

9 September 2020

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability GPO Box 1422 Brisbane QLD 4001

Via email: DRCenquiries@royalcommission.gov.au

Dear Commissioners

Re: Experience of people with disability during the ongoing COVID-19 pandemic

I have been actively following the public hearings associated with the COVID-19 pandemic, from 18-21 August 2020, and would like to congratulate the Commission and Senior Counsel on the number of issues explored and the wide range of witnesses that have appeared.

Overall, the hearings stressed the importance of pandemic responses being proportionate and considered, finding an appropriate balance between suppression of the virus and respect for the fundamental human rights of people with disability.

While the hearings dealt directly with the functions and services of government during the COVID-19 pandemic, the appearance of representatives from the NDIS Quality and Safeguards Commission at the hearing (Mr Graeme Head AO, the NDIS Quality and Safeguards Commissioner and Ms Samantha Taylor the NDIS Quality and Safeguards Commission Registrar) raised some broader systemic issues related to the health and wellbeing of NDIS participants to which I would like to draw the Commission's attention.

As you are aware, the NDIS Quality and Safeguards Commission is responsible for registering and regulating the disability service 'industry', which includes, among a variety of other tasks, receiving and responding to complaints and recording and monitoring serious and reportable incidents.¹

Senior Counsel, in closing remarks made at the COVID-19 pandemic hearing, drew the attention of Commissioners to areas of interest and significance, including 'whether the responses of the NDIA and the NDIS Quality and Safeguards Commission to the circumstances presented by the pandemic appropriately address the needs of NDIS participants', and 'whether there needs to be greater outreach and auditing of disability services to ensure they are operating safely in the time of pandemic'.²

My concerns in relation to the operation of the NDIS Quality and Safeguards Commission and its role in this space were highlighted by the tragic death of NDIS participant Ms Ann-Marie Smith in Adelaide earlier this year. While Ms Smith's death cannot be attributable to circumstances related to the pandemic, I am of the view that the measures I suggest below in response to this

¹ NDIS Quality and Safeguards Commission, *What we do*, August 2020, < https://www.ndiscommission.gov.au/about/what-we-do>.

² Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Transcript of Proceedings in the matter of a Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Day 4, 21 August 2020, p-411 https://disability.royalcommission.gov.au/system/files/2020-08/Transcript%20Day%204%20-%20Public%20hearing%205%2C%20Sydney.pdf

tragic incident are equally relevant and applicable to the NDIS operating in a pandemic environment or other emergencies.

It is vital that the Commission and the NDIS take a proactive and preventative approach to the provision of safeguards and monitoring for NDIS participants. This approach needs to find an appropriate balance between supporting autonomy to the greatest extent, while monitoring service quality and the health and wellbeing of vulnerable NDIS participants.

I offer the following observations and suggestions to the Commission for consideration.

Identifying vulnerable individuals

The Government of South Australia's Safeguarding Task Force, Interim Report³, noted that it is critical that the NDIA has a clear concept of 'vulnerability' for its participants and has processes in place to identify vulnerable participants for which appropriate safeguards can be put in place to prevent abuse, exploitation or neglect. While it is important to avoid being overprotective, and recognise that not all people with disability are vulnerable and need protection, it is critically important that the NDIS has systems of monitoring and oversight that will identify risks to vulnerable participants, and act on them before they suffer harm from abuse, neglect or infection during a health pandemic or emergency.

Changes to improve the responsiveness of the NDIS Incident Management System

As noted, the NDIS Quality and Safeguards Commission requires service providers to report the deaths of participants and other serious incidents, including the alleged abuse and neglect of participants. It also requires NDIS service providers to have an incident management system, including procedures for identifying, assessing, recording, managing, resolving, and reporting incidents. While this system, once fully embedded into the Scheme, will provide a great deal of information that will assist in safeguarding NDIS participants, it does appear to lack any 'red flags' for risk.

Rather than focusing on just reportable 'incidents', Ms Smith's case and the COVID-19 pandemic highlight the need for the auditing and monitoring processes of the NDIS to be reviewed to identify particular issues that might be indicators of risk or 'red flags' that trigger NDIS responses or interventions. Some of the ways these indicators of risk could be identified and monitored include:

- Monitoring the person's access to health services.
- A requirement for service providers to introduce their own systems of oversight, incorporating
 early detection of potential instances of neglect, harm or exploitation.

Supporting and monitoring access to health services

Numerous reports over the past decade have identified that many people with disability have complex health issues, including the 2016 report of my predecessor, Upholding the Right to life and health: A review of deaths in care of people with disability in care. To ensure that the health of vulnerable NDIS participants is maintained, this cohort should have annual health assessments prepared by their GP that should be used to develop an annual health plan, documenting the various doctors and medical specialists the person should see, the frequency of those visits and so on.

While the provision of mainstream health services is outside of the responsibility of the NDIS, the NDIS should still be aware of the health needs of its participants, especially when complex medical conditions are involved. This issue is equally relevant in ordinary circumstances as well as in a pandemic or other public health emergency. This group of NDIS participants should have

³ Government of South Australia Safeguarding Task Force, Interim Report, 15 June 2020.

⁴ The Public Advocate Qld, Upholding the right to life and health: A review of deaths in care of people with disability in Queensland, 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

NDIS plans that acknowledge their health needs and make provision for the necessary disability supports to manage conditions on a daily basis and implement annual health plans, including support to attend medical appointments. There are significant risks for the NDIS to be funding disability supports for people with complex health conditions without acknowledging those conditions and understanding the disability supports required to manage them and keep people healthy. A siloed approach to the provision of NDIS services, and disregard of their reliance on mainstream health system services may lead to poor health outcomes or death for some participants.

To address these risks, there needs to be a critical 'point of contact' established between the NDIS, State-based health services and Primary Health Networks to allow the NDIS to follow up on whether its participants are accessing the health services they need. For instance, NDIS-funded Support Coordinators could be authorised and required as part of their role to coordinate the implementation of participants' annual health plans.

Additionally, the NDIS could set up a series of 'risk flags' for participants with complex health conditions. These could include a risk flag with Medicare to identify any NDIS participant who has not made a Medicare claim for a medical appointment in the past 12 months, or a flag with local health services for participants who had been taken to a hospital emergency department during the same time period. Based on information from media reports, a Medicare risk flag would have alerted the NDIS to the circumstances of Ms Smith, as it seems she had not seen a doctor in over five years prior to her death.

It is critical to the safety and wellbeing of NDIS participants who are funded for high levels of personal care on which they are completely dependent for day to day wellbeing, that the NDIS takes an active interest in their health needs and monitors these types of flags.

Requiring service providers to have their own systems of oversight

Another potential method of monitoring and oversight could be to require service providers to institute regular, independent 'health and wellbeing' checks of their NDIS clients. The checks could also involve monitoring the standards of care and support provided by their workers to those clients. The checks could be introduced as a component of the regulatory and registration system for NDIS service providers.

For example, service providers could be required to undertake their own 'inspections' of their workers 'in the field' and to obtain feedback from clients on their satisfaction with their individual services, at least annually. This could entail the supervisor/inspector observing the worker delivering care services to the client and assessing their skills, satisfying themselves that the worker is delivering services to a requisite standard. This inspection would also allow for the supervisor to at the least observe the client and their wellbeing. The supervisor/inspector could also obtain feedback from the client, although this may be difficult for the NDIS participant to do with confidence, with the worker present. In any event, some form of internal inspection process could ensure that someone independent of the direct care worker had 'eyes on' the person with disability at regular intervals that could be set according to the NDIS participant's level of vulnerability.

It is acknowledged that such a regime would not work for sole disability support workers or smaller support providers. An alternative scheme may need to be considered in these circumstances, including a requirement for these service providers to organise their own independent inspections.

Another issue that must be addressed to minimise neglect and exploitation of vulnerable NDIS participants is to ensure that participants do not receive services from a sole worker for an extended period. Instead, workers should be assigned on a rostered basis, which would enable peer monitoring to operate informally.

Many people with disability develop quite close relationships with their support workers and may want to use the services of one person exclusively. While this can often be a positive outcome for the person with disability, it needs to be balanced with appropriate safeguards and monitoring to minimise the risk of any neglect or abuse that may go undetected.

Provision of advocacy supports for vulnerable clients

Another method to ensure the safety and wellbeing of vulnerable NDIS participants is to fund advocacy supports. For particularly vulnerable participants, with high support needs and few informal supports, an advocate could provide a valuable link into the community and a level of independent oversight of the person's health and wellbeing, while empowering that person to express their views and exercise choice and control in their lives.

The role of a funded independent advocate would need to be recognised within the NDIS, and the advocate should be able to readily see the NDIS participant alone, free from the influence or intrusion of support workers. Where this access is denied or interfered with, it should also be regarded as a risk flag for the NDIS participant that should be explored by the Commission.

I have recently had discussions with Mr Ben Gauntlett, Disability Discrimination Commissioner, Australian Human Rights Commission in relation to this issue. We are of the view that the National Disability Strategy should contain a national safeguarding framework to achieve a consistent approach to the monitoring of services and risks for people with disability across all Australian jurisdictions.

I trust that this additional information is useful to the Royal Commission's deliberations.

Yours sincerely

Mary Burgess

Public Advocate (Queensland)