



DEAF VICTORIA

Health Advocacy Project

FINAL REPORT

April 2021



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Executive Summary

Funded by the Victorian Department of Health (the Department), the **Deaf Victoria Health Advocacy Project** explored the core components of a service model that supports high quality, accessible health care for Victorians who are Deaf or hard of hearing.

The project approach included a policy and document review, literature review, jurisdictional scan, community engagement (n = 138), and stakeholder consultations.

Key identified issues relating to the accessibility of healthcare include:

- Health literacy, which is recognised as a fundamental skill required in maintaining health and accessing local healthcare. Sufficient levels of health literacy facilitate access to preventative and ongoing health care information, a greater understanding of chronic conditions and adoption of changes in lifestyle, increased comprehension of diagnoses and treatment, and greater adherence to medical advice. **45.2% of respondents indicated they do not receive sufficient information to self-manage their health.**
- The access needs of the Deaf and hard of hearing community are diverse, with no 'one-size fits all' approach. Rather, an individual will have access requirements based on their preferred method of communication and other factors including English literacy and Auslan fluency. Whilst the most identified support needs when accessing healthcare include Auslan-English or Deaf Interpreters and Auslan accessible resources, there are a range of other access supports an individual may require. **16.9% of respondents were asked about access requirements in the hospital setting. There are limited accessible resources to enhance communication between the health care provider and the Deaf or hard of hearing patient.**
- Communication is key to enabling patients to decide among different options of care, strengthening autonomy and capacity for self-management. Failure to provide requested communication and access support exposes government agencies and their clients to significant social and economic risks and can have a significant impact on the quality of life for Deaf or hard of hearing patients. Such impacts may include reduced or adverse health outcomes, and increased cost of treatment. **Fewer than half of community members were engaged in active communication in the hospital setting.**
- Victorian Government guidelines note that organisations must not directly or indirectly discriminate against people who have limited English proficiency or use a form of sign language. Discrimination includes: refusing to provide a service; providing a poor quality service; and/or having unreasonable requirements, conditions or practices within the organisation that disadvantages clients because of their race, disability or other attributes. **36.9% of respondents reported they were satisfied with the access support provided.**
- Service agencies require strategies to address access and equity issues to ensure people's overall needs are met; the delivery of cultural competence training; and assessment of service effectiveness. The effectiveness of care is not routinely measured. **38.1% of respondents were asked to provide feedback regarding their care in the hospital setting.**
- **Access to Auslan interpreters is variable across the Victorian public health system.** Identified barriers to access include inadequate patient awareness of their rights and capacity to self-advocate, variable implementation of hospital accessibility practices, and inadequate interpreter supply. In the absence of access to a certified interpreter, ad hoc communication methods are employed, including writing notes, lip-reading and/or family or friends.
- There is limited support available to enhance navigation of the often complex health system. Many community members state the need to continually advocate for their rights regarding access requirements, including in stressful situations and complex environments. **There is an opportunity to strengthen a proactive approach to enhance access and navigation support and enhance advocacy support at an individual and systemic level.**

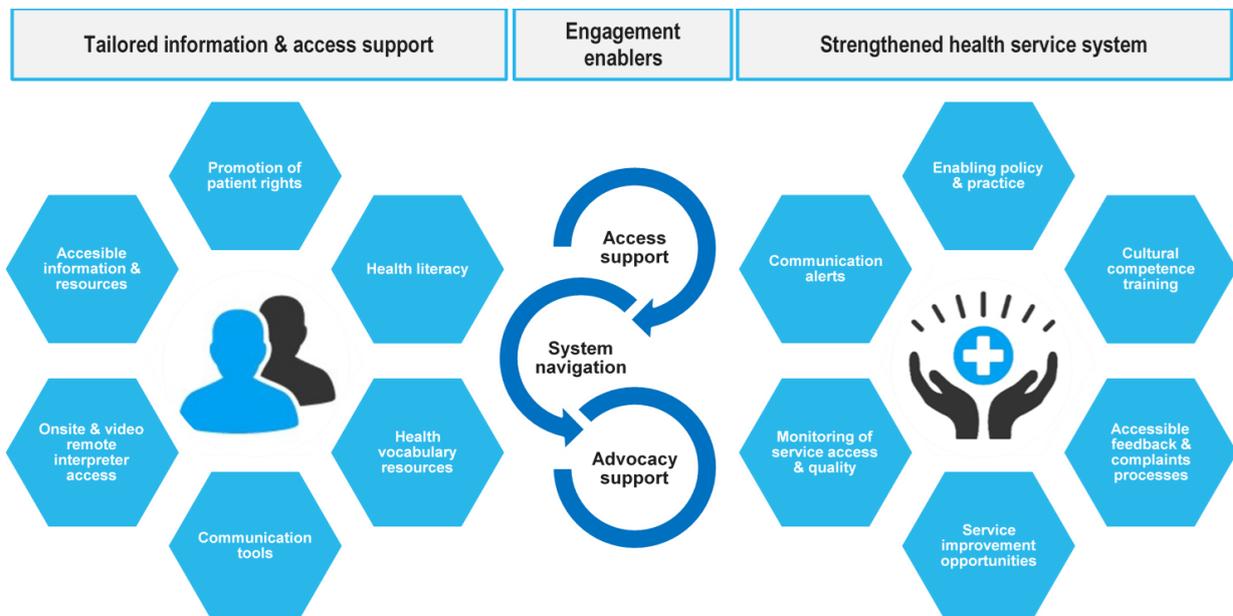
Many of the identified key issues around access, equity, communication, discrimination, inadequate interpreter supply and training, and limited supports to navigate a complex system, were also raised in the 2021 *Royal Commission into Victoria's Mental Health System*. This indicates that what we are dealing with is a systemic problem.

Improved access to health information and communication support for Deaf and hard of hearing patients has the potential to significantly enhance health care experiences and outcomes for the Deaf community. Recommendations to improve the quality and safety of care provided to hospitalised patients include:

- Initiatives focused on access and information for the Deaf or hard of hearing patient;
- Initiatives focused on strengthening the health service system response; and
- Enabling initiatives that empower Deaf or hard of hearing patients to engage fully in their health care management and achieve optimal health outcomes.

The identified service model components that may drive high quality, accessible health care for patients who are Deaf or hard of hearing are outlined in Figure ES-1.

Figure ES-1: Minimum service model components



The following report provides an outline of key considerations relating to the further development of these core components, and actions to support implementation.

1. Background, Objective & Approach

Background

In 2014, Deaf Victoria commissioned an inquiry into the access of Auslan Interpreters in Victorian hospitals. The project interviewed 72 Deaf and hard of hearing (DHH) people about their experiences. Key issues identified included: a lack of Auslan interpreting support and reliance on alternative methods of communication, including family members; inadequate skillset of Auslan Interpreters and inconsistent interpreter booking systems; and ineffective complaints processes.

The review found that access to Auslan interpreters in Victorian hospitals was largely dependent on the knowledge of frontline staff, in-house interpreter booking officers and language service providers, and the ability of Deaf patients to advocate for themselves.

There has been significant reform in the sector since the review. Key changes include:

- The implementation of the National Accreditation Authority for Translators and Interpreters (NAATI) Certification Scheme;
- The roll-out of the National Disability Scheme (NDIS) and the resultant choice for Deaf people in relation to interpreter bookings for outpatient appointments, most of which can now be booked via an Auslan-specific agency such as Auslan Connections, Auslan Services, Echo Interpreting, or National Auslan interpreter Booking Service (NABS); and
- An increase in the variety of tools available for video remote interpreting (VRI) and understanding of how to utilise these tools by both practitioners and patients, as a result of the COVID-19 global health emergency.

Project objective

Funded by the Victorian Disability Advocacy Futures Grants program, the Deaf Victoria **Health Advocacy Project** seeks to explore new models of accessing mainstream health for Victorians who are Deaf or hard of hearing.

The objective of this project stream is to identify the core components of a service model that supports high quality, accessible health care.

The **project approach** included:

- **Situation analysis:** Desktop research was undertaken to develop a comprehensive understanding of the current policy context and service delivery, together with the underlying principles of existing service models. This project stage included: policy and document review, a literature review, and jurisdictional scan. *Refer to Desktop Review Summary Report;*
- **Community engagement:** To seek qualitative information from Deaf and hard of hearing Victorians in relation to barriers/enablers of service delivery in the health and hospital settings, an online English survey (n = 124) and four small group Auslan forums (n = 14) were conducted. *Refer to Community Engagement Thematic Summary Report;*
- **Stakeholder consultations:** To provide critical contextual and qualitative information, online consultations were undertaken with the following stakeholder groups: Ambulance Victoria; Able Australia (Deafblind Victoria); ASLIA; Deaf Children Australia; Deaf Victoria; Department of Health & Human Services; Expression Australia; Health Issues Centre; National Disability Insurance Agency; Victorian Equal Opportunity & Human Rights Commission; Victorian Health Diversity Network; and
- **Synthesis & Reporting:** The findings of the abovementioned stages were synthesised, together with recommendations for the development of identified service model components. This report identifies the core components of an accessible service model for public health services, and the key actions required to support implementation.

2. The Case for Change

The Deaf and hard of hearing community is diverse. Deaf Victoria note that:

'Every deaf person's hearing loss is different, and therefore every individual's support needs and equipment are different'.

Deaf people commonly use sign language as a preferred language for face-to-face communication. In 2016, there were 3,130 Victorians who use sign language at home. Australian Sign Language (Auslan) is the recognised language of the Australian Deaf community. Many Auslan users ascribe their experiences as one that aligns with cultural and linguistic identity. It is well recognised that people from culturally and linguistically diverse backgrounds may find it difficult to navigate unfamiliar services, require additional services, and/or face discrimination.

The following provides a review of the current policy context, together with the identification of the key accessibility issues as identified by a literature review, jurisdictional scan and community feedback.

Legislative & policy context

Victorian Government and Commonwealth Government legislation clearly outline the responsibility for equitable access to services by Victorians who are Deaf or hard of hearing. Government departments and agencies have a responsibility to ensure people who are Deaf or hard of hearing are provided clear information and assistance, when needed, particularly to enable informed decision making and consent.

Government policy supports the delivery of culturally and linguistically appropriate services through the provision of accessible information and certified interpreters. Service agencies require strategies to address access and equity issues and ensure people's overall needs are met. Further, Departments are required to deliver cultural competence training and assess the effectiveness of service delivery.

In 2019 the Australian Commission on Safety and Quality in Health Care launched 'My healthcare rights', the second edition of the Australian Charter of Healthcare Rights.¹ The Charter describes the rights that consumers, or someone they care for, can expect when receiving health care. Key principles of the Charter are outlined below.



Victorian Government guidelines note that organisations must not directly or indirectly discriminate against people who have limited English proficiency or use a form of sign language. Discrimination includes: refusing to provide a service; providing a poor quality service; and/or having unreasonable requirements, conditions or practices within the organisation that disadvantages clients because of their race, disability or other attributes.

1. <https://www.safetyandquality.gov.au/sites/default/files/2019-06/Charter%20of%20Healthcare%20Rights%20A4%20poster%20ACCESSIBLE%20pdf.pdf>

Royal Commission into Victoria's Mental Health System – 2021

In the context of the legislative and policy environment, the recent Royal Commission into Victoria's Mental Health System can also prove instructive. It outlines many of the same issue for mental health as for the Deaf and hard of hearing community, including:

- **Service planning:** mental health services will be planned and commissioned to respond to diverse communities, including professional translation and interpreting services for diverse communities such as the Deaf community.² (Refer to *Strengthened health service system* in Chapter 4).
- **Integrative digital technology:** a co-design of the Victorian mental health website with diverse communities to support mental health and wellbeing services. The expanded use of telehealth and digital technologies will support those in rural and remote areas and those who are culturally and linguistically diverse, thereby enhancing service availability across the state.³ (Refer to *Onsite & video remote interpreter access* in Chapter 3).
- **Enhancing interpreter workforce:** Increasing the number of interpreters with specialist mental health knowledge. It has been recommended that The Mental Health and Wellbeing Division of the Department of Health works in partnership with NAATI, language services professionals, registered trainings organisations and consumers in order to improve the capacity of the interpreter workforce. It has been recommended that the Victorian Government provide ongoing funding to support delivery of NAATI-certified Auslan/English interpreters and Deaf interpreters mental health training course. Scholarships should be developed to support uptake of specialist mental health interpreters.⁴ (Refer to *Cultural competence training section* in Chapter 4).

There is also a direct linking by the Commission of mental health services and the Deaf community with the compelling evidence regarding the negative impact of discrimination on mental health and wellbeing and on one's ability to access mental health services including:

- Experiences of discrimination for the Deaf and hard of hearing community is linked with higher prevalence of mental illness;
- Discrimination can extend to marginalisation of non-traditional families, adding further complexities for families, carers and supporters to support someone living with a mental illness, while maintaining their own individual wellbeing; and
- The complexity of mental health and the fragmented system can leave people without access to necessary and timely treatment, care and support which can be further compounded by cultural, language and communication barriers, including those who are Deaf or hard of hearing and those with limited communication skills. Generally, the mental health system is inaccessible for deaf and hard of hearing people, particular for those who use Auslan.⁵

The report outlined that in order to promote inclusion and address inequities, increased transparency in access to language services within mental health must be an immediate priority. This is explored in the *Strengthened health service system* section below.

Health knowledge & information

Health literacy is recognised as a fundamental skill required in maintaining health and accessing local healthcare. Sufficient levels of health literacy facilitate access to preventative and ongoing health care information, a greater understanding of chronic conditions and adoption of changes in

2. Royal Commission into Victoria's Mental Health System. Volume 1 – A new approach to mental health and wellbeing in Victoria. Available <https://finalreport.rcvmhs.vic.gov.au/>

3. Royal Commission into Victoria's Mental Health System. Volume 1 – A new approach to mental health and wellbeing in Victoria. Available <https://finalreport.rcvmhs.vic.gov.au/>

4. Royal Commission into Victoria's Mental Health System. Volume 3 – Promoting inclusion and addressing inequities. Available <https://finalreport.rcvmhs.vic.gov.au/>

5. Royal Commission into Victoria's Mental Health System. Volume 3 – Promoting inclusion and addressing inequities. Available <https://finalreport.rcvmhs.vic.gov.au/>

lifestyle, increased comprehension of diagnoses and treatment, and greater adherence to medical advice.

Community survey results:

- 45.2% of respondents indicated they do **not** receive sufficient information to self-manage their health.

Health sector information, access & communication support

The access needs of the Deaf and hard of hearing community are diverse, with no 'one-size fits all' approach, rather an individual will have access requirements based on their preferred method of communication and other factors including English literacy and Auslan fluency.

Community survey results:

- **Accessibility needs are not being met**, with:
 - ▶ 25.4% of respondents reporting that services met their cultural needs; and
 - ▶ 36.9% of respondents reporting they were satisfied with the access support provided.
- **The principles of the Charter of Healthcare Rights are not consistently applied**, with:
 - ▶ 42.3% of respondents reporting health care services and treatment met their needs;
 - ▶ 46.4% of respondents reporting they were involved in open and honest communication;
 - ▶ 46.9% of respondents reporting they were treated with dignity and respect;
 - ▶ 55.1% of respondents reporting they felt safe; and
 - ▶ 56.7% of respondents reporting they could understand and use health information provided.

Communication is key to enabling patients to decide among different options of care, strengthening autonomy and capacity for self-management. Effective communication between patients and healthcare providers is essential to the provision of high quality, patient-centred health care. The quality of communication with healthcare providers is a major contributor to patient satisfaction. Patient satisfaction with the hospital experience is a complex and multifaceted phenomenon and may in turn influence further health service utilisation decision-making (e.g., refusing follow-up) and the level of patient compliance with prescribed treatments and recommendations.⁶

Failure to provide requested communication and access support exposes government agencies and their clients to significant social and economic risks and can have a significant impact on the quality of life for Deaf or hard of hearing patients. Such impacts may include reduced or adverse health outcomes, and increased cost of treatment. Further, it is noted that communication barriers can lead to poorer personal empowerment, social inclusion, self-efficacy and autonomy and may also lead to low self-esteem, symptoms of anxiety, depression and greater mental health issues.

The perceived barriers to positive hospital experiences relate to a lack of understanding by hospital staff around Deaf culture and access needs, resulting in a failure to provide the patient with appropriate care and access supports.

6. Sirch L, Salvador L & Palese A. Communication difficulties experienced by Deaf male patients during their in-hospital stay: findings from a qualitative descriptive study. Scand J Caring Sci (2017) 31.

Community survey results:

- **There is evidence of a failure to facilitate communication in the hospital setting**, with:
 - ▶ 16.9% of respondents asked about access requirements;
 - ▶ 20.3% of respondents receiving access support in a timely manner; and
 - ▶ 47.5% of respondents receiving the requested support.
- **Fewer than half of community members were engaged in active communication**, with:
 - ▶ 48.5% of respondents reporting they was able to give informed consent when required;
 - ▶ 47.1% of respondents reporting they received information about follow-up care;
 - ▶ 44.1% of respondents reporting they understood the information they received;
 - ▶ 39.1% of respondents reporting they received clear information about their condition;
 - ▶ 33.3% of respondents reporting feeling understood;
 - ▶ 32.4% of respondents reporting feeling they could understand; and
 - ▶ 31.8% of respondents reporting being encouraged to participate in choices related to their health care.

Communication resources

Whilst the most identified support needs when accessing healthcare include Auslan-English or Deaf Interpreters and Auslan accessible resources, there are a range of other access supports an individual may require.

There are limited Auslan accessible resources to enhance communication between the health care provider and the Deaf or hard of hearing patient. The provision of English information brochures relating to medical treatment, medication use and side-effects, procedure of follow-up care (e.g., post-surgical dressing) etc. contributes to the perception of disempowerment for patients using Auslan as their first language who rely on visual information.

Access to Auslan interpreters is variable across the Victorian public health system. Identified barriers to access include inadequate patient awareness of their rights and capacity to self-advocate, variable implementation of hospital accessibility practices, and inadequate interpreter supply. In the absence of access to a certified interpreter, adhoc communication methods are employed, including writing notes, lip-reading and/or family or friends.

Community engagement and advocacy

Several issues relating to community engagement have been identified:

- Deaf or hard of hearing consumers are not adequately engaged in service design and improvement;
- There is limited support available to enhance navigation of the often complex health system;
- Many community members state the need to continually advocate for their rights regarding access requirements, including in stressful situations and complex environments. There is an opportunity to strengthen a proactive approach to enhance access support, and also enhance advocacy support at an individual and systemic level; and
- The effectiveness of care is not routinely measured.

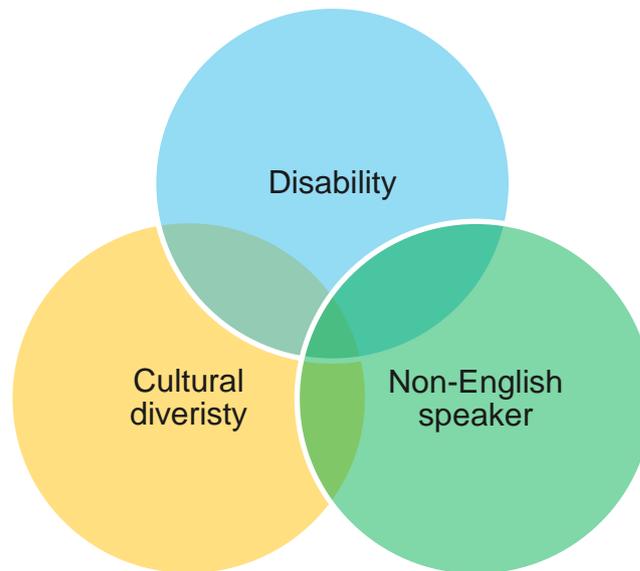
Community survey results:

- **Feedback and complaints:**
 - ▶ 38.1% of respondents were asked to provide feedback regarding their care; and
 - ▶ 41.3% of respondents felt confident providing feedback.

Cultural diversity

As noted, the Deaf or hard of hearing population is a heterogeneous group. While access services have historically been delivered within the context of disability, there is a shift from some members of the community towards identifying as a cultural or linguistic diversity.

Figure 2-1: Challenging the cultural fit



A perceived challenge for Deaf or hard of hearing patients is the potential to ‘fall through the gap’ based on how they identify and the relative understanding of their access support requirements in each ‘sector’.

In December 2020, the Victorian Legislative Council Legal and Social Issues Committee released the findings of the *Inquiry into the Victorian Government’s COVID-19 contact tracing system and testing regime*. The inquiry reviewed the impact on culturally and linguistically diverse communities. The Committee noting that culturally and linguistically diverse residents of Victoria were neglected in the Victorian Government’s response to the pandemic and encouraged the Victorian Government to learn from the experiences of the COVID-19 pandemic to better tailor information, support, and policies to the diverse population of Victoria.

Critical enablers of communication were noted to include interpreters, community leaders, written material, and infographics.

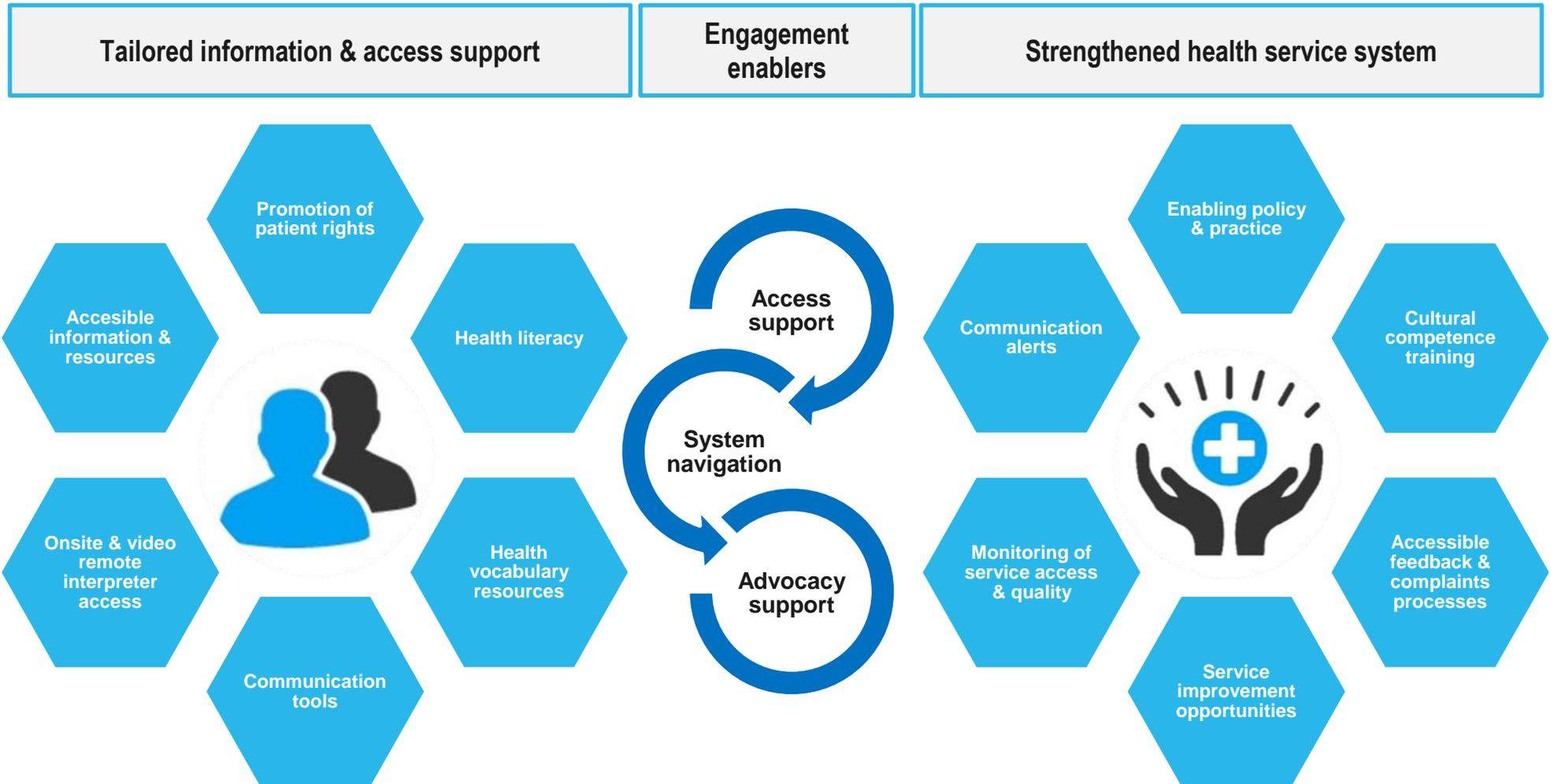
Minimum service model components

Improved access to health information and communication support has the potential to significantly enhance health care experiences and outcomes for the Deaf community. Recommendations to improve the quality and safety of care provided to hospitalized patients include:

- Initiatives focused on access and information for the Deaf or hard of hearing patient;
- Initiatives focused on strengthening the health service system response; and
- Enabling initiatives that empower Deaf or hard of hearing patients to engage fully in their health care management and achieve optimal health outcomes.

The over-arching components are illustrated in Figure 2-2 and further outlined in the subsequent sections.

Figure 2-2: Minimum service model components



3. Information & access support

The following outlines the core service model components relating to the **direct support** of Deaf or hard of hearing patients, together with recommended actions for implementation.

Promotion of patient rights

In Victoria, Departmental and funded organisations are responsible for ensuring clients are made aware of:

- Their right to communicate in their preferred language;
- When and how to ask for an interpreter;
- Provision of an interpreter is at no cost to the client; and
- That interpreters are professionals and confidentiality is part of their code of conduct.

Further work is required at a statewide level to actively promote patient rights relating to communication needs and interpreter access. Funded by the Department, Deaf Victoria are delivering a series of education workshops in metropolitan and major regional centres to educate deaf consumers about accessing health services and their communication rights in these settings.

The development and distribution of accessible resources to support patient awareness of the advantages of engaging certified interpreters is also recommended.

Health literacy

'Health literacy means people can obtain, understand and use the health information and services they need to make appropriate health decisions'.⁷

Approaches to enhance health literacy and empower self-management by Deaf patients include the provision of tailored health promotion initiatives to raise health knowledge in Deaf communities. This may include topics such as: communicating medical history; understanding and managing mental health; making informed decisions about one's health; and medical screening tests.

It is proposed that the Victorian Government OPTimising HEalth LIterAcy (Ophelia) approach to developing and evaluating health literacy interventions be considered to support this service model component. This will require consideration of Deaf-friendly approaches, such as skills-based learning, visual aids and visual metaphors.

Accessible information & resources

A core component of an optimal service model for Deaf and hard of hearing Victorians is enhanced health literacy through development and collation of accessible resources that support patients to manage their own health and make informed decisions. This requires access to culturally appropriate health information in sign language and includes options for preferred information channels, including conversations, online resources (including captioned videos) and accessible (plain English) hard copy publications. Ie

7. Hill, S. (2014). Report of the Victorian 2014 Consultation on Health Literacy. Melbourne: Centre for Health Communication and Participation, La Trobe University. Available: <https://hic.org.au>

Community survey results:

- 95.2% of respondents identified an interest in learning more about health care; and
- 67.0% of respondents prefer health information directly from health care practitioners, with a preference for both website-based resources and webinars for respondents under 55 years of age, and hard-copy publications and face to face seminars for respondents 55 years and older.

There is limited health information available in accessible formats. It is proposed that a **centralised portal** (a health literacy hub) be developed for accessible health information providing links to trusted health information.

The Victorian Government Better Health Channel provides health and medical information to improve the health and wellbeing of people and the communities they live in. The Channel commonly links to government, educational and other not-for-profit health and health-related organisations. The information provided aims to help people understand and manage their health and medical conditions. The information is not accessible to those Victorians with low English proficiency and does not include accessible formats or captioning. This presents a significant service gap for the Deaf or hard of hearing community.

Communication tools/supports

A core service model component includes access to communication tools, both hard copy publications and technology-based solutions (online/app-based approaches). These tools may include:

- An Interpreter Card that lets healthcare providers know an interpreter is required;
- A visual Pain Scale to help reporting of symptoms (including location of pain, degree of pain, and period of time since onset, amongst other components); and
- Auslan Ward Communication tool.

Ambulance Victoria are currently developing the concept of a 'connected paramedic' to enable improved safety and quality of care for all patient cohorts. This is based on the concept of access to detailed health information and reduces the risks associated with unknown or misunderstood information. Clearly providing essential medical information in an emergency can be challenging and stressful, particularly when interpreters may not be available on demand. Extending this concept, a key area for development is the development of the 'personal passport' which is used to outline important information. In the healthcare setting, this may include:

- An outline of accessibility requirements (e.g. English fluency level, interpreter requirements, lipreading requirements, available adaptive technologies, etc.) – this would be directly applicable in other settings;
- Patient medical history, including allergies, medications, current conditions and past procedures; and
- Instructions relating to further contact (e.g. mobile number for text, email address, etc.).

It is proposed that this passport may also include additional relevant information including:

- Links to clarify rights and responsibilities;
- Links to health literacy resources;
- Links to interpreter services, booking profile, and how to book an interpreter;
- Links to advocacy services; and
- Links to patient feedback/complaint pathways (refer to section 4).

Whilst it is recognised that health services are accountable for ensuring effective communication between staff and patients, the community support the development of a health-based communication resource which can be personalised and used when communicating with health care workers. This empowers the patient and may contribute to significantly reduced stress and anxiety in healthcare settings.

Additional communication technologies and services may include:

- The ability to make/amend appointments online or via text;
- Availability of a speech to text conversion and/or auto-captioning mobile (transcribe) applications; and
- The ability to receive follow-up care (e.g., pathology results) via VRI with an interpreter.

In addition, a **communication pack** may include the following communication resources:

- Communication alert sign for staff to put on patient bedside chart to alert staff of access requirements;
- Provision of a pen and notebook at patient bedside;
- Patient information and resources, including Braille and large print options for patients who are Deafblind; and
- Information for healthcare workers regarding access supports (e.g. Frequently Asked Questions regarding booking, and working with, interpreters).

Onsite & video remote interpreter access

Access to Auslan-English and/or Deaf Interpreters is variable across health services.

Whilst Auslan interpreting has traditionally been delivered onsite, there has been significant community and workforce exposure to VRI during the Coronavirus (COVID-19) health emergency. VRI has great potential to improve access to interpreters, particularly for regional and rural residents and in after hours or emergency situations. There are a range of software tools available, ranging from encrypted videoconferencing equipment to the use of Skype, Microsoft Teams, Zoom and other similar programs through personal devices including handheld devices, laptops, or desktop computers. It is noted that there have been concerns across the health sector regarding privacy using commercial platforms, and barriers encountered by people who are Deaf or Hard of Hearing in accessing telehealth, including unfamiliarity with equipment and a lack of home access to equipment and internet services/data connectivity. These barriers encountered by Deaf people in accessing telehealth must be overcome.

Proposed approaches to enhance access to interpreters include:

- Review of Government policy relating to the use of VRI and app-based technology;
- Testing of Information and Communications Technology (ICT) infrastructure (e.g., bandwidth) to support mobile apps and VRI;
- Availability of a portable 'bedside' tablet for on-demand VRI interpreter access;
- Review of definition of 'critical points of care', minimum booking times for Auslan interpreters (both onsite and VRI), and booking procedures (e.g. multiple patients per booking);
- Access to a 24-hour emergency interpreter service through an Auslan-specific language service provider (and staff training on how to access); and
- Integrated interpreter booking systems that notify community members when a booking has been confirmed and/or amended. It is noted that a failure to be notified in advance of interpreter availability may cause anxiety. This is increased in the health setting due to the need to both provide and receive important medical information.

Health vocabulary resources

The use of terminology in health communication can be a complex issue. Misunderstandings may arise when patients do not fully understand the terms used by their healthcare practitioners. The use of pictograms (descriptive symbols that help to convey information regarding medication and health) to supplement written and verbal language has been shown to increase patient retention, comprehension, recall, and adherence.

Auslan Signbank was designed to address the question of language standardization in Deaf communities by facilitating the sharing of information and language attitudes within the Auslan-using community.⁸ The Medical Signbank project was established in 2008 to directly grow the lexicon of Auslan for health terms and facilitated the development of a web-based interactive, multimedia dictionary and database of Auslan. It was used to create an effective, accepted, and shared sign vocabulary for the discussion of medical and mental health issues by deaf clients and health professionals in interactions mediated by Auslan interpreters.

Community members and interpreters have supported ongoing investment in this resource.

Key actions

Key actions to support the further development of identified components are outlined below.

Table 3-1: Information & access support: recommended actions

CORE COMPONENT	ACTIONS
Accessible information & resources	<ul style="list-style-type: none"> ▪ Development of a targeted Health Literacy Strategy, which will outline, amongst other issues: <ul style="list-style-type: none"> ▶ Community engagement approach; ▶ Responsibilities for initial and ongoing commissioning of content; ▶ Priority content topics; and ▶ Resource format requirements (electronic and hard copy publications, plain-English and visual, etc.).
Centralised health information portal	<ul style="list-style-type: none"> ▪ Accessible information to be developed and made available on the Better Health Channel. ▪ Links to resources to be provided on an accessible centralised health information portal led by an appropriate organisation (consideration may be given to the DeafNav portal – see below).
Communication tools/supports	<ul style="list-style-type: none"> ▪ Establishment of a Reference Group, including representation from the community and health services, to support the development of visual aids/tools, a health focused communications pack, and a 'personal passport'. ▪ Distribution of resources to health services and direct to the community.
Interpreter access (including on-demand VRI)	<ul style="list-style-type: none"> ▪ Review of Government Language Services Policy, interpreter booking conditions, and interpreter booking systems. ▪ Review of Government policy relating to the use of VRI and app-based technology, including testing of ICT infrastructure and investment in portable 'bedside' tablets. ▪ Provide ongoing statewide access to a 24-hour interpreter service through an Auslan-specific provider.
Health vocabulary resources	<ul style="list-style-type: none"> ▪ Review and refresh Auslan Signbank content.

DeafNav is:

- A centralised portal for Australian Deaf or Hard of Hearing communities and their extended professional, supportive and personal networks.
- Funded by the NDIS Information, Linkages and Capacity Building funding program to help people access and navigate information about deafness, the Deaf community, supports and services.
- Led by Expression Australia in partnership with DeafCanDo and Deaf Services.

8. <https://www.auslan.org.au/>

4. Strengthened health service system

The following outlines the core service model components relating to **health service approaches** to accessible care for patients who are Deaf or hard of hearing, together with recommended actions for implementation.

Enabling policy & practice

'Specific policies and measures are required to strengthen communication during hospitalisation to ensure delivery of safe and high-quality care'.⁹

Core service model components at a health service level include:

- Clear **hospital policies, procedures and processes** relating to access supports. Considerations include:
 - ▶ Pre-admission questionnaires and provider-initiated discussion regarding access requirements;
 - ▶ Medical record standards (i.e. communication alerts recorded in the patient's record) and information sharing between health professionals;
 - ▶ Reasonable adjustments, including capacity to contact health-care staff, book appointments, receive test results and request repeat prescriptions by e-mail or text;
 - ▶ Interpreter booking procedures, scheduling extended medical appointments where an interpreter is required, policy directions regarding interpreter access for carers, and emergency/afterhours access; and
 - ▶ Provision of accessible patient information and health advice, including in sign language, with captions on online videos etc;
- Hospital staff orientation programs and in-service training programs relating to assessing access needs, and practical training on how to work with interpreters; and
- Investment in technology and accessible tools (e.g., mental health screening tools).

The Alfred Health Access and Inclusion Plan priority areas include:

- Continuous policy & systems development;
- Collaborative consumer consultation;
- Accessible built environment;
- Accessible communication;
- Inclusive organisational culture; and
- Responsive feedback processes.

Alfred Health aim to: develop a guide to producing accessible communications in collaboration with people with disabilities; develop more pictorial and video guides to explain service; improve website accessibility, including transcripts to accompany videos on website; and increase captioned content broadcast on hospital television.

It is proposed that Deaf Victoria partner with the Department and the Victorian Health Diversity Network to develop a self-assessment tool, a set of standards, and template proformas for best-practice policies.

Table 4-1 outlines an assessment tool created to support the study that may be adapted to facilitate process improvement in Victorian health services.

9. Sirch L, Salvador L & Palese A. Communication difficulties experienced by Deaf male patients during their in-hospital stay: findings from a qualitative descriptive study. *Scand J Caring Sci* (2017) 31.

Table 4-1: Assessment tool: Improving Access to Care for Deaf Individuals¹⁰

COMPONENT	ACTION
Policy & procedure	<p>Adopt policy to ensure:</p> <ul style="list-style-type: none"> Standard and routine determination and documentation of preferred mode of communication; the request for, presence of, or patient's refusal of an interpreter during a medical visit; A Deaf or hard of hearing patient is appropriately identified as needing an interpreter when referred for further testing or care; 24/7 availability of certified interpreters; and Clear, easy method for staff to access policies and guidelines.
Staff education	<ul style="list-style-type: none"> Include disability legislation and its requirements to new employee training. Ensure all employees receive training on Deaf culture and sign language and how to effectively communicate with Deaf or hard of hearing patients. Develop annual competencies on ensuring access to quality care for Deaf or hard of hearing patients.
Access to effective information	<ul style="list-style-type: none"> Install a VRI system and ensure access to all institutional departments. Adopt an accessible visual communication tool for communication on routine matters. Ensure that all TV's have closed-captioning and that staff know how to activate it. Ensure that institution has listening devices in good working order.
Patient education materials	<ul style="list-style-type: none"> Make available Auslan patient education materials on the in-house system or with a link for the patient to access directly.
Organizational support for access	<ul style="list-style-type: none"> Adopt a method to ensure that patient satisfaction data is collected from Deaf or hard of hearing patients. Extend patient visit block time to allow for interpretation. Appoint one staff person to oversee services for Deaf or hard of hearing patients.
Collaboration with the community	<ul style="list-style-type: none"> Conduct community outreach to inform available services. Actively promote patient rights. Monitor website accessibility

Cultural competence training

Cultural competence training is widely inadequate across the Victorian public health system. It is understood that in many services, training primarily focuses on the cultural needs of Victorians who identify as Aboriginal or Torres Strait Islander, followed by patients of non-English speaking backgrounds (with a primary focus on refugee and asylum seekers), with limited, if any, focus on Deaf awareness training.

Training is non-standardised across public health services and is largely delivered via online learning modules. A core component of the optimal service model is a compulsory and standardised e-learning Deaf awareness training module for health service staff that includes the perspectives of Deaf patients. Key topics may include:

- Legislative rights and responsibilities
- Statewide policies and organisation-specific procedures;
- Delivery of culturally appropriate care;
- Accessibility requirements;
- Consequences of communication barriers; and
- Assessing the need for an interpreter, and how to book and work with interpreters.

In addition to training modules, other core model components include:

- Health service reporting of annual training completion; and
- Health service resources, including business-hours and after-hours agency contacts and frequently asked questions.

10. Improving Access and Quality of Health Care for Deaf Populations A Collaborative Project of the Sinai Health System and Advocate Health Care – Final Report (2012)

Communication alerts

A core service model component is the ability for patient management systems to support best-practice care by facilitating proactive information sharing regarding access requirements and altering healthcare staff to requirements in advance. This may enable reasonable adjustments including:

- Longer appointment times to enable comprehensive informed consent, including sight translation of written documents;
- Pre-admission for planned admission via interpreter (standard process by telephone);
- Appropriate interpreter access before and after theatre procedures and critical points of care; and
- Clear masks/face shields to enable lip-reading.

Service improvement opportunities

Consumer and community participation is integral to continual service improvement and the provision of equitable care and access to services that are responsive to the needs of the community.

The Victorian Government is committed to involving people in decision making about health services. Participation in health is an essential principle of health development, clinical governance, community capacity building and the development of social capital. Participation occurs when consumers, carers and community members are meaningfully involved in decision making about health policy and planning, care and treatment, and the wellbeing of themselves and the community.¹¹

A core component of delivering accessible service models is the inclusion of Deaf or hard of hearing community members in service development. In Victoria, public hospital Community Advisory Committees are one such mechanism to facilitate consumer participation.

A key enabler to ensure community members contribute to service design and continuous quality improvement is capacity building through partnership with key organisations including the Health Issues Centre.

Monitoring of service access & quality

A core component of the optimal service model is the collection and analysis of routine consumer experience and patient satisfaction data. Whilst feedback about the healthcare experience is essential to continuous quality improvement, it is traditionally sourced through telephone surveys and written English surveys, both of which may be inaccessible for Deaf and hard of hearing patients. It is noted that the Victorian Healthcare Experience Survey (VHES) is not currently available in an Auslan-accessible format.

Routine monitoring of service access and quality via a performance framework may include consideration of measures including:

- Cultural competence training attendance;
- Availability of captioned videos online;
- Availability of translated patient materials;
- The number of met/unmet interpreter requests;
- The number of met/unmet adjustment requests; and

11. <https://www2.health.vic.gov.au/about/participation-and-communication/consumer-participation>

- The number and nature of complaints.

Other system outcomes relating to the safety and quality of care may include assessment of clinical indicators including:

- Emergency department attendances for ambulatory care sensitive conditions;
- Inpatient length of stay;
- Unplanned readmissions; and
- Sentinel events, and near-misses.

In 2014, the Victorian Auditor-General's Office recommended that DHHS:¹²

- Develop and report annually on their **cultural diversity plans** in consultation with the Office of Multicultural Affairs and Citizenship and the Victorian Multicultural Commission; and
- Include in their reporting of progress on cultural diversity plans explicit reference to:
 - ▶ How information/data has been used to **increase accessibility of services** for culturally and linguistically diverse communities; and
 - ▶ The effectiveness of service delivery to culturally and linguistically diverse communities as an integral part of **program evaluation**.

Accessible feedback & complaints processes

A core service model component is a Patient Experience Framework that enables access to appropriate feedback and complaint processes and choice for Deaf or Hard of Hearing patients in how data is collected and used. The objective is to empower community members to share both their positive and negative experiences and for data to be collected to identify systemic accessibility gaps.

Customised pathways may include:

- *An English feedback form pathway* allowing patients to access and log the feedback online or through the mail;
- *An Auslan or English videoconference pathway (e.g. Zoom, Microsoft Teams)* allowing feedback in Auslan or with an interpreter as preferred; and/or
- *A moderated online group forum, or test facility*, to facilitate anonymity where desired.

Further, it is well recognised that providing feedback about negative experiences can be traumatic, with concern for discrimination in the future. In addition to selecting the method of providing feedback, patients are to choose whether they require lodgement of a formal feedback/complaint with the service provider, or if they would like their de-identified experience noted for data collection at a systemic level.

Clear communication to the community about the objectives of reporting to encourage engagement via their chosen pathway will be a key enabler of improved data collection to drive systemic responses.

This will complement additional project work led by Deaf Victoria to empower healthcare consumers to share their stories with the broader deaf community to improve awareness and service access.

Key actions

Key actions to support the further development of identified components are outlined below.

12. <http://www.audit.vic.gov.au/publications/20140529-Migrants-Services/20140529-Migrants-Services.pdf>

Table 4-2: Strengthened health service system: recommended actions

CORE COMPONENT	ACTIONS
Policy & practice	<ul style="list-style-type: none"> ▪ Development of a health service self-assessment tool, a set of standards, and template proformas for best-practice policies.
Cultural Competence Training	<ul style="list-style-type: none"> ▪ Review recommended Learning Management System Cultural Competence Training frequency, format and content. ▪ Develop a Deaf Awareness module, with input from community members and health service workers. ▪ Distribute, monitor uptake of training, and evaluate effectiveness of training.
Communication alerts	<ul style="list-style-type: none"> ▪ Review effectiveness of patient management systems.
Service improvement opportunities	<ul style="list-style-type: none"> ▪ Build capacity of community members to contribute to service design, safety and quality initiatives, and ongoing assessment of service effectiveness.
Service monitoring	<ul style="list-style-type: none"> ▪ Develop a Performance Framework. ▪ Develop pathways for the collection, analysis and reporting of patient satisfaction and outcome data.
Feedback & complaints pathway	<ul style="list-style-type: none"> ▪ Develop a Patient Experience Framework and supporting resources. ▪ Develop customised pathways (as outlined above). ▪ Develop an electronic database to collect and monitor feedback and complaints. ▪ Develop a reporting protocol for alerting the Department and individual health services of key strengths and identified opportunities for improvement.

5. Engagement enablers

The following outlines the core service model components relating to **enabling initiatives** that empower Deaf or hard of hearing patients to engage fully in their health care management and achieve optimal health outcomes, together with recommended actions for implementation.

Access support

A core component of an accessible and inclusive health system is the capacity to receive assistance to identify and obtain the required access and communication supports. There are long-standing models of employing Hospital Liaison Officers to improve the patient journey and empower patients to participate fully in their health care management and achieve better health outcomes.

Hospital Liaison Officers

Existing models include:

- Aboriginal and Torres Strait Islander Liaison Officers, who explain hospital services and procedures to patients, liaise between the patient and hospital staff, provide culturally appropriate information to hospital staff, refer patients to other support services, and provide support and practical assistance to significant others and/or family members.
- Disability Liaison Officers (DLO's) support patients with disability, their carers and hospital staff. They work with the health care teams to provide safer, accessible and more inclusive care during a hospital stay and outpatient clinic appointments.
- DLO support has been bolstered at Victorian public hospitals during the COVID-19 pandemic, with each health service able to develop the role in line with identified needs. Key roles have included:
 - ▶ Providing the primary contact for people with disability to provide support to access COVID-19 assessment and treatment services, and work to address barriers that prevent people with disability from accessing services including fear, uncertainty and issues with accessibility;
 - ▶ Supporting people with disability to access COVID-19 assessment and treatment services,
 - ▶ Supporting people with disability to access non COVID-19 services which may have been impeded by the pandemic; and
 - ▶ Strengthening the enabling systems to support the ongoing operation of the role.

Other role titles may include Access Officer, Equity Officer or Disability Advisor. Similar roles also exist in the Victorian vocational education sector to improve educational outcomes for learners with a disability. There is widespread support for sustained funding of this role.

Whilst further work is required to develop the model of care, preliminary consideration include:

- Employment of a social worker, support worker, nurse or other health professional who has broad expertise in disability access requirements and hospital systems, together with familiarity with the Deaf culture, interpreter booking systems and how to work with interpreters;
- The role will suit someone with lived experience, particularly those with experience or understanding of intersectional identities, including cultural and linguistic diversity, LGBTIQ+, and disability;
- The ability for referrers, patients and their carers/families to contact the health service representative in advance of a planned visit/admission to proactively identify access requirements;
- The reporting line for the officer and how they can be empowered to drive cultural shift and the behaviour of clinical and non-clinical hospital staff, including responding to individual patient requirements and also identified trends in performance;
- The requirement for community outreach and in order to develop community trust, and linkages with peak bodies in order to develop subject matter expertise across four main types of disability (physical, sensory, psychological and intellectual); and
- The capacity to engage in a community of practice with other access officers to share experiences and resources to further develop skills and knowledge.

System navigation

Due to increasing complexity of the health system, effective health sector access and navigation is becoming of greater importance for consumers, carers and health professionals. It is further recognised that people from culturally and linguistically diverse backgrounds may find it difficult to navigate unfamiliar services, require additional services, and/or face discrimination.

The *Victorian 2014 Consultation on Health Literacy* project found that:¹³

- Specialised roles as navigators or experts on service availability may facilitate timely access to services;
- The role of service navigator may be occupied by health professionals, consumer or carer advocates; and
- Community members already play a critical role in assisting consumers navigate services. Training and recognition of these community members is required; More community information relating to availability of navigators and online resources may be of benefit.

There are various navigation models employed in health services. These include the provision of information on services, entitlements and sources of support, and a liaison role between patients, their family/carers and health and social services. It is proposed that the core service model component of navigation support would be provided by the dedicated Access Officer and that this would include navigation outside of the individual health service (e.g. referrals to primary and community health providers). There are existing models under which an Access Officer supports system navigation.

Advocacy support

The *Victorian Advocacy Futures Plan 2018-2020* notes that disability advocacy is a critical safeguard to prevent abuse and neglect and to uphold, promote and protect the rights of people with disability.¹⁴

Deaf Victoria receives funding from the Department and the Office of Disability to provide advocacy, information and referrals about issues to strengthen community participation and quality of life for Deaf or Hard of Hearing Victorians.

Access to advocacy support has been identified as a core component of an accessible service model for Victorians who are Deaf or hard of hearing.

Community survey results:

- 75.0% of respondents would have liked someone else to advocate on their behalf in the hospital setting.

Several community members and stakeholders have noted the need for continual advocacy (i.e. starting the conversation again at every interaction), and that support workers and interpreters are often expected to advocate on behalf of the patient. This adds responsibilities that lie outside these professional roles.

The Victorian Government *State Disability Plan 2017-2020*¹⁵ outlines priority actions for health services to ensure the best health outcomes for Victorians with a disability, including initiatives involving partnerships between disability agencies and health services to better identify and advise on systemic issues faced by Victorians with a disability in using universal public health services.

13. <https://www2.health.vic.gov.au/about/participation-and-communication/health-literacy>

14. <https://www.statedisabilityplan.vic.gov.au>

15. https://www.statedisabilityplan.vic.gov.au/application/files/2314/8062/9382/1610033_Victorian_state_disability_plan_2017-2020_Text_WEB.pdf

The *National Disability Advocacy Program* provides access to effective disability advocacy that promotes, protects and ensures full and equal enjoyment of all human rights for people with disability. The program supports disability advocacy agencies to undertake three types of advocacy:

- Self-advocacy;
- Individual advocacy; and
- Systemic advocacy.

The current model predominantly provides reactive advocacy when access barriers are identified by individuals either during or after a hospital visit. It is recognised that there is a need to shift the focus to also include proactive systemic advocacy and that this requires improved data capture.

Core considerations relating to an overarching service model may therefore include:

- A pathway that enables community members to receive advocacy support in a way that they feel comfortable. This may include:
 - ▶ An on-demand patient advocacy service from Deaf Victoria that provides advice to the individual (e.g. text-based and VRI service) and/or to the health service on behalf of the individual;
 - ▶ Direct access to a Hospital Access Officer to support individual cases; and
 - ▶ Enquiries or complaints to the Victorian Equal Opportunity and Human Rights Commission; and
- Initiatives to empower individuals who are Deaf or Hard of Hearing by teaching **self-advocacy** skills and providing access to **peer advocates**. This may include the self-advocacy toolkit resources and coursework developed by Deaf Victoria with funding from the National Disability Insurance Agency Information, Linkages and Capacity Building program, and other publications developed by the Disability Advocacy Resource Unit (DARU). These resources must be tailored to meet the needs of community members who may have a wide range of existing advocacy skills.

Advocacy support is to align with the accessible feedback & complaints pathway to ensure data is collected to support identification of systemic accessibility issues.

Key actions

Key actions to support the further development of identified components are outlined below.

Table 5-1: Engagement enablers: Recommended actions

CORE COMPONENT	ACTIONS
Access support	<ul style="list-style-type: none"> ■ Development of an Access Officer Model of Care, including consideration of role objectives, training requirements, guidelines, partnerships etc. ■ Access Officer employment, ongoing support, and evaluation.
System navigation	<ul style="list-style-type: none"> ■ Review existing System Navigator models, with consideration of how to strengthen engagement by the Deaf or hard of hearing community.
Patient advocacy support	<ul style="list-style-type: none"> ■ Deaf Victoria to further develop patient advocacy services, including a service model that facilitates strengthened self-advocacy, individual advocacy pathways, and systemic advocacy.

6. Implementation planning

The above sections have outlined the proposed actions required to embed the identified core service model components in Victorian public health services.

The overarching activities to support implementation include:

1. Deaf Victoria to develop an **Accessibility Position Statement** that highlights at a minimum:
 - ▶ Relevant National and State legislation;
 - ▶ The core components of accessible care for the Deaf or hard of hearing community;
 - ▶ Evidence of key barriers and issues faced by patients who are Deaf or hard of hearing; and
 - ▶ Proposed strategies for improvement.
2. Assessment of core roles and responsibilities of key partners (e.g., health services, peak bodies) and the associated resource implications. This includes consideration of the enablers to support broad engagement of both community members and health service staff.
3. Engagement of community representatives to ensure the community contribute to design and development of initiatives and resources.
4. Development of an Evaluation Framework, including outcome indicators, to support continuous quality improvement and ongoing investment.

It is noted that there are key learnings that may be applicable in other settings (e.g., justice, education, employment etc.). Consideration is to be given to approaches to communicate these learnings with community members and other relevant departments and organisations.

LIST OF ABBREVIATIONS

ASLIA	Australian Sign Language Interpreters' Association
DARU	Disability Advocacy Resource Unit
DHH	Deaf or Hard of Hearing
DHHS	Department of Health & Human Services
ICT	Information and Communications Technology
NAATI	National Accreditation Authority for Translators and Interpreters
NABS	National Auslan Booking Service
NDIS	National Disability Scheme
VRI	Video Remote Interpreting

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