Office of the Public Advocate

Submission to the Joint Standing Committee on the NDIS about the transitional arrangements for the NDIS

10 August 2017

The role of the Public Advocate (Queensland)

The Public Advocate was established under the *Guardianship and Administration Act 2000* (Qld) to undertake systems advocacy on behalf of adults with impaired decision-making capacity who live in Queensland.

The primary role of the Public Advocate is to promote and protect the rights, autonomy and participation of Queensland adults with impaired decision-making capacity in all aspects of community life. More specifically, the Public Advocate has the following functions:

- promoting and protecting the rights of adults with impaired capacity 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]

Response to the Terms of Reference

As Queensland Public Advocate, I am committed to addressing issues relating to the National Disability Insurance Scheme (NDIS) transition that affect Queenslanders with cognitive and/or intellectual impairments, psychosocial disability, and other conditions that impact upon decision-making capacity. As approximately 60-70 per cent of current NDIS participants have a condition or impairment that may contribute to impaired decision-making capacity on a temporary or ongoing basis,[2] I anticipate that the comments in this submission will have implications for many, if not most, NDIS participants.

This submission is structured in accordance with points A. through D. of the Terms of Reference for the Inquiry. Comments relating to points i. through iv. of the Terms of Reference are incorporated into these sub-sections.

[1] *Guardianship and Administration Act 2000* (Qld) s 209.
[2] According to the 3rd quarterly report to the Disability Reform Council (subsequent reports do not specify this data), most participants in the scheme have an impairment that affects mental functioning. See: National Disability Insurance Agency, 31 March 2016, *Quarterly Report to COAG Disability Reform Council*, viewed 10 August 2017, <https://www.ndis.gov.au/html/sites/default/files/documents/Quarterly-Reports/11-report-coag.pdf> p. 32.

A. Boundaries and interface between the NDIS and mainstream service provision

Transitional supports

In its June 2017 Position Paper on costs in the NDIS, the Productivity Commission acknowledged that people with disability rely on a range of services including mainstream and specialist services and community supports. The Commission highlighted that the interface between the NDIS and mainstream services is not clear and that it needs to become seamless.[3]

The impact of this is that some people with disability who are currently receiving supports and services from state- or federally-operated agencies may not be identified as potential NDIS participants and provided with the supports necessary to transition to the scheme. I am particularly concerned about people with decision-making disability who reside in residential aged care facilities, forensic disability services, authorised mental health facilities, boarding houses, and long-stay health care facilities. In addition, I am concerned that people with decision-making disability who are living highly transient lifestyles (that is, are chronically homeless or are cycling in and out of the criminal justice system) are also not being linked with the NDIS.

Many of these individuals do not have family members, advocates or the support of disability service providers[4] to facilitate access and entry into the NDIS. It is therefore crucial that government-operated and -funded agencies engaged in their care and support provide them with intensive assistance to:

- identify their need for support to consider their options;
- determine their eligibility;
- facilitate involvement by nominees and plan nominees (where appropriate);
- make contact with Local Area Co-ordinators (LACs) and NDIS planners;
- undertake pre-planning and facilitate the development of NDIS plans;
- source accommodation (where appropriate);
- coordinate essential health and medical care and treatment; and
- undertake the transition from institutional to community living.

Failure to undertake any of these aspects of transitioning may result in individuals missing out on the NDIS entirely or, worse, transitioning to the community without adequate supports and care. For some people with high level needs, the consequences may be very serious. The

[3] Productivity Commission, June 2017, *National Disability Insurance Scheme (NDIS) Costs – Productivity Commission Position Paper*, viewed 10 August 2017, <http://www.pc.gov.au/inquiries/current/ndis-costs/position/ndis-costs-position.pdf> pp.32, 181-182.
[4] Disability services have strong financial incentives to transition existing consumers to the new system before state/territory-based sources of funding cease.

Productivity Commission reported that the implications of this outcome, in the mental health space alone, are 'significant'.[5]

> Government agencies and service providers need to make greater efforts to facilitate the transition of eligible people with disability to the NDIS. Particular attention should be given to transitioning people with disability to community-based arrangements in line with the fundamental tenets of the NDIS and the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD).

Reasonable and necessary support

A high quality NDIS plan will provide a comprehensive blend of NDIS funded supports, unpaid supports, and the identification of mainstream services to achieve participants' goals. Managing the interface between paid, unpaid and mainstream supports can be complex. This requires planners to have a clear understanding of what constitutes 'reasonable and necessary support' and a sound knowledge base about which system can provide what type of support.

The Productivity Commission noted that the "concept of 'reasonable and necessary supports' is not specifically defined in the *National Disability Services (NDIS) Act 2013* (Cth), nor does it provide direct guidance on how to determine whether a support is a reasonable and necessary support".[6] It also observed that 'flexibility' in determining supports is a key reason why 'reasonable and necessary support' is not defined in the NDIS Act.[7] The Commission has defined reasonable and necessary support as "… those that help participants live as ordinary a life as possible, including care and support to build their skills and capabilities, so that they can engage in education, employment and community activities".[8]

While the above explanation provides a broad sense of what constitutes a reasonable and necessary support, it is likely that in the initial stages of the scheme, NDIA planners may find some decisions about what supports are reasonable and necessary for an individual challenging.

For example, the Administrative Appeals Tribunal recently explored issues relating to reasonable and necessary support in the case of Ms Jessica King, a woman with cerebral palsy and mild intellectual disability.[9] Ms King was refused physiotherapy sessions and gym membership as part of her request for reasonable and necessary supports under her NDIS plan, even though the physio and gym sessions played a crucial role in enabling her to walk. Victoria Legal Aid assisted Ms King to successfully challenge the NDIA's decision and have her physiotherapy sessions and gym membership fully funded through the scheme.

The concept of reasonable and necessary support was also tested with respect to transport arrangements in participants' plans. Victoria Legal Aid assisted Mr Liam McGarrigle, a young man with autism, to contest a decision by the NDIA to only fund 75% of his transport costs for

[5] Productivity Commission, June 2017, *National Disability Insurance Scheme (NDIS) Costs – Productivity Commission Position Paper*, viewed 3 August 2017, <http://www.pc.gov.au/inquiries/current/ndis-costs/position/ndis-costs-position.pdf> p. 33.
[6] Ibid p. 24.
[7] Ibid.
[8] Ibid p. 3.
[9] Victoria Legal Aid, 19 June 2017, *NDIS decision overturned, allowing support to help woman walk*, viewed 7 August 2017, <https://www.legalaid.vic.gov.au/about-us/news/ndis-decision-overturned-allowing-supports-to-help-woman-walk>.

taxis and other transport associated with aspects of his NDIS plan, with the expectation that his family or informal support network would fund the balance.[10] The Administrative Appeals Tribunal confirmed the decision of the NDIA to only fund part of his transport costs. On appeal, the Federal Court determined that the Tribunal made an error of law on the basis that once a decision is made that the support is 'reasonable and necessary', then the scheme requires that support will be fully funded. The decision is currently under appeal by the NDIA.

Confusion around the funding of transport costs has also occurred in Queensland in relation to the state's taxi subsidy scheme. The scheme subsidises taxi travel for half of the total fare up to a maximum of $25 per trip for people with severe disabilities. At the commencement of the NDIS in Queensland, the state government ceased the scheme for NDIS participants. However, in July 2017, the government reversed that decision.[11] The reinstitution of the scheme is only until June 2019, after which date the availability of funding and support for transportation for people with severe disabilities in Queensland remains unclear.

The NDIA needs to develop a scheme for providing up-to-date internal guidance to NDIS planners about the types of supports that are being approved for participants, especially when the supports or needs of the participant are unusual. This could be done through regular internal information circulars and/or discussion groups to achieve greater certainty and consistency in NDIA decision-making.

The NDIA needs to develop processes to assist it to achieve greater consistency and clarity about what constitutes a reasonable and necessary support under the *National Disability Insurance Scheme Act 2013* (Cth), including better information and training for planners.

National Disability Advocacy Program

I strongly support advocacy as an essential mechanism for promoting and protecting the rights of people with disability in line with the CRPD.[12] Both individual and systems advocates play a critical role in upholding the key rights and principles in the CRPD. Access to individual advocacy is particularly crucial for those people who have impaired decision-making capacity and whose impairments make it difficult for them to report breaches of their human rights (including acts of violence) in ways that will be understood, acknowledged and acted upon.

I therefore welcome the Australian Government's recent announcement to continue funding disability advocacy services under the National Disability Advocacy Program to 30 June 2020.[13] This announcement will bring considerable relief to a vast range of stakeholders in the disability sector, especially people living with disability.

[10] Victoria Legal Aid, 28 March 2017, *NDIS test case win for young Liam McGarrigle in Federal Court*, viewed 7 August 2017, <https://www.legalaid.vic.gov.au/about-us/news/ndis-test-case-win-for-young-liam-mcgarrigle-in-federal-court>.
[11] Queensland Government, 20 July 2017, *Taxi Subsidy Scheme*, viewed 8 August 2017, <https://www.qld.gov.au/disability/out-and-about/taxi-subsidy>.
[12] United Nations, *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008).
[13] The Hon Christian Porter MP, 9 August 2017, *Media* releases*: Turnbull Government investing $60 million in disability advocacy*, viewed 10 August 2017, <https://christianporter.dss.gov.au/media-releases/60-million-disability-advocacy>.

A robust advocacy sector requires significant investment beyond existing levels to ensure people with disability, irrespective of their participation in the NDIS, have access to advocacy support when they need it.

While not technically part of the NDIS, I urge the Joint Standing Committee to ensure that the National Disability Advocacy Program is sufficiently and continually resourced throughout Australia for people with disability irrespective of their NDIS participation.

B. Consistency of NDIS plans and delivery of NDIS services

NDIS planning

There have been widespread concerns expressed by numerous stakeholders about NDIS planning. Issues with inconsistent and poor-quality planning are thoroughly discussed in the Productivity Commission's recent report.[14] The Productivity Commission identified a number of issues which undermine the planning process and resulting quality of plans including:

- the speed of NDIS rollout and use of phone planning;
- a lack of consultation with participants about plans and subsequent plans;
- a lack of clear and transparent information, including information in alternative formats;
- failure to identify and consider complex needs of participants;
- failure to address language barriers for people from different cultural and linguistic backgrounds;
- a lack of pre-planning knowledge and support (the Productivity Commission specifically noted the lack of availability of LACs, the group expected to undertake this function); and
- a lack of knowledge, skills and experience of planners, including a failure to enact culturally sensitive practice.[15]

As a result of these issues, the cost effectiveness of the planning process is at risk due to the large numbers of people with disability requesting early reviews.

I have raised similar concerns about the quality and inconsistency of NDIS planning with the previous CEO of the NDIA, Mr David Bowen. In my letter of 30 May 2017, I discussed the planning process for NDIS participants in relation to the health care needs of people with impaired decision-making capacity.[16] I also outlined many of the concerns I have about NDIA planning in general, particularly the failure to address people's core needs. As stated in my letter:

[14] Productivity Commission, June 2017, *National Disability Insurance Scheme (NDIS) costs – Productivity Commission position paper*, viewed 3 August 2017, <http://www.pc.gov.au/inquiries/current/ndis-costs/position/ndis-costs-position.pdf>, pp.153-178.
[15] Ibid.
[16] Office the Public Advocate (Queensland), 2016, *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*, viewed 2 May 2017, <http://www.justice.qld.gov.au/public-advocate/activities/past/deaths-of-people-with-disability-in-care >.

> If NDIS plans are not addressing people's core needs, specifically their health care needs, there is a risk of catastrophic outcomes for members of this group which, based on my office's report and the findings of the University of New South Wales[17] and the New South Wales Ombudsman,[18] were foreseeable. This will have terrible consequences for NDIS participants and their families, but will seriously impact the NDIA's credibility and effectiveness as one of the great social reforms of our time.

I have attached this letter as Appendix 1 to this submission for the Joint Standing Committee's information. As at 9 August 2017, I have not received a response from the NDIA.

> The NDIS planning process should undergo immediate independent review with the aim of improving both the planning process and the quality of NDIS plans, reducing requests for early reviews, and ensuring that plans address the fundamental needs and interests of participants.

The delivery of NDIS services to people with disability from culturally and linguistically diverse (CALD) backgrounds

CALD Engagement Strategy

I support the Productivity Commission's recent finding that there has been a general lack of monitoring of the NDIS rollout[19] with respect to key aspects of Operational Plans. This has meant that some features of the Operational Plan are being rolled out late (or not at all) which is significantly impacting some groups of NDIS participants. An example of this is where the Operational Plan for Queensland states: "The parties will work together to ensure that the national NDIA CALD Engagement Plan is implemented in a way that is responsive to Queensland's CALD communities."[20] I note, however, that the NDIA CALD Engagement Plan has not yet been released.[21] This is concerning given that there are less than two years left of the roll out, that people from CALD backgrounds are expected to comprise around a quarter of all NDIS participants,[22] and that people with disability from CALD communities have encountered a range of problems during the lead up to full implementation, particularly in relation to the provision of interpreter services.

Interpreter services

NDIS plans for participants from CALD backgrounds do not consistently address their interpretation and translation needs. Access to credentialed interpreters and the provision of translated and easy-English information are critical first steps to ensuring that NDIS participants

[17] J Trollor, P Srasuebkul, H Xu & S Howlett, 'Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data', *BMJ Open*, vol 7, iss 2, 2017.
[18] J McMillan & S Kinmond, 'The needless deaths of people with intellectual disability must be urgently addressed', *ABC News*, 9 Feb, 2017, viewed 3 April 2017, <http://www.abc.net.au/news/2017-02-09/analysisa-ombudsman-on-healthcare-for-intellectually-disabled/8255738>.
[19] Productivity Commission, June 2017, *National Disability Insurance Scheme (NDIS) Costs – Productivity Commission position paper*, viewed 3 August 2017, <http://www.pc.gov.au/inquiries/current/ndis-costs/position/ndis-costs-position.pdf>, pp.312-317.
[20] Australian Government, NDIA, Queensland Government, 20 July 2016, *Operational Plan between the National Disability Insurance Agency (NDIA), Queensland Government and Commonwealth Government for transition to the National Disability Insurance Scheme (NDIS). Final version 1.0*, viewed 8 August 2017, <https://www.ndis.gov.au/medias/zip/documents/h30/h8b/8799560433694/QLD-Operational-Plan-accessible-version.docx>, p. 18.
[21] Response from the NDIA CEO (dated 22 May 2017) to my letter of 3 April 2017.
[22] Ibid.

from CALD backgrounds are able to understand important information, communicate their needs, make informed decisions, and access services and resources. Having access to interpreter support is, as such, essential to enacting the NDIS' stated objective of increasing choice and control, and maximising autonomy and participation.

What should be of enormous concern to government is that, by not implementing policies supporting the provision of interpreter services and other mechanisms for people from CALD backgrounds to overcome barriers to accessing the NDIS, the NDIA, and its disability provider partners, are vulnerable to complaints of racial discrimination. I raised the risk of complaints of racial discrimination with Mr Bowen in my letter of 3 April 2017 (which is attached to this submission as Appendix 2). The issue went unanswered in his response (see Appendix 3).

The Australian Government should instigate mechanisms for conducting periodic reviews of the NDIS Operational Plans and holding relevant agencies accountable for delivery of outcomes against targets. Any delay in delivering outcomes must be reported and explained.

With respect to delivery of the NDIS CALD Engagement Strategy and the funding of interpreter services for NDIS participants from CALD backgrounds, I urge the Joint Standing Committee to recommend that the CALD Engagement Strategy be completed and released as a priority, and that interpreter services be made available for NDIS participants from CALD backgrounds who require them, including to support people to be able to communicate with their disability service providers.

Continuity of support

Earlier this year I made a submission to the Joint Standing Committee on the NDIS in relation to the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.[23] In this submission, I raised serious concerns about the removal of crucial supports to people with psychosocial disability who are not considered eligible for funding under the NDIS. My submission highlighted that:

> …early reports about the NDIS suggest that a significant proportion of people with psychosocial disability who are currently receiving supports through the Personal Helpers and Mentors Services (PHaMs) and PIR programs may not be successful in securing NDIS funding. If this trend continues, and PHaMs and PIR are phased out, many people with psychosocial disability could find themselves without essential supports and resources to live functionally in, and contribute to, their communities. It is therefore critical that individuals who require these (and similar) services have on-going access to these services post-rollout of the NDIS, irrespective of their eligibility for NDIS funding.[24]

My concerns were recently echoed by the Productivity Commission which reported that people with disability who are not eligible for support under the NDIS may lose continuity of

[23] Office of the Public Advocate (Queensland), February 2017, *Joint Standing Committee on the NDIS – Mental Health: Inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, viewed 8 August 2017, <http://www.justice.qld.gov.au/__data/assets/pdf_file/0009/512937/20170223-opa-submission-final.pdf>.
[24] Ibid pp. 5-6.

support.[25] According to the Commission, this scenario represents a key risk to the financial sustainability of the NDIS in terms of 'scope creep' and over-reliance on informal supports.[26]

The Productivity Commission recommended, as do I, Commonwealth and State/Territory Governments must provide greater clarity about the interface between services offered under the NDIS and what will be done to ensure continuity of care to people with disability who are not NDIS-eligible.

I also recommend that Commonwealth and State/Territory Government-funded long-and short-term disability-based services continue for those people with disability who are not initially considered eligible for the NDIS in order to support ongoing recovery and to avoid the potential for crisis occurring in people's lives.

C. Rollout of the Information, Linkages and Capacity Building Program

The rollout has begun on the Information, Linkages and Capacity Building (ILC) framework. I have reviewed the list of successful proposals for national readiness grants under the Capacity Building for Mainstream services and Community Awareness and Capacity Building arms of the ILC.[27] These national readiness grants are worth approximately $14 million[28] and were aimed at building "the capacity and readiness of organisations and the community to operate within a nationally consistent approach to the ILC and building the foundations required to deliver ILC on a national scale".[29]

While I note that the services and projects funded under the first phase of the ILC program (the national readiness initiative) are intended to be implemented on a nationwide basis, there are strong indications that a number of the programs will primarily (and may only) be delivered in the service provider 'catchment' area or state. As such, the programs do not appear to be part of a national project or consortium of services capable of building capacity consistently across the country as required by the ILC funding guidelines.

I recognise that the NDIA can only fund the proposals for ILC projects and services that are received as part of the grants process, and that the disability services sector is still immature in terms of the development of the range of services and programs it can offer in different jurisdictions. However, I suggest that the Committee point out to the NDIA the need for the ILC program to deliver a nationally consistent range of services across all jurisdictions, and that the next phase of the ILC program should have a focus on achieving greater consistency of services and projects across all states and territories.

[25] Productivity Commission, June 2017, *National Disability Insurance Scheme (NDIS) costs – Productivity Commission position paper*, viewed 3 August 2017, <http://www.pc.gov.au/inquiries/current/ndis-costs/position/ndis-costs-position.pdf>, p.52.
[26] Ibid p.33.
[27] *Information, Linkages and Capacity Building (ILC) Grants – National Readiness 2016-2016: Successful Applicants – Capacity Building for Mainstream Services*, viewed 3 August 2017, <https://www.ndis.gov.au/communities/ilc-home.html>.
[28] NDIS, *Information, Linkages and Capacity Building*, viewed 3 August 2017, <https://www.ndis.gov.au/communities/ilc-home>.
[29] Australian Government Community Grants Hub, 2017, *ILC National Readiness Grants*, viewed 3 August 2017, <https://www.communitygrants.gov.au/grants/ilc-national-readiness-grants>.

D. Other transitional issues

In addition to concerns about the speed of the rollout and the impact it is having on the quality of NDIS plans, I am also concerned about the substantial increase in the rate of transitioning that will need to occur during the final stages of rollout. I anticipate that the rapid increase in the pace of the rollout will have a detrimental effect on both the quality of participant experiences and the viability of the scheme as a whole.

Similar concerns are echoed by multiple agencies and groups including the Productivity Commission, First Peoples Disability Network,[30] and the Australian Government National Commission of Audit (the National Commission of Audit). The National Commission of Audit raised particular concerns about the rapid increase in numbers of people entering the scheme during the final stages of rollout:

> The scheduled roll-out of the NDIS is highly ambitious. This increases the risk of inadequate delivery of disability services to participants and also poses significant financial risks to the scheme as a whole. The current schedule anticipates that the system will be able to satisfactorily cope with an increase in the number of people covered by the scheme from 30,000 in 2015-16 to 450,000 in 2018-19.[31]

The Productivity Commission further describes the scale, speed and nature of the reforms as unprecedented in Australian history.[32]

If issues associated with planning are not resolved, and the necessary strategies and systems are not established and implemented well before the last year of rollout when thousands of people with disability will be entering the scheme each week, the result could be disastrous. Poor plans and inadequate provider preparation could put many participants' wellbeing and plan outcomes at risk.

The Joint Standing Committee should urge the NDIA and the Australian Government to heed warnings from public agencies and community groups about threats to the viability of the NDIS and scale back the speed of rollout and/or extend the rollout deadline. This approach should be complemented with a media campaign to ensure that people with disability and the Australian community do not lose confidence in government's commitment to delivering the scheme.

Concluding comment

As Public Advocate, I am committed to promoting and protecting the rights, autonomy and participation of Queensland adults with impaired decision-making capacity in all aspects of community life. To that end, I support a rollout of the NDIS that streamlines the transition of

[30] See, for example: A Volkovsky & D Gooch, '*Concern over speed of NDIS rollout in Indigenous Communities, as NSW launches approach*', ABC News, 20 April 2017, viewed 7 August 2017, <http://www.abc.net.au/news/2017-04-20/concern-over-speed-of-ndis-rollout-in-indigenous-communities/8458076>.
[31] Australian Government National Commission of Audit, no date, *7.2 The National Disability Insurance Scheme*, viewed 7 August 2017, <http://www.ncoa.gov.au/report/phase-one/part-b/7-2-the-national-disability-insurance-scheme.html>.
[32] Productivity Commission, June 2017, *National Disability Insurance Scheme (NDIS) costs – Productivity Commission position paper*, viewed 3 August 2017, <http://www.pc.gov.au/inquiries/current/ndis-costs/position/ndis-costs-position.pdf> p 2.

people with impaired decision-making capacity and provides the supports necessary for them to do so safely and effectively. I am particularly concerned that individuals with impaired decision-making capacity living in institutional environments are provided with genuine choice and opportunities to transition into the NDIS and into lifestyles that are more closely aligned with the principles of the CRPD.

I strongly support robust and consistent planning processes that provide NDIS participants with all the reasonable and necessary supports they require to live ordinary lives as members of the Australian community, and deliver plans that reflect their aspirations and interests.

I look forward to the imminent release of the CALD Engagement Strategy, along with the implementation of localised initiatives to strengthen NDIS rollout in Indigenous and rural/remote communities, as critical features of the transition process for vulnerable and marginalised people with disability.

I also support the implementation of an ILC program that is developed in accordance with a clear strategy that delivers the key features of the program consistently across all Australian states and territories.

Finally, I urge the Joint Standing Committee to ensure that those individuals with disability who do not qualify for supports under the NDIS continue to receive support, at a minimum, under their current service arrangements.

I commend the Joint Standing Committee on its highly relevant inquiries with respect to the NDIS rollout, and am grateful for the opportunity to provide comment on the NDIS transition. If additional information is required about any aspect of this submission, I would be pleased to discuss the submission further.

Yours sincerely

Mary Burgess
Public Advocate (Queensland)

Appendix 1

Office of the Public Advocate

30 May 2017

David Bowen
CEO National Disability Insurance Scheme
GPO Box 700
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Dear Mr Bowen

The role of the Public Advocate (Queensland) was established under the *Guardianship and Administration Act 2000* (Qld) to undertake systems advocacy on behalf of adults with impaired decision-making capacity. The conditions that may impact upon a person's decision-making capacity include, but are not limited to, intellectual disability, acquired brain injuries, mental illness, neurological disorders (such as dementia) or problematic alcohol and drug use. Not all people with these conditions will experience impaired decision-making capacity. However, it is likely that many people with these conditions may, at some point in their lives, if not on a regular and ongoing basis, experience difficulties with making decisions. For some, impaired decision-making capacity may be episodic or temporary, and may be managed using supports at specific times in their lives, while others may require lifelong support with decision-making and communicating choices and decisions. A number of people who have conditions of this sort are expected to become participants in the NDIS.[1]

The primary role of the Public Advocate is to promote and protect the rights and interests of all Queensland adults with impaired decision-making capacity, particularly their right to maximum participation in decisions affecting their lives. As such, I welcome the introduction of the NDIS in Queensland, which aims to afford people with disability greater choice and control over the supports and services they receive.

An introduction to *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*

I am writing to inform you about a report published by my predecessor, Jodie Griffiths-Cook, *Upholding the right to life and health: A review of the deaths in care of people with disability in*

[1] Approximately 70 per cent of current NDIS participants have a primary disability that may contribute to impaired decision-making capacity. See National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council: 12th Quarterly Report to COAG Disability Reform Council,* 30 June 2016, viewed 2 May 2017, <https://www.ndis.gov.au/medias/Report-to-the-COAG-Disability-Reform-Council-for-Q4-of-Y3-PDF-2.5MB-?context=bWFzdGVyfHJvb3R8MjU3NDk3M3xhcHBsaWNhdGlvbi9wZGZ8aGUwL2hhMi84Nzk4MDM0NzIyODQ2LnBkZnw0ZjZkYzM0MTI5NDRjZGEzZjkyMmEyZjQyNzJhM2M1YjQyMWNiMDA0YTVhZjJjYjBjNWUzNTU1MzAxMWFjNzg0>, p. 34

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Queensland[2] (the report). The report was tabled in the Queensland Parliament in March 2016 and generated strong media interest around the country.[3]

The Queensland Government recently provided a formal response to the report. The response noted that the Queensland Minister for Disability Services, Minister for Seniors and Minister Assisting the Premier on North Queensland, the Honourable Coralee O'Rourke, forwarded a copy of the report to you for your consideration in formulating and implementing the NDIS.

I am writing to you to seek your advice on how the NDIA will use the report to inform the NDIS planning process to avoid preventable deaths and strengthen health and longevity outcomes for NDIS participants with impaired decision-making capacity.

The report presented a number of disturbing facts about the health and mortality of Queenslanders living with cognitive and intellectual disability. More than half (53 per cent) of deaths reviewed in the report were determined by an expert panel to be potentially avoidable. Most deaths (59 per cent) were unexpected 24 hours earlier and involved relatively young men and women: nearly half (47 per cent) were in their 40s or younger. The report also provides numerous examples where adverse health outcomes were experienced by people with disability due to such factors as inadequate support for health-related matters, poor access to adequate medical assessment and health care, and lack of training for disability support staff and medical/health care professionals.

Additional evidence supporting the report's findings

Findings from the report are supported by research undertaken in other Australian jurisdictions. At the University of New South Wales, Professor Jullian Trollor and colleagues investigated the causes of mortality across a cohort of 42,204 adults with intellectual disability and concluded that adults with intellectual disability experience premature mortality and unequal health outcomes, and that the proportion of deaths for this group that occur from preventable causes was more than double that of the general population.[4] The authors also determined that the life expectancy for people with intellectual disability was approximately 26 years less than that of the general population.[5] The authors recommended that urgent action in policy and services is required to address the premature deaths and health inequalities experienced by adults with intellectual disability.

This view is echoed by the New South Wales Ombudsman who recently stated:

[2] Office the Public Advocate Queensland, *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*, 2016, viewed 2 May 2017, <http://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwj5gc36wtDTAhWJVrwKHWCDAJoQFgghMAA&url=http%3A%2F%2Fwww.justice.qld.gov.au%2F__data%2Fassets%2Fpdf_file%2F0008%2F460088%2Ffinal-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf&usg=AFQjCNERlnRU1OpaB6IwtnZD4pdCXs_UYg>.

[3] For example: B Vonow, 'Anger at disabled deaths in care', *The Courier-Mail*, 17 March 2016, p. 5; 'Wrong meals killed disability residents,' *The Australian*, 17 March 2016, p. 2; 612 ABC, 7:45 am news, 17 March 2016.

[4] J Trollor, P Srasuebkul, H Xu & S Howlett, 'Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data', *BMJ Open*, vol 7, iss 2, 2017.

[5] E Worthington, 'People with intellectual disabilities twice as likely to suffer preventable death, study finds', *ABC News,* 9 Feb 2017, viewed 3 April 2017, <http://www.abc.net.au/news/2017-02-08/study-finds-intellectually-disabled-two-times-preventable-death/8248772>.

> "…it is critical that action is taken as a matter of priority to address this situation, and to close the gap and improve health outcomes for people with disability in NSW ahead of the full transition to the National Disability Insurance Scheme (NDIS)".[6]

These authoritative positions views are supported by an ongoing stream of anecdotal evidence and media reports, including a recent *Four Corners*[7] programme on the ABC which highlighted multiple failures in relation to the health and wellbeing of service users by the disability service organisation, Lifestyle Solutions (a registered provider of NDIS services[8]).

Factors relevant to the implementation of the NDIS

Evidence consistently indicates that the wellbeing and lives of people with cognitive and intellectual disabilities who live in residential care continue to be at risk. While some of the factors that are contributing to unsatisfactory health and longevity outcomes for this group are outside the jurisdiction of the NDIA (such as the training of medical, hospital and professional health care personnel), there are numerous matters that fit within the NDIA's purview. I refer you to the following themes in the report.

- There is an urgent need for disability services to develop service systems and approaches that adequately identify and address known risk factors and vulnerabilities for people with disability including respiratory disease, epilepsy, diseases of the circulatory system, choking/food asphyxia, and psychotropic medication.
- There is an urgent need to better integrate health care and disability support in disability services. This integration must include:
  - ensuring people with disability are supported to undertake all recommended medical and health care screening and check-ups;
  - ensuring people with disability are supported to address existing health conditions;
  - ensuring support staff are trained in known health risks for people with disability, have awareness of the signs of serious illness, and know how to respond appropriately to these risks and signs;
  - ensuring support staff are adequately informed about, and trained in how to respond to, people's existing health conditions;
  - ensuring support teams are properly coordinated to respond to people's health care needs in a consistent and holistic way;
  - ensuring people with disability are supported to make health care decisions to the greatest degree possible, undertake advance care planning, and access appropriate end-of-life care; and
  - ensuring that the deaths of people with disability who die while living in supported accommodation are reported to the Coroner.

[6] J McMillan & S Kinmond, 'The needless deaths of people with intellectual disability must be urgently addressed', *ABC News*, 9 Feb, 2017, viewed 3 April 2017, <http://www.abc.net.au/news/2017-02-09/analysisa-ombudsman-on-healthcare-for-intellectually-disabled/8255738>.
[7] L Besser, K Toft & J McGregor, 'Fighting the system', *Four Corners (ABC)*, 27 March 2017, viewed 2 May 2017, <http://www.abc.net.au/4corners/stories/2017/03/27/4641276.htm>.
[8] National Disability Insurance Agency, *NDIS: Find registered service providers*, viewed 4 May 2017, <https://www.ndis.gov.au/medias/zip/documents/h98/h55/8800400080926/Provider-Lists-20170228-accessible-version.xlsx>.

Improving outcomes: Strengthening NDIS planning

I propose that many of these issues could be addressed through improvement in one aspect of NDIS operations: strengthening planning for participants. Ensuring the development of comprehensive, evidence-based and person-centred NDIS plans that recognise this group's particular health needs is critical to improving health and longevity outcomes for people with impaired decision-making capacity. A robust NDIS plan should, at the very least, incorporate the supports required to address the full range of a person's health care needs associated with their disability, allow time for support staff to become fully informed about the person's needs and how to respond to them, and provide for adequate coordination of essential health care supports, as well as support to attend medical and therapeutic appointments.

Feedback from Queensland NDIS launch sites has indicated, however, that current planning activities are not consistently generating the kind of high-quality plans that are likely to deliver better health outcomes for at-risk participants. I have, for instance, heard reports that:

- plans are generally being developed by telephone rather than through face-to-face engagement (direct engagement with participants may reveal useful information about additional supports that may be needed but have not been requested);
- plans are developed as a result of what people with disability are perceiving to be a casual conversation with an NDIA representative (and thus vital detail about people's specific health care and other needs is not being presented for consideration);
- plans do not generally have any focus on the health needs of participants, or make reference to their health conditions;
- plans are being finalised without the involvement of independent plan nominees who know the person and their health care concerns well (while a useful source of information, I do not consider the person's existing service provider to be an independent plan nominee); and
- participants are generally being advised that their plans will be reviewed on an annual basis.

I am also concerned that information being provided to prospective NDIS participants is not adequately preparing them for discussions about their health care needs during planning meetings. Material disseminated through the NDIS website, including the *Getting Ready for Your Planning Conversation*[9] booklet, provides only minimal reference to managing health care issues and improving health and wellbeing. Ensuring that NDIS plans are robust enough to optimise participant wellbeing will, however, require that individuals with disability and their nominees are well prepared for planning conversations. In which case, participants and nominees will ideally provide planners with detailed information about:

- existing health care supports and current gaps in those supports;
- the support needed to undertake regular health assessments that include screening for conditions common to the general population (such as skin or ovarian cancer) and conditions strongly associated with specific disabilities or the long-term use of some prescription medications;
- what supports will be necessary to manage chronic or life-limiting illnesses and conditions; and

[9] *NDIS: Getting ready for your planning conversation*, viewed 2 May 2017, <https://www.ndis.gov.au/medias/documents/h68/h80/8798779670558/Checklist-Getting-ready-for-your-planning-conversation-21.10.16-accessible.pdf>.

- the supports required to maintain good health (such as assisting people to start and maintain exercise programs) and sound health care regimens.

For people with the chronic health conditions that many people with conditions impacting their capacity have, coming prepared to planning meetings requires much more thought, analysis and evidence-gathering than is inferred by the pre-planning information currently provided.

Developing plans that maximise people's health outcomes should be a priority for planners. This will require that planners are sufficiently knowledgeable and skilled to manage the tensions inherent in undertaking planning for people with impaired decision-making capacity. While the NDIA is obligated to facilitate optimal choice and control for participants, agency policy must also recognise some people with severe cognitive, intellectual and/or psychosocial disability will have considerable difficulty understanding or communicating the full range of their health needs, and will very probably require informed and independent support during the planning and review processes. They may require support with:

- recognising the importance of good health as vital to attaining their goals and aspirations and meaningful social and economic participation;
- understanding and articulating that they have serious and/or life-threatening health conditions;
- realising that they will need on-going support to manage their health care needs; and
- gathering and presenting information about their health history, current conditions, current health care regimen, and health trajectory that can inform the development of health-related aspects of their NDIS plans.

It may also be appropriate in such instances to recommend the inclusion of authoritative and/or evidence-based approaches to managing people's health care needs into the plan. This may include, for example, incorporating support hours to develop an advance health directive and undertake (and follow through with) an annual Comprehensive Health Assessment Program (CHAP) review,[10] a validated and widely-used health assessment tool developed for the Australian context. Sourcing evidence will also require liaising with other stakeholders, such as independent plan nominees, existing service providers and Local Area Coordinators, to learn about the participant, the local area and the available health resources and determine what supports will be required to access these resources.

Concluding comment

My concerns about NDIS planning were recently echoed by Dr Ken Baker, CEO of National Disability Services (the peak body for disability services), who stated that essential supports are being excluded from some participants' plans.[11] I wholeheartedly agree with this conclusion and reiterate that constructing robust plans cannot be achieved on the basis of a single phone call. Nor can initial plans be left for 12 months between reviews. For the NDIS to be person-centred in the truest sense, people's plans need to be carefully tailored to meet their individual needs and be based on the best possible evidence and available resources. For the NDIS to uphold its commitment to choice and control to the fullest possible extent, participants must be provided with opportunities and, if necessary, the supports required to develop the plans that will shape their lives.

[10] N Lennox, C Bain, T Rey-Conde et al., 'Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: A cluster randomised trial'. *International Journal of Epidemiology*, vol 36, iss 1, 2007, pp. 139-46.
[11] See D Conifer, 'NDIS complaints mount, disability service providers demand urgent improvements', *ABC News*, 4 May 2017, viewed 4 May 2017, <http://www.abc.net.au/news/2017-05-04/ndis-disability-service-providers-say-urgent-improvements-needed/8494934>.

While I understand the pressures the NDIA is facing to fully implement the NDIS according to schedule, I am very concerned that the quality of NDIS plans is being compromised as a result. If NDIS plans are not addressing people's core needs, specifically their health care needs, there is a risk of catastrophic outcomes for members of this group which, based on my office's report and the findings of the University of New South Wales and the New South Wales Ombudsman, were foreseeable. This will have terrible consequences for NDIS participants and their families, but will seriously impact the NDIA's credibility and effectiveness as one of the great social reforms of our time.

Urgent action is required to establish systems that improve the health and longevity of people with disability. NDIS planning and plan review processes are foundational to ensuring that the health and longevity outcomes for people with cognitive and intellectual disability improve under the NDIS. If the NDIS is to be instrumental in achieving this objective, I recommend that the NDIA review my office's report and consider how the key recommendations may inform the planning and plan review processes for NDIS participants.

I look forward to your advice regarding the actions the NDIA is taking on these matters.

Yours sincerely

Mary Burgess
Public Advocate (Queensland)

Office of the Public Advocate

Appendix 2

3 April 2017

David Bowen
CEO National Disability Insurance Scheme
GPO Box 700
Canberra ACT 2601

Dear Mr Bowen

The role of the Public Advocate (Queensland) was established under the *Guardianship and Administration Act 2000* (Qld) to undertake systems advocacy on behalf of adults with impaired decision-making capacity. The primary role of the Public Advocate is to promote and protect the rights and interests of all Queensland adults with impaired decision-making capacity (including those from culturally and linguistically diverse, or CALD, backgrounds), particularly their right to maximum participation in decisions affecting their lives.

As Public Advocate, I am writing in support of AMPARO Advocacy's recent letter to you expressing concern that the needs of people with disability from CALD backgrounds are not being appropriately responded to in the NDIS.

People with disability from CALD backgrounds may encounter significant additional barriers to accessing the NDIS and increasing their social and economic participation in Australian society. These barriers need to be addressed as part of a comprehensive CALD strategy. The delay in implementing a robust NDIS CALD strategy with well-resourced and targeted access and equity measures, including interpreter services is, according to AMPARO Advocacy, causing serious concern for people from CALD backgrounds with disability, their families, and many agencies across the multicultural and disability sector. I therefore support AMPARO Advocacy's call for the immediate development, publication and implementation of an NDIS CALD strategy.

I am particularly concerned about AMPARO Advocacy's comments that plans for NDIS participants from CALD backgrounds are not addressing their interpreting and translating needs. Access to credentialed interpreters and the provision of translated and easy English information are critical first steps to ensuring that people are able to understand important information, communicate their needs, make informed decisions, and access services and resources. Having access to interpreter support is, as such, critical to enacting the NDIS' stated objective of increasing choice and control, and maximising autonomy and participation. It is not evident, however, that the NDIA has developed and implemented a policy that honours the Australian government's commitment to an inclusive society and delivers outcomes for people from CALD backgrounds comparable with those for other Australians. I note the following section from the Australian government's multicultural access and equity policy guide for Australian government departments and agencies:

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> The Multicultural Access and Equity Policy (the policy) acknowledges we live in a multicultural society and that there is an obligation on Australian government departments and agencies to ensure their programmes and services are accessible by all Australians, responsive to their needs, and deliver equitable outcomes for them, regardless of their cultural and linguistic backgrounds… This policy relates not only service delivery departments and agencies but all Australian Government activity, including policy development and advice … as well as activities conducted on behalf of government by contractors and service delivery partners.[1]

The multicultural access and equity policy is, however, unclear in its references to people from CALD backgrounds who also have a disability. While it provides for language services for people experiencing difficulties in accessing services based on factors such as disability, it also states that the policy does not extend to other sectors of the community such as Indigenous Australians and people with disability. These statements are apparently contradictory. The Australian government further states that the distinct needs of these specific groups (such as people from CALD backgrounds with disability) are being addressed through other targeted initiatives.[2] This is not the case, however, with respect to people with disability from CALD backgrounds, and constricted access to the NDIS (as a result of unaddressed language barriers) remains an issue of critical concern for CALD communities.

By not implementing policies supporting the provision of interpreter services and other mechanisms for people from CALD backgrounds to overcome barriers to accessing the NDIS, the NDIA, along with its disability provider partners, is leaving itself vulnerable to complaints of racial discrimination. I therefore support AMPARO Advocacy's position that NDIS applicants be provided with access to easy English material (along with translated versions of this material) and credentialed interpreters when communicating with the NDIA, local area coordinators, planners and registered service providers as they develop and enact their NDIS plans. I also recommend that the NDIA develops and implements a comprehensive policy supporting the delivery of language interpretation services to NDIS participants with disability from CALD backgrounds. This policy should closely align with the intent of the Australian government's multicultural access and equity policy and the principles of the *National Disability Strategy 2010-2020* which require government programs to be non-discriminatory, facilitate accessibility, and contribute to the full and effective participation and inclusion of all people with disability in society.[3]

I am also concerned that the current NDIS participation rates of people with disability from CALD backgrounds are significantly below what some groups in the CALD service delivery sector have anticipated. The NDIA reports that the actual proportion of participants from CALD backgrounds has decreased from 4 per cent[4] in June 2016 to 3.3 per cent in October 2016.[5] The most recent NDIA quarterly report does not include any updates on CALD participation rates[6] — a matter which I hope will be remedied in the next quarterly report. Low participation rates indicate that the NDIS is not yet effectively addressing the longstanding disadvantage and additional barriers faced by this group as

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[1] Australian Government 2015, *The multicultural access and equity policy guide for Australian government departments and agencies*, Department of Social Services, Canberra, viewed 13 March 2017, p. 3.
[2] Ibid, p. 5.
[3] Australian Government 2011, *2010-2010 National Disability Strategy: An initiative of the Council of Australian Governments*, Department of Social Services, viewed 13 March 2017, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-strategy>, p. 22.
[4] National Disability Insurance Agency 30 June 2016, *Quarterly Report to COAG Disability Reform Council*, viewed 8 March 2017, <https://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports>, p. 22.
[5] National Disability Insurance Agency October 2016, *National Disability Insurance Scheme: COAG Disability Reform Council quarterly actuarial report*, ver. 1, viewed 8 March 2017, <https://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports>, p. 44.
[6] See the 2nd NDIA quarterly report for 2016-2017 at <https://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports>.

they attempt to access and participate in specialist disability service systems. They also reflect a system that has been designed and developed without sufficient consideration of the needs of people from CALD backgrounds with disability.

I also support AMPARO Advocacy's recommendation that accurate data about participation of people from CALD backgrounds, including countries of origin, be collected. Failure to collect adequate data about this group will impact on the NDIA's ability to monitor the participation rates of people from CALD backgrounds, inform targeted strategies with diverse communities, and ensure effective policy development and planning.

In conclusion, I support the efforts of AMPARO Advocacy, people from CALD backgrounds with disability and their families and allies to strengthen the accessibility of the NDIS for participants from diverse cultural backgrounds. I similarly seek a strong commitment from the NDIA to ensure that an NDIS CALD strategy is developed and released in the near future, and that this strategy includes appropriate funding of interpreter services to support people from CALD backgrounds to access the NDIS and participate in discussions with both the NDIA and service providers about the development and enactment of their NDIS plans; that the NDIS is made fully accessible to all people with disability, including those from CALD backgrounds in line with the *National Disability Strategy*; and that urgent action be taken to improve rates of participation in the NDIS for people with disability from CALD backgrounds.

I look forward to your advice regarding the actions the NDIA is taking on these matters.

Yours sincerely

Mary Burgess
Public Advocate
Office of the Public Advocate (Queensland)

Appendix 3

MC17-000346

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ndis.gov.au

Ms Mary Burgess
Public Advocate of Queensland
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Dear Ms Burgess

Thank you for your email of 3 April 2017 regarding support for people with disability from Culturally and Linguistically Diverse (CALD) backgrounds under the National Disability Insurance Scheme (NDIS). I note you have also provided a copy of this letter to the Minister for Social Services, the Hon Christian Porter MP. The Minister has asked me to reply to you on his behalf.

The National Disability Insurance Agency (NDIA) is developing a Cultural and Linguistic Diversity Strategy (the Strategy) to articulate how the NDIA will ensure the needs of people from culturally and linguistically diverse backgrounds with disability are met in the design, development and implementation of the NDIS.

The NDIA has brought together a Cultural and Linguistic Diversity Stakeholder Advisory Group (Advisory Group) comprising peak bodies, advocates and service providers from CALD communities to work with the NDIA in developing the Strategy.

The final version of the Strategy was presented to the Advisory Group on 20 April 2017 and will now progress for endorsement through the NDIA's internal governance structure. It is expected the Strategy will be endorsed and published mid to late 2017. The NDIA is currently considering opportunities to launch the Strategy and will notify Advisory Group members prior to its release.

The Advisory Group workshopped the Cultural and Linguistic Diversity Action Plan (the Action Plan), an internal document, which will sit under the Strategy and guide the NDIA's activities in implementing the Strategy. As part of this, the NDIA is developing a reporting and monitoring framework that will track and monitor the implementation of the Strategy.

While this Strategy is in development, NDIA staff have been engaging and building connections with their local CALD communities to understand their needs and how best to provide local CALD individuals and communities with information about the NDIS. NDIA staff are working with CALD community groups and individuals regarding their understanding of disability, recognising that many CALD individuals may not be aware of the social model of disability and the rights of people with disability in Australia.

The NDIA continues to develop communication materials regarding the NDIS, in multiple languages and in easy English formats. The NDIA is also exploring options to collaborate with CALD organisations to translate other NDIS documentation and forms.

In relation to translation and interpreting services, at present, the NDIA funds translation and interpreting services for all activities that are undertaken by the NDIA and Partners in the Community.

This covers CALD individuals who, amongst other things:

- attend information sessions about the NDIS;
- visit NDIA offices (with or without an appointment) seeking information about the NDIS;
- interact with the NDIA to access the NDIS;
- participate in pre-planning activities;
- undertake planning development activities (over the phone or face to face); and
- implement their plans with a coordinator or supports - *the coordinator of supports works with the participant to find service providers that are able to support the participant in their preferred language via interpreters, with bi-lingual staff or other methods.*

The NDIA is also working to ensure participants and their families/carers are able to access interpreting services (in languages other than English) when accessing funded supports in their NDIS plan, as required. The NDIA is updating guidelines for staff that articulate how providers and participants access the service to support translation/interpreters for CALD participants.

With regard to CALD data; as recognised in the report to the Council of Australian Governments Disability Reform Council for Quarter 2 of Year 4 of the NDIS, there are some current limitations to the data available in relation to the proportion of participants that are culturally and linguistically diverse. This is due to the data warehouse of the new Customer Relationship Management (CRM) system being under development. Ongoing enhancements to the CRM, data warehouse and business practices will address these issues.

For the purpose of the NDIS estimates, a person is considered to be of CALD background based on:

a) Country of birth (born in a non-English speaking country, as defined by the Australian Bureau of Statistics (ABS));
b) Language spoken at home (other than English).

By 2019-2020, there are estimated to be 460,000 NDIS participants. About 20 per cent of these participants are estimated to be of CALD background.

The NDIA reports Cultural and Linguistic Diversity with a nationally consistent definition, documented by the ABS. This allows the NDIS to be benchmarked against population norms. The NDIS will continue to update its definition in line with any updates communicated by the ABS.

If you would like to discuss your concerns further, I encourage you to contact Ms Jillian Paull, Branch Manager, Scheme Practice Approaches, on (03) 5272 7815 or at: Jillian.Paull@ndis.gov.au.

Thank you for bringing your concerns to the Minister's and my attention.

Yours sincerely

David Bowen
Chief Executive Officer
National Disability Insurance Agency

22 May 2017