



Health outcomes and experiences for South Australians with disability

Stakeholder feedback — what we heard

May 2020



Government of South Australia

Health Performance Council

Health outcomes and experiences for South Australians with disability – what we heard

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The Health Performance Council acknowledges the diverse Aboriginal peoples of South Australia and their participation in the life of South Australia. We acknowledge and respect their spiritual relationship with their respective country and we acknowledge them as the custodians of their country and that their cultural and heritage beliefs are still important to them today.

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Contact

Health Performance Council Secretariat (contact: Andrew Wineberg)
PO Box 3246
RUNDLE MALL SA 5000
Australia

Tel: +61 8 8226 3188

Email: HealthHealthPerformanceCouncil@sa.gov.au

This report may be requested in large print or other formats on request.

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A note on language

We recognise that there are many terms used to describe the people who are in scope of our review, including ‘people with disability’, ‘people living with disability’, ‘people experiencing disability’, ‘disabled people’ and many more.

In this report, we have generally used the term ‘people with disability’ and similar phrases. This echoes the language used by the office of the Minister for Health and Wellbeing in first referring this review to the Health Performance Council¹ and is consistent with the language used by the Australian Institute of Health and Welfare². We have sometimes used other phrasing including a slightly longer form of person-first language, ‘person living with a disability’, which is widely used including by the World Health Organization³.

We acknowledge and respect that different people have different preferences as to which form of language ought to be used. We do not intend by our choice to offend or upset, nor to criticise or denigrate the preferences of others.

Introduction

Our review

The Health Performance Council is a statutory body which provides expert advice to the Minister for Health and Wellbeing about the operation of South Australia's health system, health outcomes for South Australians, and the effectiveness of community and individual engagement methods. The Council's advice focuses on health outcomes not only for the South Australian population as a whole, but also for particular population groups. All of the Council's reports are published on our website (<https://www.hpcsa.com.au>).

The Minister for Health and Wellbeing, Hon. Stephen Wade MLC, commissioned us to undertake a review of matters pertaining to health outcomes for people with disability and of their experiences with the health system. This is a significant project which involves a number of strands gathering and analyse insights from a variety of sources of data, but, most importantly, from people's lived experiences.

Two members of the Health Performance Council with expertise in the field are leading the project: Ellen Fraser-Barbour, a disability sector professional and advocacy expert who has lived experience of disability; and Professor Jennene Greenhill, a senior academic and leader with interests including clinical and rural education.

We have been assisted in the design and delivery of the project by an advisory group made up of a mix of stakeholder interests, including consumer representatives, health providers and commissioners, and disability sector agencies.

We expect to report comprehensively and provide advice to the Minister – which we will openly publish – that can result in positive change for people in the State living with disabilities and for their families, friends and carers.

This report

In our preliminary work, we heard a mix of different experiences; some positive, while others signified a range of areas in need of improvement: particularly around hospital services, workforce training opportunities, complaints handling systems and lack of continuity of care at the interface between the mainstream health system and the disability system.

We identified a need to understand better the issues that people with disabilities experience, how these might impact on their overall health and wellbeing, and what would matter most if the health system were to change. We therefore initiated a consultation exercise to learn directly from stakeholders. We sought feedback from people with lived experience of disability and engaging with the health system, family members of people a disability, carers of people with a disability, healthcare and disability services workers, and anyone else with an interest in the topic.

Our purpose in producing this document is to summarise and report on the key issues that came up in the responses, and to provide an opportunity for stakeholders to reflect on whether we have properly identified the issues and what should be the priorities for action.

Review roadmap

In accordance with the commission from the Minister, this review aims to inquire into:

- the health status of South Australians with disability including quality of life outcomes and life expectancy
- the experience and outcomes of mainstream health services and specialist disability health services in meeting the needs of people with disability
- the interaction of health services and disability services, in particular the National Disability Insurance Scheme and its scoping of health services to medically stable people with disability.

This report represents one component of a broader range of work being undertaken by the Health Performance Council to incorporate into our final review report. There are currently four separate strands of work which have been or are expected to be completed for incorporation into the final review:

1. *[completed]* Audit question setting and broad outline of the key issues to be pursued
2. *[in progress]* Analysis of record-level linked administrative statistical collections from the Department of Health & Wellbeing, Department for Human Services and Attorney-General's Department *[in progress]*
3. *[this report]* Primary data collection from stakeholders, most especially from those with lived experience of disability, about experiences in engaging with the health system. Subject to advice from others and grant of ethical oversight where applicable, this work stream is also expected to include:
 - a) *[in progress]* liaison with key Aboriginal community contacts for in-depth story gathering
 - b) *[in progress]* targeted input and advice from stakeholders representing specific population groups including culturally and linguistically diverse communities
4. *[to follow]* Audit analysis and final report with advice to the Minister for input into policy proposals.

Stitched through the design and delivery of all of these work streams, with the guidance of our project advisory group, has been to engage widely and frequently with all interested parties.

Three workshops were planned in the course of this review to provide input and advice from a broad range of stakeholders. The first workshop was held on 28 August 2019 to establish a broad outline of key issues to be pursued and the list of audit questions. The second is planned, along current SA Government COVID-19 workplace guidelines, to be held by video and teleconference in May or early June 2020 to update on progress of the work, share and sense-check the developing material, and consider implications of emerging findings for generating policy advice to the Minister. The third workshop is planned to be held following analysis of the linked administrative datasets and completion of work stream 3, to give a specific opportunity for stakeholder feedback on emerging findings and input to shape the council's advice to the Minister for the final report.

Materials from our work streams are published on the Health Performance Council website as they become available: <https://www.hpcsa.com.au>.

Method

What we did

Our advisory group guided us on the initial framing of the project, helping us to develop overarching principles for the project and for the stakeholder consultation that would feed into it and guiding us, including through our language, on issues of focus such as on trauma, distress and systemic ableism in healthcare.

We worked with the state government's Public Sector Innovation Lab⁴ to facilitate a consultation process involving direct contact with users, families or advocates of people living with disability and interacting with the health system. This included four methods for people to give us feedback:

- Web-based feedback submission portal, with a single, open-ended request for respondents to write whatever they liked
- a special email submission address for written submissions
- a roadshow of whole day drop-in sessions to which stakeholders were publicly invited to come along to share their thoughts in person with a member of our team
- structured group listening sessions with a facilitator.

Roadshow drop-in sessions were open to all and no advance booking was required. Two of the drop-ins were in regional South Australia (Berri and Mount Gambier) and two were held in Adelaide. The structured group sessions required pre-booking, and, owing to low take-up, these were instead operated as additional drop-in sessions.

The consultation was intentionally designed to allow stakeholders freedom to tell us whatever was important to them on the topic of health outcomes and experiences for people with disabilities. As a guide to assist, we provided some suggested prompting questions for people to consider when sharing their stories:

Your experiences with the health system

- What works well?
- What are the opportunities for improvement?
- What are health care professionals doing well and what lessons could they learn?
- What has been your experience using different types of health service – GPs, pharmacies, hospitals?

The health and disability systems

- What are your experiences of continuity of care between health and disability services?
- Has this been affected by the introduction of the National Disability Insurance Scheme?
- What are the things that you, or people you know, would like to have access to?

Anything else?

- Don't let us limit you – tell us anything you think we should know.

How we promoted the consultation

- We created an online hub on the Department of Premier and Cabinet's *YourSAY* website⁵. The consultation was promoted by *YourSAY* from 10 February to 03 April 2020 with an email and social media campaign.
- We ran a targeted direct email campaign to 850 recipients.
- We placed advertisements for our regional drop-in sessions in the *Murray Pioneer* and *The Border Watch* newspapers.
- Health Performance Council member Professor Jennene Greenhill gave radio interviews about the work on ABC South East SA and on ABC Riverland.
- And we solicited a snowball promotion campaign through our partner stakeholders through which we encouraged leaflet drops, social media posts, and word of mouth promotion.

The *YourSAY* promotional campaign's four Twitter™ posts were shown 12,000 times, it was emailed to 38,000 recipients, and it reached 12,000 people through Facebook™. Overall, the campaign is estimated to have achieved a combined reach of 45,000 people and generated 3,500 visits to the website over the 8-week period.

Overall, an estimated 63% of *YourSAY*'s users are female (37% male, and less than 1% other) and cover the adult age range but with more 40-49 year olds than any other age bracket; their Facebook™ users trend older, peaking in the 55-64 year old bracket⁶. We do not have any demographic analysis available for our other promotional channels.

Whom we heard from

Recognising that we were asking people for potentially quite sensitive and personal information, we intentionally did not seek much demographic information from people who gave us feedback. At individual interviews, many people proactively chose to disclose information about themselves. In our online submission portal, we asked people, optionally, to identify broadly which categories they exemplified – such as whether they themselves were living with disability, or were a family member or carer of someone with disability.

We had 117 responses through our online submission portal, 6 email submissions, and 18 individual interviews at drop-in sessions or arranged on request with people by phone or in person. Four out of every five of our informants (80%) had direct lived experience of disability, either themselves living with a disability, or as a family member or friend of someone with a disability, or both. Only relatively few, no more than 10% in any category, were healthcare workers, professional carers, government agencies, service providers or from other groups of people.

23 794 words typed into our online survey

23 individual interviews and direct mail submissions

2 visits to regional South Australia

Limitations and validation

Individual informants and online portal respondents were self-selecting in that they had found out about or review and volunteered to give us information. This means that we cannot consider the feedback, and the people who gave it to us to be properly representative of the whole community. We recognise this as a bias inherent to our method.

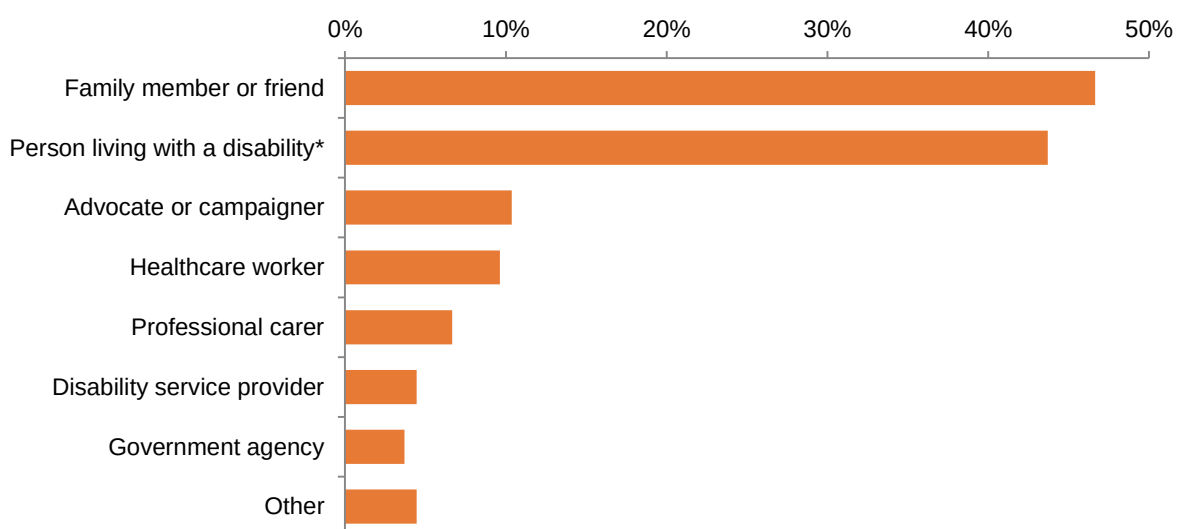
We observe that only a minority (44%) of our respondents were people who themselves were living with a disability, which may be considered to be an under-representation of our core stakeholder group and hence a bias to the balance of power in the feedback we received and are able to analyse from our consultation. Although we are not able to determine definitively why the proportion was not higher, we recognise that it might in part reflect underlying barriers to being heard and being able to take part in these sort of consultation exercises for many people with disabilities.

This consultation was designed to be broad, but it was not fully inclusive, especially when it comes to the views and needs of Aboriginal people and of a diverse range of cultural backgrounds. We are seeking to specifically consult with Aboriginal community members in South Australia and with people of diverse cultures and languages.

When we first designed this project, we intended that we would take the feedback and expose it to validation with the community at a broad stakeholder forum at which we would also then collaboratively agree on priorities for next steps and further inquiry. The forum had been planned for 1st April and we had secured the attendance at the event of Hon. Stephen Wade MLC, Minister for Health and Wellbeing. Owing to the state of emergency in South Australia occasioned by the 2020 coronavirus pandemic, we indefinitely postponed our forum and we are instead soliciting community stakeholder validation directly through the dissemination of this interim report.

Whom we heard from

Only includes people who chose to tell us. Adds to more than 100% because people can be in multiple categories



** Including people who identified as being disabled, having a disability, or other self-descriptions*



We had many reports of lengthy waiting times to see specialists, which could delay vital diagnoses and result in people becoming more sick or even passing away before they could receive treatment. In emergency departments too, we were told of patients waiting for a long time and often in pain – and this was more so for public hospital emergency departments than private hospitals.

'My GP is over 20km away and there is no public transport in my regional town.'

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transport a danger. This tough stance on transport funding was said to stand in stark contrast to other states and was a false economy for the health system if it meant that people ended up needing more frequent or longer hospital attendances.

Even with access to transport, we heard that getting to a GP or other service was not always easy. We were told that key services were lacking in regional South Australia compared to Adelaide, and that not having key services available in each region serves to cut off disabled people from their families and other vital social support.

We were told of rigid health system operating practices that were at odds with the needs of people with disabilities, especially where they have conditions or health needs which vary over time. It was unfair, it was said, to have medical appointments which are hard to change at short notice or with cancellation fees, and services which could be needed at any hour of the day were perplexingly often only available during working hours. Some respondents also noted a dilemma in that the only times their conditions made it relatively easy for them to get to their GP, was when they were not ill enough to need to go.

‘I have to be well enough to go to the doctor’

Services provided under The National Disability Insurance Scheme did not necessarily fare better with enabling access, we heard (see also *Key theme 5: National Disability Insurance Scheme*, on page 17), with lengthy waits and also long travel times that were not covered by SA Health’s subsidised ‘PATs’ patient transport scheme.

The COVID-19 pandemic became of increasing prominence as our consultation progressed. Some respondents in the later part of the consultation period expressed some concerns about the impact of the disease, fearing that waiting times for existing services would further increase and that people with disabilities will be given lower priority for medical services in the event that they became infected.

The arrangements for COVID-19 testing services were criticised as there seemed to be an expectation that people would have access to their own car to drive to a testing facility. We were told that this amounted to putting up a barrier to access to people with a disability who were more likely to be reliant on public transport or on others to drive them. There was also worry expressed that governments are forgetting about people with disabilities in structuring their various economic response and stimulus packages, and also on the effect on their health should routine health and care services be ceased because of the COVID-19 disease.

However, an unexpected benefit for many of public health measures being taken in response to the COVID-19 pandemic was that remote consultations between doctors and patients had quickly become the norm and a given – whereas previously it had been difficult for people with disability to access. This was much lauded by many of our respondents who gave us feedback in the later part of our consultation indicating that for some people telehealth was actually a more accessible and flexible option which better suited their needs, and there was much hope expressed that telehealth could continue once things return to normal.

‘I’ve been asking for telehealth for years! Thank you for seeing what is possible after all’

Key theme 2: Health and care system

Hospitals are not well equipped to meet the needs of patients with conditions other than those for which they are primarily admitted, according to our respondents. Respondents told us of having to bring their own equipment to hospital, sometimes at the cost of several round trips by car each time, because what was on the wards was just not suitable for them.

Health services were not designed with consideration of access needs specific to people with disability. This included inadequate parking, doorways too narrow for wheelchairs, and even brand new facilities which did not have fully accessible toilets.

‘I was appalled and disappointed with the disabled toilets at the new RAH [Royal Adelaide Hospital]. We should be able to go to the toilet without having to ask strangers to assist us [with opening the door]’

For children with disabilities, it was suggested to us that early interventions should be encouraged of therapeutic supports for them and their parents, and families should be given more advice about the ongoing nature of conditions to help prepare them for the enduring nature of permanent disability. The issue of long waiting lists was said to be especially pernicious in the case of children, for whom the delays can have disproportionately large developmental consequences, and we were told that the health system should recognise and respond to this as a matter of priority. And there was said to be a gap in provision, many services and clinics running for younger age groups but not so many for teenagers or young adults, a problem for young people at a developmentally important time in their lives.

Non-clinical interventions, such as art and music programmes, were held in high regard by some respondents but were not available everywhere. Community centres too, we were informed, were vital hubs which served a great many people including with disability-specific programmes and services and provided an important role in reducing loneliness and social isolation; however, it was suggested that there should be better referral pathways between health professionals and community centres, and there should be collaborative research between the health system and the research sector to address social isolation and loneliness as an important part of patient recovery and health management, as well as contributing to the national body of evidence.

Some respondents thought there was systematic under-funding and under-resourcing of the health system, evidenced for instance by the difference in rate of growth over time between number of hospital beds and the population of the state, said to sit poorly with the likely greater healthcare needs of an ageing population.

We heard concerns about the risk of mistreatment or malpractice in the health system and of reports of a culture of harassment and intimidation. We had reports of, for example, people with disabilities in hospital having their food left on trays without assistance being offered to assist with eating. These were issues of systemic lack of thought and care for people’s needs, it was suggested, and often unintentional and not demonstrating any lack of care by frontline workers, but they caused increased distress and trauma. Experiences like these were also harmful longer term because they could lead people to hold off from attending healthcare systems early. Some respondents questioned whether it would be possible for there to be a team of trained visitors created who could enter and observe service providers and report back to a commission convened for that purpose.

There was reported to be a systemic lack of data collection in hospitals. Not being only of secondary statistical use, the missing data meant that clinicians were devoid of information

necessary for patient care such as whether a person was hard of hearing or had any other accessibility needs. Some appreciated the high quality of Australia's good statistics collections, but it was suggested to us that current collections on patient satisfaction missed a key point: that of collecting and analysing information not just on satisfaction with service per se but as to whether their needs had been addressed. Proper data on unmet need would be vital to guiding a research program that could address the quality of care and health outcomes for people with disabilities.

Some respondents expressed concern to us for what they observe from existing data: that people with disabilities die younger than others and have an increased risk of suicide. But it was noted that the death and disability toll varied by condition and, perhaps unfairly, that funding did not vary accordingly. The capture of patient data had the potential to make a difference and it was suggested that government bodies ought to consider themselves morally bound, having collected sensitive patient data, to use that data to effect change.

Key theme 3: Health workforce

Much of what we heard related to the provision, attitudes and knowledge of the health workforce in South Australia.

We had reports that the quality of service received from staff could be rushed, that GPs were too busy to understand or investigate issues, and that hospitals did not have enough medical staff at times to satisfy patients' needs. It was said that some GPs lacked understanding or interest in people with disability because they took up a lot more of their time than other patients and that it was a struggle to get a GP to make a home visit. We even heard objections to some doctors not being native English speakers, which was said to make them especially hard to understand for patients with brain injuries.

Staff were said not to be well accommodating of the needs of people with autism and of the simple things they could do to help. Understanding was lacking that, for someone with autism, a visit to hospital could be especially frightening but that could be eased by allowing access to a sensory calming space. Allowing extra time to prepare in advance of appointments, facilitating access to have a walk-through the facility in advance – these were simple things that could be done to mitigate unnecessary trauma and psychological distress, but staff, we were told, did not have the training to understand. To some extent, it was also a systemic issue: supermarkets and airports could make accommodations with 'quiet hours', sensory quiet spaces and opportunities to walk through spaces to become accustomed and prepare in new environments, so why could healthcare facilities not do this also?

We heard that some less common disabilities were poorly understood by staff, which was a danger to patients and also a source of frustration, distress and long lasting distrust. Even some relatively common conditions, such as ME/CFS, were poorly understood by medical professionals to the point that some of those living with the illness were wont to give up on their doctors in favour of self-management of their condition. There was also said to be poor understanding of Advance Care Directives and of how they interact with orders of guardianship.

Staff needed to better understanding of how people with disabilities could present, we were told. For instance, that patients with dementia – often, on account of their supported residential situation, admitted unaccompanied to emergency departments late at night – could become confused, frightened and cause people to shut down and be unable to

communicate. For other conditions, too, people could come across as aggressive, and staff needed to understand better that this was a consequence of their condition: it was counter-productive and unfair to label them as 'violent' in these avoidable circumstances.

Some people with disabilities told us they felt demeaned at times by healthcare workers, that they were being treated as if they lacked intelligence. Some health professionals were said to be too quick to lay the blame for any medical condition on a person's disability. We were told that health staff need better understanding of how to interact with people who have 'invisible' disabilities and with the issues and needs of patients with dementia, for whom simple procedural changes to reduce noise and avoid unnecessary conversations near the patients could reduce anxiety and confusion.

'Please don't argue in front of the patient about the value for money of their treatment!'

It was felt that hospital staff made assumptions of needs from what was visible about patients; asking, rather than assuming, should be the approach. It might not be obvious, for example, that a person with an acquired brain injury might quite simply require reminders of their appointments, something that might not be visibly apparent to staff. And we were told that hospitals do not always know how to communicate with patients who are assisted by specialist communications equipment. This was an example of where disability support workers might be of assistance, but they were said to be missing in hospitals.

Education and training may be needed to improve attitudes and knowledge, and it was put to us that disability ought to be a compulsory core part of training and not just available as an elective. There is a need for comprehensive professional development about caring for people with disabilities for all staff across the continuum of care. It was suggested that although younger allied health professionals do get some education on disabilities, the bulk of the current generation of GPs had not received the same level training, especially on less common disabilities. Doctors did not routinely read medical literature, we were told. And poor training meant not only that medical practices were deficient but were also falling behind the state of the art research, resulting in inadequate care and management of conditions.

Although we were told of much that could be improved in relation to the health workforce, it is important also to say that many of our respondents took great pains to tell us that they had high regard for the health professionals they had been in contact with and for the care and treatment that they had received.

Key theme 4: Continuity and systems interfaces

We had a mixed set of responses when it came to continuity of care between different health care providers. Some respondents told us that they had good experiences, with providers of healthcare communicating well with one another, but others said that continuity of care was poor or limited.

There were systemic assumptions, it was said, of there being a fit and competent carer ready to provide support; this discharge predicate did not always apply and was an unfair burden on many. But discharge plans were not always well discussed with families who thereby did not feel properly integrated into how to care for their family member on leaving a facility. It was even cynically suggested to us that hospital discharge planning for people with disabilities was often driven by a desire simply to open the bed for another patient with no thought given to identifying supports or necessary equipment; and that, ironically, this

discrimination might be causing more attendance at hospitals subsequently. Things could be better: in Queensland for instance, we were told that discharge planning looked further ahead and involved a good 'step down' rehabilitation service which avoided the need for people to be 'institutionalised'.

Respondents told us about issues of poor continuity between different bodies within the health system. A sense of frustration in lack of responsiveness came through as we were told of people feeling they were 'passed from pillar to post' and of facing unfamiliar staff who didn't know them on each return visit. We also had suggested to us that more should be done to enable health records to be shared between different facilities. Staff should routinely update *My Health Record*⁷ and the State health system should seek to migrate to a centralised system of electronic health records for each patient accessible by default to all health professionals.

'Accessing and sharing vital health information is not easy for anyone with a disability and language issues'

Regarding workforce education, it was suggested that health professionals be educated on what other services exist for people with disabilities and encouraged to make use of this knowledge to give better referrals and provide information on where to go for further support. It was also suggested that this could be made easier, for both health staff and people with disabilities, if a centralised and organised directory of services, NDIS contacts and other relevant information were to be maintained and distributed.

It was suggested to us that lateral thought should be given to breaking down the boundaries between disparate systems. Some facilities were designed to serve a particular group of service users and people told us that they were unable to make use of those facilities because they did not strictly meet the criteria even though it would be useful to them. Fresh thinking might even be more cost-effective for the government than maintaining strict boundaries between who could access different facilities, we were told.

A particular concern was expressed about people living with both a disability and another condition. There was a tendency, we heard, to compartmentalise each condition and for any health service to attend to only one health issue in isolation instead of considering and addressing more systemically the needs of each patient. It was claimed that lack of continuity was aggravated by a culture of exclusion and rivalry between the medical professions, leading to too few referrals by a doctor to specialists in another field. Issues were said to be particularly of concern for people who also have mental health conditions, which were poorly catered for in people with disabilities.

Compartmentalisation was said to extend beyond the different components of health system. For example, we heard of speech and occupational therapy needs of children being dismissed as the responsibility of the education sector. People with a behavioural management issue could be in unsafe situations for either themselves or those they live with. The health system tends to dismiss such matters as being the responsibility of the disability system, police and (In the case of children) child protection officials being reluctant to intervene in what they regard as disability or health issues. There needs to be better intersectoral communication and collaboration on a range of key projects designed to improve the continuity of care.

Key theme 5: National Disability Insurance Scheme

More than one in three of our respondents told us of issues relating to the National Disability Insurance Scheme, the Australia-wide care and support scheme for people, generally under 65 years old, with permanent disabilities.

Although there was some good spoken of the scheme, there was much frustration expressed. The transition from State-provided services to NDIS had not been smooth, respondents telling us of having to endure a lack of care and support during a long gap between the cessation of State provided services and the ability to benefit from NDIS. The NDIS was not universally felt to be for the better, and there was some yearning expressed for what some felt to have been a better care and support system under the previous systems.

We were told of a perception that NDIS had cultivated a 'make-work' environment', with what is seen as pointless bureaucracy serving no end but to create employment in the service sector. Some observed that out of pocket costs for healthcare visits have jumped as a result of the introduction of NDIS, and that service providers are wont to quote a higher price as soon as they learn that there is NDIS or My Aged Care involvement. There was a feeling that some organisations which now provide services funded through the scheme had lost sight of their purpose, becoming more focussed on maximising monetary value than on empathy or care for their clients.

'Many NGOs are now big business'

'The money does not go to the people who need it. It goes to the people who manage the packages'

Cross-cutting with other issues of care continuity (on page 15), we were told that the NDIS did not have the best interface with the health system, with an unhelpfully rigid demarcation between what the system regards as health issues and as disability issues making it difficult to implement recommendations for managing complex diagnoses. In some cases, this was said to result in people not going to hospital out of fear of how it will – or won't – work for them.

'NDIS stops at the hospital door'

We were told starkly that NDIS local coordinators were not helpful and effectively put up barriers for people trying to get support under the scheme. Extensive paperwork was required to be processed to receive an NDIS support package, which caused lengthy waits in hospital well beyond the time that was clinically necessary; poor communication between health service staff and disability liaison officers was also said to be not helping.

'NDIS has blown out waiting lists [...] to come home from hospital'

We heard that despite the scheme's ostensive nation-wide provision, some found there to be a lack of qualified or properly trained support workers, putting people with disabilities at risk of getting inappropriate care. Echoing what we heard in other contexts (Key theme 1: Access to services, on page 11), we were told that regional clients were particularly badly served with there being lengthy waits and long travel times to see specialists. It wasn't helping that there were frequent changes in personnel, making for an infuriating need for frequent repetition of one's story.

There was dissatisfaction expressed with the NDIS application process, reported to be complicated and sometimes too difficult for people to navigate and complete by themselves, even for those who consider themselves competent and learned in the ways of government

systems. If even an intelligent person with good advocacy skills could have a great deal of difficulty navigating the system, it was rhetorically put to us, how difficult and daunting must it be for others?

‘The NDIS is pointless bureaucracy that doesn’t help the person with the disability’

Getting approved for NDIS support could be difficult, lengthy and a cause of uncertainty. It was said to us that the scheme was too narrow in scope, its eligibility criteria excluding too many people with mental illnesses and also those with combinations of disabilities which might not each qualify alone but in combination ought to. And as NDIS was limited to matters relating to disabilities, there was some angst expressed about the continued need to have to navigate both the NDIS and the health system for ongoing care and treatment, as well as having to continue to pay for additional care privately.

Recognising that NDIS is a federal responsibility while the Health Performance Council has a State-wide remit, as the impacts are realised at State level it was thought by some that the South Australian state government could seek build better links with NDIS, even if only to bring pressure to bear on the federal government to influence change to bring about improvements.

‘Were my hair not already grey, dealing with the NDIS would have sent it that way.’

Key theme 6: Personal finance

We were told of a perverse incentive for someone with a disability to stay out of work, a reluctance to get a job out of fear of thereby losing entitlements to important help with medications as a result of coming off the disability support pension. It was suggested that this might be solved easily and at net gain to the public purse though a tiered system of allowing people with disabilities who are earning to retain some financial support with medications, or even allowing a notional \$1 disability support pension to be claimed as a gateway to vital medications support.

Necessary medications for various conditions were reported to be hard to access under the national Pharmaceutical Benefits Scheme. For some disabilities, especially those that are less common, medications and other dispensed items were said to be not available under Medicare and not well covered by private health insurers: the only option was to spend considerable sums directly. It was said that there were some specific unfair practices in South Australia compared to other states, such as the lack of a garment subsidy for people who have particular garment needs.

The cost of attending a GP was said to be problematic, especially because not all GPs offer bulk billing. Because a patient can nonetheless recover most of the payment after the fact, this came across as unnecessarily bureaucratic and serves to deprive the impecunious of access to healthcare.

‘All GPs should bulk bill’

Even something as simple as changing one’s GP was seen as a financial burden because of the cost of getting a copy of all of one’s health records for transfer to the new GP. Also maintaining a driving licence was said to be too expensive for people with disabilities compared to others because of the annual medical assessments that were required.

Not just people themselves with disabilities, but also their family members could be affected financially by disability. Respondents told us of expectations to pay for fuel – and time – to escort their family members both to medical appointments and to routine engagements in daily life. It was felt unjust that what seemed like arbitrary measures were applied to determine whether someone would qualify for their investment of time and money in caring for another to be recognised through government provided benefits.

People felt aggrieved at what they perceived as inequity in the mix of government policies and schemes allowing access to financial support. It was felt to be unfair that someone could be shut out from access to disability support schemes and allowances because their partner earns at a level where the system expects them to provide support. The National Disability Insurance Scheme being a universal entitlement for anyone who qualifies struck as unjust for people over 65, who are not eligible for NDIS, finding aged care services to be means tested.

Key theme 7: Government and society

People with disabilities told us of failures more widely in society and institutions, with people feeling that they were just not supported or recognised.

There is a lack of understanding of disability across government, we heard. Schools were said to be inadequate for children with disabilities. Some people with disabilities who relied on public housing might object to having to live in the same areas as drug addicts. Government agencies did not recognise that people with disabilities, who might also have mental health issues, might struggle to comply with complex instructions at unstaffed facilities and should not face punishment for needing services to be made accessible to them.

Another area of concern was public transport, which could be difficult to use for some people with disabilities. Although there are priority seats set aside for people who require them we are told that it can be very difficult having to explain or feel the need to justify to someone else why they should give priority. For those taking to private transport, there were said to be too few priority car parks and little enforcement of their use to keep them for those in need.

People with incontinence were also said to be very poorly provided for with access to bathrooms and rarely had their needs considered in such things as the design of building access security protocols. Councils are not accounting for visual and sensory needs of people with disabilities in the design of their public realms. And for disabled people, the streets of Adelaide were said not conducive to cycling, not only effectively reducing mobility means, but also preventing something that could be therapeutically useful.

Families of people with disabilities were forgotten about, according to respondents. Siblings were specifically identified as a group who were systematically ignored and not recognised for the care they provided. There was said to be difficulty in getting awareness in the system of the needs and wishes of family members – referral pathways were limited and very little support was provided. A peer support network could be a useful thing to set up, we were told, and recognition was needed at system level that family members were important. Education was the key, of medical staff but also of other key players such as teachers.

It could be very difficult to live with someone with extensive care needs, but society's institutions were said to be set up such as to put unduly high expectations on family members with little respite. The go-to suggestion for getting support — advice to visit a psychologist — is wholly disconnected from the actual need for more substantive strategies and long-term solutions for people.

‘I became known as [her] mum — I lost my whole independence’

Society varies in how well it accommodates people with disabilities, we were told. There were some positive things to share – some supermarkets, for instance, now having regular sensory shopping hours which are much appreciated by people with autism. But other accommodations were not made, and it was not only hospitals that were devoid of ramps for level access but all manner of other public and private buildings too. There was also a feeling expressed that attitudes were too rigid, shown for instance in medicinal cannabis not being more easily available. And society also needed to be more comfortable with people with disabilities having diverse sexualities, with reports given to us of people seeming uncomfortable at the idea of a person with a disability having a same sex partner.

‘Stop calling my fiancée or partner my “friend” when we have clearly identified each other multiple times’

Respondents felt that it would be useful if employers could be encouraged and supported to retrain and otherwise enable employment for people with disabilities. The public sector was suggested by some to be worse than the private sector in employing people with disabilities. Understanding needs, learning to be less judgmental, working with people who might have higher levels of absence, and knowing how to help people with disabilities in the workforce deal with change would all be helpful. For people with disabilities who are out of work, the pressure to conform to the same conditions of government income support as those without disabilities was felt to be unjust and that it could even be exacerbating their disabilities.

Many people with disabilities, we were told, rely heavily on third sector organisations – such as ‘peak bodies’ and local support groups, and others – for various assistance and support. One source of consternation was the myriad forms and paperwork that were often required to be filled in by people with disabilities. Not everyone can handle the forms without assistance and it was felt that more help should be available for completing paperwork – maybe a service should be established specially designed for that purpose.

Information could be better disseminated too, we were told. This is not just about providing more information more accessibly but also about making system changes. An example we were given was that of the federal *My Aged Care* service which could improve its provision of guidance on how the system works by reducing waiting times at its call centre and having more agents who speak clearly in the user’s preferred language.

Some respondents wanted there to be changes in how society refers to people and their disabilities. There was not a completely clear consensus expressed on which language constructions ought to be used, but it was felt important that people should be recognised as equals and that an undercurrent of ableism was unhelpful in this regard. Regardless, people should not be identified by their disability and it was found offensive and degrading always to be referred to – in hospital or otherwise – as ‘the person with the disability’.

‘Disability is not a dirty word. It is ok to be disabled’

Finally, we heard clearly the call for action and frustration that many people with disabilities have on an apparent unremitting cycle of government consultation without proper action to follow.

‘Stop spending our money on consultations. We’ve been consulted enough!’

Glossary

Advance Care Directive	A legal mechanism by which adults in South Australia may appoint people to be able to make decisions for them and to express wishes, preferences and instructions as to their future health care and end-of-life and living arrangements. https://advancecaredirectives.sa.gov.au/
CFS	Chronic Fatigue Syndrome (also known as Myalgic Encephalomyelitis or ME/CFS)
Guardianship order	An authority of the court for a person to make certain decisions for another about their personal affairs such as their accommodation, health and lifestyle. http://www.sacat.sa.gov.au/
HPC	Health Performance Council [South Australia]
MBS	Medicare Benefits Schedule: Services provided under the federal government subsidised Medicare scheme
ME/CFS	Myalgic Encephalomyelitis / Chronic Fatigue Syndrome
NDIS	National Disability Insurance Scheme – operated by the National Disability Insurance Agency. The Australian Government programme for funding support needs for people under 65 with permanent and significant disabilities. https://www.ndis.gov.au
PATS	Patient Assistance Transport Scheme: SA Health's scheme for providing subsidies towards travel and accommodation for rural and remote South Australians who have to travel to attend medical appointments.
PBS	Pharmaceutical Benefits Scheme: The Australian Government's system for providing access to subsidised medication and related services.
SA	South Australia
SA Health	A brand name for various hospitals, organisations and other services making up South Australia's public health system.

Notes and references

¹ Private correspondence from Office of Minister for Health and Wellbeing to Director of HPC Secretariat, 06 March 2019.

² For instance: Australian Institute of Health and Welfare; 2019. *People with disability in Australia*. <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia> [accessed 31 March 2020]

³ For instance: World Health Organization; 2020. *Disability*. <https://www.who.int/health-topics/disability> [accessed 31 March 2020]

⁴ <https://publicsector.sa.gov.au/culture/south-australian-public-sector-innovation-lab/>

⁵ <https://yoursay.sa.gov.au/decisions/yoursay-engagements-people-with-disability-health-system-experiences>

⁶ Figures are approximate, indicative only, and have been rounded for reporting. Source: private communication to Health Performance Council Secretariat from Better Together team, Department of Premier and Cabinet, Government of South Australia, 16 April 2020.

⁷ *My Health Record* is the online health information summary service maintained by the Australian Digital Health Agency: <https://www.myhealthrecord.gov.au/>

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