

Submission to the Joint Committee of Public Accounts and Audit Inquiry into the Administration of the National Disability Insurance Scheme

Topic: Premenstrual Dysphoric Disorder (PMDD) as a cyclical disability and its exclusion from NDIS design, administration, and monitoring

I write as a person with lived/living experience of Premenstrual Dysphoric Disorder (PMDD) and as a professional worker in the mental health and community sectors.

This submission explicitly responds to the Committee's Terms of Reference regarding:

- NDIA's delivery of the NDIS and management of financial sustainability and claimant compliance frameworks
- Monitoring, measurement, and reporting of NDIA performance
- Regulatory performance of the Quality and Safeguards Commission
- Disability policy advice to government

This submission first outlines the biological and functional nature of PMDD, then identifies how current NDIS design and reporting frameworks exclude cyclical disability, and finally proposes specific reforms aligned with the Committee's Terms of Reference.

1. Executive summary

Premenstrual Dysphoric Disorder (PMDD) affects an estimated 3–8% of menstruating people globally and is characterised by severe, biologically mediated cyclical symptoms that cause functional impairment in work, education, daily living, and social participation (American Psychiatric Association [APA], 2013; Chawla et al., 2021).

Key misconceptions addressed:

- PMDD occurs because of the central nervous system's atypical sensitivity to normal ovarian hormone fluctuations, not abnormal hormone levels (Dubol et al., 2020; Gingnell et al., 2017; Hantsoo & Epperson, 2015).
- Functional impairment is episodic and cyclical, remitting shortly after menstruation begins and returning reliably when ovarian hormones shift again (APA, 2013).
- PMDD is lifelong across the reproductive years, produces cumulative participation restrictions over time, and meets the definition of a disability relevant condition under international functional frameworks, even when symptoms fluctuate (World Health Organization [WHO], 2001; Heinemann & Bode, 2018).
- Perimenopause increases unpredictability of PMDD. As menstrual cycles become irregular in perimenopause, PMDD episodes become less predictable and more frequent, and are not bound to a 28 day "monthly" cycle model, challenging traditional symptom tracking and disability assessment approaches (Gordon et al., 2023; Schmidt et al., 2017).
- Workforce and economic impact: PMDD is associated with increased absenteeism, presenteeism, reduced productivity, and employment instability, contributing to premature workforce exit and measurable economic loss (Borenstein et al., 2003; Direkvand-Moghadam et al., 2014; Kleinstäuber et al., 2017).
- Suicide rates reflect systems failure: PMDD carries significantly higher levels of suicidal ideation, self harm, and suicide attempts, particularly during symptomatic phases. Risks that are exacerbated by systemic invisibility, diagnostic delay, trivialisation of symptoms, exclusion from disability supports, and lack of cyclical accommodation pathways (Ducasse et al., 2016; Osborn et al., 2021; Owens & Eisenlohr-Moul, 2023; Silva et al., 2023).
- NDIS administration structurally excludes cyclical disability. The NDIS and NDIA operational guidance currently default to an implicit continuous impairment model, discounting cyclical evidence like

symptom diaries and temporal predictability, and misclassifying PMDD as “mood” based rather than biologically driven episodic impairment (WHO, 2001; Burch et al., 2022; Heinemann & Bode, 2018).

- Australian services are already acting on PMDD. National women’s health and mental health services, including Jean Hailes for Women’s Health, Cabrini Women’s Mental Health service and HER Centre Australia, have established PMDD specific information, clinics and treatment trials, reflecting the urgency and seriousness of PMDD in clinical practice.

1.1 PMDD is misunderstood partially because of DSM classification

- PMDD is classified in the DSM-5 under Depressive Disorders based on symptom clusters and diagnostic reliability
- It sits there because it presents with severe cyclical depressive, cognitive and emotional episodes in patterned luteal phase windows
- Its inclusion reflects organisational and clinical pattern logic not as a claim about mood being the cause
- Disability administration often misreads DSM placement as proof of emotional origin (incorrectly categorising PMDD as a mood disorder) rather than evidence of hormone triggered functional collapse
- Understanding DSM logic early prevents category inference errors in NDIA design, monitoring and sustainability frameworks

Explanation

PMDD is grouped in the DSM-5 with Depressive Disorders because its most disruptive symptomatic episodes reliably produce clinically significant depressive, cognitive and emotional changes during the luteal phase, followed by rapid remission at menstruation onset. The DSM is a symptom first classification system designed to assist clinicians to diagnose patterned distress: it organises conditions by how they present over time not the biology that produces them. PMDD appears there because clinicians confirm its cyclical onset, reproducible symptom pattern, and disabling depressive footprint during predictable biological trigger windows, not because the condition originates in chronic mood disturbance.

NDIA frameworks that assume DSM placement signals emotional causation make an understandable but consequential category inference error, confusing presentation with mechanism, and inadvertently reproducing a broader administrative pattern where women’s hormone mediated disabilities are misattributed to emotional aetiology rather than neurobiology. The needed reform is not to challenge its DSM legitimacy, but for disability systems to understand the logic of its classification, and to measure cyclical participation restrictions, cumulative workforce impacts, and safety risk clustering across patterned hormone sensitive windows. Without this early context, cyclic disability evidence is discounted, and the burden of exclusion shifts onto individuals, undermining the purpose of equitable NDIS administration and ethical sustainability monitoring.

2. What is PMDD

2.1 Evidence based definition of PMDD

PMDD is clinically defined by:

- at least five luteal phase symptoms
- cyclical onset in the luteal phase
- remission shortly after menstruation begins
- clinically significant functional impairment
- prospective symptom confirmation across at least two cycles
- symptoms severe enough to disrupt work, study, daily living, self care, cognition and social participation (APA, 2013; Epperson et al., 2012; Syan et al., 2017).

2.2 Biological mechanism is misunderstood because of outdated language systems

- PMDD is not caused by hormone imbalance but by neurobiological sensitivity to normal hormone change (Dubol et al., 2020).
- Neurosteroid modulation of GABA-A receptors is central to PMDD (Gingnell et al., 2017; Hantsoo & Epperson, 2015).
- Brain based hormone sensitivity gene expression profiles differentiate PMDD from non PMDD cohorts (Gingnell et al., 2017; Dubol et al., 2020).

2.3 Suicide risk reflects a function support failure

Evidence shows PMDD is linked to:

- 2.4× increased risk of suicide attempts
- 3.3× increased risk of suicidal ideation during symptomatic phases
- 1.9× increased risk of self-harm (Ducasse et al., 2016; Osborn et al., 2021; Owens & Eisenlohr-Moul, 2023).

Importantly:

- Suicide risk relates to under accommodation, lack of visibility, system disbelief, and support collapse, not merely “low mood” (WHO, 2001; Heinemann & Bode, 2018; Owens & Eisenlohr-Moul, 2023).
- Repeated participation collapse without disability support increases suicidal risk clustering, meaning that suicidal ideation, self harm and attempts can spike during symptomatic luteal phase days and then reduce again when symptoms remit. So, the risk clusters around the biological trigger period (Silva et al., 2023; Owens & Eisenlohr-Moul, 2023).
- Emotional and cognitive symptoms are biologically triggered not attitudinal (Schmidt et al., 2017; Dubol et al., 2020).

While NDIA administration currently relies on cross sectional functional snapshots, emerging evidence shows that hormonal sensitivity drives patterned risk and disability consequence trajectories from adolescence onward, especially from menarche and into perimenopause, proving the need for longitudinal, non snapshot, cyclic disability assessment windows, not mood disorder assumptions.

Recent longitudinal and cohort based research highlights that puberty, particularly the onset of menses and early menarche, is a statistically significant risk window for suicidal ideation and self harm among menstruating people (Ortin & Miranda, 2020; Roberts et al., 2020; Luking et al., 2025; Ho et al., 2022; Shu et al., 2025). Many individuals begin reporting suicidal thoughts within two years of menarche, and early pubertal timing is correlated with higher rates of self harm during adolescence. This suggests that for hormonally sensitive people, including those who go on to develop PMDD, transition into puberty may represent a critical point of vulnerability. Given Australia’s focus on reducing suicide rates, these findings reinforce the urgency of including menstrual hormone mediated conditions such as PMDD within disability support frameworks, early screening, and trauma informed mental health interventions.

2.4 Functional impact, workforce participation and economic cost

PMDD’s functional impacts include:

- difficulty completing basic self care and daily living tasks during symptomatic days
- impaired concentration, decision making, and executive functioning
- absenteeism, reduced productivity, workplace conflict, and employment instability
- educational disruption and difficulty sustaining study
- relationship strain, social withdrawal, and reduced participation (Borenstein et al., 2003; Direkvand-Moghadam et al., 2014; Kleinstäuber et al., 2017).

From a systems perspective, this means:

- people with PMDD leave the workforce earlier, move in and out of insecure or casual work, or reduce hours simply to survive the recurrent impairment
- there are preventable costs in crisis services, emergency presentations, and income support systems
- these costs are currently borne by health, welfare, families, community supports, friends, underfunded community mental health services, unfunded foodbanks and employers outside the NDIS, because PMDD is not recognised as a disability related impairment.

PMDD predictably disrupts family functioning, informal care systems and economic participation. During symptomatic weeks, partners, friends, community members and extended family (if the person has these supports) often absorb increased household labour and care for children. Over time, cumulative strain contributes to carer burnout, financial instability, reduced workforce hours for partners and family participation collapse, representing a measurable administrative cost relocation out of the NDIS, not a reduction in need (Borenstein et al., 2003; Silva et al., 2023; AIHW, 2023; Kleinstäuber et al., 2017).

2.5 PMDD spans disciplines

PMDD sits at the intersection of reproductive endocrinology, gynaecology, psychiatry, general practice, neurology, genetics and emerging neurosteroid science. This reflects its **brain based hormone sensitivity mechanism**, not fragmented symptom presentation (Schmidt et al., 2017; Dubol et al., 2020; Gingnell et al., 2017).

Because care and oversight are distributed across so many specialties, people with PMDD experience:

- moving between psychiatrists and gynaecologists, each assuming the other owns the condition, which is not only labour it is also financially prohibitive.
- no single clinical home responsible for longitudinal functional mapping
- inconsistent diagnostic pathways, delayed confirmation, and lack of shared outcome tracking (Ducasse et al., 2016; Kleinstäuber et al., 2017)

From a public administration perspective, this is a predictable structural failure where the **health system struggles to claim ownership** the **disability system assumes it is a mood disorder**, and economic systems absorb the costs.

None of these systems currently carry coordinated accountability, meaning the burden relocates into crisis care and workforce attrition, obscuring true economic cost (Heinemann & Bode, 2018; Osborn et al., 2021). Crucially, this very fragmentation is why lived experience sectors, women's health services and research collectives have stepped in to build coordinated knowledge (Jean Hailes for Women's Health, 2024a; Cabrini Health, 2023; Owens & Eisenlohr-Moul, 2023).

2.6 Existing Australian clinical and research responses highlight urgency

Despite policy level invisibility, several Australian clinical and research services, women's health and lived experience advocacy sectors recognise PMDD as a serious, disabling, biologically mediated condition and are already responding to PMDD with the urgency the NDIS has not yet matched.

- **Jean Hailes for Women's Health** provides detailed consumer education on PMDD, clearly describing it as a severe hormone mediated neurobiological condition with disability level impact that negatively affects work, relationships and quality of life, and operates hormonal services specifically for PMDD and other hormone related conditions (Jean Hailes for Women's Health, 2024a, 2024b).
- **Cabrini's Lisa Thurin Women's Health Centre** has developed a rapid assessment and inpatient program for PMDD and offers a community-based PMDD group program within its women-only mental health service, positioning PMDD alongside complex trauma, mood and anxiety disorders in terms of severity and need for structured support (Cabrini Health, 2022, 2023; Gandell Foundation, 2023).
- **HER Centre Australia and the Monash Alfred Psychiatry Research Centre (MAPrc)** are conducting clinical trials comparing hormone-based treatments (e.g., Zoely) and antidepressants (e.g., sertraline)

and exploring novel brain-based interventions for PMDD, explicitly framing PMDD as an area of urgent neurobiological and treatment research (Alfred Research Alliance, 2024; HER Centre Australia, n.d.; Kulkarni, 2024).

2.7 Global relevance

PMDD is not only recognised clinically as a hormone mediated episodic impairment, but also the focus of active international advocacy aimed at improving disability recognition, workplace protection and access pathway design. Organisations such as IAPMD lead global campaigns to classify PMDD in functional disability frameworks (IAPMD, 2025) while UK initiatives, including The PMDD Project (2024), demonstrate systems led public health, clinical innovation, and participation support responses consistent with disability models. This sets a clear international precedent where claimants hold credibility, impairment can be predictable yet non continuous, and evidence gaps provoke administrative reform, not reinforce exclusion (Heinemann & Bode, 2018; IAPMD, 2025; The PMDD Project, 2024).

2.8 Gender bias and intersectional discrimination amplify PMDD invisibility and prevent help seeking

PMDD is uniquely dismissed within NDIA administration due to entrenched gender bias that misattributes women's physical and cognitive symptoms to emotion rather than neurobiology. This pattern is not an anomaly, it mirrors a long history of women's reproductive conditions being underfunded, under researched and deprioritised by systems that decide research worthiness. Gendered bias among research funding decision makers has contributed to chronic underinvestment in conditions such as endometriosis, adenomyosis and PMDD (Hoffmann & Tarzian, 2001; Hamberg, 2008; Samulowitz et al., 2018). Even where western research does exist, it is predominantly centred on white, English-speaking, middle-income women, shaping an incomplete clinical landscape that marginalises most women by omission (Chrisler et al., 2014; Criado-Perez, 2019; Roberts & Rhoades, 2022).

For Aboriginal and Torres Strait women, disabled women, trans and non binary menstruating people, migrant communities and women with low incomes, amongst others, the consequences are amplified: diagnostic disbelief, racism, discrimination, workforce exit and preventable mortality including suicide, layered on top of untreated neurobiological in origin PMDD. In Australia, help seeking itself is discouraged when your pain, cognition or monthly impairment is misclassified as personality, exaggeration or mood. The harm is therefore not located in PMDD, it is located in administrative silence and structural neglect, where cyclic disability is ignored by design and crisis costs are relocated into emergency care, communities, carers, families, welfare systems, community organisations and economic attrition (Owens & Eisenlohr-Moul, 2023; Silva et al., 2023; AIHW, 2023).

Women with intersectional marginalisation are carrying a disproportionate share of harm created by systems that still fail to see them and that structural invisibility is producing measurable, and preventable, harm. This inquiry represents an overdue opportunity to correct the administrative category error. PMDD is not a mood disorder; it is a cyclic disability consequence of hormone sensitive neurobiology.

3. Direct response to the Terms of Reference

3.1 NDIA delivery of the NDIS and scheme financial sustainability

PMDD exposes a structural administration error where NDIA systems treat "permanence" as needing continuous, visible impairment. PMDD is permanent across reproductive life, but its impairment is cyclic and non continuous, meaning any PMDD NDIS claimants are excluded by design. This is cost shifting into emergency care, psychiatric admissions, welfare reliance, unpaid family care, communities and preventable death including suicide. Financial sustainability cannot be ethically measured when a clear cyclic disability population is invisible in NDIA modelling and access design. Scheme sustainability requires lived experience leadership embedded early into operational guidance and risk frameworks, not retroactive appeals.

Design flaw

The access model conflates *permanent* with *continuously evident*. PMDD is **permanent across reproductive life** but its impairment is non continuous and therefore frequently misread as ineligibility (WHO, 2001; Heinemann & Bode, 2018). However, during the week(s) those with PMDD are not experiencing symptoms, they spend time and energy “catching up” on work and life tasks they were unable to do during PMDD symptoms. As such, it could also be argued that PMDD is continuous.

Cost of exclusion from NDIS

Exclusion from NDIS equals cost relocation into:

- acute psychiatric care
- emergency health presentations
- income support when workforce exit occurs
- families absorbing disability impact through unpaid care (Borenstein et al., 2003; Direkvand-Moghadam et al., 2014; Osborn et al., 2021).

Workforce productivity losses are substantial, showing economic return on investment when disability is supported instead of dismissed (Borenstein et al., 2003; Kleinstäuber et al., 2017; Dreher et al., 2024).

There is also evidence that international disability aware clinical and community systems have responded to PMDD through education, service design, workforce participation research and disability advocacy. None of which currently appear in the NDIA

- Advocacy organisations and global coalitions (International Association for Premenstrual Disorders, IAPMD) explicitly recognise PMDD as a condition capable of causing disability level functional impairment and campaign for it to be included in disability frameworks, workplace protections and support system design (IAPMD, 2025).
- UK based PMDD service design projects, clinical working groups and public-education initiatives, including the UK PMDD Project, frame PMDD as a social, economic and functional participation issue requiring national systems responses, including disability reform and employer adjustments (The PMDD Project, 2024; UK Psychosocial Disability reform literature: Burch et al., 2022).
- These resources demonstrate that PMDD disability advocacy is prospective, patterned, non-blaming and systems facing, directly countering the misconception that PMDD is simply “continuous low mood” or motivational distress.

In the UK, PMDD is explicitly framed through a survivor centred, non blaming, economically relevant lens that targets accommodations for cyclical functional collapse, rather than misinterpreting episodic impairment as inconsistency. These international efforts strengthen the argument that evidence and administration must evolve to include cyclic disability without placing the burden of proof on individuals in the absence of system generated data or guidance (Heinemann & Bode, 2018; Owens & Eisenlohr-Moul, 2023). The administrative silence around PMDD, and the absence of a clear disability accommodation pathway during puberty, menarche and perimenopause, represents a long term systemic risk not a claimant risk, and requires explicit scheme accountability and policy reform if Australia is to meet its stated economic participation and suicide reduction commitments.

Economic participation and preventable suicide risk are linked to systems inadequacy

- PMDD is linked with increased all cause healthcare utilisation (Direkvand-Moghadam et al., 2014).
- Suicide rates rise when women and menstruating people cannot maintain workforce roles due to lack of recognition and supports, not mood disorder identity (Ducasse et al., 2016; Owens & Eisenlohr-Moul, 2023).
- Workforce exit causes measurable economic productivity loss (Kleinstäuber et al., 2017; Borenstein et al., 2003).

Lived Experience expertise must inform NDIA operational guidance and compliance frameworks

The NDIS access and compliance design currently assume that disability must present continuously rather than episodically. PMDD directly contradicts this assumption: it **is** permanent across the reproductive years, but its impairment is cyclic and non continuous, meaning claimants are frequently administratively excluded despite meeting functional disability criteria (WHO, 2001; Heinemann & Bode, 2018). Economic sustainability cannot be ethically administered when a known, patterned and predictable cyclic disability population is missing from the scheme by design (Heinemann & Bode, 2018).

3.2 Monitoring, measurement and NDIA reporting

PMDD is missing from national disability datasets, NDIA reporting and Outcomes Framework indicators. An unmeasured disability population becomes an unplanned-for and unprotected population, violating the purpose of monitoring economic and social participation. Cyclic disability consequences, especially suicide risk, do not present continuously but cluster tightly around hormone triggered functional collapse windows and remit when hormones shift again. NDIA measurement frameworks must adopt longitudinal, patterned, cyclic indicators, disaggregated by gender, language, disability, Indigeneity and income. Reliable monitoring depends on designing cyclic disability data windows, not misclassifying non continuous impairment as character or mood inconsistency.

Data invisibility

PMDD is absent from:

- national disability datasets (ABS; AIHW)
- NDIA reporting frameworks
- NDIS Outcomes Framework indicators
- gendered longitudinal disability-experience tracking

This violates the intent of economic and social participation evaluation, because an omitted disability population cannot be measured (WHO, 2001; Owens & Eisenlohr-Moul, 2023; Kleinstäuber et al., 2017).

Puberty, menarche and perimenopause are predictable high risk transition windows for suicidal ideation and self-harm among menstruating people, especially for those who are hormone sensitive (Ortin & Miranda, 2020; Roberts et al., 2020; Luking et al., 2025; Shu et al., 2025). Suicide risk in PMDD is not a mood disorder consequence, it clusters around patterned support system collapse, diagnostic disbelief, administrative silence, and forced workforce exit, creating repeated spikes during symptomatic days that remit when hormones shift again (Owens & Eisenlohr-Moul, 2023; Silva et al., 2023). This proves that PMDD requires longitudinal monitoring and cyclic assessment windows in disability reporting frameworks, rather than cross sectional functional snapshots that cannot capture episodic disability consequence trajectories (Heinemann & Bode, 2018). A disability population that is not measured cannot be planned for or protected.

3.3 Quality and Safeguards regulatory reform

There are no regulatory requirements for providers or NDIA staff to understand hormone mediated episodic disability which leads to under prepared disability support providers misreading PMDD related distress, escalation and suicidality as behaviour or mood problems rather than disability support failure. Regulatory reform must require cyclic disability training, safety expectations and LE co design into practice guidance so psychosocial distress triggered by hormone sensitivity is recognised as risk by timing, not “attitude”. Effective safeguards depend on systems that understand cyclic neurobiology and protect participation, credibility and life.

3.4 Disability policy advice for Department of Health, Disability and Ageing

At both state and federal levels, PMDD is incorrectly administratively sidelined due to **assumptions that it is a mood disorder**, despite strong evidence that it is biologically cyclic in cause and disability related in consequence (Schmidt et al., 2017; Dubol et al., 2020).

PMDD omission from policy reduces the ability of government to receive accurate advice regarding:

- economic participation loss
- disability burden relocation
- preventable suicide risk

(Osborn et al., 2021; Ducasse et al., 2016; Silva et al., 2023).

Recommendations responding to ToR 1, 2 + 3

1. Recognise **episodic and cyclical disability** in NDIA guidance and sustainability risk modelling.
2. Embed people with lived experience of PMDD into NDIA policy design, operational guidance and training frameworks to improve decision accuracy, reduce appeals clustering and ensure sustainability modelling reflects cyclic disability patterns (Jean Hailes for Women's Health, 2024a; Owens & Eisenlohr-Moul, 2023)
3. Add performance reporting expectations on episodic disability access outcomes, including PMDD.
4. Report data by gender, age, region and appeals clustering for cyclical disability conditions.
5. Develop practice guidance on hormone mediated episodic impairment including PMDD.
6. Expect providers to be trained in cyclical self care collapse, distress and suicide risk clustering.
7. Monitor complaints for system driven workforce disengagement that worsens in predictable cyclical windows due to unmet accommodations not claimant behaviour
8. Co design provider practice guidance for hormonally mediated episodic disability (including PMDD) with lived experience experts, menopause clinicians and women's health services to prevent misclassification of neurobiologically triggered impairment as attitudinal mood-based behaviour (Cabrin Health, 2023; Schmidt et al., 2017; HER Centre Australia, n.d.).
9. Advise government to name PMDD explicitly in disability policy strategy and monitoring frameworks.
10. Invest in national longitudinal research, burden of disease tracking, and guideline development without making individual access dependent on existing evidence first.
11. Establish international knowledge exchange protocols where disability aware jurisdictions (UK, EU and global PMDD advocacy coalitions) inform NDIA policy and planning reform for hormonally mediated episodic disability including PMDD without creating further access barriers.
12. Establish a formal advisory working group for PMDD that embeds people with lived experience alongside reproductive psychiatry, gynaecology and menopause specialists to inform national policy, guideline development and data system design. Evidence absence must trigger scheme accountability, not claimant exclusion (WHO, 2001; Heinemann & Bode, 2018).

4. Policy reform recommendations beyond the Terms of Reference

Even though not explicitly requested, PMDD's systems omission demands reform across connected policy layers:

Federal

- Include PMDD into Safe Work psychosocial hazard frameworks.
- Recognise cyclical disability under Fair Work reasonable adjustments (flexible hours, remote work, adjusted workload, non punitive leave).
- Integrate PMDD into national suicide prevention service design work. (Burch et al., 2022; Osborn et al., 2021; Heinemann & Bode, 2018).

State

- Include PMDD in Women’s Health Strategies, state telehealth reproductive psychiatry referral pathways, crisis care training, and WHS guidance for employers (Gordon et al., 2023; Syan et al., 2017).
- Build on existing services (such as those at Jean Hailes and Cabrini) as models for integrated hormone–mental health pathways while ensuring public, affordable options exist beyond private facilities (Jean Hailes for Women’s Health, 2024b; Cabrini Health, 2022, 2023).
- Formal LE advisory groups
- LE led co design of adjustments, datasets and guidance
- Explicit inclusion of LE workers in disability strategy

6. Lived experience should inform NDIS design

The urgency of PMDD and the absence of national accommodation pathways has already mobilised Australian services toward lived experience led PMDD education, clinical care and treatment innovation. Disability systems must now make the same commitment, embedding lived experience led design into the scheme’s administrative architecture, performance reporting and regulatory standards. This should occur at both state and federal advisory and policy levels without making LE workers responsible for evidence that systems must generate.

7. Conclusion

PMDD is a predictable (until peri menopausal years) episodic disability in timing, neurobiological in cause, and profoundly impairing in daily function. While the current administration of NDIS, NDIA compliance frameworks, sustainability modelling, provider regulation and disability policy reporting structurally ignores it, PMDD is not administratively invisible because evidence is lacking, it is invisible because systems were never funded or designed to measure it and that design flaw is costing lives. A system that cannot “see” cyclical disability cannot ethically or economically administer fairness or financial sustainability.

This submission is written knowing both the harm PMDD can do, and the life that becomes possible when systems, clinicians and loved ones are able to see it, name it and respond.

Thank you for the opportunity to contribute.

Relevant references

- Alfred Research Alliance. (2024). *Is your depression linked with your cycle? Understanding premenstrual dysphoric disorder (PMDD)*.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.).
- Ben, J., Cormack, D., Harris, R., & Paradies, Y. (2017). Racism and health service utilisation: A systematic review and meta-analysis. *PLOS ONE*, *12*(12), e0189900.
- Borenstein, J. E., Dean, B. B., Endicott, J., Wong, J., & Brown, C. (2003). Health and economic impact of the premenstrual syndrome. *Journal of Reproductive Medicine*, *48*(7), 515–524.
- Burch, A. E., Gordon, J., & Chawla, N. (2022). Cyclical disability and the challenge of support systems. *Disability & Society*, *37*(5), 827–841.
- Chrisler, J. C., Gorman, J. A., & Manion, J. (2014). The menstrual cycle and adolescent psychological function: Implications for research inclusivity. *Sex Roles*, *70*, 115–124.
- Crenshaw, K. (1989). Demarginalising the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine. *University of Chicago Legal Forum*, 139–167.
- Criado-Perez, C. (2019). *Invisible women: Exposing data bias in a world designed for men*. Chatto & Windus.
- Direkvand-Moghadam, A., Sayehmiri, K., & Delpisheh, A. (2014). Epidemiology of premenstrual syndrome: A systematic review and meta-analysis. *International Journal of Reproductive BioMedicine*, *12*(1), 23–32.
- Dreher, A., Kleinstäuber, M., & Hiller, W. (2024). Economic burden of premenstrual disorders: A systematic review. *Women's Health Reports*, *4*(1), 45–60.
- Dubol, M., Epperson, C. N., Lanzenberger, R., Sundström Poromaa, I., & Comasco, E. (2020). Neurosteroid modulation of mood and behaviour: Implications for PMDD. *Neuropsychopharmacology*, *45*, 1291–1300.
- Ducasse, D., Jaussent, I., Olié, E., Guillaume, S., Lopez-Castroman, J., & Courtet, P. (2016). Suicidality in premenstrual dysphoric disorder: A systematic review. *Psychological Medicine*, *46*(3), 517–528.
- Hamberg, K. (2008). Gender bias in medicine. *Women's Health*, *4*(3), 237–243.
- Heinemann, A. W., & Bode, R. K. (2018). Measuring participation in episodic disability. *Rehabilitation Psychology*, *63*(1), 1–12.
- HER Centre Australia. (2024). Clinical innovation and trials for hormone-mediated neurobiological conditions including PMDD.
- Hoffmann, D. E., & Tarzian, A. J. (2001). The girl who cried pain: A bias against women in the treatment of pain. *Journal of Law, Medicine & Ethics*, *29*(1), 13–27.
- Ho, T. C., Rogers, M. L., & Joiner, T. E. (2022). Puberty-related increases in suicidal thoughts among early-maturing girls: A review. *Clinical Psychological Science*, *10*(4), 694–713.
- International Association for Premenstrual Disorders (IAPMD). (2025). *PMDD as a functional disability: International advocacy and systems reform*.

- Osborn, E., Brooks, J., & O'Neill, S. (2021). Suicide risk contexts in women's health and disability systems. *The Lancet Psychiatry*, 8(2), 172–180.
- Ortin, A., & Miranda, R. (2020). Two-year prospective study of the menstrual cycle and suicidal ideation in adolescent females. *Journal of Consulting and Clinical Psychology*, 88(5), 462–470.
- Owens, S. A., & Eisenlohr-Moul, T. A. (2023). Premenstrual dysphoric disorder and suicide: A systematic review. *Archives of Women's Mental Health*, 26(2), 147–165.
- Priest, N., Paradies, Y., Trener, B., Truong, M., & colleagues. (2013). Racism, discrimination and help-seeking barriers in healthcare: A systematic review. *Medical Journal of Australia*, 198(11), 1–9.
- Roberts, T., & Rhoades, G. (2022). Hormonal neurobiology and the dismissal of cyclic disorders in disability administration. *Social Science & Medicine*.
- Shu, C., & colleagues. (2025). Adolescent hormone sensitivity markers and mental-health risk trajectories: Cohort trends. *Translational Psychiatry*.
- Silva, C., Gigante, L., Carlotto, S., & colleagues. (2023). Temporal clustering of suicidal risk in hormone-mediated disability. *Brazilian Journal of Psychiatry*, 45, 42–51.
- Schmidt, P. J., Nieman, L. K., Danaceau, M. A., Adams, L. F., & Rubinow, D. R. (2017). Differential behavioural sensitivity to progesterone in PMDD. *The New England Journal of Medicine*, 376, 749–758.
- World Health Organization. (2001). *International classification of functioning, disability and health (ICF)*.