



Our ref: 20-HPC-2212

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Hon. Kelly Vincent and Dr David Caudrey
Co-Chairs of the Safeguarding Task Force

By e-mail

Dear Ms Vincent and Dr Caudrey,

Feedback on Safeguarding Task Force report of 31 July 2020

Thank you for the opportunity to provide feedback on your July 2020 report on gaps in oversight and safeguarding for people living with disability in South Australia.

It was a pleasure for Ellen Fraser-Barbour and me to meet with you on 14 July to share information and reflections to help your drafting of the report. The Health Performance Council has now reviewed your report and, on behalf of the whole Council, I would like to provide some feedback on areas that we believe could be identified more strongly and clearly as safeguarding gaps and recommendations for action in the final report you intend to produce at the end of September.

Workforce

In our four-yearly report to the Minister for Health and Wellbeing for 2015–2018, the Health Performance Council advised the Minister to ensure that the health workforce reflects the communities who are served, including by setting targets, increasing diversity data recording, and undertaking annual staff surveys¹.

We strongly believe that a similar objective should apply to better secure safeguarding, and that action should be taken to ensure that people with disabilities have a greater workforce participation rate. Even aside from the issue of equity in workforce participation, we reiterate our view that unless more effort is made routinely and deliberately to employ people with disabilities across the workforce then there remains too great a risk of missing opportunities to identify vital evidence to inform and safeguard the provision of maximal care to people living with disability in South Australia.

¹ Health Performance Council, *Review of the performance of South Australian health systems, the health of South Australians and changes in health outcomes over the reporting period 2015-2018*. Available from <https://www.hpcs.com.au/reviews/2015-2018-report>

Involvement and engagement

The Health Performance Council believes that consumers of a health service should be encouraged and enabled to have active participation in the planning and delivery of the services they consume. We said as much to the Minister in our four-yearly report, recommending that the Minister ‘Involve and engage consumers in system development and evaluation, and ensure their voices are heard at executive and board levels’.

We believe that your Task Force report would be strengthened by calling out more expressly a gap in leadership and contribution to health service design, planning and delivery by people in the state who are living with disabilities. It is necessary to advocate for people with disabilities to be valued members of the workforce able to provide input during the creation, production and evaluation of meaningful outcome measures.

Rural and remote South Australia

Many of the Health Performance Council’s reviews have noted inequity and discrimination between different groups of people in South Australia. In our report of what we heard from the stakeholder consultation we conducted for our own review of matters pertaining to health outcomes and experiences for South Australians with disability², we reported some stakeholder concerns about the Adelaide-centric tendency of the system. We suggest that your report expressly recognise the safeguarding gap that can arise from the health system not recognising the needs of people with disabilities outside of Adelaide, including as to a lack of appropriate facilities and key services outside of Adelaide and the need for sometimes lengthy and hard-to-obtain travel.

Care plans

We note your reflection in your July report that the NDIS “has not seen itself as the case manager ultimately responsible for safeguarding vulnerable participants. This has to change [...]”. We would amplify this observation and go further to suggest that it ought to be recommended that there be mechanisms devised to ensure that customised case management plans are put in place particularly for people who are vulnerable or who have cultural needs that need to be respected. We suggest further that, consistent with all our advice to listen to and respect consumers and carers, people should be able to have a say in what constitutes a measure of success in their own care by contributing to their own determination of appropriate outcome measures. The value of outcome measures is in their evaluation and monitoring. While recognising the need to maintain adequate protections of personal privacy, it is important that there also be meaningful reporting in aggregate of the evaluation of the outcome measures in the care plans.

Data

The Health Performance Council has advised government and other stakeholders of the difficulties we have faced in getting hold of adequate and sufficiently complete data to be able to answer questions of access, equity, quality and safety of the state’s health system. The various components of the health systems in the state individually collect and hold large amounts of data but too little of that data is incorporated into central data warehouses for analysis and what does get stored is often of poor quality, with missing, under-reported and mis-reported data items.

² Health Performance Council, *Health outcomes and experiences for South Australians with disability Stakeholder feedback — what we heard*. Available from <https://www.hpcsa.com.au/reports/health-outcomes-and-experiences-for-people-living-with-disability>

We have found in the pursuit of our review work many gaps in the collection of relevant data, especially for vulnerable populations, making it difficult or impossible to form an adequate picture of health outcomes and journeys and of how these compare with or contrast to those of others in the population. Furthermore, even when data is known to be collected and stored, we have been thwarted in our attempts to gain access to data for analysis by what seem to be systemic cultural issues of poor or lacking statistical and information governance.

Especially, access to linked record-level data from multiple sources, under secure arrangements to protect the confidentiality of individuals, has become markedly worse in our experience: analysis including multi-source linked record level data that was readily achieved by us in a three month project in 2013 became an 18-month project of endurance when repeated in 2018, and we have reluctantly now abandoned hopes for a nearly 2-year-long effort to obtain linked data to inform our own review of matters pertaining to health outcomes and system experiences for people with disabilities.

From the lack of data, at point of collection or for subsequent analysis, we can only infer that, contrary to the professed preferences of those running our health system bodies, decisions must be being made without the benefit of being informed by data. We assert that this affects vulnerable populations such as people with disability in our state and amounts to a safeguarding gap. We have previously called for a whole-of-state-government data strategy to enable interoperability, connectivity and timely access to South Australia's data assets as a matter of the utmost importance. We would suggest that your Task Force report might endorse such recommendation as a call to action to address this safeguarding gap.

Thank you again for the opportunity to comment on your July 2020 report. I hope that the information in this letter of feedback is useful to you. On behalf of the Health Performance Council, I wish you every success with the completion of your final report.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Steve Tully', with a stylized flourish at the end.

Steve Tully
Chair
Health Performance Council

11 September 2020