

Contraception, Consent, Respectful Relationships & Sexuality

for

Women and Girls, Feminine Identifying & Non-binary People with Disabilities in the ACT

"I have been in a position that my disability has not had any effect of me having a safe, consensual and respectful relationship. I wish that was for all women with disabilities."

Winner 2012 International Women's Day Award, Community Category Winner 2015 ACT Chief Minister's Inclusion Awards, Excellence in Championing Human Rights

STRONG WOMEN STRONG VOICES

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WWDACT

Women* with Disabilities ACT (WWDACT) is a systemic advocacy and peer support

organisation for women, girls, non-binary and feminine identifying people with

disabilities in the ACT. WWDACT follows a human rights philosophy, based on the

Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on

the Elimination of (all forms of) Discrimination Against Women (CEDAW). WWDACT

is a Disabled People's Organisation, governed by women* with disabilities, and its

proposals and recommendations to government are consistent with Article 4 (3), and

Article 29 of CRPD which outline the imperative for consultation with disabled

peoples.

* Note: Throughout this document, and generally, WWDACT uses "Women * with

disabilities" to refer to women, girls, feminine identifying and non-binary people with

disabilities.

Project Officer:

Karen Hedley

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Women* with Disabilities ACT acknowledge and pay respect to the Ngunnawal

peoples, the traditional custodians of the ACT Region, on whose land our office is

located. We pay our respects their Elders past, present and emerging. We

acknowledge their spiritual, social, historical and ongoing connection to these lands

and the contribution they make to the life of the Australian Capital Territory.

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1. Background

WWDACT has many years of experience researching and writing about the rights of women* with disabilities to have the freedom to make their own decisions and have control of their bodies, sexuality and relationships.

Recent relevant publications include:

- Contraception and Consent: A Comparative Analysis of the Legal
 Frameworks for Accessing Contraception, August 2017 (Part 1 of this project)
- WWDACT Letter Supporting the Crimes (Consent) Amendment Bill 2018,
 March 2018
- WWDACT Submission to the Justice and Community Safety Directorate:
 Sexual Assault Guidelines Restorative Justice Referrals, February 2018
- WWDACT Submission to Discussion Paper: Domestic and Family
 Violence Policy Approaches and Responses, September 2017
- Contributing our voices! A summary of feedback from the Have Your
 Say! Forum with women with disabilities in the ACT, September 2015

These publications are on the WWDACT website: www.wwdact.org.au/publications/.

In 2018 WWDACT agreed to expand membership to women, girls, feminine identifying and non-binary people. This is the first data collected from this group.

2. Introduction

WWDACT's Contraception and Consent Project began in 2017, when Part 1 focused on researching and comparing frameworks across the world for guardianship, decision making, and consent to contraception and sexual health education.

"The issue of contraception and consent for women with disabilities touches on various complexities in the social structure of human society. Contraception deals with the reproductive rights of women which are recognised as human rights by the CEDAW. Consent deals with the capacity to make decisions for him/herself which is closely entwined with full legal capacity recognised for an individual before the law. The latter is a corner stone of the CRPD. Moreover, behind contraception and consent, relies the question of sexuality. Yet, the sexuality of people with disabilities is polluted by social taboo and ignorance." 1

The report, CONTRACEPTION & CONSENT, A Comparative Analysis of the Legal Frameworks for Accessing Contraception, made a series of recommendations for rethinking the legal and political frameworks around these areas.

The second part of this project looked at the experiences and knowledge of ACT women* with disabilities, families, and health and education professionals. It identifies what is being done well in the ACT, where there are gaps in services and information, and what women*'s needs are. Information was gathered via two online surveys, and conversations with survey participants.

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¹ CONTRACEPTION & CONSENT, A Comparative Analysis of the Legal Frameworks for Accessing Contraception, WWDACT & Maella Ducassoux, August 2017 www.wwdact.org.au

3. Methodology

In 2017 in Part 1 of the Project, WWDACT was given valuable assistance by Dr Max Halupka, from the University of Canberra's Institute of Governance and Public Analysis (IGPA) in the development of the preliminary versions of the surveys to be used in Part 2 of the Project.

A preliminary survey for stakeholders was distributed to GPs via two issues of the enewsletter of the Canberra Primary Health Network. Although eight responses were received in 2017, these were considered not current when Part 2 commenced and are not included in this analysis.

The two preliminary surveys were further refined in late 2018 to collect information from:

- Women, girls, feminine identifying and non-binary people with disabilities in the ACT;
- Family members, partners, and health & education professionals in the ACT.

In 2019 the updated surveys were publicised widely (see Appendix 1) via the fortnightly WWDACT e-Bulletin and social media, including WWDACT's Facebook page. Women* were surveyed through online and hard copy surveys and offered the opportunity for a one-on-one interview.

The survey for women* with disabilities was written in plain English and included a glossary of terms. Limited by using a free account on Survey Monkey, the survey included only nine questions, which were designed to elicit information about women*'s experiences with contraception, consent, relationships and sexuality in the ACT.

In order to reach both groups, an email was also sent on 28 August 2019 to sixtyone (61) local people and organisations, such as disability service provider
organisations, considered to have an interest in the outcomes of this study. The
email contained only a short introduction to the project and links to both surveys. It
also included an offer to supply a hard copy version of each on request.

Almost no local disability services opened or shared the email.

Survey for Women* with Disabilities

Twenty-seven (27) women* with disabilities completed the survey. All completed the survey independently. Participants included one respondent in the 12-18 age bracket, and twenty-six (26) adults over 18. The online survey was completed by twenty-six (26) respondents. One survey was completed in hard copy, at a WWDACT Social Drop-In (a casual event hosted by WWDACT Directors & CEO, held every 6-8 weeks in various venues across Canberra).

Survey for Family Members & Professionals

To inform this report, stakeholders were surveyed through online surveys. This survey was written in plain English and included ten questions designed to elicit information about respondents' experiences supporting women* with disabilities regarding contraception, consent, relationships and sexuality in the ACT.

In January 2019 the project officer made contact with a number of teachers via social media. Several of these teachers completed the survey and provide a representative sample of teachers providing specialised education (i.e.: Learning Support Teachers) rather than fully mainstream classes. The online survey was completed by nine stakeholders.

3.1. Email Response

An email was sent through Mailchimp to sixty-one (61) local people and organisations considered stakeholders in the outcomes of this survey. This included:

- Local disability organisations;
- Community organisations;
- ACT Government departments, programs and ministers;
- Influential women* with disabilities based in the ACT.

Twenty-one (21) of the emails were opened, with a total of 201 opens, five (5) individual clicks, and a total of twenty-three (23) clicks. This indicates that those who opened the email forwarded it to colleagues.

The highest 'opens' and 'shares' came from:

- The Project Officer,
- YWCA,
- The Womens Health Service, ACT Government,
- Minister for Women, ACT Government,
- LAC Information contact, Feros Care, and
- ACT Human Rights Commission.

Very few of the local support services to which the email was sent took further action to 'open' or 'share' the document. This was a limitation on the 'reach' of the survey and in turn limited response numbers.

4. Results

4.1. Survey 1 – for Women* with Disabilities

Twenty-seven (27) women* with disabilities completed the survey.

Question 1 – Were the women answering supported to do so?

Who is answering this survey?

- I am, on my own
- I am, with support from mum and dad
- I am, with support from someone else in my family
- I am, with support from a support worker
- I am, with support from a teacher / teacher assistant
- Someone else is answering on behalf of the woman with disabilities

All respondents (27) completed the survey independently.

Knowing more about our laws and rights is always important. Currently I'm trying to work out some sexuality stuff, what romance actually is, and haven't even started on my own gender ID yet!

Question 2 – Age of respondents

What is your age?

- 5-11 years old
- 12-18 years old
- 18-30 years old
- 30-45 years old
- 45-60 years old
- Over 60

Participants included one (1) minor in the 12-18 age range, and twenty-six (26) adults over the age of 18.

Table 1: The Age Distribution of Women* Respondents.

Age Distribution of women* respondents	n = 27
5-11 years old	0
12-18 years old	1
Over 60 years old	1
18-30 years old	7
45-60 years old	8
30-45 years old	10

Question 3 - Education

Tell us about your education

Education is school (primary school, high school and college). It is also learning after school, at CIT, TAFE or university. Choose all that apply.

(Each of the dot points was asked for each level of education, in a matrix format)

Primary School (K-6), High School (7-10), College (11&12), CIT or TAFE, University

- Were you in mainstream education, with people without disabilities?
- Were you in a special class or school, only for people with disabilities?
- Were you sometimes in a mainstream class and sometimes in a special class?

Respondents were able to mark all levels of education that they had completed.

Twenty-three (23) of the respondents identified that they had completed primary school, with twenty-two (22) of those women* having attended a mainstream primary school. Only one (1) respondent had attended a combination of both mainstream and special classes.

Twenty-three (23) respondents had completed High School level of education, with twenty-one (21) in mainstream classes and two (2) attending a combination of mainstream and special classes.

Twenty (20) respondents had completed College with two (2) attending both mainstream and special classes.

Twenty respondents had graduated to CIT/TAFE education with one woman* attending a combination of mainstream and special classes. At CIT/TAFE attending 'special classes' is probably a reference to having Disability Supports offered through the CIT Student Support office, or a course offered for people with disabilities.

It is observed that all the respondents had attended predominantly mainstream education, and only one or two had accessed a combination of mainstream and special classes.

The majority of respondents had attended university, indicating a highly educated group who may not accurately represent all women* with disabilities.

Table 2: The Type and Level of Education of Women* Respondents.

Type & Level of Education	A	В	С	Total n = 27
Primary School (K-6)	22	1	0	23
High School (7-10)	21	2	0	23
College (11&12)	18	2	0	20
CIT or TAFE	10	1	0	11
University	22	0	0	22

- **A** mainstream education, with people without disabilities
- **B** sometimes in a mainstream class and sometimes in a special class
- **C** special class or school, only for people with disabilities

Comments indicated that there had been some flexible approaches to schooling: "[I] started to attend school part-time in grade 9, and CIT we had a scholarship group for our first semester which included other PWD [people with disabilities]." One respondent also felt it important to reiterate that schooling was "not in disabled education stream".

Question 4 – Learning about sex

Tell us about when you learned about sexuality and relationships. Choose all that are true for you.

- At Primary School K-Y6
- At High School Y7-10
- At college Y11-12
- As an adult 18yrs+
- My family taught me
- From my friends
- SHFPACT
- Other

The vast majority (20) of respondents learned most information about sexuality and relationships in high school. Many also learned in primary school (14) and as an adult (12).

Concerningly, only 9 respondents received sex education in the college years (years 11 & 12), when most young people are experimenting sexually and becoming more aware of sexuality.

This is confirmed by the Fifth National Survey of Secondary Students and Sexual Health which was carried out in 2013 and involved over 2000 Year 10, 11 and 12 students. The survey found that: "The majority of students (69%) have experienced some form of sexual activity."²

Comments made by respondents showed that online resources were the preferred way to learn more.

² 5th National Survey of Australian Secondary Students and Sexual Health 2013, Australian Research Centre in Sex, Health and Society, April 2014 https://yeah.org.au/wp-content/uploads/2014/10/31631-ARCSHS_NSASSH_FINAL-A-3.pdf.

Table 3: The Level of Education of Sex and Sexuality of Women* Respondents.

Sex & Sexuality Education	Total n = 27
High School (7-10)	20
Primary School (K-6)	14
As an adult, 18+	12
From my friends	11
My family taught me	10
College (11&12)	9
Other (see below)	4
SHFPACT	1

In the 'Other' category respondents were also able to nominate other sources of information and the four (4) responses received cited Facebook and the internet:

• [I am] Always learning! Love researching and reading on my own.

Recomm	ondation	That education on sexuality, contraception, consent and
Recomm	ommendation 1	respectful relationships be continued and increased in college
	••	(Years 11 & 12).

Question 5 – Questions and Information Sources

If you have questions about relationships, sexuality, contraception and consent, who do you:

- 1. Feel comfortable asking
- 2. Think will give you good answers and support?

Twenty-one respondents to this question said that they felt doctors gave good answers and support to their questions (33% of responses), and they felt very comfortable (27% of responses) asking questions of doctors. Respondents also said they were comfortable asking friends for information (28% of responses) but trusted this information source slightly less (20% of responses). Therapists attracted only 17% of responses to each question, with other family members having a slightly lower endorsement rate (15% of responses to each question). Respondents said they were least comfortable asking parents and guardians (13% of responses), and not very comfortable with the answers to their questions of this group of contacts (15% of responses).

Individual 'Other' comments included going to the 'internet for answers' and at least one commented that she had 'never had support' in asking these questions or getting answers.

"Sexual activity can often be a trigger for panic attacks, which is often difficult terrain to navigate especially with new sexual partners."

Table 4: The persons Women* with Disabilities may seek information from in regards to Relationships, Sexuality, Contraception and Consent.

Note: 27 women* answered this question, with multiple selections.

Where individuals direct questions about relationships, sexuality, contraception and consent	Α	В
Doctor	16	20
Friends	17	12
Therapist	10	10
Other family (sister, aunt etc)	9	9
Parents / Guardian	8	9
Teacher	0	0
Support Worker	0	0

- A Comfortable asking
- B Good source of information

Recommendation 2.	That organisations developing resources for sex education, consider having them available online whenever possible.
Recommendation 3.	That alternative ways for GPs (or other health professionals) to spend time with women* with disabilities be investigated
	and trialled.
Recommendation	That further research be done into why women* (including
4.	under 18's) don't feel comfortable asking teachers and
	support workers for sex education support and information.
Recommendation	That, following research into reasons, relevant
5.	recommendations be made to increase likelihood that
	teachers and support workers would be asked for sex
	education support and that advice given be informed and
	appropriate.

Question 6. Contraceptive Use & Sexual Activity

Tell us about your use of contraceptives, and sexual activity.

Tick all that apply to you.

Being 'sexually active' means that you have sex with another person.

Twenty-three respondents answered this question. Of these, fifteen (15; 65%) said that they are sexually active at present. Five respondents indicated they are not using contraceptives at present, but it is not possible to determine whether this applied to the women* who are sexually active or not.

Thirty-one different kinds of contraception were nominated as being 'in use' but it is not possible to determine from the results whether more than one type of contraception is being used simultaneously or whether different types of contraception have been used in the past and at present. It appears that none of the respondents is using a diaphragm.

Individuals were able to nominate 'Other' types of contraception in use. Responses included:

- Using IUD for endometriosis;
- Unprotected [sex] at times;
- Husband had vasectomy (2 respondents);
- "I am trying to conceive";
- "I'm not currently sexually active, but when [I was] married I have used the pill, implanon, depo provera and condoms at various times. Mainly implanon.".

Table 5: The Assessment of Sexual Activity of Women* Respondents.

Assessment of sexual activity	Total n = 23
I am sexually active	15
I am not sexually active	8

"I have been in a position that my disability has not had any effect of me having a safe, consensual and respectful relationship. I wish that was for all women with disabilities."

Table 6: The Type of Contraception Used by Women* Respondents.

Contraceptive Use	Total n = 27
I am using an IUD or Mirena (or similar)	6
I don't use all contraceptives at the moment	5
I am using 'the Rod' or Implanon (or similar)	4
I've had a hysterectomy, or my tubes tied (sterilisation)	4
I am taking 'the Pill'	3
I am using condoms	3
Other (see above)	6
I am using 'the Ring' or a diaphragm (or similar)	0

Recommendation 6.	That education and information about the various options for contraception be regularly updated and provided to women* with disabilities and to those providing sex education and support.
Recommendation 7.	That education continues to be provided about safe sex and contraception, throughout a woman*'s life.
Recommendation	That further research be done into why women* (including
8.	under 18's) don't feel comfortable asking teachers and
	support workers for sex education support and information.
Recommendation	That, following research into reasons, relevant
9.	recommendations be made to increase likelihood that
	teachers and support workers would be asked for sex
	education support and that advice given be informed and
	appropriate.

Question 7. Decision Making & Staying Safe

Do you know enough to keep you safe, and make good decisions? Choose all the answers you would like to know more about.

- Relationships
- Sexuality (gender identification, beliefs, preferences etc)
- Consent
- Safe, respectful relationships
- Contraception
- Your rights
- Having a family
- Sexual health (checkups, STI's etc.)
- Puberty
- Menopause
- My body
- Social skills
- Making decisions
- Other

Eight (8) women* in the under-30 age group and nineteen (19) women* in the older age group responded to this question. Information about menopause was the most highly ranked category with thirteen (13) women* in total nominating it as the area for which more information is sought. This reflects the age demographic of the respondents with 67% in the 30-60 year age range.

Women* also want information about their rights (11 respondents), sexual health (11 respondents), and sexuality (10 respondents). A range of other areas of information were nominated (see Table 7) with approximately one-third (8 respondents) wanting information on matters such as relationships, consent, safe/respectful relationships, contraception, social skills, my body, and making decisions.

Individual responses to the 'Other' response choice included:

- knowing more about our laws and rights is always important. Currently I'm
 trying to work out some sexuality stuff, what romance actually is, and haven't
 even started on my own gender ID yet!;
- Sex with Chronic pain;
- I'm comfortable with my knowledge;
- No one has the info to keep themselves safe in relationships because women* in general in Australia aren't safe from DV [Domestic Violence], and women* with disabilities are even more at risk than the average women.

The ACT Health Care Consumers Association had scheduled a workshop on managing intimacy and chronic pain for late 2018 (see Appendix 2), indicating that the organisation had assessed a need for this information in the community.

Unfortunately, it had to be cancelled and a new date has not been announced.

Table 7: The Areas of Interest for Additional Information and Education depending on the age groups of Women* Respondents.

Additional Information / Education needed	Total n = 27	12 to 30 yrs n = 8	30 to 60+ yrs n = 19
Menopause	13	3 (38%)	10 (53%)
Your rights	11	5 (63%)	6 (32%)
Sexual health (checkups, STI's etc.)	11	3 (38%)	8 (42%)
Sexuality (gender identification, beliefs, preferences etc)	10	4 (50%)	6 (32%)
Relationships	9	2 (25%)	7 (37%)

Additional Information / Education needed	Total n = 27	12 to 30 yrs n = 8	30 to 60+ yrs n = 19
Consent	8	2 (25%)	6 (32%)
My body	8	3 (38%)	5 (26%)
Social skills	8	3 (38%)	5 (26%)
Making decisions	8	2 (25%)	6 (32%)
Safe, respectful relationships	7	4 (25%)	3 (16%)
Contraception	7	2 (25%)	5 (26%)
Having a family	6	2 (25%)	4 (21%)
Puberty	6	1 (13%)	5 (26%)

The percentages in Table 7 indicate the relative importance of each factor to each age group. Although menopause was the most frequently nominated subject for which more information is sought, it was desired more by the older age group (53% versus 38%). In contrast, the younger age group showed greater interest in information about rights (63% versus 32%); sexuality (50% versus 32%); social skills and the body (both categories scoring 38% versus 26%). The older age group seeks more information on relationships (37% versus 25%) and perhaps not intuitively, on puberty (26% versus 13%). Because of the small numbers of respondents overall, these are just indications of areas of interest to be pursued.

Because of the inherent health and disability complexities that women* with disabilities manage, the concept of having a 'Health Passport' has been proposed in research³ and by governments⁴, including being promoted as a tool in supported decision making⁵.

Recommendation 10.	That further information on decision making and staying safe be developed and made easily available for women* with disabilities, including online.
Recommendation	That information should be provided in both plain English,
11.	and Easy Read visual versions with pictographs. Images
	should depict women* from a range of cultures, ages and
	gender identifications.
Recommendation	That information development should be itemised according
12.	to women*'s needs, e.g.: 1 Menopause, 2 Rights, 3 Sexual
	Health, 4 Sexuality and so on, so that it is easily searchable.
Recommendation	That a suite of resources, including a website should be
13.	developed jointly by relevant local ACT organisations which
	have appropriate expertise.
Recommendation	
14.	That a "Health Passport" be considered for development.

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³ "The passport contains different information related to the previous diagnoses of the person, as well as their decision-making support wishes." p28, CONTRACEPTION & CONSENT, A Comparative Analysis of the Legal Frameworks for Accessing Contraception, WWDACT & Maella Ducassoux, August 2017

⁴ New Zealand Ministry of Health (Manatû Hauora), Health Passport information. https://www.health.govt.nz/your-health/services-and-support/health-care-services/health-passport.

⁵ European Union, *Choices: a platform on decision making*, http://www.right-to-decide.eu/2014/10/health-passport-2/

Question 8. Disability's Effects on Safe Respectful Relationships

How do you think your disabilities affect your ability to have safe, consensual, respectful relationships? This might be with or without sex. Tell us about the advantages, as well as the disadvantages, such as:

- You need help physically
- You can't speak or say no out loud
- You'd like to try more new things
- You find it hard to meet people for relationships

Key themes taken from the responses:

(i) Negative

- Difficulty in meeting people, especially respectful people;
- Need for physical support;
- Sex is painful or physically difficult;
- Side effects of medications and disabilities increase vulnerability⁶;
- Being taken advantage of / assaulted.

(ii) Positive

- More difficulty means better communication is needed and thus stronger relationships;
- Broadminded in seeking out various relationships in order to meet different needs i.e.: polyamory.

Recommendation That women* are educated and supported to use online dating in a safe and assertive manner.

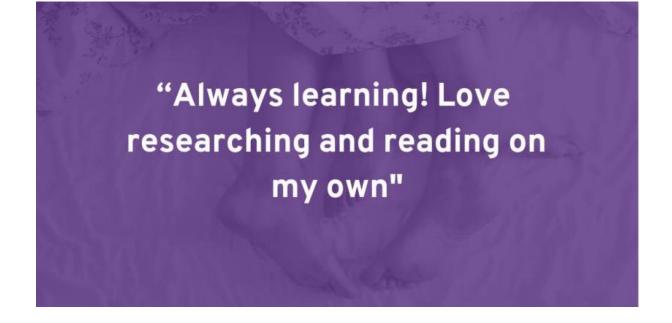
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⁶ The respondent did not clarify the nature of this vulnerability

Recommendation 16.	That accessibility to mainstream social events is promoted and supported in the local community.
Recommendation 17.	That sex education resources developed include how to use existing funding and networks to support and explore sexuality and relationships.
Recommendation 18.	That women* are supported to strengthen their ability to communicate and state their relationship and intercourse needs.
Recommendation 19.	That health professionals are encouraged and educated to consider each woman*'s experience with pain, its impact on sexuality, and ways to manage its impact.

More detailed information which emerged in response to this question included physical limitations, pain limitations, energy and health limitations.

Some women* found it difficult to meet people for relationships. Some respondents reported that they need physical support for relationships. Others were concerned that the side effects of medications and disabilities increase their vulnerability [to being hurt emotionally or physically] in relationships, with explicit concerns about being taken advantage of in some way or assaulted.



Physical Limitations (including pain)

One respondent thought that her physical limitations made the need for good communication with a partner more imperative and that her negotiations about sex, consent and relationships were better as a result.

Some respondents named the physical limitations they experience as more limiting, for example, making it very difficult to meet anyone when too unwell to work or study. These limitations are heightened when they know that their peers are engaged in forming relationships and having sex.

In some instances, the conditions due to disability also make a 'normal' relationship and relationship activities much more difficult to do. For this reason, one respondent nominated a preference for polyamorous relationships even whilst acknowledging that this results in exposure to higher levels of risk of abuse arising from being physically weaker. This can be countered by individuals developing a low tolerance for bad behaviour from other people.

Some physical conditions result in increased joint pains during sexual activities. For some conditions, such as endometriosis, it can cause physical pain or even cramping, if there is any penetration or at orgasm.

For some, physical exhaustion places a constraint on forming new relationships, and pain detracts from having any sex drive at all - with this having an impact on forming new relationships or in relationships with long-term partners. It was noted that having a good relationship with an understanding partner meant that a sexually active relationship can be maintained.

Energy/health issues

For some, the medication taken which has a positive effect on one condition can have a direct, or indirect, effect on their sex drive.

A medication I was on for 14 years to help with sleep completely
ruined my libido. My Dr [sic] never warned me about this side effect.
 Since I've come off it — I have a sex life again ⊕ But don't sleep
well.

"I find it hard to meet people for relationships and find I sometimes settle for someone not good for me because I don't feel like anyone else will want me. I find it hard to talk about my disability before becoming sexually active which can sometimes make things more difficult."

Self-Esteem issues

One woman* felt that her condition made it hard to meet people and therefore, she was aware of forming unwise relationships because of her fear of not being good enough or not wanted by anyone. Women* stated their experiences of early conditioning as to their unattractiveness for partners, and the unlikelihood of them even forming relationships. From an early age, getting married and forming a family are not portrayed as options. Where there are partners, these are often assumed to be 'carers', and any abuse in the partnership is nullified because a degree of sympathy is accorded to that person and the burden of disability is reinforced.

In another case cited, the carer had taken advantage of the woman*, although no further details were given. Where a carer or support worker is involved in a relationship with a woman* with disabilities, the dynamics of the interaction are more complex and make it more difficult to end the relationship.

Supporting them through a 'bad' experience
"involves explaining the law, and her rights
to a safe and fulfilling sexual experience.
And on a few occasions having that
discussion with her parents"

Respondents noted that it is sometimes difficult to actually talk about the impact of a disability prior to becoming sexually active with a prospective partner, and that this mis-timing can impact the relationship itself.

In one instance cited, the existence of the disability did not have any effect on the woman* forming a safe, consensual and respectful relationship. In another, the disability led the woman* to be explicit about what she wanted in a partner.

Dating apps

A number of the respondents use dating apps. They reported that men (in particular on the 'Tinder' app) will state that they "never want to have a relationship with a disabled woman".

Alternatively, in dates resulting from apps such as Tinder, women* have been used by people who have negative motives — just wanting sex or to be controlling or abusive. Respondents to the survey had been targeted on "Tinder dates" resulting in significant abuse, including rape. It was noted by women* with significant physical disabilities that they were vulnerable to such abuse, had few avenues to make a quick escape, and felt they would not be believed if they reported the abuse. The nature of the disability can dictate the nature of vulnerability in dating situations.

These observations make it imperative that courses are available to enable women* to improve their feelings of self-worth and develop self-esteem.

"A medication I was on for 14 yrs to help with sleep completely ruined my libido. My Dr never warned me about this side effect. Since I've come off it — I have a sex life again but don't sleep well."

Other issues

One of the respondents reported that sexual activity was often a trigger for panic attacks and that this made the relationship terrain difficult to navigate, especially with new sexual partners. One reported that barriers to forming relationships had meant that she had never had a real partnership and remained apprehensive about 'doing something wrong'. When there is little opportunity to form respectful relationships, women* can feel that they are at risk of Domestic Violence, of not being believed by police, and of the risk to children of child abuse.

Question 9 - Follow up & additional information

Thank you for completing our survey.

Optional: If you are 18 or older, and would like to answer more questions, face to face, please provide your name and contact details. If you prefer not to give your name on the survey, please email the Project Officer on projects @wwdact.org.au or call 0468324695.

Questions might include asking about your preferred services, use of funding, information and resources you've found useful and so on.

"Men never want to have a relationship with a disabled woman. I have been used so many times by people who just want sex or to be controlling or abusive.

I have been targeted on tinder dates and raped.

I was abused and who could I tell that would believe me? I'm a quadriplegic, what chance did I have to stop him?

Case Study

Speaking can sometimes be difficult due to my condition. This means I can have issues expressing myself. I sometimes get spasmodic shakes due to my condition and sometimes this can be mistaken as a sign of direct pleasure from sex when it isn't. I sometimes find sex emotionally difficult due to previous sexual assault. I feel less likely to report sexual abuse for fear my medical condition will be brought up if it were to go to court (as it already has been when I previously was in the supreme court attempting to get justice for the sexual assault I experienced). My disability was used to make me feel ashamed and inadequate in the court room. I felt like I was shaking in shock when I first saw the police but this was used to portray me as a liar as my spasms are caused by a neurological condition which can be increased by stress/being nervous.

4.2. Survey 2 – for stakeholders (family, friends, health and education professionals)

Question 1 – About the respondents

What is your relationship to the women* with disabilities you know? Select all that apply:

- Parent / Guardian
- Partner / Intimate relationship with her
- Other family member / Unpaid Carer / Friend
- Professional Disability sector
- Professional Health & Medical, including therapists
- Professional Education

Nine (9) respondents completed the survey.

Participants included:

- 1 Parent / Guardian;
- 2 Other family member / Unpaid Carer / Friend;
- 4 Professional Health & Medical, including therapists;
- 2 Professional Education.

Question 2 - Contraceptive Use & Sexual Activity

Tell us about her/their use of contraception and sexual activity. Select all that apply:

- I don't know this information
- She uses contraception but is not sexually active
- She uses contraception and is sexually active
- She doesn't use contraception but is not sexually active
- She doesn't use contraception and is sexually active

While several respondents said they didn't know, and one commented that this information was private, one third (n = 3) replied regarding multiple women*.

Most women* known to these respondents were not sexually active. Use of contraceptives by these women* was split equally between use and non-use.

Of the women* they knew were sexually active only 40% used contraceptives, with 60% being sexually active without protection from Sexually Transmitted Infections (STIs) or possible pregnancy.

Table 8: The Use of Contraceptives and Sexual Activity of Women* with Disabilities as reported by relevant Stakeholders.

Contraceptive Use & Sexual Activity	n = 9
She uses contraception but is not sexually active	4
She doesn't use contraception but not sexually active	4
She doesn't use contraception and is sexually active	3
She uses contraception and is sexually active	2
I don't know this information	2

One of the educators stated that they had taught a Year 9/10 class of four (4) males and four (4) females with disabilities. Of the girls, three (3) were not sexually active but there was a possibility that the fourth girl was sexually active. Three (3) respondents had contact with more than one woman* with disabilities. One respondent viewed giving further information about clientele as a breach of privacy and gave no specific answer to this question.

That health professionals be encouraged and supported to create and maintain an ongoing and open dialogue with women* with disabilities about sexual health, contraception and consent.

Question 3: Experience Supporting Women* with Disabilities

Have you had experience supporting a woman with disabilities to learn more about:

Contraception Consent

Safe, respectful relationships?

- Yes, once or a few times
- Yes, often
- No

Please share your thoughts about these experiences

Most of the survey respondents had helped women* learn about these topics at least once or twice (45%), and two (22%) had done it often. Two respondents had never helped with this area (one health professional, and one family member / unpaid carer / friend).

Assumptions made about women* with disabilities' ability to have intimate relationships were raised as being a barrier to giving this type of support.

Alternative contraceptive methods such as the Billings Method⁷ were suggested as a more common option than was suggested by respondents to Survey 1.

Several people praised SHFPACT⁸ and their educational resource SoSAFE⁹, saying that it provides "practical knowledge" to "understand and manage their feelings and relationships".

Table 9: The Stakeholders' Experience in Supporting Women* with Disabilities.

Experience Supporting Women* with Disabilities	n = 8
Yes, once or a few times	4
Yes, often	2
No	2

Please share your thoughts about these experiences:

Taught the SoSafe program to Year 9/10 students (4 females) with disabilities
 (ASD, ID). Focused on talk touch triangle, consent, safe helpers, steps to a
 relationship, contraception (particularly condoms, though briefly discussed
 others) in relation to unwanted pregnancies but also STIs. Socially these girls
 can engage relatively well, but intellectually and emotionally they are very

⁷ The Billings Method "involves the observation of the variations in cervical mucus secretions found at the vaginal opening. This can be used to identify fertile days because the hormone changes through a woman's cycle affect the consistency of these secretions felt at the vaginal opening." Family Planning NSW, Fertility awareness based methods of contraception, lactational amenorrhoea and withdrawal https://www.fpnsw.org.au/health-information/contraception/fertility-awareness-based-methods-contraception-lactational

⁸ Sexual Health and Family Planning ACT https://www.shfpact.org.au/

⁹ SoSAFE is a set of tools and training developed by SHFPACT to promote social safety for people with an intellectual disability and autism https://www.shfpact.org.au/community-health-promotion/sosafe-program

vulnerable in terms of sexual relationships. You could say they have the hormones of a teenager but generally the capacity of a Year 3 student to understand and manage their feelings and relationships. Which means it's incredibly important that we are giving them practical knowledge to support them as they navigate it all. Needed to do a lot of scaffolding as the 'assumed knowledge' of a peer in a mainstream setting is not necessarily there, e.g. did not know what 'masturbate' meant.

- Raised awareness of the Billings ovulation method, which is safe, cost
 effective and does not interfere with any individual faith/religious beliefs and
 pre-existing health conditions. Given these advantages, there should be more
 education on this method by doctors and healthcare practitioners.
- I work mainly with women* from NESB [Non English Speaking Background],
 so I address contraception, consent and safe relationships as part of a crosscultural conversation. In these cultural backgrounds assumptions are often
 made that the woman cannot lead a sexual life, so they have often not had
 good discussion about sexual matters at all.
- We found SHPACT very helpful with resources and ideas to support us talking with her. Our GP was also fantastic.

Recommendation That actions are taken to raise public awareness of the rights of women* with disabilities to safe, sexual relationships.

Recommendation That the ACT Government continues to fund and increase funding for SHFPACT to present SoSAFE to more women*.

Question 4 – Supporting Women* Through a 'Bad' Experience

Have you supported a woman* with disabilities through a situation that involved an unsafe, non-consensual, disrespectful relationship or sexual experience?

Please share your thoughts about these experiences

Just over half (56%) of our stakeholders had supported a woman* with disabilities through an unsafe, non-consensual, disrespectful relationship or sexual experience once or twice. Nearly half (44%) had not had to provide this support, and nobody needed to do this often.

Comments included needing to understand and explain the law and the woman*'s rights, needing to also speak with her parents, and to deal with the outcome of an unplanned pregnancy. In their comments respondents also noted that many women* with disabilities are not aware of their right to sexual fulfillment.

Table 10: The Stakeholders' Experience in Supporting Women* with Disabilities through a 'Bad' Experience.

Supporting Women* through a 'bad' experience	n = 9
Yes, once or a few times	5
No	4
Yes, often	0

Please share your thoughts about these experiences:

- Involves explaining the law, and her rights to a safe and fulfilling sexual
 experience. And on a few occasions having that discussion with her parents;
- Pregnancy unplanned.

Recommendation That the right of women* with disabilities to sexual fulfilment and satisfaction be promoted.

Question 5 – Confidence & Knowledge

Tell us about your current confidence and knowledge in supporting women* with their sexuality and relationships.

In what ways do you feel prepared or confident to provide this support? (training, previous experience, resources, etc)?

Respondents were divided with most indicating in their comments they felt confident of their ability and knowledge to tackle these subjects, and several stating they lacked confidence.

One health professional explained that despite feeling confident and having relevant skills, having time and appropriate opportunities to impart this knowledge were lacking.

- I've had 15 years' experience working with students with disabilities and I've completed SoSafe training a few times.
- Very lacking. Not sure how to approach the discussion.

- SoSafe training and resources, plus teaching it this year. I'm a teacher and my
 number 1 focus is on building strong relationships with all students so that I
 can support them appropriately if this or other situations arise.
- Explaining the Billings ovulation method.
- Previous experience.
- Having enough opportunity with women* on their own can be challenge. I
 have the skills.
- No confidence.
- I think I feel well prepared for the current stage of life she is at now.

"We found SHFPACT very helpful with resources and ideas to support us talking with her.
Our GP was also fantastic."

Question 6 – Barriers

What makes things harder for you?

What stops you being as prepared / able to provide the support and information needed?

Respondents identified the biggest barrier to being able to support women* with disability around sexuality and relationships as lack of time (6 respondents). Other barriers included lack of funds (3), not knowing who to ask/where to go (3) and lack of information/experience (3). In their comments, respondents noted that the community values could be influenced by anti-faith sentiment, comments in the community, and the Murdoch media. Another limitation is the lack of gender-specific interpreters through the Translating and Interpreter Scheme (TIS).

"Socially these girls can engage relatively well, but intellectually and emotionally they are very vulnerable in terms of sexual relationships."

Table 11: The Barriers faced by Stakeholders in informing Women* with Disabilities about sexuality and relationships.

Barriers	n = 9
Lack of time	6
Lack of funds	3
Not knowing who to ask / where to go	3
Lack of information / experience	2
Not my job / Someone else will do it	0
Personal beliefs (including religion)	0

Recommendation 24. That funding and other opportunities are available to ensure women* with disabilities can be effectively supported when needed.

Question 7 - Knowledge of Rights & Responsibilities

How confident are you about your knowledge and understanding of rights, responsibilities and law in these situations?

Our respondents were happy with their own level of information around rights and legislation. Their predominant choice of Confident rather than Very Confident would seem to indicate further learning and understanding would be possible.

Table 12: Stakeholders' Knowledge of Rights and Responsibilities around Sexuality and Relationships of Women* with Disabilities.

Knowledge of Rights & Responsibilities	n = 9
Confident	6
Very Confident	3
Unsure or neutral / Not particularly confident / Not at all confident	0

"Having enough opportunity with women on their own can be challenge. I have the skills."

Question 8 - What's needed?

What could make things easier for you?

What knowledge or resources would you like to have?

When and how would be best to receive this knowledge or resources?

Summary of needs identified by respondents include:

- Continued support by SHFPACT with SoSAFE;
- Further resources including fact sheets on rights, responsibilities and the law,
 local and national supports, including mainly visual resources;
- Visual resources with people from a variety of cultural backgrounds;
- A quick and easily locatable repository for these resources;
- Support and education groups;
- Training (respondents did not specify what training or for whom);
- I'm really happy with the SoSafe program in terms of content resources.
 Would be great to have some factsheets/one pagers about rights,
 responsibilities and the law, as well as external supports (whether ACT-based or national) that we can refer students to (or access ourselves, depending)
 where further intervention/support is needed;
- Knowing how to access information and good quality professional advice quickly at the time we need it rather than having to go on a hunt for it.

	That all resources and websites recommended for	
Recommendation	development in this report be promoted widely and that	
25.	women* with disabilities and other stakeholders be made	
	aware of their availability.	

Recommendation 26.	That relevant organisations be encouraged to set up and run support and education groups for women* with disabilities.
Recommendation 27.	That further research is undertaken to determine gaps in training for stakeholders, including family members and carers, health and education professionals, and support workers.

"I work mainly with women from NESB, so I address contraception, consent and safe relationships as part of a cross-cultural conversation. In these cultural backgrounds assumptions are often made that the woman cannot lead a sexual life, so they have often not had good discussion about sexual matters at all"

Question 9 – Other Comments

Do you have any other comments?

You can also email the Project Officer at projects @wwdact.org.au

A single final comment was received: "Respect religious diversity in our communities".

Question 10 - Updates

OPTIONAL If you would like to hear more about the results and recommendations from this project, please provide your name and email address:

Three (3) respondents provided their details.

5. Discussion

5.1. Limitations

Twenty-seven (27) women* and nine (9) stakeholders participated in the two surveys. There are about 3000 women* with disabilities in the ACT between the ages of 15 and 24, a further 1,400 of primary school to Year 10 age (5-14 years), and about 32,600 in total.

However, the distribution method used for the survey means that it is not possible to estimate the number of potential respondents that were reached, or to calculate the actual response rate to the survey. Even though a comprehensive distribution network was used, the survey may have actually reached limited numbers of potential respondents. Nevertheless, the number of responses from women* with disabilities exceeded WWDACT's expectations.

The survey answers given therefore are a reflection, albeit powerful and informative, of individual experiences rather than a statistically significant sample.

5.2. Learnings from the Survey Process

WWDACT used a free account on Survey Monkey to create the survey for which survey questions are capped at ten. Having this ten-question limitation resulted in individual questions being expanded to capture a greater range of information.

In the end the survey for women* had nine questions, and the survey for stakeholders had ten questions. As a result each question had too many parts, resulting in:

- Layouts for some questions that were complex and confusing,
- Data that is more difficult to analyse and extrapolate from,
- Having to include a 'glossary' and explanatory statements in with the main questions, adding to complexity.

After this experience WWDACT prioritised purchasing a paid account and recent surveys have been simpler and easier to complete.

During the course of the project, feedback was received that not defining 'sexual activity' and 'having sex with another person' was confusing and required further explanation. However, these terms had been deliberately left undefined to allow individual interpretation, and to avoid adding additional text. In future this could be stated and examples given of what it might mean to women*.

6. Recommendations

Recommendations

- 1. That education on sexuality, contraception, consent and respectful relationships be continued and increased in college (Years 11 & 12).
- 2. That organisations developing resources for sex education, consider having them available online whenever possible.
- **3.** That alternative ways for GPs (or other health professionals) to spend time with women* with disabilities be investigated and trialled.
- **4.** That further research be done into why women* (including under 18's) don't feel comfortable asking teachers and support workers for sex education support and information.
- That, following research into reasons, relevant recommendations be made to increase likelihood that teachers and support workers would be asked for sex education support and that advice given be informed and appropriate.
- **6.** That education and information about the various options for contraception be regularly updated and provided to women* with disabilities and to those providing sex education and support.
- 7. That education continues to be provided about safe sex and contraception, throughout a woman*'s life.
- 8. That further research be done into why women* (including under 18's) don't feel comfortable asking teachers and support workers for sex education support and information.

Recommendations

- **9.** That, following research into reasons, relevant recommendations be made to increase likelihood that teachers and support workers would be asked for sex education support and that advice given be informed and appropriate.
- **10.** That further information on decision making and staying safe be developed and made easily available for women* with disabilities, including online.
- 11. That information should be provided in both plain English, and Easy Read visual versions with pictographs. Images should depict women* from a range of cultures, ages and gender identifications.
- **12.** That information development should be itemised according to women*'s needs, e.g.: 1 Menopause, 2 Rights, 3 Sexual Health, 4 Sexuality and so on, so that it is easily searchable.
- **13.** That a suite of resources, including a website should be developed jointly by relevant local ACT organisations which have appropriate expertise.
- **14.** That a "Health Passport" be considered for development.
- **15.** That women* are educated and supported to use online dating in a safe and assertive manner.
- **16.** That accessibility to mainstream social events is promoted and supported in the local community.
- **17.** That sex education resources developed include how to use existing funding and networks to support and explore sexuality and relationships.
- **18.** That women* are supported to strengthen their ability to communicate and state their relationship and intercourse needs.

Recommendations

- **19.** That health professionals are encouraged and educated to consider each woman*'s experience with pain, its impact on sexuality, and ways to manage its impact.
- **20.** That health professionals be encouraged and supported to create and maintain an ongoing and open dialogue with women* with disabilities about sexual health, contraception and consent.
- **21.** That actions are taken to raise public awareness of the rights of women* with disabilities to safe, sexual relationships.
- **22.** That the ACT Government continues to fund and increase funding for SHFPACT to present SoSAFE to more women*.
- **23.** That the right of women* with disabilities to sexual fulfilment and satisfaction be promoted.
- **24.** That funding and other opportunities are available to ensure women* with disabilities can be effectively supported when needed.
- **25.** That all resources and websites recommended for development in this report be promoted widely and that women* with disabilities and other stakeholders be made aware of their availability.
- **26.** That relevant organisations be encouraged to set up and run support and education groups for women* with disabilities.
- **27.** That further research is undertaken to determine gaps in training for stakeholders, including family members and carers, health and education professionals, and support workers.

7. Glossary

Words	Meaning
Consent	Saying yes. In this survey we mean when you say yes to private or intimate things like kissing, touching each other or having sex.
Consensual	A relationship where both people have said yes to the relationship, and what happens in it.
Contraception	Ways to prevent pregnancy and STI's (See below). Contraceptives can include condoms, 'the pill' (contraceptive pill) and 'the rod' (Implanon) and more.
De-identified	We take out anything in your answers that might enable someone else to know they are yours.
Independently	Women* completed the survey without support from others.
Mainstream education	This is when everyone learns together. Children with disabilities are in the classes with children with no disabilities.
Menopause	when a woman*'s body changes so she is no longer able to have babies. This includes her periods stopping and her hormones changing. This is usually between 40 and 60 years old.
Methodology	The way the project and the survey were done.
NESB	Acronym for Non-English Speaking Background
Professionals	We used this term for everybody who was paid to work with women* with disabilities.

Words	Meaning
Puberty	When a girl's body starts to change so she is physically ready to have a baby. This includes her breasts growing, her period starting, and growing body hair. This is usually between 10-18 years old.
Relationships	The way we get on with others. They can include our friends and families. In this survey, relationships are how we get on with a boyfriend or girlfriend. We are talking about intimate relationships, when you might kiss, or touch private parts
Sexual Health	This includes check-ups with the doctor, such as pap smears, breast checks and tests for STI's
STI's or Sexually Transmitted Infections	These are "germs" that can be passed from one person to the other person when you are having sex. They can make you unwell. They include chlamydia, HIV or AIDS, and genital warts.
Stakeholders	We used this term to describe the other people in a woman* with disabilities life. This included family, doctors, teachers, therapists and more.
Special	Known as special schools or classes – segregated or separate from mainstream and others without disabilities.
Sexuality	Sexuality is more than just sex. It is also how you feel about sex and your body. It is your gender, and who you find sexy.
Women* with disabilities	WWDACT uses this term to refer to women, girls, feminine identifying and non-binary people.

Appendix 1 – Email Invitation



Contraception and Consent Surveys

As Part 2 of our Contraception and Consent Project, WWDACT is surveying women with disabilities* and their allies and professionals. We are wanting to hear about experiences and education around:

- Sexuality
- · Sex education
- Contraception
- Consent
- · Safe, respectful relationships, and more

Please share this email with anyone you think would be interested.

" "Women with Disabilities" includes girls, feminine-identifying and non-binary people with disabilities.



surveymonkey.com/r/MRJG9ZF

Or print out a copy:

Download PDF

Download Word Document



surveymonkey.com/r/MS9DKK9

If you have any questions or problems, please contact Karen on projects@wwdact.org.au, or Clare on ceo@wwdact.org.au

Appendix 2 – Proposed/cancelled workshop



What women* want to know more about:

- Menopause
- Their Rights
- Sexual Health
- Sexuality, including gender identification, beliefs and preferences

*Women is used to represent Women, Girls , Feminine Identifying and Non-binary People with Disabilities