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**Vision Australia Submission: ACT Draft Disability health Strategy 2023-2033**

Submission to: ACT Health – Disability and Community Policy

Date: 25 July 2023

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# Introduction

Vision Australia is providing this short submission about the ACT Draft Disability Health Strategy because maintaining optimal health and wellbeing and being able to access health services on an equal basis with the rest of the community, are essential if people who are blind or have low vision are to participate fully and independently in society. Article 25 of the UN Convention on the Rights of Persons with Disabilities, which Australia has signed and ratified, asserts that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.”

We find much that is commendable and encouraging in the ACT Draft Disability Health Strategy (“the Strategy”) and it is certainly framed to harmonise with the principles and rights asserted in the Convention. Nevertheless, recent experience has shown that without specific and robust measures, combined with a thoroughgoing approach to all aspects of health planning, many people with a disability, and especially people who are blind or have low vision, may fall through the cracks with their health needs unmet. We therefore offer the following information and suggestions to help ensure that the Strategy will maximise health outcomes for the blind and low vision community.

# Nature of the Blind and Low Vision Community

People who are blind or have low vision constitute a diverse and dispersed community. Surveys that Vision Australia’s Government Relations and Advocacy team has conducted over the past four years have shown consistently, for example, that 30-40% of respondents have concurrent disabilities in addition to blindness or low vision. Hearing impairment is the most common, but disabilities such as balance impairment, hemiplegia as the result of stroke, and diabetic peripheral neuropathy are not infrequently reported. Even among people who are blind or have low vision and who do not have additional disabilities there is wide variation in the nature, extent, and duration of blindness or vision impairment, and the functional impact that blindness or low vision has in the context of everyday life and activities.

This diversity has significant implications for the design and delivery of government and community services, including health services. For example, a person who has been blind for many years and whose primary literacy medium is braille will want to have key information available to them in braille. On the other hand, a person who has developed a vision loss as the result of age-related macular disease is unlikely to have learnt braille and so will want information in other formats, such as audio or electronic text. A person who is blind and also has a significant hearing impairment may not be able to use audio as an effective modality for accessing important information, and it will therefore need to be provided in other formats.

As well as being a diverse community, the blind and low vision community is also extremely dispersed geographically, and the majority of people do not attend disability-specific centres or access disability-specific services on a regular basis. The failure to appreciate the dispersed nature of the blind and low vision community was a mistake we observed repeatedly through the COVID-19 pandemic. Health authorities incorrectly assumed that because they were providing COVID testing services or vaccines to disability group homes they were thereby meeting the needs of the entire disability community. They also wrongly assumed that all people with a disability would be known to the staff in their local health districts and could therefore be easily identified. These unwarranted assumptions ignored the heterogeneous and decentralised nature of the blind and low vision community. The result was that all too often people who are blind or have low vision were left to fend for themselves during critical phases of the pandemic.

Vision Australia and other organisations have developed great expertise and experience in understanding and meeting the diverse needs of the blind and low vision community, and although we do not provide services to all people who are blind or have low vision, we do have extensive networks within the community. We believe it is essential for initiatives such as the ACT Disability Health Strategy to incorporate, as a key component, the development and leveraging of disability-specific expertise, experience and networks. This should be planned as a “business as usual” undertaking. A key learning from the COVID-19 pandemic is that strong links between government, the community and the disability sector are essential for effective and inclusive emergency preparedness and management, but they must be developed prior to the emergency – they are extremely unlikely to emerge fully-formed of their own accord once an emergency is underway and there are escalating demands on time, energy and resources.

Again, drawing on experiences during the COVID-19 pandemic, we can provide an instructive example. Over the past decade or so, Vision Australia has worked collaboratively with a number of the major banks on the design and delivery of inclusive and accessible products and services. An important by-product of that collaboration has been the establishment of mutual trust and effective communication channels. Early in the COVID pandemic one of the major banks contacted us for assistance in developing guidelines and procedures that bank branch staff could implement to ensure that blind or vision-impaired customers would be assisted appropriately and safely while attending a bank branch. Once developed, these guidelines and procedures were shared with the Australian Banking Association and became recognised best practice for the banking industry during the pandemic and especially while physical distancing measures were in place. The result was that bank staff had confidence in their capacity to assist customers who were blind or had low vision, and, in turn, those customers experienced lower levels of stress and anxiety when attending a bank branch because they knew that procedures were in place to keep them safe while allowing them to complete their transactions with dignity and independence.

The collaborative networks that had already been established between Vision Australia and the banking sector were integral to the success of this initiative, and it is very doubtful that they would or could have developed from scratch during the pandemic. Successful co-design depends on establishing patterns of trust and cooperation, and the effective co-design and delivery of emergency services for people with a disability depend at least as much on patterns that are already established as on patterns that develop during the emergency itself.

# Focus Areas

In our view, the five Focus Areas outlined in the Strategy are well-chosen and comprehensive. We offer the following comments to particularise them for people who are blind or have low vision.

## Focus Area 1 – Health Information and Literacy

The achievement of health literacy by people who are blind or have low vision is absolutely founded on having full and independent access to health-related information. A mistake that is frequently made by service or program planners is to assume that all people who are blind or have low vision access information in the same way using the same format. Recalling the diversity of the blind and low vision community described above, it is not surprising that this is not the case at all. Not only do people access information in different accessible formats, but they may also access different categories of information in different formats. For example, a person whose primary literacy medium is braille will usually prefer information to be provided in braille but may use electronic text (including electronic braille) for “just in time” information such as rapidly changing public health updates. A person who has low vision may use large print as well as electronic text in conjunction with screen magnification software.

Where information is provided in digital form, such as on a website or via social media, it must comply with accessibility standards if it is to be fully accessible to people who are blind or have low vision. The internationally recognised standard is the Web Content Accessibility guidelines that have been developed by the World Wide Web Consortium. It is essential that these Guidelines be followed at all stages in the design and distribution of information channels, apps and content.

A key finding from the two surveys that Vision Australia conducted during the COVID-19 pandemic is that much public health information was not accessible to many people who are blind or have low vision, either because it was not provided in accessible formats, or because the design of websites and apps did not comply with accessibility standards such as the Web Content Accessibility Guidelines. For example, updates about COVID hotspots were often distributed on social media in the form of screenshot images, which were completely inaccessible to people who are blind or have low vision and who use screen-reading or screen-magnification software. The online vaccine consent form was not accessible because it had not been designed in compliance with the Web Content Accessibility Guidelines, and when the COVIDSafe app was first launched it was also not accessible for the same reason.

An obvious consequence of inaccessible information is that people are not able to make informed choices or seek the most appropriate services. A less obvious but equally deleterious consequence is that people lose trust in authorities that are seen to be excluding them by failing to make information accessible. Numerous respondents to our surveys said that they did not download the COVIDSafe app even after its initial accessibility shortcomings had been rectified because, by this time, they no longer had confidence that the app would be accessible.

It is also important for service planners to bear in mind that people who are blind or have low vision often miss out on information that is provided through less formal channels such as signage, billboards, magazine articles, and brochures available in doctors’ waiting rooms. This information contributes to the development of health literacy, and it must also be provided in ways that are accessible to people who are blind or have low vision.

It is not difficult to provide information in a range of accessible formats and to design websites, apps and content distribution mechanisms so that they are fully accessible and inclusive. We think that the Strategy needs, however, to include more detail about the range of accessible formats that are typically required, the importance of complying with standards such as the Web Content Accessibility Guidelines, and the contribution that organisations with relevant expertise can make in the co-design of health literacy initiatives.

## Focus Area 2 – Service Access, Design, and Delivery

The most significant implication of blindness and low vision for the design and delivery of health services is that people who are blind or have low vision do not have access to visual information that is provided “at a distance”, such as signage, posters, visual displays, and navigational queues. For example, if a person who is blind goes into a building where a health service is situated, they will not immediately be able to identify key locations such as the reception desk, lift banks, corridors, or directional signage. They will not be able to read the building directory unless it is in an accessible format, and they will not be able to locate a particular office or suite based on the number displayed visually above the door. When they do locate their desired service (with the assistance of staff) they will not be able to complete paperwork without human assistance.

The point of this example is not to imply that people who are blind or have low vision cannot access health services equally and independently but, rather, to emphasise the need for careful design and delivery of services in ways that take account of the diversity of needs. It is especially important that service designers do not lapse into complacency and assume that access will somehow just take care of itself.

Service design must begin with the facilities in which the services are located. For example, if the lift destination and control system in a building is not accessible to people who are blind or have low vision, then any accessibility and inclusion features of the services themselves will be effectively diminished. Buildings must comply with the Access to Premises (Buildings) Standards that have been developed under the Disability Discrimination Act, to provide non-discriminatory access for people with a disability, and service designers must ensure that ICT that forms part of the delivery complies with standards for accessible ICT procurement (Australian Standards AS/EN301:549). Without compliance with relevant standards, health services will not be accessible to people who are blind or have low vision on an equal basis with the rest of the community. We believe that the Strategy must pay more attention to such compliance as a necessary condition for services to be accessible and inclusive to all people with a disability and particularly to people who are blind or have low vision.

Over the past few years a number of projects have been undertaken to design and deliver specific health services that are more accessible and inclusive. Two that we are aware of are in NSW: one is a Health Care Passport that will result in a passport-like document that outlines a person’s specific health needs and which could be carried by a person with a disability and presented to staff at a hospital or other health service. The second project focused on the development of a document that outlined the “top 5 priorities” for assistance when a person who is blind or has low vision attends hospital (for example, “I will need assistance filling out the lunch and dinner menus”, or “Please ensure that staff address me by name so I know who they are talking to”). Both these projects are examples of innovative service design, and together with similar projects they highlight the importance of cross-jurisdictional collaboration and awareness. To achieve maximum effectiveness, the Strategy must incorporate mechanisms for monitoring projects that are being developed in other states and territories, and assessing how they can be leveraged in the ACT context.

## Focus Area 3 – Emergency Planning, Preparedness, and Management

From the results of the surveys that we conducted during the COVID-19 pandemic, it is clear not only that significant mistakes were made by failing to plan emergency services for people who are blind or have low vision, but also that most of them were eminently foreseeable and easily preventable. We have already mentioned the failure to make the online vaccine consent form accessible to people who are blind or have low vision. Other mistakes include the failure to identify taxi pickup and dropoff points on the maps of vaccine hub facilities, the failure to allocate specific staff who could be contacted for special assistance when attending a vaccine hub, and the failure to provide sufficient training to security staff about the right of people to be accompanied by a Seeing Eye Dog into the vaccine hub. These and other mistakes caused significant stress and anxiety, and they could all have been prevented through prior consultation with organisations such as Vision Australia who have expertise in identifying and addressing the needs of the blind and low vision community.

Another gap that quickly became apparent in recent emergencies, including the 2019-20 bushfires and the 2022 floods, is the lack of information available to emergency service planners about the location and needs of people with a disability. Our understanding is that some local government areas have established voluntary registers that allow people with a disability to identify themselves and their needs. These registers can then be used during emergencies to locate and assist those people who have included their data. These initiatives are isolated and embryonic, but we believe that their development will be essential for adequate, inclusive and needs-responsive emergency planning and management in the future. We would like to see a greater focus on this in the Strategy, combined with a robust approach to data protection and privacy.

We strongly believe that it is critical for emergency planning and preparedness to include ongoing and structured consultation with the disability sector, including organisations such as Vision Australia that have expertise in blindness and low vision. As we have noted previously, the development of such consultative practices must happen during “business as usual” times – when an emergency arises it is often too late to lay the foundations for effective consultation. “Consult early and consult often” must be the principle upon which emergency planning and preparedness for the disability sector is based.

## Focus Area 4 – Workforce

While we are aware of very few people who are blind or have low vision employed in the delivery of primary healthcare, there are many more employment opportunities in areas such as health administration, design and policy development. In practice, however, these opportunities are limited by the lack of accessible ICT procurement policies. For example, we know of people who are blind who have qualified for employment in senior health policy roles only to find that they could not use the organisation’s computer system because it did not comply with accessibility standards. The only solution to this systemic problem is for government departments and agencies, as well as employers in the private sector, to implement accessible ICT procurement policies that require all ICT products and services to comply with the relevant Australian standard (AS/EN301:549). We believe that the Strategy must, as a minimum, include mechanisms that will result in 100% ICT accessibility for all ACT government bodies during the life of the Strategy.

Probably the most frequent feedback we receive from clients about their experiences with the healthcare system is that staff are often poorly trained to provide needs-appropriate assistance. People report that staff in medical centres will not assist them to complete patient information forms or assist them to find their way to and from the facility to a taxi pickup point. Some hospital patients report that both medical and nursing staff have little awareness of their needs as a person who is blind or has low vision, especially if they also have additional disabilities such as hearing impairment or balance disorders. This lack of awareness results in patients feeling more stressed and anxious, especially when visiting a new facility for the first time, and in some cases, patients may choose not to visit a health facility at all.

Adequate disability-specific awareness training must be a key component of education and induction programs for all healthcare workers. In our view, the Strategy provides a timely opportunity for developing and implementing such training through the ACT.

## Focus Area 5 – Data and Research

We are not aware of any attempt to collect data about the healthcare experiences of people who are blind or have low vision, the general health and wellbeing of the blind and low vision community. Nevertheless, obtaining such data is important for the design and delivery of appropriate healthcare services, policies and procedures. We believe that the Strategy should include opportunities for working with disability organisations on the co-design of data collection projects, bearing in mind that each disability has unique requirements that must be addressed individually (for example, through the collection of disaggregated data).

# Conclusion

Throughout this short submission we have stressed the need for the Strategy to take account of the unique needs of the blind and low vision community, and to engage in detailed consultation with organisations with relevant experience and expertise as the primary means of ensuring that its aims and objectives are achieved. We commend the work to date and look forward to further opportunities to participate in activities and initiatives that will result in more positive and inclusive health outcomes for ACT residents who are blind or have low vision.

# About Vision Australia

Vision Australia is the largest national provider of services to people who are blind, deafblind, or have low vision in Australia. We are formed through the merger of several of Australia’s most respected and experienced blindness and low vision agencies, celebrating our 150th year of operation in 2017.

Our vision is that people who are blind, deafblind, or have low vision will increasingly be able to choose to participate fully in every facet of community life. To help realise this goal, we provide high-quality services to the community of people who are blind, have low vision, are deafblind or have a print disability, and their families.

Vision Australia service delivery areas include: registered provider of specialist supports for the NDIS and My Aged Care Aids and Equipment, Assistive/Adaptive Technology training and support, Seeing Eye Dogs, National Library Services, Early childhood and education services, and Feelix Library for 0-7 year olds, employment services, production of alternate formats, Vision Australia Radio network, and national partnership with Radio for the Print Handicapped, Spectacles Program for the NSW Government, Advocacy and Engagement. We also work collaboratively with Government, businesses and the community to eliminate the barriers our clients face in making life choices and fully exercising rights as Australian citizens.

Vision Australia has unrivalled knowledge and experience through constant interaction with clients and their families, of whom we provide services to more than 30,000 people each year, and also through the direct involvement of people who are blind or have low vision at all levels of our organisation. Vision Australia is well placed to advise governments, business and the community on challenges faced by people who are blind or have low vision fully participating in community life.

We have a vibrant Client Reference Group, with people who are blind or have low vision representing the voice and needs of clients of our organisation to the board and management.

Vision Australia is also a significant employer of people who are blind or have low vision, with 15% of total staff having vision impairment.