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Commentary

Improving health care for disabled people in COVID-19 and beyond: Lessons from Australia and England



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ABSTRACT

COVID-19 has exacerbated pre-existing difficulties children and adults with disability face accessing quality health care. Some people with disability are at greater risk of contracting COVID-19 because they require support for personal care and are unable to physically distance, e.g. those living in congregate settings. Additionally, some people with disability have health conditions that put them at higher risk of poor outcomes if they become infected. Despite this, governments have been slow to recognise, and respond to, the unique and diverse health care needs of people with disability during COVID-19. While some countries, including Australia, have improved access to high-quality health care for people with disability others, like England, have failed to support their citizens with disability. In this Commentary we describe the health care responses of England and Australia and make recommendations for rapidly improving health care for people with disability in the pandemic and beyond.

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Introduction

Across the world governments have been slow to recognise the unique and diverse health care needs of children and adults with disability during the COVID-19 pandemic. This has exposed them to higher risks of infection and death.^{1–3} A US study found the case fatality rate from COVID-19 was 4.5% for people with intellectual and developmental disabilities under 75 years, compared to 2.7% in the rest of the population.⁴ Data from England suggests cause of death for over 700 people with intellectual disabilities was COVID-19 related,⁵ with a much younger peak age of COVID-19 related death than the general population.^{5,6}

This Commentary describes the health care responses of England and Australia and makes recommendations for rapidly improving health care for people with disability in the pandemic and beyond. We start with a brief review of the health and social

care situations pre-pandemic. We then describe and compare how the Australian and English governments have responded to health care needs of people with disability during the pandemic. We conclude by drawing on our learnings from the COVID-19 responses in both countries to chart a new way forward for government and society, ultimately to improve health outcomes for people with disability.

The situation before COVID-19

In Australia and England, people with disability experience worse health outcomes, poorer quality health care and more difficulties accessing preventative health care and health promotion than the rest of the population (see [Box 1](#) for summary). For example, Trollor and colleagues found a 27 year life expectancy gap for people with intellectual disability in Australia, largely due to deaths from avoidable causes.^{7,8} In England, people with intellectual disability aged 0–74 are four times more likely to die than their peers without disability of same age and sex.⁹

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Box 1

What is known about the health care experiences of people with disability

- Inadequate health care workforce capacity, including primary care¹⁰
- Accessible forms of communication and information not always available (e.g Auslan/BSL interpreters,¹¹ easy read material¹²)
- Discriminatory practices that prevent access to health care on an equal basis to others¹³, including life-saving treatments
- Lack of effective, targeted health promotion programmes¹⁴
- Low levels of participation in preventative health programs (e.g. mammographic screening¹⁵)
- Lack of coordination across sectors including health, education, and social care and across different levels of government¹⁶

The health and social care systems

Responding to public health emergencies such as COVID-19 requires a coordinated public health response across all levels of governments and portfolios. Having governments who can rapidly coordinate across governments and portfolios is essential in crises such as COVID-19 where decisions need to be made quickly and implemented promptly, with ongoing monitoring and evaluation and adjustment of responses.¹⁷ In both Australia and England complexities in cross-jurisdictional responsibilities for health and disability care hampered optimal public health responses.

Table 1 briefly outlines systems of government; jurisdictional responsibilities in relation to funding, provision and regulation of health care and disability services and the health sector response to COVID-19. Of particular note, government-funded universal health care is available to all residents in both countries, although in Australia patients may incur some costs.

In Australia, complexities have arisen in mounting a coordinated public health response to COVID-19 because, while the Commonwealth government has some responsibilities, the States and Territories are responsible for implementation of the pandemic response in their own jurisdictions including public health orders, contact tracing and testing. In terms of the health service response, the Commonwealth has been responsible for making changes to funding for Medicare to enable Telehealth while the States and Territories have overseen hospital responses.

In Australia, most disability services are provided through the National Disability Insurance Scheme (NDIS), jointly funded by the Commonwealth and State and Territory governments. Individuals with severe, permanent disabilities, aged less than 65 years at entry into the NDIS, are provided with individual budgets to purchase the services and supports they need in a quasimarket. The NDIS is administered and regulated through Commonwealth agencies, the National Disability Insurance Agency (NDIA) and the NDIS Quality and Safeguards Commission respectively. However, the NDIS was only introduced in 2013 and not all people who are eligible for the NDIS have transitioned to the Scheme with some still receiving supports through State and Territory governments. Furthermore, some services are not yet regulated by the NDIS Quality and Safeguards Commission but rather by State and Territory government regulatory authorities.

In England, while NHS services are centrally funded they are commissioned through 135 local clinical commissioning groups and health services are largely provided by almost 7000 primary care general practices and 223 NHS Trusts. This creates challenges in terms of who is responsible for the oversight of the activities of the health services and in coordinating coherent and consistent public health responses. Public Health England is the executive agency of the Department of Health and Social Care (separate from NHS England) responsible for public health functions, while Directors of Public Health are located within local authorities. Public Health England's testing and tracing capacity was overwhelmed early in the pandemic and in May 2020 a new agency, NHS Test and Trace, was established to take over these responsibilities. NHS Test and Trace contracts private companies to deliver these services centrally alongside local test and trace efforts; however widespread problems have been reported including lack of co-ordination with local public health personnel, delays in getting test results, and errors in contact tracing.¹⁹

Social care in England, funded via national government subventions and local taxes on property and businesses, include supports for people with disability that are not health care (e.g. home care, personal assistants). Disability services are means tested with strict eligibility criteria and are organised by 152 local authorities in England. Individuals notionally receive personal budgets, with the vast majority of social care services provided by the independent sector. While in theory most social care support is provided via self-directed support, in practice there is wide variation in the restrictions placed on people with disabilities using social care.

Over the last 10 years health care funding has broadly kept pace with inflation in England, although this is insufficient to keep pace with growing population health need, while social care funding has been severely cut. This has sharpened cost shunting between health and social care to the detriment of supports for people with disability. There is also wide geographical variation in how health and social care services are organised and provided.

Public health responses to COVID-19

The World Health Organisation planning guidelines to support country preparedness and response to COVID-19 contains a number of pillars including: country-level preparedness, planning and monitoring; risk communication and community engagement; surveillance, rapid response teams and case investigation; points of entry (i.e. borders, travellers); laboratories; infection prevention and control; case management; and operational support and logistics.²⁰ Of particular note for people with disability is the emphasis on multi-sectoral, multipartnership collaborations such as between health and disability services; tailored messaging with 'at risk' groups through engagement with trusted community groups; surveillance systems particularly for 'at risk' groups; establishment of rapid response teams to investigate outbreaks and contact trace within 24 hours; prioritised training of health care workers in infection control and ongoing monitoring; and development of workforce surge capacity. The United Nations policy brief, *A Disability Inclusive Response to COVID-19* emphasises accessible information, facilities, services and programmes; meaningful participation and inclusion of people with disability; infection control and access to PPE; non-discrimination in access to health care; and preparing services and institutions and the discharge of people in institutions such as hospitals and aged-care into the community, if possible.²¹

The COVID-19 pandemic trajectories in Australia and England

England's population is over double that of Australia's (England

Table 1

Description of governance arrangements; funding, provision and regulation of health and disability services; and responsibilities in public health emergency responses to COVID-19 in Australia and England.

Australia	England
<i>Governance</i>	
Commonwealth (national); 5 States and 2 Territories; and local governments. Portfolio responsibilities mainly spread across Commonwealth and States and Territories.	National and local government with differing portfolio responsibilities.
<i>Funding and provision of health services</i>	
Public hospitals jointly funded through State and Territories and free at point of care. State and Territory governments responsible for on-the-ground delivery of hospitals.	All health services funded by National Health Service (NHS) England and NHS Improvement. 135 Clinical Commissioning groups across England that commission services in their locality although some health service commissioning (such as specialist mental health hospitals and most primary care) is retained nationally. Almost all health services are free at the point of delivery.
Private hospital care is provided by private and not-for-providers and are part funded through Medicare (Commonwealth government) and patient's private health insurance. Patients generally incur some costs.	It is estimated that, in addition to health services provided via private health insurance, approximately 25% of the NHS budget is spent on private sector services (including primary care, optical services and dental services, which are all private enterprises) ¹⁸
GP, medical specialist and some allied health services are provided by private providers and funded through Medicare (Commonwealth government). The Commonwealth government sets a rebate for services and if the providers charges above the rebate the patient incurs the additional cost. Some States and Territories also fund Community and Mental Health services.	
<i>Regulation of health practitioners and services</i>	
Medical, nursing and allied health practitioners regulated through National Australian Health Protection Regulation Agency.	Care Quality Commission UK regulates all health and registered social care services (some social care services such as supported living services are unregulated).
State and Territory governments responsible for registration and regulation of public and private hospitals.	
<i>Responsibilities for health emergency response to COVID-19</i>	
Predominantly State and Territory responsibility including for testing, contact tracing, quarantine, declaration of state of emergency, interstate borders, public health restrictions or legislation (e.g. mandated mask wearing, interstate borders), guidelines.	Responsibility of both English government and local authorities. Public Health England (PHE) is an executive agency of the Department of Health and Social Care (i.e. not NHS) and local Directors of Public Health in local authorities. Public Health England's local health protection teams are responsible for responding to cases in hospitals, care homes, and prisons through the individual institutions, in collaboration with local authorities.
Some activities were commissioned to private providers (e.g. security for hotel quarantine, contact tracing in some jurisdictions). These are provided at a local level (e.g. contact tracing), with different approaches to control (e.g. centralisation/decentralisation).	NHS Test and Trace responsible for contact tracing and testing and following up less complex cases. They are commissioned through private providers. Since 2013 public health functions were collected into one national agency in England, Public Health England, with local Directors of Public Health moving from health services to local authorities.
Commonwealth government responsible for national border, distribution of medicines and personal protective equipment through national stockpile.	From August 2020, with statutory formalisation by Spring 2021, a new agency, the National Institute for Health Protection, will include NHS Test and Trace and the former Public Health England.
Cross-jurisdictional response is negotiated through a range of bodies with joint membership i.e. national cabinet (PriMinister and State Premiers and Territory Chief Ministers), Australian Health Protection and Prevention Committee (Commonwealth and State and Territory Chief Health Officers).	
<i>Funding and provision of disability services</i>	
Most disability services are provided through the National Disability Insurance Scheme (NDIS), jointly funded by the Commonwealth and State and Territory governments but 'owned' by the Commonwealth Government.	Funded via national government subventions and local taxes on property and businesses. Disability services are means tested, meaning that some people will incur a cost if their earnings or assets are over the threshold. The delivery of services is organised by 152 local authorities in England, with individuals receiving services, personal budgets or direct payments from local authorities. These individuals also have the right to a personal health budget, allowing them to spend money that would normally have been spent by the NHS on a person's care in a more flexible way. The majority of disability services are provided by the private for-profit and not-for-profit providers.
Individuals with severe, permanent disabilities, aged less than 65 years at entry into the NDIS, are provided with individual budgets to purchase the services and supports they need in a quasimarket. People who acquire a disability through a traffic accident or workplace injury may receive funding through other schemes. The NDIS began implementation in 2013 and is expected to be rolled out to all eligible participants in 2020.	
Disability services are provided through a mix of government, for profit and not-for-profit providers.	
<i>Regulation of disability services</i>	
NDIS funded services are regulated through the National Quality and Safeguards Commission (Commonwealth Agency) however the Commission is newly established and still being rolled out. In some jurisdictions (e.g. Western Australia), services are still being provided by the State or Territory governments and those governments are responsible for regulation.	Care Quality Commission UK regulates all health and registered social care services.

56,286,961 as of mid-2019²² vs Australia's estimated resident population 25,714,485 as of 25 October 20, 20²³). Table 2 compares the number of tests, cases and deaths between Australia and England. England has 18 times the number of cases and 22 times the number of deaths *per capita* (noting England's cases and deaths are a likely undercount due to inadequate testing earlier in the pandemic). Data reported by ourworldindata, shows the test positivity on November 5th, 2020 was 8.3% in the United Kingdom and <0.01% in Australia (data not presented for countries in UK separately).²⁴ Given the sensitivity and specificity of PCR testing for SARS CoV-2 is unlikely to vary much between Australia and England, these differences in test positivity suggest that the number of cases in England is much higher than the 18 times higher case load calculated based on official statistics.

Australia's first wave of COVID-19 began in March and ran until late May/early June and was largely driven by travellers arriving from overseas. Infections from unknown sources were less than 10%. Unlike in other countries, Australia did not see outbreaks among people with disability living in congregate environments in the first wave, although there were two outbreaks in aged care facilities. In late June infections in Victoria, Australia's second most populous state with a population of 6.4 million (of which 4.9 million live in the capital city Melbourne), started to rise as a result of breaches in the quarantine of returned travellers in hotels and delays in contact tracing. The Victorian second wave ran until October 2020 and was predominantly locally acquired. This Victorian second wave saw outbreaks in congregate and crowded settings such as aged care, disability group homes and high-rise public

Table 2
COVID-19 tests, cases, test positivity and deaths in Australia and England.

	Australia	England
No. of tests (cumulative)	9,212,619 ^a	29,992,927 ^b
Cases		
a. Cumulative	27,686 ^c	1,073,300 ^d
b. Average in last 7 days	64 ^e	138,990 ^f
Test positivity^g		
April 1, 2020	0.9%	26.8%
October 25, 2020	<0.001%	8.3%
Deaths	907 ^h	44,304 ⁱ

^a Tests done as of 11 November.²⁷

^b Tests done as of 10 October.²⁸

^c Cumulative cases as of 11 November 2020.²⁷

^d Cumulative cases as of 10 November 2020 according to date specimen taken.²⁸

^e Cases reported in last 7 days to the November 11, 2020 (58 in travellers returning from overseas who were in quarantine and 6 locally acquired).²⁷

^f Cases reported in last 7 days to November 6 2020.²⁸

^g Proportion of positive tests reported on ourworldindata website on 5 November 2020. Note England's estimates are based on United Kingdom as not reported by country.²⁴

^h Death defined as probable or confirmed case unless clear alternative cause of death until November 11, 2020. No time limit applied.²⁷

ⁱ Death where COVID-19 died within 28 days of confirmed positive test until October 31, 2020. If include all deaths where COVID-19 on death certificate England had 53,102 until 10 November.²⁸

housing estates, with significant levels of infection among health care workers as well as aged-care and disability workers.²⁵ The Victorian government introduced public health restrictions in late June, first with significant restrictions on movement in areas with high levels local area with higher case numbers and the lockdown of high-rise public housing estates with outbreaks. In July, Victoria saw some of the strictest restrictions on movement (essential work, exercise, care and education), curfews, closure of schools and most retail and services, with restrictions gradually easing in late October. From mid-July masks became mandatory in Melbourne and later regional Victoria. Victoria accounts for 74% of all cases and 90% of all deaths reflecting the outbreaks in aged-care in the second wave.

Across England, the first wave of COVID-19 began in March and slowly reduced after a peak in April assumed to be largely driven by people travelling/returning from overseas, facilitated by the late and partial imposition of quarantine, physical distancing and other measures such as face covering. In this first wave substantial numbers of care homes (44% of all care homes in England up to 23 July, when reporting ceased)²⁶ continued to experience outbreaks, with information absent on the experiences of younger people with disability or adults being supported by social care. There was progressive relaxation of restrictions in England, although many towns and cities with high levels of deprivation and overcrowded housing saw increasing rates of COVID-19 in summer 2020 and the imposition of varied degrees of local lockdown. The COVID-19 testing and contact tracing regime continues to be problematic, with people being advised to travel long distances to be tested (when tests are available at all) and many tests not being processed. Despite the introduction of three-tier system in an attempt to reduce spread in local areas with higher rates of COVID-19 cases in mid-October, by early November the English government announced a second period of national lockdown. This second period is anticipated to last four weeks and will see the closure of all non-essential shops, restaurants and leisure services although not schools and universities.

Health responses for people with disability in COVID-19

Australia's emergency response plan does not mention people

with disability even though it identifies other 'at risk' populations including people living in aged-care and Aboriginal and Torres Strait Islander Australians.²⁹ When national guidelines for the prevention, control and management of outbreaks in residential care facilities were released in March 2020, disability residential settings were not mentioned.³⁰ Lobbying from advocates and academics saw the Australian and many State and Territory governments take action with a National Management and Operational Plan for people with disabilities³¹ developed in April 2020. The Plan covers prevention, testing, access and use of personal protective equipment (PPE) for people with disability and disability support workers (referred to as personal care attendants in England) and health care and disability service provision. States and Territories have also released their own plans.

A website has been launched with tailored, accessible information and resources for people with disabilities, families, health care providers and disability services.³² Publicly funded telehealth has enabled access to some health services. Coronavirus hotlines have been established for people with disability and their families and carers as well as for health professionals seeking advice from colleagues about the clinical care of people with disabilities. Disability Liaison Officers were introduced to public hospitals in Victoria. Disability NGOs and advocates have worked with health departments, health care professionals and academics to develop and disseminate templates for individualised emergency preparedness COVID-19 plans, hospital passports and return to school plans for children with disability. As part of the COVID-19 response, State governments have discharged people with disability from hospitals into the community, some of whom had languished in hospital for months or years.

Nonetheless, people with disability still reported difficulties in accessing care including health care providers' unwillingness to listen to them about their needs (e.g. need for direct support to continue if hospitalised). This feedback led one State government to issue a directive that people with disability who needed support workers or carers in hospital were able to do so, despite hospitals placing restrictions on all visitors.

In the first wave, the disability service sector response varied, with providers deciding on their own pandemic responses, resulting in inconsistent decisions where some ceased services, such as day programs, while others remained open.³³ The quasi-market of the NDIS can partly explain this with providers' financial viability at risk if they close.³⁴ These inconsistencies left the disability sector vulnerable when the second wave emerged in Victoria. A survey of support workers in June revealed that 22% had not received any infection control training and, even when they had, 48% wanted more. Workers were ill-equipped to use full PPE in settings where a resident was COVID-19 positive.³⁵ Many services did not have the necessary PPE nor had a back-up or surge workforce been identified.

Over the months of July, August and September 2020 outbreaks in disability residential settings started being reported in media releases from the Victorian government, however there is still no comprehensive data available on infections among people with disability and workers. There are also likely infections and deaths among people with disability less than 65 years living in aged-care homes however these are also not available at the moment. The difficulties in obtaining data reflects ongoing issues with the lack of disability data in Australia as well as the fact that services have different reporting arrangements depending on how they are regulated.

These different systems of regulation and oversight have impacted on how well prepared services have been to respond to these outbreaks. Despite the fact that the National Management and Operational Plan for People with Disability in COVID-19

recommended the need for an outbreak management plan specifically for disability residential settings this was not developed and is only now being considered. Services were instructed to develop their own plans and were responsible for managing outbreaks, something they did not have the public health and health care skills to do. There had been no outreach to services managing disability residential service to ensure they were prepared. It was not until the end of August, that the Victorian and Commonwealth governments developed a Disability Emergency Response Centre, with representatives from Commonwealth and State government and the NDIA and NDIS Quality and Safeguards Commission, to manage outbreaks through infection control procedures, deploying PPE, testing and nursing support. They also restricted the movement of workers, financially compensating services where worker hours were reduced. Workers employed on casual contracts could also access paid leave so they did not attend work when sick. There is now direct outreach to services providing disability residential support to help them prepare and to improve workforce training. These changes are welcome, however these concerns had been highlighted previously^{36–38} and identified in the National Plan.³¹ Some of the difficulties implementing these initiatives stemmed from different systems of regulation with some disability residential services being regulated by the Victorian government and others by the NDIS National Quality and Safeguards Commission. Because Victoria has faced a second wave that has seen outbreaks in group settings they have had to overcome barriers to effective prevention, control and management of outbreaks, however, other States and Territories are not prepared.

While advocates and academics in Australia raised concerns early on that people with disability might be deprioritised in health care (e.g. triaged out of ventilator access),^{39,40} intensive care has not reached capacity and so these concerns have not been realised so far.

England has not had a co-ordinated COVID-19 government response for people with disability. There is no national strategy concerning people with disability, and people with disability's NGOs are not included in policy development. Policy announcements/guidance with substantial implications for people with disability are released piecemeal, without accompanying accessible versions. Accessible guides and information about COVID-19 have not been available, with disability NGOs and self-advocacy groups having to fill the gap.

Access to, and availability of, health care has worsened for people with disability in England in the (first) peak of COVID-19 infections. Initial government policy was to 'protect' the intensive care capacity of hospitals to deal with COVID-19, and the same rhetoric is being used in the second wave of COVID-19 in England. Older people have been discharged from hospitals to care homes without testing, resulting in a high number of COVID-19 deaths amongst care home residents in England.⁴¹

Initial clinical guidance on 'triaging' and rationing access to critical care for all people with COVID-19 recommended use of a frailty index designed for people with dementia. This meant people with disability with COVID-19 were less likely to get access to critical care such as respiratory support.⁴² A high profile campaign and legal action overturned aspects of these guidelines.⁴³ However, an ongoing audit of COVID-19 critical care services in England reports people requiring assistance with daily living less likely to receive advanced respiratory support and more likely to die than other groups.^{44,45} There have also been cases where primary care services have issued blanket Do Not Resuscitate (DNRs) notices to groups of people with disability without consultation, and where DNRs have been found on people with disability's notes without consultation.⁴⁶

COVID-19 testing and the provision of PPE in England has

Box 2

Recommendations to optimise people with disability's health care going forward

- Governments, health care professionals and services listen and respond to health needs and concerns of people with disability
- Tailored health care strategies for population-level emergencies (e.g. pandemics, floods) and routine health care that cover the diverse needs of people with disability living and working in a range of settings
- Individualised health care plans that cover both emergencies and routine care to direct workplaces and health, educational, and social care providers about how to respond to protect and improve the health of those they support. Where appropriate, these could include informed directives about advanced care.
- Active engagement of medical schools and health care professional bodies to upskill them on health care provision for people with disability and to provide them with access to relevant information and professional expertise
- Regular provision of a range of health care modalities including telehealth and outreach into homes
- Regular provision of accessible information for both population-level emergencies and routine care
- Accessibility as a requirement for accreditation of health care facilities
- Social care workforce recognised as an essential workforce and provided with priority access to protective equipment, health care and other requirements (e.g. paid leave) to protect their health as well as that of people with disability
- Disability and health care sectors work together to ensure social care is provided in a safe way that protects the health of people with disability in health emergencies and routine care
- Governments work together across jurisdictional and sectoral boundaries to facilitate optimal health care planning for people with disability
- Data is collected on disability in all health datasets so outcomes can be measured rapidly and followed by timely responses

focused on hospitals, only being extended to care homes for younger adults and other groups in mid June 2020. Problems with testing and the provision of PPE are still widespread, and support for the majority of people with disability living independently is lacking.

Worse still, rather than step-up support for people with disability, emergency COVID-19 legislation in England has included measures for local authorities to 'ease' their social care duties for adults with disability and education for children with disabilities.^{47,48} A government-sponsored social care COVID-19 taskforce, reporting in September 2020, again focuses largely on care homes for older people and excludes recommendations made to the taskforce by advisory groups of people with disabilities.⁴⁹

Because England has faced greater challenges than Australia due to the scale of the pandemic it is likely that it has been harder for advocates to capture the attention of governments. Further, the NDIS grew out of an organised 'grass roots' campaign so advocates are very accustomed to lobbying government. Nonetheless, without significant action to improve the prevention of SARS-CoV-

2 infection among people with disability and support staff, priority testing and careful health care planning, people with disability in England will continue to experience appalling outcomes in this pandemic. England's lack of response for people with disability amounts to gross neglect and contravenes obligations under the United Nations Convention of the Rights of Persons with Disabilities, to which the UK and Australia are signatories.⁵⁰

COVID-19 – what have we learnt and how can we do better?

Pandemics are experienced collectively and our actions affect each other. At this time the motivation (and will) to work together is greater. Decisions that government have avoided for years – e.g. finding accommodation for hospital-bound people with disability – have been made in a matter of days in Australia. We must learn from this pandemic, keep our urgency about longer-run health inequities and fix the broken health care system for people with disability.

Based on Australia's and England's experiences in COVID-19 we make a number of recommendations (see [Box 2](#)). First and foremost, governments and providers immediately listen to people with disability about their health and plan health care reform. We recommend action across health and other sectors, and across jurisdictional boundaries, in developing policies to improve the health of people with disability as well as detailed plans for emergency response to pandemics or natural disasters. Co-production of health care plans with people with disability and families will ensure decisions are not made 'on the run' by health care providers unfamiliar with a person's disability, social situation and health problems. Upskilling of health professionals is needed through education (including with people with disability) and leadership within the professions. Information and health care facilities must be made accessible as part of routine practice and as a requirement for accreditation of providers. The social care workforce must be recognised as an essential care workforce that prioritises protecting their own health and the health of people with disability. And, finally, we must have quality data collected which includes people with disability in government datasets and reported publicly. Without that we cannot know where problems have occurred and respond effectively.

COVID-19 poured gas on the long-burning issues people with disability face in accessing health care. When the worst of the fire is out these inequities won't have disappeared. We need to learn from Australia's pandemic response – action to improve health is possible.

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Declaration of competing interest

AK is a member of the Committee overseeing the development and implementation of the Management and Operational Plan for people with disability in COVID-19 for the Commonwealth government and regularly meets with the Victorian government in relation to their response to COVID-19 for people with disabilities.

GL is a member of the NSW Community of Practice for Disability and the NSW Department of Health Community of Practice for Rehabilitation.

GL and GC participate in the regular roundtable for the Management and Operational Plan for people with disability in COVID-19 for the Commonwealth government.

This paper was written independent of their roles on these government committees.

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