Scottish Parliament Social Justice and Social Security Committee

Budget scrutiny 2026-27, Future Social Security Spending in Scotland

Written submission by Dr Lynsay Matthews, Mhairi Campbell and Dr Eileen Harkess-Murphy (University of the West of Scotland) and Julie Riddell (University of Glasgow)

Introduction

We welcome the opportunity to respond to the Scottish Parliament's Social Security Committee inquiry on future social security spending in Scotland.[1]

This response draws on findings from recently published research by Mhairi Campbell, Dr Lynsay Matthews and Dr Eileen Harkess-Murphy (University of the West of Scotland), and Julie Riddell (University of Glasgow).[2] The research, 'Premenstrual Dysphoric Disorder – The welfare State: Recommendations for Reform', explores the experiences of people with Premenstrual Dysphoric Disorder (PMDD) who have applied for a social security benefit, including Adult Disability Payment (ADP) in Scotland. Insights were also gathered from professional stakeholders with experience of supporting individuals through the social security system.

The research informed the final report of the Scottish Government's Independent Review of Adult Disability Payment (ADP).[3] Mhairi Campbell contributed to the review as a member of its Advisory Group.[4]

PMDD is a severe hormone-based mood disorder that can significantly impact daily life. We welcome growth in social security spending to ensure that Scotland has a devolved system that prioritises the rights and needs of those who require support. However, our research shows there are significant gaps in the current system which must be addressed to ensure it operates effectively and aligns with the rights-based model envisioned by the Scottish Government. Without addressing these gaps, there is a risk of worsening existing inequalities and excluding those already facing barriers to assessment and support.

This response provides evidence on how people with PMDD experience the current

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[1] https://yourviews.parliament.scot/sjssc/future-social-security-spending-in-scotland/consult_view/

[2] Campbell M, Matthews L, Riddell J, Harkess-Murphy E. (2025). Final report. Premenstrual Dysphoric Disorder and the welfare state: recommendations for reform. University of the West of Scotland. https://doi.org/10.5281/zenodo.15492686

[3] https://www.gov.scot/publications/independent-review-adult-disability-payment-final-report/

[4] https://www.gov.scot/groups/adult-disability-payment-independent-review/

social security system in Scotland and offers recommendations to ensure future spending priorities are fair and inclusive. While the focus is on PMDD, many of the challenges identified are shared by people living with other fluctuating or hidden health conditions.

Summary of key points

- PMDD is under-recognised and under-researched, despite affecting 1 in 20 women and people who menstruate.
- The current ADP assessment model fails to reflect the lived reality of fluctuating conditions like PMDD.
- Key challenges include: inadequate support for fluctuating conditions; lack of a trauma-informed approach across all aspects of the social security system; lack of awareness and accessibility of support with social security applications.

We recommend:

1. Embedding trauma-informed approaches across all systems, processes and organisational practices
2. Providing mandatory trauma-informed training and resources for all decision making personnel within Social Security Scotland and the Department of Work and Pensions
3. Implementing trauma-informed decision letter templates as standard practice
4. Reforming eligibility criteria for fairer assessment of mental health related symptoms
5. Reforming eligibility criteria for fairer assessment of fluctuating conditions
6. Applying the social model of disability to the assessment of fluctuating conditions
7. Enhancing training on fluctuating conditions for decision-makers
8. Strengthening the outreach and promotion of available support services for applicants
9. Providing clear, accessible, and supportive application guidance
10. Establishing peer support and independent advocacy services

What is PMDD?

PMDD is under-researched and often overlooked in policy and practice, affecting 1 in 20 women and people who menstruate. It is a severe hormone-based mental disorder that causes debilitating psychological symptoms in the latter half of the monthly menstrual cycle. In the UK, an estimated 1.1 million people have PMDD, of which 72% will experience suicidal ideation, 50% will self-harm, and 33% will attempt suicide. On average, diagnosis takes between 12 and 20 years.

Within the UK, there are approximately 22 million people of reproductive age, with approximately 1.2 million living within Scotland. We know that 1 in 20 people who menstruate will be living with PMDD, meaning around 1.1 million people in the UK (60,000 people in Scotland) will be living with PMDD. This is similar to the number living with bipolar disorder.

Based on 2022 Scottish Census data, approximately 1 in 4 women (n=225700) aged 16-49 reported living with a mental health condition. If everyone with PMDD reported having a mental health condition, this would suggest that 1 in 4 people with a mental health condition could actually have PMDD. This highlights the scale of a largely invisible issue, with the number of people living with PMDD comparable to those diagnosed with bipolar disorder.

Question 1. To what extent do you welcome the growth in devolved social security spend? Please explain your response.

As outlined further in our response to Question 3, our research findings highlight key gaps in the social security system for those living with fluctuating conditions like PMDD. We therefore welcome the growth in devolved social security spending, as well as the Scottish Government’s decision to invest additional resources in Adult Disability Payment, beyond the funding it receives from the UK Government.

However, this additional spend must be used effectively to ensure that support is fair and inclusive for everyone entitled to it. People must be able to access social security in a timely and accessible manner, free from judgment and stigma, and delivered in a trauma-informed way.

Question 2. To what extent are you concerned about the growth in devolved social security? Please explain your reasons.

While we welcome the growth in devolved social security spending, we are concerned that funding may not be allocated in a way that reflects the full breadth of disabilities and long-term conditions requiring support. Any increase in spending must be firmly grounded in the rights of those who require support, with an understanding of – and commitment to address – the current challenges people face when accessing social security.

Our research highlights ongoing systemic barriers to accessing ADP for people living with fluctuating conditions. Further detail on the challenges of evidencing such conditions in the current social security system is provided in our response to Question 3.

Question 3. What is the evidence that spending on devolved social security is effective in supporting those who need it?

Despite the Scottish Government’s intention to deliver a fairer, rights-based model of devolved social security, our research shows that many eligibility criteria and regulatory structures risk reproducing inequalities that we have seen in the UK welfare benefits system. We recommend that the following gaps are addressed and prioritised in future social security spending plans.

1. *Inadequate support for fluctuating conditions*

PMDD is a severe hormone-based mood disorder, with internationally recognised diagnostic criteria and treatment guidelines. However, it remains an unrecognised and unfamiliar diagnosis for many professionals. This lack of awareness adds a burden to applicants when they need support.

PMDD symptoms are not constant, yet can have a severe impact on physical, cognitive and emotional functioning. People typically experience symptoms during the luteal phase of the menstrual cycle – typically for 1-2 weeks per month. However, the effects often extend beyond this phase due to individuals navigating trauma responses (e.g. post-traumatic stress disorder), other mood disorders, tiring recovery time, and ongoing management issues such as counselling and/or health service appointments.

Under current ADP rules, applications are assessed against twelve daily living activities and two mobility activities, with points awarded if the applicant meets or exceeds the relevant ‘descriptors’ for each activity. To receive points, a condition must impact someone more than 50% of the time. However, this threshold fails to reflect the lived experience of fluctuating conditions like PMDD, creating a systemic barrier to accessing support. As one participant explained:

> *“I think definitely the PMDD, you’re affected for more than ten days most o’ the time. You know, even if that’s if you’re not having symptoms on they days, it’s like the kinda aftermath o’ that, isn’t it, that you’re recovering from. And the low self-esteem, you know, it does definitely affect ye more than fortnightly, PMDD. But trying tae, trying tae you know convince people o’ that is, is very hard” (Person with PMDD, Scotland)*

The prescriptive, inflexible nature of the application process also makes it challenging to evidence the mental health symptoms, which are often debilitating. Participants noted differences in how physical and mental health symptoms were assessed, despite their psychological symptoms having the most detrimental impact on their life. In some cases, PMDD was omitted entirely from decision letters, even when it was central to the application. This felt unprofessional and confusing, and had a significant impact on applicants. One participant shared:

> *"So when I got my decision it just wasn't even mentioned, it was only focused on my other health condition, which is more physical in nature"* (Person with PMDD, Scotland)

Obtaining supporting evidence from health professionals was described as another key barrier. Participants reported inconsistencies in the availability of medical reports, instances of health professionals refusing to give reports or not responding to requests, and some people receiving documents for free, while others were asked to pay.

There was also variation in understanding what constitutes 'good practice' when completing applications. For example:

> *"The top tip that I was told is to write it from the perspective of your worst days."* (Person with PMDD, Scotland)

> "*People do always say you should take your worst day. But actually you shouldn't. I've been in so many tribunals where people have come across like they've exaggerated*." – (Professional stakeholder, Scotland)

Future social security spending in Scotland must be guided by lived experience to ensure that the system is safe, fair and trustworthy, and reflects the nuances and specific experiences of conditions like PMDD.

2. Lack of a trauma informed approach

People with PMDD are known to have a higher prevalence of past trauma than people without PMDD. However, research participants described experiences that did not align with trauma-informed care. This was evident in all aspects of the social security process, including applications, assessments, and both written and verbal communication.

Future social security spending should ensure all decision-making personnel receive mandatory trauma-informed training, including specific awareness of fluctuating conditions like PMDD, developed with input from researchers, experts and people with lived experience.

3. Lack of awareness and accessibility of support

Another key challenge to accessing social security is that many people are unaware that support exists to help with the application process. PMDD causes significant cognitive changes, which can make it difficult to think, concentrate and make decisions. It can therefore be very difficult for people with PMDD who are experiencing exhausting and overwhelming psychological symptoms to begin and complete an application, typically at a time when support is most needed. This was described by one research participant as follows:

> *“If you consider even the task of filling out all the information as a daily living activity is like impossible without the important support of other people”* (Person with PMDD, Scotland)

Participants also described the application process as both emotionally traumatic and logistically challenging, with many relying on friends and family to complete it. The practical demands of the application process were especially difficult to manage when applicants were at their most unwell and vulnerable. As one participant described:

> *“The task of like filling out all the information as a daily living activity is like impossible, without the important support of other people. And that like cultural capita of like what is required, like all these insider tips of like what is required in order to communicate our symptoms and our struggles in a way that’s palatable for the form”* (Person with PMDD, Scotland)

Most research participants were unaware that support existed to help with the application process. They described that despite reading all the information, they saw no mention of services to support them with their application:

> *“I wasn’t aware of that [support] {…} it’s not on any of the social security documents. It’s not on anything that’s come through the door”* (Person with PMDD, Scotland)

On hearing that support was available, some participants described reluctance to engage, based on concerns about transparency or quality of the support. People described fear, anxiety and panic about applying, with some feeling unable to appeal an application that was rejected.

Even when aware of support, some participants felt that the information that was provided was not accessible for individuals facing additional barriers, such as cognitive impairments or neurodiversity:

> “*Reasonable adjustments are talked about everywhere, but they seem to be forgotten about in the ADP process. There is no consideration to how the info is presented or worded*” (Person with PMDD, Scotland)

Professionals with experience of supporting people also described the emotional impact of the application process, and the enormous pressure on support services due to funding cuts and lack of staff.

In this regard, it is crucial that the outreach and promotion of available support services for applicants is strengthened, with clear, accessible and supportive application guidance, and strong peer support and independent advocacy services are made available.

4. Specialist knowledge

We note that the UK Government Department for Work and Pensions recently published research exploring how specialist and condition-specific training or experience in health assessments could potentially improve the process for benefit claimants.[5] The findings highlight that specialisation was generally considered beneficial for claimants, particularly in improving trust in the assessor and improving confidence and satisfaction with the assessment outcome. Given that PMDD is often under-supported and misdiagnosed, we recommend that consideration is given to the value of specialist support for PMDD.

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[5] https://www.gov.uk/government/publications/specialism-in-the-health-assessment-initial-exploratory-research/specialism-in-the-health-assessment-initial-exploratory-research#research-methods