

11 September 2020

Mr Scott McNaughton
General Manager – National Delivery
The National Disability Insurance Agency

Email: supportcoordination@ndis.gov.au

Dear Mr McNaughton,

NDIS Support Coordination – External Consultation September 2020

As the Public Advocate for Queensland, I am appointed under the *Guardianship and Administration Act 2000* to undertake systemic advocacy to promote and protect the rights and interests of Queensland adults with impaired decision-making capacity.

It is projected that more than 110,000 Queenslanders will be NDIS participants by 2023, significantly more than the 67,000 that are currently active participants.¹ A proportion of these participants are people with disability and associated complex health conditions.

These participants generally receive classes of support from the NDIS which include; high intensity daily personal activities, assistance with daily personal activities, specialist positive behaviour support and specialist disability accommodation. Many also receive, or are eligible to receive, recently introduced disability-related health supports, which include reasonable and necessary supports for conditions like epilepsy, dysphagia, diabetes and other respiratory issues, as well as incontinence, nutrition, wound and pressure care and podiatry.²

The endorsement of policy by the Disability Reform Council in June 2019³ to approve the inclusion of disability related health supports in NDIS plans represented a major step forward for this cohort. It provided vital recognition and funding, as well as increased clarity surrounding the provision of these type of supports to people with disability which are essential to their overall health and wellbeing.

We now need to consider, for particularly vulnerable members of this cohort, ways to coordinate disability-related health supports to ensure that people maintain their health and wellbeing and are not at risk of abuse and neglect.

While it is important to avoid being overprotective of people with disability, and recognise that not all people with disability are vulnerable and in need of protection, it is critically important that the NDIS has systems of monitoring, coordination and oversight that will either avoid or identify risks to vulnerable participants, and act on them before a participant suffers harm.

¹ Queensland Productivity Commission, *Issues Paper – Inquiry into the National Disability Insurance Scheme Market in Queensland*, June 2020 <<https://qpc.blob.core.windows.net/wordpress/2020/06/NDIS-Issues-Paper.pdf>>

² NDIS, *Disability related health supports, Information for health sector and practitioners*, Version 2 June 2020, < <https://www.ndis.gov.au/media/1671/download>>

³ Ibid, p 1.

As noted in the Discussion Paper accompanying this consultation, the role of support coordination is to 'assist a participant to understand and navigate the market-based system of NDIS supports, and interactions with other service systems' and that 'a support coordinator assists a participant to understand and implement the funded supports in their NDIS plan, to connect with mainstream services, and to achieve their NDIS plan goals'.⁴

The use of support coordinators to coordinate disability-related and other health supports for members of this cohort fits well with this definition.

Consideration of the expansion of the role of a support coordinator to perform these tasks also addresses the recommendations of the recent independent inquiry, conducted by the Hon Alan Robertson QC for the NDIS Quality and Safeguards Commission into the death of Ms Ann-Marie Smith, an NDIS participant in South Australia.⁵ In his report, Mr Robertson QC made reference to, and supported, the introduction of plans to include strategies to minimise risks and gaps for participants by acknowledging and coordinating a participant's health care needs.⁶ A report prepared in 2016 by my office also highlighted the need for disability-related health supports to be coordinated for particularly vulnerable people. This report reviewed the deaths of 73 Queenslanders with disability in care and found more than half of these deaths were preventable, with many dying from undiagnosed or poorly managed medical conditions.⁷

In order for people with disability and complex health conditions to remain well, it is vital that the health care they receive from mainstream health services and the disability-related health supports they receive from the NDIS are integrated and coordinated, with both a maintenance and preventative focus.

To achieve this, it is imperative for support coordination resources to be used to provide the following supports for NDIS participants with complex health needs:

- The making of appointments and coordination of services (including the availability and funding of transport and support workers to take the person to the appointment) to facilitate at least annual GP visits (and more frequent where necessary), including an extended visit for the GP to undertake an annual health assessment and develop and/or review an Annual Health Plan for the participant. This plan should document the various health conditions of a person with disability and complex health needs, and outline the various medical, specialist and allied health appointments the person requires, as well as preventative health measures including vaccinations and health screening. It should also provide for the monitoring and review of the person's conditions over the course of the plan.
- The implementation of NDIS participants' Annual Health Plans by making appointments and coordinating visits with practitioners, specialists and other allied health professionals throughout the year. This process would also include appointments for preventative health measures, such as annual vaccinations for influenza and, other public health screening programs.
- Monitoring and reporting of incidents that may constitute red flags for the person's health and safety, including incidents such as visits to the Emergency Department, admissions to

⁴ National Disability Insurance Scheme, *Discussion Paper – Support Coordination*, External Consultation, August 2020, <https://www.ndis.gov.au/media/2562/download>, p5

⁵ Alan Robertson SC, *Independent review of the adequacy of the regulation of the supports and services provided to Ms Ann-Marie Smith, an NDIS participant, who died on 6 April 2020*, Report to the Commissioner of the NDIS Quality and Safety Commission, 31 August 2020

<<https://www.ndiscommission.gov.au/sites/default/files/documents/2020-09/independent-review-report-commissioner-public-310820.pdf>>

⁶ *Ibid*, p 48.

⁷ The Public Advocate (Qld), *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*, March 2016, <https://www.justice.qld.gov.au/__data/assets/pdf_file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf>

hospital or changes to a person's everyday health and wellbeing that are noted by service providers (e.g. Increased number of epileptic seizures, insomnia, a substantial weight gain or loss, respiratory issues) and coordination of additional appointments with medical professionals if required.

The addition of this disability related-health support coordination role would require additional resourcing in a participant's plan and, depending on the nature of a participant's needs, may constitute a specialised role, more like a 'health case manager' role that is performed separately or in addition to the general coordination of funded supports.

The provision of health support coordination for selected NDIS participants will also require further detailed analysis and consideration of the following;

- Development of an appropriate definition of people with disability and complex health conditions or particular vulnerabilities that require this higher level of supports and coordination of disability-related health supports. This definition could potentially be developed in conjunction with the NDIS Quality and Safeguards Commission as an element of its response to the Independent Inquiry into the death of Ms Smith.
- Appropriate qualifications and levels of experience for people undertaking this role. As noted in the discussion paper, there are currently few requirements for support coordinators in terms of qualifications and experience, and limited information regarding the quality of existing support coordination services. The provision of health support coordination brings the need for a level of liaison, management, communication and negotiation skills, including interaction with and between mainstream health and disability service systems. This type of role would also involve a much higher level of responsibility as a type of health case manager and accordingly, should require qualifications and experience in health, social work or an associated discipline or transferrable skills from another sector in which they have had significant experience developing the skills required for the role.
- Ensuring the case-loads of health support coordinators are appropriate to the level of work and engagement required to ensure the provision of quality services to this cohort.

Thank you for the opportunity to provide input into this review. Please feel free to contact me if you require clarification of the information provided or would like to discuss any of the matters I have raised further.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Mary Burgess', written in a cursive style.

Mary Burgess
Public Advocate (Queensland)