



Engagement with Disability Elders of All Ages

Amplifying Community Insights

People's Health Voice – Outcomes of Engagement with Disability Elders of All Ages

The People's Health Voice team were grateful to meet with the Disability Elders of All Ages group to talk about health access and inclusion in South Australia.

Our conversation focused on barriers to health access and inclusion, and how the health system could be more responsive to the needs of people living with disability.

We also talked about how a 'People's Health Voice' – a new State-wide advocacy body focused on increasing health equity – could work to include the voices of people living with disability in health system and policy reform.

A summary of the issues raised in our conversation is presented below, and (with the agreement of the DEAA group) will be communicated to health system leaders to guide system improvement and reform.

As we co-design the 'People's Health Voice' we will also be guided by these issues as we work towards building our equity-focused platform.

The need for medical evidence across systems

We heard that it can be a difficult process to obtain the medical evidence required for access to other systems of support (e.g. NDIS, Companion Card). In many cases, this requires making and attending an appointment with one care provider to provide consent for records to be shared with another. This process, and the complicated paperwork involved, can be a significant challenge for people needing access supports or experiencing sensory issues.

"We have to make a request for information, and we have to go to the doctor for that every time to allow A to talk to B. And if you have communication or understanding difficulties, it's like filling out a Year 12 physics exam, just to get permission for them to share the information"

After authorizing sharing of medical information, we heard it can then be difficult to ascertain whether payment for the appointment and report should come out of health, NDIS or other categories of funding support.

Rural health access

We heard significant concern around GP access in rural areas. In particular, we heard about the need to make GP appointments up to a month in advance in parts of the Yorke Peninsula, which can lead to diagnostic and treatment delays. Having to travel long distances to access other healthcare services (including travel to Adelaide for specialist appointments) requires access to an appropriate vehicle, adequate petrol and other travel and accommodation supports that are not always readily available or affordable.

We also heard that a lack of post-hospital pathways for people living with disability can result in young people being placed in nursing homes in the absence of more appropriate accommodation options in rural areas.

Holistic disability awareness training

Disability advocates explained that it would be useful for health providers to receive disability awareness training that moves beyond a strictly medical model to convey the social determinants and lived experience of disability. We heard from the group that this would help health providers to take an empathetic orientation towards the emotional, social and physical needs of patients living with disability.

Guide dogs

We heard that not all health providers understand and accommodate patients who need the support of assistance animals. We heard about the significant practical and emotional importance of allowing assistance animals to accompany patients taken to hospital by ambulance, but were also told of instances in which dentists, private hospitals and even eye specialists would not allow guide dogs to enter consulting rooms.

Complexity of health information and forms

Disability advocates explained that the complexity of written and verbal information conveyed in medical settings can make it difficult for many patients to access appropriate care, maintain medication and appointment regimes, and provide informed consent to treatment.

We heard that patients' understanding would be supported, in many instances, through the provision of information and forms in 'easy read' or 'plain English' versions, and for providers to take the time to offer and explain these alternatives.

General Practice

Absence of walk-in and same-day appointment options

We heard that the reduction in walk-in and same-day appointment options can have a disproportionate impact on people living with disability. For example, for parents of sick children who are unable to drive, it is often not possible to travel long distances when reserve appointments at local clinics are full and it is hard to get child seats into a taxi. While telehealth options can ameliorate some of these issues, we heard that an orientation to the broader context of people's lives (caring responsibilities, digital access and literacy, responsibilities towards others who may be immune compromised) is paramount.

Hospital system

Equipment availability/ Lack of differentiation

Concerns were raised with us as to the lack of differentiation experienced by people living with disability when they enter acute care contexts. For example, we heard about experiences in which:

- health providers spoke to carers and family members rather than communicating directly with the patient
- medication errors were made for people of small stature because dosages were based upon age instead of weight
- requested tests were not undertaken because they required lifting the patient out of a wheelchair and nurses were not equipped to do this
- equipment was inappropriately sized for small adult patients, such that blood pressure reading was not possible, or full-sized tubes risked injury to patients' throats
- patients living with disability were inappropriately assigned non-electric beds
- patients were unable to reach their food, drink or the call button to seek assistance
- wheelchair users attended appointments in locations without a weigh chair, meaning that medication dosages were prescribed either based

upon an approximate or previous weight, or prescription was delayed to a subsequent appointment at which a weight chair was available.

We also heard from patients who had seen hospital staff become visibly distressed at not being able to provide the level of care needed by those with a disability for reasons of overwork/staffing shortage.

“Staff get upset because they aren’t allowed to give you the care, or they can’t manage it all and they pass it on to the support worker”

Responding to feedback

We heard accounts from people living with disability that hospital staff are not always responsive to feedback. Disability advocates indicated dissatisfaction with processes that, for example, followed dosage mistakes, and felt that there was not always openness from staff in terms of communicating patients’ options to access more appropriate or inclusive care at alternative locations.

Privacy/confidentiality

People living with a range of disabilities indicated dissatisfaction with healthcare settings in which reception staff sit behind tall desk partitions, their faces obscured by computer screens. For wheelchair users and people with low hearing, this distance from staff can affect communication and require patients to use a loud voice when providing personal details, undermining confidentiality and privacy.

Personalised care

A phrase repeated throughout our discussions was a need for healthcare staff to ‘take the time to personalise care’ for people living with disability. For example, we heard that being offered the opportunity to have a topical anaesthetic applied before vaccinations, or to use a canula to avoid multiple needles, can make an enormous difference to the distress experienced by patients with sensory issues. Having the opportunity to discuss options of this kind can have a significant impact upon patients’ feelings of safety and comfort in medical settings.

Parking

Parking was raised as a key access issue, particularly in the context of hospital visits and admissions. We heard that there are often limited accessible spaces and, when these are full, patients have to pay for parking despite already bearing the cost of their existing parking sticker. We heard that attempts to

challenge parking fees when leaving hospital are often dismissed, or people are told to follow up via online channels that can be difficult to find and navigate.

Ageism

We heard that older people living with disability feel they can experience ageism in the health system when it comes to accessing scans and tests in the course of managing chronic health conditions.

“I’m finding there is a blockage having an issue for a long time, and then getting older – they say you’re the too hard basket. There’s a limit if you have chronic conditions to be managed properly. The combination makes it hard”

A quiet space in the emergency department

We heard a strong desire for a quiet, calm space in or adjacent to hospital emergency departments that could be used by people living with disabilities that involve sensory sensitivities. Advocates indicated that patients using such a space could still be triaged in the usual way, but would be able to avoid sensory triggers that could exacerbate their existing distress.

“There’s no reason why we can’t have a sensory gentle quite place – it’s already overwhelming when we’re sick and anxious. We need to feel safe”

(Re) Scheduling

We heard that frequent rescheduling of appointments/planned surgeries have significant flow-on effects for people living with disability. For example, we heard anecdotes of patients having surgical procedures cancelled after they had arrived in hospital having fasted – which can have flow-on effects in terms of the management of co-morbidities (e.g. diabetes, medication management, etc).

Visual impairment

We heard a need for clear and consistent processes documenting the support needs of patients with visual impairment. We were given examples where a failure to communicate these needs during staff handover resulted in patients being unable to find their meals, access the bathroom etc., increasing the risk of falls and injury.

We also heard calls for improved supports for people with visual impairment to *visit* patients in hospital. Examples were raised in which the absence of appropriate signage, volunteer support and information personnel resulted in visitors being helped by members of the public to navigate hospital spaces.

Costs

Costs were raised as a significant barrier to full healthcare access for people living with disability. For example, we were told about people delaying specialist appointments because they are too costly, and heard a strong call for upfront information about costs and alternatives (waivers, healthcare card options) for expensive services such as dental, optical and medical imaging. We heard that people living with disability often require more frequent access to medical care, but have to balance long delays (public system) against often prohibitive costs (private system).

Aspirations for the People's Health Voice

"It needs to be more than talking – it needs to make change and have some power behind the group so that things have a chance of changing, and then reevaluating to see where we think there are even more issues that need to be changed"

"We need to focus our attention on things that impact our specific concerns. That's what's going to make the difference. We need to be able to give detailed, strategic advice"

"We need bureaucrats to remove the attitudinal, environmental and organizational barriers to people who live with disability and offer equitable, inclusive, accessible healthcare by enabling medical and other staff to behave respectfully towards patients and visitors".