

Sexual and Reproductive Health Monitoring Framework and Data Strategy

Submission to the Australian Institute of Health
and Welfare

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Overview

Disclaimer

The Australian Institute of Health and Welfare (AIHW) conducted a public consultation on its draft Sexual and Reproductive Health Monitoring Framework and Data Strategy. Submissions were collected through an online form with a set of specific questions. This document presents those consultation questions, with the Commission's responses appearing in the boxes below.

Submission

Section 1: Monitoring framework

The AIHW is seeking feedback from stakeholders about the extent to which the monitoring framework:

- is framed around the right questions
- contains conceptual relationships and layers that make sense
- has domains and subdomains that capture the important issues, and
- captures the key SRH areas that need to be monitored in Australia.

1. Please rate your level of agreement with the following statement.

"The monitoring framework (pages 22–27) captures the domains and relationships that are important for sexual and reproductive health in Australia."

Please select one option:

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

Please add any additional comments to explain your rating (optional):

The framework includes relevant domains such as agency, autonomy, and safety, which are critical to monitoring sexual and reproductive health outcomes. The framework also identifies 'people with disability' as a priority population.

However, the framework fails to expressly capture important and often overlooked domains that frequently impact people with disability, particularly women and girls with disability. This includes involuntary sterilisation, reproductive coercion such as forced contraception, and discrimination in

parenting. These gaps limit the framework's ability to monitor implementation of Australia's human rights obligations and reflect the sexual and reproductive health experiences of people with disability.

2. How well does the draft monitoring framework address your SRH data questions/needs? What are its strengths and/or limitations? Please explain your response.

The inclusion of domains such as 'agency', 'autonomy', and 'safety' in the draft framework aligns with human rights principles. However, the framework does not adequately address the needs of people with disability, particularly in relation to monitoring the diminishment and violations of rights experienced by people with disability in the sexual and reproductive health system. These are systemic, ongoing, and largely invisible in current data systems.

The Australian Human Rights Commission (the Commission) highlights several critical gaps:

(1) Women and girls with disability experience multiple and intersecting forms of discrimination that significantly impact their sexual and reproductive health outcomes. International human rights treaties require governments to take targeted action to eliminate this discrimination and ensure equal access to health care, including sexual and reproductive health. Article 6 of the *Convention on the Rights of Persons with Disabilities* (CRPD)¹ recognises that women and girls with disability face heightened risks of exclusion and rights violations. CRPD Articles 17, 23 and 25² specifically affirm the rights of people with disability to bodily autonomy, respect for family, and health. The *Convention on the Elimination of All Forms of Discrimination Against Women* (CEDAW)³ Articles 3 and 12 affirm the rights of women to health and bodily autonomy. The *International Covenant on Civil and Political Rights*⁴ (ICCPR) and the *International Covenant on Economic, Social and Cultural Rights*⁵ (ICESCR), affirm the rights to bodily autonomy, freedom from violence, and respect for home and family.

The Commission recommends including 'women and girls with disability' as a priority population in the SRH Monitoring Framework to ensure their experiences are visible in the national data systems, to support policy responses that uphold their rights and align Australia's monitoring framework with its international obligations.

(2) Involuntary sterilisation is a serious human rights violation, that disproportionately affects women and girls with intellectual, cognitive and psychosocial disability in Australia. It remains a permitted and ongoing practice despite the recommendation from the Disability Royal Commission

and advocacy from civil society⁶, and several recommendations from multiple UN treaty bodies and the Human Rights Council⁷ calling for its prohibition through uniform legislation. Given its severity, this practice should expressly be captured in the SRH framework. Including involuntary sterilisation as a national indicator under the 'agency' and 'autonomy' domains is essential to uphold Australia's obligations under the CRPD, including Article 31⁸, and to track implementation of Recommendation 6.41 of the Disability Royal Commission⁹.

(3) Reproductive coercion and abuse include denial or forced use of contraception, or pressure to terminate or continue pregnancies. This form of gender-based violence is recognised in the *National Plan to End Violence Against Women and Children 2022–2032*¹⁰. The framework currently lacks indicators to monitor these experiences, which are especially prevalent among women with disability and must be addressed to ensure inclusive and trauma-informed SRH policy.

(4) Discrimination in parenting and family planning is an area where people with disability face systemic exclusion. The framework should include indicators that track discrimination in access to reproductive technologies, child removal practices, and the availability of culturally safe parenting support programs. These indicators are necessary to uphold the rights to family life and reproductive autonomy¹¹.

(5) Supported decision-making and informed consent are foundational to the exercise of legal capacity and autonomy. Under Article 12 of the CRPD¹², people with disability have the right to equal recognition before the law and must be supported to exercise their legal capacity in all areas of life, including sexual and reproductive health. Further to this, Article 15 of the CEDAW¹³ supports the principle of equal legal capacity for women. Legal capacity means having the right to make decisions and have those decisions respected, but legal capacity is often denied through substitute decision-making mechanisms such as guardianship, Mental Health Tribunals and courts¹⁴. The draft framework seeks to measure how social determinants of health and other social structures influence access, effectiveness, and outcomes related to SRH. For people with disability, the social context is defined by systems that lawfully permit restrictions on the exercise of legal capacity. The framework should therefore monitor how decisions regarding sexual and reproductive health are made, including whether they were made autonomously, with support, or through substitute decision-making, and how consent was provided in each case.

In summary, while the framework has strong conceptual foundations, it must be strengthened to reflect the rights, needs and experiences of people with

disability. Without these additions, the framework risks reinforcing exclusion and failing to identify where rights are not being upheld.

3. How easy was it to understand the draft monitoring framework? Which parts were easy/hard to understand and why?

The framework is generally easy to understand and well-structured. The use of domains and subdomains helps clarify the conceptual relationships. However, the absence of explicit references to disability-related issues makes it harder to assess how the framework will contribute to the protection, promotion and fulfilment of rights. For example, while the 'agency' and 'autonomy' domains are relevant, they do not clearly address specific practices or indicate the type of data that might be collected.

Including examples or indicators that reflect the experiences of people with disability would improve clarity and ensure the framework is accessible and relevant to a broader range of stakeholders.

Section 2: Data strategy

The AIHW is seeking feedback about the extent to which the data strategy:

- includes the critical data gaps for each of the priority areas
- presents correct and up-to-date information regarding data collections
- captures all suitable key data sources
- suggests areas for future data development that are logical and well-founded.

4. Please rate your level of agreement with the following statement.

"The data strategy (Pages 28–38 and Appendices D-H, Sections D.2, E.2, F.2, G.2, H.2) describes current and/or future priorities for data development that are important for the 5 initial priority topics."

Please select one option:

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

Please add any additional comments to explain your rating (optional):

The data strategy outlines important areas for development across the five initial priority topics. However, it does not sufficiently address the data needs of people with disability, particularly women and girls. This is especially pronounced for First Nations women and girls with disability, whose experiences are often absent from national datasets. Despite evidence from the Disability Royal Commission¹⁵ and civil society submissions¹⁶ documenting reproductive coercion, involuntary sterilization and discrimination in parenting, there is limited data on these issues. First Nations women and girls with disability face compounded disadvantage due to the systemic impacts of systemic racism and ableism¹⁷. This includes higher rates of child removal practices shaped by a long history of discriminatory policies, which continue to influence how First Nations women and girls are perceived and treated in relation to their parenting¹⁸.

The strategy should include mechanisms that capture data on involuntary sterilisation, reproductive coercion, and discrimination in parenting, and collect disaggregated data that reflects the intersecting, lived experiences of marginalised groups.

5. The priority topics identified and outlined for the first stage of the data strategy are:

1. menstrual disorders, symptoms and related conditions (including endometriosis)
2. contraception
3. pregnancy loss before 20 weeks' gestation (including miscarriage)
4. termination of pregnancy, also known as abortion
5. perimenopause and menopause.

These initial priority topics represent a starting point for the data strategy and reporting, with the intention to expand them over time to include other important areas of SRH.

a. Do you have any comments in relation to data sources and/or data collection described in the data strategy, for any of these 5 priority topics?

The Commission welcomes the inclusion of topics such as contraception and termination of pregnancy, which are highly relevant to the rights of people with disability. However, the data sources referenced in the strategy do not

currently capture whether these services are accessed voluntarily, with informed consent, or with appropriate decision-making support.

For example, there is no national dataset that disaggregates sterilisation procedures by consent status, disability type, age, gender, or cultural background. This gap has been identified by both the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability¹⁹ and Women With Disabilities Australia²⁰. Critically, the absence of disaggregated data obscures the experiences of First Nations women and girls with disability, who face intersecting forms of discrimination and are at heightened risk of reproductive rights violations due to the legacy of colonisation and child removal²¹. Without this data, it is impossible to monitor rights violations or ensure accountability.

The Commission recommends that all five priority topics include indicators that reflect the experiences of people with disability, including whether services are inclusive, rights-based, and delivered with appropriate safeguards.

b. What are your recommendations for future or additional priority areas of focus?

The Commission recommends the following additional priority areas for future data development:

- (1) Women and girls with disability: include as a priority population.
- (2) Involuntary sterilisation: include as a standalone priority area under the 'agency' and 'autonomy' domains.
- (3) Reproductive coercion and abuse: monitor practices that might include denial of or forced contraception, pressure to terminate or continue pregnancies, and lack of access to reproductive health services.
- (4) Discrimination in parenting and family planning: such as child removal practices, access to reproductive technologies, and availability of culturally safe parenting support programs. These issues are compounded for First Nations women and girls with disability, who face intersecting pressures that often result in heightened scrutiny of their parenting and reduced autonomy in reproductive decision-making.
- (5) Supported decision-making and informed consent: observe service-level safeguards, including access to support agreements, use of supporters, and provider training. Include specific monitors of how these supports are accessed and experienced by culturally and linguistically diverse communities, including First Nations woman and girls with disability, who may face

additional barriers due to systemic discrimination, language and cultural safety concerns.

These additions would align the data strategy with Australia's obligations under the CRPD (Articles 6, 12, 17, 23, 25 and 31)²², CEDAW (Articles 3, 12, and 15)²³, and the ICCPR²⁴ and ICESCR²⁵.

6. Were there any aspects of the data strategy that you did not understand or require further clarification?

Yes - Which sections of the data strategy were hard to understand or require further clarification? How could these aspects be improved?

No - Which aspects of the data strategy were clear and easy to understand? Please elaborate on what worked well.

The structure and presentation of the data strategy are clear and well-organised. To support transparency and accessibility, it is important future reporting outputs are available in accessible formats that are easy to understand and navigate. This may include, easy read versions, Auslan-interpreted videos, and translated materials for culturally and linguistically diverse communities.

Section 3: Overarching areas

7. Are the overall goals of the draft framework and data strategy clear? (Please indicate which goals were clear and which require further clarification.)

Yes, the overall goals are clearly stated and well-structured. The framework's central question, "How timely, accessible and high-quality is sexual and reproductive health care for all in Australia?", is supported by a person-centred, life course approach and a socio-ecological model that considers individual, service-level and structural factors.

However, the goals could be strengthened by more explicitly referencing how the framework will monitor rights-based outcomes for priority populations, including people with disability. While equity is a guiding principle, the framework would benefit from clearer articulation of how it will track experiences of discrimination, including intersectional discrimination, coercion, and exclusion, particularly in relation to informed consent, reproductive autonomy, and parenting rights.

8. Is the terminology used in the report appropriate? Please provide details and suggest alternative terminology where required.

Generally, the terminology is appropriate and reflects current public health and policy language. The glossary (Appendix L) is comprehensive and helpful. However, the following improvements are recommended to better align the framework with international human rights standards:

- Replace 'vulnerable groups' with 'priority populations' consistently, as already used in Section 2.5.
- Clarify the use of 'agency' and 'autonomy' in the framework by linking these terms to legal capacity and supported decision-making, especially for people with disability.
- Use 'informed consent' and 'supported decision-making' more explicitly when referring to service-level safeguards (e.g. under the 'Services' level in Figure 3.4).

9. Do you have any suggestions around the governance of this work as it progresses? Please provide any suggestions on advisory committees, ongoing stakeholder engagement, consent processes (e.g. from jurisdictions and private entities) and return of information processes (see pages 39-40).

The AIHW's current and proposed governance arrangements (Section 5.1) are a strong foundation. For future governance (Section 5.2), the Commission recommends:

- Establishing an inclusive advisory committee with representation from people with disability through their representative organisations, including women with disability and First Nations .
- Embedding co-design principles throughout implementation, consistent with the National Disability Research Partnership's guidance on embedding lived experience.
- Ensuring transparent consent processes for data sharing across jurisdictions and private entities, aligned with the Five Safes framework²⁶ and CRPD Article 31²⁷.

Developing mechanisms for returning information to communities, including accessible formats and feedback loops.

10. How can the AIHW ensure ongoing stakeholder engagement, use and uptake of the SRH monitoring framework and future reporting?

To support ongoing engagement and uptake, AIHW should take these actions to ensure the framework remains relevant, inclusive, and widely used:

- Actively collaborate with the National Disability Research Partnership to ensure co-design and lived experience informs both the design and ongoing evaluation of data collection and reporting.
- Establish a standing stakeholder reference group that includes people with disability through their representative organisations.
- Provide regular updates and consultations, including accessible formats and culturally safe engagement practices.
- Develop training and guidance materials for service providers and data custodians on inclusive data practices.
- Ensure that reporting outputs are accessible, including Easy Read formats, visual summaries, and tailored content for different stakeholder groups (as outlined in Table 2.3).

11. Do you have any other feedback on the draft SRH monitoring framework and data strategy?

N/A

References

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- ² United Nations (2006). *Convention on the Rights of Persons with Disabilities – Article 17: Protecting the integrity of the person; Article 23: Respect for home and the family and Article 25: Health*.
- ³ United Nations (1979). *Convention on the Elimination of All Forms of Discrimination Against Women – Articles 3 and 12*.
- ⁴ United Nations General Assembly (1966). *International Covenant on Civil and Political Rights*.
- ⁵ United Nations General Assembly (1966). *International Covenant on Economic, Social and Cultural Rights*.
- ⁶ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). *Final Report – Volume 6: Enabling autonomy and access*, (Recommendation 6.41, pp. 37); Australian Lawyers for Human Rights (2018). *Australian women and girls with disabilities still face forced sterilisation and abortions*; Women With Disabilities Australia (2013). *Dehumanised: The Forced Sterilisation of Women and Girls with Disabilities in Australia*.
- ⁷ United Nations Committee on the Elimination of Discrimination against Women (2018). *Concluding observations on the eighth periodic report of Australia* (pp. 6-7); United Nations Committee on the Rights of the Child (2019). *Concluding observations on the combined fifth and sixth periodic reports of Australia* (pp. 7-8); United Nations Committee on the Rights of Persons with Disabilities (2019). *Concluding observations on the combined second and third periodic reports of Australia* (pp. 9); United Nations Human Rights Council (2021). *Report of the Working Group on the Universal Periodic Review* (pp. 21).
- ⁸ United Nations (2006). *Convention on the Rights of Persons with Disabilities – Article 31: Statistics and data collection*.
- ⁹ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). *Final Report – Volume 6: Enabling autonomy and access* (Recommendation 6.41, pp. 37).
- ¹⁰ Australian Government. (2022). *National Plan to End Violence against Women and Children 2022–2032*.
- ¹¹ United Nations. (1979). *Convention on the Elimination of All Forms of Discrimination Against Women – Articles 3 and 12*.
- ¹² United Nations. (2006). *Convention on the Rights of Persons with Disabilities – Article 12: Equal recognition before the law*.
- ¹³ United Nations. (1979). *Convention on the Elimination of All Forms of Discrimination Against Women – Article 15*.
- ¹⁴ The Organisation for Economic Co-operation and Development (2021). *OECD Framework and Good Practice Principles for People-Centred Justice*.
- ¹⁵ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). *Final Report – Volume 6: Enabling autonomy and access*.

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- ¹⁶ Women With Disabilities Australia (2013). *Dehumanised: The Forced Sterilisation of Women and Girls with Disabilities in Australia*; Office of the Public Advocate: Victoria (2022). *Submission to the DRC: Parents and children with disability*.
- ¹⁷ Women With Disabilities Australia (2024). *Redressing reproductive violence against women with disability: A briefing paper*; Law Society Journal (2022). *State-sanctioned torture: Women with disability continue to suffer forced sterilisation*; MSI Australia (2022). *Apology for forced medical procedures linked to colonisation and racism in Australia*.
- ¹⁸ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). *Final Report – Volume 9: First Nations people with disability*.
- ¹⁹ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). *Final Report – Volume 6: Enabling autonomy and access*.
- ²⁰ Women With Disabilities Australia (2013). *Dehumanised: The Forced Sterilisation of Women and Girls with Disabilities in Australia*.
- ²¹ Law Society Journal (2022). *State-sanctioned torture: Women with disability continue to suffer forced sterilisation*; MSI Australia (2022). *Apology for forced medical procedures linked to colonisation and racism in Australia*.
- ²² United Nations (2006). *Convention on the Rights of Persons with Disabilities*.
- ²³ United Nations (1979). *Convention on the Elimination of All Forms of Discrimination Against Women*.
- ²⁴ United Nations General Assembly (1966). *International Covenant on Civil and Political Rights*.
- ²⁵ United Nations General Assembly (1966). *International Covenant on Economic, Social and Cultural Rights*.
- ²⁶ Australian Institute of Health and Welfare. (n.d.). *The Five Safes framework*. Australian Government.
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