



Women With Disabilities Australia (WWDA)

Towards Reproductive Justice for young women, girls, feminine identifying, and non-binary people with disability (YWGwD)

Report from the YWGwD National Survey

November 2022



Women
With
Disabilities
Australia
(WWDA)



WWDA
youth
network

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Women With Disabilities Australia (WWDA) has Special Consultative Status with the Economic and Social Council of the United Nations.

Awards

Winner

National Human Rights Award 2001

Winner

National Violence Prevention Award 1999

Winner

Tasmanian Women's Safety Award 2008

Nominee

UNESCO Prize for Digital Empowerment of Persons with Disabilities 2021

Nominee

National Disability Awards 2017

Nominee

French Republic's Human Rights Prize 2003

Nominee

UN Millennium Peace Prize for Women 2000

Certificate of Merit

Australian Crime & Violence Prevention Awards 2008



About Women With Disabilities Australia (WWDA)

Women With Disabilities Australia (WWDA) is the national Disabled People's Organisation (DPO) and National Women's Alliance (NWA) for women, girls, feminine identifying, and non-binary people with disability in Australia. As a DPO and an NWA, WWDA is governed, run, and staffed by and for women, girls, feminine identifying, and non-binary people with disability.

WWDA uses the term 'women and girls with disability', on the understanding that this term is inclusive and supportive of women and girls with disability, along with feminine identifying and non-binary people with disability in Australia.

WWDA represents more than 2 million women and girls with disability in Australia, has affiliate organisations and networks of women with disability in most States and Territories, and is recognised nationally and internationally for our leadership in advancing the rights and freedoms of all women and girls with disability. Our organisation operates as a transnational human rights organisation - meaning that our work, and the impact of our work, extends much further than Australia. WWDA's work is grounded in a human-rights based framework which links gender and disability issues to a full range of civil, political, economic, social, and cultural rights. All WWDA's work is based on co-design with and participation of our members. WWDA projects are all designed, governed, and implemented by women and girls with disability.

Disabled People's Organisations (DPOs) are recognised around the world, and in international human rights law, as self-determining organisations led by, controlled by, and constituted of, people with disability. DPOs are organisations of people with disability, as opposed to organisations which may represent people with disability. The United Nations Committee on the Rights of Persons with Disabilities has clarified that States should give priority to the views of DPOs when addressing issues related to people with disability. The Committee has further clarified that States should prioritise resources to organisations of people with disability that focus primarily on advocacy for disability rights and, adopt an enabling policy framework favourable to their establishment and sustained operation.¹

About the WWDA Youth Network

The WWDA Youth Network is the youth branch of Women With Disabilities Australia (WWDA), run by and for young women, girls, feminine identifying, and non-binary young people with disability between the ages of 15-30.

The WWDA Youth Network uses the term young women and girls with disability to refer to young women, girls, feminine identifying, and non-binary young people with disability (aged 15-30) across Australia.

The WWDA Youth Network is currently coordinated by WWDA's Youth Development Officer, in collaboration and co-design with WWDA's Youth Advisory Group (WYAG), made up of a diverse group of young women and non-binary young people with disability across Australia.

The aim of WWDA Youth Network is to specifically voice the needs and rights of young women and girls with disability. We are a national voice, working as part of Women with Disabilities Australia (WWDA), to empower young people through the provision of information, resources, mentoring and leadership programs. More information about the WWDA Youth Network can be found at wwda.org.au/campaign/wwda-youth/.

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Acronyms

CaLD:	Culturally and Linguistically Diverse
CRPD:	Convention on the Rights of Persons of Disabilities
CSE:	Comprehensive Sexuality Education
DPO:	Disabled People's Organisation
LARC:	Long-Acting Reversible Contraception
LGBTIQ+:	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, Plus
NDIS:	National Disability Insurance Scheme
RSE:	Relationships and Sexuality Education
WWDA:	Women With Disabilities Australia
WYAG:	WWDA Youth Advisory Group
YWGwD:	Young Women, Girls, and Gender diverse people with Disabilities

Glossary

Ableism: A system that places value on people's bodies and minds based on societally constructed ideas of normality, intelligence, excellence, desirability, and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, misogyny, colonialism, imperialism, and capitalism. This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's language, appearance, religion and/or their ability to satisfactorily [re]produce, excel and "behave." You do not have to be disabled to experience ableism. However, People (or WGwD) with disabilities often experience ableism daily (sometimes multiple times) as overt (obvious/public) and covert (concealed/subtle) forms of discrimination.

Autonomy: The agency to choose whether or not to act in a certain way or have certain experiences. A person has a right to determine their own life and make their own decisions, even when those decisions are not one's others would make.

Cisgender: A term used to describe people whose gender is the same as that assigned to them at birth (male or female).

Co-design: Co-design is a collaborative, participatory approach to design which actively engages and places decision capacity in the hands of end users. Co-design goes beyond simply involving stakeholders in the beginning stages of design. Participants engage in problem-solving, decision-making and feedback processes throughout the project cycle, allowing for genuine and meaningful contribution.

Contraception: The intentional management of ovulation and subsequent menstruation through various social, cultural practices or medical intervention such as ritual, hormones, technologies, or surgical procedures.

First Nations: Aboriginal and Torres Strait Islander peoples are the first peoples of the land now called Australia, meaning they and their continuing sovereign Nations have existed for thousands of years prior to colonisation.

Forced Sterilisation: Refers to the performance of a procedure which results in sterilisation in the absence of the prior, free, and informed consent of the individual who undergoes the procedure, including instances in which sterilisation has been authorised by a third party, without that individual's consent. This is considered to have occurred if the procedure is carried out in circumstances other than where there is a serious threat to life. Coerced sterilisation occurs when financial or other incentives, misinformation, misrepresentation, undue influences, pressure, and/or intimidation tactics are used to compel an individual to undergo the procedure. Coercion includes conditions of duress such as fatigue or stress. Undue influences include situations in which the person concerned perceives there may be an unpleasant consequence associated with refusal of consent. Any sterilisation of a child, unless performed as a life-saving measure, is considered a forced sterilisation.

Gender experiences: Trans, transgender, gender diverse, cis and cisgender are all experiences of gender and are distinct from male, female, and non-binary gender identities.

Heteronormative: A world view or perspective that promotes or assumes heterosexuality as the status quo or default sexual orientation.

Intersex: Intersex is an umbrella term used to describe a wide range of innate bodily variations of sex characteristics. Intersex people are born with physical sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit typical definitions for male or female bodies.

Menstruation: Menstruation is menstrual tissue from inside the uterus exiting via the cervix that happens about once a month and is commonly known as a menstrual cycle or having a menstrual period.

Non-binary: Genders that sit within or outside of the spectrum of the male and female binary are non-binary.

Queer: A term used to describe a range of sexual orientations and gender identities. Although once used as a derogatory term, the term queer now encapsulates political ideas of resistance to heteronormativity and homonormativity and can often be used as an umbrella term to describe the full range of LGBTIQ+ identities.

Restrictive Practice: Any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability. These can include, but are not limited to, chemical restraints, mechanical restraints, physical restraints, environmental restraints, and seclusion.

Reproductive Health: The state of complete physical, mental, and social well-being in all matters relating to the reproductive system, its functions and its processes. Reproductive health is a part of sexual health.

Reproductive Justice: Loretta Ross defines reproductive justice as:

1. the right not to have a child.
2. the right to have a child; and,
3. the right to parent children in safe and healthy environments.

In addition, reproductive justice demands sexual autonomy and gender freedom for every human being.

Substituted Decision-making: YWGwD are often denied or limited in expressing their views in line with their evolving capacities and are perceived as 'fixed' in their capacities to understand or participate in decision-making affecting their lives. Their decisions are routinely substituted by third parties, including families, guardians, legal representatives, and service providers.

Supported Decision-making: This is when people with disability need support to make choices and decisions. This may involve someone explaining information about different choices or providing counselling and emotional support to someone having difficulty making decisions.

Sexual and Reproductive Self-Determination: The ability to freely determine any decisions relevant to one's own body and sexual and reproductive health.

Segregated and/or Closed Setting: A place in which people are kept away from the rest of the community, such as disability group homes, prisons, youth detention centres, residential aged care facilities, psychiatric wards, 'special' schools, or Australian Disability Enterprises (ADEs), also known as 'sheltered workshops.' The sheltered and/or 'hidden' nature of segregated and closed settings means it is difficult for people, especially people with disabilities, to speak up about violence, harassment, abuse and/or exploitation in these settings, make a complaint, or seek information or assistance.

Sexuality: Is a central aspect of being human throughout life and encompasses sex, gender identities and roles, culture, sexual orientation, sensuality, pleasure, intimacy, reproduction, and platonic care. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles, and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, and religious and spiritual factors.

Sexual Orientation: Refers to an individual's sexual and romantic attraction to another person. This can include, but is not limited to, heterosexual, lesbian, gay, bisexual, and asexual. It is important to note, however, that these are just a handful of sexual identifications – the reality is that there are an infinite number of ways in which someone might define their sexuality. Further, people can identify with a sexuality or sexual orientation regardless of their sexual or romantic experiences. Some people may identify as sexually fluid; that is, their sexuality is not fixed to any one identity or label.

Sexual Health: a state of physical, emotional, mental, and social well-being related to sexuality; it is not merely the absence of disease, dysfunction, or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and fulfilled.

Trans and gender diverse: These are umbrella terms that describe people whose gender is different to the legal sex that was assigned to them at birth. Trans people may position 'being trans' as a history or experience, rather than an identity, and consider their gender identity as simply being female, male or a nonbinary identity. Some trans people connect strongly with their trans experience, whereas others do not. The processes of transition may or may not be part of a trans or gender diverse person's life.

Trauma-informed: Trauma-informed care is a framework for human service delivery that is based on knowledge and understanding of how trauma affects people's lives, their service needs and service usage.

Introduction



Introduction

Across Australia, there is an absence of sexual and reproductive health information and resources that meet the needs of women, girls, feminine identifying, and non-binary people with disability (YWGwD).

Ableism, a system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence, and productivity,² is what lies at the root of this absence. Ableism remains embedded within Australian health and education systems, infantilising YWGwD, enabling violence and denying young disabled women and gender diverse people information and resources that speak to their sexual and reproductive concerns, aspirations, and human rights.³

In the medical system, this ableism is largely rooted in the dominance of the Medical Model of Disability, which views disability as a 'deficit' within the individual.⁴ In contrast, WWDA uses and endorses the Human Rights Model of Disability,⁵ which recognises that disabilities are a social construct and impairments must not be taken as a legitimate ground for the denial or restriction of human rights. The Convention on the Rights of Persons with Disabilities (CRPD) is an international intersectional human rights treaty, to which Australia is a party and to which WWDA utilises to guide and inform our work.

In Australia, the prevalence of medical ableism and dominance of the medical model means that access to inclusive and trauma-informed sexual and reproductive health care remains severely restricted for YWGwD. In responses to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability *Issues Paper on Health care for people with cognitive disability* Issues Paper, health communication was consistently identified as a major barrier to accessing health care.⁶ Respondents, including professional medical bodies and community advocates, highlighted "deeply rooted discriminatory attitudes that persist within the health sector". They drew attention to negative attitudes about people with disability and a lack of workforce training for health professionals who are rarely equipped to communicate with people with cognitive and intellectual disability.⁷

In addition to negative bias and a lack of training and understanding from health professionals, communication barriers are often created and upheld through a lack of access to health information and resources that are in accessible formats, such as screen reader friendly websites, and information in Easy Read, Plain English and/ or Auslan.

For YWGwD, this is particularly problematic, limiting critical access to information and resources that support their sexual and reproductive health, safety, and wellbeing. Without access to inclusive and intersectional sexual and reproductive health information and resources, YWGwD continue to frequently be denied the ability to make decisions about their own bodies, on the basis that they don't have the knowledge or capacity to do so.⁸

For many years, WWDA has called on successive Australian Governments to fund the development of resources that build YWGwD's knowledge about their sexual and reproductive health and rights, so that they can be empowered to make their own, informed, and autonomous decisions in health systems. WWDA has also long advocated

for the development and enactment of national uniform and legally enforceable legislation prohibiting the sterilisation of children, and the sterilisation of adults in the absence of their prior, fully informed, and free consent. However, to date, Australian Governments remain of the view that it is acceptable for third parties, such as parents, guardians, courts, and tribunals to make decisions about certain aspects of the sexual and reproductive health and rights of YWGwD.⁹

Methodology

In 2021 WWDA received a small funding grant through the Consumers Health Forum of Australia (CHF) to conduct a number of activities including a survey. The Youth Health Forum Incubator Grant had been made available to organisations partnering with young people to focus on the ‘missing middle’ in health care; that being young people who do not have the knowledge or resources to access health services as needed. Receiving this small grant enabled WWDA to conduct research on YWGwD’s knowledge and experiences of menstruation and contraception, and to develop resources to address the gaps in information for this community. Due to the small amount of CHF grant funding, WWDA also utilised funding and resources from its National Women’s Alliances (NWAs) funding grant, which has been provided to WWDA to, amongst other things, consult with Australian women to identify issues affecting Australian women; contribute to, and be included in, the development, implementation, and evaluation of government gender-equality and women’s rights policies; and gather and analyse evidence to develop solutions to priority issues affecting Australian women.

As part of these funding grants, WWDA worked with its Youth Advisory Group (WYAG), made up of a diverse group of YWGwD, to co-design a survey aimed at identifying gaps in resources that are available to YWGwD on their sexual and reproductive rights and health – specifically in relation to menstruation and contraception and to gain ideas for resource development. Across multiple consecutive meetings, the members of the group shared what they would like to be included in the survey, provided input into the questions being drafted, and reviewed the draft questions. In between meetings, the questions were sent for additional review for those who could not attend the meetings or wanted to add any additional information. After being given final approval by the WYAG, the survey was launched 10 December 2021.

The survey was designed using an intersectional feminist approach that recognises the overlapping and concurrent forms of oppression experienced by YWGwD in relation to their age, disability and gender, as well as other factors such as: class, sexual orientation, appearance, race, ethnicity, religion, nationality, citizenship, language, political, religious or spiritual beliefs, marital or relationship status, pregnancy or parental status, or criminal record.¹⁰ This approach specifically acknowledged that identity markers (such as “Woman”, “Disabled”, “Aboriginal or Torres Strait Islander”, “Culturally and Linguistically Diverse” or “LGBTIQA+”) do not exist independently of each other, but rather inform each other.

The survey utilised both qualitative and quantitative methods and was open to young women, girls, feminine-identifying and non-binary people (aged 15-30) with all types of disability, as well as their families and supporters. To ensure the survey reached a broad

range of YWGwD, WWDA made it available in multiple accessible formats, including through the provision of an Easy English version for individuals with intellectual disability, low literacy levels or for those who speak English as a second language. The survey was promoted through a wide range of platforms, utilising WWDA's social media channels, email bulletins, websites, and extensive network of members. The survey was launched 10 December 2021, closed on 10 January 2022, and received a total of 186 responses.

This report summarises the results from the survey, highlighting the key findings and trends identified amongst responses. De-identified direct quotes from survey responses have also been included in the report. Limitations exist in the survey having been designed for the grant purpose, rather than a survey to conduct broader research about community experiences and perspectives. In situating these findings within Australian and international contexts, this report provides recommendations for future work supporting the sexual and reproductive health and rights of YWGwD to include building on the existing work in the area of Reproductive Justice.

Language and Gender

This report is committed to acknowledging the need for gender inclusive language when discussing contraception and menstruation. Our work strives to accommodate anyone who identifies outside of the gender binary. In doing so, we acknowledge the complexities and continual evolution of language in this domain. In response to some of the notes made by survey participants, this section aims to explain the terms and language used to address gender.

The survey included participants with a wide variety of gender identities, including those who identified as women, men, non-binary, intersex, transgender, genderless, genderfluid, agender and genderqueer.

The survey used the term 'women, girls, feminine identifying and non-binary', while the report uses the term 'young women, girls and gender diverse people', abbreviated to YWGwD. In relation to our definition of contraception and menstruation products, we have taken on feedback to use gender neutral terms. For example, rather than the medical model language of 'male condom' or 'female condom', we use the social model terms 'external condom' and 'internal condom'.

With a variety of different gender experiences, some survey participants noted their objection to the survey terminology. One participant found that using the non-gendered term 'people' or 'people who menstruate' to be more appropriate. For others however, the terms 'women' and 'girls' are important markers of visibility. This language may speak to lived experiences resulting from how societies have traditionally defined and enforced masculinities.

As such, the term 'young women, girls and gender diverse people' has been used to reflect a range of gender identities and the diversity of lived experiences. It stands in solidarity with attempts to defy the gender binary and recognises the importance of paying continued attention to the politics of language in this domain.

Literature Review



Literature Review

YWGwD across Australia and the world face severe barriers to fulfilling their sexual and reproductive health and rights (SRHR).¹¹ SRHR encompass the ability to make free and informed choices about ones' own body, sexual and reproductive health, intimate relationships, and parenting.¹² This includes the right to sexual pleasure, expression of sexual identity, association, equity, privacy, freedom, autonomy and self-determination.¹³ Despite the prevalence of disability in Australia, YWGwD are rarely addressed in statistics, policies, and programmes surrounding SRHR. Underpinning this omission is the concept of 'sexual ableism', which operates through '[a] system of imbuing sexuality with determinations of qualification to be sexual based on criteria of ability, intellect, morality, physicality, [and] appearance'.¹⁴ As such, YWGwD are systematically desexualised, or their sexuality is viewed as inappropriate. Research continually fails to accommodate gender perspectives and the multifaceted discrimination, marginalisation and compounded human rights violations that YWGwD face in accessing their SRHR.

The Australian Charter of Healthcare Rights highlights that the rights to access, safety, respect, partnership, information, privacy and giving feedback apply to all people in all places where health care is provided in Australia.¹⁵ However, this literature review highlights how these rights are not upheld for many YWGwD in relation to their SRHR.

Access to information & services

Access to comprehensive sexuality education (CSE) is fundamental to fulfilling SRHR. YWGwD are likely to be as sexually active as their peers without disabilities, yet are far less likely to access the same quality of education.¹⁶ As defined by the International Planned Parenthood Foundation (IPPF), a rights-based approach to CSE seeks to equip young people with the knowledge, skills, attitudes and values they need to determine and enjoy their sexuality – physically and emotionally, individually and in relationships.¹⁷ It views 'sexuality' holistically and within the context of emotional and social development. It recognizes that information alone is not enough. It is asserted that young people need to be given the opportunity to acquire essential life skills and develop positive attitudes and values. As such, CSE is made up of seven key components: gender, sexual and reproductive health and HIV, sexual rights and sexual citizenship, pleasure, violence, diversity (including disability) and relationships.

CSE is learning that begins at birth and can continue throughout life.¹⁸ It can be adapted and led within various cultural contexts, age-appropriate and enable intergenerational knowledge sharing. Embedded throughout the lifespan, it not only prevents sexual abuse and enables supportive relationships, but it also empowers all YWGwD to have control over their own sexual and reproductive bodies, lives, and futures. Benefits are lifelong and intergenerational.

CSE must give young people the tools to:

- **Acquire accurate information**

On sexual and reproductive rights, information to dispel myths, references to resources and services

- **Develop life skills**

Such as critical thinking, communication and negotiation skills, self-development skills, decision making skills; sense of self; confidence; assertiveness; ability to take responsibility; ability to ask questions and seek help; empathy

- **Nurture positive attitudes and values**

Open-mindedness; respect for self and others; positive self-worth/esteem; comfort; non-judgmental attitude; sense of responsibility; positive attitude toward their sexual and reproductive health.¹⁹

In Australia, CSE is referred to by the Australian Government as Relationships and Sexuality Education. However, current frameworks lack a comprehensive scope, particularly in relation to disability, and are not mandated. So, while curriculum content is universally available to schools, it is up to each individual school as to if and how relationships and sexuality education is embedded in learning. Numerous studies show that relatives, teachers and health-care providers are generally anxious, untrained and unwilling to discuss sexuality with YWGwD.²⁰ Information is rarely delivered in accessible formats and alternative languages, and rarely addresses disability-specific needs and wants.²¹ Furthermore, even when sexual and reproductive health education is provided, it is largely cis-heteronormative, Eurocentric, body negative, sex negative and concerned with disease and pregnancy prevention,²² leaving key components of CSE absent.

In their collaborative research with young adults with intellectual disabilities, Frawley and Wilson found that young people themselves often do not find current education approaches useful, preferring instead to talk to each other or to seek counsel from other young people who they see as knowledgeable.²³ While sexual consent education will be mandatory in Australia school curriculums from 2023,²⁴ it is unclear how this will address the more expansive need for comprehensive sexuality education, including pleasure, which can address the unique needs of YWGwD, particularly for those in segregated schools, units or classrooms.

Across Australia, there is also an overarching lack of disability access to sexual and reproductive health services, including GP settings, hospitals, local surgeries, and clinics.²⁵ Common barriers to accessing these services include:

- negative and hostile attitudes among service providers
- an absence of physical accessibility with regard to buildings and equipment (e.g., exam tables and diagnostic equipment)
- a lack of information in accessible formats (e.g., in Braille or Easy English)

- communication barriers (e.g., the lack of training for service providers on communicating with young women and girls with intellectual disabilities or a lack of access to Auslan interpreters); relatives and caregivers acting as gatekeepers to information and services; a lack of accessible transportation to or from services; the affordability of services; and the isolation of girls and young women with disabilities living in institutional settings such as disability group homes or youth detention centres.²⁶

During disaster and emergencies YWGwD experience the greatest barriers to sexual and reproductive health, including pandemic restrictions, bushfires, and floods. Sexual and reproductive health products and services are rarely accessible during a crisis and often the last form of health care to be re-established.²⁷ YWGwD are disproportionately affected in natural disasters and emergency situations due to a lack of accessibility in evacuation, response, and recovery efforts, and a lack of attention to disability issues in planning and preparedness. Australia is witnessing a significant increase in both the severity and frequency of natural disasters, and the link between climate change and extreme events, including pandemics, is increasingly recognised. Disaster planning and prevention in Australia needs to consider these significant implications for the ability of YWGwD to fulfil their SRHR now and in the future.

Self Determination

Reproductive rights and freedoms encompass for example: the right to bodily autonomy, the right to reproduce and/or parent, the right to sexual pleasure and expression, the right for their bodies to develop in a normal way, the right to sex education, to informed consent regarding birth control, to abortion, to choose if or when to be a parent, to access sexual and reproductive health information, resources, medical care, services, and support; the right to experience and express their sexuality; the right to experience love, intimacy, sexual identity; the right to privacy, and the right to be free from interference.²⁸

A lack of access to information and services directly restricts YWGwD from exercising self-determination over their bodies. It is difficult for YWGwD to challenge restrictive practices and advocate for their own desires and needs without resources that outline their SRHR. Guardianship legislation in Australia continues to permit judges, health-care professionals, family members and other guardians to consent to restrictive practices on behalf of persons with disabilities as being in their 'best interest', preventing them from being able to make important life decisions in regard to their medical, accommodation, social relationships, and support services preferences.²⁹

For example, when managing menstrual and contraceptive choices, many YWGwD are presented with far more limited options than their non-disabled peers. There is an on-going lack of education, resources, support for menstrual health and appropriate sanitation facilities that meet the needs of YWGwD.³⁰ Too often, menstruation management prioritises the convenience of caregivers to the denial of a young person's dignity, integrity, and autonomy. Non-consensual and coercive sterilisation, alongside forced contraception use including via long-acting reversible contraceptives (LARC's), are viewed as appropriate means to avoid menstruation management and reduce

the care burden.³¹ Similarly, YWGwD are more likely to receive contraception by intra-uterine device or injection to reduce daily care requirements. Contraception can also be manipulated as a tool to hide sexual abuse by preventing pregnancy. In these circumstances, YWGwD may not be aware of alternatives to the choices made by caregivers or given access to the information and resources needed to pursue their own decision-making.

Relationships

Constraints on sexual and reproductive self-determination directly impact the ability of YWGwD to express their own gender and sexual identities and form relationships within which to express their sexual and emotional desires. Beyond sexual, romantic, or formally recognised intimate relationships, it is also vital to note the importance of other forms of relationships (e.g., friendships, mentors, community groups) to express and affirm gender and sexual identities.

Women and girls with disability report limited opportunities and difficulty negotiating relationships, often due to lack of support and paternalistic attitudes. In an exploratory study of the experiences of lesbian and bisexual women with intellectual disabilities, participants reported severe stigma surrounding discussions of their sexuality, limited social contact, lack of self-worth and significant mental health struggles with depression, addiction, and loneliness as major barriers to building romantic relationships.³² A lack of opportunities and support to develop social connection meant that they felt left to ‘figure it out’ in isolation.

In Australia, the National Disability Insurance Scheme (NDIS) has failed to produce a clear and comprehensive policy to fulfil the SRHR of participants at all life and development stages. This leaves YWGwD largely unsupported to establish relationships within which to affirm their gender and sexual identities and express and freely pursue their sexual and reproductive desires.³³



Parenting

Prejudicial attitudes and stereotypes about the reproductive capacity of YWGwD directly influence decisions made about their reproductive rights. As YWGwD are continuously desexualised or viewed as overly sexual, dependent and recipients of care rather than capable of being care-givers themselves, the right to bear and/or parent children is frequently unsupported or denied. Across the variety of pregnancy options available (eg., abortion, adoption, and parenting), YWGwD are consistently disempowered to realise their preferred outcome. This also extends to the denial of YWGwD pursuing parenting options without giving birth, including adoptive parenting, or providing kinship or foster care.

Currently, the legal, policy and social support environment within Australia gives rise to the removal of children from parents with disability at ten times the rate of non-disabled parents.³⁴ Furthermore, significant discrimination is experienced in accessing assisted reproductive technologies (such as in-vitro fertilisation (IVF) and assisted insemination). Many women with disability - particularly single women with disability and women with disability in same-gender relationships - report being deemed by fertility consultants/clinics as ineligible for assisted reproductive services. Australia's universal health system (Medicare) covers the treatment of assisted reproduction for women who are deemed 'medically infertile'. However, single women and lesbian couples who are deemed not to be 'medically infertile' are denied access to Medicare rebates. This is also the case for single women and/or lesbian couples who have private health insurance.³⁵

WWDA maintains that the denial of YWGwD's right to be pregnant and/or parent children and the lack of support to ensure equitable opportunities to do so in safe and healthy ways constitutes serious violations of human rights.

Gendered disability violence

Violence against YWGwD occurs on a continuum that spans interpersonal and structural violence. Structural violence can be defined as the social arrangements that put individuals and populations in harm's way. The arrangements are structural because they are embedded in the social, political, and economic organization of our social world; they are violent because they cause injury to people (typically, not those responsible for perpetuating such inequalities). Structural violence is marked by unequal access to the determinants of health (for example, good quality housing, education, health care and employment) which then creates conditions where interpersonal violence is more likely occur. Because of multiple marginalisation's due to gender, age, and disabilities, YWGwD are particularly at risk of violence, including physical violence, sexual violence (including forced sterilisation, forced contraception, forced abortion, menstrual suppression), abuse (including psychological abuse, financial abuse and controlling behaviours), neglect and exploitation.

Restrictions on self-determination constitute serious violations of human rights and are recognised as a form of gendered disability violence.³⁶ In the broader population, gender-based violence is generally understood in the context of domestic, spousal, intimate

partner, or family violence.³⁷ However, this does not capture the range of relationships and settings in which YWGwD experience violence. Conceptualisations of gendered disability violence must recognise that there are a broad range of perpetrators including support workers, parents, co-residents, healthcare professionals, teachers, and guardians; and that violence can occur anywhere, including in institutions or service settings such as group homes, medical services and detention centres.

Rates of sexual violence towards women with disabilities range from four to ten times higher than for other women.³⁸ This statistical variation demonstrates how exposure to assault due to gender and disabilities compounds with other marginalised identities. For example, youth is a significant factor, with YWGwD being particularly at risk between the ages of 15-19 and 68% of women with an intellectual disability being subjected to sexual abuse before they reach 18 years of age.³⁹ Of the L(G)BTIQ+ people who reported harassment or violence in the last 12 months, 46% had a disability.⁴⁰ Furthermore, First Nations women are 34 times more likely than non-Indigenous women to be hospitalised due to domestic violence.⁴¹ Young people under the age of 25 make up 15% of the population incarcerated in Australian women's prisons.⁴² Half of the total population entering prisons have psychosocial disabilities, and all incarcerated people are recognised to be at high risk of sexual violence.⁴³ The interaction between these identities highlights the importance of intersectional analysis. The gendered disability violence experienced by YWGwD is intensified in correlation with various other identity factors and forms of oppression.

Public and Political Participation

YWGwD in Australia and across the world continue to experience significant barriers to participation in all aspects of public life, including in the development of sexual and reproductive policy, programs, and services, as well as legislative and organisational decision-making processes. Too often, their views are ignored or disregarded in favour of 'experts', 'professionals', parents, guardians, and carers, as well as representatives of organisations not controlled and constituted by women with disabilities themselves.⁴⁴ This also extends to research conducted about YWGwD relationships and sexuality. Frawley & O'Shea note that 'research about sexuality in the lives of people with intellectual disabilities rarely includes people with disabilities as more than research subjects'.⁴⁵

There is a critical need for YWGwD to lead sexual and reproductive research and service delivery, progressing sexual and reproductive rights within both domestic and international law and policy. This report aims to contribute to these existing gaps in research by summarising the findings from our survey on the experiences of YWGwD with accessing sexual and reproductive health information and resources. WWDA's hope is that this report may serve as a critical intervention in the existing literature on the SRHR of young women, girls, and gender diverse people with disabilities, bringing forward the voices of our community and ensuring that 'nothing about us without us', a phrase used in reference to self-determination for people with disabilities, is realised.

Intersectionality



Intersectionality

Intersectionality is a tool for revealing and transforming the interworking of power and oppression. The term was coined by Black legal scholar Kimberle Crenshaw in 1989, drawing from Black feminist voices who had been making this analysis for decades.⁴⁶ Intersectionality reveals the “conceptual limitations of single-issue analyses.”⁴⁷ As Crenshaw demonstrated in her work, “Intersectionality was a prism to bring to light dynamics within discrimination law, regarding racism and sexism specifically, that weren’t being appreciated by the courts.”⁴⁸

An intersectional approach allows for the analysis of how the multiple, different identities that individuals hold intersect with one another, influencing their interactions with systems, services, and the broader community. For YWGwD, intersectionality serves to reveal the grievous human rights violations they are subjected to, not only on the basis of gender, but also their disability – ableism and sexism serving to compound one another. This framework challenges the way Australian law attempts to neatly compartmentalise forms of discrimination like sexism and ableism, rather than recognising the complex interplay between systems of oppression and power structures. Critically, intersectional analysis also serves to demonstrate the compounding oppression specific communities of YWGwD face, highlighting, for example, the specific forms of violence and abuse First Nations women with disabilities face in the colony, subjected to racism, ableism, sexism, homophobia, and transphobia.

To gain more in-depth analysis of the YWGwD completing the survey, participants were asked to identify themselves according to gender, sexuality, cultural and linguistic background, age, forms of disability or chronic illness. It also allowed contributors to identify whether they had experiences of foster, kinship, or residential care; imprisonment; the sex work industry; living in rural, regional or remote communities; migrant, refugee or temporary visa status; and/or poverty.

Gender and Sexuality

Of 186 participants, 157 identified as women and 4 identified as men. 23 identified as non-binary and 13 as transgender. Three participants described themselves as agender and two others identified as genderfluid/genderqueer. Significantly, almost 60% of participants identified as LGBTIQ+, which is significantly higher than the broader young Australian population.

The confluence between queer and disabled identities has been increasingly documented with the emergence of crip theory. Drawing from both queer of colour critique and critical disability studies, it offers a critical process to consider how certain bodily or mental experiences, including gender and sexuality, have been made marginal, invisible, pathological, or deviant.⁴⁹ Concepts of heterosexuality and able-bodiedness are both enmeshed in similar constructs of ‘compulsory normativity’, with communities experiencing suppression of their sexualities as a result of queer identification or disability. As such, experiences of disability, gender non-conformance and queerness share common histories of oppression that are now recognized as a source of ally-

ship. New terms such as ‘neuroqueer’ represent the merging of these identities and are gaining popularity in the fields of neurodiversity studies and critical autism theory.⁵⁰ This may partially explain the high rates of identification with queerness and gender non-conformance among YWGwD. The overlap of these identities is significant and outlines the necessity for SRHR resources and education that can account for the specific needs of young people at this intersection and provide identity-affirming care for trans and gender diverse young people.

Forms of Disability

Competing models of disability inform how disability is identified. Where the medical model isolates physical impairment from social contexts, the social model highlights the influence of social forces on impaired bodies. Beyond the social model, the embodiment theory of disability understands the disabled body and its social representation as being mutually defining and transformative.⁵¹ Disability is a category with blurred boundaries and the likelihood of comorbidities makes identifying with a single category of disability unrealistic for many.

The experience of disability across vast variations of impairment, visibility, stages of life, environments, access to resources and intersecting identity factors is difficult to capture categorically. While prevailing representations of disability are ones with overtly visible characteristics, many forms of disability are not so apparent. Identifying as disabled can be a source of political solidarity, but it can also present significant social costs. Given the prevailing negative attitudes to disability, it is unsurprising that people with disabilities may prefer not to disclose their status.

The survey asked participants to choose which forms of disability they saw as applying to them. Definitions of each category were not given and was therefore dependent on participants own understanding of the terms.

- 13.8% identified with cognitive/intellectual disability
- 41.5% identified as neurodivergent
- 49% identified as having psychosocial disability/ mental illness
- 18.2% identified as having physical disability
- 3.14% identified as blind or vision impaired
- 10.7% identified as Deaf/deaf or hard of hearing
- 16.4% identified as ‘None of the above’. This may partially represent carers, family members and professionals who were also invited to take the survey. It may also represent YWGwD for whom none of the above categories is an accurate representation of their disabled identity
- 1.3% chose ‘Prefer not to say’.

Age

The majority of participants (59%) were between the ages of 15 – 18 at the time of the survey, with an additional 4.3% under 15. Key access points to SRHR resources and services for this age group include schooling, paediatric health services, friends and peers, community, family members and carers. The internet is a key source of information and social connection for this age group. 82% of adolescents in Australia report using the internet, and of these 88% are online more than once every day.⁵² For YWGwD, internet use may be affected by affordability, education and support, not having accessibility devices (e.g., screen readers), low literacy levels and safe-guarding from parents, guardians, support staff and teachers.⁵³ Restricted internet use directly impacts independent access to services and information, social connection and self-representation in online spaces. As such, the internet is a crucial resource through which YWGwD can achieve greater autonomy over their SRHR. It is important to note that as this survey was distributed online, it is unlikely to have reached YWGwD who lack internet access.

One in three (31.7%) survey participants were aged between 19-30. This period of early adulthood is recognised as a significant stage of emotional, social, and personal growth. YWGwD within this age group may wish to further pursue independent sexual and romantic relationships and self-expression, and/or begin parenting. For some, there can be challenges to maintaining continuity of care as they transition out of secondary schooling and paediatric services. There may also be increased pressures for this age group related to gaining financial independence, independent housing and pursuing tertiary education.

Almost five percent (4.8%) of the remaining participants were between 31-50 years of age, representing the carers and family members of YWGwD who were also eligible to complete the survey.



Cultural and Linguistic Diversity

The term 'CaLD' is used to include any person who belongs to or identifies as being from a cultural and/or linguistic background that differs from the dominant white Anglo-Celtic culture in Australia. This includes differences in cultural/ethnic identity, language, country of birth, religion, heritage/ancestry, national origin, and/or race and colour. This term does not include Aboriginal and Torres Strait Islander Peoples and does not aim to provide an absolute definition to what CaLD represents. We recognise that using CaLD terminology is problematic as it reduces the complexities of varied groups into a single category. We recognise that this label is inherently 'othering', and that broad generalisations cannot and should not be made about those who identify as CaLD. However, we do recognise that cultural and linguistic barriers can lead to sexual and reproductive injustice.

The inclusion of CaLD as an identity category highlights the limitations of the survey to reach and represent diverse communities. Only 8.79% identified as CaLD, with 4.4% having migrant or refugee status. A small number (1.1%) were identified as being on a temporary visa. Approximately 28% of the broader population in Australia may be defined as CaLD,⁵⁴ which is significantly higher than the self-identification rates present in this survey.

This may be the result of several factors. Firstly, there was no comprehensive definition of CaLD given to participants during the completion of the survey, which may have caused participants to overlook their potential identification with this category. Furthermore, while the survey was made available in Easy English, this was primarily to increase access for people with cognitive/intellectual disability. Due to funding constraints, the survey was not translated into any other languages.

There is an ongoing need for culturally and linguistically specific surveys to greater represent the diversity among YWGwD in further research. This is particularly important when addressing topics relating to SRHR, which may be culturally sensitive and require in-depth consultation and co-design with communities to develop appropriate research frameworks.

Aboriginal and/or Torres Strait Islander [First Nations]

Almost three percent (2.75%) of participants identified as Aboriginal and/or Torres Strait Islander. The Australian Bureau of Statistics (ABS) has indicated that 45% of Aboriginal and Torres Strait Islander people report some form of disability.⁵⁵

As a result of ongoing settler colonisation and displacement, Aboriginal and/or Torres Strait Islander people experience extreme forms of structural violence. This contributes to a disproportionately high percentage of disability within communities and has implications for the ability to access SRHR information and resources. As such, discussions of SRHR for YWGwD from Aboriginal and/or Torres Strait Islander communities must recognise the ongoing imposition of coercion and violence by institutional and healthcare settings in Australia. Supporting sexual and reproductive health and self-determination for First Nations YWGwD should not be seen as separate from efforts to supporting political self-determination and sovereignty for First Nations communities.

The First Peoples Disability Network Australia (FPDN) highlights that healthcare delivery for First Peoples with disability must be centred on:

- Centring perspectives, histories, and Laws of First Nations communities in delivery of healthcare services and education
- Respect for Elders of First Nations communities and their knowledge in securing appropriate healthcare for First Nations people with disabilities and their families
- Employing appropriately trained and registered Aboriginal and Torres Strait Islander Healthcare Workers
- Recognising the richness and diversity of First Nations communities across Australia and potential for differing perspectives of health and disability
- Providing culturally relevant care as directed by First Nations communities.⁵⁶

Geographic Location

Survey results found 1.08% of participants were based in the Australian Capital Territory, 22.04% in Queensland, 25.81% in NSW, 1.61% in the Northern Territory, 5.91% in South Australia, 3.23% in Tasmania, 21.51% in Victoria, 18.82% in West Australia.

Significantly, around 20% identified as being from rural, regional, or remote areas. This term is used to refer to areas outside of Australia's metropolitan zones. Although the following generalisations may not apply to all communities, there are demographic trends as a result of geographic location that may impact SRHR outcomes for YWGwD.

Rural, regional, or remote areas may be more likely to be under-resourced in specialist health, education and transportation services,⁵⁷ resulting in less options equipped to support YWGwD to access sexual and reproductive healthcare. This may leave YWGwD more susceptible to the effects of inconsistent funding or funding cuts to communities outside of metropolitan districts. Furthermore, an increased reliance on internet access to services (e.g., telehealth appointments) and information heightens the implications of the digital divide impacting YWGwD in these areas.

Financial Situation

While only 4.4% of participants identified as living in poverty, there are multiple reports of financial concerns evident in open answer responses throughout survey. Difficulties surrounding the affordability of menstruation products and medication were noted by 1 in 4 respondents, suggesting that finances are a significant barrier to accessing SRHR resources for YWGwD in the survey. The survey did not provide a definition of poverty, which may have influenced the low rates of identification with this category.

Poverty has various manifestations, including lack of income and productive resources, hunger and malnutrition, ill-health, limited access to education and other basic services,

homelessness and inadequate housing, unsafe environments, and social discrimination and exclusion.⁵⁸ Although there is no gender and disability disaggregated data relating to poverty, available data demonstrates that forty-five per cent of people with a disability in Australia live in poverty, more than double the OECD average of 22%.⁵⁹ 11.2% of people with disability experience deep and persistent disadvantage, more than twice that of the national prevalence.⁶⁰ This rate is significantly higher for First Nations peoples with disability.⁶¹

The Disability Support Pension (DSP) provides financial support to working age Australians who have a permanent physical, intellectual, or psychiatric impairment that prevents or limits their capacity to engage in employment. The DSP is largely inadequate to support women with disability⁶² and fails to take account of the non-optional, extra costs experienced by women with disability, as a direct result of their disability and/or impairments. DSP eligibility has been tightened to such a degree that 25-30% of people with disability are now receiving the much lower Newstart unemployment payment,⁶³ which has further entrenched poverty. The rate of successful DSP claims has declined markedly – from 69% in 2011 to 29.8% in 2018.⁶⁴ While governments have significantly reduced the number of people receiving the DSP, this has not translated into increased employment and economic security for people with disability, particularly women with disability.⁶⁵

As of 2020, the poverty line (measured as 50% of median income) was \$457 per week for a single adult.⁶⁶ The single rate of Youth Allowance (plus Rent Assistance and Energy Supplement) is \$168 per week below the poverty line.⁶⁷ For YWGwD ineligible for the DSP or Youth Allowance, parental income does not necessarily reflect independent financial means to access sexual and reproductive health resources. For those under guardianship orders, restrictions to financial autonomy can also affect access.

Period poverty – a lack of access to menstrual products, facilities, and menstrual health education – disproportionately affects marginalised groups, including those who are unemployed, homeless, or displaced due to domestic violence.⁶⁸ The Period Pride report, based on responses from more than 125,000 Australians, found that more than 1 in 5 (22%) people who menstruate have had to improvise on period products due to the cost. The concerns surrounding the affordability of menstruation products expressed by 1 in 4 participants of the WWDA Youth SRHR survey adds to the evidence that YWGwD are at greater risk of experiencing financial barriers to their sexual and reproductive healthcare needs.⁶⁹

Research Limitations and Under-Represented Groups



Research Limitations and Under-Represented Groups

Online surveys such as the WWDA Youth [SRHR Survey](#) are limited in their ability to access and represent certain demographics of YWGwD. The following groups are identified as having little or no representation within the survey.

YWGwD and Sex Work

Two participants (1.1%) indicated having experience in sex work. It is currently unclear as to what percentage of YWGwD in Australia have experiences in this field. Due to the stigma surrounding this form of employment and lack of safety mechanisms for workers, the risk of disclosure is likely to limit data. The low levels of representation within this survey render it unable to provide conclusive statements on this topic, although this may indicate an area for further collaborative research and representation.

Incarceration

None of the participants of the WWDA Youth survey reported experiences of incarceration, yet it is evident that young people with disabilities, including those with intellectual and/or cognitive disability, acquired brain injury, psychosocial disability and those who are D/deaf or hard of hearing (particularly for First Nations communities) are overrepresented in prison systems.⁷⁰ Due to the high risk of physical and sexual violence, as well as severe impacts on mental health, experiences of incarceration are likely to exacerbate existing disabilities and chronic health conditions for YWGwD. As existing data is unlikely to capture the full scope of rights violations occurring in these settings, there is an on-going need for greater representation of YWGwD who are currently, formerly, or at risk of incarceration.



Foster, Kinship and/or Residential/Institutional Care Settings/Spaces

Six respondents (3.3%) indicated having experience of foster, kinship, or residential care. As of 2020, there were 16,100 young people aged 12-17 living in out of home care, with some remaining in these settings until the age of 25. For the jurisdictions with available data (disability status data was not available for South Australia), it was estimated that 20% of young people aged 12–17 living in out-of-home care had disabilities.

WWDA has previously acknowledged the increased risk of gender-based violence and human rights abuses in these settings.⁷¹ Institutionalisation (in settings such as group homes for eg) is characterised by segregation and isolation and the loss of liberty and security, personal choice, autonomy, and freedom of movement. The 2015 Report from the Senate Inquiry into 'Abuse and neglect against people with disability in institutional and residential settings', found "that institutional and congregate care models of service delivery are themselves major factors in the prevalence of violence, abuse and neglect of people with disability."⁷² WWDA has consistently raised the fact that practices that deny YWGwD their sexual and reproductive rights are widespread, particularly in group homes and other institutional settings and that these practices are rarely subject to oversight, monitoring or review.⁷³

YWGwD in foster, kinship or residential care are often exposed to compounding challenges to their health and education, directly impacting their SRHR.⁷⁴ This can result from placement instability, financial stress, lack of transitional and continuing support and many other factors. The CREATE Foundation highlights the need for more representation of young people in out-of-home care that directly combats the stigma marginalisation that they experience.⁷⁵

Survey Findings



Survey Findings

Access to Sexual and Reproductive Information and Resources

The following questions were put forward to survey participants to gauge their level of access to sexual and reproductive information and services.

- What access needs they have in relation to menstruation and contraception use
- How they first learnt about menstruation and contraception
- What resources are helpful/unhelpful
- What information on contraception and menstruation they believe is missing for YWGwD
- What should be considered when developing resources for YWGwD about menstruation and contraception
- How comfortable they feel with their knowledge about menstruation and contraception (sliding scale out of 100)

In this section, we outline the key survey findings and use de-identified direct quotes from respondents to highlight how individual experience reflect broader trends.

Where are YWGwD learning about menstruation and contraception use?

Most participants reported first learning about menstruation and contraception through school-based health education. Other commonly reported sources of information were family members, friends, and the internet. While most participants indicated that school-based education provided their introduction to information on SRH, it was reported to be severely lacking in comprehensive, relevant information for YWGwD.

‘Our teacher didn’t know what dental dams or PrEP were. We were taught everything from the lens of preventing pregnancy only (which is important of course) but very little about STI’s. There was also barely any focus on consent and communication, past the basic yes/no.’

‘They didn’t even include disabled people’s and gender diverse peoples (,) made it very broad and I learnt unrealistic ideas about menstruation’

Online resources (e.g., period tracker apps, websites, YouTube, Tik Tok, Instagram, podcasts) were found to be the most helpful resource on menstruation, contraception use and sex education. Online resources were reported to be more accessible and comprehensive, highlighting the vital role that equitable internet access has for YWGwD to fulfil their SRHR.

‘There is an abundance of useful YouTube videos on contraception, as well as online articles. I really like Healthline. I think they use gender neutral language when discussing periods.’

‘I honestly think that the show on Netflix ‘sex education’ is a great resource for this and ideas surrounding LGBTQIA+, STI, relationships, etc while still being entertaining and funny.’

Significant gaps in knowledge of contraception, safer sex, and menstruation

Survey participants were asked to indicate, on a slide scale, whether they agreed or disagreed with the survey question: *“I feel comfortable with my level of knowledge on contraception/safe sex and the different types or methods of contraception.”*

67% of survey respondents (122 respondents) indicated they were ‘comfortable with my level of knowledge on contraception/safe sex and the different types or methods of contraception.’

Survey participants were also asked to indicate, on a slide scale, whether they agreed or disagreed with the following statement: *“I feel comfortable with my level of knowledge on menstruation/periods and menstrual health.”*

79% of survey respondents indicated they were ‘comfortable with their level of knowledge on menstruation/periods and menstrual health.’

Most survey participants (94.9%) said that they currently menstruate or have menstruated with an additional 1.5% expecting to menstruate in the future. Despite almost all participants having experienced menstruation, the responses showed they lacked comprehensive knowledge about menstrual health. Given the prevalence of complications with menstrual health among YWGwD and its interactions with disability, chronic mental and physical health issues as well as chronic pain (further explored in Sexual and Reproductive Health), this has significant negative implications for quality of life among survey participants. Similarly, the majority of participants currently use, have previously used or plan to use contraception, yet the lack of knowledge about contraception is even greater. As noted by many participants, this has implications far beyond pregnancy prevention, as contraception can have multi-faceted uses for health and menstruation management and enabling sexual experiences.

What information do YWGwD want to access about menstruation?

Overall, 98 respondents said that there was a lack of information about menstruation for YWGwD. The majority of these respondents (58) said that there was a lack of information on menstruation management for YWGwD. This included information on how to identify health cycles, whole of cycle care, pain management, understanding anatomy, when to seek medical help for abnormal or painful periods, sex during menstruation, a comprehensive range of menstrual products and interactions with medications and/or pre-existing conditions.

‘Menstrual health advice accessibility is very small and limited, people who menstruate may often not know what it looks like when it’s healthy, when it’s not healthy, and when something may be wrong. It’s even less accessible for those with disability as their health and lifestyle is potentially overseen and decided for them by possibly doctors or carers in every other health aspect.’

Respondents identified concerns about accessible options for menstruation management (16), including adapted options to assist sensory difficulties or physical requirements, assistance with hygiene and interaction with existing disabilities.

‘Product use for people with different disabilities. E.g., I have significant spasticity in my legs so I am unable to use tampons. I also have issues with my hands that can make using products difficult so used to need help. I don’t regularly need help anymore as I now use period underwear.’

Gender inclusivity was a significant concern, with 15 participants identifying a lack of information, inclusive language and representation for transgender, non-binary, gender diverse people.

‘As a nonbinary person the fact that most resources are very binary gendered puts me off’

“...the impact periods can have on the mental health of non-binary and other non-cis feminine identifying people. This part is mainly about how heavily stigmatised periods are and how heavily associated they are with women only. (“if you have a functioning uterus that menstruates, then you’re a woman”)”

The need for access to information at an earlier age was highlighted by six respondents, with some noting that they only received information after their first period.

‘By the time they taught us in school, I already had my period.’

Menstruation and its intersections with mental health was identified as a key issue by five participants, particularly relating to the increased likelihood of mood swings, suicidal thoughts, or dysphoria. Several participants also requested more information about sustainable and reusable menstruation management products and practices.

What information do YWGwD want to access about contraception?

Comprehensive information about contraception use

YWGwD reported needing more detailed information about all forms of contraception available (including internal and external condoms, daily and emergency contraceptive pills, injectable forms such as the contraceptive injection or rod, hormonal and copper IUDs, surgical sterilization and fertility awareness/cycle tracking methods), where to access contraception, side effects and interactions with disability and other medications, as well as uses for contraception other than pregnancy and disease prevention e.g. regulating menstrual cycles and pain prevention.

Accessible and disability-specific information for YWGwD

Participants highlighted a lack of information about contraception available in accessible formats such as Easy English, Auslan and screen-reader friendly websites. There is also a need for disability-specific information that is representative of and relevant to YWGwD. Examples include information about contraception use for managing chronic health issues, low maintenance contraception options or how to discuss and seek support for contraception with people close to YWGwD, including families, friends, carers, educators, and health professionals.

Information about contraception for young men, boys & gender diverse people (YMBwD) with disability

Several participants raised the need for more resources for YMGwD to understand and take shared responsibility for contraception use. These responses highlight a gendered burden on YWGwD to be responsible for contraception use and its most commonly associated uses for pregnancy and STI prevention.

Privacy and rights when accessing sexual and reproductive healthcare

Several YWGwD requested more information about privacy and rights when interacting with healthcare professionals, independent Medicare records and accessing independent Medicare cards for YWGwD aged 14 and over. This information was identified as essential to accessing contraception independently and securely, particularly in situations where YWGwD are experiencing coercion towards or away from contraception use.

What information do YWGwD want to access about sex?

Information with a sex-positive disability lens

- Participants said they wanted information to support having sexual experiences that accommodate accessibility requirements, including sensory, physical, and cognitive needs
- There were numerous requests for peer-led resources centering the voices and experiences of YWGwD
- The survey findings highlighted a need for CSE with an integrated disability lens that supports YWGwD to understand their rights to self-determination over their sexual and reproductive lives.

Pleasure

Participants highlighted the lack of disability-affirming resources to promote pleasure for YWGwD, including information on pleasure, masturbation, and the right to freely express and explore sexuality safely.

Resources for queer and LGBTIQ+ YWGwD

YWGwD have called for resources that are validating of queerness, LGBTIQ+ relationships, non-monogamy, and relationships beyond heteronormative models of sex. In particular, the survey results had numerous requests for information about practicing safer sex and preventing STI infection for queer couples.

Private and Confidential Access to Information

Due to shame and stigma surrounding sexuality, there were requests for anonymous discussion forums or other means for YWGwD to access reliable information confidentially.

Information for people who support YWGwD and the broader community

Participants noted that carers, family members, friends, health care professionals, educators and other people who support YWGwD require more information and awareness to support the SRHR of YWGwD and combat stigma surrounding sexuality.

Consent/boundaries

Consistent with international literature, participants noted that there is an urgent need to increase skills to navigate consent and boundaries. This includes (but is not limited to) interrogating social expectations, promoting communication, and providing education to help YWGwD identify coercion at earlier ages.

Sexually transmitted infections (STIs)

YWGwD reported experiencing confusion about where to access clear, reliable, and comprehensive information about different forms of STIs, particularly for those in LGBTIQ+ relationships. This was compounded by shame and stigma when asking for information or accessing healthcare to address concerns about STIs.

Trauma informed health resources

References to experiences of sexual assault were frequent throughout the survey. The prevalence of sexual assault points to a need for trauma-informed health information resources that provide support for survivors. Participants also noted the importance of



beginning CSE earlier in life to help YWGwD and the broader community recognize and prevent sexual assault.

What are the key barriers to accessing information and resources?

Inadequate CSE

It is clear that school-based relationships and sexuality education (where the majority of participants first learnt about menstruation and contraception) is failing to provide CSE relevant to YWGwD. Existing frameworks are failing to provide education on the seven key domains outlined by international guidelines: gender and gender diversity, sexual and reproductive health and HIV, sexual rights and sexual citizenship, pleasure, violence, diversity (including disability) and relationships. Yet as limited as current curriculums are, YWGwD separated from mainstream schooling are missing out on a key access point to SRH education widely available to their peers. WWDA has consistently argued that segregation of students with disabilities into 'special schools' are in contravention of Australian's obligations under the human rights treaties to which it is a party.⁷⁶

In Australia, State and Territory Government education departments approach relationships and sexuality education as a 'shared responsibility' between parents/guardians and the education system. However, there are no mechanisms in place to ensure YWGwD are receiving relevant CSE that is disability- and gender-affirming. All too often relationships and sexuality education are seen as sexual abuse prevention rather than an avenue of empowerment, agency, and independence.

Many participants in the survey reported family members (usually maternal figures) as another primary source of SRH education. Others however, reported difficulty or awkwardness in speaking to parents/guardians about topics relating to their SRH. Previous research has also demonstrated that family members can be active enforcers of restrictive practices against YWGwD and/or uphold ableist belief systems that lead to restricted, delayed, or incomplete access to CSE. They may simply be lacking the relevant tools and knowledge to provide disability specific CSE. These increased barriers present a severe challenge to sexual health access and equity for YWGwD.

Affordability

Difficulties surrounding the affordability of menstrual products were noted by 24% of respondents, highlighting that finances are a significant barrier to accessing SRHR resources for YWGwD. Financial dependence on family members for menstruation and contraception products leaves significant numbers of YWGwD without independent access or the means to use their preferred options.

Due to high rates of chronic pain associated with menstruation, most respondents reported needing medication or other forms of assistance to manage their cycles. Beyond contraceptive devices and menstrual products, these forms of treatment must be considered as part of the on-going financial burden of upholding SRHR for YWGwD.

'Period poverty is a massive problem that needs to be addressed but isn't talked about enough.'

Shame and stigma

A lack of information to normalize menstruation and counteract shame and stigma was noted by many participants. Participants reported difficulties having conversations with family members, health professionals, educators, carers, and other adults in their lives about their SRHR. Shame and stigma surrounding sexuality and disability contributes to systematic oppression of YWGwD that affects their access to information and resources and ability to exercise self-determination. International CSE guidelines highlight the importance of life-long education about SRHR beginning from birth. However, shame and stigma actively prevent YWGwD from accessing information early enough, often under restrictions for 'age-appropriate' material. This has far-reaching consequences and prevents YWGwD from understanding and exercising self-determination over their SRHR.

Accessible information and resources

Equitable access to SRHR information and resources is dependent on the delivery of information and education in accessible formats for YWGwD and their families, support persons, friends, advocates, healthcare professionals, educators, and the broader community. These formats include, but are not limited to, Easy English translations and summaries, subtitles, Australian Sign Language, screen-reader friendly websites and appropriate colour contrast.

The impact of Disability on Sexual and Reproductive Health

Impacts of disabilities and chronic illness on experiences of menstruation

40 participants indicated having a disability or chronic illness that impacted menstruation, with the most common being poly-cystic ovarian syndrome or endometriosis. Significantly, 14 suspected they had a condition that had not been diagnosed, implying barriers to accessing appropriate medical support. While severe or chronic pain was commonly reported, many participants spoke about not knowing when to ask for medical help. This appeared to stem from an overall lack of information about menstruation and what help was available to help them manage their symptoms.

Assistance to manage menstruation and pelvic pain

Due to high rates of chronic pain associated with menstruation, most respondents reported needing medication or other forms of assistance to manage their cycles. The most common were pain medication (71 participants), hormonal contraception (67 participants) and heat packs (48 participants).

A small number reported accessing specialist treatment such as surgery, physio/chiro, endocrinology, or endometriosis specialist treatment.

Natural or alternative methods, such as breathing exercises, massage, traditional plant-based treatments, acupuncture, stretches and electro stimulation machines were also popular. Several participants noted that despite experiencing how effective these methods were, there was little information or assistance available for accessing them.

These forms of treatment are important to consider as part of the on-going financial burden of menstruation for YWGwD. As many participants noted having inadequate information about managing their cycles, it is likely that information about pain relief and the treatments available is lacking and significantly impacting on menstrual health and quality of life.



Significance of contraception for managing disabilities, medical conditions, and chronic pain

While contraception use is most associated with pregnancy prevention, the YWGwD indicated that it is significant for many other health purposes. YWGwD reported using (hormonal) contraception for managing disabilities or medical conditions (16%), managing pain and discomfort (41%) and to manage menstruation or heavy bleeding (48%). However, the benefits of contraception use for these purposes does not appear to be well understood by all YWGwD. For example, some YWGwD who identified as queer did not believe that contraception use was relevant to their personal circumstances, as they were not in need of pregnancy prevention methods. This highlights the overall lack of comprehensive information about contraception use and the various methods available and purposes it can serve for YWGwD.

Hormonal contraception side effects

39 participants indicated not using hormonal contraception because of negative side effects. There is increasing evidence to suggest that both oestrogen and progesterone (active in oral contraceptive pills) influence brain function, which may be responsible for the negative mood changes and depression commonly associated with their use. This can have serious implications for the mental health of YWGwD. However, participants report that concerns about contraception side effects are frequently dismissed by health care providers. Furthermore, several participants reported not receiving adequate information about potential side effects at the point of administration. The phenomenon of negative experiences of oral contraception pills leading to discontinuation demonstrates the severe impacts of not receiving adequate information and not being taken seriously by health professionals. Accessible and comprehensive information, supportive communication and positive rapport with health professionals are elements of care which must be embedded in health care systems for YWGwD to fulfil their SRHR.

Assistance needed to manage menstruation

YWGwD reported needing assistance in several different forms to manage their menstruation. The most common form of assistance needed was financial (21 participants), with assistance using menstrual products (10 participants), accessing medication (9 participants), and managing hygiene (3) also common. Six participants cited that they wanted or needed further support to manage their menstruation.

The Impact of Disability on Sexual and Reproductive Self Determination

Almost 17% of YWGwD surveyed indicated that someone else decided what form of contraception they used. More than 20% of respondents stated that their parents or guardian decided the form of contraception they used. 23% of participants indicated that their doctor decided. Three participants were unaware who made this decision for them.

When asked who decides the types of products, medications, and other assistance to help with period management, 12% of respondents indicated that someone else made this decision for them. Over 35% of these indicated that these decisions were made by parents or guardians, and 25% indicated the decisions were made by their doctor.

The most common response for not using contraception while sexually active was the need to conceal it from parents/family and guardians (16 participants). 10 participants also indicated that they did not use contraception because of a lack of access to health advice, with a further six participants indicating they didn't have support to use it effectively. The impact of cost and financial dependence was a significant factor, with 17% indicating they did not use contraception because it was too expensive.

'Since I still live at home it's hard to go to the doctor discreetly to get a higher dose of birth control for contraception because my parents think I'm on it for period only.'

Numerous responses reported that doctors and other health professionals did not provide comprehensive information or ignored concerns raised by YWGwD about contraception and menstruation. Many indicated feeling uncomfortable discussing sexual and reproductive health concerns with their GPs due to a lack of disability-affirmed care or feeling belittled. Stigma surrounding sexuality was also identified as a barrier to accessing care and asserting self-determination.

'The doctor - treats me like a child and disregards my concerns for what he thinks is best. Won't let me switch contraceptive medication despite mine not fully working.'

'I have found that GPs are uncomfortable talking about the issue with people, especially if they have intellectual or psychosocial disability. Unfortunately, many people that I know reside in supported living services and end up on intervention that ceases their menstruation and they do not end up receiving any information to support them to become independent in this aspect of their lives.'

Evidence of Barriers

The YWGwD surveyed are largely dependent on parents and guardians for financial assistance to afford contraception and menstruation resources, and access to health services (e.g., transportation, assistance with attending appointments, consent for medical procedures). This presents considerable challenges to self-determination where their wishes conflict with opinions held by their parents/guardians. Several participants highlighted the impacts of lack of access to private and confidential healthcare and called for more information regarding independent Medicare records and rights and privacy with GPs. A lack of access to information about their sexual and reproductive health rights and services directly impacts on the ability of YWGwD to exercise self-determination over their menstruation and contraception use.

Opportunities for enabling self-determination include removing financial barriers to accessing contraception and menstruation products, co-designing resources with and for YWGwD to manage and self-determine their SRHR, and peer support programs to empower sexual citizenship and sexual and reproductive rights.

Sexual and Reproductive Violence

Experiences of sexual and reproductive violence were not the focus of the survey questions, however there were numerous reports of violence impacting or relating to experiences of contraception use and menstruation. These reports highlighted the ongoing effects of sexual trauma on mental and physical health and a lack of trauma-informed support and resources to fully empower these YWGwD.

These findings support existing evidence that YWGwD are commonly denied choice and self-determination over their sexual and reproductive lives, with healthcare professionals, family members, guardians and intimate partners making decisions in place of YWGwD. It is critical that the denial of self-determination, whether due to structural or interpersonal factors, is addressed as a serious form of sexual and reproductive violence towards YWGwD.

Conclusion: Moving Towards A Reproductive Justice Framework



Conclusion: Moving Towards A Reproductive Justice Framework

This report has examined the experiences of young women, girls, and gender diverse people with disability in Australia and their access to contraceptive and menstruation resources. In identifying key trends, evidence of barriers and opportunities for YWGwD to exercise greater self-determination over their SRHR, it is apparent that far greater community responses are required than what current healthcare and legislative frameworks currently provide.

This report incorporates an intersectional analysis to highlight how collective identities shape individual experiences of health and rights. However, dominant SRHR frameworks in Australia show a lack of interrogation of how an individual's ability to exercise self-determination in their reproductive life (and beyond) is impacted by power inequities targeting certain communities and collective identities.

For example, a sexual and reproductive rights framework is primarily concerned with protecting individual legal rights to reproductive health care services. This leads to a focus on objectives such as keeping abortion legal, standardizing sex education, and increasing access to family planning services. Yet, a legal right to reproductive services does not mean those services are accessible, equitably distributed, and non-coercive. A sexual and reproductive rights framework sees its primary purpose as the protection of individual choice and rights through legal mechanisms and pursues this through elected officials, the courts and advocacy organisations. It is less capable of evaluating how experiences of race, poverty, disability, and other factors affect an individual's ability to advocate, exercise choice and fulfil their legal rights.

Likewise, a sexual and reproductive health framework tends to conceptualise health outcomes as a consequence of service accessibility, insurance, and individual care provided. This framework therefore sees the primary solution to poor health outcomes as the need to improve and expand access to health services, for example, by building more health infrastructure in rural areas, training more health workers in sexual and reproductive services, providing cultural competency training for health workers, or embedding relationships and sexuality education throughout the curriculum from prep onwards. While these elements are critical, the focus on individuals does not address the root causes of inequity and ableism, nor promote systems change. It does not consider how or by whom those systems are designed and delivered by, and how this affects how they are experienced by certain communities, particularly YWGwD.

It is necessary to consider more holistic frameworks that place gender, disability, and other forms of social justice at their centre. In the United States, the reproductive justice movement has been in operation for decades. In Australia however, a similar framework is yet to be engaged in a model that enables intersectional community leadership.

Defining Sexual and Reproductive Justice

Reproductive justice is a movement and framework for thinking about how experiences of reproduction interact with multiple oppressions of race, class, gender, sexuality, disability, age, and immigration status. The framework emerged with the concept of intersectionality. Led by a small community of African American women, the movement emerged in the mid-1990s to address the dominant reproductive rights/pro-choice paradigm in the United States. This was primarily concerned with protecting an individual's choice and legal rights to access reproductive health services without consideration of broader social barriers. Instead, reproductive justice emphasises how an individual's reproductive agency is affected by intersecting social and identity factors. For example, while the dominant reproductive rights movement focuses primarily on legalising abortion rights, reproductive justice emphasises how legal rights are meaningless to a young disabled person living in poverty who cannot afford to pay for abortion or is unable to travel to receive appropriate care.

This definition makes much broader demands than simply securing legal rights and individual choice. It depends on access to specific, community-based resources including high-quality health care, housing and education, a living wage, a healthy environment, and a safety net for times when these resources fail. It demands that the needs, wishes and experiences of the most marginalised are made central to achieving reproductive justice for the broader community. These demands are also central to disability justice movements, demonstrating the intimate link between reproductive justice and disability justice.

Moving the emphasis away from individual choice and rights, a reproductive justice/human rights framework makes claims on the incarceration system, the immigration system, and the health care system, for example, to block structural and institutional degradations associated with fertility, reproduction, and maternity or parenthood, and to recognize and protect the reproductive health and parenting rights of persons under their purview. This is particularly relevant to people with disability, who are at increased risk of contact and institutional harms in these systems.

As a conclusion to this report, it is put forward that the reproductive justice framework and the work of community organisations such as SisterSong Women of Colour Justice Collective⁷⁷ provide a crucial insight into how all people with disabilities can think about, organise for, and realise full personhood in harmony with their reproductive capacity. The results of this survey demonstrate that YWGwD need to be front and centre in redefining reproductive justice in the Australian context.

Endnotes



Endnotes

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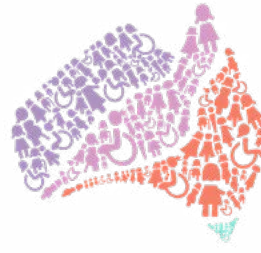
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Women
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Women With Disabilities Australia (WWDA) has Special Consultative Status with the Economic and Social Council of the United Nations.

Awards

Winner
National Human Rights Award 2001

Winner
National Violence Prevention Award 1999

Winner
Tasmanian Women's Safety Award 2008

Nominee
UNESCO Prize for Digital Empowerment of Persons with Disabilities 2021

Nominee
French Republic's Human Rights Prize 2003

Nominee
UN Millennium Peace Prize for Women 2000

Certificate of Merit
Australian Crime & Violence Prevention Awards 2008

Nominee
National Disability Awards 2017