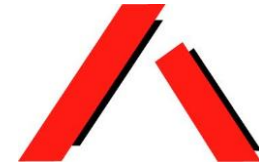


4 August 2021



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Dear Committee Secretary,

Public Hearing – National Disability Insurance Scheme Amendment (Improving Supports for At Risk Participants) Bill 2021

We refer to the above inquiry and to our appearance at the Public Hearing on 2 August 2021. Thank you for the opportunity to provide evidence to this important inquiry.

Further to our written and oral submissions, we wish to provide further brief submissions in relation to the right to privacy. While QAI's submissions to date did not address the issue of privacy associated with the potential amendments, we wish to express our support for the submissions made by our colleagues at the Public Hearing regarding the potential risks associated with the proposed amendments insofar as they create the potential for the infringement of privacy rights of participants. We also endorse the submissions regarding the inadequacy of the consultation, and the importance of addressing this omission.

The right to privacy is enshrined in Article 22 to the Convention on the Rights of Persons with Disabilities, which requires States Parties to ensure:

- That no person with disabilities, regardless of their place of residence or living arrangements, is subjected to arbitrary or unlawful interference with privacy, and are protected by law against interference or attacks on their privacy; and
- Protection of the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

While the right to privacy is protected in Queensland,¹ which binds public entities including registered NDIS service providers,² non-registered NDIS service providers are not bound and there is no protection at a commonwealth level, nor is there equivalent protection in the majority of states and territories.

¹ *Human Rights Act 2019* (Qld), s 25.

² *Human Rights Act 2019* (Qld), s 9.

We note that, even as the law presently stands without the passage of the amendment Bill, people with disability experience significant and routine infringements of their right to privacy. We are concerned that the rights to privacy of people with disability are not afforded the same consideration or value as the rights of people without disability, including the right to privacy of workers providing supports for people with disability. This is of grave concern, given the significant power imbalance that exists in service provision relationships, particularly where the recipient has disability, which can be exacerbated and abused by the inappropriate sharing of information. The Robertson Report, and the evidence presented to the Disability Royal Commission, has documented some examples of the violence, abuse and neglect that people with disability can endure from their service providers.

QAI supports the recommendations made by the Australian Federation of Disability Organisations (AFDO) regarding the need for clarification and transparency regarding the circumstances in which a participant's privacy can be breached and the safeguards and protections afforded, as well as routine independent oversight by the Office of the Australian Information Commissioner and Privacy Commissioner.

We provide the following case study of but one example of the eliciting of inappropriate and unnecessary information by a service provider.

Case study

Iris* has experienced a lifetime of care, being born with significant disability. She has also experienced significant violence, abuse and neglect. Since the introduction of the NDIS, Iris has reported a decline in her service and support provision. Recently, Iris sought QAI's advice and assistance following the request for information by an Occupational Therapist preparing a report for Assistive Technology funding for a wheelchair, seeking our client to confirm if she is sexually active and how she would classify her sexual status. Iris was distressed by this question and did not understand why this information was requested. She notes:

Who gives them the right to ask this? ... I don't think they should be allowed to ask this or many of the other questions. It's almost like disabled people have no privacy or dignity, are treated like an entertainment joke. If they asked an able person these questions, they would be sued so why are they allowed to ask a disabled person this? It's so wrong. And why does the NDIA feel they need to know if we are currently having sex?

Further, despite that Iris had signed a privacy release form indicating that she did not consent to sharing or discussing her details with the coordinator, plan manager or health professionals, her private health information was subsequently shared. When Iris questioned this breach, the response was that the support coordinator felt "she would not mind her talking to him" and that it was largely "generic information" that was shared.

** Name has been changed*

Thank you for the opportunity to provide these additional submissions. We are happy to provide further information or clarification upon request.

Yours faithfully,

Matilda Alexander
Chief Executive Officer
Queensland Advocacy Incorporated