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# Submission on Issues Paper: Promoting Inclusion - Hospitals

15th June 2021

## Introduction

Despite its national reputation as an egalitarian society, for many years Australia has excluded many people from full enjoyment of the privileges of living here. Changing community attitudes and awareness of human rights have led to many attempts to change this aspect of Australian life over the past fifty years. The Disability Discrimination Act and the sequential National Disability Strategies, with their State and Territory counterparts, have demonstrated the nation's commitment to offering equal opportunities to people with disabilities. The National Disability Insurance Scheme provides one of the first mechanisms for collecting national data about people with disabilities and for learning about our needs, our goals and our progress towards achieving them. No matter what efforts are made by individuals or what policies and programs are implemented by governments, Australia will not become an inclusive society until all aspects of the community consider and value equally the needs of all Australians, including those with disability.

Statistics cannot capture exclusion. They do consistently reflect the lower proportion of people with disability who participate in various aspects of society, including employment, higher education and home ownership. While many individuals who are blind or vision impaired first experience exclusion as a personal issue, their repeated exposure to it and their discovery, through meeting or discussing with their peers, that these experiences have been shared by so many others, eventually lead them to realise that the barriers we confront are systemic. Versions of these exclusions have been experienced by all members of the BCA Board, its volunteers and the majority of the staff, who are blind or vision impaired. These concerns are demonstrated in the numerous case studies of people BCA has supported with individual advocacy.

This Disability Royal Commission is a unique opportunity to tell Australia what life is like for people with disability and to explain how this makes us vulnerable to violence, abuse, neglect and exploitation. We need to be included fully in society by having full access to public transport, education, employment, healthcare, citizenship and all activities of daily life. Blind Citizens Australia is pleased to respond to the Promoting Inclusion Issues Paper.

Blind Citizens Australia (BCA) is the national representative organisation of Australians who are blind or vision impaired. Our mission is to inform, connect and empower Australians who are blind or vision impaired and the broader community. We provide peer support and individual advocacy to people who are blind or vision impaired across Australia. Through our campaign work, we address systemic barriers limiting the full and equal participation of people who are blind or vision impaired. Through our policy work, we provide advice to government and the community on issues of importance to people who are blind or vision impaired. As a consumer-based organisation, our work is directly informed by lived experience of blindness and vision impairment. Our members, our directors and a majority of our staff are blind or vision impaired.

This submission will focus on two of the key questions from the Issues Paper on Promoting Inclusion.

* Question 3: Do you think Australia is an inclusive society? If not, why not?
* Question 4. How can an inclusive society support the independence and choice and control of people with disability?

## Hospitals in Australia

BCA will be lodging other submissions in relation to some of the barriers which exclude people who are blind or vision impaired. In this submission, we will concentrate on the exclusion experienced by people who are blind or vision impaired when they attend hospital or access healthcare. They may do this as an in-patient, outpatient, parent, carer, or visitor. Barriers can be experienced wherever a person who is blind or vision impaired interacts with the healthcare system, but our members tell us that their feelings of exclusion are most profound when these experiences take place in hospital.

The experiences detailed in this submission reflect formal and informal discussions and conversations held with members of BCA over many years. In 2019, BCA sought member input to design a new Healthcare Policy. Such policies form the basis of BCA's individual and systemic advocacy. Members were asked for their experiences, good and bad, of healthcare providers and a workshop was held at our National Convention to explore the topic of best practice for hospital treatment of people who are blind or vision impaired.

There are many points in a patient's journey where the hospital system may lead them to feel vulnerable, excluded, or neglected. Experiences can be more positive where there is an ongoing relationship with a medical provider or where an admission is planned. Often, however, a hospital admission happens in an emergency. Some hospitals maintain best practice for patients with disability. For the person going to hospital, however, there is often anxiety about whether plans that have been carefully made will be implemented, and whether or not hospital procedures and staff will respect them as a person and take their disability-related needs into account when providing healthcare. At a time which is often stressful, even if in a good way such as at the birth of a child, people who are blind or vision impaired have the additional worry of how they will be treated.

People who are blind or vision impaired can be excluded by hospitals in several areas, which will be covered in detail below.

### Information, communication and accessibility

Lots of information is given and received before and after a hospital stay. This information is often presented on paper. Although some pre-admission and admission procedures can sometimes be completed electronically, websites are not always accessible for use with screenreaders and magnification software, input sessions often have limited time windows and documents are often required to be uploaded.

Information about conditions, tests, and procedures are often handed to patients in pamphlet form. Links to websites may be supplied, but usually with little knowledge about their accessibility.

### Physical accessibility of hospitals

Hospitals have often been constructed in many stages, reflecting changing standards in building design and community expectations. Often people with sight require assistance with directions. There are seldom clues to assist people who are blind or vision impaired with wayfinding. Often a trip to hospital has not been planned and there has been no time for training in how to navigate the building, ward or room. Hospitals are usually busy places. Staff have little time to assist people who are blind or vision impaired to their destination. Even if a person feels confident to make their own way, things move often in hospitals, with corridors frequently obstructed and waiting-rooms difficult to navigate. These issues have all been exacerbated during the current pandemic, where physical contact is problematic and where accompanying people have been discouraged or banned.

Once a patient who is blind or vision impaired reaches a ward, they may be left in a room about which they know nothing. At best, they are shown where the call button is and how to operate it. There may be other people in the room, about whom they will know nothing. They may be sedated or unwell and may find it difficult to draw on their customary skills of mobility. They may also be without their usual mobility aids, such as their dog guide or white cane. Searching for a chair or bathroom with a drip attached or with restricted movement after surgery can be humiliating, but nursing staff do not always have the time or willingness to assist. Where a person does become confident getting around their room, furniture and medical equipment may be shifted without thought and changes in their medical condition or hospital logistics may result in them being moved to a new ward or room at short notice.

### Food and medicine

Hospital staff are trained to disturb patients as little as possible. In some cases, ancillary staff are instructed to drop off menu sheets and meals without interacting with the patients. Most people who are blind or vision impaired can tell a story about a time they were in hospital when their food came and went without them knowing, when they knocked their meal-tray on the floor because they did not know where it was, or they dropped their medication because they had not been told it was there. They will be given the basic meal because no-one assisted them to read them with reading the menu and helping them fill in their selections. Food often arrives in a bewildering series of unidentifiable packages, on a tray so artfully packed that there is little room for manoeuvre. Such incidents result in the person's need for nutrition and medication being neglected. Furthermore, they leave the person feeling vulnerable and humiliated.

### Respect and privacy

Any person who is blind or vision impaired staying in hospital will have to decide whether or how they want to disclose their disability. Some like to have a sign near their bed, explaining their situation, so that all staff will follow appropriate procedures, such as identifying themselves and explaining their actions. Others feel that this is an invasion of their privacy, may make them vulnerable and will expose them to negative assumptions. Patients wearing wristbands identifying them as blind have been deemed to be falls risks, simply because of their disability.

Before and during their stay in hospital, a person who is blind or vision impaired will frequently be required to discuss private information, such as symptoms, diagnosis and medical history. Whether this is to fill in a form or for the purposes of consultation, they will not always know who else is in the room or what they can hear. It is difficult for the user to give sensitive healthcare information privately and independently. People who have hearing impairments or who are from culturally and linguistically diverse backgrounds will have extra challenges when seeking and giving healthcare information.

It will frequently be assumed that friends, family or even support workers have full knowledge of the medical condition and personal affairs of a person who is blind or vision impaired. They will be asked questions about the patient's symptoms and background and will often be asked to fill in forms on their behalf. Test results and explanatory pamphlets will be given to family members, who it is assumed will explain them to the patient. It might be taken for granted that the other people are the ones to make decisions about medical care. In this way, the person who is blind or vision impaired is infantilized excluded from their own medical treatment.

Further, a person who is blind or vision impaired will interact with many people in a hospital. Often, they will not know who they are, what their role is or what it is they are doing or going to do. They may not know the extent to which they are being observed by medical students or other patients or their visitors. It is incumbent on hospitals to have procedures whereby people who are blind or vision impaired about whom is interacting with them, and what their role is in relation to their medical care.

### Consent and confidentiality

A signature is usually required for consent. Although some practitioners are meticulous about ensuring informed consent, many are busy and do not have time to read aloud the many details on the consent form. Patients who are blind or vision impaired may need to have explained to them the implications of not consenting or alternative treatment options.

It is also important in the provision of information about consent, including information about tests, procedures or medication is provided to people who are blind or vision impaired in a sensitive manner to alleviate any eavesdropping on sensitive information. This includes assisting people who are blind or vision impaired to fill out forms. People who are blind or vision impaired may not be aware of whom is around them when they are sharing information, verbally, or digitally through enlarged text.

### Post-Hospital care

Patients are often discharged with a printed sheet of instructions for follow-up care and a review appointment. Patients who are blind or vision impaired may need information about their medication in their preferred format, as verbal instructions can become confusing. They may be told to visit their GP or return to the hospital in certain circumstances, without recognition that, as they are unwell, they will not have access to their usual methods of transport.

Filling a script can be difficult for a patient recovering from surgery. Some pharmacies offer free delivery. Some medications, generally those produced in Europe, have braille labels on the outer package. Generic medications contain no tactile labels or markings. Information about dosage, side effects and contraindications is usually in extremely small print.

### Feedback

It is likely for it to be difficult for a person who is blind or vision impaired to give feedback anonymously. Although there may be printed information about complaint procedures prominently displayed, these will not be obvious to someone who cannot see or read them; nor can they discreetly ask staff about such procedures. A patient who is blind or vision impaired who is dissatisfied with how they are being treated is unlikely to complain, for fear of reprisal. A person who has a negative experience is most likely to wait until they are home to complain and may be challenged as to why they did not seek a remedy sooner.

### Negative assumptions and stereotypes

People who are blind or vision impaired having a connection with a hospital will inevitably be asked questions about their sight. Some conditions causing vision loss are relatively rare and medical professionals often like to satisfy their curiosity about how and when they arose, how they were diagnosed and what treatment has been received. Many patients who are blind or vision impaired feel pressured to allow themselves to be exploited as an educational opportunity.

As with the general community, patients may also be asked how they accomplish certain tasks and details about their personal circumstances which other patients would not be asked. In many cases, none of this information will be relevant to their current treatment. Acknowledging the power imbalance that exists between health professionals and patients, few would assert their right not to answer. Further, most people who are blind or vision impaired have been schooled in the importance of being polite and compliant. Not answering may lead to the patient being regarded as unco-operative. Answering will lead to a loss of privacy and potential judgment. Such questions are asked without any recognition that the questioner would not welcome such intrusion into their own life or of the potential trauma responses they may trigger.

Even without information about a patient's vision loss, a person who is blind or vision impaired in hospital will often feel judged by hospital staff. In unfamiliar surroundings, without adequate preparation and feeling unwell, people still feel they need to achieve a certain standard as patients who are blind or vision impaired. They may be seen as needy if they constantly ask for assistance with trivial things, such as operating the television. They may struggle to maintain self-esteem when they cannot accomplish tasks, they can usually do unassisted, such as spreading toast with a plastic knife and rock-hard butter or showering while attached to a plethora of tubes. Women delivering babies report anxiety about demonstrating their ability to take care of their infants. This diminution in self-esteem can persist long after the person has left hospital.

### Public screening and prevention programs

Most public information, healthcare promotion and preventative education is delivered through posters and pamphlets displayed at hospitals. Patients who are blind or vision impaired not only do not have access to their contents, they are unaware of their existence.

Several publicly funded screening programs aim to increase rates of early detection of diseases, thereby increasing the chances of effective treatment and survival.

All Australians receive a free bowel-testing kit every two years after they turn 50. These kits arrive in the post, after receipt of a print letter advising they are on the way. The kits contain an information booklet, test-tubes, labels and even a pen. No aspect of the information contained in the kit is accessible to a person who is blind or vision impaired. There is no way for a person who is blind or vision impaired to collect the necessary samples and complete the test safely and independently. The majority never use their kit and are denied the opportunity of early detection. They may be at a higher risk of later treatment of bowel cancer than those who are able to participate in the program.

Women over 50 are entitled to a free mammogram every two years, to detect early signs of breast cancer. Reminder letters are sent out in print. The online booking system is inaccessible, and the telephone booking system insists on citing of a reference number. Personal information is required at appointments, which cannot be supplied electronically. Test results are again mailed in print. Women who are blind or vision impaired are denied the opportunity to participate in this important preventative program with privacy and dignity.

Finally, cervical cancer screening is a service regularly offered by GPs and women's health services. This service however is confronting to receive if you cannot have information about the procedure provided in accessible, preferred format, and clear descriptions of what the procedure will entail in lieu of being able to visually see what is happening when a test takes place.

It is important that staff provided screening services have awareness training in the accessibility needs for people who are blind or vision impaired receiving any screening service. Further, it is critical that all national screening programs provide accessible, preferred format material about services.

## Recommendations: An inclusive society

BCA has developed a Healthcare Policy. The Healthcare Policy supports the independence, choice and control of people who are blind or vision impaired interacting with healthcare service providers. It is founded on the Australian Charter of Health Care Rights (2nd edition 2019), produced by the Australian Commission on Safety and Quality in Health Care. The Charter describes the rights that consumers, or someone they care for, can expect when receiving health care.

These rights apply to all people in all places where health care is provided in Australia. This includes public and private hospitals, day procedure services, general practice, and other community health services. BCA's Healthcare Policy explains how healthcare policies, practices and procedures can be modified so as to include people who are blind or vision impaired in the exercise of these rights.

Australians who are blind or vision impaired would be more able to exercise independence and choice and control when interacting with hospitals if the following recommendations were adopted and implemented:

1. People who are blind or vision impaired can only exercise independence and have choice and control if they have respect. This requires full recognition of their human rights and an acknowledgement that their disability is only a part of who they are. Hospital staff must take into account that people who are blind or vision impaired may also be women, First Nations people, people from culturally and linguistically diverse communities, people who identify as LGBTIQA+, people of low socio-economic status, live in regional or remote areas, or be older people. One individual may have several of these characteristics. Services must be affordable, culturally safe, and accessible to all people.
2. People who are blind or vision impaired need to have accessible, confidential options, in order to provide information to healthcare providers. People who are blind or vision impaired should not be required to disclose private information in public venues, or without other mechanisms to ensure privacy. Any arrangements to protect privacy must take into account digital eavesdropping (e.g., preventing others seeing enlarged text displays on devices etc.) and aural eavesdropping (e.g., other bystanders overhearing information, especially where the person who is blind or vision impaired may not be aware of their presence).
3. Hospital staff should ensure that information provided by people who are blind or vision impaired is handled in adherence with privacy and confidentiality legislation and service policies. Explanations of how it will be stored and kept private must be made available to people who are blind or vision impaired in their preferred alternative format.
4. Hospital staff should be aware of confidentiality and respect for privacy, when dealing with family, friends or other support people who may accompany people who are blind or vision impaired, including interpreters. Respect for privacy means that explicit consent is given by the person who is blind or vision impaired before any disclosure of personal information, including sensitive medical information, such as diagnoses, prognoses, and conditions, to anyone else.
5. Hospital staff must take steps and have procedures in place, to ensure that people who are blind or vision impaired can exercise choice and control by giving genuinely informed consent. This would necessitate providing consent documents in the person's preferred format. If a person who is blind or vision impaired declines a treatment or procedure, healthcare service providers need to make clear to the person any risks and benefits of accepting or declining that treatment or procedure. If the individual persists in declining it, their opinion must be accepted, as it would be for an individual who is not blind or vision impaired. A person experiencing vision loss, in particular, has the right to choose which, if any, treatment or services they receive.
6. Genuinely informed consent must be sought before the person who is blind or vision impaired is observed by medical students, or other people peripheral to their care, in a way which genuinely permits refusal.
7. Hospitals should commit to ensuring that their premises, services and information are accessible by developing and implementing a disability action plan, in consultation with people with disabilities or their representative organisations. People who are blind or vision impaired must be able to access the plan in their preferred format.
8. Hospitals should be equipped to source or produce the alternative format that blind or vision impaired people prefer. Accessible format documents may include braille, large print, electronic and audio formats.
9. Hospitals should ensure that all information pertinent to the treatment of a person who is blind or vision impaired is available to that person in their preferred alternative format. This includes advice but about preparing to come to hospital, information about their illness or condition and its symptoms, progress or management, information about treatment options, including medications and discharge summaries and instructions.
10. Where information is conveyed via video content, visual displays, ticketing systems and touch screens and displays, these require accessible solutions for users who are blind or vision impaired.
11. Websites must comply with current Web Content Accessibility Guidelines (WCAG 2.1).
12. Hospitals should meet the physical access requirements of people who are blind or vision impaired by including appropriate lighting, tactile and contrasting signage, human assistance available if required, touchscreens with audio output etc. All lifts should have braille labels and spoken announcements. Physical access also means complying with legislation which allows the presence of a dog guide, except within areas where the dog’s presence is specifically prohibited by law, such as operating theatres, burns and intensive care units. An environment in which healthcare meets the accessibility needs of people who are blind or vision impaired includes features or support to assist independent navigation. The environment needs to be free from trip hazards and other obstacles. Providing physical accessibility includes planning and providing for people with disabilities in evacuations or emergencies. Risk assessments can be undertaken by the healthcare facility to ensure that foreseen risks to safety are eradicated as soon as they are identified.
13. Hospitals should provide disability awareness training for all staff directly providing service to people with disabilities. Such training should be conducted by people with disabilities or by organisations directly representing them. Staff training should re-enforce that there are laws which prevent any member of staff or healthcare service from discriminating against people, in particular because of their disability. Staff should be trained in providing navigation assistance for people who are blind or vision impaired, if the person has requested or consented to receiving it. Staff offering physical or guiding assistance should orient the person to the space, who is in the space and also keep discreet any private information like the reason the person they are assisting is visiting the hospital.
14. Health practitioners can display partnership by taking into account the power imbalance in the practitioner-client relationship and by not exploiting their power with any client. Practitioners should adhere to the codes of ethics and ethical guidelines of their respective governing bodies.
15. Hospital staff include a person who is blind or vision impaired in their healthcare by honouring their right to direct verbal communication regarding treatment, procedures, information and choices. Direct communication necessitates staff verbally identifying themselves and their role at the beginning of any interaction, addressing the person directly, communicating whilst tests and treatments occur, explaining and warning about their physical actions and checking that the person who is blind or vision impaired understands what is or will be happening. Staff must convey visual information in accessible formats and/or verbally, depending on the situation and the preferences of the individual, rather than relying on intermediaries to convey information.
16. Complaints processes and information about them need to be accessible to people who are blind or vision impaired in their preferred alternative format and their complaints and feedback should receive consideration and resolution.
17. A person experiencing progressive vision loss should be given accessible information about their condition, including potential outcomes and possible treatments. They should be referred to appropriate services, in accordance with Vision 2020's referral Pathways tool.
18. People who are blind or vision impaired, especially women and girls, should be given accessible and tailored information about their reproductive health, rights and choices.
19. People living with blindness or vision loss should not be asked questions about their condition by healthcare providers unless the information is relevant to the service being provided.
20. Publicly funded screening programs should be fully accessible to people who are blind or vision impaired, including the ability for information about the participant, the test and the results to be available in the person's preferred alternative format. Assistance should be provided so that people who are blind or vision impaired can complete the necessary procedures discreetly and without reliance on friends or family. Such assistance should be free and well publicised.
21. Anti-discrimination cases need to result in significant consequences for healthcare providers which clearly breach the Disability Discrimination Act 1992 (DDA). It is critical that appropriate penalties are issued, to dissuade healthcare providers from breaching the DDA.
22. BCA supports the strengthening of the DDA to ensure that people with disabilities are protected by a legislative requirement to remove systemic discrimination, in addition to specific cases that are brought before disability anti-discrimination commissions. Systemic discrimination should lead to significant penalties.
23. Cases proceeding to post-conciliation levels at state Equal Opportunity commissions, or the Australian Human Rights Commission should be low or no-cost. The cost of pursuing an action at Federal Court level, if conciliation fails, is prohibitive to most people who are blind or vision impaired. There is also the risk of bearing the defendant's costs if the case fails. These costs and risks often outweigh any potential benefit to be gained from pursuing Federal Court action.
24. Federal, state and territory governments should fund, support, recognize and consult member-based organisations that represent and advocate for people with disabilities, including groups which represent people with specific disabilities.