STANDING COMMITTEE ON EDUCATION AND COMMUNITY INCLUSION Mr Michael Pettersson MLA (Chair), Mr Jonathan Davis MLA (Deputy Chair), Ms Nicole Lawder MLA

Submission Cover Sheet

Inquiry into access to services and information in Auslan

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Submission to the inquiry of the Education and Community Inclusion Committee into access to services and information in Auslan

15 July 2022

About Women's Health Matters

The Women's Centre for Health Matters Inc. (Women's Health Matters) is an independent, non-partisan think tank that works to improve the health and wellbeing of women in the ACT and surrounding region. Women's Health Matters believes that the environment and life circumstances which each woman experiences affects her health outcomes. Women's Health Matters focuses on areas of possible disadvantage and uses research, community development and health promotion to provide information and skills that empower women to enhance their own health and wellbeing. Women's Health Matters undertakes research and advocacy to influence systems change with the aim to improve women's health and wellbeing outcomes. Women's Health Matters is funded by ACT Health. The findings and discussion presented in this document are those of Women's Health Matters, and not necessarily those of the ACT Health Directorate.

Introduction

In 2021, Women's Health Matters conducted survey and focus group research on the health needs and experiences of women with disabilities in the ACT, and in February 2022 we released the report on this research, "I have to ask to be included..." The views of ACT women with disabilities about their health and health needs, access to services, supports and information, and barriers to maintaining health. ¹

The report makes ten recommendations towards improving the health and wellbeing of women with disabilities in the ACT, including recommendations that relate to the delivery of health information.

We are making this brief submission to contribute the findings of our research as they relate to the inquiry's terms of reference on access to services and information, particularly in health care settings. We know that many Deaf people do not identify themselves as people with a disability, and note that our research was not specifically focused on the experiences and needs of Deaf people. However, we believe that, although general, our findings and recommendation may be useful for the Committee to consider.

¹ Women's Health Matters, "I have to ask to be included..." The views of ACT women with disabilities about their health and health needs, access to services, supports and information, and barriers to maintaining health, Canberra, 2022, https://www.womenshealthmatters.org.au/wp-content/uploads/2022/02/Womens-Health-Matters-Women-with-disability-health-and-wellbeing-report-February-2022.pdf

Access to health information

Our research found that for women with a disability, accessing health information specific to their health needs was often challenging. While most women reported that there was no health and wellbeing information that they were not able to obtain, over 35% of women reported that they were lacking information about the complexities and nuances of specific conditions. Local research shows that women with disabilities in the ACT often found it difficult to find information, as it was unavailable, not accessible, or not specific.²

This was also spoken about in the focus groups and interviews, which demonstrated this as a significant source of frustration. This is a concern, as a lack of accessibly health information can lead to a lack of access to essential healthcare.

The main source of health information for women in our study was their GP, which contrasted with the general population of women surveyed by Women's Health Matters, who predominantly seek general health information online.³

Barriers faced by the women seeking health information were affordability and wait times to consult a health professional.⁴ In our study women with disability also reported that they had difficulty trying to find health information, that health professionals did not have the right information, and that finding information that is specific to disability was difficult.

Women also talked about being frustrated and discontented with health professionals, and that they faced stigma wanting health information. Some women also discussed how anxiety going to health professionals, and mental health and burn out reduces their ability to access health information.

Unanimously, a need was expressed for information to be made more accessible via alternative formats. The absence of suitable and specific formats such as providing information in braille, large print or Auslan is a significant barrier to health information.⁵ It can also create additional barriers for accessing necessary but routine health care such as health screening.⁶

Women with a disability in focus groups and interviews reported the inability to find appropriate health information was a barrier to health. They identified the need for it to be made available in more formats: some women do not have capacity to use internet resources, and some found coordinating between different services and need to self-advocate challenging. Older women and women with cognitive disabilities in the focus groups found assumptions around access to the internet or taking internet literacy for granted to be problematic.

Several women with disabilities found that navigating health information systems when neurodiverse was particularly difficult, as did women with cognitive disabilities.

² J Gough, 'Contributing our voices! A summary of feedback from the Have Your Say! Forum with women with disabilities in the ACT', Women with Disabilities ACT, Canberra, 2015.

³ E Hoban, ACT women's health matters! ACT women's views about their health; their health needs; their access to services, supports and information; and the barriers to maintain their health, Women's Centre of Health Matters, Canberra, 2018

⁴ A Carnovale, *Strong women, great city: A snapshot of findings from a survey of ACT women with disabilities*, Women's Centre for Health Matters and Women with Disabilities ACT, Canberra, 2012.

⁵ Women with Disabilities Australia (WWDA), WWDA Position Statement 4: Sexual and Reproductive Rights, 2016, https://wwda.org.au/wp-content/uploads/2020/05/5ea654fbfc3264166cbe2ffe Position Statement 4 - Sexual and Reproductive Rights FINAL WEB.pdf

⁶ Department of Health, *National cervical screening program toolkit for engaging under screened and never screened women, National Cervical Screening Program*, Canberra, 2017, https://www.health.gov.au/sites/default/files/documents/2020/12/national-cervical-screening-program-toolkit-for-engaging-under-screened-and-never-screened-women.pdf

Recommendation:

We recommend that ACT Health work with other government agencies (such as the Office for Disability) and community organisations (such as WWDACT and WHM) to provide health information that is accessible and suitable to women with disabilities in their diversity, in a process that identifies the most urgently needed types of information and formats (e.g. Easy English, videos in Auslan, screen reader friendly websites).

Conclusion

In light of our research findings, and this recommendation, we welcome the inquiry's aim of reporting on options to strengthen and enforce measures to increase provision of services and information in Auslan. Auslan is as a key means by which health information (as well as other services and information) is provided to the community.

We support the Committee's intention to engage directly with Deaf people about their experiences and needs through this consultation. We encourage the ACT Government to build on this consultation by resourcing practical work with Deaf people and stakeholder organisations to implement positive actions arising from the inquiry.