

I. About Us

- SIUMAN (the Malay word for "sane") is an Organisation of Persons With Disabilities (OPD) in that it is a collective of mental patients and allies fighting for socioeconomic and political equity and equality for the mentally ill in Malaysia, initiated amidst the COVID-19 pandemic in 2021.
- SIUMAN works with any and all parties and organisations with progressive views on mental health and firmly believes that mental health advocacy should not stop at just awareness and destigmatisation efforts.
- SIUMAN strongly believes that mental patients should participate in the political process (including direct action) to push for meaningful legal reform and policy change.

II. Executive Summary

1. This submission starts with an overview of the general state of disability rights in the Malaysian context, with ties to the legislative framework including the Persons with Disabilities Action Plan 2016-2022 (officially in Malay: *Pelan Tindakan Orang Kurang Upaya 2016-2022, henceforth referred to as PTOKU*), produced by the Ministry of Women, Family, and Community Development of Malaysia. It then follows case studies that illustrate the barriers to equitable access and discriminatory practices against Persons with Disabilities (PWD) that are enabled by the legislative framework, followed by recommendations to address those barriers and discrimination through the social model of disability with respect to people with lived experience (PWLE) comprising PWD, clients, users, and patients.
2. Malaysia signed the Convention on the Rights of Persons with Disability (UN CRPD) in April 2008 and introduced the Persons with Disability Act 2008 (PWDA) before its ratification of CRPD in July 2010. Malaysia has yet to submit or undertake any state reporting since its ratification¹.
3. Malaysia's ratification to the CRPD² was with reservations to Article 15 and Article 18³, and interpretative declarations to Article 3 on general principles, Article 5 on equality and non-discrimination, and Article 30 on participation in cultural life, recreation, leisure and sport.

III. Legislative framework

4. Malaysia acknowledges the social model of disability, as outlined in the PWDA 2008⁴ that outlines the role of environmental, attitudinal and societal barriers to be what actually disables someone with an impairment to effectively participate in society. PWDA makes an important distinction between disability and impairment, whereby disability is the outcome/result of the interaction of a person with an impairment with inaccessible public spaces and negative social norms.

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https://www.ohchr.org/sites/default/files/Documents/HRBodies/CRPD/Tentative_forecasts_Country_reviews.docx

² https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?CountryID=105&Lang=en

³ <http://indicators.ohchr.org>

⁴ <https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/86297/117930/F139356912/MYS86297.pdf>

5. However, the PWDA does not mandate any discrimination protections, nor does it mandate universal access in any aspect of life for PWD to participate effectively on an equal basis with others in society. The preamble makes PWD rights relative to nondisabled rights, while Part V protects the government in discriminating against PWD. In essence, while PWDA covers and addresses many aspects of PWD rights, the lack of enforcement and compliance, oversight and redress mechanism renders it ineffective in addressing discrimination against PWD in Malaysia.
6. The hollowness in the PWD Act is further amplified by the lack of intent to amend the Federal Constitution (FC) of Malaysia which at present, does not explicitly recognise disability within Article 8(2).
7. PTOKU 2016-2022 was launched in 2016 and has ten Core Strategies based on the Incheon Strategy to Make the Right Real for Persons with Disabilities in Asia and the Pacific (Incheon Strategy) covering access to inclusive healthcare services, education, employment, planning & decision making as well as other aspects of social participation⁵. However, PTOKU has largely been ignored, with many of the Goals unfulfilled and unmet. SIUMAN has made enquiries through public engagements sessions involving officials from the PWD Development Department (officially in Malay: *Jabatan Pembangunan OKU*, henceforth referred to as *JPOKU*), and it was indicated that PTOKU would not be debated in Parliament. The lack of Parliamentary oversight further diminishes efforts to reduce barriers for PWD to effectively and meaningfully participate in society.
8. Section 309 Penal Code which criminalised suicide attempts was repealed by Parliament in early 2023⁶. The Mental Health Act 2001 (MHA) and Criminal Procedure Code were also amended as part of the Repeal Bill Package to decriminalise suicide attempts. However, SIUMAN raised concerns about the proposed amendments, particularly the usage of the word “dangerous” in the amendments to the MHA, and the lack of reporting and oversight mechanisms in the apprehension of persons engaging in suicidal behaviour⁷. SIUMAN managed to secure a meeting with the Deputy Law Minister, Mr. Ramkarpal Singh to present our concerns, but the amendments were passed as originally proposed.
9. The Health White Paper (HWP) was announced by former Health Minister, Mr. Khairy Jamaluddin in 2022⁸, and passed by Parliament in early 2023⁹. The aim of the HWP was to reform the national healthcare services in order to “future-proof” it. However, no client groups or patient-advocates were included in the HWP Advisory Council¹⁰.

IV. Persons with Disabilities in Public Office

10. PWD with selected disabilities are disqualified as potential election candidates by the virtue of the inclusion of ‘unsound mind’ as a category for disqualification. The broad interpretation of unsound mind, a concept based in law as opposed to medical

⁵ [https://www.jkm.gov.my/jkm/uploads/files/JPOKU/PelanTindakan_OKU\(EMAIL\).pdf](https://www.jkm.gov.my/jkm/uploads/files/JPOKU/PelanTindakan_OKU(EMAIL).pdf)

⁶ <https://www.thestar.com.my/news/nation/2023/05/23/attempted-suicide-no-longer-a-crime>

⁷ <https://drive.google.com/drive/folders/1UcaRjmTsetv4DBdQS7DK6cse1bVMQmtW>

⁸ <https://parlimen.gov.my/ipms/eps/2023-06-12/CMD.29.2023%20-%20CMD%2029.2023.pdf>

⁹ <https://www.nst.com.my/news/nation/2023/06/920508/dewan-rakyat-passes-health-white-paper>

¹⁰ <https://www.nst.com.my/news/nation/2022/08/827065/kj-unveils-health-white-paper-advisory-council-lineup>

conditions, combined with the lack of explicit discrimination protections results in broad based discrimination against PWD in taking up public office¹¹.

11. It is estimated that PWD amount to roughly 15% of the overall population but are severely underrepresented in the Parliament with only PWD lawmakers within the Senate (Upper House). The 15th General Election that took place in November 2022 had one candidate who ran for Parliament on a platform of disability advocacy.

IV. Disability inclusion, discrimination, and protection through the National Action Plan for Persons with Disabilities 2016-2022

Equitable access to quality healthcare for PWD

12. Two objectives are outlined in PTOKU (p. 6); to increase the accessibility of healthcare services to ensure the wellbeing of PWD, and to strengthen and expand accessibility of more comprehensive habilitation and rehabilitation services and programs covering health, employment, education and social aspects to support the inclusive participation of the disabled in society. The involvement of PWD in policies regarding them have been outlined in PTOKU as well (pp. 46-47). The Health White Paper (HWP) Advisory Council any client-advocates, even though they are service users, with PWD being particularly vulnerable. Member of Parliament, Mr. Syahredzan Johan urged the Government Of Malaysia to include stakeholders retroactively¹², although the HWP was already framed from the lens of nondisabled persons.
13. A notice at Putrajaya General Hospital went viral on social media¹³ that mentions those who have certain mental disorders (Schizophrenia, Major Depressive Disorder, Bipolar Disorder, Dementia) are disqualified from performing the Hajj pilgrimage. The carelessly worded notice in a public hospital stigmatises those with mental disorders without accounting for remission and recovery period¹⁴.
14. In early 2023, a member of SIUMAN Collective intervened with a client from the disabled community who wished to be admitted at Selayang General Hospital for suicidal ideation. However, after spending several hours in the emergency room, the request for admission was rejected, with the excuse that the psychiatric ward was full of persons with psychosis. The SIUMAN member then brought the community member to Hospital Universiti Putra Malaysia (HUPM), a teaching hospital, where he was assessed and admitted. This indicates that there was a valid basis for him to be admitted that was denied when he attempted the same at the previous hospital. Being physically disabled, he faced a number of barriers to access healthcare and emergency services.
15. On 3rd May 2023, SIUMAN attended a consultation with Deputy Law Minister, Mr. Ramkarpal Singh, joined by representatives from MINDAKAMI (a mental health

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https://www.jac.gov.my/spk/images/stories/10_akta/perlembagaan_persekutuan/federal_constitution.pdf

¹² <https://www.nst.com.my/news/nation/2023/06/920443/dont-rush-raising-public-healthcare-fees-say-mps>

¹³ <https://twitter.com/nukm4n/status/1648672309555900417?s=20>

¹⁴

[https://www.moh.gov.my/moh/resources/Penerbitan/Garis%20Panduan/Garis%20panduan%20Umum%20\(Awam\)/E-BOOK_GARIS_PANDUAN_PEMERIKSAAN_KESIHATAN_BAKAL_HAJI_EDISI_8.pdf](https://www.moh.gov.my/moh/resources/Penerbitan/Garis%20Panduan/Garis%20panduan%20Umum%20(Awam)/E-BOOK_GARIS_PANDUAN_PEMERIKSAAN_KESIHATAN_BAKAL_HAJI_EDISI_8.pdf)

advocacy group), Women in Power (women empowerment group). The consultation meeting was attended by representatives from the Ministry of Health and the Attorney General's Chambers to discuss our concerns with the Section 309 Penal Code Repeal Bill Package. During the meeting, it was revealed that the planned National Suicide and Fatal Injuries Registry (NSFIRM) which was planned to start operating in 2023¹⁵ would be delayed. The NSFIRM was to replace the long dormant National Suicide Registry (NSRM)¹⁶, and with the delay, data collection and analysis on suicides and suicide attempts would be hampered.

16. Recommendation

- a. SIUMAN recommends that the Health Ministry appoints a rights-based disability advocate to oversee healthcare planning and decision-making to ensure that healthcare services are accessible for all disabled persons within one year.

Access to education for PWD

17. Two objectives are outlined in PTOKU (p. 5), namely; to increase access to education for PWD, especially children, on an equal basis with others; and strengthening support mechanisms. However, there is a distinct lack of discrimination protections, and accessibility in education facilities on all levels is not mandated.

18. SIUMAN has come across many examples of institutions of higher learning that have exclusionary policies that target PWD, among others. Open University Malaysia (OUM), owned by a consortium of Malaysia's eleven public universities¹⁷, is one such institution. Their Bachelor of Medical and Health Sciences programme excludes those with mental illnesses, as well as Persons Living with HIV (PLHIV)¹⁸. This is not isolated, as other public institutions of higher learning all refer to the Ministry of Health's (MOH) guidelines¹⁹.

19. Recommendation

- a. SIUMAN recommends that the Government of Malaysia implements discrimination protections and an equal opportunity policy at all levels of education within one year.

Employment security for PWD

20. Three objectives are outlined in PTOKU (p. 4); increasing employment opportunities for PWD in all employment sectors whether public or private; increasing opportunities for PWD to work on their own (self-employment) through participating in entrepreneurship and economic empowerment programs; and encouraging the involvement of PWD in vocational training and other employment support programs provided by the government, the private sector and NGOs.

¹⁵ <https://www.astroawani.com/berita-malaysia/moh-developing-national-suicide-registry-be-completed-2023-325359>

¹⁶ <https://pubmed.ncbi.nlm.nih.gov/19227674/>

¹⁷ <https://www.oum.edu.my/about-open-university-malaysia/>

¹⁸ <https://www.oum.edu.my/all-programmes/undergraduate-programme/bachelor-of-medical-and-health-sciences-with-honours/#1676855562415-12995430-4b67>

¹⁹

https://www.moh.gov.my/moh/resources/Penerbitan/Garis%20Panduan/Pen%20Peg%20Perubatan/standards_guidelines_for_ma_education_programme_3rd_edition.pdf

21. The Malaysian government has a 1% PWD in civil service policy, which was made a Key Performance Index (KPI) during former Prime Minister Ismail Sabri's tenure. However, despite the policy being in place since 1988²⁰, and being made a KPI, PWD only make up 0.4% of the civil service²¹. Only 4 ministries have achieved the goal of 1% PWD employment²². There is also no publicly available or accessible data on the role for which PWD are hired for and the percentage of PWD within management and decision making levels.
22. PWD with mental disorders are obliged to to reveal their mental health status, but are not protected from discrimination in employment²³. The amendments to the Employment Act omitted discrimination protections for PWD in employment, including pre-employment²⁴. Employers can be penalised for failing to comply with the Director General's order, following an investigation, but the employer will not be penalised for the discrimination itself. Discrimination is also not explicitly defined.
23. PWD jobs under the Malaysia Short-term Employment Programme (MySTEP) initiative²⁵ are on a contract basis, with employers getting rebates and other financial incentives for hiring PWD²⁶. However, employers are not obliged to provide reasonable accommodations, neither are workplaces audited for accessibility.
24. Recommendations
 - a. SIUMAN recommends discrimination protections and equal opportunity mechanisms to be added to the 1% PWD Policy in civil service immediately.
 - b. SIUMAN also recommends that the Ministry of Women, Family, and Community Development release data on the roles that PWD currently occupy in the civil service, including the types of disabilities within one year.

Planning and decision-making involving PWD for PWD

25. Two objectives are outlined in PTOKU (p. 8), namely: ensuring the involvement of PWD in planning and decision-making on national policies, including through political participation; and increasing the awareness and involvement of the PWD in the voting process.
26. Since former Senator Ms. Ras Adiba's term ended, Malaysia currently lacks a Senator for PWD²⁷. Due to 'unsound mind' provisions in the Federal Constitution²⁸, those with psychosocial disabilities are excluded from being appointed Senator and

²⁰ https://jas.uitm.edu.my/images/ARCHIEVE_2014/2.pdf

²¹ <https://focusmalaysia.my/almost-1-year-on-pm-asked-for-updates-on-1-oku-in-civil-service-kpi/>

²² <https://www.nst.com.my/news/nation/2021/11/746449/only-four-ministries-comply-one-percent-oku-employment-policy-nsttv>

²³ <https://www.freemalaysiatoday.com/category/nation/2020/09/17/you-break-the-law-if-you-hide-mental-health-problems-workers-told/>

²⁴ <https://wao.org.my/employment-act-amendments-progress-but-gaps-remain-2/#:~:text=The%20Bill%20does%20not%20prohibit,Discrimination%20is%20not%20defined.>

²⁵ <https://www.mof.gov.my/portal/en/news/press-citations/one-pct-quota-for-disabled-community-under-mystep-remains-mof#:~:text=%22The%20one%20per%20cent%20quota,with%20the%20set%20time%20limit%2C>

²⁶ <https://themalaysianreserve.com/2022/04/01/some-0-4-quota-allocated-for-oku-in-mystep-has-been-filled/>

²⁷ <https://www.freemalaysiatoday.com/category/nation/2023/05/30/where-is-new-senator-to-represent-persons-with-disabilities-ask-groups/>

²⁸

https://www.jac.gov.my/spk/images/stories/10_akta/perlembagaan_persekutuan/federal_constitution.pdf (p. 43)

cannot hold elected office. Article 119 (2) and (3)(a) further diminish the rights of PWD with mental disorders to vote. The lack of explicit discrimination protections also prevents Members of Parliament from revealing their own mental health issues due to the possible repercussions.

27. Former Ministry of Women, Family and Community Development, Ms. Rina Mohd Harun rolled out a cashless financial support mechanism called JKMPay²⁹ in February 2021. The trial programme effectively restricted the distribution of financial aid where qualified persons needed to sign an agreement to participate in JKMPay, and would be denied financial aid if they refused to sign the trial agreement. The programme was also rolled out without the input of the PWD community.
28. Ms. Rina Mohd Harun also rolled out MyDaftarOKU to facilitate online PWD registration in November 2021³⁰, a prerequisite to access state-funded social support and affirmative action. However, the website itself does not conform to web accessibility standards, and most of the registration process still needs to be completed offline³¹. As of January 2023, the Welfare Department has registered 637,537 PWD³², which is far below the estimated 4.7 million PWD, or 15% of the population³³.
29. Recommendations
 - a. SIUMAN recommends that the Government of Malaysia audit existing processes of governance, including public communications, websites and other digital assets to ensure compliance with accessibility standards within one year.
 - b. SIUMAN also recommends that the Government of Malaysia upgrade the PWD Development Department (JPDKU) to a full-fledged department under the Ministry of Women, Family and Community Development (KPWKM) with at least 50% of officers and employees with disabilities within one year. If there is no qualified PWD candidate for the position of director, a goal should be set to have a PWD JPDKU director within five years.
 - c. SIUMAN further recommends that the Government of Malaysia increase the number of Senators representing Persons with Disabilities from different categories of PWD within two years.

Social inclusion of PWD

30. Two objectives are outlined in PTOKU (p. 3), namely; improving the accessibility to the physical environment in both urban and rural areas based universal design design); increasing accessibility and usability of public transport facilities; increasing accessibility to information and communication; and to reducing barriers to banking and insurance services.

²⁹

<https://www.jkm.gov.my/jkm/index.php?r=portal/articles&id=cGxxTWpWRkVNbFBLdkZaRU5Fb1RxQT09>

³⁰ <https://www.nst.com.my/news/nation/2021/11/744468/jkm-receives-close-5000-applications-oku-digital-card-nsttv>

³¹ <https://oku.jkm.gov.my/>

³²

[https://www.jkm.gov.my/jkm/uploads/files/STATISTIK%20PENDAFTRAAN%20OKU%2031012023%20\(2\).pdf](https://www.jkm.gov.my/jkm/uploads/files/STATISTIK%20PENDAFTRAAN%20OKU%2031012023%20(2).pdf)

³³ <https://www.thesundaily.my/home/staggering-88-of-disabled-persons-not-registered-MB3553394>

31. The Greater Klang Valley area has been experiencing regular breakdowns of the Light Rail Transport system and suffers from poor connectivity³⁴. Any measures to rectify these faults have generally failed to be inclusive of PWD, with accessibility needs of PWD hardly considered³⁵. The focus on massive transportation projects such as the Mass Rapid Transit (MRT) on the Greater Klang Valley is also inequitable, and public transport accessibility and connectivity suffers in areas outside the Greater Klang Valley.
32. In October 2021, Former Minister of Finance, Tengku Zafrul (currently the Minister of Investment, Trade and Industry) announced that all TV news broadcasts should provide sign language interpretation³⁶. This was a welcomed move, however sign language interpretation is only one aspect of PWD-accessible communications. There is no cohesive policy for PWD-accessible public communications that applies to all ministries.
33. Recommendations
 - a. SIUMAN recommends that the Government of Malaysia adopt a PWD-accessible public communications policy to ensure that PWD are meaningfully included in public discourse within one year.
 - b. SIUMAN also recommends that the Government of Malaysia audits public transportation infrastructure to ensure accessibility through universal design within one year.
 - c. SIUMAN further recommends that the Government of Malaysia establish a Disability Affairs Unit under the Office of the Chief Secretary of each Ministry and the Office of the Secretary of State Governments within two years.

³⁴ <https://selangorjournal.my/2022/05/its-2022-but-public-transport-woes-remain/>

³⁵ <https://www.sinardaily.my/article/188665/malaysia/national/enhance-public-transport-accessibility-for-the-disabled>

³⁶ <https://www.freemalysiatoday.com/category/nation/2021/10/29/all-tv-news-broadcasts-to-have-sign-language-interpreters/>

V. Summary of Recommendations

34. SIUMAN recommends that the Government of Malaysia, through its relevant ministries, to perform a full audit on the implementation of PTOKU 2016-2022, to table and debate the outcome of the audit in the parliament, and to do this within one year.
35. SIUMAN also recommends that the Government of Malaysia remove all reservations to CRPD, ratify the UN CRPD Optional Protocol, amend PWD Act 2008 to mandate access and discrimination protections for PWD, while meaningfully including PWD in the process, within one year.
36. SIUMAN calls on the Government of Malaysia to audit all legislation with a PWD element, including but not limited to the Penal Code and the Mental Health Act, to ensure compliance with UN CRPD standards within two years.