application of this principle has met with challenges as the NDIS has rolled out across Queensland and Australia more generally, with a lack of interaction and coordination between the NDIS and, in particular, mainstream health and justice services, being areas of particular concern.

In relation to the health services, my office published the *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland* report. This report presented the findings from an investigation into the deaths of 73 Queenslanders with intellectual disability living in disability and supported accommodation between 2009 and 2014.³

The report found that, of the 73 deaths investigated, 59% of the deaths were unexpected and over half (53%) were considered to be potentially avoidable. Many of the potentially avoidable deaths occurred as direct result of health and disability service failures associated with managing complex conditions including; dysphagia or swallowing conditions, epilepsy, chronic respiratory conditions, gastronomy feeding and pressure injuries.

¹ *Guardianship and Administration Act 2000* (Qld) s 209.

² Commonwealth of Australia (Department of Social Services), *'Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape Discussion Paper'*, 2019.

³ Office of the Public Advocate (Qld), *'Upholding the right to life and health; A review of the deaths in care of people with disability in Queensland, A systemic advocacy report'*, Brisbane 2016.



Since the release of the report, I have been advocating for:

- A Queensland Government response to health system failures that includes the development of individual health care plans for people with disability and complex health conditions. These plans should be reviewed annually and used to inform the NDIS supports required to adequately coordinate and support access to health care; and the
- The development of NDIS plans that:
 - acknowledge the complex health issues of participants and incorporate the disability supports necessary to address health care needs, provide for adequate coordination of essential health care supports, and support attendance at medical and therapeutic appointments.
 - include actions to improve the integration and communication between mainstream health services, registered NDIS service providers, and other disability support services to ensure people with disability with complex health conditions are accessing the health services they need.

The Disability Reform Council has announced that the NDIS will fund disability-related health supports where the supports are a regular part of the participant's daily life, and result from the participant's disability.⁴ This represented a significant step forward, meaning that NDIS participants will be able to access supports related to conditions including dysphagia, diabetes, incontinence, epilepsy, wounds and pressure sores, respiratory issues, nutrition and foot care. While, this goes some way towards addressing these issues, there remains a lack of detail and clarity around a range of disability-related health supports, for example, the funding of nursing supports for wound care management, and physiotherapy supports for management of respiratory issues.

To compliment the efforts of the NDIA, the health system needs to develop individualised health care plans for people with disability and complex health conditions. For NDIS participants, the health care plans should fully integrate with the person's NDIS plan (as outlined above). This will require significant collaboration between the NDIA, Primary Health Networks and State- and Territory-based health services.

The integration of individualised health care plans with NDIS participant plans could be a tangible and meaningful commitment by the NDIA to the connected principle in the Participant Service Guarantee.

Improved coordination and integration of institutional services with the NDIS would be another meaningful and tangible demonstration of the connected principle. I continue to have long-standing concerns about the many people with impaired decision-making capacity living long-term in other institutions, including the Forensic Disability Service, prisons and secure mental health units, who require support to apply for the NDIS and/or to access NDIS plans. The engagement of these cohorts with the NDIS has been limited and ad hoc, potentially exposing them and the community to risk because they may be released from those institutions without appropriate supports or causing them to be detained for longer periods because those supports are not in place. Liaison with guardians and advocates in other jurisdictions indicates that this is a national problem.

I invite a commitment from the NDIA to assist people residing in State- and Territory-based institutions to access the NDIS (not just use the NDIS once they have become a participant). This commitment would include the active referral (within a certain timeframe) by local NDIA representatives of people in need of support to access the NDIS to an appropriate advocacy agency or representative, including follow up to make sure that contact has occurred and discussions regarding the NDIS and potential eligibility have commenced.

It is recognised that the role of Local Area Co-ordination (LAC) encompasses assisting people to access the NDIS however the complex issues and barriers for people with psychosocial disability

⁴ Department of Social Services, *Meeting of the COAG Disability Reform Council Gold Coast 28 June 2019 Communique* (9 July 2019) Department of Social Services <<https://www.dss.gov.au/disability-and-carers-programs-services-government-international-disability-reform-council/communique-28-june-2019>>.



noted above require more intensive support. This support role requires more than an individual conversation and may extend across months, with multiple issues potentially needing to be resolved to support a person's access to the NDIS.

Decisions are made on merit

It is respectfully suggested that this standard be expanded to include the mechanisms that are available for the review of decisions. While there are operational guidelines currently associated with the NDIS that detail the processes applicable to the review of decisions (internal and external), a commitment in principle to the right of NDIS participants to review of decisions should also be made.

This commitment could potentially be complemented by the development of standards setting maximum wait times for the completion of internal and external reviews. In 2018, Sara Gingold from Disability Services Consulting reported that internal reviews conducted by the NDIS were taking up to 9 months to be completed, and that by the time appeals reached the Tribunal, the plan in question had expired, meaning that the review was effectively nullified.⁵ An article in the *Newcastle Herald* on 27 December 2018⁶ also told of the experiences of a family for whom it took 14 months to have a case heard in the Administrative Appeals Tribunal.

These types of delays are unacceptable and have the effect of obstructing or frustrating participants' review and appeal rights, which is inconsistent with the obligations of the NDIA as a Commonwealth agency to act as a model litigant. The setting of benchmarks and monitoring of timeframes for reviews and appeals as a component of the Participant Service Guarantee is therefore imperative. The review of decisions is an important right available under the NDIS for participants and potential participants making the completion of reviews in an acceptable timeframe one of the critical indicators in a best practice or service guarantee framework.

The accessibility principle

The accessibility principle is very relevant to people who experience impaired decision-making capacity. It is well-recognised that adults with impaired decision-making capacity have experienced significant problems accessing the NDIS in Queensland. Access is particularly problematic where potential participants do not have an existing support or advocacy network, have not previously been in receipt of disability support funding, or are currently residing in an institution (like a secure mental health unit, public health facility or a correctional facility).

For a significant number of these potential NDIS participants, barriers to accessing the NDIS are immense and can often result in them not attempting to access the scheme. This may potentially lead to a significant proportion of vulnerable Queenslanders not having the disability supports they require for everyday living and to be active members of the community. A lack of supports can also cause a 'spiral' effect on other elements of a person's life, potentially resulting in them not being able to access other mainstream services like education, health transport, employment and accommodation. The consequences of this spiral are often tragic, resulting in the permanent institutionalisation of some, or the premature and often avoidable deaths of others, or their involvement in the criminal justice system.

Additional principles

An additional key principle suggested for inclusion in the Participant Service Guarantee is the *protection and respect of human rights* of all people inquiring, seeking access to the NDIS, or

⁵ Gingold, Sarah, 'The AAT slams the NDIA's "unsatisfactory state of affairs"', Disability Services Consulting, accessed online 17/10/2019, <<https://www.disabilityservicesconsulting.com.au/resources/aat-slams-ndia>>.

⁶ Beaumont, Anita, 'Fighting NDIS planning decisions through tribunal a long and frustrating process, Hunter families say', *The Newcastle Herald* 27 December 2018, accessed online 17/10/2019, <<https://www.newcastleherald.com.au/story/5768924/ndis-there-seems-to-be-this-policy-push-to-keep-plans-to-a-minimum/>>.



interacting with the scheme for plan development and reviews. This inclusion would recognise that the NDIS was designed to further Australia's commitment to the United Nations Convention on the Rights of Persons with Disabilities,⁷ as well as other international human rights treaties.

The principles should commit to respecting human rights, protecting human rights and fulfilling human rights.⁸

Given that the Participant Service Guarantee is one of the overarching elements of the NDIS, it is critical that it acknowledge and reinforce human rights obligations. This inclusion would continue to reinforce the provisions related to upholding human rights that are included in the NDIS Code of Conduct which applies to registered NDIS providers and their employees, unregistered NDIS providers and their employees, providers delivering information, linkages, and capacity building (ILC) activities, providers delivering Commonwealth Continuity of Support Programme services for people over the age of 65 and all NDIS Commission employees (in addition to the Australian Public Service Code of Conduct).

Measuring compliance with the principles

Compliance with the principles in the Participant Service Guarantee should also be monitored, measured and reported. While the potential service standards included in Attachment A work well for those principles that rely on numbers and where data can be relatively easily captured (e.g. timely) it is anticipated that the remainder will require the administration of a survey of participants to gather additional data and qualitative insight.

Potentially, a series of statements for participants, families and carers (where relevant) for standards that require direct participant input could be included in the current questionnaire administered to NDIS participants, which provides data for the quarterly reporting regime.

It will be important, however, for the data to be disaggregated and analysed by a range of locational, demographic and disability type characteristics to ensure that the service standards are being upheld consistently. The sample size and structure employed for the current survey will therefore need to be interrogated to ensure that it will accommodate the degree of cross analysis required to ensure service consistency.

It is also particularly important for this data, in the interests of transparency and accountability, to be made available disaggregated to each state and territory, enabling agencies like the Office of the Public Advocate to identify systemic issues, trends and challenges for NDIS service provision, nationally and locally.

The most critical factor is, however, the timing associated with the commencement of measurement. The collection of data to facilitate measurement of the principles needs to be implemented at the time the guarantee is introduced rather than being retro-fitted later.

NDIS Act and Rules

Unfortunately, competing priorities within a small office have limited the response that I can provide regarding the NDIS Act and Rules within the timeframe set under this consultation.

I have been informed by the Department of Social Services that this consultation represents the first stage of the process associated with the revision of the Act and will be followed by a position paper released for consultation early in 2020.

⁷ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008) ('*Convention on the Rights of Persons with Disabilities*').

⁸ *Ibid.*



A summary of the issues that I intend to discuss in more detail in consequent rounds of consultation regarding the NDIS Act and Rules is provided below.

Area	Issues
Access to the Scheme	<ul style="list-style-type: none">• Access pathways for people who are homeless, residing in institutions including secure mental health facilities, prisons, forensic disability services or public health facilities• Integration with National Disability Advocacy Framework and Strategy• Prohibitive costs associated with obtaining assessments to facilitate access to the Scheme
Registration of service providers	<p>Consideration of compulsory registration of service providers that are involved in the provision of high intensity daily personal and daily personal activities, which have a significant impact on the day to day health of NDIS participants</p> <ul style="list-style-type: none">• This means that this class of support would join those where compulsory registration is required, including specialist disability accommodation provision, the use of a regulated restrictive practice and the development of positive behaviour support plans
Scheme inclusions	<ul style="list-style-type: none">• Rules to be updated to reflect the 28 June 2019 decision of the Commonwealth of Australian Governments (CoAG) Disability Reform Council to fund disability health related supports• Clarification regarding funding for the provision of sexuality supports under the Scheme
Reviews and Inquiries	<p>Implementation of the recommendations of the Productivity Commission that relate to the relationships between the NDIS and the National Disability Agreement (NDA)⁹ including (summarised);</p> <ul style="list-style-type: none">• Recommendation 2.1 – links between the NDIS and the NDA• Recommendation 2.3 – single set of outcomes across the NDA and NDIS• Recommendation 3.1 – sharing of responsibility for the NDIS across all States and Territories• Recommendation 3.2 – clarification of the role of the Information, Linkages and Capacity Building (ILC) program• Recommendation 3.5 – A gap analysis of identified community needs and government objectives assessed against available and planned services• Recommendation 3.6 – clarification and articulation of NDIS provided services and services provided via State and Territory based mainstream systems• Recommendation 5.3 – Utilisation of similar performance frameworks across the NDIS, NDA and National Disability Strategy.

Thank you for the opportunity to contribute to this consultation on the NDIS Participant Service Guarantee and to outline some preliminary issues for consideration in the NDIS Act and Rules review. I look forward to the outcomes associated with this process and to making further contributions regarding the review of the Act and Rules.

Yours sincerely



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⁹ Australian Productivity Commission, *Review of the National Disability Agreement*, Study Report (2019), Canberra, Australia. Accessed online 21/10/2019 <<https://www.pc.gov.au/inquiries/completed/disability-agreement/report/disability-agreement-overview.pdf>>.

