2025

THE DATUM INITIATIVE

EMPOWERING COMMUNITIES THROUGH DATA

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asian-pacific resource & research centre for women

MONITORING THE SDGS AT 10 YEARS

SEXUAL AND REPRODUCTIVE HEALTH AND THE LIVED EXPERIENCES OF WOMEN AND INDIVIDUALS ASSIGNED FEMALE AT BIRTH WITH DISABILITIES IN MALAYSIA

Monitoring the SDGS at 10 Years:
Sexual and Reproductive Health and the Lived Experiences of Women and Individuals Assigned Female at Birth with Disabilities in Malaysia

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About DATUM Initiative
The Datum Initiative is a Malaysia-based non-profit research organisation committed to addressing structural inequities through ethical, participatory, and data-driven inquiry. We work alongside communities too often rendered invisible, including stateless persons, persons with disabilities, indigenous women, and gender-diverse individuals, to build data competencies, influence policy inclusion, and amplify marginalised voices.

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About ARROW
Asian-Pacific Resource and Research Centre for Women (ARROW) is a regional, feminist, global-south non-profit organisation based in Malaysia with a consultative status with the Economic and Social Council of the United Nations. ARROW works towards an equal, just and equitable world that enables all women and young people to be equal citizens in all aspects of their lives, and that protects and advances their sexual and reproductive health and rights. For more details: https://arrow.org.my/.

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Glossary

ABLE-BODIED. A term meant to represent people who do not have any disabilities. It is ableist in nature as it discriminates against anyone with disabilities. Some community advocates prefer either nondisabled or pre-disabled.

ABLEIST/M. Analogous to racism, but directed at Persons with Disabilities and a driver of discrimination on the basis of disability.

ADHD. Attention Deficit and Hyperactivity Disorder. A neurological learning disability that affects an individual's ability to concentrate on a single or multiple tasks.

AUTISM/AUTISM SPECTRUM DISORDER (ASD). A neurological condition that may affect an individual's social, sensory, and behavioural abilities.

BIM. Bahasa Isyarat Malaysia or Malaysian Sign Language is the language that is used by deaf Malaysians. It is distinct as its own language and with nuances that differ greatly from Bahasa Malaysia and English. A person who is fluent in BIM may not necessarily be fluent in Bahasa Malaysia or English.

CEDAW. Convention on the Elimination of All Forms of Discrimination Against Women. A UN convention that defines all forms of discrimination that women face and the steps needed to be taken by society to eliminate them.

CRPD. Convention on the Rights of Persons with Disabilities. A UN convention that defines the basic rights that persons with disabilities should be given in any society.

CSO/NGO. CIVIL SOCIETY ORGANISATION/NON-GOVERNMENTAL ORGANISATION. An organisation that is not part of the government that seeks to support and fight for social causes. The support can come in the form of raising public awareness, engaging with communities, or influencing policymakers on issues.

HEALTH WHITE PAPER. A policy recommendation paper that was produced by the Malaysian Ministry of Health in 2023 that underlines structural gaps and issues in the Malaysian healthcare system and suggestions to overcome them.

OKU REGISTERED. A Person with Disability who has registered their status with the government. Registration provides an official recognition that grants certain benefits, but it also requires disclosure of the disability to employers and insurance providers. As Malaysia does not have a comprehensive anti-discrimination policy protecting Persons with Disabilities, employers may refuse to hire, and insurance companies may deny coverage on the basis of disability. For this reason, some Persons with Disabilities may choose not to register if the benefits do not outweigh the potential costs.

PERSON WITH DISABILITY (PWD)/*ORANG KURANG UPAYA (OKU).* As defined by the CRPD and recognised under the PWD Act: "Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others." Disabilities may be physical, sensory, learning-related, or psychosocial in nature.

SDG. Sustainable Development Goals are a major policy by the UN that highlights important indicators that each country must strive to meet in order to create a sustainable, equitable and just society.

SRHR. Sexual Reproductive and Healthcare Rights. The legal rights that someone has over their sexual reproductive organs and its related healthcare.

TOKENISM. When a person is selected for a position purely to fill a needed quota instead of their actual qualifications and competency for the position.

1. Executive Summary

This report investigates the structural, legal, and lived realities surrounding the sexual and reproductive health and rights (SRHR) of disabled women and individuals assigned female at birth in Malaysia. Despite the government's ratification of key international conventions, domestic implementation of these commitments remains fragmented, inconsistent, and in many cases, largely performative. This includes the Convention on the Rights of Persons with Disabilities (CRPD)[1] and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).[2]

Drawing on both legal analysis and in-depth qualitative interviews, this report identifies significant gaps across Malaysia's healthcare, education, and legal systems that continue to marginalise disabled women and individuals assigned female at birth. Although the legislative framework acknowledges the social model of disability in principle,[3] its application is weakened by:

- outdated and ableist language (e.g., "deaf and dumb" still used in medical documentation);
- lack of implementation or enforcement mechanisms;
- inconsistent inter-agency coordination;
- and an overarching paternalistic approach that undermines the autonomy and agency of Persons with Disabilities (*Orang Kurang Upaya*, or OKU in Malay).

Key laws such as the Persons with Disabilities Act 2008 (PWDA)[4] and provisions within the Federal Constitution do not adequately guarantee full and equal participation of Persons with Disabilities in civic life, education, employment, or healthcare access. Thus, the empirical foundation of this report is based on interviews with seven individuals (disabled women and individuals assigned female at birth) across different regions in Malaysia.

Their accounts reflect distressingly consistent themes:

- limited or no access to early SRHR education;
- condescension, neglect, and ableist assumptions by healthcare professionals;
- marginalisation in the workplace, particularly for those with invisible disabilities;
- social stigma attached to *Orang Kurang Upaya* (OKU) registration, and its perceived link to state surveillance or diminished dignity.

Despite these challenges, participants also shared powerful moments of resistance, innovation, and community-building. Digital technologies (such as screen readers, messaging platforms, and online disability forums) emerged as crucial tools of survival and empowerment. Through virtual communities, participants were able to access information on SRHR, connect with peers, and navigate state institutions with greater confidence. These platforms, often taken for granted by nondisabled persons, proved to be life-changing in providing affirmation, knowledge, and a sense of belonging. Key findings from the report include:

- The absence of reliable, accessible SRHR information tailored to disabled women and individuals assigned female at birth, particularly those with sensory, learning, or psychosocial disabilities (the term "mental" is used in the Malaysian categorisation of Persons With Disabilities).
- A healthcarauthe system that routinely fails to provide inclusive communication methods or accommodate the access needs of disabled patients.
- Structural barriers to employment, compounded by tokenistic inclusion practices and lack of reasonable accommodations in the workplace.
- A lack of meaningful access to redress or justice, even when legal frameworks appear to offer protections.
- The crucial role of digital access in building disability solidarity and improving SRHR literacy.

To address these challenges, the research team has proposed the following recommendations:

1. **Policy and Legal Reform**
- Remove discriminatory language from all legal and institutional documentation.
- Enact and implement a Mental Capacity Act grounded in Article 12 of the CRPD to ensure equal access to consent, particularly in healthcare and legal decision-making.
- Amend the Persons with Disabilities Act 2008
- Bridge the policy gap between outdated and forthcoming national disability and health plans, ensuring transparency in delays and implementation.

2. **Disability-Inclusive SRHR Education**
- Collaborate with community leaders and NGOs to deliver culturally sensitive, accessible, and age-appropriate SRHR education.
- Expand the availability of inclusive educational materials across digital and physical platforms.

3. **Healthcare System Transformation**
- Introduce and enforce universal accessibility protocols in all health facilities.
- Include disabled women and individuals assigned female at birth in the design and monitoring of SRHR services.
- Establish participatory accountability mechanisms to gather regular feedback from the disabled community.

4. **Capacity Building for Frontline Workers**
- Provide mandatory training for healthcare providers, social workers, and educators on inclusive communication, SRHR rights, and disability sensitivity.

5. **Inclusive Governance and Oversight**
- Involve disabled women and individuals assigned female at birth, alongside representative organisations, in the co-design of national policies.
- Audit and publish the outcomes of the *Pelan Tindakan OKU 2016–2022*[5] and submit results to parliamentary oversight.

This report does not merely document systemic failure; it also captures the **powerful resilience, resistance, and expertise of disabled women and individuals** assigned female at birth in Malaysia.

Their demands go beyond physical access; they call for **structural transformation, meaningful recognition, and full participation in society**. Without urgent, cross-sectoral reform, Malaysia risks continuing a cycle of exclusion that undermines its international commitments and, more importantly, the **rights and dignity of its own citizens**.

2. Introduction

Bridging the gap between grassroots realities and policy agendas remains a critical challenge in Malaysia, particularly for women and girls with disabilities. This report responds to that gap by documenting their experiences and translating them into evidence that can inform policy and public discourse.

2.1 PURPOSE OF THE REPORT

This report emerges from a collaborative research effort between the **Datum Initiative** and the **Asian-Pacific Resource and Research Centre for Women (ARROW)**, focusing on the lived experiences of women and girls with disabilities in Malaysia. It seeks to document and analyse the structural, social, and institutional barriers they face, particularly around sexual and reproductive health and rights (SRHR), healthcare access, education, and social stigma.

The report serves two primary audiences:

- **Policymakers**, aimed at improving policy responses and legislative frameworks; and
- **Civil society and the wider public**, through advocacy and outreach efforts that centre the voices of disabled women and amplify their concerns.

Crucially, this report is not only about disabled women, rather it is with and for them. Their insights and lived experiences are foundational to the analysis presented here. This report will be returned to them, in accessible formats, as part of our commitment to knowledge-sharing and participatory research.

2.2 CONTEXT: DISABILITY, GENDER, AND SRHR IN MALAYSIA

Disabled women in Malaysia occupy one of the most marginalised intersections of society, often excluded from both gender equality agendas and disability policy frameworks. Access to sexual and reproductive healthcare, autonomy in decision-making, and inclusion in leadership and advocacy remain limited. These challenges are magnified for women in rural and underserved areas, where public services are scarce, awareness is low, and stigma runs deep.

Despite progress on paper, many of Malaysia's policies remain ill-equipped to address the everyday realities of disabled women. Key indicators tied to the **Sustainable Development Goals (SDGs)—including access to reproductive health services (SDG 3.7), universal health coverage (SDG 3.8), and equality in public life (SDG 5.1, 5.4, 5.5, 5.6)**—reveal persistent gaps. This report aims to ground these indicators in actual community data and lived narratives.

2.3 RATIONALE AND RELEVANCE TO THE 10TH ANNIVERSARY OF THE SDGS

2025 marks the 10th anniversary of the SDGs, a critical midpoint in assessing global progress. Yet for many marginalised communities—including disabled women in Malaysia—this milestone is a sobering reminder of how far we still have to go.

By focusing on specific SDG targets related to health, gender equality, and inclusion, this report offers a grounded, community-based lens for assessing progress. It centres the following SDG targets and indicators:

- **SDG 3.7 & 3.8:** Access to SRHR services and essential health coverage
- **SDG 5.1, 5.4, 5.5, 5.6:** Gender equality, unpaid care recognition, leadership participation, and reproductive rights

The **Datum Initiative** envisions this work not as a standalone product, but as part of a longer-term project to build data capacity within CSOs, decentralise data ownership, and ensure that knowledge production includes (and is led by) the communities most affected by exclusion. This report is one step in that process.

3. Grounded Methods and Inclusive Study Design

3.1 HOW TO READ THIS REPORT

This report emerges from a research process shaped by significant structural and institutional limitations. Despite close collaboration with disability advocates and community-based actors, the research team encountered considerable difficulty accessing comprehensive, current, and disaggregated data on the status of Persons with Disabilities in Malaysia, particularly women and girls. Official datasets intended to reflect the reach of policies or track disability-related indicators were frequently incomplete, outdated, or simply unavailable. Many governmental initiatives claimed to be "in progress" or "soon to be launched," but had not materialised at the time of writing. Other materials, including rigorous documentation by advocacy groups and civil society organisations, remain under embargo or in bureaucratic limbo, pending ministerial approval or political will.

As a result, this report should be read with an understanding that what we, the research team, present as the "official landscape" (the legislative frameworks, policy initiatives, and institutional mechanisms relating to SRHR and disability) constitutes, at best, a fragmented map. These frameworks reflect governmental intentions more than outcomes. They reveal a discursive architecture of inclusion and protection that, in practice, often fails to translate into lived realities for Persons with Disabilities in Malaysia.

In contrast, the testimonies and narratives we collected through in-depth interviews offer a raw and unfiltered look into the everyday experiences of women and girls with disabilities. With only seven participants, the depth and emotional weight of the insights shared were striking; each narrating different, yet overlapping, forms of marginalisation, neglect, and trauma. These are not isolated cases. Rather, they illuminate how policy gaps, inaccessible systems, and deep-rooted societal biases converge to shape the lived realities of disabled women across urban and rural settings.

We have structured the findings thematically, focusing on key domains where barriers to access, care, participation, and recognition were most visible. These themes emerge not only from participants' engagements with the state (such as healthcare or employment) but also through their interactions with broader social, familial, and digital landscapes. Each section centres the voices of the participants through anonymised pseudonyms, foregrounding their subjectivities as knowledge producers, not just respondents.

We advise readers to approach the following sections with care. The material includes difficult truths and lived accounts of discrimination, medical neglect, and institutional abandonment. These are not presented to shock but to confront the silence that often surrounds disabled lives in Malaysia. This report refuses sanitisation or erasure. Instead, it seeks to bear witness; written responsibly, ethically, and with deep respect for those who shared their stories. Their courage demands an equally courageous engagement with the uncomfortable, and often painful, realities they endure. We consider this an essential and irreplaceable contribution to the national conversation on disability rights, gender justice, and inclusive development.

3.2 METHODS AND APPROACH

This study adopts a grassroots-focused, participatory approach to data collection in collaboration with civil society organisations (CSOs) that work closely with women and girls with disabilities across Malaysia. The aim is to foreground lived experiences and community-led perspectives on sexual and reproductive health and rights (SRHR), access to care, and broader gender justice concerns.

3.2.1 DATA SOURCES

Two primary sources of data were utilised for this pilot study:

1. Desk Review

A targeted review of government policy documents, shadow reports, civil society statements, and existing literature on disability and SRHR in Malaysia. This included reports aligned with Sustainable Development Goal (SDG) indicators related to health, gender, and inclusion.

2. In-Depth Interviews

Seven semi-structured interviews were conducted with women and girls with a range of physical, sensory, and psychosocial disabilities. The interviews were designed to capture both structural barriers and everyday lived experiences, and participants were selected to reflect diversity in disability type, ethnicity, age, and geography.

3.2.2 RESEARCH TEAM

- **Dr. Vilashini Somiah (University of Malaya) and Dr. Benjamin YH Loh (Monash University Malaysia)**, are co-founders of the Datum Initiative and co-led the research as social scientists trained in qualitative methods. They were responsible for research design, instrument development, data analysis, and final synthesis of findings.
- **Hasbeemasputra Abu Bakar**, Community Engagement & Lived Experience Advocate with *Rangkaian Solidariti Demokratik Pesakit Mental* (SIUMAN), contributed his expertise as a lived experience advocate and disability rights organiser. Neurodivergent and living with bipolar disorder and profound hearing loss, Hasbee helped co-develop the interview tools to ensure disability-inclusive language and approaches, and assisted in identifying suitable respondents.
- **Dr. Nadirah Babji**, a public health professional with experience in reproductive and humanitarian health, supported the fieldwork phase. Her role included conducting interviews, ensuring alignment with gender-sensitive and health equity standards, and contributing to the transcription and thematic framing of the data.

3.2.3 RESEARCH QUESTIONS

The study was guided by three core research questions:

1. Policy and Access:

How do current health and social protection policies in Malaysia address the SRHR, unpaid care work, and overall well-being of women and girls with disabilities? Where are the most urgent gaps in access, equity, and participation?

> *Aligned with SDGs 3.7, 3.8, 5.4, 5.6*

2. Lived Experience and Visibility:

How do the lived experiences of disabled women and girls reflect broader policy realities and social attitudes? How do public narratives and CSO efforts shape their visibility, value, and participation in both paid and unpaid spheres?

> *Aligned with SDGs 3.7, 3.8, 5.1, 5.4, 5.5, 5.6*

3. Participatory Knowledge Production:

How can inclusive, community-based research be designed to empower disabled women and girls as co-creators of knowledge and policy influence, particularly in the realms of health, gender justice, and bodily autonomy?

> *Aligned with SDGs 5.1, 5.5, 5.6*

3.3 PARTICIPANTS OVERVIEW

Participants were selected through purposive sampling with the intent to reflect a range of disabilities and social backgrounds. Though originally aiming for broader national coverage, the short data collection window (two weeks) and logistical constraints meant most participants sampled \based on contacts among the research team and further snowballed. The team recruited participants from across Malaysia including the Klang Valley, Sabah, Sarawak, Johor, and Pahang to ensure some regional representation. Participants included both individuals registered as Persons with Disabilities with the Welfare Department of Malaysia and those not formally documented.

TABLE 1: DEMOGRAPHIC PROFILE OF PARTICIPANTS INTERVIEWED FOR THIS STUDY, INCLUDING AGE, LOCATION, GENDER, AND TYPE OF DISABILITY

PARTICIPANT NAME AND AGE				
Ethnicity/Religion	**Gender Identity**	**Disability Type**	**Registered Disability**	**Location**
PAUZIAH (Age: 50s)				
Malay/Muslim	Ciswoman	Deaf	Yes	Klang Valley
MEI (Age: 40s)				
Chinese/Christian	Ciswoman	Physical	Yes	Sarawak
AYU (Age: 20s)				
Malay/Muslim	Ciswoman	Learning	No (diagnosed)	Klang Valley
IMAN (Age: 20s)				
Malay/Muslim	Agender/Transmasc	Multiple (Physical, Learning, Psychosocial)	Yes (Only Learning Disability)	Johor
LAKSHMI (Age: 50s)				
Indian/Hindu	Ciswoman	Blind	Yes	Klang Valley
FARAH (Age: 40s)				
Malay/Muslim	Ciswoman	Deaf	Yes	Pahang
MARY (Age: 40s)				
Kadazan/Christian	Ciswoman	Deaf	Yes	Sabah

The interview instrument was adapted for inclusivity, flexibility, and cultural nuance, with efforts made to respect language diversity, accommodate different communication needs (including sign language and text-based tools), and avoid condescending or infantilising language often encountered in disability research. Throughout, the team remained critically aware of how normative assumptions (such as able-bodiedness as a default) shape both research and public policy. Instead, this study centres disabled people as epistemic agents and challenges prevailing narratives of what constitutes "normal."

All interviews were conducted using online meetings using either Google Meet or Zoom. This allowed for each interview to be recorded and transcribed. Participants were asked to read and sign a consent form before the recording began. All interviews were conducted in English, Malay or Malaysian Sign Language with the aid of a Sign Language interpreter who would join in the call. The transcripts were then anonymised and the recordings destroyed to protect the identities of the participants. Each participant was provided with financial reimbursement for their participation.

3.4. LIMITATIONS AND REFLEXIVITY

This pilot study was conducted within a tight timeframe of just two weeks, which posed several challenges. The short duration required interviews to be scheduled and completed quickly. While the research team made every effort to be sensitive, the accelerated pace could at times feel overwhelming, triggering, or emotionally taxing for some participants, especially those who had not previously shared such experiences. As researchers, we approached each interaction with care, attempting to accommodate participants' comfort levels and schedules as much as possible.

A major limitation was the presence of linguistic and communication barriers. Some participants, particularly those who are Blind, Deaf, or have learning disabilities, use specific modes of communication or alternative languages that fall outside standard Malay or English. These include unique localised sign systems or assistive technologies. This posed a challenge in ensuring accurate understanding and deep engagement, and highlighted the importance of accessible and inclusive communication strategies. In some cases, interviews conducted via messaging platforms like WhatsApp allowed more inclusive participation, though this also meant a slower, non-linear exchange of ideas, which required additional time and flexibility from the research team.

Another significant limitation was the sample itself. Due to time and access constraints, most participants were individuals already somewhat engaged in advocacy or had past experience working with civil society organisations. Reaching out to Persons with Disabilities who are not connected to these networks—what we might call "everyday" disabled individuals—proved more difficult. Many in this broader group may lack the language, confidence, or past exposure necessary to articulate experiences with SRHR in formal interview settings. Their voices remain essential and require more time and relational trust to be meaningfully included in future phases of the research.

It is also important to reflect on the deep scepticism many Persons with Disabilities hold towards researchers and institutions, often due to a long-standing, extractive dynamic in which information is taken but little is returned. Participants expressed that interviews frequently feel condescending, infantilising, or overly patronising—for instance, being told they are "brave" simply for existing or sharing their truths. This feedback is vital. It reminds us that disability research must actively resist these harmful tropes and engage participants as experts of their own lives, not as inspirational objects.

Embedded in these extractive practices is a more insidious issue: the dominant framing of able-bodiedness as the norm. The term "able-bodied" implicitly centres the nondisabled experience as the standard, while casting disability as deviation. In contrast, using the term "nondisabled" reorients the gaze; it places Persons with Disabilities at the centre of analysis and acknowledges that so-called normalcy is a social construction shaped by those with institutional and epistemic power. This critical distinction reminds the research team that inclusive research must go beyond representation and challenge the normative assumptions that underpin even our best intentions. To paraphrase Angela Davis, "In an ableist society, it is not enough to be non-ableist. You have to be actively anti-ableist.

Finally, our research team recognises the critical need to avoid treating Persons with Disabilities as a monolithic group. While all participants shared barriers related to SRHR, their experiences were deeply shaped by the specific nature of their impairments—whether sensory, physical, learning, or psychosocial. This heterogeneity must be acknowledged and centred in both analysis and policy response.

4. Legislative Frameworks and Existing SRHR Indicators

This section critically examines Malaysia's legal, policy, and institutional frameworks as they pertain to the sexual and reproductive health and rights (SRHR) of women and girls with disabilities. While Malaysia has ratified key international instruments and developed national plans of action, gaps persist in implementation, legal protections, and inclusive service delivery. This analysis underscores where legal frameworks fall short and highlights the pressing need for reform to ensure that the SRHR of all Persons with Disabilities are upheld and realised in practice.

4.1 MALAYSIAN SDG INDICATORS

As disabilities are not part of the general SDG framework, we refer to the SDG-CRPD Resource Package by the UN Human Rights Office of the High Commissioner (OHCHR) which maps out SDG indicators based on The Convention on the Rights of Persons with Disabilities (CRPD).[6] Table 2 indicates all SDG-CRPD indicators that Malaysia is currently reporting. Indicators excluded from the table indicate that the indicator is not available from the Malaysian government or Malaysia reports having this indicator but with no disaggregation into gender or disability as part of the indicator definition.

TABLE 2: SDG-CRPD INDICATORS THAT ARE REPORTED BY MALAYSIA WITH THEIR LAST REPORTED VALUE[7]

PARTICIPANT NAME AND AGE

SDG	Indicator		Value	Year
1: No Poverty	1.1:	People living on less than $2.15 a day.	0.42	2025
3: Good Health and Wellbeing	3.8:	Universal health coverage (UHC) index of service coverage.	75.99	2021
4: Quality Education	4.6:	Literacy Rate among youth, adults and both men and women.	99%	2022
5: Gender Equality	5.3.1:	Number of women aged 20-24 years who were married or in a union before age 15 and before age 18.	2663	2017
	5.5.1:	Proportion of seats held by women in (a) national parliaments and (b) local governments.	a) 13.5%	2025
8: Decent Work and Economic Growth	8.8:	Fundamental Labour Rights are effectively guaranteed.	58%	2023
11: Sustainable Cities and Communities	11.1:	Proportion of urban population living in slums.	21.6%	2022
	11.2:	Population with convenient access to public transport in cities.	38.47%	2020

4.2 INTERNATIONAL COMMITMENTS: CRPD, CEDAW, AND THE SDGS

Malaysia is a signatory to several international human rights treaties, including:

- The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW),
- The Convention on the Rights of Persons with Disabilities (CRPD), and
- The 2030 Agenda for Sustainable Development (SDGs).

Despite ratifying the CRPD in 2010, Malaysia has yet to submit its initial State Party report, which was due in 2012.[8] The country also maintains several reservations and interpretative declarations that undermine the full implementation of CRPD principles, particularly around equality, freedom from torture, liberty of movement, and social participation.[9] Furthermore, no meaningful national consultations have been undertaken with civil society groups, particularly those representing disabled women and girls, to guide the reporting process or implementation.

This failure to domesticate and operationalise treaty obligations—especially under CRPD Articles 6 (Women with Disabilities) and 25 (Health)—reinforces institutional and social exclusions from SRHR for disabled populations.

4.3 NATIONAL LEGAL AND POLICY FRAMEWORKS ON DISABILITY AND HEALTH

4.3.1 FEDERAL CONSTITUTION

The Federal Constitution does not explicitly recognise disability as a protected category under Article 8(2), despite Malaysia's obligation under the CRPD to prohibit all forms of discrimination on the basis of disability. Unlike gender, which was incorporated into Article 8(2) in 2001, disability remains excluded, leaving Persons with Disabilities vulnerable to legal invisibility and unequal protection under the law.

Furthermore, Article 12, which guarantees rights in respect of education, similarly omits disability as a protected category,[10] enabling discriminatory practices within educational systems to persist unchallenged.

Equally significant is Article 5, which guarantees the right to life and personal liberty. Malaysian courts have interpreted "life" to encompass more than mere existence, extending to dignity, livelihood, and quality of life.[11] From this perspective, denial of reasonable accommodation, healthcare access, and social participation for PWDs could be construed as a constitutional violation of Article 5, since such deprivations undermine the possibility of living a dignified life. In this sense, Article 5 provides an indirect constitutional foundation for the right to health and autonomy for PWDs, even in the absence of explicit anti-discrimination provisions.

4.3.2 PERSONS WITH DISABILITIES ACT 2008 (PWDA)

Although the PWDA references CRPD principles and adopts the human rights social model of disability,[12] it lacks enforceable rights. The act contains no anti-discrimination clause, offers no recourse for legal redress, and frames rights as conditional and relative to nondisabled persons. Alarmingly, Part V of the Act offers legal indemnity to government bodies, shielding them from lawsuits related to discrimination against Persons with Disabilities.

Efforts to amend the PWDA, announced in 2023,[13] have yet to yield legislative updates. Civil society remains excluded from meaningful participation in the drafting process, and no clear timeline has been communicated for tabling the revised bill.

4.3.3 MENTAL HEALTH ACT 2001 (MHA)

While the recent decriminalisation of suicide attempts marks progress, the 2023 amendments to the MHA introduced the term "dangerous" to describe those engaging in suicidal behaviour,[14] re-stigmatising mental health conditions and reinforcing fear-driven perceptions of mental illness. The law still lacks accountability mechanisms and reporting obligations related to the detention of persons engaging in suicidal behaviour.

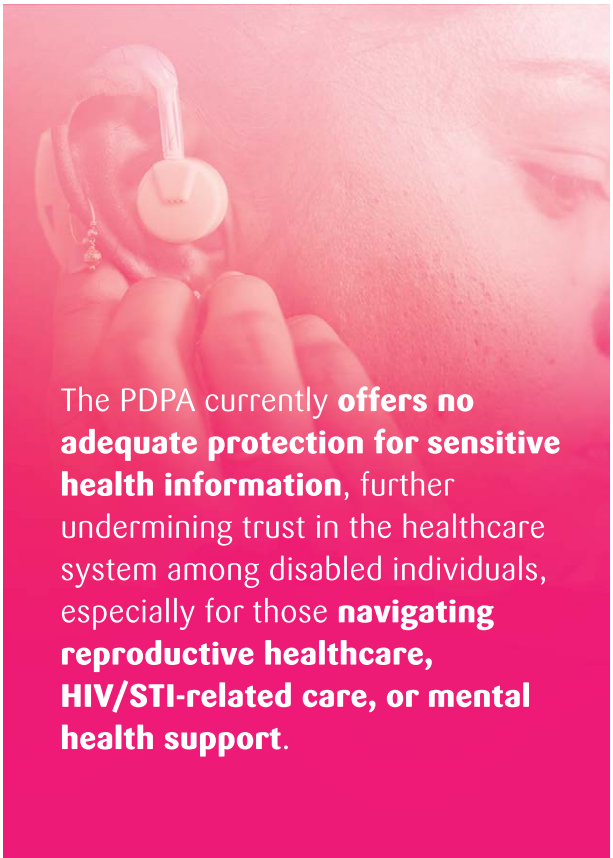
4.3.4 PERSONAL DATA PROTECTION ACT 2010 (PDPA)

The PDPA currently offers no adequate protection for sensitive health information,[15] further undermining trust in the healthcare system among disabled individuals, especially for those navigating reproductive healthcare, HIV/STI-related care, or mental health support.

4.3.5 CIVIC PARTICIPATION AND POLITICAL REPRESENTATION

Persons with Disabilities comprise approximately 16% of Malaysia's population, yet their political representation is negligible. Only one disabled Senator currently sits in Parliament. The continued use of the term "unsound mind" in the Federal Constitution as grounds for disqualifying individuals from holding public office directly discriminates against persons with psychosocial and learning disabilities.

The definition of "unsound mind" is inconsistently applied; it is broad and ambiguous in disqualifying candidates, yet narrowly interpreted in criminal law. This legal incoherence continues to disenfranchise disabled individuals and stifle civic participation.



4.4 EXISTING SRHR INDICATORS AND GAPS IN DISABILITY INCLUSION

National SRHR indicators aligned with SDG targets—such as SDG 3.7 (universal access to SRHR), 5.4 (unpaid care work), and 5.6 (bodily autonomy)—lack disaggregated data for Persons with Disabilities. This absence of disability-specific data severely limits policy responsiveness, service design, and budget allocations.

Malaysia's own *Pelan Tindakan OKU 2016–2022* aimed to address accessibility and social inclusion, including through health and education pillars. However, there has been no public audit of its outcomes, no independent review, and as of 2025, no follow-up plan has been initiated. The Ministry of Women, Family and Community Development (KPWKM) has yet to clarify its post-2022 strategy, despite repeated calls from civil society to present a roadmap for disability inclusion.

Teras Strategik 4 Pelan Tindakan OKU 2016-2022 outlines specific plans to expand access to healthcare for Persons with Disabilities, including increasing and expanding sexual and reproductive healthcare services for women with disabilities, increasing the number of healthcare professionals and medical practitioners trained in disability, and upgrading existing medical facilities to incorporate universal design but no information of outcomes is publicly available.[16]

The 1% Disability Employment Quota for civil service, a three decade old policy and touted as a KPI under the previous administration,[17] remains unmet. The failure was acknowledged in Parliament in 2024,[18] but no reforms have since followed. Advocacy efforts continue to push for employment protections and a formal review of the PWDA to include workplace anti-discrimination measures.

5. Institutional Frameworks and Policy Implementation

5.1 OVERVIEW OF NATIONAL HEALTH POLICIES

Malaysia's public healthcare system is guided by the National Health Policy and the Malaysian Health White Paper (HWP). While both emphasise universal health coverage, neither mainstream the rights of Persons with Disabilities (especially women and girls) in their SRHR provisions.

5.2 DISABILITY AND SRHR IN THE MALAYSIAN HEALTH WHITE PAPER (HWP)

The HWP, tabled in 2023, aims to restructure Malaysia's healthcare system through "whole-of-society" reforms. Yet it fails to adequately address intersectional marginalisation, particularly at the nexus of disability, gender, and reproductive health. It makes only cursory mention of disability inclusion, and no comprehensive strategy exists to address SRHR for women and girls with disabilities.

5.3 ANALYSIS OF INSTITUTIONAL APPROACHES TO INCLUSIVE HEALTH

Malaysia's fragmented policy landscape lacks coordination and transparency. There is no dedicated, cross-sectoral body tasked with overseeing disability-inclusive health planning. This results in inconsistent data collection, policy silos, and the persistent neglect of marginalised disabled populations, including migrants, stateless persons, and Indigenous communities.

6. Thematic Findings from the Pilot Study

6.1 "NO ONE TOLD US": EXCLUSION FROM SRHR EDUCATION AND INFORMATION

The pilot study revealed a significant and consistent gap in knowledge and access to SRHR among women and girls with disabilities. While stigma affects all women in Malaysia seeking SRHR information, respondents highlighted that nondisabled individuals often have informal support systems (friends, family, peers) who may share similar experiences and can offer advice. In contrast, women and girls with disabilities frequently face isolation, both socially and informationally, with fewer accessible sources of guidance.

Most sex education materials currently provided by the Ministry of Education and relevant state actors do not consider the unique access needs of Persons with Disabilities. Among our respondents, only one participant, **Pauziah**, a deaf woman in her 50s, recalled having access to tailored SRHR resources. She described attending a workshop by the National Population and Family Development Board (*Lembaga Penduduk dan Pembangunan Keluarga Negara* or LPPKN in Malay), which provided information on family planning, pregnancy, and early childcare, notably with the inclusion of sign language interpreters. This was, however, an exception rather than the norm.

In cases where a disability intersects directly with SRHR needs, government and private healthcare systems often fail to provide adequate support or information. **Pauziah**, for example, shared that when she asked a healthcare provider how to avoid another pregnancy, she was bluntly told to ask her husband to use a condom. When she followed up by asking where

to obtain one, the provider casually responded, "Any store," offering no further guidance, thus disregarding her genuine lack of knowledge on condom usage.

Another participant, **Lakshmi**, a blind woman in her 50s, emphasised the absence of accessible guidance on breastfeeding or protecting herself from sexual harassment. She also expressed her struggles with menstruation management, particularly the difficulty of determining whether she was bleeding, a task complicated by the lack of tactile or sensory-friendly aids. Her testimony highlights how basic aspects of reproductive health are made more challenging by the invisibility of disability within healthcare systems.

Most participants reported only becoming aware of SRHR concepts once they became sexually active, or when they were preparing for childbirth. **Lakshmi** further remarked that she never understood the urgency or relevance of SRHR education until pregnancy became a reality. This reactive approach to education represents a structural failure to embed SRHR awareness early in life.

For queer and gender-diverse respondents, the barriers were compounded. One trans-masc respondent **Iman**, who also experiences physical and learning disabilities, shared that seeking information or medical advice regarding their SRHR often came with the fear of being flagged in the healthcare system. For them, accessing help often involved complex trade-offs between visibility and vulnerability.

As a result of these systemic exclusions, nearly all participants relied heavily on the Internet to obtain SRHR information. A woman from Sarawak with an invisible physical disability, **Mei**, described using Google and online forums to learn about sexual health, especially in the absence of physical access to health educators or trained professionals. However, this approach carries its own risks, particularly the lack of quality control or contextual relevance. For queer women especially, finding safe, affirming, and medically accurate content online is fraught with misinformation and potential harm.

Mary was the only respondent who received early sex education from a parent. Her mother, aware of the increased vulnerability of disabled women to sexual violence, proactively taught her about bodily autonomy and sexual assault from a young age. Her narrative highlights how familial foresight can serve as a rare protective factor in a largely unsupportive environment.

One particularly poignant account came from the same deaf Kadazan woman from Sabah, **Mary**, who detailed her extensive reliance on self-directed online research to understand her condition. She spoke of doctors who were often dismissive, condescending, or uninterested in her input. Her only option was to become a self-advocate, researching medical conditions online and then presenting her findings to professionals during consultations. Yet even then, she faced resistance and rarely had the opportunity to engage in meaningful dialogue with healthcare workers.

These findings underscore a systemic and structural neglect in the way SRHR education is designed, delivered, and accessed by women and girls with disabilities in Malaysia. The assumption that SRHR is only relevant upon marriage or motherhood ignores the full scope of rights, autonomy, and health that disabled individuals are entitled to throughout their lives. Furthermore, the reliance on nondisabled norms in healthcare and education reinforces exclusion. The consistent theme of "self-advocacy in the face of systemic disregard" speaks volumes about the resilience of our respondents, but also signals a profound policy and institutional failure. Importantly, the language used around disability and SRHR often defaults to a framework that centres nondisabled individuals as the normative reference point. Terms such as "able-bodied" subtly suggest a standard from which Persons with Disabilities deviate. A shift toward terminology like "nondisabled" recentres the experience of the disabled and disrupts this implicit hierarchy. As several respondents have indicated, the issue is not their bodies, but the system's inability (or unwillingness) to accommodate and include them.

6.2 "YOU DON'T LOOK SICK": DISCRIMINATION AND DISMISSAL IN HEALTHCARE SETTINGS

A recurring theme across all interviews was the systemic lack of care and accessibility within Malaysia's healthcare system, especially in government facilities. Many participants reported that unless a facility already had accessible systems in place, staff were often unwilling to make even minor accommodations. This institutional inertia disproportionately burdens Persons with Disabilities, who are then expected to navigate inaccessible systems without adequate support.

For example, **Pauziah**, a deaf participant in the Klang Valley, described the profound difficulties she faced when visiting government clinics. Despite informing clinic staff that she was deaf, her name was still called out via an audio-based queue system. She waited for hours only to be chastised for not responding, highlighting the lack of basic disability awareness among staff. Similarly, **Mary**, also deaf and from Sabah, would avoid government clinics if she could as she would often be subjected to lengthy wait times despite her disability. She would prefer to self-medicate with homeopathic remedies than endure the uncertainty in waiting.

Even when the need for a sign language interpreter was clearly communicated, it was routinely dismissed. Healthcare staff assumed that deaf individuals could write or read Malay or English fluently, ignoring that *Bahasa Isyarat Malaysia* (BIM or Malay Sign Language) is a distinct first language, and literacy in Malay or English may be limited. **Pauziah** recounted an instance where, in the midst of pain, she struggled to write her symptoms and was brushed off when she requested an interpreter. However, she also recalled one rare positive experience with a female gynaecologist who used anatomical diagrams to communicate, demonstrating an inclusive and patient-centred approach, even without an interpreter. Despite this, **Pauziah** noted that she was still commonly labelled as "deaf and dumb" in medical records, revealing the enduring use of outdated and stigmatising terminology in clinical practice.

Medical paternalism was also widely reported. Participants across all disabilities (physical, sensory, psychosocial, and learning) frequently shared that healthcare workers preferred to speak to caregivers instead of directly to them, assuming that they lacked the capacity to understand or decide for themselves. **Mei**, a participant with a physical disability, explained how, during her childhood diagnosis, doctors provided minimal information to her parents and painted a bleak future, telling them she was unlikely to succeed academically or live independently.

For adults with learning or neurodevelopmental disabilities, infantilisation was especially acute. **Iman**, who is autistic, shared that her diagnosis was not given to her directly, but instead handed to her parents in a sealed letter, despite the fact that she was in her twenties. Such dismissive treatment reinforces the narrative that disabled individuals are passive recipients of care rather than active decision-makers in their own health journeys.

Documentation and official letters—so crucial for workplace accommodations—were also difficult to obtain. **Mei**, requesting a letter for less physically demanding tasks at work, was dismissed by her doctor who stated she "looked fine" while standing. This casual dismissal speaks to the broader structural disbelief in invisible disabilities or fluctuating conditions.

In contrast, a few participants noted that private healthcare institutions, though more expensive, tended to be more accommodating and respectful. **Lakshmi**, a blind participant, shared that her experiences during pregnancy were markedly better at a private hospital, where she was treated with dignity and compassion, unlike her interactions with public facilities.

The inconsistency of care from government facilities was a common concern. **Farah**, who lives with a mental health condition, spoke of a disappointing encounter with a substitute doctor during her

scheduled government clinic appointment. The temporary doctor lacked both interest and expertise, prescribing medication without proper consultation, which left her feeling dismissed and dehumanised.

In rural areas or smaller towns, the lack of specialised knowledge among medical staff exacerbated the issue. **Mei**, a participant with a rare physical disability, explained that she was the only person in her region with her condition. As a result, doctors had neither the knowledge nor the community infrastructure to support her, leaving her to "self-educate" and advocate for her own care.

Adults with learning disabilities were also repeatedly misunderstood. Many healthcare providers continued to view ADHD or similar conditions as "children's problems," often refusing treatment or medication. **Iman** was denied ADHD medication by a government psychologist, despite having a formal diagnosis from a psychiatrist.

Stigma was another pervasive thread; particularly for women with invisible disabilities. **Iman**, who is autistic, was doubted and belittled for not having "the autism look." **Farah**, with a psychosocial disability, was subjected to ableist jokes by her doctor who didn't take her condition seriously, while **Mary** shared her frustration at the communication breakdown with doctors who were unwilling to simplify medical explanations or ensure she understood. Medical jargon was used without translation or clarification, reinforcing the idea that disabled patients were not worth the time or effort.

The intersection of gender, disability, and cultural norms was most evident in how healthcare providers responded to sexual and reproductive health questions. Women with disabilities were frequently denied vital SRHR information unless they were married, based on heteronormative and moralistic assumptions that they were asexual or undeserving of reproductive autonomy. One respondent shared that she was explicitly told to only return for information "once she became sexually active or wanted children," denying her proactive agency over her body and choices.

Overall, this theme reveals a healthcare system that not only lacks the training and infrastructure for inclusive care but also perpetuates paternalism, stigma, and structural discrimination. The system assumes that disabled women are dependent, passive, and asexual, reinforcing barriers to access and contributing to a wider climate of distrust, frustration, and health inequity. There remains an urgent need for systemic reform grounded in respect, agency, and the lived experiences of women and girls with disabilities.

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6.3 WORKPLACE BIAS, TOKENISM, AND STRUCTURAL INEQUITY

Employment remains one of the most challenging arenas for women and girls with disabilities, not only in terms of access, but in terms of retention, dignity, and equity. The workplace frequently becomes a site where ableist assumptions, discriminatory practices, and tokenistic gestures converge, forcing many to navigate jobs that are unaccommodating at best and exploitative at worst.

One of the first barriers arises during job applications: the declaration of disability. **Iman**, who lives with multiple disabilities, described how this act of disclosure opened the floodgates for invasive questioning. Hiring managers, under the guise of curiosity or ignorance, often interrogated her condition, remarking that they had "never seen anything like it before." These experiences were not isolated; many participants shared how such interactions were laced with ableism, disbelief, and patronising sympathy.

Beyond hiring, disabled employees are often left out of key organisational processes. **Pauziah**, a deaf woman, explained how she was routinely excluded from staff meetings and departmental town halls. No provision, such as sign language interpretation or accessible summaries, was ever made for her. When she asked about it, she was told these were "company affairs" that did not concern her, and that she should simply "focus on work." This recurring theme of exclusion from decision-making processes was reported by multiple participants and reflects a broader devaluation of disabled workers' contributions beyond task completion.

Invisible disabilities present additional challenges in the workplace. **Mei**, who lives with a physical condition not immediately apparent, found that despite disclosing her disability, she was offered no accommodation. Her superiors failed to grasp the extent of her limitations, denying requests for shorter hospital rounds or designated parking closer to the building. Her experience is emblematic of how invisible disabilities are often dismissed or downplayed, resulting in workers being forced to push beyond their physical limits.

For others, their employment was directly linked to disability-focused programmes or quotas. **Iman** was hired under such a scheme, only to later discover she was being used as a token figure, photographed for promotional materials to demonstrate the organisation's commitment to inclusivity to the donor behind the programme. While she expressed gratitude for the opportunity, she was also acutely aware that her role served more as proof of compliance than genuine inclusion.

This sense of double marginalisation—of being both a woman and disabled—was a consistent thread throughout the interviews. **Lakshmi**, a blind woman, shared how her opinions were frequently disregarded by male colleagues, and how she was overlooked for promotions despite her seniority and experience. She described social events where people would avoid addressing her directly, choosing instead to speak to those around her, as if her presence was invisible. This erasure extends from the professional to the personal, underpinned by gendered and ableist assumptions about competence and leadership.

For women with psychosocial and learning disabilities, the challenges of formal employment can become overwhelming. **Farah**, who lives with several such conditions, found formal work environments rigid and intolerant of her needs. As a result, she chose to pursue freelance work instead, where she could stipulate clear boundaries and accessibility requirements. In her contracts, she specifies communication windows, forbids unnecessary late-night messaging, and requests clients to respect her time. This autonomy allows her to manage her condition while maintaining productivity, an example of self-determined access on her own terms.

Perhaps the most layered and evocative narrative came from **Mary**, a deaf indigenous woman from Sabah. Initially, her story brimmed with hope: she found an employer who not only welcomed her but also hired seven other deaf colleagues, some as clerical staff and others as factory workers. The company, to its credit, was generally supportive; some colleagues learned basic sign language, and her supervisors defended their inclusive hiring to sceptical international stakeholders. However, over time, cracks emerged. Despite years of loyal service, **Mary's** salary remained stagnant, and bonuses were minimal. When she attempted to organise her fellow deaf colleagues to advocate for fairer treatment, they were reluctant. Gratitude had become a double-edged sword. She explained that many of them feared appearing

ungrateful, believing they should simply be thankful to have jobs at all.

Her story crystallises a disturbing pattern: when organisations frame disability employment as an act of charity rather than a human right, it creates a dynamic ripe for exploitation. Employers, emboldened by their self-ascribed altruism, may neglect fair remuneration, career advancement, and meaningful inclusion, believing that mere employment is enough.

These testimonies underscore the urgent need to move beyond superficial inclusion. Disability employment must not stop at hiring; it must be rooted in respect, equity, and recognition of the full humanity and potential of Persons with Disabilities. Inclusive workspaces require more than quotas or token gestures; they require structural change, disability-led policy, and a conscious dismantling of the ableist norms that continue to shape the world of work.

6.4 THE COST OF REGISTRATION: NAVIGATING THE OKU SYSTEM WITH INVISIBLE AND STIGMATISED DISABILITIES

For women and girls with disabilities in Malaysia, the decision to register under the *Orang Kurang Upaya* (OKU) status is rarely straightforward. While registration can unlock essential services, support, and legal recognition, it also brings with it a host of complex trade-offs. For many, registering as OKU is not simply an administrative act; it is a deeply fraught personal, social, and political decision that requires balancing survival with stigma, care with compromise, and access with autonomy.

At the heart of this dilemma lies the reality that private insurance and state welfare often operate in contradiction. **Iman**, who lives with multiple disabilities (both psychosocial and learning) was explicitly advised to register only her learning disabilities, as mental health conditions are often disqualifying in the eyes of private insurers. A single tick-box on a registration form can mean a lifetime of exclusion from insurance coverage, particularly for critical illnesses. However, individuals are forced to navigate a broken system by gaming it (registering selectively or withholding diagnoses) not out of deceit, but out of survival. It speaks volumes about the inadequacies of both private and public healthcare ecosystems when individuals must self-censor their disabilities just to retain a chance at essential coverage.

Pauziah, a deaf participant, acknowledged the practical value of registration, especially for accessing subsidised care, medication, and assistive devices. For those with visible or mobility-related disabilities, the benefits are often more immediate and tangible. Yet even here, barriers remain.

Many state provisions exist more in form than in function. For instance, the inclusion of sign language interpretation in government television broadcasts was initially heralded as a major step forward, but **Pauziah** remarks that the interpreter's image was relegated to a minuscule box in the corner of the screen, barely visible to deaf viewers. It was only after the allegedly highly publicised entry of a particularly well-known OKU senator that the interpreter's display size was increased. This case illustrates a broader pattern: real change often only occurs when disability rights are championed by those in power or fame, rather than through meaningful engagement with community-led civil society organisations.

Another core tension lies in the visibility, or lack thereof, of certain disabilities. Participants with invisible disabilities often faced interrogation and disbelief when attempting to access services. The expectation that disability must be outwardly apparent in order to be valid is both discriminatory and dehumanising. Ayu, a woman with a learning disability, described how her legitimate need for support was questioned, simply because her condition wasn't visible to the untrained eye. This is not only humiliating, but creates an implicit hierarchy of disability, where only those who "look disabled" are treated as deserving.

Even practical aspects of state support are riddled with complications. Accessible parking, for instance, should be a basic accommodation. Yet participants noted that designated OKU lots were often poorly located, lacked proper access for wheelchairs, or were blocked by non-disabled drivers. **Mei** described being harassed—even with an OKU sticker displayed—until bystanders were satisfied she was "disabled enough" to be there. This public policing of disability status reflects deep-rooted ableist assumptions that continue to permeate daily life.

For some, registering as OKU was seen as tantamount to permanently adopting a public disability identity; one that may invite stigma, pity, or even exclusion. Both disabled persons and their families voiced reluctance, fearing that official status could lead to greater discrimination in work, education, and social settings. This fear is not unfounded. There exists a painful internal calculus: is it better to "pass" as nondisabled and struggle quietly, or to claim official recognition and risk being dismissed or devalued?

Internalised ableism emerged as a key subtheme. Participants spoke of the pressure to cope independently and "not burden the system" unless absolutely necessary. Several expressed the belief that as long as they could manage their conditions in private, it was better to avoid formal recognition. This speaks to a broader societal failure to frame disability as a normal part of human diversity, rather than a deficit to be hidden or managed.

Ultimately, the decision to register or not is not a neutral one. It is shaped by the inconsistencies of state support, the inadequacies of the healthcare system, the stigma embedded in public discourse, the very real discrimination in employment and education, and the emotional labour of negotiating identity and dignity. What is urgently needed is not just better policy, but better design—one that centres the lived experiences of disabled people and makes rights and recognition not contingent on trade-offs, but foundational to dignity.

6.5 NAVIGATING ISOLATION: THE DIGITAL TURN TOWARD COMMUNITY AND CARE

For nearly all interview participants, the Internet served as the most accessible and consistent source of information on sexual and reproductive health and rights (SRHR). Search engines, online forums, and digital communities helped fill major gaps in formal education and healthcare guidance (where most local government websites lacked disability accessibility options); especially in cases where the disability was rare, stigmatised, or poorly understood.

This digital reliance, however, is not simply about convenience. Many participants, particularly those with multiple, invisible, or less common disabilities, and those living outside urban centres like the Klang Valley, spoke of deep loneliness and alienation. **Mei** noted that she felt isolated growing up as the information about her condition was limited and she could not turn to anyone to ask. It was only when she was older was she able to read up on her own using the Internet and that opened up her world to the options for her condition.

The stigma around disability, reinforced by family attitudes and broader societal microaggressions, left many without safe spaces in their immediate environments. This was more pronounced for queer disabled persons such as **Iman**, who could only use the Internet as the main resource about queerness and disability but with added risk as it was difficult to verify or trust the information that often came from lived experiences of others.

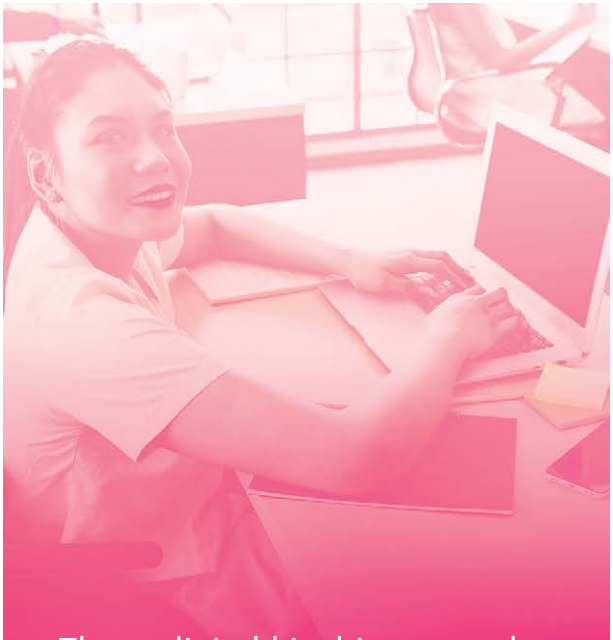
The discovery of peer-led digital communities became a turning point. Some participants stumbled upon these networks through casual searches, others were introduced via friends or disability advocates. These spaces offered practical SRHR advice, emotional support, and strategic guidance on navigating healthcare systems and state bureaucracy. In these forums, lived experience was not only validated and became a vital source of survival knowledge.

For **Mei** and **Farah**, gaining access to online communities of people with the same disabled conditions and advocacy was life-affirming as their voices were finally heard in a supportive manner and their concerns were taken with respect and empathy.

As a small but important aside, it is worth noting that all interviews conducted for this study were emotionally charged. Participants often recounted deeply personal and traumatic experiences, speaking of systemic neglect, social isolation, and repeated encounters with discrimination. These recollections were frequently tinged with pain, frustration, and exhaustion. Yet, a palpable shift occurred in nearly every conversation when the topic turned to their connection with other disabled individuals and the communities they had found, most often online.

In these moments, participants became visibly more animated, hopeful, and even joyful. Their tone changed from guarded to expansive. These digital kinship networks, many of which only became accessible through technological advancement and reliable internet, emerged as vital sources of empowerment and support. For blind and deaf participants in particular, technologies such as screen readers, speech-to-text converters, and messaging apps were essential tools. Platforms that allowed communication in shared languages, such as *Bahasa Isyarat Malaysia* (BIM), became crucial spaces for knowledge exchange, especially when navigating complex SRHR issues or medical terminology.

Participation in these online communities was, for many, a turning point. It was the first time they felt fully recognised; not as burdens or problems to be solved, but as whole persons with agency, complexity, and value. These digital spaces provided more than just information; they offered affirmation, solidarity, and a broader network of care. For participants, it meant being part of something larger than themselves, a collective that resists invisibility, demands dignity, and dares to imagine better futures.



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7. Recommendations

7.1 POLICY AND LEGAL REFORMS

- **Remove discriminatory language:** Legal, medical, and institutional documents should undergo a comprehensive review to remove derogatory and outdated terms such as "deaf and dumb". Language shapes practice, and institutional vocabulary must reflect dignity, personhood, and equality.
- **Enact the Mental Capacity Act with inclusive safeguards:** The proposed Mental Capacity Act must affirm the right of all Persons with Disabilities to equal legal capacity, in line with Article 12 of the UN Convention on the Rights of Persons with Disabilities (UN CRPD).[19] Legal capacity is foundational to exercising consent, particularly in health, financial, and end-of-life decision-making. However, we must interrogate what "free, prior, and informed" consent truly means in a context where access to information, legal recourse, and justice is neither guaranteed nor equitably distributed. Rights without redress are performative. Furthermore, questions of capacity are not limited to disability, they are also essential to ageing populations navigating decisions around enduring power of attorney, advance medical directives, and guardianship.[20] A comprehensive, inclusive Mental Capacity Act would not only protect Persons with Disabilities, but also strengthen Malaysia's preparedness for its demographic transitions.
- **Amend the Persons With Disabilities Act to meaningfully domesticate CRPD principles:** The social model of disability posits the response to "disability" should be accessibility based on universal design, reasonable accommodations and protection from discrimination on the basis of disabilities. However, despite the social model of disability being the fundamental basis of the PWDA, the Act does not reflect this. Redress and accountability mechanisms must be institutionalised, and the PWDA must provide and enable legally enforceable minimum standards for accessibility and reasonable accommodations in all areas of life. Discrimination on the basis of disability must be acknowledged and enforced by law (where there is none currently) and redress mechanisms must be made available and accessible. The Act must create an enabling environment, an obligation we took on when we ratified the CRPD.
- **Amend Article 8 and Article 12 of the Federal Constitution of Malaysia to recognise "disability"**.

7.2 DISABILITY-INCLUSIVE SRHR EDUCATION

- **Culturally grounded community engagement:** Collaborate with Disabled Persons' Organisations (DPOs), NGOs, and community leaders to deliver culturally sensitive SRHR education that centres lived experience.
- **Accessible, inclusive CSE:** Develop and disseminate comprehensive sexuality education (CSE) that is age-appropriate, disability-inclusive, and available in accessible formats, including Malaysian Sign Language (BIM), Braille, Easy-Read formats, and digital media.

7.3 HEALTHCARE SYSTEM REFORM

- **Implement universal accessibility protocols:** All public healthcare facilities should implement standardised inclusive infrastructure and communication systems, which includes visual and audio queueing systems, sign language interpretation, adjustable examination tables, accessible formats for medical information (such as websites and digital materials), and provisions for augmentative and alternative communication methods.

- **Address planning gaps:** The gap between the Ministry of Health's (*Kementerian Kesihatan Malaysia* or KKM in Malay) national healthcare plans for Persons with Disabilities (spanning from the conclusion of the 2011–2020 Plan to the delayed launch of the 2024–2030 Plan in December 2025) must be formally acknowledged and scrutinised. This discontinuity has left critical service gaps for at least five years.
- **Co-design SRHR services:** Women with disabilities must be included in the design, implementation, and monitoring of SRHR services. Services must reflect an understanding of the diverse needs of women with physical, sensory, learning, and psychosocial disabilities.
- **Institutionalise accountability mechanisms:** Establish participatory feedback systems to regularly collect and respond to user experiences of SRHR service access, quality, and safety, particularly from disabled women across different geographic and socioeconomic contexts.

7.4 CAPACITY BUILDING FOR FRONTLINE WORKERS

- **Mandatory training programmes:** Equip healthcare workers, social workers, and public-facing civil servants with training on disability justice, inclusive communication strategies, and rights-based approaches to SRHR. Integrate inclusivity and disability awareness modules into Continuing Medical Education (CME) for doctors and Continuing Professional Development

  (CPD) programmes for all relevant professionals, ensuring these trainings are accredited and count towards CME/CPD requirements.
- Training must challenge ableist assumptions, promote trauma-informed care, and centre the agency and personhood of women and girls with disabilities.

7.5 INCLUSIVE POLICYMAKING

- Ensure representation of disabled women and girls in all stages of policy development, including health, education, transport, and disaster preparedness. Representation must go beyond tokenism and include meaningful power-sharing and compensation for lived expertise.

7.6 AUDIT AND ACCOUNTABILITY FOR DISABILITY ACTION PLANS

- **Audit the *Pelan Tindakan OKU 2016–2022*:** The plan should be formally reviewed and its implementation outcomes submitted for Parliamentary scrutiny. All failed indicators must be publicly acknowledged and accompanied by a time-bound remediation roadmap.
- Despite civil society engagement, including participation in a 2024 WHO Malaysia-KKM focus group discussion on accessible healthcare services, the Ministry of Health declined to proceed with the working group proposed by WHO Malaysia. Instead, the group's findings were relegated to KKM's "Quality of Life" division. This raises serious concerns about the Ministry's commitment to structural reform and inclusive health governance.
- The unacknowledged five-year policy vacuum between the 2011–2020 and forthcoming 2024–2030 Healthcare for Persons with Disabilities Plans must be critically addressed. The lack of an interim plan left significant gaps in service delivery and access without accountability or interim guidance.

8. Conclusion

8.1 REFLECTIONS ON THE WAY FORWARD

The denial of foundational rights (such as accessible education or public healthcare) creates a ripple effect that obstructs the realisation of broader, aspirational rights. It is difficult to demand the "right to be forgotten" or to enjoy digital privacy in a hyperconnected world when basic mobility infrastructure remains absent or inaccessible.

Rights cannot be pursued in silos. The cost of inaccessibility is often distributed across sectors, and the impact is compounded when solutions are designed without lived experience. Co-designed, multisectoral approaches (grounded in dignity, solidarity, and care) must become the norm. Reframing rights not as privileges but as everyday needs, shifts the narrative from charity to justice.

Instead of asking abstract questions about equality, we propose a grounded approach: *Can a wheelchair user travel safely by public transport to enjoy a day out?* This is the kind of practical, holistic question that reveals systemic gaps, and it is precisely the kind of question that emerges from community wisdom.

8.2 REAFFIRMING THE NEED FOR STRUCTURAL CHANGE

Systemic exclusion cannot be resolved with piecemeal reforms. An intersectional, rights-based framework—one that recognises interlocking forms of discrimination, marginalisation, and state neglect—is necessary to shift the structural foundations of policy, service delivery, and governance. The inclusion of disabled women and girls must be a non-negotiable benchmark for Malaysia's progress on both human rights and development indicators.

8.3 LOCATING HOPE IN ONGOING ADVOCACY

Despite institutional resistance, there is hope in the persistent labour of advocates, researchers, and community leaders. In February 2023, project co-researcher Hasbeemasputra participated in a national webinar on "Risk Communication and Community Engagement for, and with Persons with Disabilities" with WHO Malaysia, attended by officers from the Ministry of Health, the Ministry of Communications and Multimedia, the National Disaster Management Agency and various other national agencies. When he raised the need for accessible health messaging, the response from the Ministry of Health's Health Education Division was telling: *"Tapi OKU bukan klien kita."* ("But Persons with Disabilities are not our clients.") This single statement captures the urgency of structural change. Persons with Disabilities are not marginal "beneficiaries" of development; they are citizens with rights, vision, and solutions. The struggle extends beyond questions of access; it is a demand for recognition, dignity, and full inclusion; one that persists not by necessity, but by the continued failure of institutions to realise the rights of Persons with Disabilities.

Endnotes

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