Improving Hospitals for People with Hidden Disability

SPEAK Project
Co-design Report

November 2022

speak
better health, together

Acknowledgment of Country

The SPEAK Project team created this report on the lands of the Boonwurrung, Bunurong and Wurundjeri Woi Wurrung peoples of the Eastern Kulin Nation.

Worimi man, Damian Griffis of the First Peoples Disability Network, says there is no word for disability in his people's language, which is wonderful. He says the focus is on "what we need to know about that person so we can ensure they can participate in the community. The Western approach to disability labels people and finds the deficit." Alfred Health respectfully acknowledges the Traditional Custodians of this land, the people of the Kulin Nations.

We pay our respect to their Elders, past and present. We acknowledge and uphold their continuing connection to land and waterways.

AlfredHealth

South West
Healthcare

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Contents

Report summary

People with disability do not get the same healthcare in hospitals as the rest of the community. We aim to improve hospital healthcare for:

- Autistic people
- People with intellectual disability
- People with communication support needs.

Method

This report shares information from co-design workshops. Co-design means people with disability are a part of improving hospitals. When we say participants, we mean people in the workshops. Participants included:

- 41 people with disability
- 12 support people (7 parents and 5 support workers).

Findings

Participants shared what it was like going to hospital. Many participants had negative experiences because of the following:

- A lack of respect and compassion from hospital staff
- Hospital staff do not know enough about disability to support patients
- The hospital is an overwhelming sensory environment
- Support people are often ignored
- Changes to healthcare are not made to meet the needs of people with disability
- People with disability did not get equitable healthcare
- A lack of disability awareness can lead to misdiagnosis and mistreatment
- A poor journey of coming to, staying in, and leaving the hospital.

Recommendations

Participants also talked about how to improve hospitals. The recommendations are the following:

- Provide a specialist service for people with disability when they come to hospital
- Give disability training to all staff who work in the hospital
- Include people with disability in making and delivering training
- Add disability support information to patient records
- Make easy-to-read information about important procedures and tests
- Include people with disability in making and testing easy-to-read information
- Make it easier for people with disability to give feedback
- Include people with disability to improve ways to give feedback.

Hospital staff were not a part of the co-design workshops. We did this for two reasons.

1. To have a safe space for people with disability to talk about their experiences.
2. Staff were not available when the hospital was dealing with COVID.

Future work of the SPEAK Project must include the following people to continue co-designing improvements in the hospital:

- People with disability
- Support people
- Healthcare staff.

> **Staff often see disability as 'this is a problem, and this is how you treat it. We must teach staff to be 'this is a person, and this is how you help them'.**
>
> – Speak Project Participant

Welcome

The SPEAK Project strives to improve the hospital experiences of people with disability. The SPEAK Project is focused on hidden disabilities. The word hidden means the disability may not be easy to see and can include:

- Autistic people
- People with intellectual disability
- People with communication support needs, which includes:
  - Deaf/hard of hearing
  - Blind/low vision
  - Speech impairment
  - Language impairment
  - Cognitive-communication disability

The information in this report comes from people with lived experiences of disability and accessing hospitals.

The report is one part of the SPEAK Project.

The SPEAK Project includes implementing the recommendations in the report by working with the following:

People with lived experience of disability

- Healthcare staff
- Researchers
- The disability community
- Other hospitals

Plain Language

When you see the word ‘**we**’, it means the SPEAK Project Team from Alfred Health and South West Healthcare.

The word ‘**report**’ means the SPEAK Project Findings and Recommendations Report.

This report uses plain language. We have tried to make this report easy to understand and not use any jargon. Please email speakproject@alfred.org.au if you have feedback about the language in this report.

Special message

The SPEAK Project report is dedicated to Annie Payne. The SPEAK Project team recognise her commitment, kindness, and compassion for improving the experiences of people with disabilities. Annie had a great sense of humour, and she was humble and gracious. After finding out she was starting palliative care, Annie continued to share her experiences and ideas to improve hospitals for people with disability. Annie's final days were dedicated to advocacy and building hope that systems and society can change to be inclusive of all people.

Thank you, Annie

Who took part?

The SPEAK Project worked with 41 people with disability in 2022. The age of participants ranged from 21 to 67, with 29 women and 11 men. The project would have benefited from including more LGBTIQA+ and First Nations participants. However, we were limited by the people who wanted to join the groups.

People who participated had been to hospitals one or more times.

They also had a lived experience of:

- Aphasia
- Acquired brain injury (ABI)
- ADHD
- Autism
- Cerebral palsy
- Deafblind
- Intellectual disability
- Vision-impairment
- And a combination of disabilities

The SPEAK Project also worked with 12 support people with lived experience of disability. The support people were:

- Family and friends
- Primary carers
- Paid support workers

The support people in the SPEAK Project supported adults with lived experience of:

- Aphasia
- Autism
- Down syndrome
- Intellectual disability
- And a combination of disabilities

4 online workshops were completed with 28 Alfred Health and South West Healthcare hospital staff. All the staff in the workshops worked in Allied Health.

What did we do?

The SPEAK Project team worked alongside people with lived experience of disability. The team used a way of working called Co-design.

What is co-design?

Every day, people with disability use services and take part in activities that support them and help them live their lives. But most of the time, services are made by people who do not have direct experience of what it is like to need or use them. Decisions are made for people, not with them.

Co-design is:

- Doing things differently
- Seeing everyone's strengths (strengths-based approach)
- Working together for equitable and inclusive change

Making changes needs diverse people to be a part of co-design, like healthcare staff, researchers, support people, service consumers, and community members.

It's more than asking people with disability what is good or bad. Co-design is about working with people to have a say in:

- What services are needed in healthcare?
- How are services made within healthcare?
- How can services be delivered within healthcare?

In the end, co-design is about making changes that matter to people with disability.

Workshops

The SPEAK Project team ran creative workshops between July and September 2022.

9 **Online workshops with people living in Melbourne**

1 **In-person focus group with Deaf-Blind Victoria**

2 **Online workshops with people living in regional Victoria**

1 **In-person workshop in Warrnambool**

In the creative workshops, participants spent time on activities including the following:

- Building relationships
- Sharing the reason why people care about making hospital better for people with disability
- Sharing stories of people advocating for themselves and other people with disability
- Doing an activity about what it is like arriving at the hospital, staying there, and leaving the hospital. The activity was called hospital journey mapping.
- Coming up with ideas about what could improve the hospital journey for people
- Being a part of activities that help come up with ideas for:
  - Training healthcare staff to support people with disability
  - Disability Liaison Officers
  - Patient information and records
  - Resources that make hospitals better for people with disability

Creative activities in between workshops

We sent participants a task to do in their own time. The tasks were about:

- What is needed to make hospitals better?
- What does a great hospital experience look like for carers?

What made co-design hard?

The SPEAK Project team is part of Alfred Health and South West Healthcare. The team worked within the hospital, and in 2021 and 2022, COVID changed how the hospital operated. Staff were unable to join the workshops. It was important to keep the project going, so the project team decided to move ahead, only working with people with disability and support people.

What worked well?

People with disability led the SPEAK Project workshops. Participants were open and comfortable sharing their ideas and experiences.

Most participants had poor and sometimes upsetting experiences of going to hospitals, and yet, they shared experiences and ideas with positivity and hope.

We worked hard to make workshops and activities accessible for all participants.

Part 1

What did we learn?

> **As a person with complex disabilities, and I stand up for other people with complex disabilities, [staff] need to understand that there are many people with intellectual disability, or a brain injury, schizophrenia, bipolar, manic depression, autism, PTSD and a lot of doctors, health professionals... they're not trained, and they get scared of violent or different behaviour, and we have to help them work better with us. And we can change society. We can teach them. We can have a positive attitude, and we can learn together. We can do it with a support worker or have a crack and do it on our own.**
>
> – First Nations participant with lived experience of intellectual disability

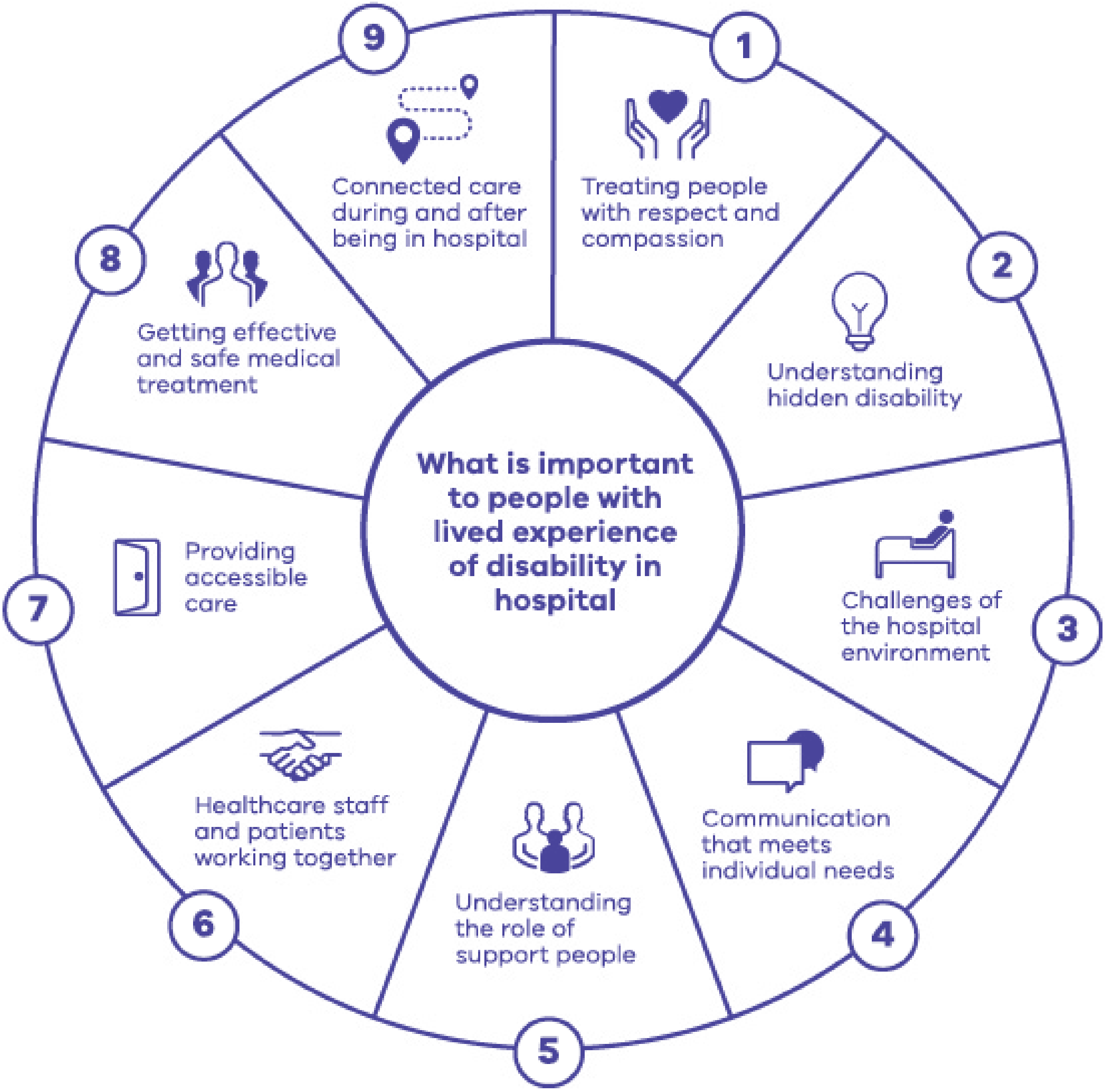
The lived experience participants in co-design groups shared what it is like going to hospital. Through workshop activities and conversations, people shared the following:

- What is working in hospitals
- What isn't working in hospitals
- What would improve going to the hospital for people with disability and their support people

The overall negative emotional experience of being in hospital for most participants included:

- Fear and uncertainty
- Overwhelm and distress
- Fear of not being understood
- Anxiety
- Helplessness
- Frustration

What we learned from the participants has been grouped under the following areas:



In the following sections, we discuss what we learned in more detail.

1. Treating people with respect and compassion

Being treated with respect and compassion was one of the most important things for all participants. When people are respected, their experiences of getting healthcare are positive.

> **I've heard of lots of bad things about people in hospital, but I've always been treated really well. It was because the people who looked after me were kind and took the time to listen to me.**
>
> – Participant with lived experience of an ABI

Kindness, listening, and trying different ways to learn about the needs of people with disability were part of the positive experiences in healthcare. Other examples of feeling respected include:

- Healthcare staff introduce themselves with their name and what they do
- The healthcare staff were patient, kind, and calm
- Healthcare staff comforted people by understanding that being in hospital is challenging
- Healthcare staff asked patients if there was anything they needed

Many participants experienced a lack of respect and compassion.

> **Why is it so seldom we experience understanding, kindness, and acceptance in hospital? And how sad that when we do, we are surprised and should be grateful...**
>
> – Participant with lived experience of Autism and ADHD

Participants shared that poor experiences in hospitals were often due to a lack of respect and compassion, such as:

- Negative attitudes to people with disability
- Seeing the disability, not the person
- Lack of patience and understanding
- Making assumptions that people with disability can't make their own decisions
- Talking down to people with disability
- Dismissing or being irritated by people with disability

> **You may get a nurse/doctor who has empathy and compassion—just a decent person who is nice and calm and explains things clearly. Then on the other side, to have somebody cruel and inhuman. But more often, I felt like some nurses and doctors had no time for people with disability. I eat quite slowly and hate really hot food. Not being able to communicate this, I remember nurses that would understand my situation and be patient and understanding. The others would not care. They would just try shoveling it in really fast. It made me feel inhumane.**
>
> – Participant with lived experience of an ABI, PTSD, ataxia, and dysphasia

It is important to treat all people with respect and compassion. When people with disability and their support people are treated poorly, it can leave them upset and very distressed.

2. Understanding hidden disability

Participants told us hospitals lacked an understanding of hidden disabilities. Hidden disabilities mean that it may not be obvious that people have access and support needs. It may not be obvious because the disability is not physical or visible.

> **[The issue] with a hidden disability, is that people may not present with having disability. It is not obvious, there is no cues for staff to pick up unless advised or told, nor does it come up on their system. People can be just considered rude or uncooperative. People treat them differently because they seem non-communicative. It happens everywhere, but it has huge implications in a hospital setting.**
>
> – Participant with lived experience of caring for someone with Aphasia

Another participant said that physical disability is easy to see.

> **[It's] that thing of "disability looks like this" … it's about mobility, it's about physical, that's easy for us to see. Easy for us to fix. I think our biggest challenge is masking.**

> **We have a disability that, for limited periods of time, with huge energy expenditure, we can cover up how our disability affects us. And we have been socially trained to do that. For the first 5 minutes at hospital, we use every scrap of energy we have to tell them our name, our Medicare number, and try to articulate what's wrong with us, and then we are absolutely done in, and we have nothing left. But what they only see is the person that spoke to them in the first 60 seconds.**
>
> – Participant with lived experience of Autism

A limited understanding of hidden disabilities can have serious results within healthcare, such as:

- People not receiving the right treatment, which can lead to serious health outcomes
- People getting misdiagnosed
- People are disempowered and stigmatised
- People feel they are not able to self-manage their stress and anxiety, leading to 'meltdowns'
- Staff misinterpreting behaviour can lead to unnecessary measures such as restraint (both physical and chemical)
- People not understanding what treatment they are getting
- People not giving informed consent for treatment
- People don't understand what to do after leaving hospital. This can lead to poor health outcomes and ending up back in hospital.

> **Lack of understanding, lack of knowledge, lack of compassion, a lot of lacks! I don't think it's the staff being unkind; if you don't have the awareness or a connection to disability, you just don't know. If you don't know, how can you be aware?! Knowledge is really important.**
>
> – Participant with lived experience of an Acquired Brain Injury

Understanding hidden disability is essential for healthcare staff. If healthcare staff can't respectfully and compassionately communicate in a way patients understand and give patients the proper treatment, people with disability can feel unsupported. Worse still, they may have poor health outcomes and end up back in hospital.

3. Challenges of the hospital environment

The hospital environment is designed to provide medical treatment for people. The physical and sensory environment can be uncomfortable for many people. For people with sensory, cognitive, and communication support needs, it can impact their health.

> **It's a sensory overload. And social overload. So many different doctors and nurses telling me stuff, everyone is in a rush, I'm trying my best to understand what's going on, but the sicker I get, the more stuff is going on, the harder it is to communicate.**
>
> – Participant with lived experience of Autism and ADHD

The hospital environment also makes it harder for people with disability to communicate.

> **I feel awful [when I do go to hospital]. I would like to go to the hospital, wait in a quiet part of the hospital, where it's not too crowded. I get achy when I wait, I can't see what's going on cause I'm blind, and I find it hard to talk and communicate the longer I'm there, and I can't understand what's going on.**
>
> – Participant with lived experience of cerebral palsy and low vision

The sensory environment in hospitals can negatively impact and add to people's health and healthcare experience.

> **I am autistic. I have had some terrible experiences. I have bipolar. It's tricky when I have a psychotic episode. People can think we are being aggressive and take it as a behaviour of concern. I know I'm noted down as having behaviours of concern. That makes me feel like a monster. If I'm manic, I can hear and see things that are not there and then being autistic, mixed in with the beeping and**

> **loud noises and flashing lights, I can get an autistic meltdown. It is confronting for staff that see a [adult] lashing out. It is not me lashing out; it's a disability.**
>
> – Participant with lived experience of Autism and psychosocial disability

However, when minor changes are made to the environment, the experience is improved.

> **When they understood I was autistic, they tried not to restrain me. When we got in the ambulance, they dimmed the lights for me and turned down the radio. In another instance of an emergency, they put me in a quiet cubicle to wait and gave me fidgets and food. These little snippets of good things that happen when they know I am autistic has been really, really positive. If it happened regularly, it would be amazing.**
>
> – Participant with lived experience of Autism

Minor changes to the hospital environment (such as dimmed lighting and quiet spaces) can significantly help patients with sensory, cognitive, and communication needs improve their healthcare outcomes and experiences.

4. Communication that meets individual needs

Good communication is one of the most important parts of getting good healthcare. However, it is also important to recognise that not everyone communicates in the same way.

> **In hospital, they expect you to always speak and say what you think and want. I can't always do that, it's difficult. It's hard to communicate, so I go along with what they are saying instead of them asking what do I need to be able to communicate.**
>
> – Participant with lived experience of intellectual disability

Participants spoke about the impact of communication when it doesn't meet their needs.

> **My first thought was, how will I communicate? A communication issue becomes more problematic than experiencing pain itself. It's really scary.**
>
> – Participant with lived experience of being DeafBlind

Poor communication can be extremely upsetting for people.

> **One time I was told that I needed urgent things done to my [injury]. They said it would be important to fix it properly. They later told me the next available appointment was 4 months away. I got really upset, because they told me it was urgent. 'If its urgent, I can't wait that long' I shouted. They shut down on me and told me to calm down. I then turned into a mess of tears and snot and lying on the floor having a meltdown, and they now see me as a problem.**
>
> – Participant with lived experience of Autism and ADHD

Every person with disability is an individual. People with disability share and understand information differently. Participants shared ways to meet the communication needs of the individual, including the following:

- Ask people 'how do you like to communicate?'
- Make sure critical supports such as interpreters and communication guides (tactile interpreters) are made available to people who need them
- Avoid medical jargon. Keep information clear and concise
- Try different ways to communicate. It's better to try different ways and fail than not to try at all. For example:
  - Writing information down in dot points
  - Using pictures to support understanding of what is being said
  - Asking yes or no questions as it requires less energy to reply
  - Asking yes or no questions is less confusing and easier to understand
- Break down information piece by piece, and check that people understand. Consider asking the person to relate each piece of information in their own words.
- Don't expect people to remember everything. Ask yourself, 'can the information be given at different times rather than all at once?'.
- Avoid saying things that could be taken literally. For example, 'I'll be back in a minute'.

- Be open to learning about and slowing down for different approaches, such as:
    - Picture or communication cards
    - Communication boards
    - Communication devices

Participants of the SPEAK Project gave other examples of improving communication between healthcare staff and people with disability.

> **Staff should reframe questions rather than repeat the same question again and again. When patients haven't understood, staff should ask it in a different way.**
>
> – Participant with lived experience in supporting a person with an intellectual disability

Importantly, asking people with disability what works for them.

> **Asking do you like pictures do you like easy words? Do you like people drawing for you? Slow down and explain things clearly and use simple, easy language, not the hospital jargon.**
>
> – Participant with lived experience of intellectual disability

Communication is a fundamental human right. People with disability have the same right to communicate as anyone. The United Nations Convention on the Rights of Persons with Disabilities states people with disability have a right **to access information in the way they need it**, and to **be able to say what they want.** For this to happen, hospitals need to be open to communicating to meet the needs of the individual. Effective communication means people with disability are respected. Good communication supports patient safety and getting effective medical treatment.

5. Understanding the role of support people

Support people can be family members, friends, carers, or support workers. Support people play an important role in the lives of people with disability. When people with disability are in hospital, the role of support people is vital.

> **I always try to help [my client] understand and help her say her point. My role as a support person is also to help make sure she expresses herself when she wants to and when she needs to. Sometimes my job is also to make sure staff don't just talk to me.**
>
> – Participant with lived experience in supporting someone with an ABI

Participants spoke about the role support people play for people with disability, including:

- Advocate for access and support needs
- Advisor to staff about support needs
- Sharing knowledge with staff about disability
- Translator of medical advice
- Communicator of symptoms and medical history
- Emotional support
- Communication support
- Behavioural support
- Sensory support

> **A lot of the time I feel like I'm seen as a nuisance in hospitals as I'm the one asking a lot of questions. It would be nice if they asked [my son with down syndrome] some questions. He can answer basic questions, but it would be nice for him to be respected. To be asked a question. I'm there as like an interpreter and his helper. It's pretty obvious that he needs a support person, an advocate.**
>
> – Participant with lived experience in supporting an adult with Down Syndrome

Participants spoke about how healthcare staff should communicate with support people and people with disability, such as:

- Look and talk directly to the person with disability, not the support person
- Be patient and wait for the person to reply
- The support person will assist with communication if needed

- Sometimes people with disability need a support person to communicate and share information with them
- Try and engage with them in partnership
- Understand that the role of the support person can change over time and in different situations

Support people in the co-design workshops shared negative experiences of being a carer, such as:

- Being dismissed
- Feeling a lack of respect
- Feeling like a nuisance
- Continuously questioned why they were there in the hospital
- Carers are left feeling emotionally drained, stressed, and exhausted due to how hard it is to advocate for the people they care for.

There are times when support people are ignored, which puts people with disability in danger.

> **I noticed he was short of breath, but I was dismissed as it wasn't a clinical observation… On a day out, I took him to a shopping centre medical clinic. They referred him to a private hospital. Long story short, he had extensive blood clots in his lungs. He was closer to death from the clots than the aneurysm that left him with aphasia. But that's how dire it can be when you don't take notice of carers and families. If you ignore the people who know the person the most, you do that with peril.**
>
> – Participant with lived experience in supporting a person with Aphasia

Participants who support people with disability shared feelings of exhaustion advocating for the safe care of the people they love.

> **You are not listened to as a parent. If I had given up and not fought to be heard, my son's appendix would have burst. You are just constantly tired and butting your head up against a brick wall all the time.**

> **We can advocate, but even we are not listened to. I just think for people with disability, trying to do that for themselves... it must be horrendous.**
>
> – Participant with lived experience in supporting an adult with Down Syndrome

Healthcare staff must understand the role of support people. Improving their experience includes better communication. Good partnerships with support people can reduce negative experiences and improve the health and safety of people with disability.

6. Healthcare staff and patients working together

Healthcare staff and patients need to work together to make decisions. Shared decisions about tests and treatments can only be made when the patient understands what is happening and what will happen next.

> **It's just small adjustments that would make you feel less distressed in an unfamiliar place. For me, staff should ask me what helps me. If I can't say, ask my support person. Staff should not assume. They should ask.**
>
> – Participant with lived experience of intellectual disability

Clear communication is an essential part of healthcare staff and patients working together.

> **Communication and explaining things clearly and slowly. This is what we are going to do. This is why we are doing it. Not just having people do things to us. And not all at once. Like, "Now we are going to do this, and this is why we are going to do it." Or "this isn't going to happen until tomorrow". And not talking about me to another nurse when I'm there. Like saying, "tomorrow, we'll get so and so to a test". And we are left thinking, 'what are they going to do to me tomorrow? For autistic people, we will be awake all night anxiously thinking about what are they going to do?**
>
> – Participant with lived experience of Autism and ADHD

Participants discussed the benefit of staff spending a little more time explaining healthcare plans and the importance of clear language. The extra time will be saved later if patients understand what is happening.

> **Staff need to know how to engage with patients. Staff should allow enough time to answer and should not rush things. Staff should be compassionate and engaging. Making sure everything is easy information and not hospital jargon.**
>
> – Participant with lived experience of intellectual disability

Another participant shared the benefit of staff and patients working together.

> **When a medical staff or someone takes the extra time to explain what is going to happen and what is going on, it helps ease the patient, reduce fear and anxiety, and helps build rapport and trust. Then the next time, or the next procedure, it's a lot calmer and easier.**
>
> – Participant with lived experience of an ABI

The workshops also raised ways to help healthcare staff and patients share healthcare plans in the hospital.

> **Having your treating team draw the plan of what's going to happen is so helpful—and having a list on the wall of your room that says what is happening, when it's happening, like morning or afternoon and who is doing it. If they had a photo of the person, that would be even better because I don't like surprises or strange people coming in.**
>
> – Participant with lived experience of Autism and psychosocial disability

Asking patients 'what do you need?' is an excellent way to improve how healthcare staff and people with disability can work together. There are opportunities to help patient understanding, including:

- Visual timetables
- Pictures, photos, and drawings
- Writing down information in clear steps

When sharing healthcare plans and information, it is vital to be clear, realistic, specific, and timely. This can reduce patient anxiety and improve the quality of care.

7. Providing accessible care

Hospitals need to give the same healthcare treatment to everyone. A key part is ensuring healthcare is accessible and safe for all, including patients and staff. Many people, including those with disability, need changes to be made to ensure they get the same quality healthcare as the rest of the community. These changes are called **reasonable adjustments**.

When reasonable adjustments are not made, people with disability are far more likely to have poor healthcare experiences.

> **It is difficult for an autistic person, who also has ADHD, to stay still for an extended period of time. Staff need to understand this and change their expectations.**
>
> – Participant with lived experience of Autism and ADHD

Another participant shared their experience of waiting rooms.

> **I feel awful [when I do go to hospital]. I would like to go to the hospital, wait in a quiet part of the hospital, where it's not too crowded. I get achy when I wait, I can't see what's going on cause I'm blind, and I find it hard to talk and communicate the longer I'm there, and I can't understand what's going on.**
>
> – Participant with lived experience of Cerebral Palsy and low vision

Waiting times can also be challenging when going to hospital as an outpatient.

> **Changes need to occur for outpatients too. Like waiting to be seen by the doctor is very difficult for people with high anxiety levels, behaviours of concern and autism.**
>
> – Participant with lived experience of Autism and psychosocial disability

The safety of patients and staff is a priority for hospitals. When changes to how care is provided are not made for people with disability, the result can increase the risk to people's safety.

> **Once, I was overwhelmed in hospital. I was pacing, but staff said I am not allowed to pace. They didn't even dim the light when I was the only person in the room. So, I was even more distressed because I was overstimulated, and they are not letting me do what I need to do to regulate my senses and calm down. Staff become a barrier here. And rather than letting me pace and dim the light, their solution was to restrain me onto the bed and inject me with medication. You could have just listened to my sensory needs.**
>
> – Participant with lived experience of Autism

Hospital staff are often challenged when patients become overwhelmed and react physically.

> **If my son has a meltdown in hospital, the hospital security will probably handle this in an inappropriate way. It only makes things so much worse for my son and the nurses. But we can prevent all this. We do not have to deal with situations where things are escalated.**
> **We need to be preventative. For this, staff need to focus on individual needs. This is where [the] hospital needs to accommodate.**
>
> – Participant with lived experience of caring for an adult with intellectual disability, Autism, and complex support needs.

Autistic participants talked about changes to their environment and the use of sensory tools to help while in the hospital.

> **[I want my] sensory needs accommodated for in terms of noise in my room, if I want to wear noise cancelling headphones, dim the lights, temperature issues like an extra blanket. [The] equipment sounds, and smell in the room... I want tactile objects with me, I should be allowed to that. Hospitals are sensory nightmares... [it is] distressing. It makes it hard to understand staff with noises in hospital.**
>
> – Participant with lived experience of Autism

The SPEAK Project participants shared examples of reasonable adjustments.

- Longer and more flexible appointment times, such as the first appointment of the day
- Regular updates and shorter waiting times (emergency and outpatient)
- Quiet, low sensory spaces for triage and appointments
- Allowing staff more time to spend with patients who require additional support while in hospital
- Checking in on patients more frequently as they may not use call bells or feel confident to ask for help
- Changing how staff ask questions and share information, such as:
    - Asking questions in stages over time instead of all at once
    - Allowing extra time for people to think of answers and reply
    - Sharing information in summary dot points and then providing detailed information later
    - Using objects like 3D skeletons or models to explain what's happening visually
    - Using images, like posters of the human body or pictorials, to visually explain problems and treatment
- Different ways of getting appointment information. For example:
    - One appointment per sheet of paper
    - Larger text sizes
    - Sending calendar invites for appointments, including notifications. If not possible, help people with disability add appointments to their phones.
- Providing care information in different formats, such as:
    - Plain language
    - Easy Read
    - Pictures and diagrams

When changes are made, even small ones, the experience of receiving healthcare is improved for patients and staff.

> **A time where it's worked well is when [my daughter with down syndrome] wouldn't do a blood test. She sat on the floor and wouldn't do it. The nurse said I can ask her if she wants to do it where she's sitting. And it worked. It just shows when you're willing to do something different, things can work much better.**
>
> – Participant with lived experience of caring for an adult with Down Syndrome

Another participant shared the positive impact of small changes in healthcare delivery.

> **When the doctor finally showed me a 360 image of my wrist from a scan, my whole being changed. I was right up close to the screen with the doctor, able to explain things to me with pictures.**
> **[This is] essential for a visual-spatial learner, which many autistics are. The words alone are just not absorbed. We need longer appointments for this; and very patient doctors.**
>
> – Participant with lived experience of Autism and ADHD

Making changes to how healthcare is provided is needed to ensure people with disability get the same healthcare as everyone else who comes to hospital.

8. Getting effective and safe medical treatment

Good medical treatment relies on healthcare professionals having important information about the person in their care. Getting the correct information needs good communication to learn about the individual's needs.

Participants with disability shared important information for healthcare staff to know. They talked about how different people experience pain.

> **I had some stomach issues, didn't want to admit myself to hospital. Being autistic, when we have physical illnesses, the pain can be quite magnified, and is more intense than what a neurotypical person might feel. I was treated so poorly, really bad sensory experience. I wouldn't want to go back again.**
>
> – Participant with lived experience of Autism

Participants also highlighted that people with disability experience and talk about symptoms differently.

> **Other people around me notice my condition long before I do. The response I got from the doctor was that it must not have been that bad if you're not feeling it. If other people notice it, but you don't feel it, it's not a problem. It scares me how little health professionals don't understand interoceptive issues in autism. I don't know what I am feeling to then know how to communicate and describe the pain to others. It can mean serious health issues about [me as a patient] don't get treated.**
>
> – Participant with lived experience of Autism

Understanding how an individual may talk about pain and symptoms is vital in getting the proper treatment.

> **She has down syndrome, and that's not going to go away. It's really triggering talking about this. [She] has a very high tolerance for pain. So when she's sick, I'm taking her to hospital. She finds it hard to explain what's wrong with her, and I just explain what she's been doing, and they look at me like I've got two heads. "Why are you here?". I know she's sick, but she's not showing the signs like other people would.**
>
> – Participant with lived experience of caring for an adult with Down Syndrome

Getting good and safe medical treatment is more likely when healthcare staff take steps to:

- Understand how each person experiences and talks about pain
- Understand how different disabilities experience symptoms
- Use plain language and avoid jargon. For example, instead of using the word benign, use not harmful.
- Try different ways to ask questions, such as:
  - Using objects and images of the human body
  - Using yes and no cards instead of the pain scale

- Check that people with disability understand what is being asked of them—for example, asking them to repeat back in their own words
- Partner with support people and patients to get a complete understanding of the patient's needs

Getting effective and safe treatment is improved when healthcare staff understand how people experience and communicate pain and symptoms. To do this requires disability awareness, communicating in an accessible way, and working with patients and their support people.

9. Connected care during and after being in the hospital

Connected care is when each stage of going to, staying in, and leaving the hospital is a consistent experience.

All participants in the SPEAK Project shared improvements at the very start of the hospital journey.

> **If a hospital admission is planned, there should be something done before you arrive at the hospital. Then the patient will have more information and will be more prepared. During conversations, staff should ask us how they can support us during the appointment or admission.**
>
> – Participant with lived experience of an ABI

Participants in the SPEAK Project discussed the difficulty of getting connected care when coming to the hospital multiple times.

> **We often have to repeat ourselves and introduce the disability over and over to different people. Every visit, its like starting all over again. It's exhausting. Each visit or episode, only the medical issue changes, the disability remains the same.**
>
> – Participant with lived experience of intellectual disability

Lived experience participants shared how staff interactions with patients were inconsistent.

> **And that is consistency. Because particularly with people with disabilities, if you've if you've built up a kind of quick relationship with somebody, and then the next, the next staff member that comes in, and that happens a lot in hospital, isn't it? You don't, you don't get, you don't get to keep a relationship with one person. Because, you know, they're moving, they're moving around kind of thing. And then so if you've, that it's the next person has the next person from the hospital has a different way of explaining things. You're back to square one.**
>
> – Participant with lived experience of an ABI

Connected care is important during healthcare staff shift changes.

> **From my own experience, when there is nurse changeover, it is also important to make my information and needs given to the next nurse.**
> **Staff should communicate with each other and share information about patients' individual access or disability needs.**
>
> – Person with lived experience of being DeafBlind.

Being discharged is when patients leave the hospital to go home or to another service. In the SPEAK Project workshops, discharge was a step in connected care with many challenges, and one challenge is communication.

> **When leaving hospital, make sure staff talk to me and ask me questions, not just my support worker. And the simplest question when I'm leaving hospital ask me "is there anything you need? Do you have any questions" and slowing down to give me time to think and answer.**
>
> – Participant with lived experience of intellectual disability

One participant shared the many challenges experienced by people with disability at discharge.

> **Staff should make sure I know where I'm going back to and I have a positive transfer, with all my supports. Often we get shunted off, and leaving hospital is really horrible. I should feel organised, happy, and confident in myself. I should be given information in easy read language or in audio. A DLO or support person should sit with me and explain me everything to make sure I know what's going to happen next. Staff should make me feel confident for my care after hospital. Staff should be educated and should not rush things in discharge. Staff should be patient. Staff should have clear communication with me. Staff should educate other staff on what information they have learnt by supporting me.**
> **Start planning about you going home earlier so it's not all rushed and there's time to make sure we know what's going to happen and how to look after ourselves.**
>
> – First Nations participant with lived experience of intellectual disability

Another participant talked about the need for extra planning around discharge.

> **Staff need to be proactive and do lots of planning before discharge. This needs to include easy read or very simple dot points of what I need to do, what my meds are and what my appointments or other stuff is so I can know what's happening.**
>
> – Participant with lived experience of intellectual disability

Better connected care during and after hospital is more likely for people with disability when:

- Admission planning, when possible, includes getting and using support and accessing information before people come to hospital
- Sharing necessary support and access information during shift changeovers for healthcare staff
- Starting discharge planning earlier and improving communication between hospital and community services.
- Making discharge information accessible to meet the needs of different people with disability (not everyone is the same) could include the following:

- Plain language
- Easy read
- Put important information first and in dot points
- Detailed information last
- Adding extra formats, like audio recording on a patient’s phone

Improving how healthcare is connected before, during, and after being at hospital for people with disability is essential when trying to make hospital a more positive experience for people with disability.

Part 2

What could make hospitals better?

According to the Pickers Institute's Principles of Patient-Centred Care, eight key areas support high-quality patient care. Alfred Health's Patients Come First strategy also uses these principles that are:

- Accessible care
- Partnership
- Effective treatment
- Communication
- Comfort and environment
- Respect and compassion
- Family, friends, and carers
- Connected care

If we apply these principles of patient-centred care in our hospitals, the healthcare outcomes and experiences of people with disability will be vastly improved. We have provided other recommendations in the following sections that will support improving the experiences of people with disability, including for people with more complex access and support needs.

A service in hospitals that helps staff and people with disability

Some people have more complex support needs. Staff with more knowledge, empathy and understanding of complex access and support needs can improve the experiences of people with disability and healthcare staff.

What is the Disability Liaison Officer (DLO) Service?

One service at Alfred Health and South West Healthcare is the DLO service, made up of Disability Liaison Officers. The DLO service currently helps with the following:

- Staff to understand and record patient access and support needs
- Give patients advice and support
- Help patients understand what is happening
- Support patients in understanding and giving consent
- Support reasonable and achievable changes to healthcare (e.g., communication support, behaviour advice, and sensory support)
- Educate staff about supporting and understanding individual patients
- Staff education about disability

- Using resources and communication tools to share information between healthcare staff and patient
- Make care plans with information about access and support needs
- Help with discharge planning

Main skills of Disability Liaison Officers

Participants in the SPEAK project said that Disability Liaison Officers should be:

- Translators, changing medical jargon into plain language
- Good communicators
- Calm and empathetic
- Kind and patient
- Advocates for both patients and support people
- Supporters of the social and human rights models of disability
- A mix of professionals and people with lived experience of disability or supporting people with disability
- Good at connecting with healthcare staff, including doctors.

DLOs can create sustainable change across the hospital by:

- Role modelling how to support people respectfully and effectively
- Advocating for people with disability and their support people
- Collaborating with healthcare staff, disability support services, and the disability community
- Providing education to healthcare staff
- Collecting and sharing patient feedback

As a part of the SPEAK Project, the DLO service is operating in the Emergency Department at the Alfred and supporting staff and people with intellectual disability, communication support needs, and Autistic people.

There was overwhelming support from participants of the SPEAK Project for a service in hospitals that helps staff and people with disability. The main recommendation for Alfred Health is to continue trialling the DLO service in the Emergency Department. It is also important to ensure that participants' recommendations are a part of improving and evaluating the service before rolling it out across other areas in Alfred Health and South West Healthcare.

Raising awareness and training about disability

Improving the experiences and healthcare outcomes of people with disability starts with awareness and education. Providing different levels of disability training is recommended by the SPEAK Project team. All participants in the SPEAK Project strongly believed disability education should be given to every staff member who interacts with patients, families, friends, carers, and support workers in hospitals.

Patient-centred care training

Patient-centred care should support staff with the knowledge and skills to meet the needs of people regardless of age, gender, disability, culture, or other factors.

When developing and delivering patient-centred care training, it is recommended to include practical skills to support people with disability, such as the following:

- Alternative communication methods
- Asking people to repeat in their own words healthcare information
- Using plain and clear language
- Working with support people

For Alfred Health, it is recommended that equitable and accessible patient-centred care training in the Patients Come First Strategy is prioritised. Fair and accessible care must not be the sole responsibility of Allied Health, the Access and Inclusion Plan or Disability Liaison Officers, it should be a holistic approach.

The SPEAK Project team recommend two levels of disability training.

Level 1: Disability awareness training

The findings of the SPEAK Project showed that healthcare staff could benefit from an increased understanding of disability and how to support people when in the hospital.

Lived experience participants of the SPEAK Project recommended disability awareness training included:

- The rights of people with disability
- The different models of disability and why they are important
    - Medical model
    - Social model
    - Human rights model

- Information about autism, intellectual disability, and communication support needs from the perspective of lived experience (and the disability community). Not just from a medical perspective.
- People with lived experience share what respect, understanding, and compassion look like for them. Also, it's just as important as getting effective medical treatment.
- Using respectful language
- Understanding that every person is an individual and has a different experience of disability
- Practical advice on how to partner with:
    - Autistic people
    - People with intellectual disability
    - People who have communication support needs (e.g., ABI, Aphasia, Deaf, Blind, DeafBlind, autism, and intellectual disability)
    - Support people, including family, friends, carers, and support workers

It is also recommended that training include understanding, respecting, and encouraging the use of resources that support people with disability when coming to hospital. The first group of resources are the ones people bring with them to hospital. These resources help with the following:

- Sensory needs, such as:
    - Sunglasses
    - Noise cancelling headphones
    - Sensory tools
    - Stuffed or weighted toys
- Communication needs, such as:
    - 'About me' information cards or books
    - Communication boards
    - Apps on mobile devices
    - Communication devices

It is important to:

- Not be judgemental about what people need to feel comfortable and safe in hospital
- Encourage staff to be aware and open to supporting people using their own resources

Additionally, introductory training is needed to help healthcare staff be aware of different resources in the hospital that can support communication, such as:

- Symbol boards
- Choice cards or picture exchange communication (PECs)
- Whiteboards
- Communication boards
- Communication books
- Social stories
- Auslan and signing cards
- Hearing amplification devices
- Awareness of Disability Liaison Officers and their role

The focus is on awareness and the confidence to use different communication resources.

The purpose of disability awareness training is to:

- Increase knowledge about the rights of people with disability to get equitable healthcare in hospital
- Increase understanding of hidden disabilities, including autism, intellectual disability, communication disability, and complex support needs
- Provide practical ways for all hospital staff to:
    - Treat people with disability respectfully and with compassion
    - Interact and communicate with people with disability
    - Help people with disability feel safe and supported

The desired outcomes of disability awareness training are:

- For healthcare staff to see the person, not just their disability
- For healthcare staff to be able to dismiss biases and assumptions about people with disability
- For healthcare staff to know how to respect people with disability and allow them to feel understood and safe in hospital
- For healthcare staff to be mindful and use respectful language for people with disability
- Increase the overall awareness of healthcare staff when assisting a person disability. As well as partnering with support people.

Level 2: Additional disability training

It is recommended that more detailed training is created to support staff in delivering patient-centred care to people with intellectual disability, communication support needs and autistic people. The additional training would cover a broader spectrum of barriers, including more complex access and support needs.

Some patients that come to hospital have more complex support needs. This requires a deeper understanding of communication, behavioural, and extra support needs.

Discussion topics between patients and healthcare staff should include:

- Communication
- Sensory support and environments
- Health equality and reasonable adjustments
- Effective treatment for the person with a disability

Communication

- Diverse and helpful communication strategies and tools
- Understanding and supporting independent choices about healthcare

Sensory support and environments

- Understanding that every person's sensory sensitivity is different
- Practical ways to work with autistic patients to improve the care environment
- Understand and encourage the use of sensory tools and strategies
- Understand how to support autistic people when they are overwhelmed or overstimulated, including self-regulating behaviours like stimming

Health equality and reasonable adjustments

- Understanding how to apply reasonable adjustments recommended (e.g., by DLOs or Allied Health staff) to ensure equitable healthcare for people with disability

Effective treatment

- Understanding how other parts of people's lives impact their health, for example:
  - Trauma (an emotional response to an upsetting event)
  - Mental health (emotional, psychological, and social well-being)

- Understanding different hidden disabilities and people's experiences of pain and symptoms
- Practical strategies for sharing important information to support informed consent
- Understanding the potential complexity of additional physical and mental health challenges for people with hidden disability

How training is delivered

Due to the COVID pandemic, most training and education programs have been delivered online. While online training allows greater flexibility, participants talked about the training being less effective than in-person 1:1 training. Several reasons mentioned were given by participants as to why online training may be less effective, including:

- A lack of human connection between the people delivering the content and staff. It is important to give staff the opportunity for relationship building, empathy, and compassion by being in the same room as people who have lived experience of disability.
- Sometimes staff rush through content to get to the end
- Fewer opportunities for staff to ask questions and talk about the content with other staff
- Fewer opportunities to learn how content can be applied in their everyday work

The lived experience participants in the SPEAK Project shared ways that could help make training practical and useful to staff, including the following:

- A combination of online and face-to-face training.
- Training content that includes people with lived experiences of disability can help promote connection and empathy
- Training content that includes healthcare staff with personal and professional disability knowledge (e.g., staff with personal disability experience, DLOs, Speech Pathologists, and Occupational Therapists)
- Simple and practical resources that staff can download or access at any time
- Activities that help healthcare staff to think about how the content applies to their role as well as practical ways they can do things differently
- Training for staff to include case studies and video scenarios of the positive impact of respectful and compassionate care on people with disability and support people
- Training for staff to include patient stories of positive and negative hospital experiences, with practical advice to support good outcomes

Training design, delivery and evaluation must include people with disability

Finally, people with disabilities must be included in hospital training design and delivery. Including people with disabilities should happen when:

- Deciding on the training content
- Explaining traits and behaviours of people with disability
- Developing content, such as videos, scenarios, case studies and stories
- Delivering face-to-face training
- Testing and giving feedback on training
- Evaluating training effectiveness

Including access and support information in patient records

Currently, there is no consistent way that people with disability have access and support needs recorded in their patient records. Without access and support information, there is an increased risk of both poor experiences and bad health outcomes for people with disability in hospitals.

> **You know how many times I go into hospital, see the staff, and tell them I have [an intellectual] disability. Then when I leave the front part and then speak to nurses and doctors, and I have to repeat that I have a disability, it's like no information gets passed on…**
>
> – Participant with lived experience of an intellectual disability

Participants in the SPEAK Project recommended that every person who comes to hospital should be asked questions about their support and access needs. Participants also suggested that people should have the choice to identify as having a disability.

Asking questions about access and disability

Participants in the SPEAK Project shared that people with hidden disability experience discrimination and stigma daily. As a result of this discrimination, some people may not want to share that they have a disability. However, people want to access the same level of healthcare as everyone else.

Therefore, people with disability need care that meets individual needs to receive the same level of healthcare as everyone else.

When asking questions about disability and access, it is recommended that:

- Healthcare staff start by asking every person who comes to the hospital if they have accessibility or support needs
- Healthcare staff should ask for specific information about access and support needs. Provide examples to help people think about their needs.
- Healthcare staff explain why they are asking questions about disability and access
- Healthcare staff to ask people if they identify as having a disability
- Healthcare staff to ask people what type of disability they have
- Healthcare staff to ask people if they have a support person with them

Care, support, and access needs

Care, support, and access needs may include:

- Different ways of communicating, such as:
  - Body language, gesturing, facial expressions, and sign language
  - Symbol boards, choice cards, communication boards, and communication books
  - Apps on mobile devices, speech-generating devices, and communication devices
- Sensory needs, such as:
  - Sensitivity to lights and sounds
  - Sensitivity to food
  - Sensitivity to temperature
- Different ways of experiencing pain and symptoms
- Other ways of talking about pain and symptom
- Needing more time to understand and reply to questions
- Needing information in different formats, such as:
  - Plain language summary
  - Information is simplified into dot points
  - Easy English (clear concepts with an image for each idea)

- Explaining the specific role that support people play in the patient's healthcare, such as:
  - Helping with communication
  - Helping with sharing details about symptoms
  - Recording important information about appointments, medication, and recovery

Patient records

When access and support needs are recorded in the patient record, it can help:

- Notify the Disability Liaison Officer Service that a patient with disability is in the hospital
- Alert staff to make reasonable adjustments for accessible care (making changes to how healthcare is provided)
- Alert staff to make reasonable adjustments to make care accessible
- Support staff in communicating with people with disability and their support people
- Improve healthcare experiences and health outcomes for people with disability

It is recommended that access and support information in the patient records requires:

- Information to be recorded in a consistent way
- Staff to know where to find patient information
- Staff to understand how to use the information
- Information to be about supporting disability, not medicalising disability
- Writing information respectfully about the patient

Providing accessible information

Accessible information is important to many people who come to hospital, including:

- People with disability with diverse levels of support needs
- People with low literacy
- Culturally and linguistically diverse people

Providing clear and easy-to-read information is needed to support people to be a part of making decisions about their healthcare.

Accessible information is needed before coming to the hospital, receiving medical treatment, recovering from medical treatment, and leaving the hospital.

The participants in the SPEAK Project gave the following recommendations:

- More accessible information about how to get to and around hospitals
- Plain language information sheets about key procedures and tests
- Easy Read information sheets about key procedures and tests using words and pictures
- Making and testing both plain language and Easy Read information sheets with people with disability

Improving ways for people to give feedback

Participants recognised the need for easy-to-access ways to give feedback. However, there were no specific recommendations for improving feedback processes.

> **I gave feedback one time and spoke to patient experience officers, I think they're called. The language they used in reply said that I 'perceived' it. This is not fair. This complaint was about the time when staff kept ignoring me, and I had a meltdown in a busy, noisy waiting room, I waited like 8 hours, and I was traumatised with the whole experience.**
>
> – Participant with lived experience of Autism and ADHD

Participants talked about:

- Navigating complicated hospital websites to find out how to give feedback
- Believing that giving feedback will not change hospital processes and systems
- Feedback forms and procedures are too hard to complete
- There are no Easy Read feedback forms

Testing hospital feedback with different people

The accessibility of hospital consumer feedback should begin with testing current processes with people with intellectual disability, communication support needs and autistic people. We recommend starting with facilitated user testing sessions to give a better understanding of how people with a disability give:

- Online feedback
- Feedback to patient liaison officers
- Feedback directly to staff
- Feedback across any other channels

Part 3

Background literature

Health equity means everyone should have a fair chance to be healthy (VicHealth, 2020). For this to happen, people must get good healthcare they can access.

The Victorian State Disability Plan (2017-2020) states the importance of health. Health is vital for people with disabilities to live a quality life. The health of people with a disability is often disadvantaged from the rest of the Victorian population (State of Victoria, 2016).

In this report, **people with disability** specifically refers to autistic people, people with intellectual disability, and people with communication support needs. These forms of disability are considered 'hidden' disabilities, as the disability requires support that is not only related to physical barriers.

People with disability do not have equal health compared to everyone else (Bishop-Fitzpatrick & Kind, 2017; Stransky et al., 2018). They have:

- Poorer physical health
- Poorer mental health
- Higher rates of conditions, such as:
    - Heart disease
    - Diabetes

(Tyler et al., 2011).

Therefore, they access health services more frequently than those not living with disability (Balogh et al., 2005).

When people with disability go to hospital, they have poorer health outcomes compared to people without disability. (Bishop-Fitzpatrick & Kind, 2017; Krahn & Fox, 2013; Stransky et al., 2018). One of the main reasons for poor health outcomes is communication differences between patients and healthcare staff. Differences can include expressive and symbolic types of communication. Poor communication between staff and people with disability means:

- It is harder to get effective treatment.
- People with disability cannot be a part of making decisions about their healthcare

(Ervin et al., 2014; O'Halloran et al., 2008).

Good communication between healthcare staff and patients means:

- People receive good healthcare
- People have positive experiences
- People being included in decisions about their care

(Rapport et al., 2019).

People with disability have a better healthcare experience when staff:

- Know about disability
- Have a positive attitude towards people with disability
- Behave respectfully towards people with disability
- Include people with disability

Other things that improve healthcare experiences include:

- Access to a Disability Liaison person
- Good admission and discharge processes and information
- Access to support resources (e.g., augmentative and alternative communication (AAC) to help hospital staff and patients communicate)
- Reasonable adjustments (changing how care is delivered or changes to the environment to give people fairer healthcare e.g., reducing sensory overload for autistic people)

(Hemsley et al., 2011; Knox et al., 2017; Straus et al., 2019).

Research shows when hospitals do not make changes (reasonable adjustments) to better support people with disability, people get:

- Inequitable healthcare
- A higher risk of the wrong treatment
- Poor quality care
- Reduced desire to seek out healthcare

(Mencap, 2007).

People with disability are at risk of not benefiting from mainstream health services in the same way as people without disabilities, without the proper support for hospital staff, including:

- Access to training.
- Access to resources to support communication in hospitals.
- Systems (including patient records) that support individual patients' support needs
- Ability to make reasonable adjustments.

Studies have shown that not prioritising people with disability can make patients in these groups feel "lost, isolated, and ignored" (Brown et al., 2016, p.976).

People with disability deserve to get high-quality health care that meets their needs and supports them to lead healthy and active lives.

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