

“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*

ACKNOWLEDGEMENTS

Thank you to those women who participated in the health and wellbeing information survey and who gave their time to contribute their insights, experiences, and opinions to this research. We hope that through documenting your views and experiences, local ACT responses can be improved so that women with disabilities health and wellbeing needs in the ACT are better understood and will be better met in the future.

We would like to acknowledge and thank Women with Disabilities ACT for their support in promoting the survey through their networks, for contributing to this report and for being strong advocates for the rights of women with disabilities.



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About Women's Health Matters

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 report are those of Women's Health Matters, and not necessarily those of the ACT Health Directorate.

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Executive Summary

Women with a disability comprise approximately 20% of the population of women in the ACT, with 41,200 women reporting that they have a disability. Just over half of people with disability in the ACT are women and girls.



Women who have disabilities are not always in poor health, though the two are often conflated, which increases stigma and discrimination for women. Some chronic diseases can lead to disability, and some disabilities can lead to chronic illness. Mostly, though, health for women with disabilities is influenced by their experiences of adversity and reduced access to resources. Women with disability have distinct experiences of health and wellbeing arising from the intersection between disability discrimination and gender discrimination.

This document reports on survey and focus group research conducted by Women's Health Matters in 2021 and makes recommendations towards improving the health and wellbeing of women with disabilities in the ACT.

Literature review

We conducted a review of recent research (both academic and other literature) and identified several key findings. Generally, a wealth of literature has established that women with disabilities are subjected to systemic marginalisation, leading to multiple forms of disadvantage in areas such as employment and income, access to support services, and violence. ^{ii iii}

Understandings of good health and self-rated health status

- In the ACT, women with disabilities understand what good health means to them in a similar way to non-disabled women, but are particularly likely to define health in terms of autonomy and being able to do the things they need to do.
- Women with disabilities in the ACT have poorer self-rated health status than the general population of women in the ACT, consistent with national data, and poorer self-rated mental health.
- For the general population of women in the ACT, the top health issues are mental health, weight, diet and fitness, and chronic disease.
- Across Australia, health issues that have been identified as particularly significant for women with disability are chronic disease (which can be unrelated to disability, or can lead to disability via ongoing impairment and/or debilitation due to pain and fatigue arising from chronic disease), mental health, and sexual and reproductive health.

Social connectedness and inclusion

- Poor social connectedness and inclusion is a known factor in poor health and wellbeing, and people with disabilities experience barriers to being socially included.
- Women with disabilities in the ACT have reported concerns about becoming socially isolated, especially in the context of the COVID-19 pandemic.

Health screening

- Health screening is often not accessible or inclusive for women with disabilities, and women with disabilities are often overlooked for screening, and face discrimination in relation to screening for conditions including breast cancer and cervical cancer.

Experiences accessing health services

- Women with disabilities face barriers to accessing health services and supports, including long wait times and lack of appointment availability, the need to travel to obtain services, and for many a lack of formal care services (as distinct from informal carers), and these barriers were increased due to the COVID-19 lockdown.
- Health care is often not appropriate for women with disabilities, including problems with physical equipment and the attitudes and behaviours of professionals (such as focusing on impairments rather than the health issues needing attention, and leaving people out of decision-making).
- Walk-in centres in which nursing staff give their time and reassurance, as well as the increased availability of telehealth and helplines during COVID-19 lockdown, are valued by women.
- To access health services and support, women with disabilities need affordable and suitable transport, which is often lacking, as well as accessible buildings and in many cases advocacy and assistance to be involved in decision-making.
- A large majority (65%) of ACT women with disabilities have reported that affordability is a barrier to health services, consistent with national findings and with evidence that women with disabilities have higher health costs, which were further increased by the impact of COVID-19.

Health information seeking

- Like women in the general population, women with disabilities look online for information on general health issues and approach a GP for more specific health information, but women with disabilities often lack access to information due to factors similar to those noted above, and particularly lack access to information about their sexual and reproductive health.

Other impacts on health and well-being

- Women with disabilities experience impacts on their health and well-being from interacting factors including lack of access to affordable and suitable housing, financial insecurity and poverty, inability to find and sustain suitable employment, caring and parenting responsibilities, and other relationships, and many of these factors have been made more difficult by COVID-19.

Methodology

The research design used both quantitative and qualitative methods to collect and interpret information on the views and experiences of women with disabilities about their health and wellbeing needs and their access to health services and supports. An initial online survey was conducted in February 2021 and collected 91 valid responses over four weeks from women who identified that they had a disability, were 16 years old or over and were living or working in the ACT or surrounding regions.

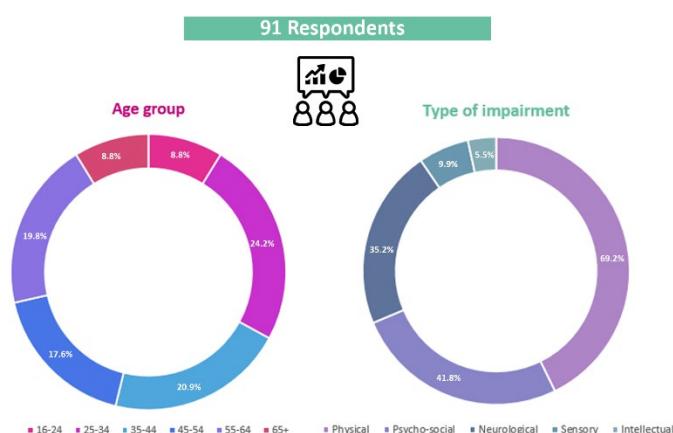
The online survey was also used to directly recruit 12 participants of various age, disability, ethnicity, and sexuality for the focus groups, which were held in March 2021 and aimed to explore in greater detail the survey findings identified in the analysis of the survey responses.

The quantitative and qualitative answers to the survey were coded and used to build themes for analysis of the focus group and interview data.

As with all surveys conducted to date by Women's Health Matters, we used a non-probability convenience sample. The findings presented in this report are therefore not statistically representative but provide an indication of the issues that exist for women with disabilities in the ACT.

Findings

Demographics



Of the 91 survey respondents, the largest proportion (24.2%) were aged 25-34, with slightly lower proportions aged 35-44 (20.9%), 45-54 (17.6%) and 55-64 (19.8), and fewer respondents aged 16-24 years (8.8%) and over 65 (8.8%).

Among respondents, the most common type of impairment was physical (69.2%), followed by psycho-social (41.8%), and neurological (35.2%). Fewer respondents had sensory (9.9%) or intellectual (5.5%) impairments.

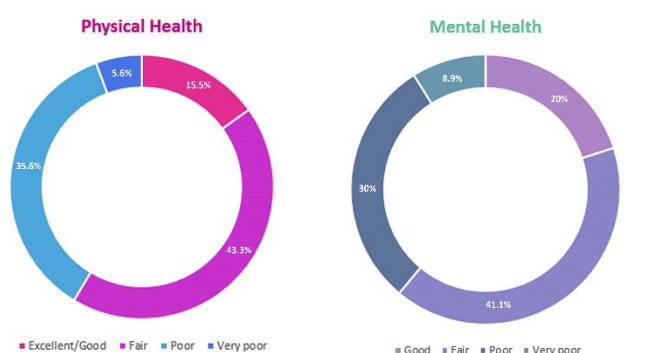
Over a third (39.6% or n=36) of respondents identified as a lesbian, gay, bi, queer, trans or intersex woman. Representation of Aboriginal and Torres Strait Islander women was much lower (n=4), as was representation of women who spoke a language other than English at home (n=3).

The largest proportion of respondents were single (44%), while 28.6% were married, and 13.2% were in de facto relationships. Smaller numbers of respondents did not say, nominated 'other' relationship status or were widowed. A significant proportion (42.9%) had caring responsibilities, of which caring for children was the most common (31.9%), with fewer reporting they provided care for siblings, partners, parents or others.

Self-rated health

Only 15.5% of respondents rated their physical health as excellent or good. The largest proportion of respondents rated their physical health as fair (43.3%), while 35.6% said their physical health was poor, and 5.6% rated it as very poor.

No respondents rated their mental health as excellent, while only 20% rated it as good. Again, the largest proportion rated their mental health as fair (41.1%), compared with 30% poor and 8.9% very poor.



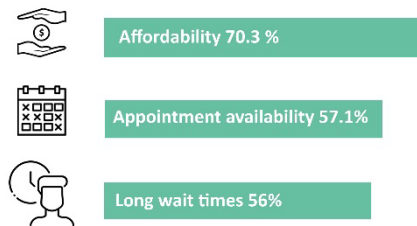
No respondents rated their mental health as excellent while only 20% rated it as good

Accessing health services

Not being able to find services in Canberra to help with achieving and maintaining good health was a common experience among respondents, with 50.5% of respondents stating that this was their circumstance, compared with 40.7% who were able to find such services.

The most widely accessed health service among respondents was GPs (89% had accessed) followed by prescription filling (82.4%). The least widely accessed types of services included those related to sexual health, health screening, reproductive health and pregnancy, and birth and baby support. A large majority of respondents reported that they have a regular GP (89%).

Barriers and difficulties accessing health services



Affordability was a particular barrier for 25-34 year olds, with over 90% of this age group reporting it as a barrier

Selecting from a list of possible barriers in accessing health services, respondents most commonly cited affordability (70.3%), appointment availability (57.1%) and long wait times (56%). Affordability was a particular barrier for 25-34 year-olds, with over 90% of this age group reporting it as a barrier.

In further comments, a significant proportion of respondents (n=23) reported there is a lack of services in the ACT to meet their needs (such as specialists for their conditions), and some noted poor experiences with the health services that they have been able to access.

In terms of sexual and reproductive health services, the proportion of respondents who reported that they *had not* accessed these services was larger (48.4%) than the proportion reporting that they *had* accessed them (38.5%). The main reasons given for not accessing sexual and reproductive health services were lack of need or relevance, older age, trauma and cost.

Where services were provided, several respondents reported that providers lacked understanding or did not believe them about their health experiences or needs. Cost, wait times and lack of capacity in peer-led services (which were often preferred) were also mentioned as problems.

Top health issues

The top health issues nominated by respondents were 'sleep, fatigue or energy issues' (64.8%), 'pain or chronic pain' (59.3%),

and 'mental health' (57.1%). Nearly 95% of respondents listed at least one of these as one of their top three health issues.

Nearly half of respondents (49.5%) reported that they had services or supports to help them address their top three health issues, while the remainder did not have these services or supports, faced barriers accessing them, or had a mixed experience.

As in the previous section addressing health services generally, respondents reported cost and affordability, poor experiences with health services, waiting times and lack of availability and accessibility as barriers to obtaining services and support with their top health issues.

Focus groups confirmed that affordability was a barrier for most women with disabilities, with subsidised services being inadequate to meet their needs. Other key barriers noted in focus groups included lack of accessible transport options, challenges arising from caring responsibilities, lack of accommodation of physical access needs, health services being targeted to acute care rather than help with chronic conditions and general support, lack of affordable preventative physical health therapies.

Many focus group participants had poor experiences with health professionals, including being disrespected and not listened to, not being believed about their pain and symptoms, having professionals focus on weight loss and exercise while dismissing their other needs, having the impact of their trauma disregarded, and having health professionals treat their disability as the main concern, to the detriment of their other health issues.

In terms of positive experiences, several participants said that remote services such as telehealth enabled them to receive healthcare that they would otherwise lack. New services (such as pharmacy deliveries) and flexible approaches developed for all people to help limit COVID-19 transmission also helped to reduce longstanding barriers experienced by

people with disabilities. The timely medical care and reassurance provided by nurses in walk-in centres were also highly valued by women in the focus groups.

Access to health information



GP or specialist



Online information

Over 1/3 of respondents were unable to obtain health information they needed

Survey respondents reported that their top choices for seeking information about general health issues and about specific health issues were their doctor (GP or specialist) and online sources. However, over a third of respondents were unable to obtain some of the health information they needed. This included information about specific conditions, with several respondents mentioning a need for more information about autism. Barriers to finding appropriate health information included affordability, wait times, and poor experiences with health professionals (similar to those noted above).

Focus groups confirmed that lack of access to appropriate health information was a barrier to health. Participants identified problems with the accessibility of information, including the lack of alternative formats such as large text or images, the complexity of navigating information without a central place to find information, and assumptions that everyone has internet literacy and access.

Women with disability who participated in the focus groups said that it was important to have support from people who understood their needs and helped them interpret health systems, such as an advocate. Yet many participants identified that good quality

individual advocacy was often not available, while the health system seemed to rely on individual consumers to know what they need.

In the context of COVID-19, some participants found they benefited from more compassionate and inclusive attitudes to health, information, and community. However, some women from multicultural backgrounds found the lack of accessible information about COVID-19 stressful, and others experienced additional isolation, particularly if connection through internet technologies did not appeal to them or was not workable.

Housing

Of respondents to the survey, the largest proportions lived in a house that they owned (37.4%), or in rental accommodation (30.8%), while smaller proportions lived in public housing (16.5%) or housing owned by their family, parents or partner (6.6%), or supported accommodation (3.3%), and 6.6% did not say where they lived.

In the focus groups, participants reported lacking agency in relation to housing and that their housing situation had negative impacts on their health and well-being.

Employment



Part-time work 27.5%



Full-time work 16.5%



Studying 9.9%

Many were not in the workforce or not seeking work (26.4%) or were unemployed (11%)

Part time work was the most common employment status among survey respondents (at 27.5%), while fewer people were in full-time work (16.5%). Substantial proportions were not in the workforce or not

seeking work (26.4%) or unemployed (11%), while 9.9% reported that they were studying.

A large majority (n=65) reported that their employment status was impacted by the barriers they face due to disability. While employment was important to respondents, several noted that pain, fatigue, the impacts of autism, and mental health problems made it difficult or impossible to maintain employment, work to their full capacity or do the type of work they wanted to do.

Many described employers failing to provide equipment or accommodations to enable their work, or actively discriminating against them. For those who had positive experiences of work, employers' flexibility and support was essential, such as adaptive technologies and working from home provisions.

Life roles

Having a disability impacted on participants' life roles in a number of profound ways. As noted above, while participants prioritised employment, their participation was often greatly restricted due to barriers associated with their disability. Similarly, many participants reported that it was not possible to maintain the kinds of social lives, relationships, education, and home activities that they would like.

While many participants had caring responsibilities (most commonly for children), they often had little support to fulfill these roles. This was due to inaccessible physical, social and economic systems interacting with their impairments or conditions, leading to them being unable to participate. For some, this meant being more dependent on others than they would want to be.

Social inclusion and engagement

Most of the respondents (63.7%) said that they did not feel included and engaged in community life.

The most common reason for not feeling included and engaged was fatigue, pain and mental health impacting on the ability to participate. Other reasons included physically

inaccessible public spaces and buildings, discrimination, and the affordability of social activities. In focus groups, participants identified transport and parking as a key barrier to social inclusion, as well as stigma and lack of understanding from others about disability, and the need for more involvement in policy and planning. Positive experiences were noted when community events built in accessible options for everyone, and when participants were part of peer support groups.

Discussion

Our research confirms that the intersection between disability and gender has specific negative impacts on the health and wellbeing of women with disability in the ACT, requiring dedicated disability- and gender-sensitive responses. It is encouraging that initial work to develop the ACT Disability Health Strategy recognises some of the specific health needs of women with disability in the ACT, as part of understanding that people with disabilities come from diverse backgrounds with implications for their health care and needs.^{iv}

Recommendation 1: ACT Government and relevant stakeholders ensure that women with disabilities are considered a distinct cohort in the ACT Disability Health Strategy, their voices listened to and their needs addressed.

The study provided further evidence that women with disabilities in the ACT have poorer self-rated physical health than the general population of women in the ACT, with only around 15% of women with disabilities rating their physical health as good or excellent in this study, compared with 58% of women in the general survey conducted by Women's Health Matters in 2018.

Similarly, the study found a significant difference between the self-rated mental health of women with disabilities in the ACT, with only 20% rating their mental health as good (and 0% excellent), compared with the self-rated mental health of women in the ACT generally, with 40% of the ACT women surveyed by Women's Health Matters in 2018

rating their mental health as good or excellent.

These disparities are consistent with the disparities found by prior ACT and national studies.

The top three health issues nominated by women with disabilities in the ACT in this study were 'sleep, fatigue or energy issues'; 'pain or chronic pain'; and 'mental health'. By contrast, other Women's Health Matters studies have consistently found that the top three health issues for women in general in the ACT are 'chronic disease', 'mental health', and 'weight diet and fitness'. The differences and similarities between these findings give more nuanced insights into the health experiences of women in the ACT, of whom women with disability are a significant proportion.

The vast majority of respondents faced barriers accessing services to address health issues, primarily the affordability of services. This barrier was exacerbated by the need to access multiple services for different conditions, which was also found in Women's Health Matters research about younger women and chronic conditions.^v Additional barriers consistent with other Women's Health Matters research included appointment availability and long wait times,^{vi vii} together with lack of specialists and services to meet participants' needs in the ACT, reduced rates of bulkbilling, low Medicare visits for allied health therapies, and lack of suitable transport options in Canberra.

Echoing other local research^{viii}, women with disabilities in this study spoke of the need for ongoing affordable health services for chronic care needs, and affordable preventative therapies and activities, in the context of a service system in which affordable services are mostly targeted to acute care. These patterns indicate significant unaddressed issues in the ACT.

Recommendation 2: ACT Government to include actions within the Disability Health Strategy to maximise an integrated and

coordinated approach to care, incorporating measures such as colocation of services to make health care more affordable and less burdensome for women with disabilities.

Importantly, only around 50% of the women who reported mental health as one of their top three health issues said that they were accessing a mental health service or professional to treat this issue. Local research also shows that mental health outcomes are influenced by the ability of women with disabilities to gain access to mental health services, particularly services specialising in disability.^{ix}

Recommendation 3: ACT Government to work with relevant stakeholders to fund and promote more disability informed mental health services.

Access to telehealth and other health technologies was also valued, and the greater availability of these during COVID-19 was noted, alongside the negative impact of the pandemic on isolation and stress associated with lack of accessible information about COVID-19.

Recommendation 4: ACT Government to continue to support the functionality of health technology, such as Telehealth, in public services and work with the Commonwealth as necessary in order to support remote access to health services, as in-person attendance at health services can be a barrier for women with disabilities.

Women mentioned the negative impact that health providers had if they were not believed or listened to. This is consistent with advocacy from disabled people's organisations that women with disabilities are often left out of decisions that impact their health^x, and with other research that has found women are often not believed or listened to, leading to misdiagnosis or a lack of diagnosis.^{xi}

In contrast, participants in the study mentioned walk-in-centres as a service that

they had good experience with because they found comfort in the treatment by the nursing staff and time they spent with them. This is consistent with studies finding that walk-in-centres nursing staff provide additional care and time when seeing clients, when other services often dismiss women's concerns.^{xii xiii}
xiv xv

Other research has shown that women's experiences of accessing sexual and reproductive health services are impacted by the perception that women with disabilities do not need to look after their sexual and reproductive health.^{xvi} Our findings in this study add further evidence to this prior research, and have confirmed that a lack of understanding by health professionals about participants' complex needs was a barrier to their sexual and reproductive health.

Recommendation 5: ACT Government to work with relevant stakeholders to improve the availability of appropriate sexual and reproductive health services for women with disabilities, and to promote these services widely with regard to the needs of women with disabilities in their diversity.

Health information was predominantly accessed through GPs or health providers and so there are barriers of cost or wait time to get timely relevant information, since GPs are expensive and it can be difficult to obtain a regular doctor. One third of women with disabilities reported that they lacked nuanced and comprehensive health information relevant to their specific health needs.

They also spoke about the need for health information to be in formats that were able to be easily accessed. This is a concern since the absence of suitable formats can create barriers for accessing routine, necessary health care such as screening.^{xvii}

Recommendation 6: ACT Health to 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).

Accessing health services, supports and health information was challenging due to the complexity of the ACT health system. More centralised information sources would benefit women navigating the health system. Women felt they lacked individual advocacy, which limited them from addressing their health needs, echoing the well-established link between individual advocacy and patient decision-making.^{xviii xix}

Recommendation 7: ACT Government to work with relevant community organisations and service providers to improve access to high-quality individual advocacy in the ACT, in order to support decision making and navigation through the complex and often fragmented health system.

In terms of broader life roles and participation, the findings of the study are consistent with other local research on women with disabilities and younger women with chronic disease. Our study found that stigma, discrimination, and practical barriers impacting on women with disability limit their social participation and relationships, while gendered expectations affected some respondents' experiences of marriage and raising children.

Consistent with existing literature, participants identified that due to social barriers disability had an impact on their caring roles, and many worried about asking for help or being perceived as incapable, while not having consistent, positive support to rely on in providing care for their children. These findings indicate that there may be a need for more disability-sensitive services and support for parents.

Recommendation 8: ACT Government to work with relevant stakeholders such as

WWDACT to identify improvements needed to ensure access to high-quality, disability-sensitive maternity services and parenting support, and to make improvements as required.

A lack of accessible and flexible options for employment was identified as a key issue.

Recommendation 9: ACT Government to work with community and business groups to improve the availability of accessible and flexible workplaces for women with disabilities, wherever possible on a universal basis to reduce stigma, since employment supports financial independence and equitable participation.

The lack of affordable, accessible opportunities for women to socialise and exercise was noted by many, and this is significant since other studies have found this lack has a negative effect on physical, mental and social wellbeing.

Recommendation 10: ACT Government to work with relevant stakeholders to increase the availability of affordable and accessible opportunities for healthy activity and social events.

The research found that barriers to access are cumulative, that quality of care and participants' sense of agency in their own health was low. These experiences negatively affected women's confidence or trust in ongoing care, which led to a sense of frustration, and an expectation of poor experiences with health services.

The cognitive load or "spoons" (measures of the limited supply of energy) required to manage these barriers reduces the number of "spoons" that women have available to pursue health-promoting, socially-connecting activities.

Notes

ⁱ Australian Bureau of Statistics (ABS), *Survey of Disability, Ageing and Carers*, 2018, Cat. No. 4430.0,

<https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>

ⁱⁱ Women with Disabilities ACT (WWDACT), *Women with Disabilities in the ACT: Quick Facts*, 2021, <https://www.wwdact.org.au/about/women-with-disabilities-in-the-act/>

ⁱⁱⁱ Disabled People's Organisations Australia and National Women's Alliances, *The Status of Women and Girls with Disability in Australia*, 2019, <https://wwda.org.au/wp-content/uploads/2020/06/The-Status-of-Women-and-Girls-with-Disability-Asutralia.pdf>, p. 35.

^{iv} D Stanford, *Future Directions of Disability Health in the ACT: Phase One of the ACT Disability Health Strategy Project*, 2021, Act Health Directorate, Canberra.

^v A Hutchison, "I don't have the spoons for that..." *The views and experiences of younger ACT women (aged 18 to 50 years) about accessing supports and services for chronic disease*, Women's Centre for Health Matters, Canberra, 2018.

^{vi} Unpublished research, A summary of the views of women with disabilities in the ACT about their health; their health needs; their access to services, supports, and information; and the barriers to maintaining their health, Women's Centre for Health Matters, Canberra, 2018.

^{vii} 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.

^{viii} Hutchison, "I don't have the spoons for that..."

^{ix} 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.

^x Women's Health Victoria, *Health – Health issues for Women*, Fact Sheet 4, Vic, 2016, [https://www.wdv.org.au/documents/Fact%20Sheet%204%20-%20Health_final%20\(May%202016\).pdf](https://www.wdv.org.au/documents/Fact%20Sheet%204%20-%20Health_final%20(May%202016).pdf)

^{xi} Hutchison, "I don't have the spoons for that..."

^{xii} C Salisbury, 'Postal survey of patients' satisfaction with a general practice out of hours cooperative,' *British Medical Journal*, vol. 314, 1997, pp. 1594-1598.

^{xiii} P Venning et al., 'Randomised controlled trial comparing cost effectiveness of general practitioners and nurse practitioners in primary care' *BMJ*, vol. 320, 2000, pp. 1048-1053.

^{xiv} P Kinnerley et al., 'Randomised controlled trial of nurse practitioner versus general practitioner care for patients requesting 'same day' consultations in primary care', *British Medical Journal*, vol. 320, 2000, pp. 1043-1048.

^{xv} A Hutchison, "We contribute..." *ACT older women's views about their health; their health needs; their access to services, supports and information; and the barriers to maintaining their health*, Women's Centre for Health Matters, Canberra, 2020.

^{xvi} C Frohmader & S Ortoleva, *The sexual and reproductive rights of women and girls with disabilities, ICPD Beyond 2014*, International conference on human rights, 2013.

^{xvii} 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>

^{xviii} Patient Advocates, *What is a patient advocate?*, Sydney, retrieved 2022, <https://www.patientadvocates.com.au/what-is-a-patient-advocate.html>

^{xix} Council of Australian Governments (COAG), *National Disability Strategy 2010-2020*, Commonwealth of Australia, Canberra, 2011, <https://humanrights.gov.au/sites/default/files/NDS%20PDF.pdf>

Recommendations

Recommendation 1: ACT Government and relevant stakeholders ensure that women with disabilities are considered a distinct cohort in the ACT Disability Health Strategy, their voices listened to and their needs addressed.

Recommendation 2: ACT Government to include actions within the Disability Health Strategy to maximise an integrated and coordinated approach to care, incorporating measures such as colocation of services to make health care more affordable and less burdensome for women with disabilities.

Recommendation 3: ACT Government to work with relevant stakeholders to fund and promote more disability informed mental health services

Recommendation 4: ACT Government to continue to support the functionality of health technology, such as Telehealth, in public services and work with the Commonwealth as necessary in order to support remote access to health services, as in-person attendance at health services can be a barrier for women with disabilities.

Recommendation 5: ACT Government to work with relevant stakeholders to improve the availability of appropriate sexual and reproductive health services for women with disabilities, and to promote these services widely with regard to the needs of women with disabilities in their diversity.

Recommendation 6: ACT Health to 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).

Recommendation 7: ACT Government to work with relevant community organisations and service providers to improve access to high-quality individual advocacy in the ACT, in order to support decision making and navigation through the complex and often fragmented health system.

Recommendation 8: ACT Government to work with relevant stakeholders such as WWDACT to identify improvements needed to ensure access to high-quality, disability-sensitive maternity services and parenting support, and to make improvements as required.

Recommendation 9: ACT Government to work with community and business groups to improve the availability of accessible and flexible workplaces for women with disabilities, wherever possible on a universal basis to reduce stigma, since employment supports financial independence and equitable participation.

Recommendation 10: ACT Government to work with relevant stakeholders to increase the availability of affordable and accessible opportunities for healthy activity and social events.

Introduction

Women with a disability comprise approximately 20% of the population of women in the ACT, with 41,200 women reporting that they have a disability. Women make up the majority of people who have disability.¹

Previous research by Women's Centre for Health Matters (Women's Health Matters) has explored the views of ACT women about their health and wellbeing and the barriers they faced in maintaining their health and accessing health services.^{2 3 4} This report presents the experiences of women with a disability in the ACT, their views about their health, what their specific health needs are, and how well they are being met. It analyses their experiences of accessing services, supports and information; and the barriers to maintaining their health and wellbeing.

Governments both local and nationally acknowledge that people with disability have human rights and deserve to have the same enjoyment in life as other people. They need to have access to health care that are equitable in quality and have access to timely and appropriate health services. They should receive health care that is free from discrimination or biases and they should be treated with *"dignity, autonomy and respect when receiving healthcare."*^{5 6}

Although women with disabilities make up a fifth of the general population of women, they are often marginalised by the social context in which they live. The built environment and the social community are mostly for those without a disability, and this can alienate and discourage further those with impairments. In this report we will be using language that highlights the barriers put forward by the non-disabled, and address women's disability as a social issue rather than one they are required to carry as a burden.

The following report summarises the results of the research and provides the findings and narratives of the 91 ACT women who responded to the survey, and of 12 women who took part in focus groups or interviews.

This report comprises several parts. The first part gives a brief review of the literature about the health needs of women with disabilities, their use of health services and information, their barriers, and other relevant themes from similar national and international research. The following section describes the methodology used. We then present the survey findings, including the demographic characteristics of the survey respondents, and the responses for each of the main sections of the survey: their self-rated

¹ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers*, 2018, Cat. No. 4430.0,

<https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>

² 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.

³ A Hutchison, *"This is what the real experience is like..." The views of same sex attracted women in the ACT about their health; their access to services, supports, and information; and the barriers to maintaining their health*, Women's Centre for Health Matters, Canberra, 2019.

⁴ A Hutchison, *"We contribute..." ACT older women's views about their health; their health needs; their access to services, supports and information; and the barriers to maintaining their health*, Women's Centre for Health Matters, Canberra, 2020.

⁵ ACT Health, *COVID-19 – An ACT Operational Plan for People with Disability*, Complementing the Australian Department of Health Management and Operational Plan for People with Disability, Canberra, 2020.

⁶ Council of Australian Governments (COAG), *National Disability Strategy 2010-2020*, Commonwealth of Australia, Canberra, 2011, <https://humanrights.gov.au/sites/default/files/NDS%20PDF.pdf>

health; the health services that they accessed; top health issues; barriers to addressing health services; barriers to accessing health information; the life roles they have taken up; and experiences of social inclusion.

The discussion section then explores the major themes from the consultation and looks more closely at the health issues, barriers that women with a disability face in the ACT. The conclusion outlines the overall key findings from the feedback from both the survey, focus groups, and interview respondents.

A note on the title

The quotation in the title of this report, *"I have to ask to be included..."* comes directly from one of the women who participated in this research. We feel that this encapsulates the experiences of women with a disability in coming up against barriers, time and time again, when attempting to access health services and information, the workforce, public transport, buildings, social events, and a sense of understanding from the ACT community.

Literature Review

The objectives of the literature review were to explore the recent available research⁷ on:

- Women with disabilities understanding of health and wellbeing, and their self-rated status of physical and mental health;
- The top health and wellbeing issues for women with disabilities, and their experiences of managing these;
- Groups of women with disabilities;
- Women with disabilities use and experiences of health and wellbeing services and supports and information services such as GP's, specialists etc;
- Women with disabilities social inclusion and engagement in community life;
- Women with disabilities caring responsibilities, and
- Women with disabilities housing, income and transport situations.

Distinct experiences of women with disability

Women with disability have distinct experiences arising from the intersection between disability discrimination and gender discrimination. A wealth of literature has established that women with disabilities are subjected to systemic marginalisation that leads to multiple forms of disadvantage. For example, they:

- make up only 34% of NDIS participants in the ACT (even though 53% of people with disability in the ACT are women)⁸
- have significantly lower labour force participation rates (65.1%) than men with disabilities (80.1%) in the ACT⁹
- are more likely to be in lower paid jobs than men with disability (nationally)¹⁰
- are 40% more likely to be subjected to domestic and family violence than women without disabilities (nationally)¹¹
- are estimated to be at least four times more likely to be subjected to sexual violence than women without disabilities (nationally)¹²

⁷ The review included both academic and 'grey' literature. Grey literature is literature produced outside of academic or commercial channels, and includes reports by government agencies as well as non-government organisations.

⁸ Women with Disabilities ACT (WWDACT), *Women with Disabilities in the ACT: Quick Facts*, 2021, <https://www.wwdact.org.au/about/women-with-disabilities-in-the-act/>

⁹ Ibid.

¹⁰ Disabled People's Organisations Australia and National Women's Alliances, *The Status of Women and Girls with Disability in Australia*, 2019, <https://wwda.org.au/wp-content/uploads/2020/06/The-Status-of-Women-and-Girls-with-Disability-Asutralia.pdf>, p. 35.

¹¹ Ibid. p. 23.

¹² Ibid. p. 23.

International human rights agreements have established that the intersection of gender and disability must be addressed by governments in their provision of health services, in order to fulfil the human rights of all people with disability. Notably, the UN Convention on the Rights of Persons with Disability commits states parties (including Australia) to “ensure access for persons with disabilities to health services that are gender-sensitive”, including in the area of sexual and reproductive health (Article 25).

Women’s understanding of what good health means

Women’s understanding of what good health means is influenced by their life situations, societal factors, and their age.¹³ Women’s Health Matters research has found differences but many similarities in what good health means to distinct groups of ACT women. Many women in the ACT general women’s health survey reported that general health meant good physical and mental health,¹⁴ whereas women in the same sex attracted survey mostly reported wholistic, physical and mental health and living without sickness,¹⁵ and older ACT women reported that good health meant being active, motivated and independent.¹⁶ Other themes about what good health meant were found by all groups of women including access to health care services, fulfilling their life roles, and maintaining social connection.^{17 18 19} Women with disabilities who participated in the 2018 ACT women’s health research specifically defined health in terms of autonomy and being able to do the things they needed to do in their life.²⁰

Self-rated health status

Self-rated health is a predictor of morbidity, mortality,²¹ and of increased health service utilisation.²² ^{23 24 25} Self-rated health can be used to indicate how a person’s health is at a specific time.^{26 27} Poor self-rated health has been found to be influenced by factors such as age, social determinants of health²⁸ and age of onset of disability.²⁹

¹³ Hoban, *ACT women’s health matters!*

¹⁴ Ibid.

¹⁵ Hutchison, “*This is what the real experience is like...*”

¹⁶ Hutchison, “*We contribute...*”

¹⁷ Hoban, *ACT women’s health matters!*

¹⁸ Hutchison, “*This is what the real experience is like...*”

¹⁹ Hutchison, “*We contribute...*”

²⁰ Unpublished research, A summary of the views of women with disabilities in the ACT about their health; their health needs; their access to services, supports, and information; and the barriers to maintaining their health, Women’s Centre for Health Matters, Canberra, 2018.

²¹ K A Sargent-Cox, K J Anstey, & M A Luszcz, ‘The choice of self-rated health measures matter when predicting mortality: evidence from 10 years follow up of the Australian longitudinal study of ageing’, *BMC Geriatrics*, vol. 10, no. 18, 2010, pp. 1-12.

²² M Jylha, ‘What is self-rated health and why does it predict mortality? Towards a unified conceptual model’, *Social Science and Medicine*, no. 69, 2009, pp. 307-316.

²³ M Bopp et al., ‘Health risk or resource? Gradual and independent association between self-rated health and mortality persists over 30 years’, *PLoS One*, vol. 7, issue 2, 2012, pp. 1-10.

²⁴ P M Smith, R H Glazier & L M Sibley, ‘The predictors of self-rated health and the relationship between self-rated health and health service needs are similar across socioeconomic groups in Canada’, *Journal of Clinical Epidemiology*, vol. 63, 2010, pp. 412-421.

²⁵ Australian Institute of Health and Welfare (AIHW), *People with Disability in Australia*, Canberra, 2020, <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/health/health-status>

²⁶ Australian Bureau of Statistics, *National Health Survey: first results 2017-18, Self-assessed health status*, Canberra, 2018, <https://www.abs.gov.au/statistics/health/health-conditions-and-risks/self-assessed-health-status/2017-18>

²⁷ AIHW, *People with Disability in Australia*.

²⁸ A Hosseinpoor et al., ‘Social determinants of self-reported health in women and men: Understanding the role of gender in population health’, *PLoS One*, vol. 7, no. 4, 2012, pp.1-10.

²⁹ E W Jamoom et al., ‘Age at disability onset and self-reported health status’, *BMC Public Health*, 2008, vol. 8, no. 10, pp. 1-7.

In the 2018 Women's Health Matters ACT women's health study, 42% of respondents rated their physical health as fair, poor, or very poor, whereas 58% said good or excellent.³⁰ In comparison, unpublished data from Women's Health Matters found that the majority of ACT women with disabilities rated their physical health (75%) as either fair, poor or very poor.³¹ Additionally, results from the 2017/2018 National Health Survey (NHS) showed that 40% of women with disabilities had rated their health as fair / poor. Women with severe or profound disabilities rated their health worse, with 62% reporting self-ratings of fair / poor. When compared to women without a disability, women with disabilities were around 7 times more likely to give a self-assessment of fair / poor.³² Similarly, 49% of women with disabilities in the *Jean Hailes for Women's Health 2020 report*, reported their health as poor or very poor, compared to 10% of women without disabilities.³³

In contrast, the 2012 Women's Health Matters report, *Strong women, great city; A snapshot of findings from a survey of ACT women with disabilities*, showed that 22% of women rated their physical health fair / poor. Researchers pointed out that women had rated their health similarly to people who had mild to moderate limitations and restrictive long-term health conditions rather than severe or profound disabilities.³⁴

The intersection between disability and age is evident when looking at self-rated health. In a recent report by Women's Health Matters, *"We contribute..."*, a report about older women's health and wellbeing in the ACT, 84% of women who had a disability rated their self-rated health as fair, poor or very poor.³⁵ An older study by Han et al identified that mortality was related to 'decline' of self-rated health rather than 'static' self-rated health in older women who had disabilities.³⁶ Multimorbid chronic disease contributes to 'risk of disability' in older women and is correlated with poor self-rated health.³⁷

Although self-rated mental health can be a predictor of overall health³⁸ there appears to be limited relevant studies about the self-rated mental health for women with disabilities in Australia. In the 2018 Women's Health Matters ACT health study 40% of women rated their mental health fair, poor, or very poor, whereas 60% rated it good and excellent.³⁹ In comparison, unpublished data from Women's Health Matters found that the majority (63%) of ACT women with disabilities rated their mental health as either fair, poor or very poor.⁴⁰ In the 2015 research, *Strong women, great city*, 20% of the women rated their emotional health and wellbeing as fair / poor. In the study, researchers asked

³⁰ Hoban, *ACT women's health matters!*

³¹ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

³² AIHW, *People with Disability in Australia*.

³³ Jean Hailes for Women's Health, *National Women's Health Survey 2020: Understanding health information needs and behaviours of women in Australia*, Jean Hailes for Women's Health, Melbourne, 2020.

³⁴ 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.

³⁵ Hutchison, *"We contribute..."*

³⁶ B Han et al. 'Change in self-rated health and mortality among community-dwelling disabled older women', *The Gerontologist*, vol. 45, no. 2, 2005, pp. 216-221.

³⁷ H M M Vos et al. 'Multimorbidity in older women: The negative impact of specific combination of chronic conditions on self-rated health', *European Journal of General Practice*, vol. 19, no. 2, 2013, pp. 117-122.

³⁸ D Levinson & G Kaplan, 'What does self-rated mental health represent,' *European Journal of Public Health*, vol. 3, pp. 287.

³⁹ Hoban, *ACT women's health matters!*

⁴⁰ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

participants to rate their emotional health rather than using the widely used mental health self-rating tool that Women's Health Matters usually ask women to complete.⁴¹ Disability impacts older women negatively, with 55% of older ACT women who had a disability rating their mental health as fair, poor or very poor, compared to 35% of older women without a disability.⁴²

The health of women with disabilities and top health issues

Women who have disabilities are not always in poor health, though the two are often conflated which increases stigma and discrimination for women. Some chronic diseases can lead to disability, and some disabilities can lead to chronic illness. Mostly though, health for women with disabilities is influenced by their *"experiences of adversity and reduced access to resources"*.^{43 44} Their health is impacted by reduced access to health services and supports, stigma and discrimination, and experience of domestic violence and sexual assault, more than other groups of women.⁴⁵ The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability continues to draw attention to the high rates of violence and abuse to which people with disability, and in particular women with disability, are subjected.⁴⁶

"As women with disabilities we experience high levels of disadvantage in all areas of our lives – social exclusion, economic insecurity and high levels of violence and discrimination. This disadvantage affects our mental and physical health and leads to greater unmet health needs than women without a disability".⁴⁷

Previously published work by Women's Health Matters found that women with disabilities are diverse in their life-stage, life roles and their impairments. In the 2012 report, *Strong women, great city*, 47% of women reported having physical impairments, with 21% sensory and 20% psycho-social, and 17% having intellectual impairment.⁴⁸

Top health issues

Women's Health Matters' previous research has highlighted the top health issues reported by the general population of women. The three issues most reported as top health issues were 'mental health', 'weight diet and fitness', and 'chronic disease'. Women who disclosed these health issues reported significant barriers to addressing these and listed affordability, lack of services, and wait times.⁴⁹ Women's Health Matters research about other groups of women such as older women and

⁴¹ Carnovale, *Strong women, great city*.

⁴² Hutchison, *"We contribute..."*

⁴³ E Emerson et al, 'Lower well-being of young Australian adults with self-reported disability reflects their poorer living conditions rather than health issues,' *Australia and New Zealand Journal of Public Health*, 2012, vol. 36, no. 2, pp. 176–82.

⁴⁴ J P Wisdom et al. 'Health disparities between women with and without disabilities: A review of the research', *Work Public Health*, 2010, vol. 25, no. 3, pp. 368-386.

⁴⁵ Ibid.

⁴⁶ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Research Report - Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia, 2021, <https://disability.royalcommission.gov.au/publications/research-report-nature-and-extent-violence-abuse-neglect-and-exploitation-against-people-disability-australia>

⁴⁷ Women's Health Victoria, *Health – Health issues for Women*, Fact Sheet 4, Vic, 2016, [https://www.wdv.org.au/documents/Fact%20Sheet%204%20-%20Health_final%20\(May%202016\).pdf](https://www.wdv.org.au/documents/Fact%20Sheet%204%20-%20Health_final%20(May%202016).pdf)

⁴⁸ Carnovale, *Strong women, great city*.

⁴⁹ Hoban, *ACT women's health matters!*

same sex attracted women also found the same top three health issues. Similarly, there were barriers to addressing these top health issues, with affordability as the most prevalent barrier.^{50 51}

Chronic disease

Women with a disability might experience chronic illness in addition to their disability, or they may experience disability from their chronic disease.⁵² Women with disabilities have diverse health issues that are not dissimilar to the general population of women. Health conditions might be separate and unrelated to their disability, be due to gendered barriers,⁵³ or due to their lack of access to specific and tailored health information, support and health services.⁵⁴

The Australian Institute of Health and Welfare has identified chronic conditions that may lead to ongoing impairment for women. These chronic conditions include emphysema, stroke, coronary heart disease, osteoporosis, arthritis or related condition, back problems, diabetes, and asthma. Chronic conditions such as these are more likely to have a greater impact on older women.^{55 56}

The symptoms of chronic disease, pain and fatigue, have been found to be debilitating for women, not only because of the immediate impact, but also because of the impact on their life roles (such as employment, caring roles and relationships), and because their experiences are often not believed or heard by health professionals. Health professionals disregarding the experiences of women with disabilities leads to misdiagnosis, delay in diagnosis and living in pain.⁵⁷ Additionally, waiting for treatment in pain is debilitating. Waits as long as six months are inappropriate as deterioration may occur within as little as five weeks from the onset of pain.⁵⁸

Mental health

Mental health conditions may be separate to a women's disability and related to barriers to health services and supports,⁵⁹ domestic and sexual violence, lack of social inclusion⁶⁰, discrimination,⁶¹ or societal attitudes and practices that are disabling.⁶² Women with disabilities may experience poor self-esteem, depression, and anxiety due to lower 'social status'⁶³, where social status means social value defined in terms of the perception by others related to respect and competence.⁶⁴ They may also

⁵⁰ Hutchison, "This is what the real experience is like..."

⁵¹ Hutchison, "We contribute..."

⁵² AIHW, *People with Disability in Australia*.

⁵³ COAG, *National Disability Strategy 2010-2020*

⁵⁴ Wisdom et al. 'Health disparities'.

⁵⁵ AIHW, *People with Disability in Australia*.

⁵⁶ P Maresova, 'Consequences of chronic diseases and other limitations associated with old age – scoping review', *BMC Public*, 2019, vol. 19, no. 1341, pp. 1-17.

⁵⁷ A Hutchison, "I don't have the spoons for that..." The views and experiences of younger ACT women (aged 18 to 50 years) about accessing supports and services for chronic disease', *Women's Centre for Health Matters*, Canberra, 2018.

⁵⁸ M E Lynch et al., 'A systematic review of the effect of waiting for treatment for chronic pain', *Pain*, vol. 136, issues 1-2, 2008, pp. 97-116.

⁵⁹ E Emerson et al., 'Lower well-being of young Australian adults with self-reported disability reflects their poorer living conditions rather than health issues', *Australia and New Zealand Journal of Public Health*, 2012, vol. 36, no. 2, pp. 176-182.

⁶⁰ 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.

⁶¹ L Krnjacki et al, 'Disability-based discrimination and health: findings from an Australian-based population study', *Australian and New Zealand Journal of Public Health*, 2018, vol. 42, pp. 172-174.

⁶² COAG, *National Disability Strategy 2010-2020*

⁶³ K Howe & S Salthouse, *Lack of data means lack of action – A clinical examination of health services for women with disabilities*, *Women with Disabilities Australia*, 2004.

⁶⁴ C Anderson, J A D Hildreth, & L Howland, 'Is the Desire for Status a Fundamental Human Motive? A Review of the Empirical Literature', *Psychological Bulletin*, 2015, vol. 141, no. 3, pp. 574-601.

experience compounding poor mental health if they are part of other minority groups, such as the queer community, who are susceptible to experiencing minority stress.⁶⁵

Mental health was influenced by the ability of ACT women with disabilities to gain access to mental health services, particularly services that have a speciality in disability.⁶⁶ Poor mental health can be a result of other factors such as lack of access to services and supports like domestic help, lack of sufficient housing,⁶⁷ ⁶⁸ or barriers to sufficient employment.⁶⁹ The social environment influences mental health and wellbeing, and positive social contact is beneficial. People with disabilities might not have the opportunity to participate in positive social contact.⁷⁰ Mental health in younger women with disabilities may be due to worrying about their future prospects.⁷¹

In the *Jean Hailes for Women's Health Survey*, 32% of women with a disability reported that they had combined symptoms of anxiety and depression.⁷² Victorian health data from 2013, found that people with intellectual disabilities were more likely to suffer from depression than people of the same age group.⁷³ Compared to women without a disability, women with a disability experience higher levels of psychological stress, especially in women who have severe or profound disability.⁷⁴

Sexual and reproductive health

Women with disabilities often miss out on important sexual and reproductive health information, health screening, and service access. This is due to falsehoods such as the view that women with disabilities are not sexually active, are not going to have children, or are not in loving relationships.⁷⁵ Women with disabilities need access to sexual and reproductive health services and support, and health information that is delivered in an appropriate way.⁷⁶

Local research indicates that women with disabilities want and need to know more about sexual and reproductive health on topics such as menopause, their rights, sexual health and sexuality. Health information needs to be tailored and specific to their needs.⁷⁷

Many women and girls with disability have been forced or coerced, against their human rights, into undergoing a surgical procedure to remove reproductive organs or participate in long-term medical

⁶⁵ T Hunter, et al. 'Queering disability: Exploring the resilience of sexual and gender minority persons living with disabilities', *Rehabilitation Counseling Bulletin*, 2020, vol. 64, no. 1, pp. 31-41.

⁶⁶ Gough, 'Contributing our voices!'

⁶⁷ Emerson et al., 'Lower well-being'.

⁶⁸ Gough, 'Contributing our voices!'

⁶⁹ Gough, 'Contributing our voices!'

⁷⁰ H Tough, J Siegrist, & C Fekete, 'Social relationships, mental health and wellbeing in physical disability: a systematic review', *BMC Public Health*, 2017, vol. 17, no. 414. pp. 1-18.

⁷¹ S Shanmukhasundaram, "The Responsibility has Fallen on Us" *Perspectives on the impact of COVID-19 on Women* and Girls with Disabilities in the ACT and Region*, Women with Disabilities ACT, Canberra, 2020.

⁷² Jean Hailes for Women's Health, *National Women's Health Survey 2020*.

⁷³ State Government Victoria, *Victoria Population Health Survey of People with an Intellectual Disability 2013*, Department of Health and Human Services, Victoria.

⁷⁴ AIHW, *People with Disability in Australia*.

⁷⁵ C Frohmader & S Ortoleva, *The sexual and reproductive rights of women and girls with disabilities*, ICPD Beyond 2014, International conference on human rights, 2013.

⁷⁶ K Hedley, *Contraception, consent, respectful relationships & sexuality for women and girls, feminine identifying & non-binary people with disabilities in ACT*, WWDACT, Canberra, 2019.

⁷⁷ Hedley, *Contraception, consent, respectful relationships & sexuality*.

contraception and medical suppression.^{78 79 80} Many women with disabilities today are still living with the consequences of having their autonomy and choices taken away and the trauma of not being able to have children.⁸¹

Social connectedness and inclusion

Social connectedness and inclusion is important for women with disabilities.⁸² Poor social connectedness and inclusion can impact mental and physical wellbeing, lead to poor health outcomes, reduced education, employment, and fulfilment in life.⁸³ Community participation is necessary for overall wellbeing, including reducing feelings of isolation, forming relationships, increasing access to health information and support for people with disabilities.⁸⁴ Barriers exist to being socially included for people with disabilities, including living and transport situations, and the built environment. Social and attitudinal barriers exist which impacts on self-esteem and people's ability to be involved, which can include negative perceptions of a person with a disability.⁸⁵ Additionally, women with disabilities who have children may feel further isolated from their community as physical barriers, such as small door spaces, limited transport options, and stairs, make it difficult to access spaces such as play groups which limit social connections with other mothers.⁸⁶

In the 2012 Women's Health Matters report *Strong women, great city: A snapshot of findings from a survey of ACT women with disabilities*, most women with disabilities reported they were somewhat satisfied or satisfied with their amount of social interaction and their ability to be socially connected, although 20% said that they were not satisfied with their level of social interaction. Furthermore, some women reported they were worried about becoming socially isolated. Most of the women said they had support networks that they could rely on if needed but only half of them felt that they were recognised for their contribution to the community.⁸⁷ More recently, during the recent ACT lockdown due to the COVID pandemic, women with disabilities reported how worried about the health implications of not seeing their friends and family, and that they felt vulnerable to isolation.⁸⁸

⁷⁸ C Frohmader, *Moving forward and gaining ground: The sterilization of women and girls with disabilities in Australia*, Women with Disabilities Australia, Tasmania, 2012.

⁷⁹ C Frohmader, *Dehumanised: The Forced Sterilisation of Women and Girls with Disabilities in Australia*, WWDA Submission to the Senate Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia, Women with Disabilities Australia, Tasmania, 2013.

⁸⁰ L Steele & B Goldblatt, *The human rights of women and girls with disabilities; sterilization and other coercive responses to menstruation*, in *The Palgrave Handbook of Critical Menstruation Studies*, https://link.springer.com/chapter/10.1007/978-981-15-0614-7_8

⁸¹ Women with Disabilities Australia, *National forum for women and girls with disability; proceedings and outcomes report*, 2016, Tasmania, https://wwda.org.au/wp-content/uploads/2016/01/PMC_WWDA_Report_National_Forum_Final.pdf

⁸² Carnovale, *Strong women, great city*.

⁸³ E Emerson et al, 'Loneliness, social support, social isolation and wellbeing among working age adults with and without disability: Cross-sectional study', *Disability and Health Journal*, 2021, vol.14, pp. 1-8.

⁸⁴ Gough, 'Contributing our voices!'

⁸⁵ M A Nosek et al, 'Self-esteem and women with disabilities', *Social Science & Medicine*, 2003, vol. 56, no. 8, pp. 1737-1747.

⁸⁶ A Storr, *Motherhood, parenting & women with disabilities: A literature review*, Women with Disability Australia, Tasmania, 2007.

⁸⁷ Carnovale, *Strong women, great city*.

⁸⁸ Shanmukhasundaram, "The Responsibility has Fallen on Us".

Health screening

Health screening is vital to find and catch early conditions that can cause morbidity and mortality. However, women with disabilities are often overlooked for health screening.^{89 90} This may be due to barriers such as services not having adequate equipment, lack of health information about the screening, health providers making assumptions about health behaviours, lack of education on issues that impact women with disabilities,⁹¹ and other barriers that most women face such as cost, being too busy, and lack of appointments.^{92 93}

Women with physical disabilities experience discrimination and face stigma from health professionals which deters them from seeking future breast screens. Peters and Cotton found that women experienced feeling they weren't in control, were ignored, not listened to, they felt helpless, alone and afraid, and experienced pain and humiliation when accessing breast screening.⁹⁴

Due to the sensitive nature of cervical screening, women with disabilities face many barriers. Some women have experienced health providers making assumptions about them including that they are not sexually active, or they will not be able to understand, consent to, or handle the procedure. Women also feared disclosing their sexual history and were concerned that the test might be painful or traumatic. This is particularly relevant if they had a past experience of sexual assault, or have had negative experiences of health providers. Women may find that relying on family members for appointments is a barrier. Health care providers may not have adequate training or knowledge to provide the needed support, and there may be physical, sensory and communication barriers. Other barriers that women with disabilities face when attending appointments for cervical screening include a lack of equipment such as hoists and adjustable tables or beds, a lack of suitable transport or facilities, and appointment times that are often too short. Additionally, health information and reminder letters may not be in plain English and other accessible formats, negatively impacting on necessary health messaging about cervical screening.⁹⁵

In some circumstances women have higher rates of screening than the general population, which is the case for women with intellectual disability (in Victoria) and breast screening.⁹⁶ However, they were less likely to have had a cervical screening test.⁹⁷ Nationally, it is unknown if women with disabilities

⁸⁹ S G Sullivan et al., 'The incidence of cancer in people with intellectual disabilities', *Cancer Causes & Control*, 2004, vol. 15, no. 10, pp. 1021-1025.

⁹⁰ E Andreson et al., 'Pap, mammography, and clinical breast examination screening among women with disabilities: A systematic review', *Women's Health Issues*, 2013, vol. 23, no. 4, 205-214.

⁹¹ E J Halcomb, K Peters & E Smyth, 'Health screening for women with physical disability in Australia general practice: A survey', *Collegian*, 2019, vol. 26, no. 2, pp. 250-255.

⁹² Carnovale, *Strong women, great city*.

⁹³ P Welch Saleeby & J Hunter-Jones, 'Identifying barriers and facilitators to breast services among women with disabilities', *Social Work in Public Health*, vol. 31, no. 4, pp. 255-263.

⁹⁴ K Peters & A Cotton, 'Barriers to breast cancer screening in Australia: experiences of women with physical disabilities', *Journal of Clinical Nursing*, 2015, vol. 24, no. 3-4, pp. 563-572.

⁹⁵ 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>

⁹⁶ State Government of Victoria, *Victoria Population Health Survey of People with an Intellectual Disability 2013*, Department of Health and Human Services, Victoria.

⁹⁷ State Government of Victoria, *Victoria Population Health Survey*.

have comparatively lower cervical screening rates, as this group was not recorded in a major report released by the AIHW in 2019,⁹⁸ and this is also the case for breast screening.⁹⁹

Access to health services

It is essential that women with disabilities have good access to health services as they often have increased healthcare needs, use health services more often, and have less resources available to access health services.¹⁰⁰ Health services and supports not only help to maintain their general health and wellbeing but ensure access to essential disability supports such as equipment.¹⁰¹

Many women with disabilities also care for others and so they access health services for themselves and for family members. In unpublished research from Women's Health Matters, 96% accessed services for themselves, 32% accessed services for their children and 17% for their partners.¹⁰² By comparison, among the general population of women responding to the same survey, 97% accessed services for themselves, 35% accessed for their children and 20% accessed for their partners.¹⁰³ The most accessed services by women with disabilities in the previous 12 months were; GPs (96%), filling prescriptions (91%) and a specialist/s (68%). Visiting a dentist was listed by 60% of women.¹⁰⁴ By comparison, among the general population of women responding to the same survey, 94% visited a GP, 82% filled prescriptions, and 64% had visited a dentist (64%). Seeing a specialist was selected by 10% of women, and 8% visited a walk-in-centre in the last 12 months.¹⁰⁵

Barriers to accessing health services and supports

Availability of health services and supports

Women with disabilities need to access a range of health services, and if services are not available when they need them it can negatively impact their health and wellbeing.^{106 107 108 109}

Women with disabilities often experience long wait times and appointment availability as barriers to health services and supports.^{110 111} Nationally, women with a disability wait longer than they feel acceptable to get an appointment to see a GP.¹¹² A report from the Australian Institute of Health and Wellbeing shows that people who have disabilities had to wait one or more days for urgent medical care and that public dental waiting lists have wait times of up to one year for dental care.¹¹³ Women

⁹⁸ Australian Institute of Health and Welfare, *Cervical screening in Australia*, Australian Government, Cancer Series, Number 123, Canberra, 2019.

⁹⁹ Australian Institute of Health and Welfare, *Breastscreen Australia Monitoring Report 2020*, Australian Government, Cancer Series, Number 129, Canberra, 2020.

¹⁰⁰ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

¹⁰¹ COAG, *National Disability Strategy 2010-2020*.

¹⁰² Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

¹⁰³ Hoban, *ACT women's health matters!*

¹⁰⁴ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

¹⁰⁵ Hoban, *ACT women's health matters!*

¹⁰⁶ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

¹⁰⁷ Carnovale, *Strong women, great city*.

¹⁰⁸ Gough, *'Contributing our voices!'*

¹⁰⁹ Shanmukhasundaram, *"The Responsibility has Fallen on Us"*.

¹¹⁰ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

¹¹¹ A Carnovale, *It goes with the territory, the views of ACT women with disabilities about health and wellbeing information*, Women's Centre for Health Matters, Canberra, 2011.

¹¹² Jean Hailes for Women's Health, *National Women's Health Survey 2020*.

¹¹³ AIHW, *People with Disability in Australia*.

experience poor access to allied health professionals due to limitations on the number of care plan visits, reduced access to specialist care due to long waiting times, and limitations accessing mental health services.¹¹⁴ At times women need to travel to Sydney to obtain essential health services to meet their needs.¹¹⁵

Delaying treatment or diagnosis due to wait times or lack of availability of appointment can lead to substantial issues for women with disabilities. If waiting in pain, patients experience deterioration of physical and psychological quality of life.¹¹⁶

Women with disabilities *who need and access support from others* often experience barriers to home care and how that care is delivered. Some women rely mostly on informal carers as they do not receive enough formal assistance.¹¹⁷ At the height of the lockdown in Canberra for COVID-19, many women who were receiving care services had disruptions in essential care due to the closure of some services. Other services were available but not easily accessed, and some services lacked enough PPE to accommodate demand.¹¹⁸ This meant that women with disabilities lacked support to do essential tasks or even go outside with autonomy. The disruptions to care have long term health consequences, influencing recovery and physical and mental health.¹¹⁹

The availability of health services was also reduced during lockdown in COVID-19 and many of the women with disabilities had disruptions to their usual medical care, their medical treatment, and experienced reduced contact with medical services.¹²⁰ Delay in health care could exacerbate current conditions and delay diagnosis and treatment.¹²¹

Appropriateness of health services and supports

Women with disabilities need to be given health care that is appropriate and right for their needs, and be able to get appropriate treatment from health providers. Women with disabilities often face issues with appropriateness of health care. Equipment, such as tables or beds, that are unsafe or inappropriate can mean their health needs go unmet.¹²²

Inappropriate treatment by health professionals impacts women with disabilities negatively and reduces access to health care. Women report that health professionals make assumptions about their disability and abilities which reduces the quality of their visit.¹²³ Health professionals often focus on women's impairments rather than health issues requiring attention. They are often left out of decisions that impact their health care and treatment, and do not receive health information in the right format to enable them to be autonomous.¹²⁴

¹¹⁴ Gough, 'Contributing our voices!'

¹¹⁵ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

¹¹⁶ M E Lynch et al., 'A systematic review'.

¹¹⁷ Carnovale, *Strong women, great city*.

¹¹⁸ Shanmukhasundaram, *"The Responsibility has Fallen on Us"*.

¹¹⁹ Ibid.

¹²⁰ Ibid.

¹²¹ Hutchison, *"I don't have the spoons for that..."*

¹²² E J Halcomba, K Peters & E Smytha, 'Health screening for women with physical disability in Australia general practice: A survey', *Collegian*, 2019, vol. 26, no. 2, pp. 250-255.

¹²³ Gough, 'Contributing our voices!'

¹²⁴ Women's Health Victoria, *Health issues for Women*.

Women in general are often not believed regarding their symptoms, and this leads to lack of diagnosis and misdiagnosis.¹²⁵ Women with disabilities often experience poor treatment by health services¹²⁶ which is compounded by difficult to navigate complaint mechanisms.¹²⁷

Walk-in-centres are often accessed by women for themselves and their families. Walk-in-centres provide an opportunity for women to access affordable and accessible nurse-led health care.¹²⁸ Women value community services that provide health care that give patients appropriate time and reassurance¹²⁹ which is often given by nursing staff.^{130 131 132}

While not necessarily new, services that increase the ability of women to access them, such as telehealth, nurses' health line and National GP services, became more available during the COVID-19 lockdown period. These particular services addressed access barriers that women had experienced before the pandemic.¹³³

Accessibility of health services and supports

Equitable access to health services and supports is essential to the health and wellbeing of women with disabilities.

Women with disabilities need to have access to affordable and suitable transport, including community transport options.¹³⁴ Women with disabilities attending health care appointments such as GPs, specialists, specialised therapy, can experience barriers to transport. A report by Health Care Consumers Association found that people with a disability or chronic condition who were not able to drive a vehicle reported experiencing complications in organising transport to health appointments, and that *"Public transport was often too infrequent or inappropriate for the consumers' condition"*. The report also found that Canberra community transport services' restrictive eligibility criteria had prevented some consumers from being able to access the service.¹³⁵ Essential community transport options are often under-funded, and many people are turned away accessing them.¹³⁶

¹²⁵ Hutchison, *"I don't have the spoons for that..."*

¹²⁶ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters..

¹²⁷ Gough, *'Contributing our voices!'*

¹²⁸ Hoban, *ACT women's health matters!*

¹²⁹ Ibid.

¹³⁰ C Salisbury, 'Postal survey of patients' satisfaction with a general practice out of hours cooperative,' *British Medical Journal*, vol. 314, 1997, pp. 1594-1598.

¹³¹ P Venning et al. 'Randomised controlled trial comparing cost effectiveness of general practitioners and nurse practitioners in primary care' *BMJ*, vol. 320, 2000, pp. 1048-1053.

¹³² P Kinnersley et al. 'Randomised controlled trial of nurse practitioner versus general practitioner care for patients requesting 'same day' consultations in primary care', *British Medical Journal*, vol. 320, 2000, pp. 1043-1048.

¹³³ T M Annaswamy, M Verduzco-Gutierrez & L Frieden, 'Telemedicine barriers and challenges for persons with disabilities: COVID-19 and beyond', *Disability Health Journal*, 2020, vol. 13, no. 4, pp. 1-3

¹³⁴ D Denmark, A Hurni & B Cooper, *No transport, no treatment*, Cancer Council, Sydney, 2011,

https://www.cancercouncil.com.au/wp-content/uploads/2011/10/No-Transport_No-Treatment.pdf

¹³⁵ Health Care Consumers Association, *'Primary health care in the ACT consumer experiences*, 23 January 2014', Canberra, 2014

¹³⁶ Denmark et al., *No transport, no treatment*.

Building access can also be a barrier. Health services need to ensure there are ramps, suitable paths, large entry ways and enough disability parking for those people with disabilities who may require it.

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Individual advocacy can improve accessibility to services that may not be usually found accessible. Reduced ability to advocate for health outcomes and not being involved in decision making are significant barrier to health services and supports.¹⁴⁰ Advocacy can improve and support people with disabilities to comprehend their rights *“through either one-to-one support, or by supporting people to advocate for themselves individually, or on a group basis.”*¹⁴¹

Affordability of health services and supports

Affordability of health services and supports is a significant barrier for women of all backgrounds.¹⁴²

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Unpublished research from Women’s Health Matters found that 65% of ACT women with disabilities reported that affordability was a barrier to health services.¹⁴⁵ In the Jean Hailes for women’s health survey, women with disabilities were found to be *“the most disadvantaged group”* regarding affordability of health care.¹⁴⁶ Women with disabilities in the ACT have experienced high costs for some services, which is an issue for those paying for multiple services and treatments.^{147 148} Lack of bulk billing doctors also has a financial impact on women with disabilities,¹⁴⁹ given that Canberra has the lowest bulk billing rates of all Australia.¹⁵⁰

Women with disabilities may have higher health services needs and higher health costs.¹⁵¹ Studies show that people who have chronic conditions need to divide their money between health services, GP visits, specialists, special equipment and essentials like rent or heating.^{152 153 154}

¹³⁷ ACT Council of Social Service (ACTCOSS), *Disability and access to health services, Factsheet Dec 2017*, Canberra, 2017, <https://www.actcoss.org.au/sites/default/files/public/publications/2017-factsheet-disability-and-access-to-health-services-0.pdf>

¹³⁸ Australian Institute of Health and Welfare, *People with disability in Australia: Access to health services*, Canberra, 2019, <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/health/access-to-health-services>

¹³⁹ ACTCOSS, *Disability and access to health services*.

¹⁴⁰ Patient Advocates, *What is a patient advocate?*, Sydney, retrieved 2022, <https://www.patientadvocates.com.au/what-is-a-patient-advocate.html>

¹⁴¹ COAG, *National Disability Strategy 2010-2020*.

¹⁴² Hoban, *ACT women’s health matters!*

¹⁴³ Unpublished research, A summary of the views of women with disabilities in the ACT, Women’s Centre for Health Matters.

¹⁴⁴ Hutchison, *“We contribute...”*

¹⁴⁵ Unpublished research, A summary of the views of women with disabilities in the ACT, Women’s Centre for Health Matters.

¹⁴⁶ Jean Hailes for Women’s Health, *National Women’s Health Survey 2020*.

¹⁴⁷ Carnovale, *It goes with the territory*.

¹⁴⁸ Hutchison, *“I don’t have the spoons for that...”*

¹⁴⁹ Carnovale, *It goes with the territory*.

¹⁵⁰ ACT Health, *More access to GP bulk billing in Canberra’s South*, Canberra, 2018, <https://www.health.act.gov.au/news/more-access-gp-bulk-billing-canberras-south>

¹⁵¹ Women with Disabilities Australia (WWDA), *‘Shut out, hung out, left out, missing out’, Response to the Australian Government’s Green Paper ‘Which way home? A new approach to homelessness’*, Tasmania, 2008.

¹⁵² V Tran et al., ‘Taxonomy of the burden of treatment: a multi-country web-based qualitative study of patients with chronic conditions’, *BMC Medicine*, vol. 13, no. 115, 2015, pp. 1-15.

¹⁵³ L M Hunt, M Kreiner & H Brody, ‘The changing face of chronic illness management in primary care: a qualitative study of underlying influences and unintended outcomes’, *Annals of Family Medicine*, vol. 10, no. 5, 2012, pp. 552-560.

¹⁵⁴ Y Jeon et al., ‘Economic hardship associated with managing chronic illness: a qualitative inquiry’, *BMC Health Services Research*, 2009, vol. 9, no. 182, pp. 1-11.

In a report by Women with Disabilities ACT, women reported that they were concerned about the increased cost of services, supports and medications during COVID lockdown due to lack of additional support services and support payments, which was compounded by reduced employment.¹⁵⁵

Health information seeking

Health information is essential for all women to look after their health and wellbeing; however, health information specific to ACT women with disabilities is often not available, not accessible, or not specific enough.¹⁵⁶

Women with disabilities tend to seek their health information from similar sources as women in the general population. When they seek health information for general health issues, they choose to look at online sources, and for more specific health information seek it from their GP.^{157 158} In the 2011 Women's Health Matters report about health information for ACT women with disabilities, respondents reported they preferred to get health information from the internet.¹⁵⁹ Women seek out online information that is trustworthy and from reputable sources, although they are cautious about the content.¹⁶⁰

Barriers to health information exist for women with disabilities, particularly if they are seeking it from a health professional. Barriers include cost, waiting times, health professional availability, time constraints, and accessibility.¹⁶¹ Lack of suitable and specific formats is a significant barrier to health information. For example, organisations seldom provide information in braille, large print, or sign language.¹⁶² This can act as a deterrent for accessing health care such as health screening.¹⁶³ In Women's Health Matters' unpublished data on the health and wellbeing of women with disability, many reported that there was health information that they were not able to find.¹⁶⁴

Women with disabilities are frequently left without access to sexual and reproductive health information.^{165 166} Women and girls with disabilities need be able to access information about sexual and reproductive health that is *"acceptable, accessible, and of good quality, and imparted and comprehended by means of supportive and protective measures such as counselling and involvement of community networks"*¹⁶⁷ This includes health information for planning, pregnancy, and having children, which needs to be designed specifically to their capabilities and comprehension.¹⁶⁸

¹⁵⁵ Shanmukhasundaram, *"The Responsibility has Fallen on Us"*.

¹⁵⁶ Gough, *'Contributing our voices!'*.

¹⁵⁷ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

¹⁵⁸ Hoban, *ACT women's health matters!*

¹⁵⁹ Carnovale, *It goes with the territory*.

¹⁶⁰ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

¹⁶¹ Carnovale, *It goes with the territory*.

¹⁶² 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

¹⁶³ Department of Health, *National cervical screening program*.

¹⁶⁴ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

¹⁶⁵ WWDA, *WWDA Position Statement 4: Sexual and Reproductive Rights*.

¹⁶⁶ S Petrony, P Horsley & A Kavanagh, *Access to health services for women with disabilities*, Women with Disabilities Victoria, Melbourne, 2010.

¹⁶⁷ WWDA, *WWDA Position Statement 4: Sexual and Reproductive Rights*.

¹⁶⁸ Storr, *Motherhood, parenting & women with disabilities*.

Other impacts on health and wellbeing

Housing

Housing, employment, and financial security is essential for the health and wellbeing of women with disabilities.¹⁶⁹ Women with disabilities require suitable, affordable, sustainable, and accessible housing. Living in accommodation that is suitable to their impairment is essential, and so if their disability status changes, they may have no choice but to move to a new house to better suit their needs. Renting can be difficult, as landlords may not make necessary changes to the house.¹⁷⁰ Women with disability are paying the highest per cent of their income on suitable housing options, even though they are often earning less, are less likely to be in paid work and are spending higher amounts on healthcare than the rest of the population. They are more likely to live in public housing and institutions than men with disabilities. Women with disabilities are often living in circumstances where they are at risk of or likely to experience violence, neglect, and sexual assault.¹⁷¹

A local report by Women with Disabilities ACT in 2015 showed that housing options were a major concern and source of stress for women. They discussed that there was a shortage of suitable housing, and noted that there were not many housing options that met their individual needs, or were close to services. Additionally, many suitable housing choices were unaffordable for women.¹⁷²

Financial security and employment

People with disability are much more likely to live in poverty than the general population, with 1 in 6 people with disability living in poverty compared with just over 1 in 10 people without disability.¹⁷³ Households that include a person with a disability tend to have *“lower incomes, less wealth, greater reliance on government pensions and allowances, and a higher incidence of financial stress”*.¹⁷⁴ Women with disabilities are often worse off financially than men with disabilities¹⁷⁵ and are often in precarious financial situations.¹⁷⁶ Accessing government support is also complicated where they may have to juggle government payments and finding suitable and sustainable employment. Women who are unable to continue employment due to their disabling condition but have not yet been diagnosed are often not able to obtain the disability support pension.¹⁷⁷ In the 2020 Women with Disability ACT report on the impacts of COVID-19, many of the women were in employment and not claiming benefits. Because of this they were not eligible for government assistance, which impacted them negatively. Some women could not continue with paid employment as they did not have the support (such as therapies) to help them to continue, or to complete schooling.¹⁷⁸

In the 2015 Women with Disabilities ACT report, women with disabilities discussed how important employment was to their ability to feel socially included. They described how important workplaces

¹⁶⁹ Gough, ‘Contributing our voices!’

¹⁷⁰ Storr, *Motherhood, parenting & women with disabilities*.

¹⁷¹ WWDA, ‘Shut out, hung out, left out, missing out’.

¹⁷² Gough, ‘Contributing our voices!’

¹⁷³ Davidson, P et al., *Poverty in Australia*, 2018. ACOSS/UNSW Poverty and Inequality Partnership Report No. 2, Sydney, 2018, https://www.acoss.org.au/wp-content/uploads/2018/10/ACOSS_Poverty-in-Australia-Report_Web-Final.pdf

¹⁷⁴ Carnovale, *Strong women, great city*.

¹⁷⁵ WWDA, ‘Shut out, hung out, left out, missing out’.

¹⁷⁶ Gough, ‘Contributing our voices!’

¹⁷⁷ Gough, ‘Contributing our voices!’

¹⁷⁸ Shanmukhasundaram, *“The Responsibility has Fallen on Us”*.

that demonstrated diversity and inclusion were. Workplaces often lacked resources to help women perform their role adequately. This was particularly challenging for women managing chronic episodic conditions that needed variable and flexible working conditions.¹⁷⁹ Women's Health Matters research with younger women who have chronic disease found that there was pressure to fulfill their work duties and some were continually running out of allocated sick leave.¹⁸⁰ Many of the women reported wanting to work but faced barriers trying to do so. They reported facing discrimination at their place of employment and when seeking employment. Women also mentioned there were hidden costs with employment such as travel costs. Flexibility was helpful in managing their employment and impairment.¹⁸¹

In the 2012 report *Strong women, great city*, many of the women with disabilities told researchers how their actual employment did not match their preferred employment status. All of the women who were unemployed wanted to be in employment. They felt that their most important employment requirements were supportive colleagues, flexible hours, and transport assistance. Some women had experienced insufficient support or opportunities, and discrimination in their employment.¹⁸²

Caring and parenting responsibilities

*"Despite our caring responsibilities, we often are not recognised as either carers or parents, nor provided with responsive antenatal and post-natal care."*¹⁸³

Women with disabilities often have caring roles which can have an impact on their own health and wellbeing. One third of the women in the 2012 report *Strong women, great city* had caring responsibilities.¹⁸⁴ In the 2020 WWDACT report on ACT women and the impacts of COVID-19, around half of the women were carers of children, of an adult or had an ad hoc caring arrangement. Some women reported their caring responsibilities had increased due to COVID-19.¹⁸⁵ More generally women's time is often taken up by child rearing and household responsibilities more than men.¹⁸⁶

Women with disabilities, like any other women, may want to have children. An older literature review undertaken by Women with Disabilities Australia showed that women with disabilities have been subjected to judgement and stigma when wanting to or thinking about having children and in some cases forced into birth control or sterilisation.¹⁸⁷ After having children, some women may worry about or even have their children taken away due to the perception that they cannot be good or adequate parents. One of the most important and contentious part of having a child appeared to be the quality and consistency of help or service provision. If women received support that was either negative or not suitable then this impacted their confidence adversely. On the converse, positive support

¹⁷⁹ Gough, 'Contributing our voices!'

¹⁸⁰ Hutchison, "I don't have the spoons for that..."

¹⁸¹ Gough, 'Contributing our voices!'

¹⁸² Carnovale, *Strong women, great city*.

¹⁸³ Women's Health Victoria, *Health issues for Women*.

¹⁸⁴ Carnovale, *Strong women, great city*.

¹⁸⁵ Shanmukhasundaram, "The Responsibility has Fallen on Us".

¹⁸⁶ S P Fullagar & P R Brown, 'Everyday temporalities: leisure, ethics and young women's emotional wellbeing', *Annals of Leisure Research*, vol. 6, no. 3, 2003, pp. 193-208.

¹⁸⁷ Frohmader, *Dehumanised*.

promoted self-confidence. They also worried about asking for help as the risk of looking like they could not cope was risky to the stability of their family.¹⁸⁸

Relationships

Relationships, whether romantic or friendship, are essential for health and wellbeing. Lack of relationships, including feeling isolated, can have significant impacts on a person's mental and physical health. Women Health Matters research has highlighted the importance and difficulty of maintaining relationships and the distress it causes when they dwindle. Women felt left out and unable to form lasting relationships as their impairments impacted their ability to engage socially and their friends often excluded them.¹⁸⁹

Conclusion

Our literature review explored the main health and wellbeing issues for women with disabilities using local reports and research together with relevant national and international studies. We explored what health services and supports women access, the barriers they face in accessing health services, and their access to information for their health. We also explored conditions that may impact on women's health and wellbeing, including how women experience life roles and other impacts on health and wellbeing, such as housing, employment, transport, and social inclusion. Our review shows that women with disabilities are impacted by their gender, how society views them and how they are treated. Women with disabilities deserve and require nuanced and specific health supports and information, and it is essential that it is affordable, available, accessible, and appropriate.

¹⁸⁸ Storr, *Motherhood, parenting & women with disabilities*.

¹⁸⁹ Hutchison, *"I don't have the spoons for that..."*

Methodology

The research design used both quantitative and qualitative methods to collect and interpret information on the views and experiences of women with disabilities about their health and wellbeing needs and access to health services and supports.

An initial online survey was conducted in February 2021 to consult with ACT women with disabilities and to collect quantitative and qualitative data.

The survey sought to answer the following research questions:

- How ACT women who have a disability understand and manage their health needs.
- Which health services, supports and information they use and whether they experience barriers to that access.
- What barriers they experience to maintaining good health and wellbeing.

Respondents qualifying for the survey were women who had identified that they had a disability, were 16 years old or over, and were living or working in the ACT or surrounding regions.

The online survey provided all participants with information about the project and an indication that, by completing and submitting the form, they were consenting to their information being stored and used for the purposes of this research. There was a chance to win one of two \$50 grocery voucher or cash.

The online survey was available via a link on the Women's Health Matters website and distributed through Women's Health Matters and Women with Disabilities ACT (WWDACT) email networks and through those of other community organisations, services providers, government networks and the Community Development Network. It was also promoted through the Women's Health Matters and WWDACT newsletter and Facebook.

The survey was open for 4 weeks. A total of 91 valid surveys were collected.

The online survey was also used to directly recruit participants for the focus groups. The final question asked women to indicate if they would like to participate, and if so to provide contact details.

The focus groups aimed to explore in greater detail the findings identified in the analysis of the survey responses. Focus groups were held in March 2021. Twelve women participated in the focus groups and replacement interviews, with groups organised by availability, giving a random demographic sample of age, disability, ethnicity, and sexuality.

The number of participants was lower than in previous focus group call outs. This was expected and can be attributed to the complex health and access needs of this marginalised group. Some offers were made to run replacement online focus groups to mitigate some barriers to participation,

however as the report found, many women with disabilities also do not find internet technologies accessible.

The quantitative and qualitative answers to the survey were then analysed and coded using Microsoft Excel. Thematic coding and analysis building on the findings of the survey was then undertaken to analyse the focus group and interview data.

As with all surveys conducted to date by Women's Health Matters, we used a non-probability convenience sample. This means that the survey was widely promoted, and all women were welcome to participate. As a result, the numbers of women in our sample does not reflect the population of women with disability in the ACT as a whole and it is therefore not representative.

Rather, the findings laid out in this report capture themes from the sample and provide an indication of the issues that exist for women with disabilities in the ACT.

Findings

Demographics: the women who completed the survey

Ninety one women completed a valid survey response in a 4 week period in February 2021. Five of the responses came from a survey filled out by parents and partners who are in caring relationships with a woman with a disability. Table 1 shows the age groups of the women who responded to the survey.

| Age | Number | Per cent |
|--------------------|--------|----------|
| 16-24 years old | 8 | 8.8% |
| 25-34 years old | 22 | 24.2% |
| 35-44 years old | 19 | 20.9% |
| 45-54 years old | 16 | 17.6% |
| 55-64 years old | 18 | 19.8% |
| 65 years and older | 8 | 8.8% |

Table 1: Ages of women who responded to the survey. Per cent does not add up to 100% due to decimal rounding.

Table 2 shows 69.2% of respondents had a physical impairment, 41.8% of respondents had a psycho-social impairment, and 35.2% of respondents had a neurological impairment.

| Impairment | Number | Per cent |
|---------------|--------|----------|
| Physical | 63 | 69.2% |
| Psycho-social | 38 | 41.8% |
| Neurological | 32 | 35.2% |
| Sensory | 9 | 9.9% |
| Intellectual | 5 | 5.5% |

Table 2: What type of impairment women reported that they experience. Per cent does not add up to 100% as respondents were able to choose multiple options

Four women identified as Aboriginal and/ or Torres Strait Islander. Three women preferred not to answer if they identified as Aboriginal and/ or Torres Strait Islander, and one did not say.

Three women spoke a language other than English at home. Three women preferred not to say.

Thirty six women reported they identified as a lesbian, gay, bi, queer, trans or intersex women, accounting for 39.6% of the respondents. Four women preferred not to say. The main sexual identities were queer, bisexual, lesbian, pansexual and there were three who identified as trans or gender non-binary.

Figure 1 shows where respondents reported that they lived. The highest number of respondents lived in Belconnen (n= 19, 20.9%), followed by Tuggeranong (n=18, 19.8%), and the Inner North (n=18, 19.8%).

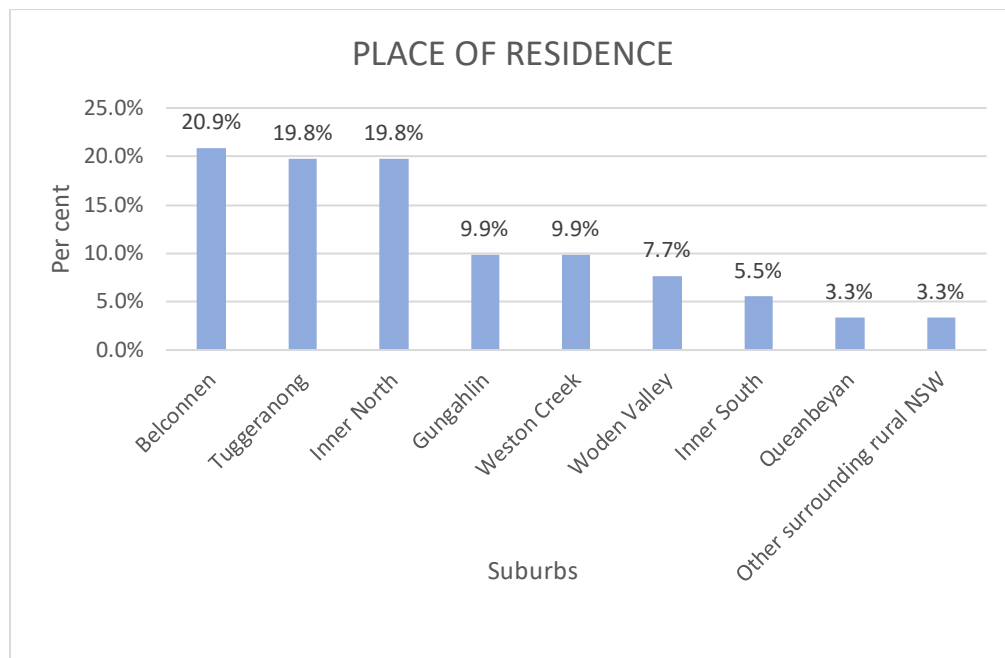


Figure 1: Place of residence of respondents. Per cent total does not add up to 100% due to rounding.

Self-rated health

Women were asked to rate their physical health, as shown in Figure 2. Just over 15% of women rated their physical health as either excellent or good (n=14). Other women rated their physical health as fair (n=36, 43.3%), poor (n=32, 35.6%) or very poor (n=5, 5.6%).

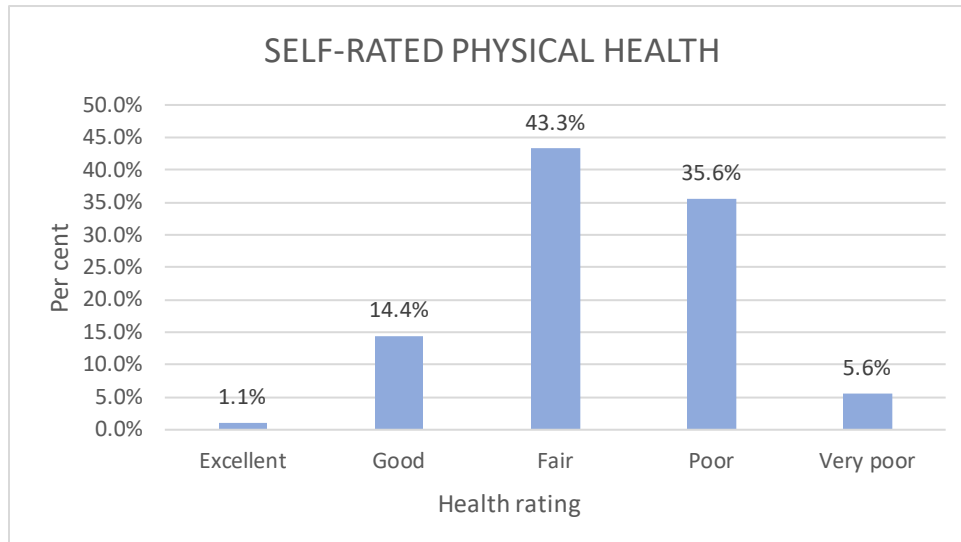


Figure 2: Self-rated physical health.

Women were asked to rate their mental health, as shown in Figure 3. Twenty per cent of women rated their mental health as good (n=18). None rated their mental health as excellent. Women predominantly rated their mental health as fair (n=37, 41.1%), while 30.0% rated it as poor (n=27), and 8.9% rated their mental health as very poor (n=8) as shown as Figure 3.

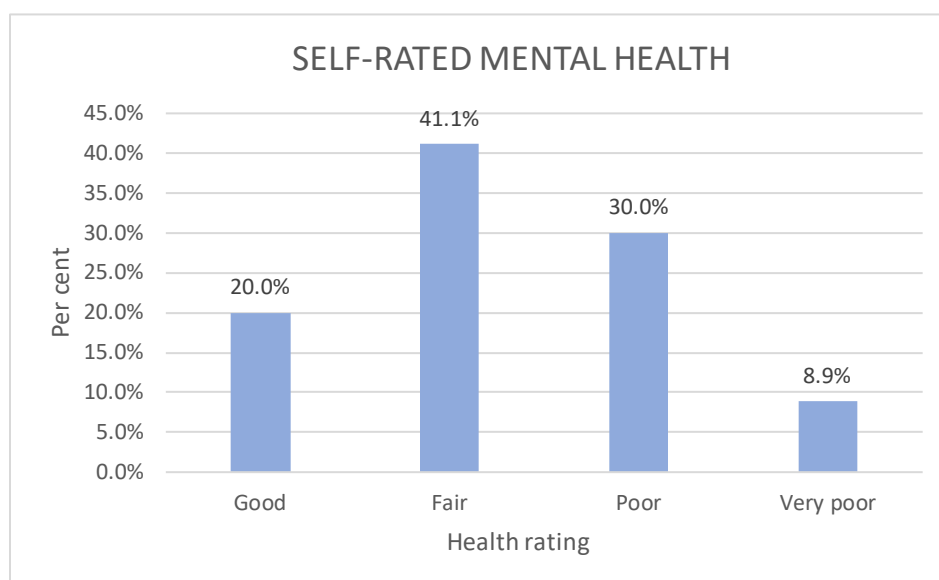


Figure 3: Self-rated mental health.

There were differences in self-rated physical and mental health between age groups, although the small number of respondents mean that these differences should be interpreted with caution. Thirty one point eight per cent of 25-34 year olds rated their physical health as good or excellent (n=7), see Figure 4. In contrast, only one woman in the 35-44 year old group rated their physical health as good or excellent.

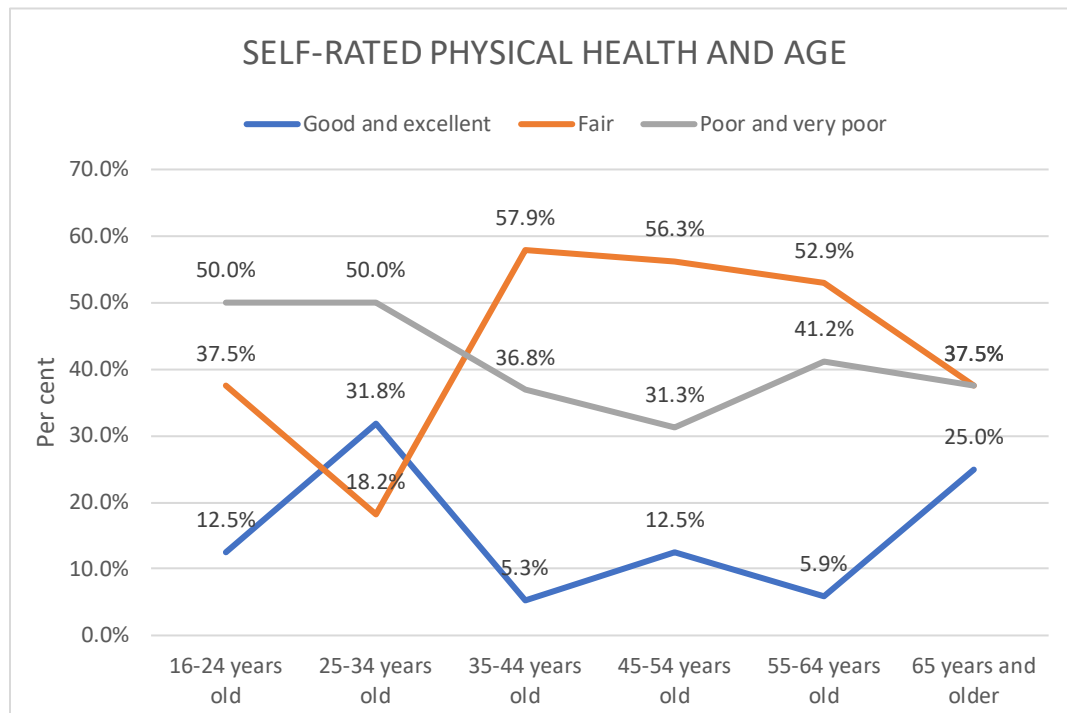


Figure 4: Self-rated physical health disaggregated by age.

Six women aged 55-64 years old had good or excellent ratings of mental health, which was higher than other age groups (35.3%). In contrast, three women aged 16-24 years rated their mental health poor or very poor (62.5%) (see Figure 5).

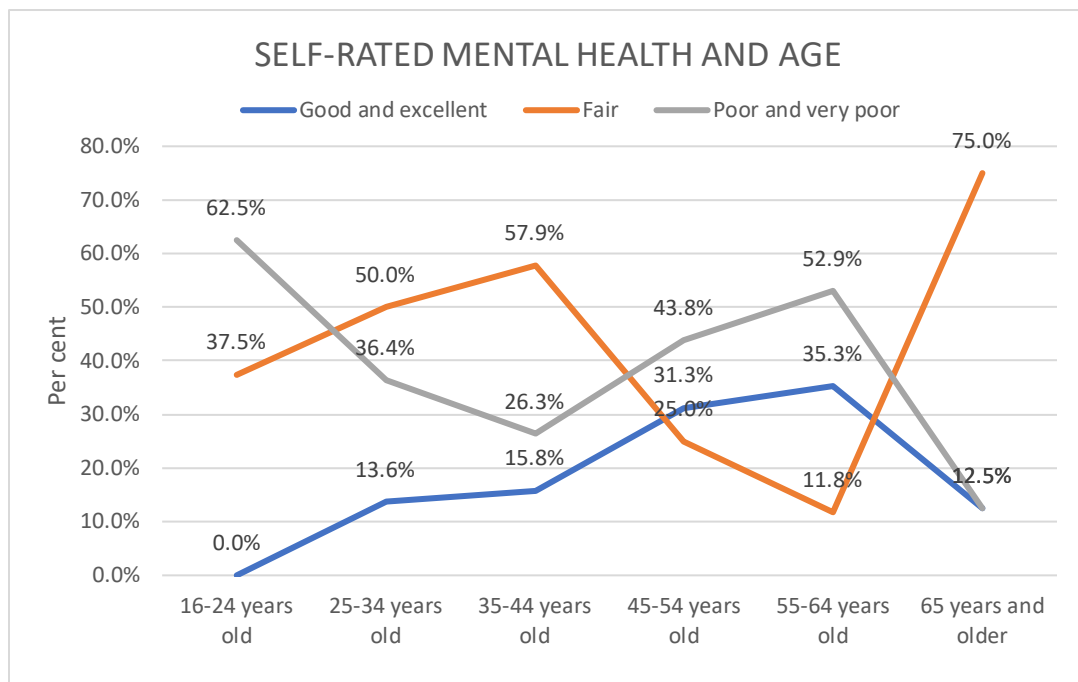


Figure 5: Self-rated mental health disaggregated by age.

Figure 6 shows that 50.0% of women who reported good or excellent physical health also reported they had poor or very poor mental health (n=7). And 45.9% of women who reported poor or very poor physical health reported poor or very poor mental health.

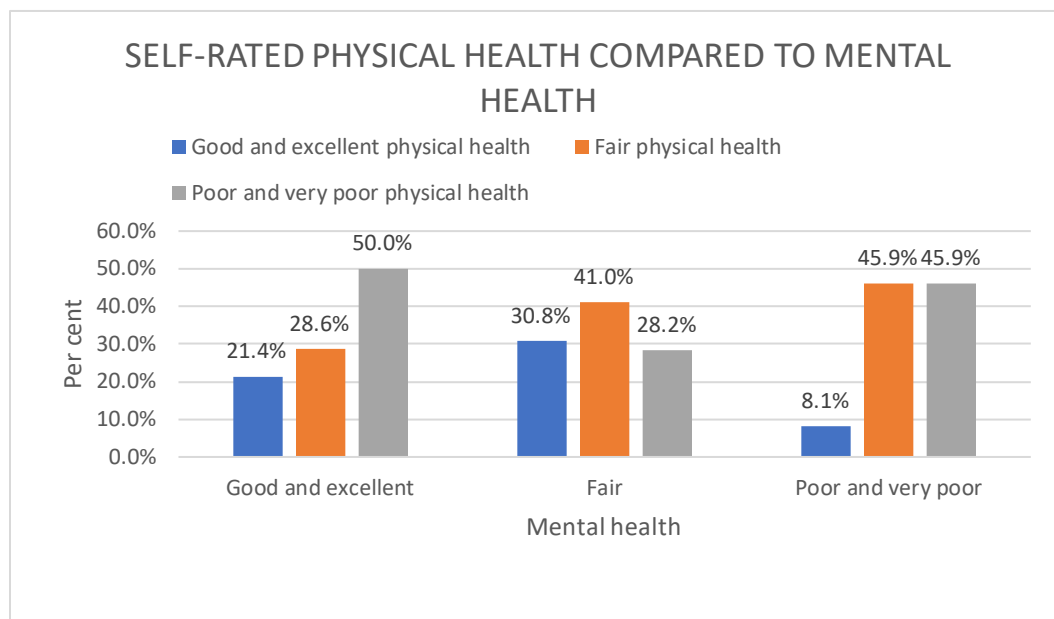


Figure 6: Self-rated physical health compared to mental health

The health services that ACT women with a disability accessed

Most women reported that they were not able to find services in Canberra to help them to obtain and maintain good health (n=46, 50.5%). Thirty-seven women responded that they were able to find services to help them to obtain and maintain good health (40.7%), and 3 reported that they did not know or had not tried. Four women did not say, and one preferred not to answer.

Women accessed a range of health services in Canberra in the last twelve months. GPs were the most accessed health service (n=81, 89.0%), followed by filling a prescription (n=75, 82.4%), and attending a specialist doctor (n=52, 57.1%) as shown in Figure 7. The Emergency Department was accessed 'For emergency' and 'For non-emergency' and listed below. Four women did not say if they accessed services.

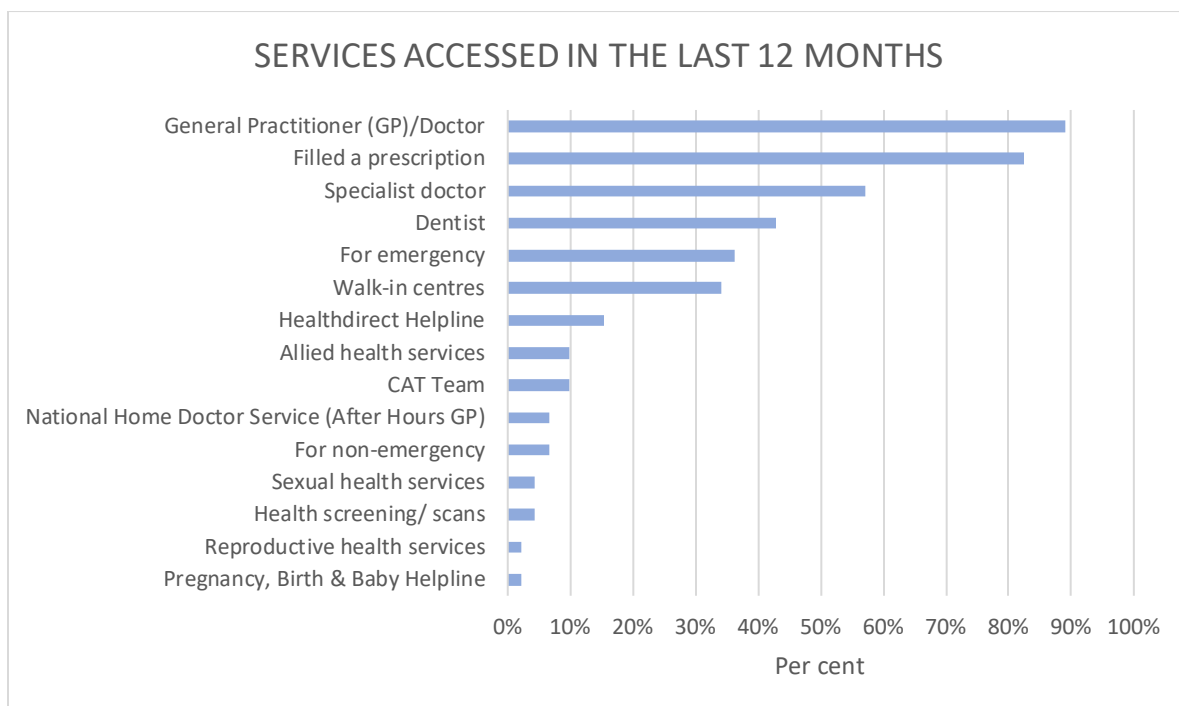


Figure 7: Services accessed by respondents in the last 12 months.

There are differences between the age groups of women accessing health services in the last 12 months, although again the small number of respondents mean these differences should be interpreted with caution. Women aged 35-44 and 45-54 accessed walk-in centres more than other age groups. Women 25-34 years old accessed the health direct helpline more than other age groups (n=7, 31.8%).

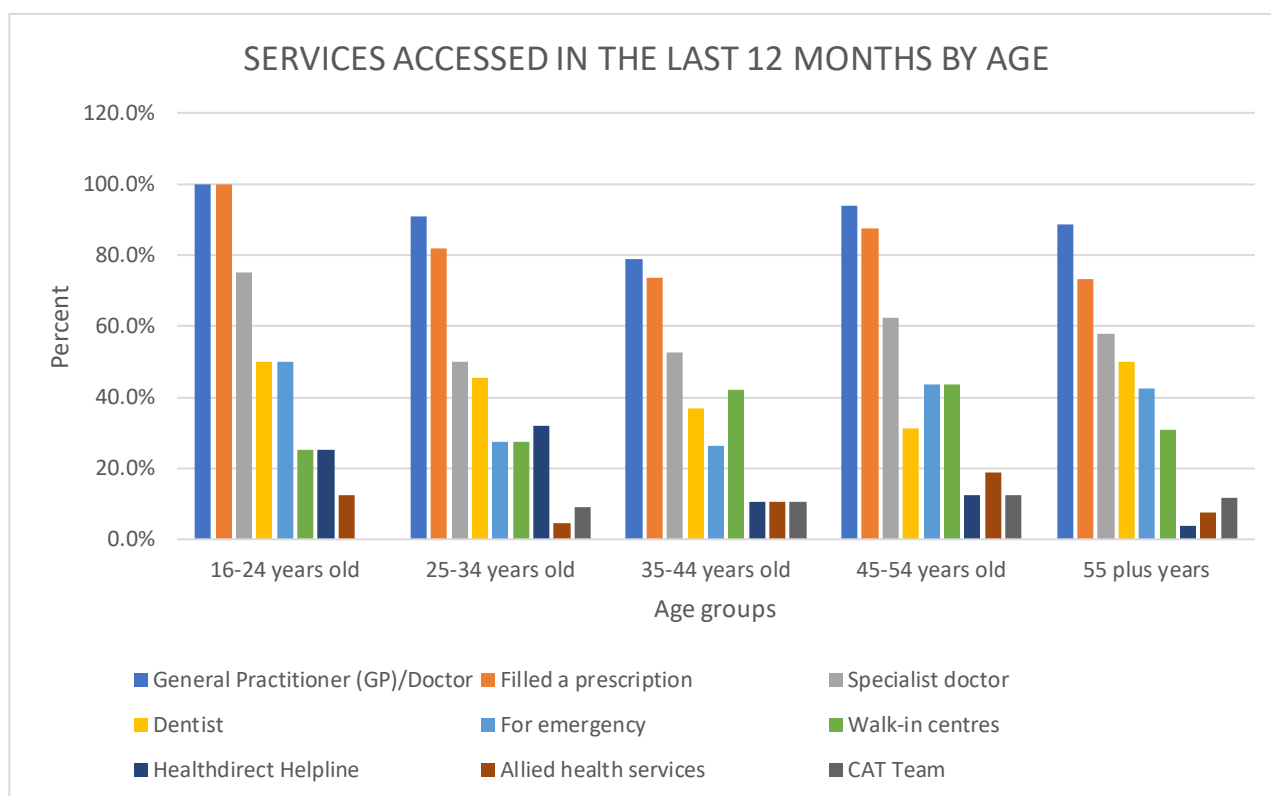


Figure 8: Services accessed by respondents in the last 12 months by age group.

Most women accessed health services for themselves (n=80, 87.9%), while 23.1% accessed for their child/children (n=21), and 18.7% for their partner (n=17). Others accessed health services on behalf of their parents (n=6, 6.6%), another family member (n=7, 7.7%), or their friends (n=2, 2.2%). Three women did not say. Five respondents who answered as carers on behalf of the women with a disability did not have the option of answering this question.

Eighty one women reported they have a regular GP (89.0%), and two did not say. Eight women reported that they did not have a regular GP (8.8%) and mentioned issues with maintaining a regular GP, such as their regular GP having left suddenly, the fact that they were looking for a new GP to get a better experience, seeing a regular GP being expensive, and wait times to see a regular GP.

Barriers or difficulties experienced when accessing health services

Survey respondents were asked if they experienced any difficulties or barriers when accessing health services. Respondents were given a list of barriers and could select any that were applicable to them. There was also space to give alternative answers to what was listed.

Eighty four women mentioned barriers to health services. The top listed barriers were affordability (n=64, 70.3%), appointment availability (n=52, 57.1%), and long wait times (n=51, 56.0%), as shown in Figure 9. One woman reported no barriers and 6 women did not say if they had barriers. Respondents who selected 'other' identified lack of services and dissatisfaction with services as barriers.

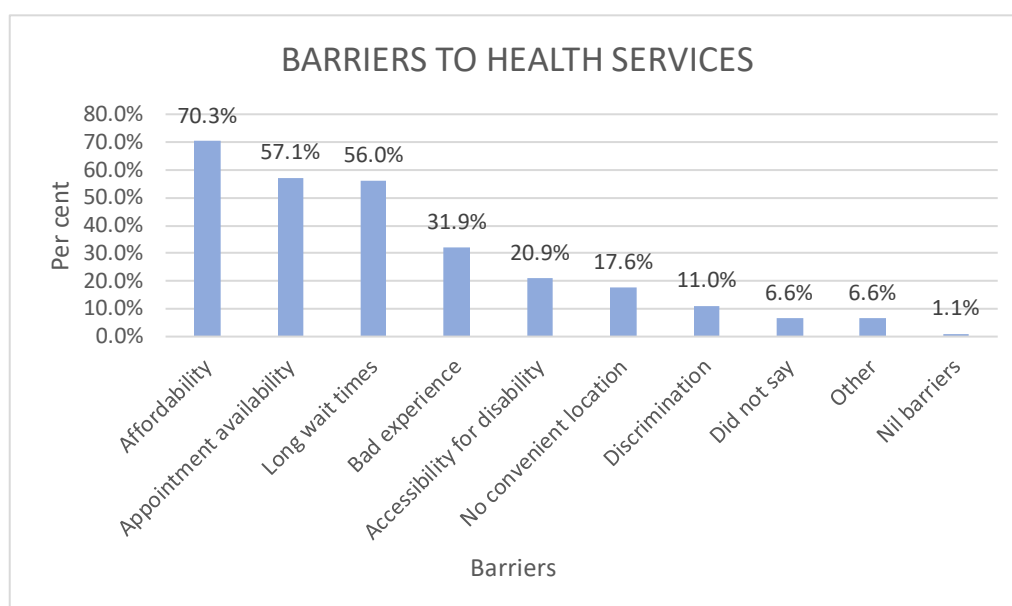


Figure 9: Barriers to health services. Per cent does not add up to 100% as respondents were able to choose multiple options

Forty six women provided further comments regarding their ability to access services and supports to maintain their good health in the ACT.

Twenty three respondents reported there is a significant lack of services in the ACT to meet their needs. Respondents reported that it was difficult to find or navigate services, or that they cannot find any services in their area, and some women reported needing to access services in different states.

"There are no specialists for my condition in Canberra".

"We are very much lacking a day unit for infusions. Both north side and southside only have cancer day units which are far from appropriate for those with autoimmune disease and there are only private services available for cancer related infusions even if it's the same drug we cannot access the private unit".

"Dr's have told us to go to Sydney or Queensland for treatment as they have more specialist to assist and know more about genetic conditions".

"I can't get adequate support for my chronic fatigue syndrome. But if I need, sutures, surgery or a plaster cast, that's available. I visit the GP for an annual check up, including skin cancer checks, & flu vaccine".

Twelve respondents mentioned how unaffordable they felt some services were, particularly if they were accessing more than one. They were frustrated with the lack of bulk billing services for specialists or GP services.

"I cannot afford the services I have to pay for, and the free ones have waiting periods of up to two years".

Some women discussed their poor experiences with health services in the ACT, reported that they were not believed, there were conflicts in terms of who was responsible for patient care and they were not able to get the help they needed.

"It is also hard to convince experts of what I want as opposed to what they think in the immediate situation. It causes mental stress and in the end they agree with my initial instincts after doing more tests that should have been instigated at the beginning. There is also the conflict between ED discharge and required follow up and the GP plan for further care. It can be confusing and not all issues addressed".

"I have Ankylosing Spondylitis - it is a very painful condition with no cure and takes away your mobility. I have tried all the pain management services in Canberra and they have been useless. I live alone and cannot walk more than about 10 steps".

"It's been difficult to actually find services, and to be confident that they will actually meet my needs without just compounding healthcare related trauma".

Other respondents discussed services negatively. They mentioned that some services were not addressing their needs, they waited a long time at the health service to see someone, and there were long wait times to get an appointment. Some women found that services were not open at times that were appropriate for their needs, for example limited after hours appointments.

Over ninety per cent of 25-34 year olds listed affordability as a barrier to health services (n=20), which was higher than other age groups. Women aged 16-24 listed bad experience higher per cent than other groups (50%, n=4), as seen in Figure 10.

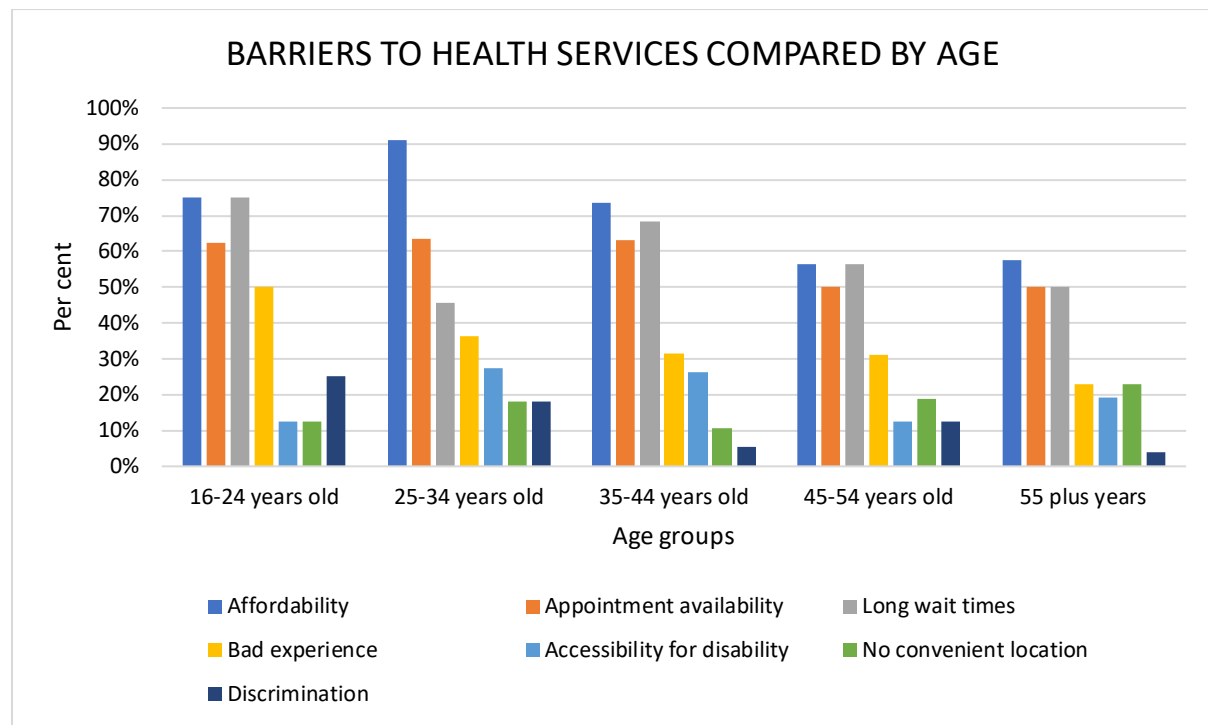


Figure 10: Barriers to health services compared by age.

Sexual and reproductive health services

Women were asked if they accessed services for their sexual and reproductive health. Thirty five women reported they accessed services for their sexual and reproductive health (38.5%) and 44 reported they did not (48.4%). Ten preferred not to say and 2 did not say.

Respondents were able to give reasons for why they did not access sexual and reproductive health services. The main reasons were that they did not need to, it was not relevant, or due their older age. Some women reported that they had experienced trauma which discouraged them, some had barriers like cost and some said that they went occasionally.

This is one women's experience with her GP, which had impacted her sexual and reproductive health:

"Whenever I raise issue or concerns about things like changes in menstrual cycles due to my paralysis doctors have no idea about what might cause it, there is little to know knowledge about how spinal injury effect female sexual health. Beyond that I would usually sort that out through my GP, but given my current GP is less than capable sexual health is one of the things that has fallen by the wayside".

Twenty eight women said that they had difficulties or barriers accessing services for their sexual and reproductive health (30.8%). Fifty nine women said they had not experienced barriers (64.8%). Four women did not say.

Women reported that they had complex sexual and reproductive health needs. Women were dissatisfied with treatment by health providers due to lack of understanding and willingness to believe in the patient's story.

"Difficulty getting doctors to do anything about female pain and sexual health. Complaints of chronic and debilitating uterine pain was met with disbelief, derision, offers of painkillers, and suggestions that I lose weight. Eventually I found a GP willing to actually run some tests and give me an OB/GYN referral, who took another 18 months of convincing that I knew my own body before he agreed to treat me".

"Complex connective tissue disorders result in most doctors not wanting to look at things comprehensively. Certain amount of assumptions that lesbians don't have certain health concerns. Health system works off Caucasian (/male) population. Not integrated with post separation abuse via family court".

"I can't afford to see a gynaecologist privately so needed to go to the hospital. I am very triggered by the hospital environment, both due to sensory issues and past trauma. However, I had no choice. My appointments at the hospital have been very distressing".

"Yes, I'm in a wheelchair and have a rare condition. I find out next week if i can start trying for a baby this year. I can't pick my team, or who will deliver. All of this is out of my hands as soon as i become pregnant. I have also had to change GP offices as they do not have accessible beds for things like pap smears etc".

Some women mentioned that sexual and reproductive health services were often either costly or there were long wait times to meet their health needs.

"I would like to, however the cost of seeing a specialist is more than I can afford. I'm currently on the waiting list through the public sector, however, I have been told the referral will take up to 12month until I see someone".

"I'm not sure what is now available in the public sector. Did have a check up at local community centre but it was ceased and was referred elsewhere which incurred a cost".

Other women mentioned peer services as essential but reported that there was not enough capacity at the services.

"Meridian is great for sexual health testing but does not offer it enough - we need more services in peer support for LGBTIQAA+ community".

"Meridian only offers sexual health testing once a month - needs to be weekly".

"Again, services like Meridian which are peer services and where I want to go - are full or they don't offer enough".

Women's top health issues

Women with disabilities were asked to identify their top three health issues. Ninety one women responded to this question.

Respondents were given a list of options and there was a text box to add their own answers. Eighty-six women listed 'sleep, fatigue or energy issues', 'pain or chronic pain', or 'mental health' as one of their top three health issues (94.5%). 'Sleep, fatigue or energy issues' were listed more than any other theme, as per Table 3.

| Top three health issues | Number | Per cent |
|--------------------------------|--------|----------|
| Sleep, fatigue or energy issue | 59 | 64.8% |
| Pain or chronic pain | 54 | 59.3% |
| Mental health | 52 | 57.1% |

Table 3: Top three health issues – percentages do not add up to 100%, participants were asked to select more than one option.

Respondents also listed issues other than 'sleep, fatigue or energy issues', 'pain or chronic pain', or 'mental health'. The fourth most reported health issue was 'weight, diet and fitness' (n=39), followed by 'chronic disease' (n=38), as shown in Figure 11.

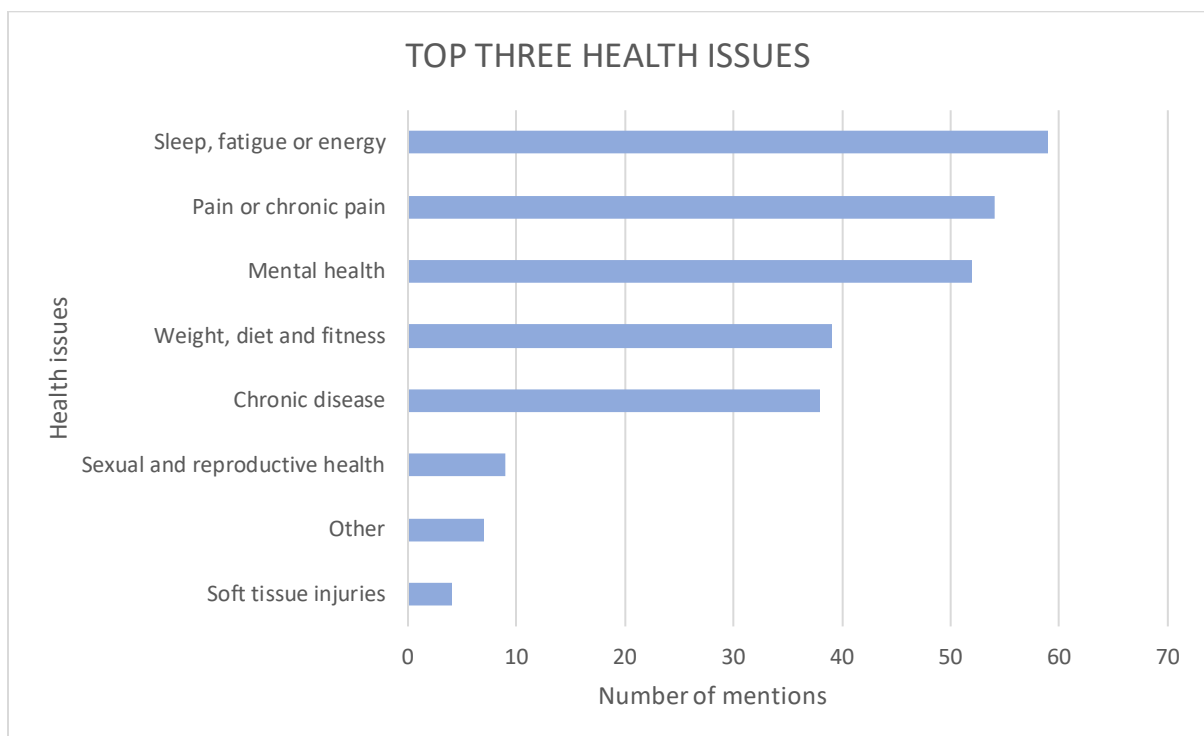


Figure 11: Top health issues for women with disabilities.

There were differences between the different age groups of women with disabilities regarding their top health issues. The 45-54 years old age group reported 'mental health' as their top health condition more than the other age groups (Figure 12). Likewise, 55-64 year old group listed 'pain or chronic pain' and 'sleep, fatigue or energy' more than the other five age groups.

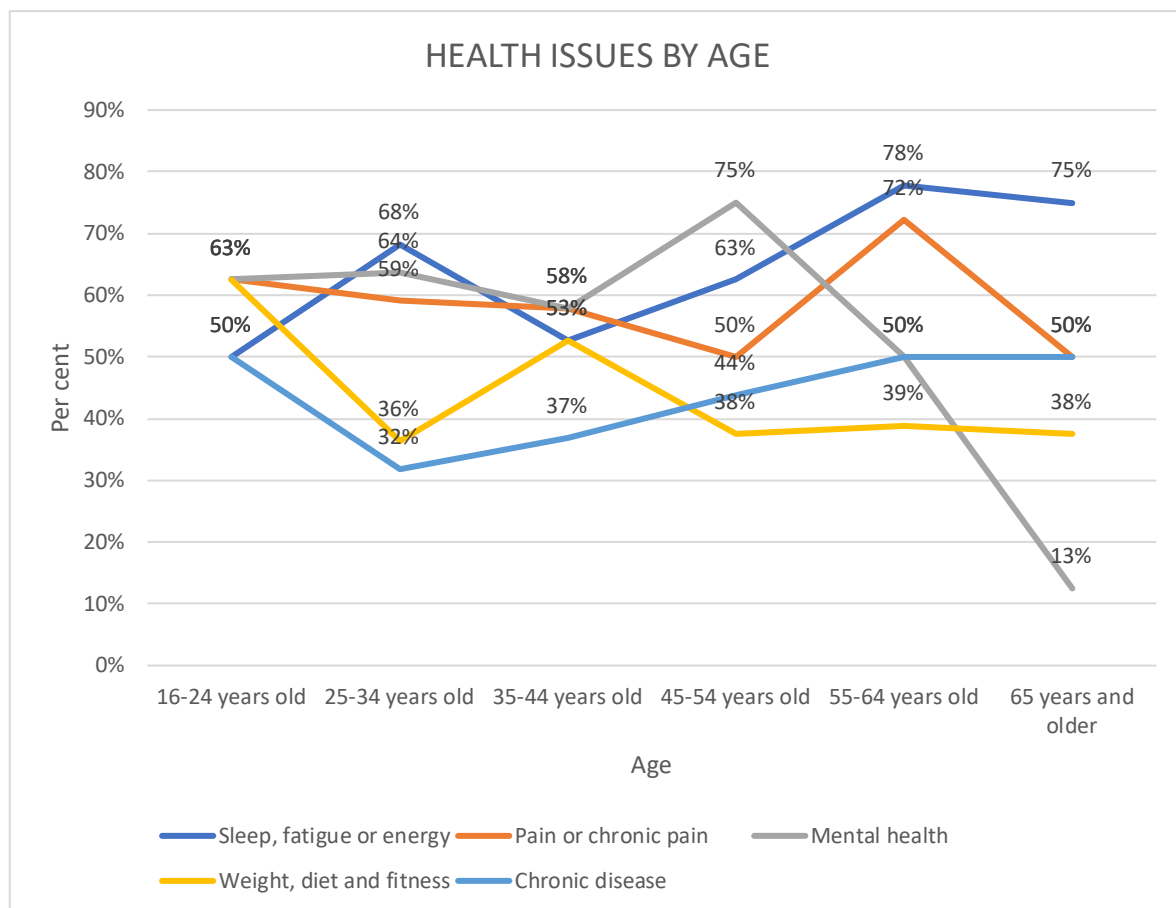


Figure 12: Top health conditions disaggregated by age.

Health services and supports for top health issues

Women were asked if they had services and/or supports to help them to address their top three health issues. Forty five women reported that there were services and supports (49.5%), and 23 women reported that they did not (n=23, 25.3%). Nine women reported that there were, but they had barriers to those services and 6 women described mixed situations.

Sixty one women told us additional information about those services and/or supports, most reported they had accessed a GP (n=35), mental health supports, such as psychiatrists or psychologists (n=26), allied health, such as dietitians, exercise physiologists and physiotherapists (n=21), and specialists, such as rheumatologists and gynaecologists (n=17).

Only 18 women out of the 35 women (51.4%) who reported 'mental health' as one of their top three health issues said that they were accessing a mental health service or professional to address their mental health issue.

Women that reported that they did not have services and/or supports to help them address their top three health issues reported issues such as feeling left behind, dismissed and treated poorly by the health profession.

"I feel I can only ask my GP, who does not appear to want to investigate or refer me to other services".

"Not particularly. I rely more on friends and loved ones for support regarding health issues, as the health services are underequipped to deal with chronic, long-term illness. Many focus on solutions for immediate problems rather than managing long-term chronic".

"Not exactly. I have endo and most Drs have given up on me".

"No, there is not much support out there for my condition".

Some women also mentioned affordability of services, not being able to find any services and supports, and how wait times impacted their ability to access services and supports.

"No, on a disability pension, I can't afford to visit private practitioners who charge a fortune for questionable results. (I blew all my savings seeking solutions at the beginning of this illness)..."

"Health care is costly. My physio does not have a hi-caps link, so I have to pay for these visits in full".

Barriers for top health issues

Women were also asked if they had any barriers to accessing health services and supports for their top three health issues. Seventy two women reported that they had barriers (79.1%), 9 reported no barriers (9.9%), and 10 women did not say. The most discussed barrier was affordability and cost of services (n=33).

"Cost is a massive barrier. For example, I would greatly benefit from sessions with a PT but absolutely cannot afford it".

"Money. Cannot afford to see a private doctor and specialists very often. I'm unemployed due to covid, so money is a challenge".

"Financial, my life is very controlled by my poverty".

"Financially, medical care is expensive to pursue when often there is no benefit. Add to that, there are no specialists in the ACT who focus on my condition. The nature of the condition makes full time work impossible for many, so financial imposts must be carefully weighed".

"Many of the health issues are exacerbated by lacking the funds for proper management and treatment. For example, my muscular disorders benefits greatly from remedial

massages, but it is an out-of-pocket cost. Since I am currently unemployed and on a Centrelink payment, it is not financially possible for me to keep up a regular treatment routine”.

Wait times were reported as a significant barrier for women, with some having to wait months to get the treatment required to meet their needs. If they could afford private health services, then they reported waiting less time.

“Been waiting for The Canberra Hospital Pain Clinic appt nearly 18 months without success, GP although very nice tends to overlook issues or ignore them”.

“Some women discussed that there are services that are accessible only if you can afford it, otherwise you need to wait for them”.

“The lack of capacity - many services have lengthy waiting lists”.

Some women discussed how they were dismissed by health professionals and that disrupts their access to adequate care.

“Don't want to be labelled a "difficult" patient. Feeling like doctors don't listen/hear what I say”.

“Yes, the poor attitude of health care staff to people with illnesses that aren't obvious to them”.

Women talked about how navigating health services and supports were difficult, particularly when needing to access multiple services.

“I also feel fatigued all the time and it is tiring going from one health professional to the next (I wish there was better communication between everyone involved in my care). I also regularly have bad experiences with health professionals who do not believe my pain, just tell me to lose weight etc. which reduces my trust in these institutions and prevents me from getting the care I need”.

“Appropriate physical access. And a general lack of understanding of the potential difficulties faced even getting to supports and services. Lack of centralised information about health service for women with disabilities”.

Some women discussed services not being open when they are available, such as after work hours.

“Working full time it's hard to fit visits in”.

“I work full-time so have trouble getting time off work”.

“Limited service hours and capacity”.

One woman also talked about how the health system was failing to address her needs adequately.

"There are services, but they are ineffective to meet my needs. They are expensive and have long waiting periods. Since restrictions on prescribing codeine for more than six months for chronic pain came into being, my pain is no longer controlled and it is very difficult for me to work".

Focus groups: barriers to health services

In the focus groups, affordability of services was a barrier to access for most women with disabilities. These women could only access the services that they needed at a subsidised rate, and found that the amount of sessions available did not meet their needs.

"I too have found it hard to access that, because I'm not working at the moment, not able to work, and so I don't have the... financial ability to fork out going to specialists and stuff so I have to rely on these services that are available to me at a heavily subsidised rate or free..."

"My big wish list in that regard would be for them to put physiotherapy on Medicare. Because I can't survive without my physio. And I've got a little health fund that gives me 10 visits a year, I can get 5 visits a year on Medicare, which is 15, and I probably go 30 times a year. So after they run out, I pay \$70-80 a visit... I have got to go. Because I just lock up, I just can't move if I don't go".

"I have a cognitive disability, but I also see a physio, occupational therapist and hydro-therapist. And I'm concerned that... NDIS can only focus on one area, instead of two when you've got dual disability, and PTSD. So they took off all my wellbeing for psychological- and I see a clinic psychologist- and they took off all the wellbeing... and said oh no you can have that or that... and I'm only on a disability pension".

Many women in the focus groups and interviews reported that a lack of accessible transport options to attend medical appointments was a barrier to access. There were issues of wait times not only for buses to appointments, but the connections between bus stops and the services themselves were often just as difficult or inappropriate for women with disabilities.

"I would like it to be easier to get access- specifically getting to the hospital. I have to go every six weeks to have an infusion... and it's very difficult to walk.... Now I have to take community transport, but then I often wait half an hour for someone to bring a wheelchair and take me up to the cancer unit. And coming back I can wait for hours for somebody to take me down, and then I might have to wait another two hours for community transport to turn up. They haven't got enough wardsmen, volunteers, whatever. And this seems to be a common issue".

"One of my biggest barriers would be... getting public transport in a timely fashion to get to specific health appointments, the hospital, currently the hospital, their bus stop are not

very accessible because they've shifted it from hospital road to pretty inaccessible spots on steep slopes...public transport isn't geared specifically to medical and health services".

One participant was interviewed with the help of her support worker. The participant was prompted by their support worker about how organising transport was difficult when you couldn't drive, and that relying on others reduced autonomy. Participant's support worker relayed that:

"Something you said that might stop you from being healthy, you said that transport can be a problem, getting to and from places, if you wanted to get to a club, or a bus to an appointment... you like to do a lot of physical activity, but sometimes getting there to those classes can be hard, because you don't drive a car, which is tough".

And the participant responded:

"I'm supposed to ask, but it's something that I would like to do for myself, because if I'm living on my own, I would need somebody to help me to find transport... yeah it's very difficult".

The factors of affordability and access came together for one participant, who described how the pitfalls of the transport subsidy scheme affected her health.

"I use the transport subsidy scheme, because I'm legally blind, and that's quite limited in how often you can use that, it's got a limited number of trips you can use... The taxi-subsidy scheme really only covers you for one and a half return trips a week... and... often you can't get a taxi, so once when I had whooping cough I waited outside for an hour in winter... because there was just none available... I actually know of people who say, well I haven't got any taxi subsidy vouchers left, so I just can't go to the doctor. So they are therefore, because it's one-a-half trips a week, if you're sick with something, that might mean that you don't get your groceries, or you can't go for a follow up".

Barriers to health services was felt doubly by women with disabilities who were also carers. They reported that juggling caring and looking after their health was very challenging and led additional feelings of stress and strain.

"It took all my cognitive load just to focus on everyday things. I was exhausted by the end of the day. And then to try and find information to- like I've had trouble with my periods, and you know, um perimenopause, and stuff... even when I- and I ended up with exhaustion and three compressed vertebrae after falling, I still had no one to help pretty much with the kids, apart for my mum. So the barriers for me were too afraid to leave the children and get out, not having the confidence, not knowing how or where to ask for help, and just not knowing what was available".

"I also was a full-time mother of a severe and complex [disability] son... he's got PTSD and anxiety because we've been subjected to a lot of violence, my children and I, through our lives... I sacrificed my life, and he's worth it, but he's severe and profound so I needed to

um leave. He now lives with my daughter... but I had many many years as a mother and a carer... it was a very challenging thirty-four years of my life”.

Here, for some women with a disability, the intersections of being a carer and experiencing family violence were further marginalising them from access to services.

For several women in focus groups and interviews who reported their physical access needs were not accommodated by health services, remote services such as Telehealth and the National Home Doctor Service (After Hours GP) enabled them to receive health care where they otherwise would not have been able to.

“I found with the telehealth thing, that was good for me was for me because leaving the house was so difficult... but telehealth got me domestic cleaning help, because the doctor went, just show me your room, and went, okay, I’m going to put in an application, you’re going to need some help, I didn’t realise it was this bad...”.

“Telehealth is fantastic. The other great thing... [is] Doctors Home Service, just brilliant. Because when you’ve got a- you know, when you’re blind and you’ve got kids, and you can’t catch public transport easily- like I’ve caught taxis with very sick kids in the middle of the night, to ED.... The more non-acute that you can have in the community the better”.

“I mean I feel telehealth was really helpful for me in that it just allowed me to just use those spoons for other things, right. So I don’t have to think about travelling to an appointment, getting there on time, doing all of these things. It was just, yeah it was simple and I guess gave me what felt like a lot of autonomy”.

“It was so much easier for me, because telehealth meant I didn’t have to get out of the house and actually go somewhere, and battle with getting in. I’d love to go back to permanent telehealth”.

For many women, the new services that became available during COVID-19 addressed barriers to access that they had experienced for long periods before the pandemic.

“Even things like my local chemist being prepared to send things out like I leave my scripts there and they’ll just send out what I need by mail and stuff. Those sort of services became available, I know you can do it, but a lot more places were doing things like that, and that was very useful for me, because quite often just leaving the house becomes a problem”.

“...people were having to reimagine different solutions to problems... different accessibility needs in the end is what we’re talking about, but it’s been brought into mainstream consciousness that actually people rely on all different methods that make their lives easier, and prior to this it felt like, yeah, accessibility was solely the domain for like disabled people and that’s it, whereas, we all need care, we all have lives that are impacted and disrupted by things like COVID and you know like a plural approach where people’s needs are met is actually yeah really crucial”.

Another health service that was seen as a more accessible alternative to the emergency department or a GP was walk-in centres. Several women with a disability in the focus groups and interviews reported that the walk-in centres gave them timely medical care and that they found the nurses very reassuring.

"I was finding difficulty breathing and things like that, and I thought well at least I'll go to the walk-in centre and they can listen to my chest, you know... the nurse came out and she said right, she listened to my chest, she did a few things and she said well, I'm not letting you do anything. She said, you can ring an ambulance, ring a friend, or if need be I'll take you to the hospital. You need to be seen. So... she was very very supportive... at this stage I start to get a bit stressed about it all... because I had driven there I thought oh and then I had to worry about the car, you know, and those little ancillary things, you know... the last nurse she was... very understanding and I think, I felt like even if I didn't have anything, it would have been nice just talking".

"I've only experienced it [the walk-in centre] twice. Once it was because my blood pressure was just crazy high... they were really nice... I find it difficult, like even when I had the asthma and stuff, and you're having an asthma attack... but you live on your own, so you call the ambulance, but you kind of wait until it's like too late sometimes because oh, you don't want to call an ambulance, I'm not dead yet, so that sort of, is it okay to call now? Whereas at the walk-in centre, the person I dealt with was very nice about that- no no no no, don't feel bad about it. And that made me feel very okay about going to the hospital".

The quality of care given by nurses at the walk-in centres was highly valued by women, and this was seen as something that removed barriers to seeking help such as 'ancillary', logistical concerns, and being unsure or feeling guilty about needing to call an ambulance.

Focus groups: trust in ongoing health care

Many women reported that the health services that they needed were not affordable on an ongoing basis, rather, they were targeted to acute care, which did not fit their more chronic needs.

"I don't want to have to be in crisis all the time, if I could get little bits of help that prevents me from going into crisis, my life could be very different.... I have been told by one of the mental health workers who come around, if you're in crisis you'll get all that help... if you got yourself to a state where you had to be in hospital, totally lost it, you would probably get the help that you need".

"I guess sort of similar experiences with counselling services that... there's limits on how many times you can see somebody... and you get that feeling that you're not, you know at this pointy end of you know things, where you just get this feeling where you're like actually you could go and do your own thing. It can be quite difficult".

"There is a need for more psychologists as lots in Canberra seem to have full books-or a huge wait to get an appointment when the need may be urgent".

"I don't always have the time to stop and go oh-gee, I'm snowed under, I'd like to talk... there was a stage where I was so isolated I could only really go to home to school to drop off the kids or to the supermarket... I was so, what's the word, in despair... so a touch[base]-service... it was simply somebody taking the load off by touching base with me – I didn't realise it was so much effort, having to call, to seek... the responsibility had been minimised, you know I look back now and I think, I'm so grateful... just one simple thing, somebody just calling... just being available".

Some of the services available when they were at a crisis point also failed to meet their needs.

"I think absolutely in terms of only being provided crisis care is something that is really difficult... I have Post-Traumatic Stress Disorder and I was feeling suicidal, was hospitalised... the psychiatric help that I eventually did receive was essentially being drugged on an anti-psychotic, when I don't have psychosis, and so it just made me incredibly sick".

Several women talked about a need for a focus on affordable preventative physical health therapies.

"It would actually be great to have something – I can't go and do any kind of sports, I can't afford it... I am petrified of breaking again and ending up back in hospital... so something where I could try and maintain and slow down the degradation I already have. Just access to, I don't know, cheaper sport... even a cheaper gym membership, I hate the gym but I will do that... I'm happy to improve my fitness and health, that would be great, but I just can't afford it, like it has to come last, you know, food's gotta come first".

"Any of that sort of stuff that you want to do [to improve your health] like aqua aerobics is so expensive... my son's got a pool, and I can't get in it, he thinks it's ridiculous. Well I can get in, I just can't get out – because there's no rail... I've got a lovely big bath in my unit but I haven't used it in all the years I've been there because if I get in I'm not going to be able to get out... I live by myself".

"[I] would... like to add the... focus on preventative health... funding slash subsidising gym memberships or providing public slash free exercise classes in parks, halls".

Another key barrier to accessing health services for women with disabilities was the impact of poor experiences with health professionals. Health professionals not listening to requests or self-reporting of health and experiences was an issue for most women with a disability. The women in the focus groups and interviews discussed how this impacts their health and wellbeing in a multitude of ways.

For some participants with intellectual disabilities, they felt disrespected when health professionals did not speak to them regarding their own health and experiences.

"I had a lovely mentor... and even in Centrelink... other doctors, some specialists... even in the chemist, they'd talk to her cause they knew I had a disability. They'd talk to her- and

she's saying, you need to talk to Louise¹⁹⁰ this is Louise's life, she's very capable to talk to you... it really makes you feel so undermined... People... they'll wanna write you off, and not talk to you, and you know I feel so humiliated, it's disgusting, and they're actually making my disability worse, and intimidating, if they don't allow... my independence".

One woman's support worker relayed that:

"one thing you said to me here was that you want doctors to talk to you directly, not to talk to the people sitting around you, and that was something you said was very important. And your words here was that you're responsible for your answers, and so you want them to ask you the questions, not mum, not dad, not... [support worker], but to ask you. And you were saying that you thought that made a good health professional".

Several women also spoke about how their pain was dismissed as a psychological symptom, and not treated appropriately.

"I think a frustrating thing with doctors is that they label you with – I've had depression and anxiety most of my life, and I've learnt to deal with it. And I don't know how many doctors have said to me oh we'll give you an anti-depressant.... Like I don't need an anti-depressant, I need you to deal with my pain. When I'm not in pain I'm not depressed... yeah, just take these... I think that's why I keep changing doctors because after a while they just put it down to oh you're depressed, take some of these. And that's not it at all".

"I saw a psychiatrist and um I was having breathing problems, and I said I think I've got asthma, and he said no no no, you're just having panic attacks... I ended up in emergency three times that week, and – you've definitely got asthma, and you've even got scarring, like you've probably had it your whole life, but that got ignored for two winters as – because, no, that's just your panic issues... it can get to that degree where they just dismiss you".

Women across focus groups and interviews continued to build on this consensus that their pain was not taken seriously, partly because of how they felt they masked it as part of their gendered presentations of symptoms as women.

"One of the things which I really feel strongly about is that doctors dismiss women's pain. They don't see, they think we're being... even if you're crawling in, I'm always crawling anywhere, and they still dismiss it, compared to men, who've got something quite mild wrong with them".

"Especially if it's not visibly in pain, so if you're just like yes I'm in constant pain... I've been told, but you're talking too well to be in this much pain, and I'm like, years of practice".

¹⁹⁰ Names have been changed for confidentiality.

"You go into a doctors office, you feel compelled to be articulate and to present well so that you don't get dismissed but also you feel that in the end your needs and the meaning of your experiences in the broader context of your life is just not understood at all... I may have PTSD but that doesn't preclude me from also having, yeah, physical symptoms as well, I'm not just hysterical, I'm not just crazy".

Several women also felt that the focus on weight loss and exercise was central to the dismissal of their pain and other symptoms.

"Pretty much every doctor I've ever gone to has said oh you're just depressed, or oh you're just fat, fix those things and come back and we'll look at it... and I'm like, when I can't walk very far because my hips will fall apart, that's just that I'm fat – is this common with fat people? Well no. Then look further. And it's something that you have to be really able to push that. And you're not always able to do that".

"Once I was diagnosed I looked back and I thought, I've had this since I was a teenager, and I was diagnosed at sixty, and that's forty years or being in pain, and being told to lose weight. And I've had so many male doctors say it looks like ankylosing spondylitis, but it can't be, because you're a woman, or it can't be because you haven't got the gene for it. But now they've discovered that less than fifty percent of people have this bloody gene".

"And if it doesn't show up on a scan... and they say do more exercise, well sometimes you need something to dull the pain so you can do the exercise".

Several women in focus groups and interviews talked about how these poor experiences with health professionals could be improved with more trauma-informed care.

"I just was really scared... went to Canberra Hospital and I remember speaking to a male registrar there asking me invasive questions about my history of trauma which is sexual assault, and then being told well the chances of you being assaulted in the mental health ward, like we can't guarantee your safety... It was really difficult, really retraumatising, no understanding of gendered violence, or just the impacts of trauma and violence whatsoever... [I] felt like I could benefit, or needed to be in a situation where I was kept safe, because I couldn't keep myself safe, but in the end it was better taking the chance that I might harm myself but at least I can try because I don't want to be in a totalising institution where I might experience violence from, you know, an external force".

"I've experienced that too, I've not gone to hospital for that same reason, because I would rather die than to ever experience that [trauma] again, was how I was feeling. Like I just can't – if that's a choice it's easy for me which one I'll take. And they don't seem to understand that..."

Women felt that health professionals not listening to their needs as they would listen to someone who did not have a disability was negatively impacting their trust and ongoing capacity to manage their health.

"I deliberately go to some doctor and I deliberately won't tell them about my mental health issues, you know it prevents me from being open completely with a doctor, which is something I really want to be able to do... I'd love to have all of that information there and be able to have that exchange and all of that, but the reality is I don't feel- have the confidence that I would be listened to or looked at".

"I think there's a lot of seeing things through a medical lens, and I have often encountered health professionals who want to know about my disability, even if I'm not trying to talk to them about my disability, it's something else. Um, I had one say to me when I was trying to get some help for depression, well of course you're depressed, you have a disability. And I was like, well I've always had a disability and I haven't always been depressed, so something's happening. But they didn't seem to be interested in exploring that".

Access to health information

Women with disability were asked about their health information seeking in the ACT. They were asked specifically about where they sought information for their general health issues and for their specific health issues.

General health issues

Eighty five women responded to this question. Women advised that their first choice for seeking general health information was their GP or specialist (n=44, 48.4%), followed by seeking information online (n=28, 30.8%). Six women did not say.

For their second choice women advised they sought information from their GP (n=29, 30.8%), and online (n=28, 29.7%), as shown in Figure 16. The 'Other' category encompasses peer support organisations, peer support groups, journal articles and library.

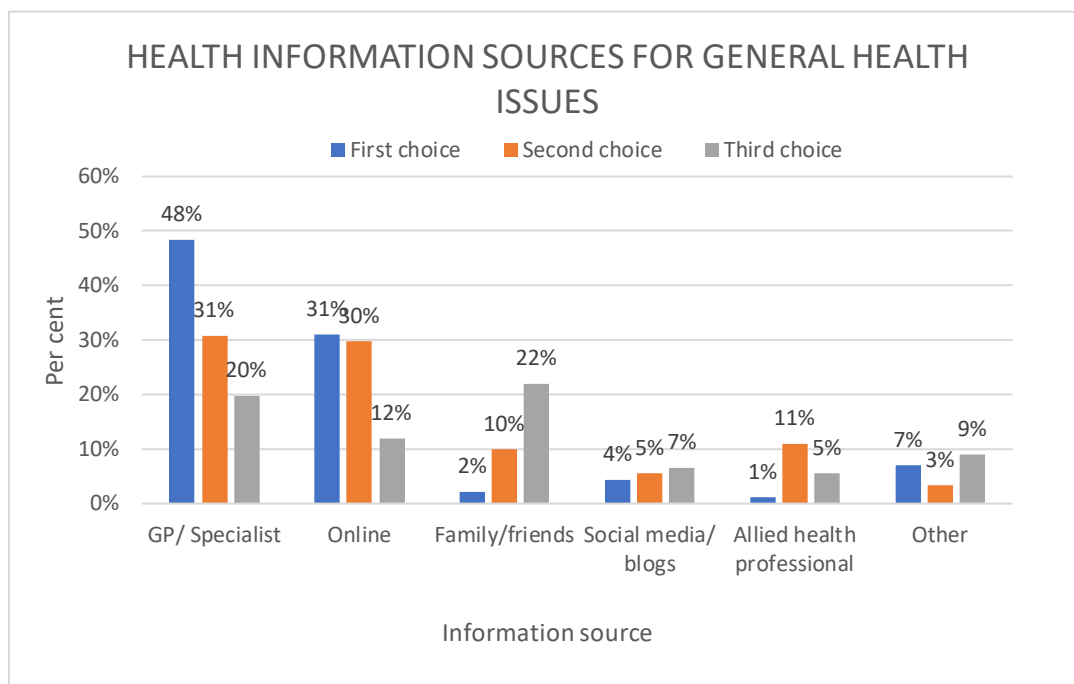


Figure 16: Health information sources for general health issues.

Specific health issues

Eighty four women with disabilities told us where they sought health information for their specific health issues. Most of the women identified their first preference for seeking health information for specific health issues as their GP (n=48, 52.7%), followed by seeking information online (n=17, 18.7%). Seven women did not say.

For their second choice, they identified online (n=21, 23.1%), followed by their GP (n=34, 37.4%).

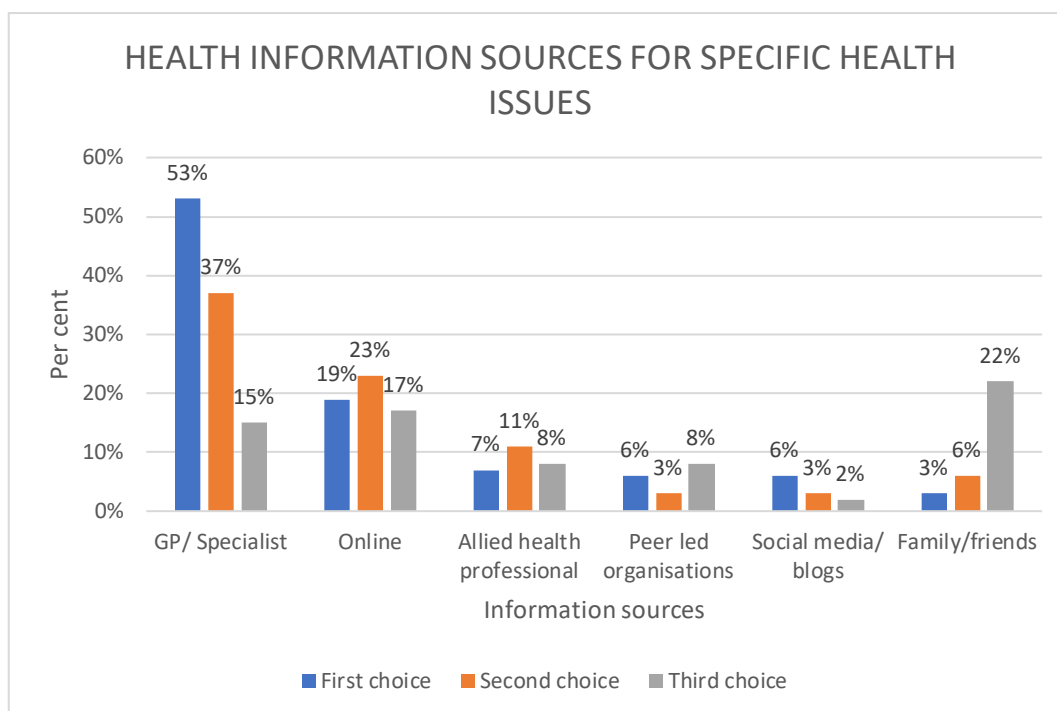


Figure 17: Health information source for specific health issues.

Difficulty obtaining health and wellbeing information

Most women reported that there was no health and wellbeing information that they were unable to obtain (n= 54, 59.3%). Just over 35% reported that there was health information that they were unable to obtain (n=32, 35.2%), and 5.5% did not say (n=5).

Thirty comments were made about the health and wellbeing information which women were not able to obtain. Women advised that they were lacking information about the complexities and nuances of specific conditions. This often-necessary information is essential for their health and wellbeing and they are unable to obtain it.

“Lack of information about how spinal injury may affect female reproductive health, lack of information about how to manage safe and supportive physical activity with combined psychosocial and physical disabilities”.

“Trauma integrated approach to post separation abuse when there is an underlying/exacerbated chronic/genetic illness”.

“Accessing accurate information relating to services available for specific disability- ie spinal cord injury”.

“Information about pain management - in easy to read and short form - as opposed to great long sheets of information. I would love to see customised information for older people [with disabilities] that is customised according to their condition/needs”.

Five women discussed their dissatisfaction with health information about autism for women in the ACT.

"I have autism. There is very little information or help available in the ACT for adults with autism that doesn't cost thousands of dollars".

"I have real difficulty accessing information about Autism (my diagnosis). Information is often limited, the internet says many different things, and specialists have massive waiting lists and cost a ridiculous amount".

"Not many health professionals are knowledgeable about Autism in adults, specifically females".

A few women discussed information that was lacking from specific sources such as GPs or specialists, and online.

"In general, Australian GPs haven't a clue about my Chronic Fatigue Syndrome. While I'd appreciate respectful support, I accept it's safer to leave them to things that they know and self-manage my chronic illness".

"I find it very hard to obtain information about how my chronic illnesses are linked. Everything is always compartmentalised by different specialists when they are connected".

Respondents were asked if they had barriers to seeking health information. Fifty women reported that they did not have barriers to seeking health information (54.9%), 36 said they did have barriers (39.6%), 5 women did not say. The main barriers reported were affordability and wait times.

"Access, cost, wait times".

"Cost, availability. long waiting times, fear of catching covid. Inability to get a telehealth appointment when you haven't seen the Dr in person before".

Women also talked about being frustrated and discontent with health professionals, and that they faced stigma wanting health information.

"Stigma. Health professionals not listening. Discrimination from family court".

"I feel my GP is judgemental in relation to some of my issues eg. being over weight. Due to my hernia and knee pain I am unable to exercise adequately".

"Trust is an issue. The condescending attitude of health professionals to 'women' with chronic fatigue syndrome is a barrier to accessing quality health care".

Women with disability also reported that they had difficulty trying to find health information, health professionals not having the right information, and finding information that is specific to disability.

"I have difficulty explaining what information I'm looking for. I'm dependent on my mum to help me. I sometimes worry if my mum wasn't around to help".

"Lack of a centralised information source, lack of disability specific information".

“Not being aware of all the reliable online sources that have information”.

“I am not sure how familiar the specialists in Canberra are about my condition - even the urologists”.

“Yes, my condition is 1 in 1 million, so yeah, it hard to find info”.

Some women also discussed anxiety going to health professionals, and mental health and burn out reduces their ability to access health information.

One woman also reported that health information does not always equate to health.

“Information is one thing, I'm very knowledgeable and can find almost anything I need online. However, information does not correlate with wellbeing for me. It doesn't result in implementation of good advice and strategies for me”.

Focus groups: accessing appropriate health information

Women with disabilities 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 with disabilities do not have capacity to use internet resources, and find coordinating between different services and needing to self-advocate more challenging.

Some 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.

“It's just expected that everybody has got a computer, and they know how to work their way around it... I live with a lot of older ladies-ladies who are older than me, you know, in close contact, and I'm the only one that's got a computer. The others don't, and they ring up for something and they're told to do it on a computer, well, I don't have a computer, you know”.

“I wonder how people manage who don't have access to the internet. Because almost everything now is on the internet... but lots of old people don't [have access]”.

“People forget, there's a lot of people that can't do technology out there, which I am one, I can do emails and stuff, but it's very very hard for me... And they just give out information as if everyone is refined and really good at... and not even a little open door for people with disabilities and technology, like me everyone- here's your information, that's it, there's no other open door to help anyone. And that happens from government, in churches, it happens in... certain service providers”.

As women reported in their responses to the survey, navigating health services and supports was especially difficult when needing to access multiple services. Women across the focus groups and interviews articulated a desire for more centralised, accessible health information resources, so that they can manage complex networks of information and services.

"You've really got to be able to do the search yourself because it's not offered, you know, you've got to dig around until you find something".

"And they don't know either, they don't know what services are available. Because one of the things that strikes me is I think I've heard three of you [participants] now say that... they have a limit on psychology sessions. I can tell you exactly how to get unlimited free psychology sessions, like this is stuff that's available, it's just nobody knows how to do it. Nobody has the information around it".

"When things go down... especially with my type of disability where its hard for me to reach out, to go out, to call, to email. And so I find that I do fall through the cracks a lot. And also not knowing what help is out there... I don't know what's available. And especially now with the NDIS, that's come in a lot has changed since from when I've accessed services in the past... and so I have found it really difficult to even know where to start... mental health caseworkers come to me and say we're here to support you... so you say okay yeah, this is what I want to be able to do. And they don't know... what's available... and the onus is on me".

"Good staff on the phones and email, like good reception staff, makes a huge difference".

Some women with who were neurodiverse found that navigating health information systems not designed with their information seeking in mind was particularly difficult.

"I find them kinda hard to figure out what is available... It's hard to actually find services. And most specific services seem to require phone calls, which is something I really struggle with. So that makes it much harder to like get information from different places and figure out what I need... I think, you know, being neurodiverse, being autistic or having ADHD, the systems aren't designed to be easy for our brains to figure out".

"I'm a visual person, so seeing trails of information, it just doesn't work for me. Seeing pictures, visual recognition, I can go boom – I can go down that path... I do everything, pretty much in colour. And sometimes it's just photos, visuals, and I know which way to go quickly. But yeah, trails of just data... and then I get either distracted or I... I flick over it and miss that bit of information.... I can do stuff, it's just when I've got so many competing responsibilities, it just hits the back burner".

Several women expressed a need for alternative formats such as large print, electronic copies of medical forms compatible with screen reader technology, pictorials, everyday or simplified language.

"Because nothing is available in larger print or in alternative formats I guess that's discrimination really, because you get all your health information and its inaccessible to people who are blind really... everywhere you go, you're presented with a form, which is miniscule... and the only time, and they say oh well we'll fill it out to you. But then, you know, you're shouting out your information to a waiting room full of people... if they'd

simply scanned the form in, you know beforehand, and sent it to you electronically, often people with you know visual disability can deal with that much better... information needs to be accessible whether your [English as a] second language or vision impaired or hearing impaired”.

“It’s important for the health care workers to use simple everyday language because it’s all about good communication”.

“I say well show me a pictorial, you know, why can’t you give me a pictorial. I’ve even said that to my NDIS coordinator... why can’t they give you a pictorial, why can’t they give you a picture... or, I say to people use your phone, sometimes people only use their phone for me but they use it a lot. I say okay, show ‘em! If they’re not getting it, find a way. That’s your job, that’s what you’re paid for”.

Focus groups: being supported to access health information about the health system

Women with a disability were more able to access health services and maintain good health when they had support from people who understood their needs and were well-placed to interpret health systems. Often this was through a key relationship with their GP as a primary health practitioner, and for other women who faced barriers to accessing a doctor (wait times, cost, availability of GPs, trust in these practitioners), this was often a family member or support worker.

“I have a wonderful lady... [who] looks after all my health journey that’s not covered by NDIS. So she carries a big book around, and I couldn’t have asked for a better person, as a retired RN, yeah but I think it’s very very difficult for people if they don’t have, know someone like I’ve got... if they don’t have someone like that it’s very difficult... my life’s been difficult, because I’ve had an intellectual disability, and a cognitive disability, and so sometimes I just can be scrambled. But the biggest problem is, anyone who has a health problem, in any aspect... you need wonderful people in your life”.

One participant described the burden of having to disclose personal information repeatedly in an attempt to coordinate their health care. When this involved histories of trauma and family violence, this had a negative impact on the women’s ability to feel safe and secure accessing health information or services.

“It would be so nice if you had like - just one person, you know, but they always move... I have... a new plan, person every year, I’ve got to retell the story too. Every year. And you know half the time it’s embarrassing some of the stuff I have to bring up, you know, of my home situation, and then beg for help, you know like I feel like... my confidence and self esteem used to be semi-okay, now it’s so far down on the floor”.

Many women across the focus groups and interviews agreed that the role of an advocate, whether in family, a friend, or a single health practitioner who understood their needs, was key to their ability to manage their health, but that this support was hard to access.

"I find that now if you don't have an advocate who's capable of doing it for you, and use the right wording, you don't have a chance... one reason why I won't even bother is I don't have the cognitive ability to, like even writing a paragraph... so doing the NDIS [National Disability Insurance Scheme] I think I can't do from the cognitive side of things, and also, I'm psychologically afraid of getting rejected... I can't have the resilience to cope with that, so I'm not going to do it. So what it's saying is your disability is not good enough... My doctor said, you need an advocate, and I'm like, where do I go? Because I don't know".

"And where is the advocacy for us? I mean that's part of the reason why I think the first question I said when I walked in here was do you guys do individual advocacy? Is because... I'd quite like to know where these services are, because... any advocacy service that I've ever been involved with was... bullshit. Like it's just so, it's so inadequate, like in every sense, we're expected to deal with this bureaucracy on our own... we don't understand it, and the advocates that we have are also ill-informed, and not available. Like I think advocacy is a really big deal".

"See the only ones that I know of for individual advocacy at the moment is ADACAS [The ACT Disability Aged and Carer Advocacy Service] and AFI [Advocacy for Inclusion]. I don't know who, I mean there would be individual probably organisations as well... you know and I'm a member of PWD [People with Disability], but that was systemic advocacy, but that's now merging, that's folding, because we're not getting any funding from the government. So we're now folding..."

This need for advocacy was part of a two-sided sense of frustration from women with disabilities when attempting to access good health and wellbeing in the ACT. In part, as described above, they felt that the systems were too complex and disconnected or siloed, which prevented them from easily accessing services that they could afford.

The other side to this was a sense that the health system expected them, as health care consumers, to be the sole source of expertise on what health supports may benefit them. This was a source of frustration for women who felt that this expertise and health information was something they needed from professionals, in order to better address their needs and improve their wellbeing. This was expressed by women across age groups.

"Often what's come for me is that when I have been in a meltdown space I feel like you know I'm surrounded by health professionals that are waiting for me to tell them what I need. And I'm like, have you met me? I'm insane right now, like I'm trying to walk in front of cars on a highway, like why are you asking me what I think I need? Like this is- I am not qualified in this space, that's the point, is I need help. I need someone to come in and go, well this needs treatment, this issue needs treatment, this is how we treat it".

"Sometimes it gets a little bit too touchy-feely, rather than somebody else make a decisive decision on our behalf when we need it. They try and put that back onto us to give the

thing- I mean this happens with not only mental health but with other things as well, and it's just- and sometimes you really need that somebody to step in and say, no, okay this is what we're going to do, because I think this might help or whatever".

Focus groups: Health information seeking in COVID-19

In the focus groups, women also reflected on their experiences of public health messaging around COVID-19, and the ways in which they felt that health information and new attitudes to health and healthy communities changed.

Many women agreed that these adaptation from health and community services were widely beneficial.

"It feels like yeah in some ways COVID actually improved things because these spaces started doing the things we actually needed them to do all along".

"I think COVID... actually made me feel more normal than I usually do, and I actually felt better last year... people were more open to talk about, you know being isolated and stuff like that, so things that I think a lot of us I think experience, the general popular were going oh, I've never experienced this before... I think a lot of the services kind of came into play... it's okay to not feel okay, it's okay to feel depressed, it's okay to feel isolated- feeling isolated is not good for your health, you know, all of these things that in the past would have been minimised a lot... I think now there is a little bit more compassion or understanding or acceptance towards those sort of things".

Community sentiment about what it meant to experience poor health shifted slightly through this public health event, and there was a sense that there was empathy for their situations for the first time. For some women from multicultural backgrounds, however, a lack of accessible health information about COVID-19 was a large source of stress.

"I'm tertiary educated, I know what websites to go to, I know how to access information, I know to interpret it, and also I know how to try and advocate for myself within health spaces, but you know, for me coming from a Chinese-Australian community, I was really concerned about like feeling as though my community was left behind. And because there was a massive gap in messaging... the government adopted a very... one-size-fits-all kind of approach, and it's like that's actually really inadequate for women with disabilities, it's really inadequate for people with culturally and linguistically diverse communities... that was something that was really concerning... how can I make sure my mum's safe, how can I make sure other people in my community are safe".

Some participants did not feel buoyed by the community or health support, particularly if remaining socially connected via internet technologies did not appeal to or work for them. For some women who had experienced periods of intense isolation at home due to poor health, the experience triggered similarly poor mental health for them. Others felt that the isolation they faced due to their disability meant they did not receive enough information about COVID-19.

“Everyone’s saying oh look, you go on the internet and do Facetime and do this and I don’t do it very well, it doesn’t do anything for me. I can pick up the telephone, ask a question, as long as it’s not a recording at the other end saying please leave a message, you know, that sort of thing... I found it terribly isolating, and I was actually a bit shocked about my own reaction... this time I thought oh I’ll be able to cope with this, you know, because I’ve been through it before, you know, being isolated and being at home. But this time, totally different scenario, because I could do things, but the whole situation meant that you couldn’t go out and do things. And the mental health, it was really just went downhill, you know”.

“I find that I self-isolate, even from social media and even from going online sometimes, I just kind of block out anything, and so I didn’t even know that COVID was happening. I had no idea because I hadn’t watched the news for months, I hadn’t gone online to get those little updates, for months, so I had no idea... the way I found out was because the GP sent out a text message to everyone, saying now that there’s COVID-19, our operations will be different... I think there probably are people like me, whether they’re constantly like that, or they’re just going through a bad patch and they’re just shut off from everything and don’t know anything”.

Housing

Thirty four women were living in a house that they owned (37.4%), 27 women lived in a rental (29.7%), and 15 lived in public housing accommodation (16.5%), as shown in Table 5.

| Lives | Number | Per cent |
|--|--------|----------|
| Lives in a house that they own | 34 | 37.4% |
| Lives in rental accommodation | 28 | 30.8% |
| Lives in public housing accommodation | 15 | 16.5% |
| Lives in a house owned by their family, parents or partner | 6 | 6.6% |
| Did not say | 5 | 5.5% |
| Lives in supported accommodation | 3 | 3.3% |

Table 5: Respondents living circumstances.

Several women in the focus groups reported that they felt they lacked agency in seeking appropriate housing, and that the housing they were in negatively affected their ability to manage their health and wellbeing.

“Women in general are not offered any way to- they have no agency in housing. And this really disproportionately effects women of colour and disabled women as well. And so

women keep ending up in really risky situations, keep ending up in locations that don't suit them... housing managers deal with this stuff really poorly, housing deals with this really poorly... I personally live in public housing and I have two neighbours who have been mistreated by housing... there is no advocacy services available... we're in the position of going, who do we call?... They completely ignore everything".

"My whole life I've been in unsafe situations, and to have that safe place for myself – without that it's impossible to even consider any sort of life. But I've got a place, and I'm now afraid to make any sort of comments, cause you don't want to be labelled oh, that difficult client, you don't want to lose your place, you don't want to use up any of, you know that favour... that sort of disempowerment, and that's housing, but also with the medical field".

Life roles

We asked a number of questions about women's life roles including the relationship status, employment, caring roles and how having an impairment impacts on their ability to do their life roles.

Relationship status

When asked about their relationship status, the largest group of women with disabilities reported that they were single, followed by being married, as shown in Table 9.

| Relationship status | Number | Per cent |
|---------------------|--------|----------|
| Single | 40 | 44.0% |
| Married | 26 | 28.6% |
| Defacto | 12 | 13.2% |
| Did not say | 6 | 6.6% |
| Other | 4 | 4.4% |
| Widowed | 3 | 3.3% |

Table 9: Relationship status of respondents.

Employment status

Table 6 shows women's employment status. Part time work was the most common employment status among survey respondents (at 27.5%), while fewer people were in full-time work (16.5%). Substantial proportions were not in the workforce or not seeking work (26.4%) or unemployed (11%), while 9.9% reported that they were studying. A small number of women reported working casually, were underemployed or retired (allocated in 'Other'), or did not say.

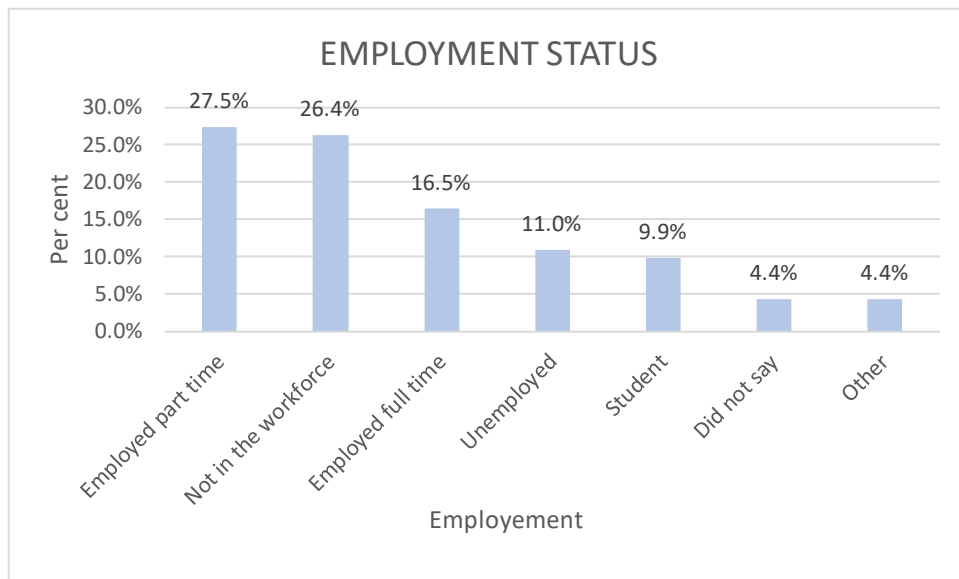


Figure 18: Employment status of respondents.

Sixty five women reported that their employment status was impacted by the barriers they face due to disability.

Women mostly reported that their symptoms of disability impacted their ability to maintain employment, work to their full capacity, and do the type of work they wanted to do. They found that doing the hours, and the office environment incredibly difficult.

"Pain and fatigue makes work difficult. I have been offered more hours but can't accept them".

"I have chronic migraine, an autoimmune disease and mobility issues following a leg injury 2 years ago. All of these conditions cause chronic pain and fatigue. I often find it difficult to cope with the bright lights and noise in the office and sitting at a desk for long periods increases my pain levels and causes swelling in my bad leg. I work part-time because of my conditions".

"I find it difficult to work more hours because it puts too much strain on me and my mental health suffers".

"I am unable to work in a mainstream kind of job due to my autism".

"Literally cannot work in any typical job setting due to autism and bipolar. Would need to work in a very supported environment but wouldn't know where to start looking for that".

"Due to my disability, my performance was affected at work. I struggled with my own expectations on how my work performance should look like, and due to me constantly not achieving my own goals and being under stress I quit in order to have a break and focus

on fixing my health with Physio, Gym, Counselling session and creating my own hobby business to help with some form of income but also as a creative outlet”.

Women described how workplaces are not compatible with their needs. They discussed that their place of employment did not provide the necessary tools, equipment, or accommodations so that they could do their role properly.

“Unable to work full-time hours. When I wanted to increase hours worked from home I was told I wasn't allowed to until I worked more hours in the office which isn't possible”.

“I am unable to walk up many flights of stairs to my workplace, multiple times every day. The lifts have not been working for about 2 months. If my knees and hernia were able to be fixed, that would improve my fitness and capability”.

“Timely support for using screen magnifier/ reader technology made it impossible for me to work at the level I was. Needed specialist technological call out support which is not available. Even though the product is bought and recommended by vision Australia wait times for support could be weeks and sometimes months. In one case I was left for a week without being able to use a computer which made the job impossible”.

“I was TPI for one day a week using superannuation insurance so no longer able to work full time. The pressure to work only one day from home makes life more difficult. Lack of government parking in Belconnen very frustrating as have to pay a premium to Wilsons to be walking distance for me to access my work”.

“I was flat out denied reasonable adjustments, resulting in burnout. I've been on graduated return to work for 12 months, but my workplace doesn't communicate with the medical professional who they expect to provide the evidence for this. It took over 6 months to get my workplace to engage with my work assist agent. All onus for developing reasonable adjustment passports is on the staff member with disabilities, despite it being triggering, subjective, and additional burden on the staff member. Cannot access salary packaging to help with management of bills and rent, so no support with real life. Flat out denied flexible working arrangements despite it being recommended by an OT paid for by work. Often the response to the impacts of my disability and more restrictions than support and adjustments. HR and Exec close rank to gaslight complainants into silence. Etc”.

Another barrier that women talked about how they have been actively discriminated against at work or when trying to obtain employment.

“I was fired from my last employment (which was a disability advocacy organisation) because both my mental and physical health went through a rough patch in the middle of last year. This is an example of the hypocrisy that exists throughout the resources and available services for people with disability. These organisations pay lip service to the

concept of disability inclusion, but are unwilling to deal with the effects it has on daily life”.



“[A senior nursing executive] has prevented me from obtaining Registered Nursing work for seven years because he incorrectly assumes that my lived experience of depression would cause me to be unprofessional with clients. He actively discriminates against me. When I have obtained nursing jobs he stops me working there”.

“Potential employers are scared by the fact that I have a disability that is not visible. Mostly I do not disclose for that reason and run the risk to my own detriment if it does become an issue. Potential employers look for instant success and does not look for the potential in a person and the ability to grow into the job”.

Some women were not able to find employment that was suitable to their needs due to the barriers they faced.

“I would like to get a part time job while I'm at school and I have dropped off several resumé, but I haven't had any calls. My disability means that my intellectual age is very young”.

“I did have part-time employment which had to be finished due to Covid, not available any longer still due to Covid, no contact through employment agency for a position as they say it is too hard to find anything”.

Some women expressed frustration with having to use sick leave which often put pressure on them as an employee and impacted their ability to fulfill their work duties.

“My employment is secure, but I often need to work from home or take sick days due to my health issues”.

“I have used up my annual allowance of sick leave in just over 4 months. In a good year I'll make it to 6 months. I have seen a gradual decline in my health that makes balancing work very difficult. I would love to see there be provisions put in place for staff who have demonstrated a long-term health issue, to be able to access purchased sick leave, similar to how purchased annual leave is available. I feel there is only so much accommodation my workplace can make (and my workplace have been very supportive) in terms of the amount of sick leave without pay I take”.

As well as discussing barriers to employment women also talked about not being able to work or not being able to find work due to their impairment.

“I was once a very busy nurse-midwife, community volunteer & tertiary student. All this slid when I succumbed to Chronic Fatigue Syndrome. I haven't been able to do full time work for 20 years due to it”.

Women were asked if they had any caring responsibilities, most women reported that they did not (n=46, 50.5%). Thirty nine women reported that they have caring responsibilities (42.9%) and six women did not say (6.6%). Table 8 show the type of caring roles that women had, five women reported multiple caring roles.

| Type of caring roles | Number | Per cent |
|----------------------|--------|----------|
| Children | 29 | 31.9% |
| Sibling | 6 | 6.6% |
| Partner | 6 | 6.6% |
| Parents | 2 | 2.2% |
| Other | 1 | 1.1% |

Table 8: Types of caring roles undertaken by respondents.

Impacts on life roles

Seventy nine women reported that their disability impacts on their ability to participate in their life roles. Respondents' answers to this question were a reflection of the complexity of their lives, citing more than one facet. In contrast some women said that it impacts everything in general. Women also highlighted the impact of societal barriers that created stigma and discrimination in a society that values the "norm" and promotes ableism.

"It's fairly impactful. I am unable to be in the world the way normal people are. I often feel quite lost or misunderstood".

"Being a disabled person does not inherently have an impact on life and relationships. It is the stigma, and society's failure in meeting the basic needs of disabled people that impedes my ability to participate in activities and relationships. The 'social model' of disability is a much more useful lens to view this question through, rather than an individualised scale".

"Constantly feel like a burden to society with judgement from an ignorant society that sees you as a leaner trying to get benefits when they can't see any evidence of your sensory disability. During my employment I was constantly fighting for reasonable adjustments to be made with meeting papers, presentations, etc. with Govt. agencies. My employer was fantastic but it was a constant battle with Govt. agencies which is time consuming, and humiliating as you are causing extra work. The same could be said for studying at university, catching unreliable taxis to meetings was a constant frustration. I have been privileged with my actual employer, friends, and family".

Many of the women discussed their incapacity to do domestic duties and daily activities, such as cooking, cleaning, and driving a car. They discussed doing domestic duties in relation to expectations

they put on themselves to complete tasks, frustration at being reliant on others, lack of independence, and wanting to be in control of their lives and their environment.

"Don't always have energy, cannot really think clearly in the afternoon; depression and grief means I have had a very difficult time with daily activities; often end up losing a day to crying".

"I feel like I'm more restricted and can't do everything I'd like to do, like drive a car or get a part time job".

"I just can't do a lot of things. This decreases my participation in social, work and home activities. Due to fatigue I can't make 3 meals a day for myself, my husband does all the cooking... I need a cleaner, I don't have the endurance to do all the cleaning I like".

Women talked about how impacted their relationships were in relation to their impairment. They discussed being reliant on their closest relationships, their significant others and on family members which they felt irritated about, and also that they had difficulty maintaining relationships like friends, and partners.

"My social life is poor because I frequently have to cancel".

"It affects my socialising in both my personal and workplace relationships. I find it hard to concentrate sometimes and oscillate between feeling like my disabilities are a superpower or an impediment".

"It impacts GREATLY!!!! due to limitations I'm having to choose one or the other always letting someone down".

"My disability and Centrelink have made me dependent on my boyfriend this is not what I want. I can't go to university full time or work full time. It's difficult for me to advocate for myself at work, at school, or to the government. I spend a massive amount of time working on Centrelink and NDIS".

"Significant impact. Especially on relationships, it's probably because I have none that I have so many professionals.... All romantic relationships have been DV [domestic violence] so am just accepting I might be single for the rest of my life I want to be mentally stable".

"Yes - I have no friends, no relationship, find it difficult to get motivate and clean house/clothes etc".

Employment was prioritised by the women and felt frustration if they had to reduce work. They also felt that employment had a significant impact on their social lives.

"I am constantly fearful I will be fired when all I do is my utmost to be a good employee. Constant burnout and exhaustion. But I'll never be able to own a home on a single income. The system is all a big joke on people with disabilities".

"I frequently have time of work reducing my ability to contribute economically to the household".

"I would love to have my job back, as I met lots of new people and had many new experiences through the position, I feel very isolated at times since I lost this interaction".

"The days I do work I cannot do much else. I am discouraged from going for a promotion as other areas won't want to accommodate my RWA".

Some women also explored how their impairment impacted on their ability to be socially included and connected, expressing exasperation about the barriers they faced.

"I am socially isolated, unable to do daily activities around my home, have to work part-time so financially affected".

"I have zero friends, zero hobbies and very limited contact with family. I struggle with personal hygiene. I feel a loser".

"I just can't do a lot of things. This decreases my participation in social, work and home activities. I.e due to fatigue I can't make 3 meals a day for myself, my husband does all the cooking. I don't go out to dinner/lunch because the chairs are too uncomfortable, it's too loud, the food has things I can't tolerate in it. I need a cleaner, I don't have the endurance to do all the cleaning I like".

Focus groups: reflections on life roles

When asked about how their disability impacted their ability to participate in life roles, many women identified how their disability had been affected by gendered life roles they played in marriage and raising children.

"I got married, I had three kids in five years, and then the father decided he didn't want kids. Took himself off, and no government that was in at the time ever made him contribute anything... I worked three jobs to get three teenage boys fed... people keep saying to me, why don't you get married again... no it doesn't appeal to me, I'm quite happy where I am..."

"Don't get married... it impacts negatively for women all the way through... there is no advantage for women... they get a cook, a cleaner – I didn't realise how much of my life was, while I was married, you know, I managed to do two diplomas, four cert IVs, by studying in the evening when my husband was on my computer.... total disadvantage, I've lost super, I've lost the potential career, to earn, to be in a way better place than if I had not. I would not have had my children so I would never barter that away... but yes as far as quality of life, the majority, total disadvantage. You're literally giving up a lot".

One participant also reflected on feeling unable to participate in romantic and sexual cultures due to their disability.

"I think dating programs could be interesting, because think that certainly people with disabilities do tend to fall through the cracks around dating, and that's- I think that that's a big, like I think that we have platonic needs but we also have sexual and romantic needs as well... it's like being gay, like I am, being gay is very loud – you know, all their events are very loud, it's very like partying and fun and parades and stuff, and I'm like, I'm way too fucking autistic for that, so where do I go, you know, where do I fit".

Many women across focus groups and interviews also reflected on how their employment status was impacted by the barriers they face due to disability.

"We moved [buildings] and there were two staircases, two steep staircases to climb up to the office, and there was no way I could do it. So I had to retire whether I wanted to or not, and I would liked to have kept working for another ten years".

"I worked for... for a while and they were excellent at putting things in place. Like I got a special chair which I know cost two thousand dollars, they gave me parking right out of the building, which I didn't have to pay for... they still expected me to be able to travel round Australia at the drop of a button, which was a nightmare because I didn't have anything else in place when I got to these places.... But nowhere else I've worked has been good".

Those who had had positive experiences of workplaces or employment described adaptability of their employers as key. This included provisions to work from home and support via adaptive technologies.

"I found the ability to work from home last year really useful. For me... working in a shared office is really awful, because I get migraines a lot... so it meant there were days where I was working in an almost-dark room because it was comfortable... so I didn't take any days off, because I didn't need any days off. Whereas the year before when I'd done a couple of months work with them... I don't think I had a full week there.... It was really interesting to be like actually I can work through a full week, I just... need to be able to work from home sometimes".

"My last workplace was good, I must say... they were very conscious of not having us sit for too long at a time... they were pretty accommodating... I started there at four days a week, and then I cut down to three, and then I cut down to two, and they were quite happy to accommodate that, so they were good, they were good to work for... that's why I worked until I was nearly 70, because they were prepared to let me cut back on hours and that sort of thing".

A key barrier to continuing work for those women with a disability who found suitable employment remained the ongoing need to ensure physical access to buildings, technologies, and accessible transport between meetings.

"I often had to get different technologies, you know adaptive technologies... but in the end, I quit... [the] massive frustration was I use a screen magnification and screen reading program, and it just would continually let me down... even though the attitudes of that workplace was just brilliant, and it came from the top, support for my adaptive technology was just not there, in a timely fashion".

"It just got too frustrating, at the time uber wasn't there, and I attended- sometimes I had three meetings to go to, and my boss would just you know give me taxi vouchers so it wasn't a problem, but I was often late for meetings, because taxis wouldn't turn up on time, or you couldn't get a taxi".

The ways in which institutions attempt to ensure public spaces meet access requirements were often ill-defined. One participant reflected on navigating the physical environment as a student at her higher learning campus:

"When places describe, we have disabled access, they need to describe what that is. Because disabled access is a hundred different things. So they need to actually say what they mean by disabled access. Apparently, CIT in Bruce has disabled access, but their ramps are steeper than regulation, and have no rails... I tried to find the library from my classroom – it took two minutes to walk there using like twelve sets of stairs. It took me two hours to find a way to get there with ramps and lifts".

Social inclusion and engagement

The majority of women did not feel socially included and engaged in community life (n=58, 63.7%). Twenty seven women reported that they felt socially included and engaged in community life (29.7%), and 6 women did not say.

"I feel that I have been under house arrest for the past 13 years".

"As I share homegrown herbs, fruit & veg' with passers by & am ready to listen to their woes, I feel treasured by my community. Most people are supportive to friends with an acute illness or injury. But they don't want to associate with the chronically ill. It's Darwinian really, survival of the fittest... Being abandoned hurts at first. Then you realise it's their issue, not yours. I pride myself on self sufficiency & prefer to hang out with evolved friends instead. They're gold".

"I feel like my disability excludes me from social life and that my friends didn't understand and left me".

Fifty eight women told us why they didn't feel included and engaged in community life. The most common barrier to feeling socially included and engage in community life was symptoms such as fatigue, pain, and mental health, which impacted their ability to participate.

"Due to the changing physical abilities associated with my condition, I feel more isolated. Contacts and friends dwindle away when I have to keep saying no to requests to go to social events, particularly long walks and standing for long periods. If I know that parking is terrible and there will be nowhere to sit, I don't go. I find it hard to sit for long periods in theatres. I have been trying to engage with different groups. I don't attend support groups for particular health issues. I have attended some and found they are misery sessions, and I feel very down after attending".

"Social connection is highly variable, depending upon my mental state".

One of the barriers to maintaining social inclusion and engagement mentioned was accessibility to public spaces and entry into buildings.

"When even the local shopping centres, recreational venues and many public buildings lack access to accessible toilets, or self opening doors to premises, where do you start"

"Accessibility is a huge issue and determines my participation".

"I am socially isolated - no family or friends in Canberra that I can contact if there is an emergency. Needing wheelchair access makes going out difficult due to lack of physical access which makes meeting people almost impossible".

"Mother's groups are not accessible to parents with physical disabilities. I struggle with fatigue, and prioritise parenting and work over my own social activities".

Some women reported that they felt disconnected from friends.

"I have to ask to be included and it is an extra effort for me. My friends will include me if I take the initiative. Sometimes it is too much effort or I am too depressed. I don't drive, so this is an extra nuisance for my friends".

Discrimination was also mentioned as a deterrent from seeking social connection.

"Other than a small circle of friends and loved ones, venturing into an unfamiliar social situation is usually mentally exhausting. Trying to avoid discrimination and making sure that the community space is inclusive and welcoming takes a lot of work that goes into engaging with community life".

"I don't have the energy to deal with all the prejudice and general trash of being really socially engaged. I am just managing to hold everything together as is".

Affordability of doing social activities also impacted on their ability to maintain social connection and feel included.

"Costs are prohibitive so I am limited in what I can afford and the type of social activities I would like to be involved in. I don't like complaining and try and be positive in all things".

"I feel excluded due to low income and stigma around mental health".

Focus groups: reflections on social inclusion

When asked more generally how women with a disability felt included in community in the ACT, they reflected on the ways in which poor infrastructure such as transport is a barrier to social inclusion as part of their health and wellbeing.

"Better public transport... where I live... is a pretty steep slope. And the bus is quite a way down from me. And I know it's within the, whatever their measurement is. But there's three or four streets above me that have to walk a very long way to get the bus... there's lots of basic simple things that could be changed".

"That's an age-old thing with [Canberra] buses, they never go where people want them to go, they go where they think they should go. And it makes it very difficult for older people and whatever, if you've gotta walk miles to the bus stop, and if it's uphill".

"Signage and wayfinding and alternate formats basically, would make a huge difference for me... and timely and flexible public transport options, to attend events... after 5pm in winter... the lighting is just so poor and the footpaths are so badly maintained, that's it's just a complete- apart from the women's safety issue of you know feeling unsafe in the poorly lit streets, it's a fall hazards, because there's loads of footpaths around... they need to think about... the journey to and from public transport".

"Like I said about the transport problem really, that's... I also need to get myself there as well. But I don't really always have that kind of transport".

One participant's support worker elaborated for the participant:

"If there was another option that was simple to use, and accessible.... so you told me some of the things that make you feel part of community. And one of the things that you said was your family. And you also said friends, and the other thing you said to me was being busy makes you feel part of the community... I think you were talking about all the classes and things you go to".

Women across focus groups and interviews agreed that more affordable parking closer to events would be useful in helping them feel that they could participate:

"The few events we've been to where there's been designated parking... then you can attend the event... it's that cognitive load [of determining if an event is accessible] and that physical exertion. By the end of it you're so goddamn tired, you've got nothing left".

"The other thing in Canberra is the cost of parking, it's – I love to go to the movies, and I go with my granddaughter... I've got a Palace Electric pensioner thing... but then it's \$10 to park in that building underneath. I've got a disability parking thing, but in the surrounding area there's two disabled parks. And I've never gone there where one of

them's been available... if it's Wilson parking, I don't know why they have disabled parking because you still have to pay, and they – you can park for less time than if you park in a normal one. And if you've got disabled parking you're probably going to take longer to do something".

As many women with a disability reported that they felt isolated and did not feel socially included, the focus groups and interviews helped to identify how stigma and lack of education about disabilities in both health service providers and the general public were key barriers to inclusion.

"I feel like I'm invisible and that I'm a burden. That's pretty much default how I feel. And that prevents me from actually seeking help or being assertive enough".

"I've been in and out of hospital and I- I don't have any social interaction, and I would like to. But I don't want to have to do it wearing a [social] mask on my face all the time, you know like pretending I'm okay, going around- because I'm too exhausted, and chronic fatigue... I would love to have that sort of safe place where you can interact socially... like just normal social interaction, but if it comes out that hey, I'm on disability pension, or hey, I haven't showered in two weeks, people are like yeah, whatever. Um yeah don't worry about coming if you don't feel like it, it's totally cool, just come when you want to".

"I'm a bit of a social butterfly, wouldn't you say [to carer]?... But often-there has often been times when socially I mightn't know people, but I've often felt like they'll talk to me, but if I begin to repeat myself they'll go talk to someone else. Like it's not giving me that grace... Mental health community coalition, who I'm a speaker for have been really good to me. But there's a lot of people that, as soon as you have trouble speaking, and sometimes you know, like, if you don't have a certain intellect, or if you have difficulties, some people with disabilities who have that intellect, but they might have difficulty-communication, that often means exclusion. That often effects me and everybody with a disability".

The women spoke about how an inability to accommodate varied capacities could improve with more education about catering for different access needs.

"So largely the barriers that I face are you know to do with access and... communication stuff, you know often you can say I'm legally blind, so like I can't see what you're talking about, and people just have very little knowledge even within the health system of what legally blind means. You know and so they just carry on regardless, yep, or start talking in a loud voice".

"I think we need to look at education more. Educating the community, because a lot of them are not- not their fault if they've never had the life experience and lived experience, there's not community education. I think we should educate people more... please remember those people that don't... have that capacity to use technology. Some people have been bluntly rude, even at the hospital, about me not being able to do it".

“Around town activities are so hard to get to and to be a part of... sometimes there’s so much, so many people – I think we’ve been to a few different community events where there’s been, where there was a spaced-off area for children with autism or whatever, a bit more room. Oh my god, they were magic! Just extra little things here and there that can actually cater, and make it accessible, we can actually attend, because it’s not too many sensory overloads”.

“When people want to come and do things you should be doing yourself... I’ve had a terrible time with that for me and my son, who’s even more severely disabled than me. So as an individual and as a mother, it exasperates you...people trying to take your independence off you, and I’ve had to be really strong and fight for my independence... I think that effects a lot of people with disabilities and its definitely affected my life”.

This included a desire for more representation of women and people with disabilities in policy and planning.

“In health services, so therefore people who are planning the health services, that work in the health services, really don’t have much contact with or knowledge of different disabilities and what they need. And so, you know it comes back to that... underrepresentation of people with disabilities. They’re seen as, you know, whatever your difference is, oh god I don’t know how to deal with that, rather than thinking about it beforehand and going, well we need to make this accessible for everybody... for people with physical disabilities and mobility restrictions... they can’t even get into the buildings often”.

“Housing I think in particular would benefit so much from having people with lived experience of any sort of disability. Women, who-who are advocating for women.... If we could find a place where, you’re actually respected and people are inclusive and understanding, there’s a lot- a lot could happen, a lot of us could contribute. And there just isn’t that. And because there isn’t a place for us to actually contribute because we don’t feel safe enough or what have you, people miss out, and it-it’s just crazy”.

“The notion of like co-design principles... [is] something that actually gives people autonomy to make decisions, not just to say – I’ve given you feedback once the decisions have been made, but to actually say, I’m part of the decision-making process... There’s all sorts of ways in which people can engage, and self-determine like what’s important to them, like what kind of housing they need, what kind of health decisions they wanna make, and yeah”.

These participants agreed that a lack of understanding led to a lack of institutional support for the independence of people with disabilities, and thus a reduced capacity to participate in and feel valued by community.

Many women in focus groups and interviews emphasised the support they had received through community-based care. Inclusion in peer-focused health supports helped them to understand their health within their communities, and empowered them.

"I'm lucky because I'm a recovering drug addict, which means that I have access to a whole heap of services and space that have meant that I now live crisis free in my life. But I access those as an addict, not as someone with mental health issues or neurodivergence... There are so many services available to addicts that are more than crisis care... therapeutic community has been proven to be massively beneficial for not just addiction issues but for mental health issues as well... addiction is as much a mental illness as any other mental illness, so it seems interesting to me that it's sort of prioritised while the others are- like you are just expected to be, I don't know, okay".

"It's yeah about healing in tandem with all of those sorts of supports that you have... I'd even be alive if it wasn't for my partner and my family... something that was really helpful was that my doctor referred me to... the MECFS society... they have a little like peer support group and a little learning to manage your symptoms and pacing and that was immensely helpful for me to sort of, you know, remove myself from a purely medicalised model of help and support and come into like a group with yeah, other women who are sharing similar things to me and being able to talk about that and learn from other people's experiences was really nice. So for me it's also been about decentring medical institutions as the sole kind of structures that can be involved in my care".

"I'm part of the Women with Disabilities ACT, and a couple of years ago they had lunches... I loved going to them, you know, because it was meeting different people and irrespective of their disability we were all just together... I've been in other support groups... and that was good because those are the people that actually understood what you were going through, so that was important... I'm now part of the men's shed... we have ours on a Friday morning, and it's majority of women... we don't care what our backgrounds have been or anything like that, as long as we all get on together and we have a purpose and just enjoy each other's company. So it's really a social thing. And that's what I think a lot of people need".

Discussion

Women with disabilities in the ACT are diverse and have different life experiences, which can be impacted by their impairment, how society is set up in an ablest way, and prevailing prejudices, stigma, and assumptions. This can have varying impacts on their health and wellbeing, their health needs, their life roles, their feelings of social inclusion, and their access to health services and supports.

Our research confirms that the intersection between disability and gender has specific negative impacts on the health and wellbeing of women with disability in the ACT, requiring dedicated disability- and gender-sensitive responses. It is encouraging that initial work to develop the ACT Disability Health Strategy recognises some of the specific health needs of women with disability in the ACT, as part of understanding that people with disabilities come from diverse backgrounds with implications for their health care and needs.¹⁹¹

Recommendation 1: ACT Government and relevant stakeholders ensure that women with disabilities are considered a distinct cohort in the ACT Disability Health Strategy, their voices listened to and their needs addressed.

Ratings of physical and mental health were poor for women with disabilities. Almost 85% of women rated their physical health as fair, poor or very poor, and similarly 80% of women rated their mental health as fair, poor or very poor. And there were differences in how age groups rated their health, specifically mental health, although this correlation did not appear to be related to ageing.

Women in this study predominantly had physical impairments, followed by psycho-social, and neurological impairments. Women with disabilities top health issues were 'sleep, fatigue or energy issues', followed by 'pain or chronic pain', and 'mental health'. By contrast, other Women's Health Matters studies have consistently found that the top three health issues for women in general in the ACT are 'chronic disease', 'mental health', and 'weight, diet and fitness'. The differences and similarities between these findings give more nuanced insights into the health experiences of women in the ACT. The health issues for women with disabilities have been found to be created or exacerbated by limitations to accessing life roles, social inclusion, health services and supports, health information, how they are treated by health providers and not always about their disability.

The vast majority of women who answered the survey reported that they faced barriers accessing services to address health issues, primarily the affordability of services. This was compounded by having to access multiple services for comorbidities, which was also found in Women's Health Matters research about younger women and chronic conditions.¹⁹² Other barriers impacting women's access to health services and supports were, appointment availability and long wait times. These findings are similar to other Women's Health Matters research.^{193 194} These barriers were influenced by systemic

¹⁹¹ Stanford, D. *Future Directions of Disability Health in the ACT: Phase One of the ACT Disability Health Strategy Project*, 2021, Act Health Directorate, Canberra.

¹⁹² Hutchison, "I don't have the spoons for that..."

¹⁹³ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

¹⁹⁴ Hoban, *ACT women's health matters!*

drivers such as lack of specialists, reduced rates of bulkbilling, low Medicare visits for allied health therapies, and lack of suitable transport options in Canberra. These patterns indicate significant unaddressed issues in the ACT.

Women mentioned the negative impact that health providers had if they were not believed or listened to. Conversely, participants mentioned walk-in-centres as a service that they had good experience with because they found comfort in the treatment by the nursing staff and time they spent with them.

We found that access to sexual and reproductive health services were impacted by complicated needs of women and the falsehoods that women with disabilities do not need to be screened or access those type of services, amounting to a breach of their human rights.

Health information was predominantly accessed through GPs or health providers and so there barriers of cost or wait time to get timely relevant information, since GPs are expensive and it can be difficult to obtain a regular doctor. One third of women with disabilities reported that they lacked nuanced and comprehensive health information relevant to their specific health needs. They also spoke about the need for health information to be in formats that were able to be easily accessed.

Accessing health services, supports and health information was challenging due to the complexity of the ACT health system. More centralised information sources would benefit women navigating the health system. Women felt they lacked advocacy which limited them from addressing their health needs.

COVID-19 was seen as a particularly difficult time for women with disabilities in this research, where women reported poor mental health and feelings of isolation especially when they were not able to get the supports they needed to maintain their life roles. However, women with disabilities expressed appreciation for the increased availability of services that made their lives easier, such as Telehealth.

Many women in our study discussed how their life roles were impacted by having an impairment. They discussed how they felt frustrated by having to rely on partners in caring and domestic roles. Others felt that they were shut out of romantic and friend relationships.

The ability to maintain employment was challenging, and many in our study were working less than they wanted to in paid employment. Reasons included workplaces not accommodating their impairment in a variety of ways.

Feelings of not being social included were influenced by their poor health and not always feeling understood in their relationships and by being left of social interactions, employment, and lack of adequate transport options to attend events.

Women's self-ratings of health

Women who answered the survey rated their physical and mental health poorly, with only approximately 15% of women rating their physical health as either excellent or good. A corresponding percentage of women, approximately 85%, rated their physical health as fair, poor, or very poor. Our

findings were similar to unpublished data about women with disabilities¹⁹⁵ and *Jean Hailes for Women's Health 2020 report* that showed that 49% of women with disabilities rated their health as poor or very poor.¹⁹⁶ This is significantly different, however to the 2018 ACT general women's study, where only 40% of women in the general population rated their physical and mental health as fair, poor, and very poor.¹⁹⁷

The women varied as to whether they rated their physical or mental health more poorly, and there was considerable variation between different age groups. Notably, the older women in our study appeared to rate their mental health more poorly in comparison to the women who had a disability in the older women study "*We contribute...*".¹⁹⁸, and it would be interesting (although beyond the scope of this study) to investigate whether that result reflects the changed context of COVID-19.

Health issues for women with a disability

Women in this study predominantly had physical impairments (69%), followed by psycho-social (42%), neurological (35%), and intellectual and sensory impairments appearing in under 10% of women. The proportion of people with physical and psycho-social impairments was higher than in previous Women's Health Matters studies,¹⁹⁹ noting that in this study we allowed women to put multiple impairment options. This highlights the growing need to acknowledge and address the impact of co-morbid disabilities and of psycho-social impairments.

The women who participated in the survey identified their top health issues as: 'sleep, fatigue or energy issues'; 'pain or chronic pain'; and 'mental health'. This differed somewhat from other studies that Women's Health Matters have undertaken, in which women generally have identified 'chronic disease', 'mental health', and 'weight diet and fitness' as their top three health issues.^{200 201 202} While 'weight, diet and fitness' was also significant in the current study, being the fourth most commonly listed 'top health issue' for women with disabilities, the greater apparent emphasis on issues of energy, pain and mental health gives a more nuanced insight into experiences of chronic disease and disability.

These three top health issues were described at times as related of their disability, separate, or due to their lack of access to specific and tailored health information, support and health services. Barriers to accessing nuanced health information, support and health services, and these barriers being related to their overall health and wellbeing, have been found in other studies.²⁰³ Importantly, only around 50% of the women who reported mental health as one of their top three health issues said that they were accessing a mental health service or professional to treat this issue. Local research also shows

¹⁹⁵ Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

¹⁹⁶ Jean Hailes for Women's Health, *National Women's Health Survey 2020*.

¹⁹⁷ Hoban, *ACT women's health matters!*

¹⁹⁸ Hutchison, "*We contribute...*"

¹⁹⁹ Carnovale, *Strong women, great city*.

²⁰⁰ Hoban, *ACT women's health matters!*

²⁰¹ Hutchison, "*This is what the real experience is like...*"

²⁰² Hutchison, "*We contribute...*"

²⁰³ Wisdom et al. 'Health disparities'.

that mental health outcomes are influenced by women with disabilities' ability to gain access to mental health services, particularly services specialising in disability.²⁰⁴

Recommendation 3: ACT Government to work with relevant stakeholders to fund and promote more disability informed mental health services.

The women who participated in the survey, focus groups and interviews often spoke about how chronic disease existed alongside their disability, but was taken less seriously when it existed alongside chronic mental illness, or alongside the health impacts of aging, or being considered overweight by health professionals. Health professionals have been known to focus on women's impairments rather than health issues requiring attention and are mistaken in thinking that the disability is causing all other health problems.²⁰⁵

Women also mentioned how the top three health issues influenced how they did their life roles, for example how chronic pain and fatigue limited their employable hours. Findings from other local studies show how health issues impact on life roles, social inclusion, and health and wellbeing.²⁰⁶ Physical and mental health was discussed by the women in focus groups and interviews, concerning how poor physical health, poor mental health, and social isolation due to poor health or poor access to life roles and social events reinforced each other. Studies show how health and wellbeing is influenced by a multitude of interrelated factors that are not always related to their disability.^{207 208}

Access to and barriers to health services and supports

The responses from women in our research supported research that affordability, availability, appropriateness, and accessibility were the key barriers women faced to accessing health services and supports.^{209 210 211} These barriers had varied, intersecting negative effects on women with a disability. Affordability of health services and supports was identified by 70% of women in our survey, similar to other local studies.²¹² Women in our study reported having to access multiple varying services which compounded their barriers of affordability, similar to findings for younger women with chronic conditions.²¹³ Some women also mentioned lack of bulk billing services and this impacted on their ability to access services. Women's Health Matters research has highlighted this issue in numerous reports about barriers to health services for women generally, and the impact that low bulk billing rates in Canberra has on women's affordability to access those services.^{214 215}

²⁰⁴ Gough, 'Contributing our voices!'

²⁰⁵ Women's Health Victoria, *Health issues for Women*.

²⁰⁶ Gough, 'Contributing our voices!'

²⁰⁷ Emerson et al., 'Lower well-being'.

²⁰⁸ Hutchison, "I don't have the spoons for that..."

²⁰⁹ Carnovale, *It goes with the territory*.

²¹⁰ Hoban, *ACT women's health matters!*

²¹¹ Denmark et al., *No transport, no treatment*.

²¹² Unpublished research, A summary of the views of women with disabilities in the ACT, Women's Centre for Health Matters.

²¹³ Hutchison, "I don't have the spoons for that..."

²¹⁴ Carnovale, *It goes with the territory*.

²¹⁵ Hutchison, "I don't have the spoons for that..."

The women who responded to the survey could only access the services that they needed at a subsidised rate which limited their ability to choose a service, and found that the amount of sessions available did not meet their needs. Women with disabilities often experience poor access to allied health professionals due to limitations on the number of care plan visits.²¹⁶ Many women reported that the health services that they needed were not affordable on an ongoing basis; rather, they were targeted to acute care, which did not fit their more chronic needs. They spoke about the need for ongoing access to psychological services and physical therapies. And a need for a focus on affordable preventative physical health therapies. These findings were also found in local research which showed that younger women with chronic disease often needed to put off essential health care to a future date where they could afford it.²¹⁷

Women in our study reported a significant lack of services in the ACT to meet their needs, that it was difficult to find or navigate services, that they could not find any services in their area, and some women reported needing to access services in different states. Because of their greater health service needs, women with disabilities accessed health services more than the general population of women²¹⁸ and they accessed specific services more often, particularly specialists who were accessed by 57% of women in the last 12 months, compared to 10% of general women.²¹⁹ Yet this study has confirmed that there is considerable unmet need, impacting negatively on the health and wellbeing of women with disabilities. One fifth of women reported that accessibility for disability was a barrier to health services and supports.

Many women also reported that a lack of accessible transport options to attend medical appointments was a barrier to access. There were issues of wait times for not only buses to appointments, but the connections between bus stops and the services themselves were often just as difficult or inappropriate for women with disabilities. HCCA found similar barriers for people with chronic conditions and disabilities in their 2014 report on health services access.²²⁰ Women discussed the need for services such as public transport to be informed by people with disabilities so that it meets their needs.

Walk-in-centres were seen as a more accessible alternative to the emergency department or a GP. Thirty four per cent of women in our study accessed walk-in-centres in the last 12 months, in contrast to only ~8% of respondents in the 2018 ACT women's health study. However, even with low use, women still acknowledged walk-in-centres as a good option when looking for alternative community services.²²¹ Several women with a disability in the focus groups and interviews reported that the walk-in-centres gave them timely medical care and that they found the nurses very reassuring. Studies about

²¹⁶ Gough, *'Contributing our voices!'*

²¹⁷ Hutchison, "I don't have the spoons for that..."

²¹⁸ Hoban, *ACT women's health matters!*

²¹⁹ Ibid.

²²⁰ Health Care Consumers Association, *'Primary health care in the ACT'*.

²²¹ Hoban, *ACT women's health matters!*

walk-in-centres see that nursing staff provide additional care and time when seeing clients.^{222 223 224} The quality of care given by nurses at the walk-in centres was highly valued by women, and this was seen as something that removed barriers to seeking help such as logistical concerns related to living alone, and being unsure or feeling guilty about needing to call an ambulance. Similar findings in the older women's health and wellbeing study showed that they often were dismissed by other health services and walk-in-centres were preferred as they validated their concerns.²²⁵

Another key barrier to accessing health services for women with disabilities was the impact of poor experiences with health professionals. Health professionals not listening to requests or self-reporting of health and experiences was an issue for most women with a disability, and breaches their human rights to healthcare. Women with disabilities are often left out of decisions that impact their health care and treatment.²²⁶ For some participants with intellectual disabilities, they felt disrespected when health professionals did not speak to them regarding their own health and experiences. This is a widespread occurrence for women, not being believed or listen to about their symptoms and health needs impacts their health and wellbeing, leads to lack of diagnosis or misdiagnosis, and particularly if in pain.²²⁷ Women across focus groups and interviews continued to build on this consensus that their pain was not taken seriously, partly because of how they felt they masked it as part of their gendered presentations of symptoms as women. It also negatively impacted on their confidence and ongoing capacity to manage their health.

This research found that barriers to access are cumulative, that quality of care and sense of agency in their own health was low. The experiences negatively affected women's confidence or trust in ongoing care, which led to a sense of frustration, and an expectation of poor experiences with health services.

The consultation draft of the Territory-Wide Health Services Plan has proposed an integrated and coordinated approach in which the ACT Government works with NGOs and the primary care sector to "support patient centred, holistic care that is delivered as close to home as possible."²²⁸ This approach has potential to address some of the issues experienced by women with disabilities, with initiatives such as improved referral pathways, community pharmacy, pain management, and colocation of services.

Recommendation 2: ACT Government to include actions within the Disability Health Strategy to maximise an integrated and coordinated approach to care, incorporating measures such as colocation of services to make health care more affordable and less burdensome for women with disabilities.

²²² Salisbury, 'Postal survey of patients' satisfaction'.

²²³ Venning et al. 'Randomised controlled trial comparing cost effectiveness'.

²²⁴ Kinnersley et al. 'Randomised controlled trial of nurse practitioner versus general practitioner care'.

²²⁵ Hutchison, "We contribute..."

²²⁶ Women's Health Victoria, *Health issues for Women*.

²²⁷ Hutchison, "I don't have the spoons for that..."

²²⁸ ACT Health, *DRAFT Territory-wide Health Services Plan 2021–2026*, 2021 https://cms.health.act.gov.au/sites/default/files/2021-06/Consultation%20Draft%20Territory-wide%20Health%20Services%20Plan_May%202021.pdf

Sexual and reproductive health

Many women with a disability faced barriers to accessing sexual and reproductive health services. Fifty percent of women had not accessed services for their sexual health, while thirty nine percent of women had. The main reasons the women gave for why they did not access sexual and reproductive health services were: that they did not need to, it was not relevant, or due their older age, some women reported that they had experienced trauma which discouraged them, some had barriers like cost and some said that they went occasionally. Other research shows women's experiences of accessing sexual and reproductive health services are impacted by the perception that women with disabilities don't need to look after their sexual and reproductive health.²²⁹ This lack of understanding by health professionals about their complex needs was discussed by women in the focus groups.

As existing research demonstrates, women with disabilities who already face challenges in accessing health care were further disrupted by COVID-19 lockdown, and these disruptions to care have long term health consequences.²³⁰ After more time has passed, we will perhaps see if this was a marked issue in relation to health screening of women with a disability.

Recommendation 5: ACT Government to work with relevant stakeholders to improve the availability of appropriate sexual and reproductive health services for women with disabilities, and to promote these services widely with regard to the needs of women with disabilities in their diversity.

Access to health information

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.²³¹ 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 such as screening.²³²

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.²³³ Barriers faced by the women seeking health information were affordability and wait times to consult a health professional.²³⁴ 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.

²²⁹ Frohmader & Ortoleva, *The sexual and reproductive rights of women and girls with disabilities*.

²³⁰ Shanmukhasundaram, *"The Responsibility has Fallen on Us"*.

²³¹ Gough, *'Contributing our voices!'*.

²³² Department of Health, *National cervical screening program toolkit'*.

²³³ Hoban, *ACT women's health matters!*

²³⁴ Carnovale, *It goes with the territory*.

Women also talked about being frustrated and discontent 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 sign language is a significant barrier to health information.²³⁵ And can create additional barriers for accessing necessary but routine health care such as health screening.²³⁶ 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.

Recommendation 6: ACT Health to 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).

Lack of support when accessing health services, supports and information

Another key theme was a need for support in accessing and managing health services, supports and information. Women reported that navigating health services and supports was especially difficult when needing to access multiple services. Participants in local research by Health Care Consumers Association reported the same, that navigation of the health system difficult and relied on their GPs for guidance. However, felt they missed out on services because they weren't aware of them.²³⁷

Women across the focus groups and interviews articulated a desire for more centralised, accessible health information resources, so that they can manage complex networks of information and services. Local research from Women's Health Matters about younger women with chronic conditions found it difficult to find services and identified the need for a central hub of information.²³⁸ There is a *"need for better navigation about the range and scope of available services for women in the ACT."*²³⁹

Advocacy or support from people who understood their needs and were well-placed to interpret health systems was seen as a key difference in the quality of information and care they would receive.

²³⁵ WWDA, WWDA Position Statement 4: Sexual and Reproductive Rights.

²³⁶ Department of Health, National cervical screening program toolkit.

²³⁷ Health Care Consumers Association, 'Primary health care in the ACT consumer experiences'.

²³⁸ Hutchison, "I don't have the spoons for that..."

²³⁹ Carnovale, *It goes with the Territory!*

This need for advocacy was part of a two-sided sense of frustration from women with disabilities when attempting to access good health and wellbeing in the ACT. In part, as described above, they felt that the systems were too complex and disconnected or siloed, which prevented them from easily accessing services that they could afford. Individual advocacy can help make the health system more transparent and help the patient to make decisions important for their health needs.²⁴⁰ ²⁴¹ The other side to this was a sense that the health system expected them, as health care consumers, to be the sole source of expertise on what health supports may benefit them. This was a source of frustration for women who felt that this expertise and health information was something they needed from professionals, to better address their needs and improve their wellbeing. This was often expressed by older women, who had tried a lot of different strategies to help manage their health.

Recommendation 7: ACT Government to work with relevant community organisations and service providers to improve access to high-quality individual advocacy in the ACT, in order to support decision making and navigation through the complex and often fragmented health system.

For some women with disabilities, health information that may seem accessible does not equate to better health, as the burnout involved in managing this information, and attempting to tailor general information to their specific needs is difficult to manage with reduced capacity. There is therefore a need to create better centralised sources of information, even for those women who do not feel barriers to access, to improve overall health outcomes.

Health services and information during COVID-19

The ACT's lockdown due to the COVID pandemic had multiple impacts on the health of women with a disability. As the Women with Disabilities ACT (WWDACT) report found, during this time, women were worried about the health implications of not seeing their friends and family, and that they felt vulnerable to isolation.²⁴² Some survey and focus group participants reflected on how difficult this period was for their mental health, particularly if remaining socially connected via internet technologies did not appeal to or work for them. Others felt that the isolation they faced due to their disability meant they did not receive enough information about COVID-19. For some women from multicultural backgrounds, the lack of accessible health information about COVID-19 was a large source of stress.

Women with a disability were at risk of not being able to access health services often crucial to their ability to live and work comfortably during this time, which also occurred in the research by WWDACT.

²⁴³ However, some women reported they found telehealth more accessible for them than seeing the

²⁴⁰ Patient Advocates, *What is a patient advocate?*

²⁴¹ COAG, *National Disability Strategy 2010-2020*.

²⁴² Shanmukhasundaram, *"The Responsibility has Fallen on Us"*.

²⁴³ Shanmukhasundaram, *"The Responsibility has Fallen on Us"*.

doctor in person. For many women, the new services that became available during COVID-19 addressed barriers to access that they had experienced for long periods before the pandemic.²⁴⁴

Recommendation 4: ACT Government to continue to support the functionality of health technology, such as Telehealth, in public services and work with the Commonwealth as necessary in order to support remote access to health services, as in-person attendance at health services can be a barrier for women with disabilities.

Many women with disabilities agreed that the adaptations from health and community services, as well as a reduction in stigma surrounding experiencing poor mental health were widely beneficial. However, for many, pre-existing discrimination and disadvantage was exacerbated by COVID-19, as a recent report from WWDACT has found.²⁴⁵

Impacts on life roles

A majority of women who answered the survey and participated in focus groups reported that their disability impacted their ability to participate in life roles in a variety of ways. This included relationships, family and caring roles, employment, and housing. Women's disabilities were one part of the complexity of their lives, however many women said that it impacts everything in their day-to-day experience. Some women also highlighted the impact of societal barriers that created stigma and discrimination in a society that promotes ableism.

Relationships and caring roles

Similar numbers of women with a disability who answered the survey were single to those married or living with a defacto partner. Women identified how their disability had been affected by gendered life roles they played in marriage and raising children. And while generally women's time is taken up with far more child rearing and household responsibilities than men,²⁴⁶ having to rely on partners was distressing for women in our study.

Just over fifty per cent of women reported that they did not have caring roles, while 40% of women did have caring responsibilities, with some of those women reporting multiple caring roles. This finding was comparable to other recent local studies about women with disabilities.²⁴⁷

Through the study, several women identified that their disability had an impact on their caring roles, were worried about asking for help or being perceived as incapable, and did not have consistent, positive support to rely on in providing care for their children. These findings are consistent with the existing literature, which has established that women with disabilities are often subjected to judgement and stigma about having children and worry about their children being taken away due to the perception that they cannot be good or adequate parents. To improve the well-being of women with disabilities who have children in their care, and to support the goals of the First 1000 Days project (to optimise the healthy development of children), there is a need for more disability-

²⁴⁴ Annaswamy et al., 'Telemedicine barriers'.

²⁴⁵ Women with Disabilities ACT (WWDACT), *Involved from the beginning: Using COVID-19 experiences to plan a better future for women, girls, feminine identifying, and non-binary people with disabilities in the ACT*, 2021, <https://d35ohva3c1yycw.cloudfront.net/wp-content/uploads/2021/11/30120013/Involved-from-the-Beginning-1.pdf>

²⁴⁶ Fullagar & Brown, 'Everyday temporalities'.

²⁴⁷ Shanmukhasundaram, *"The Responsibility has Fallen on Us"*.

sensitive services and support in relation to parenting, as well as the kinds of universal accessibility and inclusive design principles that make it easier to participate as a person with caring responsibilities.

Recommendation 8: ACT Government to work with relevant stakeholders such as WWDACT to identify improvements needed to ensure access to high-quality, disability-sensitive maternity services and parenting support, and to make improvements as required.

When asked about relationships, women reflected on feeling unable to participate in romantic and sexual cultures due to their impairment, and also because most of their energy was taken up by maintaining employment. Women in the *“I don’t have the spoons for that...”* reported being left out of being able to form romantic or even friendships as their impairments impacted their ability to engage socially.²⁴⁸

Employment

Women across focus groups and interviews also reflected on how their employment status was impacted by the barriers they face due to disability. Women mostly reported that their symptoms of disability impacted their ability to maintain employment, work to their full capacity, and do the type of work they wanted to do. A local study showed women sought to be employed but faced barriers such as difficulties managing chronic episodic conditions and cited a lack of flexibility in workplaces.

²⁴⁹

Women in our study described how workplaces are not compatible with their needs. Barriers including the hours required by employers being challenging when dealing with fatigue and pain, or managing these in a shared office environment. Some women expressed frustration with having to use sick leave which often put pressure on them as an employee and impacted their ability to fulfill their work duties. This was also highlighted in Women’s Health Matters research with younger women with chronic disease in their *“I don’t have the spoons...”* report.²⁵⁰

Women also reported that often their place of employment did not provide the necessary tools, equipment, or accommodations so that they could do their role properly. Workplaces often lacked resources to help women perform their role adequately.²⁵¹ Women in our study who had had positive experiences of workplaces or employment described adaptability of their employers as key. This included provisions to work from home and support via adaptive technologies, consistent with the intent of disability discrimination law.

Another barrier that women talked about was not being able to find work due to their impairment, including being actively discriminated against at work or when trying to obtain employment. Gough found similar barriers for women, with employers being reluctant to hire people with a disability.²⁵²

²⁴⁸ Hutchison, *“I don’t have the spoons for that...”*

²⁴⁹ Gough, *‘Contributing our voices!’*

²⁵⁰ Hutchison, *“I don’t have the spoons for that...”*

²⁵¹ Gough, *‘Contributing our voices!’*

²⁵² Ibid.

Recommendation 9: ACT Government to work with community and business groups to improve the availability of accessible and flexible workplaces for women with disabilities, wherever possible on a universal basis to reduce stigma, since employment supports financial independence and equitable participation.

Housing

The majority of women with a disability who responded to the survey were living in a house that they owned, approximately 37%, followed by living in a rental, approximately 30%, with 93pprox.. 17% living in public housing accommodation. In local research women with disabilities were heavily concerned about their housing situation as they couldn't access suitable housing.²⁵³ Likewise in focus groups, several women reported that they felt they lacked agency in seeking appropriate housing, and that the housing they were in negatively affected their ability to manage their health and wellbeing.

Social Inclusion

Women reported that their disability shaped their life roles, and this was often reflected in a lack of social inclusion, as they were unable to fully participate in key social relationships or the workforce. Stigma around having poor health means that many women who have disabilities feel misunderstood by friends, family and the wider community. In response to the survey, women with a disability spoke about feelings of isolation and difficulty forming and maintaining relationships. These social and attitudinal barriers can impact self-esteem and their ability to be involved in social relationships.²⁵⁴ For those women with disabilities who struggle with chronic illness and poor mental health, this is often reinforced by a lack of access to social events and community.

Barriers to being socially included for people with disabilities are often related to living and transport situations, as well as the built environment.²⁵⁵ When asked more generally how women with a disability felt included in community in the ACT, they reflected on the ways in which poor infrastructure such as transport is a barrier to social inclusion as part of their health and wellbeing. Women across focus groups and interviews agreed that more affordable parking closer to events would be useful in helping them feel that they could participate. The inaccessible infrastructure in the ACT contributed to the sense of frustration at a lack of independence for women in this study and other Women's Health Matters research which would allow them to fully participate in community.

²⁵⁶ ²⁵⁷

Several women spoke about wanting to participate in more social events and attend more public exercise classes. The lack of affordable, accessible places for them to socialise had a negative effective

²⁵³ Ibid.

²⁵⁴ Nosek et al., 'Self-esteem and women with disabilities'.

²⁵⁵ Nosek et al., 'Self-esteem and women with disabilities'.

²⁵⁶ Hutchison, "We contribute..."

²⁵⁷ Courtney-Bailey P, Hutchison A, Tran J, & Weins S, *Making ACT bus stops work for women. Women's perception of safety from recent changes to some of ACT's bus stop location*, Women's Centre for Health Matters, Canberra, 2019, <https://www.womenshealthmatters.org.au/wp-content/uploads/2020/10/Making-ACT-bus-stops-work-for-women-FINAL.pdf>

on their physical, mental and social wellbeing, a finding discussed in other studies ²⁵⁸ The stigma surrounding disability alongside the inaccessibility and unaffordability of many social events and activities had a compounding effect on women's ability to feel included and engaged in the ACT.

Recommendation 10: ACT Government to work with relevant stakeholders to increase the availability of affordable and accessible opportunities for healthy activity and social events.

More positively, many women in focus groups and interviews emphasised the support they had received through community-based care. Inclusion in peer-focused health supports helped them to understanding their health within their communities, and empowered them. They also discussed a desire for more representation of women and people with disabilities in policy and planning, consistent with the broader research and advocacy consensus that this representation is essential for achieving an equitably society.

The barriers that women with a disability face with inaccessible infrastructure in the ACT, in conjunction with a lack of inclusive attitudes have a cumulative effect on these women not feeling socially included. The lack of access to community, as a resource for wellbeing and connectivity negatively affects the health of women with disabilities.

Managing information, services and isolation- A commentary

These findings demonstrate that for women with a disability, navigating complex health systems and multiple barriers requires large amounts of time and energy. The barriers that women face to accessing health services need be understood in tandem with the barriers to accessing health information. Barriers such as availability, appropriateness, accessibility, and affordability, as well as gendered experiences of not being listened to by health professionals contribute to a frustration and alienation from health services, and community more broadly.

For women with a disability, the barriers to health services and lack of information on how to access affordable or subsidised care, and how to find services that are appropriate to chronic care rather than acute care make them feel as though health services cannot understand the kind of support that they need. In response to the survey, women articulated that when needing to access multiple services with a scarcity of both appropriate care, and the energy and finances required to access it, they needed more support. This support and advocacy from people who understood their needs and were well-placed to interpret health systems was seen as a key difference in the quality of information and care they would receive.

Women reported a sense that the health system expected them, as health care consumers, to be the sole source of expertise on what health supports might benefit them. This was a source of frustration for women who felt that this expertise and health information was something they needed from professionals, and also that the burnout involved in managing this information, and attempting to tailor general information to their specific needs, was extremely difficult to manage with reduced

²⁵⁸ E Emerson et al., 'Loneliness, social support, social isolation and wellbeing among working age adults with and without disability: Cross-sectional study', *Disability and Health Journal*, 2021, vol.14, pp. 1-8.

capacity. Managing their health information in such an individual way contributed to their feeling overwhelmed and isolated.

Women articulated that overcoming the barriers to accessing services (wait times, physically getting transport to appointments, leaving other responsibilities to attend appointments, physically getting into buildings, dealing with inappropriate forms and check-ins) was often coupled with the effort required to actually find the appropriate treatments (finding an empathetic GP who they could afford to see as often as they needed, and who was available frequently, who was willing to continue to explore further options when things weren't working).

The Women's Health Matters 2018 report, *"I don't have the spoons for that..." The views and experiences of younger ACT women (aged 18 to 50 years) about accessing supports and services for chronic disease'* discussed how the spoons analogy was used by women with chronic disease as a way of helping other people to understand the impact the invisible symptoms of their chronic disease had on their energy levels.²⁵⁹ Christine Miserando's spoon theory is used to explain the sudden and unexpected loss of energy that is common in many people who have a chronic disease.²⁶⁰ This theory argues that people without chronic disease start the day with a seemingly unlimited amount of energy to do what they want, but people with chronic disease only have a limited supply of energy or spoons available each day. Every basic task or action uses a varying number of them. The phrase "running low on spoons" has been adopted as a useful way of communicating the need for rest to others.²⁶¹

This 2018 Women's Health Matters research found that women were concerned about the relationship between the time taken to attend appointments and the number of "spoons" they had to expend, as those with chronic disease were found to have significant time demands with constant treatment burden.²⁶² Just as for these women with limited "spoons", fighting stigma was another burden of having a chronic disease²⁶³, for women with a disability surveyed in this research, fatigue or energy issues being their most reported top health concern shows how limited spoons were also taken up trying to manage stigma and complex, often inaccessible health systems.

In order to feel that health professionals listened to them or believed them, women had to mask their pain or disagreement. The information, skills and emotional labour required to do this, in order to access health services, was taxing on individuals. The ongoing labour of this process needs to be accounted for, to understand the many stages of information seeking, finding services, and finding various treatments and referrals as women attempt to access affordable, appropriate, and accessible services.

The findings of this research concerning women with a disability demonstrate that the barriers to access are cumulative, and that quality of care and sense of agency in being listened to, and amount

²⁵⁹ Hutchison, "I don't have the spoons for that..."

²⁶⁰ C Miserandino, "The Spoon Theory". But You Don't Look Sick', 2003, <https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>

²⁶¹ Hutchison, "I don't have the spoons for that..."

²⁶² A Sav et al., 'Treatment burden among people with chronic illness: what are consumer health organizations saying?', *Chronic Illness*, vol. 9, no. 3, 2012, pp. 220–232.

²⁶³ Hutchison, "I don't have the spoons for that..."

of support to manage complex health systems was low. The experiences negatively affected women's confidence or trust in ongoing care, which led to a sense of frustration, burnout, and an expectation of poor experiences with health services. The barriers to accessing health information, and health services themselves are cumulative as they are part of the same health journey. The cognitive load or spoons required to manage these barriers runs alongside other health issues which reduce the number of spoons these women have. This research has also demonstrated how the life roles of these women are affected by disability; these women live complex lives and manage the intersections of complex health systems, stigma and isolation, which are barriers and causal factors in their poor physical and mental health outcomes.

Conclusion

This study demonstrates that women with a disability experience barriers to accessing health services, information, and social inclusion in the ACT.

This research highlights significant barriers to health services for women with disabilities. Having a complex condition or disability can impact on the way a person is treated in a medical setting and in society which impacts on their ability to interact with health services in a positive way.

It has also highlighted psycho-social impairment as one of the main disabilities facing women, and highlights the need for gender specific responses needed for addressing mental health in a nuanced way. This includes acknowledging that mental health and physical health are interrelated, but not taking this as a rationale to dismiss or avoid providing treatment or services for either.

Health services were not affordable for women with a disability, or not available to treat chronic rather than acute issues. Poor appointment availability and long wait times were barriers, alongside a lack of services in the ACT to meet their needs, which meant that women with a disability often had to travel interstate to access health services.

The research also found that information about health, and about health services was not provided in accessible ways for women with a disability. Not only does a lack of information result in their not being able to look after their health, the ongoing search for this information, specific to their needs, is draining for women who are often already managing complex physical and mental health needs.

For women with a disability, barriers to access are cumulative, and their sense of agency in their own health was resultingly low. These experiences negatively affected women's trust in the quality of ongoing care they might receive, which led to a sense of frustration, and an expectation of poor experiences with health services. Poor physical health, poor mental health, and social isolation due to poor health and poor access to life roles and social events cyclically reinforced each other.

Key social determinants of health such as secure economic foundations and supportive social networks²⁶⁴ were largely absent for women with a disability in this research. This demonstrated how understanding the intersections of marginalisation that women with disabilities face, in terms of inaccessibility of the workforce, public transport, buildings, social events, alongside their taking on gendered caring roles, exposure to family violence, and poor mental health was key to designing services appropriate to improving their health and wellbeing.

The research findings largely reflect the information presented in the literature review, suggesting that these key concerns in international and national studies can be generalised to the ACT to a certain extent. Some barriers to accessing services and information are common to women with disabilities regardless of location, and this research has illuminated the ways these common barriers operate in

²⁶⁴ Hosseinpoor et al., 'Social determinants of self-reported health'.

the ACT, as well as highlighting some specific issues with the ACT's health service and city infrastructure.

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