SPEAK Project Evaluation Surveys & Interviews (Stage 1):
Summary of Findings

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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.

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> It's important to realise that disability isn't just a handful of people, it's more people than you would think that get admitted [to hospital], and so there's a need to be aware of what is actually best practice and what's going to be helpful to those patients... We need to be getting it right."
>
> – Healthcare worker

Executive Summary

People with disabilities have the same right to the highest standard of health care as any other Australian but frequently experience health inequities and poorer health outcomes. The SPEAK Project is a service improvement initiative that aims to build capacity in the health workforce and improve processes and systems to meet the healthcare needs and improve healthcare experiences for people with disabilities – particularly, patients with an intellectual disability, communication disability or who are autistic.

The project has five main objectives which include developing and testing a disability support service, delivering training to healthcare staff, expanding access to resources to support staff to work effectively with people with disabilities in hospital, developing improved feedback systems to amplify the voices of people with disabilities and improving data systems that support better healthcare journeys for people with a disability.

The SPEAK Evaluation seeks to understand the implementation of the SPEAK Project across three stages. Stage one activities include surveys and interviews conducted with People with disabilities (PWD) and their support people, as well as healthcare workers (HCW) at Alfred Health and South-West Healthcare.

Nine people with a disability and 21 support people completed stage one surveys, and two people with a disability and six support people completed stage one interviews. 193 healthcare workers across Alfred Health (n=142) and SWH (n=51), completed stage one surveys and six healthcare workers completed stage one interviews.

Findings from the surveys and interviews highlighted the importance of treating PWD with respect and dignity, recognizing the role of support people, providing staff education, improving consumer feedback, promoting the Disability Liaison Officer (DLO) service, improving when/how disability data is captured, greater access/knowledge about disability resources for staff, and accommodating reasonable adjustments for PWD. From these findings several key recommendations have been made.

This report summarises the findings of Stage 1 surveys and interviews and provides recommendations for progressing the project activities.

Contents

1.0 Background & Purpose

People with disabilities (PWD) experience significant health inequities and poorer healthcare outcomes compared to the general population (Bishop-Fitzpatrick & Kind, 2017; Stransky et al., 2018).

The SPEAK Project is a service improvement initiative conducted by Alfred Health (Major metropolitan hospital - Primary site) with outreach to South West Healthcare (Regional-based health service - Secondary site). The aim of the SPEAK Project is to build capacity in the health workforce and improve processes (and systems) to meet the healthcare needs and improve healthcare experiences for people with an intellectual disability, communication disability or who are autistic.[1] These aims are both practical and aspirational.

The SPEAK project has five main objectives: (1) Develop and test a disability support service, (2) Deliver training to healthcare staff, (3) Develop and promote the use of a range of resources to improve communication between staff and people with disabilities (PWD) - including accessible patient information resources, (4) Improve ways for PWD to give feedback, and (5) Improve data systems to enable proactive identification and planned support of PWD.

The SPEAK Evaluation seeks to understand the impact of the implementation of the SPEAK Project. This includes education/training outcomes (such as knowledge of hospital staff), change in level of confidence in staff to work with patients with a disability, effectiveness of the program in providing a consultation service, the appropriateness of developed resources and the effectiveness of data collection systems.

The SPEAK Project's Evaluation activities have been broken up into three stages across the project. The following report aims to provide a summary of the findings of Stage 1 activities.

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[1] Note: Autism, intellectual disability and communication disability are sometimes described as 'invisible' disabilities. Findings from codesign workshops, conducted as part of the SPEAK project, identified the term 'hidden disabilities' to describe the same. Both terms are used interchangeably within this report.

2.0 What did we do?

As part of Stage 1 Evaluation activities, surveys and interviews were conducted people with disabilities (PWD) and their support people, as well as with healthcare workers (HCW) at Alfred Health and South West Healthcare (SWH).

2.1 Recruitment

2.1.1 Eligibility

PWD were eligible to participate if they:

- were age 18 or over
- A current or recent patient at The Alfred or SWH,
- had autism, intellectual disability or communication disability/communication support needs, and
- communicated either using (i) Auslan with interpreter, or (ii) basic English (no interpreter required).

Support people were eligible to participate if they:

- met the SPEAK Project definition of support person
- were age 18 or over; and
- communicated either using Auslan (with interpreter) or basic English.

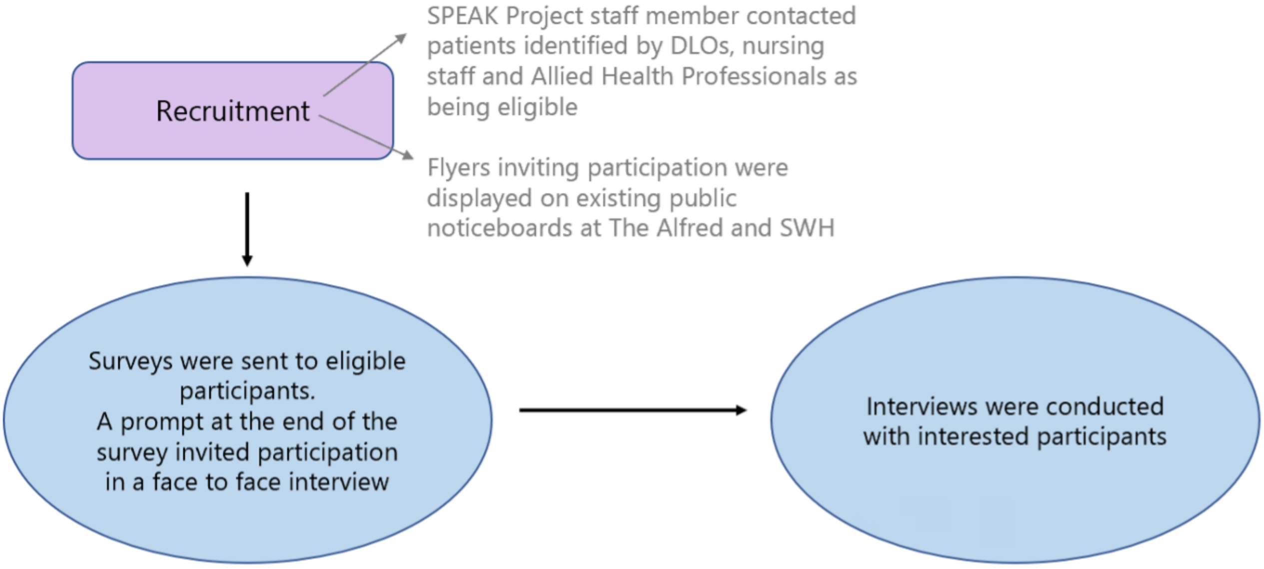
In the context of the SPEAK project, 'support people' are defined as people who are actively supporting an autistic person, person with intellectual disability, or communication disability accessing health care at The Alfred or SWH. A support person can include a family member, friend, carer, or support worker.

Healthcare workers (including support staff such as ward clerks, cleaners, porters) were eligible to participate if they:

- work at Alfred Health or SWH
- have come into contact with a patient who has an intellectual disability, communication disability / communication support needs, or is autistic.

2.1.2 Recruitment Process

Figure 1 (below) shows the recruitment process used for PWD and support PERSON surveys and interviews.



SPEAK Project staff member contacted patients identified by DLOs, nursing staff and Allied Health Professionals as being eligible

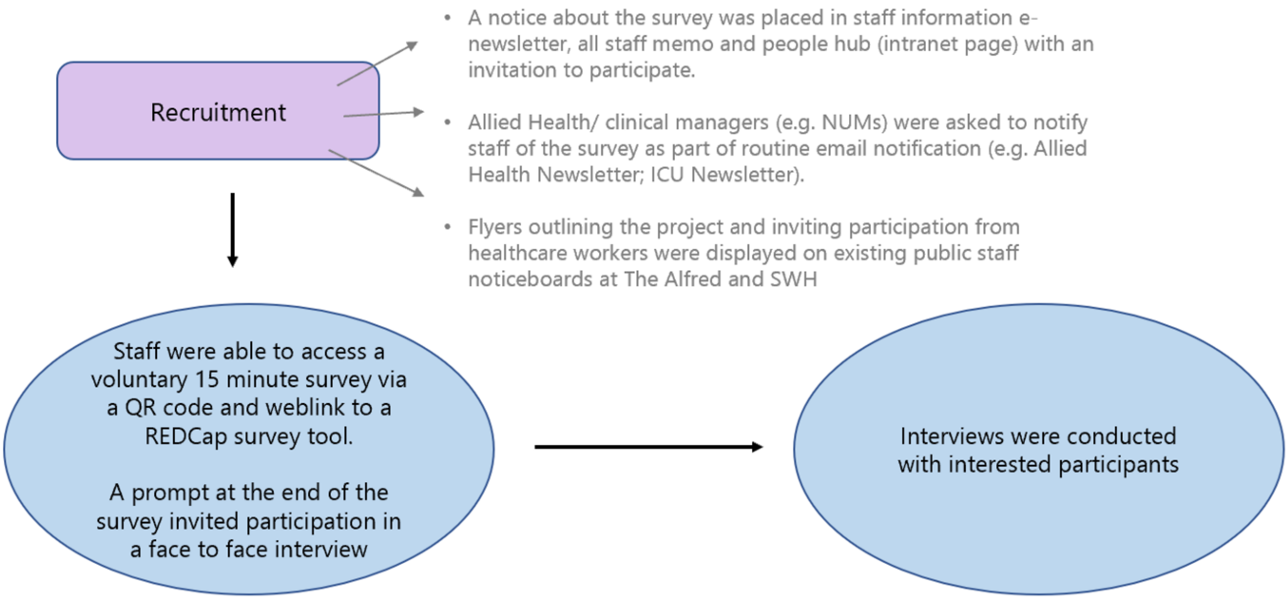
Flyers inviting participation were displayed on existing public noticeboards at The Alfred and SWH

Surveys were sent to eligible participants.
A prompt at the end of the survey invited participation in a face to face interview

Interviews were conducted with interested participants

Figure 1: PWD and support person survey and interview recruitment process

Figure 2 (below) shows the recruitment process used for HCW surveys and interviews:



- A notice about the survey was placed in staff information e-newsletter, all staff memo and people hub (intranet page) with an invitation to participate.
- Allied Health/ clinical managers (e.g. NUMs) were asked to notify staff of the survey as part of routine email notification (e.g. Allied Health Newsletter; ICU Newsletter).
- Flyers outlining the project and inviting participation from healthcare workers were displayed on existing public staff noticeboards at The Alfred and SWH

Staff were able to access a voluntary 15 minute survey via a QR code and weblink to a REDCap survey tool.

A prompt at the end of the survey invited participation in a face to face interview

Interviews were conducted with interested participants

Figure 2: Healthcare worker survey and interview recruitment process

2.2 Surveys - Design & Key Areas Covered

PWD and support person surveys were made available in plain language and Easy English versions. Participants were able to access the survey via a weblink to a REDCap survey tool, or through completion of a paper-based version. For participants completing the survey independently, consent was implied as explained in the participant information statement at the commencement of the REDCap or paper-based survey. For PWD who required some assistance/support from a SPEAK team member to complete the survey, verbal consent was gained prior to the commencement of the survey administration. These surveys aimed to gather information regarding the hospital experience of PWD and their support people.

HCWs were able to access the online staff survey through REDCap.

HCW surveys aimed to gather information to understand staff members' capacity (perceived knowledge, capability and confidence) to meet the needs of PWD within the relevant healthcare facility.

Surveys were collected during the period May to August 2022.

2.3 Interviews - Design & Key Areas Covered

Semi-structured interviews were conducted with PWD, support people and HCWs.

PWD and support person interviews focused on more in-depth data regarding the hospital experience of PWD and their support person/s, reflections on the effectiveness of communication and feedback processes, perceptions of the ability of staff to meet specific support needs, positive aspects of the hospital stay, and opportunities for improvement.

HCW interviews focused on gathering more in-depth data regarding staff level of confidence in working and communicating with PWD, views on the hospital processes in place to support PWD, and staff perceptions of education and training to better support people with a disability in hospital.

Interviews were conducted during the period June to September 2022.

2.4 Data Analysis

Survey data was analysed using descriptive statistics. Responses to open-ended questions in each of the three surveys were thematically grouped to highlight key concepts.

3.0 Who Participated?

People with Disabilities and their support people

- 8 PWD completed surveys – 5 completed online surveys, and three completed paper-based Easy English surveys. Some survey responses for paper-based surveys were incomplete.
- 21 support people completed plain language surveys.
- 2 PWD and 6 support people participated in interviews.

Healthcare Workers

- 193 HCWs across Alfred Health (n=142) and SWH (n=51) completed surveys
- 6 HCWs participated in interviews (Alfred Health: n=5; SWH: n=1)

HCW interview participants included: 3 nurses (a senior nurse, Associate Nurse Unit Manager & a psychiatric nurse), 2 allied health professionals (an audiologist and a dietician) & 1 ward clerk.

4.0 What Did We Find?

A summary of the findings from Stage 1 Surveys and Interviews are outlined below.

4.1 Survey Findings

4.1.1 PWD Surveys

People with disabilities completing the survey indicated that they had the following disabilities:

Hidden Disabilities	n
Intellectual Disability only	1
Communication Disability only	1
Autism plus Intellectual Disability	2
Intellectual Disability **and** Communication Disability or communication support needs	3
All three disabilities – Autism, Intellectual Disability and Communication Disability or communication support needs	1
TOTAL	**8**

Two respondents were aged 18-25 years, two respondents were aged 26-40 years, two respondents were aged 41-50 years, and two respondents were aged over 60 years. All eight respondents indicated that they needed a carer or support person with them when they came to hospital.

PWD had varied responses in relation to questions asked about their experiences as a patient in hospital. Key findings were:

Experiences as a patient in hospital

- All participants indicated that they had difficulty with information provided by staff or given to them. The majority of PWD indicated that they understood information in hospital 'Sometimes' or 'Not much'.
- More than half of PWD indicated that they were not involved in decisions about their healthcare.
- None of the participants felt that hospital staff helped them deal with issues/ fears about their health or healthcare – 1 participant responded 'Sometimes' and the majority responded 'Not Much'.
- All participants responded that sensory issues (e.g. the lights, smells or sounds) were a problem for them in hospital.

Patient-Staff communication

- The vast majority of PWD selected 'Sometimes' or 'Not much' when asked if hospital staff gave them time to ask questions
- Respondents were asked whether communicating with hospital staff was easy.
- Only one person indicated 'Quite Often' and the rest responded 'sometimes', 'not really' or 'never'.
- Respondents who selected 'sometimes' made reference to occasions where some nursing staff were easier to communicate with, as follows:
- "Some nurses were better to talk to than others and I could talk to some staff but not other staff" and "My one on one nurse sometimes listened if I had a nice one".
- A participant who had selected 'not really' explained, "I have short term memory loss, I ask for paperwork on it but they never come back with it".

Consent

- In response to the question: "I was able to give consent for any treatment or care" - Five PWD indicated that they were able to give consent for treatment or care, one indicated they were not able to and one indicated that they did not know.

Feedback (including complaints if unhappy with care)

- Responses to this question were variable. Two participants indicated that they were not able to give feedback about how they felt as a patient, one participant indicated that they were able to give feedback, and two indicated 'sometimes'. The two respondents who completed this question on the paper-based surveys selected "I don't know".

Choice of having a family member, friend or other support person with them

- All respondents indicated that they needed a carer or support person with them when they came to hospital. Further information was not provided regarding specific support requirements.
- 75% of participants said they were not given the choice to have a support person with them in hospital.

Understanding disability and support needs

- None of the respondents indicated that they were asked about their disability and the care they needed when they arrived at the hospital.
- Only one of the respondents indicated that staff asked their support person about their disability or care needs; the other six respondents answering this question indicated that their support people were not asked.
- Only two of the respondents indicated that they received support from a Disability Liaison Officer.

Overall rating of hospital staff

- Two PWD rated hospital as 'Average'. Only one person rated hospital staff as being 'Good', with more participants relaying that their experience of staff was 'Not very Good' or 'Bad'.
- The two participants completing questions on paper-based surveys about their overall rating of care indicated that the staff did a good job and that they "got good care".

Other information PWD felt was important for staff to know:

- *"Ask about people [with] disabilities and what they're comfortable and not comfortable with. Ask before you bring lots of doctors or people into the room. Don't ask when they are all already in your room. Check again if people are comfortable with that many people in the room"*
  (Person who is autistic and has an intellectual disability)
- *I am not just a physical patient. I have a lot of other needs too that were not getting met."*
  (Person who is autistic and has an intellectual disability and communication disability)
- *"When I'm sick I need my parents. I tried to be brave and the nurses were really nice to me, but I'm afraid to go back because I need my mum and dad."*
  (Person with intellectual disability)

4.1.2 Support Person Surveys

The support person survey was completed by 21 people; 16 supported people who had received health services from Alfred Health and 5 from SWH. Key findings are outlined below.

Patient disability

Support people identified that the people they supported had the following disabilities:

Hidden Disabilities	**n**	**%**
Intellectual Disability only	5	24
Communication Disability only	4	19
Autism plus Intellectual Disability	2	10
Intellectual Disability **and** Communication Disability	6	29
All three disabilities – Autism, Intellectual Disability and Communication Disability	4	19
TOTAL	**21**	**100**

Support people relationships with PWD

- Support people completing the survey held the following relationships to the PWD – parent (57%), other family member (19%), paid carer/support worker (19%) and spouse/partner (5%).
- The ages of PWD that support people were supporting varied considerably as seen in Figure 3.

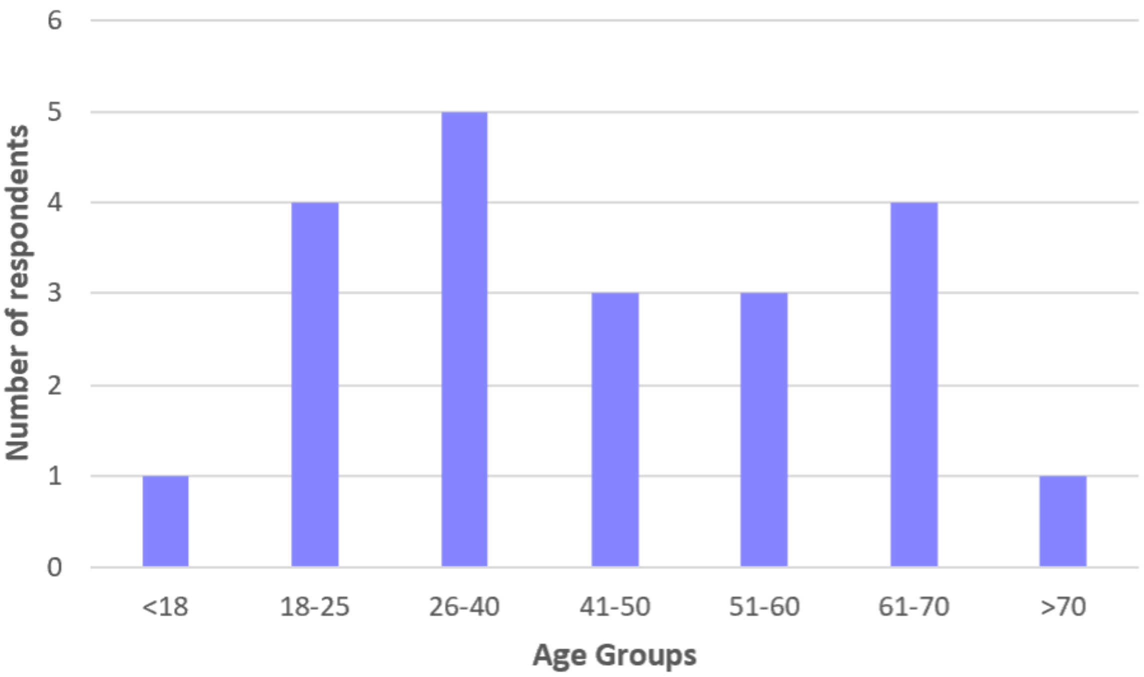


Figure 3: Ages of people with disability being supported by survey respondents.

Support needs in hospital

- 90% of PWD that the respondents supported always needed their help to access healthcare. Some of the reasons they required support included (in respondent's words):
  - Needing 1:1 care;
  - Practical support, such as prompting to make bookings & provision of transportation
  - Support to provide reliable information
  - Reduced cognition / intellectual disability
  - Person is 'non-verbal'
  - Support for understanding information provided and medical decision making
  - Severe physical and intellectual disabilities
  - At risk of seizure if becomes anxious due to memory and cognitive issues.

> **Due to the nature of the person's disability, they require assistance with all aspects of their support, and repeated experience has shown that they are at risk due to the lack of support that they receive in hospital.**
>
> Paid support worker/carer

- When asked to think about a recent hospital visit with the person that they support, 38% of respondents indicated that neither they, nor the person that they support were asked about the disability and care needs of the PWD.
- When the person they supported arrived at hospital only 24% of respondents indicated that the staff knew that the PWD had disability specific care needs.
- In relation to communication-specific needs, 19% of respondents felt that the communication needs of the person they support were not met at all.
- The majority of respondents indicated that staff needed to be reminded about information that had already been provided about the person's support needs 'always' (48%) or 'sometimes' (43%).
- Only 29% of respondents felt that the information they had provided was well-used and 43% felt some of it was used. Only 14% of respondents felt information provided by the PWD themselves was well-used and 33% felt that some of it was used.

Decisions around healthcare for PWD

- When making decisions about the person they supported, 47% of support people felt they were always included (38% felt included sometimes and 14% felt they were never included).
- In terms of including the person with a disability themselves only 24% of support people felt that the PWD were 'always' included when making decisions (48% said sometimes and 29% said PWD were never included).

Provision of information and resources to support people and people with a disability

- 86% of support people respondents felt that they were given information by staff that they could understand most or all of the time. But only 33% of them felt that the person with a disability was given information that they could understand most or all of the time.
- For those who may have required disability support resources (n=13), 23% indicate that they were provided or used by staff, 46% indicated they were not provided or used by staff, and 31% were not sure.

Disability Liaison Officers (DLO)

- When asked about whether the PWD that they support had received support from a DLO at their hospital, 52% indicated that they had. Note: 9.5% of the total group were not sure.

Staff knowledge, attitudes and behaviours regarding PWD

Support people were asked to indicate how often they felt that staff showed good knowledge, attitudes and behaviour regarding providing healthcare to PWD (See Figure 4).

- One of the things that the respondents highlighted was the lack of disability-specific knowledge held by hospital staff as demonstrated by this respondent's feedback.

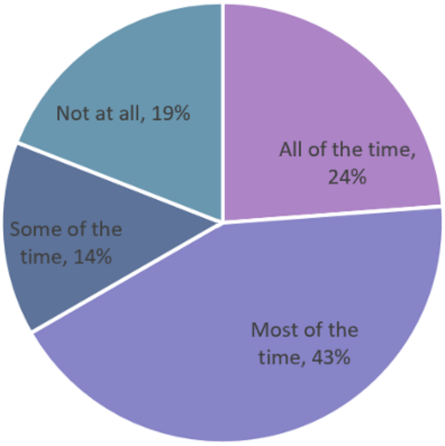


Figure 4: Respondents view of how often they thought staff showed good knowledge, attitudes and behaviours for providing healthcare to PWD.

> **I think that there is a gap in the knowledge of how best to support people with a disability. People just don't know what they don't know, and that is fine, but it would be good to see the organisation upskill to create an environment that empowers consumers more. Healthcare is such a huge part of my family member's life, and it could look very different.**
>
> Other family member supporting someone who was 26-40 years old

- Respondents were also asked to indicate how they would rate the staff at The Alfred or South-West Healthcare on their ability to provide appropriate healthcare for the person they support. Fifty-two percent indicated 'very good' or 'excellent' whereas twenty percent indicated 'bad' or 'not very good' (See Figure 5).

Figure 5: Respondents rating of hospital staff on their ability to provide appropriate healthcare for the person they support.

Providing feedback

57% of respondents indicated that they would know how to give feedback to the hospital if they wanted to.

When asked whether it would be easy for them or the PWD they support to give feedback, 71% indicated that they could do it, 19% indicated that both they and the PWD they support could do it, and 10% indicated that neither they nor the PWD they support would easily be able to provide feedback.

What was positive and what was negative about recent hospital visits

- Positives
  - Staff were kind, caring, dedicated, professional, and engaged.
  - The PWD received good medical care, medical needs were met and they were provided with information about care.
  - The Disability Liaison Service supported their hospital experience.
- Negatives
  - Poor communication with the patient and with family, with the manner of some staff being described as ‘rude’, and staff using unfamiliar medical terms.
  - Concerns that the person’s basic and specific care needs were not met and that they were not safe.
  - Support people were restricted in their ability to stay with the PWD and this was negative and ‘traumatic’.
  - They also told us about other negative factors, such as: the wait times in the emergency department, the lack of staffing at the hospital, and the response to feedback from executive.

4.1.3 Healthcare Worker Surveys

There were 193 responses (Alfred Health: n= 142; SWH: n=51) to HCW Surveys. 61% respondents worked in clinical role (n=118) & 39% worked in non-clinical roles (n=75).

There were 193 responses (Alfred Health: n= 142; SWH: n=51) to HCW Surveys. 61% respondents worked in clinical role (n=118) & 39% worked in non-clinical roles (n=75).
The majority of clinical respondents were Nursing (37%) and Allied Health (55%); and the majority of non-clinical respondents were Administration/desk staff (39%) and Ancillary Staff (e.g. orderly, cleaner, kitchen staff) (28%).

Note: For the purpose of this report, HCW survey data will concentrate on responses from Alfred Health staff members as this is where the SPEAK initiatives are initially being introduced.

Alfred Health staff who completed surveys indicated that they worked in the following areas of the health service:

Health Service Area	Number of Responses (n)	Percentage (%)
Emergency	32	19%
Acute Medical	29	17%
Rehabilitation	20	12%
Outpatient/Community Health	17	10%
Acute Mental Health	15	9%
Community Mental Health	15	9%
Community/Home-Based	7	4%
Other*	33	20%
TOTAL	**168****	**100**

** Note: respondents were able to select more than one response

* ‘Other’ included a wide range of responses including administration (n=5), ancillary services (n=9), ICU (n=3), other clinical services (n=11), security (n=1), research (n=1), education (n=1)

Disability-related training

- Only 31% of Alfred Health respondents indicated that they had some training that had helped them to work with PWD, particularly people who have an intellectual disability, communication disability or who are autistic.

- The majority of training was group-based and face to face (64%), followed by on-line training (23%) and individual face to face training (13%). Following the training 82% felt confident or very confident to work with people with disabilities and 18% felt somewhat confident.

Understanding “invisible disability”

- 69% of Alfred Health survey respondents indicated that they knew what was meant by the term ‘invisible disability’, twenty-three respondents shared their understanding of the term ‘invisible disability. There was a range of understanding. They used such phrases as:
  - “A disability that may not be obvious” (Nurse)
  - “A disability that is not immediately apparent” (Non-clinical role)
  - “Disabilities that are not visually observable. This may include sensory disabilities (vision or hearing impairment), intellectual disabilities or psychological conditions that impact an individual’s interactions with others” (Case manager)

Best ways to support staff to work with PWD

- Survey respondents were able to choose up to three options. The most popular identified by Alfred Health staff were in-person support from an expert in disability (49%), group training (43%), training in the use of communication resources (41%) and training to help avoid, reduce or de-escalate behaviours (40%)
- Other responses received were: allowing sufficient staff time/resourcing to do the work well); allowing family visitation to be more present on the ward; enabling smaller disciplines (e.g. audiology & speech pathology) sufficient resources to provide assistance to services when required; support for staff to be accepting and non-judgemental; training for managers; and training to recognise symptoms or behaviours of concern resulting from hidden disabilities.

Recording of disability in the Electronic Medical Record (EMR)

- Of a total of 69 responses;
- Only 28% of respondents were confident or very confident that a patient’s disability type would be recorded in the EMR at Alfred Health.
- Only 9% were confident or very confident that a patient’s disability support needs would be recorded in the EMR, and
- Only 17% of Alfred Health respondents were confident or very confident that they could find information about a patient’s disability in the EMR when they need it. (See Figures 9,10 & 11 for more details)

HCW confidence that disability type would be recorded in the EMR

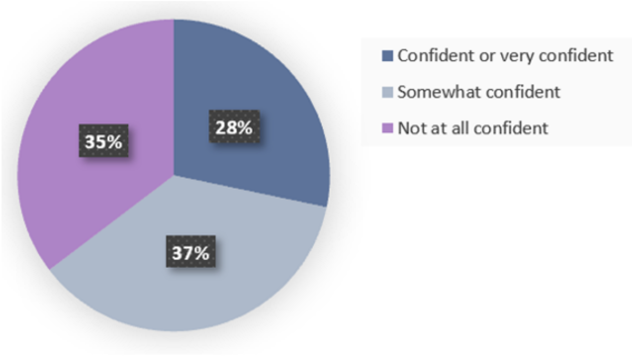


Figure 9

HCW confidence re: finding patient disability information in the EMR

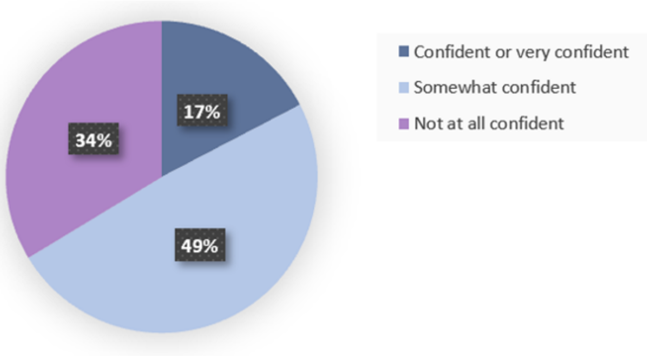


Figure 10

HCW confidence that accessibility needs (including communication and/or sensory support needs) would be recorded in the EMR

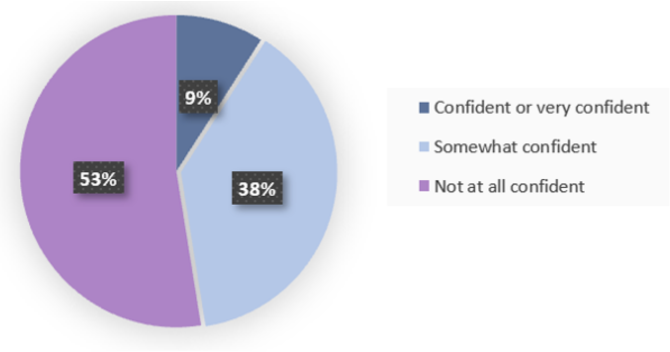


Figure 11

Disability Liaison Officers

- Only 50% of Alfred Health staff members responding to the survey indicated that they were aware of Disability Liaison Officers (DLO) or the Disability Liaison Service.

Feedback systems

- 77% of survey respondents indicated that they knew how patients could provide feedback to Alfred Health.
- Only 10% of respondents felt that the feedback systems were accessible for PWD (55% felt that they were not accessible, and the remaining 35% were not sure).

Level of stress when working with PWD

- 44% of Alfred Health staff members indicated that they experienced working with PWD as ‘somewhat stressful’, and 4% reported ‘very high stress’.
- Supports identified by staff to help reduce level of stress when working with PWD included; having access to staff with expertise in disability (39%), more training (38%), receiving education from PWD (36%) and being able to spend more time with a patient with disability related support needs.

Confidence in providing healthcare to PWD

- Of 116 respondents, 53% felt confident in recognising that a person may be autistic, have an intellectual disability or communication disability. 39% felt somewhat confident and 9% felt not at all confident.
- Of the same group, 47% felt confident working with or providing healthcare to an autistic person, a person with an intellectual disability or communication disability. 40% felt somewhat confident and 9% felt not at all confident.

Information resources

- When asked about the resources that are available to help Alfred Health staff work with PWD, 48% of staff responded that they had no resources available.
    - 32% of respondents said they had access to Easy-English health information
    - 27% said they knew about/had access to plain language forms
    - 17% said they knew about/had access to plain language health information

4.2 Interview Findings

Analysis of the interviews conducted with PWD, support people and hospital staff from Alfred Health and South West Healthcare resulted in eleven key themes which will be summarised below. Surprisingly many themes were shared between all three groups, with only two themes being specific to some groups. These are indicated in the descriptions that follow.

4.2.1 Importance of support people as members of the care team

Participant interviews highlighted the crucial role played by support people during hospital admissions of PWD. Interview findings showed that support people play a critical role in 'providing emotional support', advocating for the person with a disability, and 'assisting with personal care'. Whilst the level of support for PWD varies based on the individual, participants highlighted the need for people with complex disabilities to have a familiar support person present during hospital admissions.

> **It's hugely valuable and important to have the carer by the bedside, really. Someone that can be the advocate... It just helps so much with the care of the patient. It helps make sure they have the best outcome that they can possibly have. And I think when we [support people] are involved as part of it all, it's helpful to the staff too.**
>
> - SP5 (Support person for person with Cerebral Palsy)

Support people were found to play a vital role in helping patients cope with the challenges posed by the hospital environment (e.g. bright light, loud noises, unfamiliar people) and streamlining care through knowledge and lived experience of supporting the person with a disability. They were also recognised as being able to help patients to express and address basic physical needs that may not be visually apparent to unfamiliar hospital staff. Participants also provided examples of how support persons improve patient safety outcomes in the hospital. Support people were described as “advocates”, “experts” and “key contacts” during hospital admissions for PWD.

4.2.2 “Having invisible disabilities has a huge impact”: Additional challenges & increased vulnerability

Participants across interview groups highlighted the challenges faced by patients with invisible disabilities in hospital. Interview data indicated that patients with invisible/hidden disabilities often feel misunderstood, and that hospital staff may not understand their support needs.

> **“I felt like they [hospital staff] got really mad at me… It freaked me out. All I could tell them was it was too hot… My whole body was drenched and I was just like “I’m too hot. I can’t think. I can’t think. I’m feeling too hot, I can’t handle it.” I don’t think anyone got that I have a lot of sensory issues with temperature.”**
>
> – PWD2 (Person with disability)

HCWs also noted added challenges PWD experience with having their support needs met. Additionally, HCWs discussed the importance of creating non-discriminatory hospital environments and ensuring that patients feel ‘safe’ to disclose their support needs and the impact of their disability to staff. Participants highlighted that people with invisible disabilities are more likely to have their needs unrecognized and unmet in hospital, increasing their vulnerability and negatively impacting patient experience.

4.2.3. Staff education is key to improving outcomes for PWD

All HCWs interviewed discussed the need for education regarding disability. Many HCWs commented on the lack of education or training provided to healthcare professionals to communicate with PWD.

> **“Unless you’re a person that is invested in your own education or directly caring for loved ones with intellectual disability or neurodivergent disorders in your personal capacity, it’s very hard to know what to do.”**
>
> – HCW4 (Healthcare worker)

HCWs with lived experience of supporting a person with a disability expressed that they were more likely to think about reasonable adjustments when working with PWD but expressed that the need for these adjustments may be overlooked by colleagues with less knowledge or experience of working with a patient with a disability.

The need for training and education was also highlighted by PWD and their support people.

> **“There’s just a whole level of understanding that’s needed when you’re caring for a patient that has a disability.”**
>
> – SP6 (Support Person)

Some HCWs raised that negative stereotypes of PWD were more likely to perpetuate without disability awareness training.

HCWs interviewed also mentioned that hospital staff encounter PWD who require additional support during their hospital stay on a regular basis. In all instances this was linked to a broader need for disability awareness training/education for staff.

> **“Good education is such a huge part of us being inclusive as an organisation. This disability space is a much bigger part of the population than people realize. We need to be getting it right.”**
>
> – HCW5 (Healthcare worker)

Across groups, participants spoke about a lack or absence of disability education for HCWs being linked to poorer hospital outcomes for PWD.

Involving people with disabilities (PWD) in staff education was considered essential by all interview participants. HCWs emphasized the significance of both consulting with and including people with lived experience in the development of education, with some mentioning that this would help ensure that training programs for staff were “meaningful” and “authentic”. Participants agreed that all staff members should receive disability awareness training – i.e. both clinical and non-clinical staff. Only one participant suggested targeting doctors and nurses specifically, citing that they were the staff members with the most patient contact.

Overall, findings from staff interviews emphasized the importance of involving PWD in designing education programs and creating inclusive training for all staff members to improve the overall patient experience for PWD.

4.2.4. Hospital staff willingness to "learn", "adapt" and "improvise" to support PWD enables a better patient experience

Across interview groups, participants identified that staff attitudes and knowledge of disability correlates to patients' experiences and that staff willingness to learn (about the impact of disability) and make reasonable adjustments to respond to the needs of PWD helped improve patients' overall experiences in hospital.

Participants emphasized the importance of staff allowing extra time, adjusting communication methods, and improvising care to respond to the needs of people with disabilities. Participants also stressed the importance of staff being aware of any alerts on a patient's file related to their disability.

> **"I would say some [staff] are better than others... Most are good, but then you get the odd one that doesn't care or look at the notes or check with the patient or the family with what they should be doing, and it creates a huge problem."**
>
> - SP5 (Support Person)

Neglecting alerts and/or key information provided by support people were viewed as having the potential to lead to serious health risks, as described by a mother of a patient with cerebral palsy who witnessed her daughter choking when a nurse failed to properly administer medication in line with the PWD's support needs re: thickening of fluids. All PWD and support people spoke about the negative impact on patients when staff were perceived to have poor attitudes towards disability. This was primarily attributed to a lack of disability awareness education (linked to the previous theme) and misconceptions about disability.

4.2.5. "Slipping through the cracks": Challenges with capturing feedback from patients with a disability

Findings from the interviews suggested that hospitals currently receive less feedback that reflects the experience of PWD (who are more likely to have more negative experiences in hospital compared to the general population).

Participants identified challenges with the process of hospitals receiving feedback from patients with disabilities. More than half of the PWD and support people interviewed reported being unsure of the proper channels to direct feedback or not being provided with accessible ways to provide feedback. The complexity of living with a disability and related day-to-day challenges were viewed as significant barriers to providing feedback.

Other barriers to providing feedback reported by participants included time, internal motivation, access to a computer/mobile device and being able to navigate the feedback process online. PWD and their support people reported feeling disempowered by the current feedback processes and being unsure if their feedback would result in tangible change or improvements in hospitals for PWD.

> **"I actually feel very disempowered when it comes to feedback. I don't know that it really makes a significant difference... You don't generally back hear from anyone, so then you sort of think "have I got the time to really sit down and put it all out there" and what are they going to do about it... so I think that you do feel very disempowered as a patient or family member of a patient [with a disability]."**
>
> – SP6 (Support person)

Together, these insights (1) highlight the need to improve hospital feedback processes and, (2) indicate that hospitals currently receive less feedback overall that reflects the experience of PWD, limiting opportunities to learn from feedback that may help to improve the hospital experience for these patients.

4.2.6. Disability data must be captured "early", "easy to find" and regularly referred to by hospital staff

Hospital staff and support people emphasized the importance of collecting and recording disability-related data "early" in a patient's admission to the hospital to ensure that staff could quickly and effectively provide the necessary support.

Most participants recommended collecting this information at the point of admission or pre-admission. Additionally, staff underscored the need for disability data to be recorded in a clearly marked and easily accessible location on the patient's file. Most staff believed that inadequate or difficult-to-find information within the EMR increased the risk of staff missing crucial details about a patient's support needs. HCWs also emphasized the need for previously recorded disability data (i.e. from a previous hospital admission) and/or notes about a patient's support needs to be collated and easily accessible to staff to avoid PWD and support people "repeating themselves multiple times". This was viewed as an important aspect of streamlining patient care during subsequent admissions.

Overall, insights from the interviews demonstrated that disability data must be captured early, clearly marked on the patient's file, collated in a specific location, updated as new information is received, and referred to by staff throughout the patient's admission in the hospital.

4.2.7. "It's a good service…but not well integrated into the system": Need for the Disability Liaison Officer role to be promoted and strengthened in hospitals

Disability Liaison Officers (DLOs) are employed at Alfred Health and assist PWD and their support people to access services across The Alfred and in the community (Note: at the time of interview, SWH did not have a specific DLO service). Not all patients and support people interviewed had used or were aware of the DLO service. Two support people provided positive feedback about the service, while another expressed the need for improvement in terms of DLO availability, noting that, at the time of the interview, the DLO service only operated on weekdays during business hours.

Of the five Alfred Health staff members interviewed, only one had utilised and was aware of how to contact the DLOs. All other staff members either had not heard of the DLO service or were aware of the service but did not know how to utilise/access it.

> **"To be honest, I don't think about accessing the DLO… I don't think we've got any reminders or any little alerts, or just something to keep in the back of your mind that if a patient comes in there is this service available. We don't have any printouts or any on-hand information for the DLOs which probably is what we're lacking in."**
>
> – HCW1 (Allied Health HCW)

> **"I know it's there. I absolutely have no idea how to contact them though. I don't think I've seen anyone ever use the service."**
>
> – HCW4 (Nurse)

All hospital staff interviewed emphasised the need for promoting the DLO service more widely to ensure integration into the broader hospital system.

4.2.8. "We need more resources": Need for more disability resources in the hospital

For the purpose of the SPEAK project, a disability resource has been defined as:

> **A communication or sensory support that facilitates the participation of a person with a sensory or communication disability or support need. The resource may be a physical object, such as a room, communication aid or sensory item or a person, such as a paid or unpaid support person or staff member.**

When asked about disability resources participants primarily discussed communication resources. The importance of good patient-staff communication was viewed as a key factor in optimizing hospital experiences for PWD. However, staff reported limited access to resources to support patient-staff communication or not being aware of resources that could help support PWD in the hospital setting.

PWD and their support people stressed the importance of patients being asked about their communication preferences and having their communication needs accommodated in the hospital. Failure to ask about use of communication aids, equipment, or devices was viewed negatively by PWD. Suggestions made by PWD and their support people regarding ways in which staff can improve communication with patients with a disability included being more prepared with resources and increasing the use of visuals and other communication resources such as social stories.

Overall, there was a clear reiteration of the need to; (1) increase the number of disability resources available in hospitals, (2) improve access to a range of practical disability resources for hospital staff, and (3) ensure that staff confirm communication preferences with PWD and accommodate this whenever possible.

4.2.9. Hospital Covid-19 policies disproportionally impacted PWD

Across interview groups, participants mentioned the negative impact that hospital Covid-19 policies had for people with a disability. Strict "no-visitor" policies were reported to have "caused immense stress and distress" for PWD and their loved ones, particularly for those who required specific support from a family member or carer. One support person shared, "having their main support person there for just an hour or two a day is just not enough."

Personal protective equipment, particularly masks, also posed a challenge for effective communication, particularly for patients or staff who rely on lip-reading and facial cues. The use of masks was also perceived as impacting rapport building with patients negatively.

> **"I think for PWD hospital can be particularly daunting for many reasons and I've been finding that with masks it's actually more difficult to help them feel at ease and build rapport… even just that little bit of warmth of a smile and the reassurance that comes with that I find is really useful in engaging people. But now it's just really difficult to do with masks …you see the confusion and the anxiety."**
>
> – HCW1 (Healthcare Worker)

4.2.10. "It's always busy": Time as a barrier to the provision of reasonable adjustments for PWD

Note: This theme was identified by healthcare workers only.

All hospital staff interviewed spoke about how having more time with a patient (including time taken to provide reasonable adjustments) is correlated to more positive patient outcomes and experiences in hospital. However, HCWs consistently mentioned being time-poor and that making these adjustments requires additional time. This is challenging for staff to prioritise amidst demanding schedules and staff shortages.

In busy settings like Emergency Departments (ED), staff reported that it can be particularly difficult to provide adequate reasonable adjustments to PWD. Expanding the DLO service and having additional staff in areas such as ED was suggested by HCWs as strategies to alleviate time pressures. Cultivating a ward culture where staff are encouraged to identify and act upon reasonable adjustments for PWD was also raised as important by HCWs. Overall, the ability of staff to accommodate reasonable adjustments for PWD was consistently raised across interviews as being essential for patient safety and key to delivering truly patient-centred care.

4.2.11. "Treat me like a person": The importance of empathy, kindness and dignified treatment

Note: This theme was identified by PWD and support people only.

People with disabilities and their support people identified kindness, empathy, respect, and dignity as crucial factors in creating positive hospital experiences. Half of the participants emphasized the importance of staff being friendly and "happy to engage" with patients, especially those with intellectual and communication disabilities.

Including the patient in their care whenever possible and speaking to them directly were also deemed essential. All participants stressed the significance of treating patients with disabilities as valued individuals, acknowledging their disability as one unique trait, and providing equitable and respectful care. "Treat me like a person" was the common sentiment expressed. PWD also highlighted staff 'friendliness' and willing to talk and engage with patients as being important. As one support person stated, "It's so important to not avoid talking to people just because they've got a disability."

Overall, a recurring theme across all interviews with PWD and their support people was the importance of "humanising" care for PWD and ensuring that they are treated with compassion and dignity.

5.0 Implications for next steps of SPEAK Project

Based on the data obtained through surveys and interviews, several practical implications for the SPEAK Project have been identified. The key (actionable) learnings and implications for the project have been mapped to the SPEAK Project objectives in the table below:

Objective	Key Learnings/Implications
1 – Develop a disability support service	• The role of disability support staff needs to be clearly articulated so that it is understood by staff and patients. • The DLO service needs to be promoted to all parties (staff as well as PWD and support people). This should include information on how to contact a DLO.

Objective	Key Learnings/Implications
2 – Deliver disability awareness training to staff	• Provide disability awareness training for all staff involved in patient care, including clinical and non-clinical staff. • Ensure staff members understand what is meant by "invisible disability" and its impact. Provide examples of related disability support needs to further staff understanding of hidden disabilities. • Provide training in the use of communication resources and de-escalation techniques to support staff members to work effectively with PWD. • Ensure staff are aware of the existing disability resources and services within the hospital to support PWD. This includes making sure that staff are aware that DLOs can provide expert disability-related knowledge directly to staff to enable them to feel supported when working with PWD. • Highlight the importance of including patients with disabilities in their care whenever possible to HCWs. • Encourage the inclusion of support people as collaborative partners in the care of people with complex or invisible/hidden disabilities. As part of this, it is important to define, understand and recognise the role of support people at an organizational level. • Including the voices of people with lived experience of disability in staff training/education will make for the most meaningful and impactful training.

Objective	Key Learnings/Implications
3 – Develop resources to improve patient-staff communication	• Ensure staff know how to communicate effectively with PWD and adapt their ways of working to respond to their needs. • Ensure staff are aware of communication preferences/supports in place (e.g. communication aids) for PWD and accommodate reasonable adjustments accordingly. • Improve staff access and use of resources that support better patient-staff communication for PWD (e.g. communication boards, pain scales, etc.) • Create and ensure staff create and are aware of Easy-English and plain language forms and health information.
4 – Improve ways for PWD to provide feedback	• Ensure that PWD and their support people feel confident about methods to provide feedback regarding their hospital experience. • Develop more accessible ways for PWD to provide feedback. • Assist staff to ensure that PWD and their support people are supported to provide feedback and that barriers to providing feedback are removed.
5 – Improve data systems	• Disability data, including key support needs for PWD, should be captured early (pre-admission or at presentation/admission). • Ensure patients' disability type and support needs are recorded in consistent and obvious locations in the EMR and that staff members feel confident finding, using and/or updating this information.

A final word...

The SPEAK Project's stage one evaluation activities included surveys and interviews with PWD, their support people and hospital staff. Through the information shared, key insights were obtained which informed several practical implications. These implications will drive the next steps of the SPEAK Project and contribute to positive change

Through continued collaboration, listening and learning from meaningful engagement with PWD, it is hoped that the improvements identified contribute to optimising care for PWD and improve their hospital experiences. This includes strengthening a range of hospital processes and systems and ensuring that hospital staff have the necessary skills and knowledge to work confidently with PWD and provide reasonable adjustments to support PWD and their support people.

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