



# WOMEN WITH DISABILITIES AUSTRALIA (WWDA)

## **Women With Disabilities Australia (WWDA)**

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Brief Submission to the Special Rapporteur on the Rights of  
Persons with Disabilities on the Right of Persons with  
Disabilities to the Highest Attainable Standard of Health

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## **About Women with Disabilities Australia (WWDA)**

Women With Disabilities Australia (WWDA) is the award winning, national Disabled People's Organisation (DPO) for women and girls with all types of disability in Australia. The key purpose of WWDA is to promote and advance the human rights and freedoms of women and girls with disability. Our goal is to be a national voice for the rights of women and girls with disability and a national force to improve the lives and life chances of women and girls with disability.

WWDA represents more than two million disabled women and girls in Australia, has affiliate organisations and networks of women with disability in most States and Territories of Australia, and is internationally recognised for our global leadership in advancing the human rights of women and girls with disability. As a DPO, WWDA is managed and run by women with disability, for women and girls with disability.

WWDA is a founding member of [Disabled People's Organisations Australia](#) (DPO Australia). DPO Australia is an alliance of four national disabled people's organisations in Australia. The key purpose of DPO Australia is to promote, protect and advance the human rights and freedoms of people with disability in Australia by working collaboratively on areas of shared interest, purpose and strategic priority.

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## Introduction

In March 2018, Women with Disabilities Australia (WWDA) surveyed our members about their experiences of accessing healthcare in Australia. The purpose of the short survey was to inform a brief submission to the United Nations [Special Rapporteur on the Rights of Persons with Disabilities](#)' study on right of people with disability to the highest attainable standard of health. The findings will also help broadly inform WWDA's ongoing systemic advocacy work, including the development of an extensive position statement on the right to access healthcare, which will complement WWDA's existing [human rights toolkit and suite of resources](#).

WWDA received forty-two responses to our survey which was a great result and better than expected.

- Eighty-five percent of respondents (36) identified as women or girls with disability.
- One person identified as a non-binary person with disability.
- Forty-five percent of respondents (19) identified, or also identified, as partners, friends, family members, carers, or guardians of a woman or girl with disability; support workers, advocates, researchers and policy makers.

The short survey asked respondents about four topics:

1. Experiences of discrimination in healthcare;
2. Barriers to accessing healthcare;
3. Informed consent and healthcare treatment;
4. What makes it easier to access healthcare.

This initial report provides an overview of responses WWDA received to the survey, and where possible, we have identified common themes, concerns and experiences. The findings contained in this brief report should be understood as indicative, and not statistically representative of, or generalisable to, all women and girls with disability. An overview of methods used have been detailed provided for reference only.

Thanks to the women and girls with disability and other people who responded to the survey and those who shared it across their networks!

## Findings

### Experiences of Discrimination While Accessing Healthcare

Eight out of ten (80%) of women with disability who responded to WWDA's survey on access to healthcare, identified that they had experienced discrimination while accessing healthcare, or knew someone who had. Respondents identified public and private hospitals, specialist clinics and community medical practices as places where discrimination most often occurred.

Negative attitudes were a common form of discrimination that women with disability experienced while accessing healthcare treatment. Attitudinal discrimination was most often experienced as, (1) healthcare professionals making negative assumptions about a person's disability and their needs; (2) an inappropriate focus on a person's disability when they were accessing medical treatment for reasons unrelated to their disability.

*If I go to a public hospital, it doesn't matter what I present with, it is assumed it's [Multiple Sclerosis] related. I'm sent to psychiatry as it must be depression. This happened once when I presented with an asthma attack.*

[...] when accessing treatment in hospitals for myself or my children, I have been spoken to more loudly than necessary [and] asked unnecessary questions about my blindness which were not relevant to the current health issue.

*Many doctors and nurses don't get that I'm a person, not a diagnosis.*

[Health professionals] make up their mind about you and what you need before you have even walked in the door...

For many women with disability, attitudinal discrimination extended to health professionals treating them as if they were children (infantilising); dismissing, ignoring or not listening to their needs; and questioning the validity of a woman's description of their health issue.

*I have a post-graduate law degree yet I am still spoken to [like a child]. [Health professionals] refuse to explain what's going on, the risk of treatments, test results, why tests are being done. [...] They also don't believe me when I say what is going on in MY body...*

I saw a new cardiologist who had never met me, but gave me a 50 minute lecture about the need to have weight loss surgery. He didn't give me an opportunity to speak. He didn't even take my pulse, or my blood pressure. He just assumed that I was immobile because of my weight. Because of my disability I have no choice of cardiologist.

Alongside attitudinal discrimination, women with disability described many other forms of direct and indirect discrimination, including:

- exclusion from community based services and programs on the basis of disability;
- exclusion from accessing income protection insurance;
- exclusion from accessing private health care due to high costs;
- lack of communication supports while accessing healthcare;
- lack of health information available in accessible formats, including sexual and reproductive health information;
- limited options for accessing healthcare services at home;
- inaccessible medical consulting rooms and equipment.

For many women with disability, gender was identified as a key site of discrimination, particularly with regard to accessing sexual and reproductive health services, and being acknowledged as having gendered and sexual lives.

*[Women with disability] aren't trusted in our reporting [of] our own symptoms or to communicate critical information about our conditions. Women with mental illness experience this at an even higher level. They are deemed hysterical and untrustworthy.*

Generally there is very little health information easily available to blind women in any format other than websites, which may or may not be accessible, and often not privately. I now need information about menopause; very little is available in libraries and what there is, is mainly designed to sell something.

*[A medical professional] assumed I wouldn't need a pap smear because I 'obviously wasn't sexually active'.*

Not being offered sexual health services on the same basis as others due to inaccessible equipment such as non-adjustable beds; not being able to have tests I require because of the same issue.

*My doctor refused to believe me about my sex life, [...].*

Repeated experiences of discrimination, limited alternative options, and inadequate complaints resolution processes sometimes led to women with disability giving up on formal complaints processes or pursuing remedies for poor healthcare treatment and discrimination.

*I'm afraid to make a complaint. Last time I made a complaint about the hospital, I organised all my evidence, but the response just said that it was appropriate care.*

I trust doctors and nurses now less than used car salespeople. At least if I complain about being sold a dodgy car, someone in authority will listen, believe me and do something. This is not the case in health when you have [a disability label].

## Barriers to Accessing Healthcare

In addition to questions regarding experiences of discrimination, respondents to WWDA's survey were presented with a list of potential barriers to accessing healthcare. They were asked to select any and all that made it hard for them to access healthcare. In addition, respondents could add their own barriers. The most common barriers to accessing healthcare identified by respondents to this question (n=25) included:

1. General inaccessibility of information, services and supports (88%)
2. Providers having limited understanding of disability (76%)
3. Previous negative experiences of accessing healthcare (56%)
4. Cost of services or treatment (52%)
5. Poor quality treatment (52%)
6. Lack of choice (48%)

Other barriers that women with disability commonly identified included limited services and shortage of specialist medical practitioners; cost of transport and distance to healthcare facilities; communication difficulties; and, lack of confidentiality. Several women identified limited access to adequate healthcare at their home as a significant issue.

*Distance doesn't matter when you are bedridden. Not physical accessibility – it's about the inaccessibility of [health professionals] being able to come to me.*

Most [General Practitioners] won't do home visits, most specialists won't do home visits, most allied health workers will on occasion, however [they] charge more.

*Diagnostic equipment is often not wheelchair accessible or the rooms in which the equipment is located is often not big enough to allow a wheelchair or hoist transfer.*

System today is not friendly and information is unclear and hard to access.



## Informed Consent and Access to Healthcare

People who completed WWDA's survey on access to health were asked if they had ever received treatment or support to which they did not provide their informed consent. A brief definition of consent and informed consent was provided with the question. Of the women with disability who answered this question (n=24), one in three women (33%) reported receiving healthcare treatment without providing their informed consent.

*I went into hospital to have fibroids removed. The night before the surgery the intern came and saw me and asked whether I was aware that the surgeon was going to do a hysterectomy. That was not what I had agreed to and I was able to stop the surgery from going ahead. The surgeon didn't understand why I refused and said 'it's not like you're using your uterus'.*

In institutional care as a child I was examined without my consent and was given contraceptive injection without my consent.

*I have had hundreds of interactions with the medical system. I have never been able to [independently] read a consent form. I have always relied on doctors etc. telling me what it said and signing it anyway.*

## Improving Access to Healthcare

Respondents were asked to describe in their own words, what would make it easier for them, and other women and girls with disability, to access quality healthcare. Written responses commonly centred around the following key ideas:

1. Increasing education of health professionals about disability to improve specialist medical knowledge and to reduce attitudinal barriers;
2. Increasing choice of doctors, specialists and treatment options in the public health system;
3. Ensuring healthcare services are affordable to people with disability;
4. Ensuring healthcare services are physically accessible and available;
5. Improving accessibility of health information to allow people to make informed healthcare decisions;

*[Health professionals] need to understand the person who has the disability & those healthcare services mob need to understand that there is all types & different level of disability a person got to live with :(*

In terms of my physical disability, more knowledgeable specialists would massively improve my access to quality healthcare.

*There is a whole system set up in rural areas where people can see their GP and specialists over Skype, and this is rebated by Medicare. People with disability who are bedridden or housebound should be entitled to use this system.*

More choice and understanding of the public health system. I understand my ability to choose and find information in the private system, but I can't afford that. I can only access services within the public system [...] that are not collaborative or consultative.

*Better education of all health professionals, based on a recognition of [human rights] of people with disabilities and an acknowledgement that [women with disability] experience issues common to all women.*

Access to healthcare must be inclusive. [...] It is also important that women with disabilities are given the tools to speak out about the discrimination they have experienced whilst accessing healthcare.

## Methods

### Aims

The aims of WWDA's brief survey on access to healthcare were to:

1. Explore women and girls with disability's experiences of accessing healthcare in Australia.
2. Gather data to help inform a brief submission to the Special Rapporteur on the Rights of Persons with Disabilities' 'Questionnaire on the right of persons with disabilities to the brief surveys as a method to engage with WWDA members around key human rights issues.

### Development

Survey questions were informed by the Special Rapporteur on the Rights of Persons with Disabilities' 'Questionnaire on the right of persons with disabilities to the highest attainable standard of health' (Appendix 2). A copy of the survey questions are provided at Appendix 1.

To minimise length, WWDA's survey only addressed questions two, three and four of the Special Rapporteur's questionnaire. The survey did not ask for personally identifiable information or request demographic information. Respondents were provided with a direct link to the questionnaire to provide an independent submission to the Special Rapporteur, if desired.

### Accessibility

To increase accessibility, survey questions and information were written in plain English and key words and concepts were **bolded**. Brief definitions provided.

Respondents could choose to complete the survey via the Survey Monkey website which meets WCAG2 accessibility standards, request the survey in hard copy, or in another format. Respondents could also complete the survey by phone or email.

### Advertising

The survey was advertised via the WWDA [Facebook page](#) and [Twitter feed, website](#), and included in WWDA's monthly email news bulletin. Respondents completed the survey online and one person opted to complete the survey by phone interview.

### Analysis

Basic statistical analysis was undertaken to identify common issues and experiences described by respondents in regard to barriers to accessing healthcare, experiences of discrimination, and experiences of consenting to healthcare treatment. Open-ended written responses were inductively coded for themes. These themes were then grouped into categories to assist with analysing and understanding the findings.

## **Confidentiality**

The survey did not ask for any personally identifiable information and no user specific information such as IP addresses, were recorded. One person completed the survey by phone interview.

## **Safety**

Information about relevant support services was included in some advertisements and on the final page of the survey. In addition, the draft survey underwent an internal review process prior to being uploaded to the Survey Monkey platform, tested and advertised.

## Appendix 1: WWDA Survey on Access to Healthcare

### WWDA Survey: Access to Healthcare for Women and Girls with Disability In Australia

The United Nations [Special Rapporteur on the rights of persons with disabilities](#), is preparing a report to be presented to the United Nations General Assembly, on the right of people with disability to the highest attainable standard of health.

[Women with Disabilities Australia \(WWDA\)](#) is writing a submission to the Special Rapporteur about this issue.

We would like to hear from our members and friends about the healthcare accessibility issues that are important to you.

- The survey includes 6 to 8 questions and should take around 10 minutes to complete.
- Your responses will help inform our written submission to the Special Rapporteur.
- You don't have to answer any question that you don't want to.
- Your responses are anonymous. Any identifying information will be removed if we use it in our written submission.
- If you need assistance to do this survey, require it in hard copy or another format, or if have any questions, please contact [chris@wwda.org.au](mailto:chris@wwda.org.au)

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#### Q1

##### I identify as:

- A woman or girl with a disability
- A partner or friend of a woman or girl with a disability
- A parent, family member, guardian, of a woman or girl with disability
- A carer or support worker that supports a woman or girl with disability
- An advocate, researcher, policy maker, or other professional in the disability sector
- Other **[OPEN]**

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The next question is about your experience of **discrimination** while accessing **healthcare**.

**Discrimination** means being treated differently or unfairly, because of who you are.

**Healthcare** is any form of treatment or support that helps you to stay healthy and well. Healthcare could include:

- Getting medical treatment in a hospital
- Visiting your General Practitioner (GP)
- Receiving community nursing services
- Sexual health services and treatment

- Family planning services
- Violence prevention services
- Accessing information about health issues
- Health insurance
- Disability-specific healthcare services or programs
- General healthcare services or programs
- Accessing mental health supports
- Accessing rehabilitation programs

## Q2

Have you, or someone you know, experienced discrimination when accessing healthcare? **[YES | NO]**

**YES** → **Q3** Please describe your experience(s) of discrimination while accessing healthcare. **[OPEN]**

**NO** → **QUESTION 4**

The next two questions are about what makes it easy or difficult to access healthcare as a woman or girl with disability.

## Q4

What can make it difficult for women and girls with disability to access quality healthcare? Select all that apply to you, or add your own.

- Cost of services or treatment
- Distance to healthcare services
- Lack of affordable transport
- Inaccessibility of buildings and services
- Inaccessibility of information
- Communication difficulties
- Limited services or shortage of specialists
- Lack of culturally responsive services
- Providers have limited understanding about disability
- Poor quality treatment
- Lack of confidentiality
- Lack of choice
- Finding time to access healthcare services
- Shame or embarrassment about health issues
- Previous negative experiences of accessing healthcare
- Other **[OPEN]**

## Q5

What would make it easier for you and other women and girls with disability to access quality healthcare? **[OPEN]**

The next question is about **informed consent** and healthcare treatment.

**Consent** means giving your permission for something to happen or for something to be done to you, such as a medical procedure.

**Informed consent** means choosing to consent only after you have been given all the necessary information about your options in a format accessible to you, including information about risks or benefits.

#### **Q6**

Have you ever received healthcare treatment or supports to which you did not provide your informed consent?

**YES** → **Q7** Please describe your experience(s) of receiving healthcare treatment or support that you did not consent to.

**NO** → **Q8**

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#### **Q8**

Is there anything else you would like to tell us about access to healthcare as a person with a disability?

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**Thanks for sharing your opinion and experiences with us!**

Our brief submission to the Special Rapporteur will be available to download on [the WWDA website](#) from April 2018.

To find out more about Women with Disabilities Australia (WWDA):

- [Sign up to receive our newsletters](#)
  - [Become a member](#)
  - [Follow us on Facebook](#)
  - [Follow us on Twitter](#)
  - [Visit our website](#)
- 

If completing this survey has raised any uncomfortable memories, feelings or thoughts, or if you are currently experiencing violence or abuse, please contact 1800RESPECT, the national sexual assault, domestic and family violence counselling service.

You can contact 1800RESPECT by phone on 1800 737 732 or chat with a counsellor at <https://www.1800respect.org.au/>

In an emergency, call 000 (Triple Zero).

## Appendix 2: Special Rapporteur Questionnaire

### Questionnaire on the right of persons with disabilities to the highest attainable standard of health

1. Please provide information on existing or planned legislation and policies to ensure the realization of the right to health of persons with disabilities, including current challenges and good practices.
2. Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) related to the exercise of the right to health of persons with disabilities in general, as well as with particular focus in the following areas:
  - Availability of barrier-free general healthcare services and programmes, which take into account all accessibility aspects for persons with disabilities;
  - access to free or affordable general healthcare services and programmes, including mental health services, services related to HIV/AIDS and universal health coverage;
  - access to free or affordable disability-specific healthcare services and programmes; and
  - access to free or affordable health-related habilitation and rehabilitation goods and services, including early identification and intervention.
3. Please provide information on discrimination against persons with disabilities in the provision of healthcare, health insurance and/or life insurance by public or private service providers.
4. Please provide information on the observance of the right to free and informed consent of persons with disabilities regarding healthcare, including sexual and reproductive health and mental health services.
5. Please describe to what extent and how are persons with disabilities and their representative organizations involved in the design, planning, implementation and evaluation of health policies, programmes and services.