

24 July 2020

The Hon Alan Robertson SC,  
Independent Review into the death of Ms Ann-Marie Smith  
NDIS Quality and Safeguards Commission  
PO Box 210  
Penrith NSW 2750

Dear Mr Robertson

I am writing to make a submission to the independent review into the death of Ms Ann-Marie Smith, which I understand you are leading.

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.

The death of Ms Smith was a terrible reminder of the importance of effective monitoring and oversight in our disability service systems to ensure the safety and well-being of some of the most vulnerable members of our community.

In 2016, my predecessor released the report, *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*. The review investigated the deaths of 73 people with disability in care in the period 2009 to 2014, finding that more than half of the deaths were unexpected and potentially avoidable. The report can be accessed at: [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](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).

More recently, I released a Position Statement 'Upholding the right to life and health of people with disability' dealing with the Queensland context following transition to the National Disability Insurance Scheme (NDIS). The Position Statement calls for a wide range of measures to be adopted to prevent the deaths of people with disability in care. This includes training for medical and health professionals and disability support workers about the health needs of people with disability; the recognition of the needs of people with disability and complex health needs in their NDIS plans; and improved coordination, integration and communication between mainstream health services, registered NDIS service providers, and other disability support services. That statement can be accessed at: [https://www.justice.qld.gov.au/\\_data/assets/pdf\\_file/0010/618409/right-to-life-and-health-position-statement-final.pdf](https://www.justice.qld.gov.au/_data/assets/pdf_file/0010/618409/right-to-life-and-health-position-statement-final.pdf).

On 25 May 2020, I wrote to Mr Graeme Head, NDIS Quality and Safeguards Commissioner, expressing my concern about Ms Smith's death. I attach a copy of that letter for your information. In reply, Mr Head informed me of your independent review and advised that I could make a submission.

## **Supporting autonomy to the greatest extent while monitoring services and health**

I have also had the benefit of reviewing the Government of South Australia's Safeguarding Task Force, Interim Report, dated 15 June 2020.

I support all of the observations and commentary in the Interim Report, including Safeguarding Gaps 1 to 9. I also would like to preface my submission by supporting the observation by disability advocate, Jacky Chant, noted in the Interim Report:

We need to be careful that people don't lose trust in the NDIS and the good things that it has done and also that we don't portray every person with a disability as needy and vulnerable.<sup>1</sup>

I am not aware from the media reports, whether Ms Smith experienced impaired decision-making capacity. I assume from her personal arrangements that she was a person with capacity, but who was extremely vulnerable because of her level of physical disability, her dependence on others for her daily care and her limited (or non-existent) social or family networks.

In the circumstances, I am of the view that Ms Smith's level of capacity is irrelevant to the issues I want to raise in this submission, as her level of vulnerability due to those characteristics, exposes her to the same risks of abuse, exploitation and neglect as those often experienced by people with impaired decision-making capacity.

As the Public Advocate, my function to promote and protect the rights and interests of people with impaired capacity includes encouraging the development of services and supports for them to achieve the greatest degree of autonomy.

I note that you have been requested by Mr Head to:

1. Identify and describe ...
  - a. ...
  - b. The extent to which any mechanisms that might have guarded against the particular vulnerability of Ms Smith, such as guardianship in relation to any lack of capacity, were available and were accessed by or on behalf of Ms Smith or applied or sought to be applied in relation to Ms Smith.<sup>2</sup>

It is important, that this, and the other reviews into the death of Ms Smith, strike the correct balance between appropriate oversight and monitoring of the services delivered to NDIS participants while respecting their right to independence and autonomy. This can be a difficult balance between ensuring vulnerable disability consumers like Ms Smith can live safe from neglect and exploitation, while avoiding excessive intrusion into their lives or limiting their rights and autonomy, driven by a desire to protect them from risk and harm.

Unless Ms Smith had impaired decision-making capacity, she could not have had a guardian appointed to protect her interests. This is appropriate. I would suggest that there are a range of alternative means of monitoring and overseeing the delivery of services to vulnerable people with disability, without the need to impact their independence and autonomy. I discuss these alternatives below.

### **Identifying vulnerable individuals**

As the Interim Report identified, it is critical that the NDIA has a clear concept of 'vulnerability' for its participants and has processes in place to identify vulnerable

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<sup>1</sup> Government of South Australia Safeguarding Task Force, *Interim Report*, 15 June 2020, p 5.

<sup>2</sup> NDIS Quality and Safeguards Commission, *Terms of Reference*, for the Independent Reviewer, undated.

participants and have appropriate safeguards in place to ensure that the neglect that occurred in Ms Smith's case cannot recur. I agree with the suggested definition of vulnerable individuals made by the South Australian Task Force:

Vulnerable individuals are those with complex support needs (including communication difficulties), cognitive challenges, poverty, domestic violence or poor connection to family/friends/services.<sup>3</sup>

While it is important to avoid being overprotective of vulnerable individuals, 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 and oversight that will identify risks to vulnerable participants, and act on them before the person suffers harm.

### **NDIS Quality and Safeguards Commission incident management system**

As noted in my letter to Mr Head, the NDIS Quality and Safeguards Commission requires service providers to report deaths of participants to the Commission and other serious incidents, including the alleged abuse and neglect of participants, including physical, verbal, and financial abuse. It also requires NDIS service providers to have an incident management system that includes procedures for identifying, assessing, recording, managing, resolving, and reporting incidents.

This incident management system is very comprehensive and will ultimately result in the recording and reporting of a great deal of relevant information that will assist to safeguard people with disability receiving NDIS supports. However, it appears the system did not identify any 'red flags' for risk that might have triggered an intervention that could have saved Ms Smith's life.

For people like Ms Smith, who are particularly vulnerable, in terms of their disability and dependence on others for care, and who have few family or community supports, there is clearly a gap in the NDIS reporting systems, in terms of monitoring the quality of NDIS services being provided, and the health and wellbeing of this very vulnerable cohort.

### **Auditing and monitoring services and quality and identifying flags for risk**

Rather than focusing on just reportable 'incidents', Ms Smith's case highlights 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 would 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
- requiring service providers to introduce their own systems of oversight.

### Supporting and monitoring access to health services

As identified in the *Upholding the Right to life and health* report, many people with disability have complex health issues. To ensure their health is maintained, this cohort of people should have annual health assessments prepared by their GP which should be used to develop an annual health plan which should document 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 with the most complex health conditions. This group of NDIS participants should have NDIS plans that acknowledge their health needs and make provision for the necessary disability supports to manage their conditions on a daily basis and to implement their annual health plans, including attending medical appointments. Ultimately, there are significant risks for the NDIS to be funding

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<sup>3</sup> Government of South Australia Safeguarding Task Force, *Interim Report*, 15 June 2020, p 6.

disability supports for very vulnerable people with complex health conditions without acknowledging those conditions and understanding the supports required to manage them and to keep people well. This siloed approach to the provision of NDIS services to participants, and disregard of their reliance on mainstream health system services will lead to poor health outcomes or death for some participants.

To address the risk of NDIS participants 'falling through the gaps' between the NDIS and mainstream health services, there needs to be a critical 'point of contact' established between the NDIS and 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 risk flag with Medicare to identify any NDIS participant who had not made a Medicare claim for a medical appointment in the past 12 months. Based on information from media reports, such a reporting requirement would have alerted the NDIS to Ms Smith's circumstances, 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 the level of personal care that it seems Ms Smith required, that the NDIS takes an active interest in their health needs, when they are so clearly vulnerable and dependent on their disability workers for all of their care and support needs.

#### Requiring service providers to have their own systems of oversight

Another means of monitoring and overseeing the provision of services to NDIS participants would be to require service providers to institute regular, perhaps quarterly, independent 'health and wellbeing' checks of their NDIS clients. Those checks would also involve monitoring the standards of care and support provided by their workers to those clients. This could be introduced as a component of the regulatory and registration system for 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 services at least annually. This could entail the supervisor/inspector observing the worker delivering care services to the client and assessing their skills and 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 condition. It would also allow for the supervisor/inspector to 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, such an internal inspection process would ensure that someone independent of the direct care worker had 'eyes on' the person at regular intervals that could be set according to the NDIS participant's level of vulnerability.

It is acknowledged that such a scheme would not work for sole disability support workers or smaller support providers. An alternative scheme may need to be considered, including requiring 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 that ideally, they should 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.

I understand that people with disability often develop quite close relationships with their support workers and may want to use the services of one person exclusively. While in many cases, this can be a positive outcome for the person with disability, it needs to be balanced with appropriate safeguards and monitoring to minimise the risk of neglect or abuse that might go undetected, as appears to have occurred in Ms Smith's case.

### **Provision of advocacy supports for vulnerable clients**

Another way to ensure the safety and wellbeing of vulnerable NDIS participants is to fund advocacy supports for this cohort. For people like Ms Smith, whose vulnerability arises from a number of factors, including their level of disability and dependence on others for care, and who have few family or community supports, an advocate could provide another link into the community and a level of independent oversight of the person's treatment and care, while empowering that person to express their views and wishes, and to exercise choice and control in their lives.

Clearly, during her final years, Ms Smith was not able to exercise choice and control in her life. Had she been funded for the services of an independent advocate, her mistreatment and neglect would have been identified and acted on. The benefit of an advocate over a community visitor or other similar oversight mechanism, is that the advocate's role is to empower the person to exercise their capacity, rather than to protect the person, although having an independent advocate clearly has a protective effect.

The role of the funded independent advocate would need to be recognised in the NDIS service system and the advocate should be able to readily access the NDIS participant and see that person alone, free from the influence or intrusion of other disability workers. Where this access is denied or interfered with, should also be regarded as a flag for risk for the NDIS participant that should be acted upon by the NDIS.

I appreciate the opportunity to contribute to your review of the circumstances of the death of Ms Smith and trust that my suggestions for better system safeguards and monitoring are of some assistance.

Ultimately, stronger systems of monitoring and accountability of NDIS service providers to ensure quality of care for vulnerable participants will lead to better health and wellbeing outcomes for this cohort.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Mary Burgess', with a large, elegant flourish at the end.

Mary Burgess  
**Public Advocate (Queensland)**

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