Engender response to the Scottish Government consultation on disability assistance in Scotland

1. INTRODUCTION

Engender has been engaged on work around gender and social security since the 2010 programme of Welfare reform and over that period we have sought to highlight the ways in women, who are twice as likely to rely on social security for their income, have been systemically and grotesquely disadvantaged by reforms. 86% of cuts as part of the ‘decade of austerity’ between 2010-2020 will come from women’s incomes. With the establishment of Social Security Scotland we successfully campaigned with other equalities organisations for the inclusion of the principle of equality and non-discrimination on the face of the Act.

We therefore welcome this opportunity to respond to the Scottish Government’s consultation on the future of devolved disability assistance within Social Security Scotland. In the UK, women are a small majority of disabled people and, as a group, disabled women are amongst the very hardest hit by welfare reform. Over half of the cuts to benefits between 2010 and 2015 fell on disabled people and their families.

Research undertaken by the UK Women’s Budget Group (WBG) found significant inequalities faced by disabled women, including:

- Disabled women earn less (22.1%) than non-disabled men, a gender pay gap four percentage points higher than between all men and women.
- Poverty rates have been increasing since 2010 and now 26% of households with a disabled person are in poverty, compared to 22% in the overall population.

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1 Engender, (2015) ‘Securing Women’s Futures: Using Scotland’s new social security powers to close the gender equality gap’.
• One in two disabled women experience domestic violence in their lifetime and they face additional barriers in seeking help and support.⁵
• Because many disability benefits were cut or frozen since 2010 while living costs have increased, they do not reflect the true extent of extra costs that disabled people face.⁶

However, research and data relating disabled women’s experience of changes to tax and ‘welfare’ since 2010 is extremely limited, particularly at the Scottish level.

We have also previously called for the new Scottish social security system to coproduce its disability benefits system based on dignity and human rights through engagement with a gender-balanced group of disabled people and ensure that the process adopts a gender lens. As the Scottish Government and Social Security Scotland are bound by the principles of equality and non-discrimination by the Social Security (Scotland) Act 2018, as well as the Public Sector Equality Duty, collecting data about experiences and outcomes for disabled women will be key to the continuous improvement of disability assistance entitlements.

All of this means it is crucial that the new entitlement rebuilds trust in the system amongst disabled people and carers who have been negatively affected by cuts and who have found assessments undignified and unfair. While the ‘safe and secure’ transition is a valuable approach which will ensure management moves from DWP to SSSA faster, there is a risk that it denies a more fulsome and thorough review of how disability assistance can meet need. Scottish Government must take this opportunity to ensure disability assistance proactively promotes equality and fairness.

2. KEY ISSUES ADDRESSED IN THIS RESPONSE

Throughout this consultation response, we have limited our remarks to areas where we feel Engender’s gender analysis could add value to the development of a disability assistance which delivers against the principles of fairness, dignity and equality and non-discrimination. Some of the key points from throughout are summarised as follows:

1. Not enough research and gender analysis has been done into the application of points-based systems. Evidence indicates that care is being used as evidence against women’s applications in a way that is external to the formal

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application process. Points-based systems should not be replicated without a thorough analysis of decision making, and training for assessors/advisors should include gender, women’s health, and inequalities.

2. The current gender-blind assessments are at least partially connected to highly gendered household dynamics and do not work for those with mental health or fluctuating conditions.

3. Proposals to maintain the ‘28-day rule’, where entitlement is suspended for example during a prolonged stay in hospital, risk undermining individual independence and dignity and causing financial hardship, especially where it cuts off passported entitlements such as carer’s allowance.

4. The option of a face-to-face assessment should always be available for individuals at their request but the Scottish Government should ensure no-one is reviewed more frequently than under PIP and explore the implementation of lifetime awards.

5. Women should not be penalised for childcare or public transport issues which impact on their ability to attend assessments.

6. Changes to disability support must not negatively impact carer’s entitlements even in the short term ahead of a more thorough review of carers support.

7. The equality impact assessment (EQIA) must be completed at the earliest opportunity and a gendered analysis of PIP undertaken before criteria and processes are replicated that may unwittingly disproportionately negatively impact on women.

8. Data collection and analysis, including gender-disaggregation, should be built into the system to ensure compliance with the continuous improvement equality and non-discrimination principles.

3. RESPONSES TO CONSULTATION QUESTIONS

QUESTION 1
Do you agree or disagree with the proposal to name disability assistance for clients aged 0-18 years old disability assistance for children and young people (DACYP)?

Disagree.

QUESTION 2
If you disagreed, please could you explain why:

We have a number of concerns relating to the proposed acronyms. Firstly, PIP is a recent introduction into the UK ‘welfare’ system. The proposed acronyms are so different to PIP that there will need to be concerted effort to ensure visibility of the
new Scottish payments when they go live. The names or acronyms should be as clear as possible to minimise disruption and maximise take-up for individuals who are eligible for them. We also believe that they are inconsistent with a rights-based approach to social security, instead reliant on a medical or charitable model. Wording which emphasises the ‘entitlement’ should be sought. As an example, we are broadly supportive of an option suggested by the Health and Social Care Alliance: ‘Independence Assistance/Payment’.

**QUESTION 3**

Do you agree or disagree with the proposal to name Disability Assistance for clients aged 16 years old to state pension age Disability Assistance for Working-Age People (DAWAP)?

Disagree.

**QUESTION 4**

If you disagreed, please could you explain why:

See answer to question 2. Furthermore the **name of the entitlement should be decoupled from ‘work’ & ‘working age’,** which is suggestive of a narrow concept of ‘work’ based on labour market participation that ignores household labour such as care, which is unconnected to any ‘working-age.’

**QUESTION 5**

Do you agree or disagree with the proposal to name Disability Assistance for clients who are state pension age or older Disability Assistance for Older People (DAOP)?

Disagree.

**QUESTION 6**

If you disagreed, please could you explain why:

See answer disagreed to question 2.

**QUESTION 7**

Do you agree or disagree with the proposal to enable multiple application channels for Disability Assistance?

Agree.

**QUESTION 9**

Do you agree or disagree with the proposal to broadly replicate the current temporary absence rules?
Neither agree nor disagree.

**QUESTION 10**

If you disagreed, please could you explain why?

Any rules on *temporary absence should not penalise individuals who meet the habitual residence test* but have been out of the UK for more than 52 weeks over the past three years. The rules should also recognise the multitude of reasons why individuals who meet the habitual residence test may be present in the rest of the UK such as for work or to stay with family, which may also include women leaving households where there is domestic abuse.

**QUESTION 11**

Do you agree or disagree with the proposal to implement a person-centred approach to making decisions about entitlement for Disability Assistance?

Agree.

**QUESTION 12**

If you disagreed, please could you explain why?

While we agree that a holistic person-centred approach which treats individuals with dignity and respect is a positive necessity, we also recognise that the balance between person-centred and subjective is a difficult one with the potential to become discriminatory. *It will be essential that training, including gender competence, for advisors addresses biases, stereotypes, and assumptions to ensure that assessors take into account the reality of women’s lives.* Additionally, it is crucial that there are accessible and practical forms of challenges where individuals feel decisions have penalised them unfairly.

**QUESTION 15**

What factors should Case Managers take into account in deciding when a Specialist Advisor should be involved?

We support the position of the Health and Social Care Alliance, who state that “Social Security Scotland should consider involving a specialist advisor when an individual is identified as:

- Living with a rare or complex condition
- Living with more than one long term condition
- Living with a fluctuating condition”

Additionally, there is now a wealth of evidence that conditions that affect women in greater numbers are poorly diagnosed with women having to self-advocate with
medical professionals for a diagnosis over many years. Examples include ME which is 4 times more likely to affect women than men.\textsuperscript{7} The House of Commons has also recently addressed the need for fibromyalgia to be recognised as a disability, a condition where women are 7 times more likely than men to be affected.\textsuperscript{8} Endometriosis takes an average of 7.5 years to receive a diagnosis.\textsuperscript{9} Advisors and Specialist Advisors should have regard to specific issues around women’s health and the gendered nature of what are understood to be long-term conditions and impairments.\textsuperscript{10}

\textbf{QUESTION 16}

Do you agree or disagree that the decision-making process for Disability Assistance for Children and Young People, and for Older People should use existing supporting information and not through face-to-face assessments?

Neither agree nor disagree.

\textbf{QUESTION 17}

If you disagreed, please could you explain why:

The option of a face-to-face assessment should always be available for individuals of any age at their request,\textsuperscript{11} so that they are in control of their application process. We see no reason to have different rules for children, ‘working-age’ people and older people, and individuals should not be asked to attend face-to-face assessments where information is readily available. However, there is no reason to presume supporting information will be gathered in relation to older people any more than those of working age. Older people will not necessarily be in closer contact with GPs or social work, for example. At the same time, where the necessary supporting information does exist the Agency should not demand a face-to-face interview unnecessarily. Appropriate support to fill out the application in the first instance should be prioritised.

There should therefore be a presumption against face-to-face assessment where supporting information is available, but the applicant should always retain the right to ask for one.

\begin{itemize}
\item \textsuperscript{8} House of Commons, (2019) ‘Commons Library debate pack - Recognition of fibromyalgia as a disability’, CDP 2019/0003.
\item \textsuperscript{9} Endometriosis UK, (2017) ‘It takes an average of 7.5 years to get a diagnosis of endometriosis – it shouldn’t’. Accessed 15/05/2019: \url{https://www.endometriosis-uk.org/news/it-takes-average-75-years-get-diagnosis-endometriosis-it-shouldnt-37491#.XOueFYhKjcs}
\item \textsuperscript{11} Or in the case of children, the request of their parent or primary carer.
\end{itemize}
QUESTION 19
Do you agree or disagree with the proposal to have no set award durations but to set an award review date when a decision on a Disability Assistance application is made?

Don’t know.

QUESTION 20
If you disagreed, please could you explain why:

Indefinite awards should be available where an individual’s health condition is not likely to change or improve. Reviews should be available on their request.

QUESTION 21
Do you agree or disagree with the proposal to set an award review date 5-10 years in the future for a person with a condition unlikely to change?

Disagree.

QUESTION 22
If you disagreed, please could you explain why:

For many individuals an award review date will be unnecessary and lifetime awards should be possible with indefinite awards. In such cases a review should occur only on request of recipient / client or their agent and the intention should be to review level of support, not the existence of the condition.

Existing PIP rules allow for ongoing awards and therefore a 5-10 year award will render some individuals worse-off than under the current system. In line with the rights-based approach to social security and the presumption against retrogressive measures, per the UN Covenant on Economic, Social and Cultural Rights, individuals should not be disadvantaged by any changes introduced to award durations. You current awards should be seen as a minimum floor, and we would welcome the introduction of lifetime awards with no reassessment.

QUESTION 25
Do you agree or disagree with the proposal that clients have 31 days to request a redetermination?

Disagree.

QUESTION 26
If you disagreed, please could you explain why:
The consultation document suggests that Scotland will be given a significantly longer period to consider redetermination requests than for other devolved benefits. This right should apply equally to individual clients.

QUESTION 29
Do you agree or disagree that STA should not be paid to people who are not living or present in Scotland?
Neither agree nor disagree.

QUESTION 30
If you disagreed, please could you explain why:
See answer to question 10.

QUESTION 31
Do you agree or disagree that STA should not be recoverable except where it is later established that the principal assistance type was claimed fraudulently when STA was awarded?
Agree.

QUESTION 39
Do you agree or disagree with the proposed approach that, generally, where there is a break in a client’s eligibility to receive the benefit, eg. due to being in residential care, they will cease to receive the benefit?
Disagree.

QUESTION 40
If you disagreed, please could you explain why:
Proposals to maintain the rules about cessation of payments (the ‘28-day rule’) risk undermining the independence and dignity of individuals whose care needs and support continue while in a residential setting or a stay in hospital. Some outgoings such as rent and bills will not end as an automatic consequence of an individual moving settings, and it is clearly undesirable where the stay is predicted to last more than 28 days but not permanent to foster further hardship and insecurity by removing assistance as an element of wider household income. This may especially
affect groups such as individuals with mental health conditions, whose stay in residential hospital settings cannot be predicted. While extra costs associated with day-to-day needs may be met by the source care in a public setting, private settings such as care homes may continue to have extra costs that the individual is required to meet.

It is not clear whether payment will be suspended, or ended and a new claim needed when the person becomes eligible again, and this should be clarified. A more tailored approach should be pursued which reacts to individual needs and offers a taper where support will no longer be needed in the same manner, as the stay becomes longer term or permanent.

We are further concerned about the impact on carers. While not the subject of this consultation, carers entitlements are causally connected to disability payments, and cessation of both entitlements at once could have sudden and dramatic impacts on the household’s ability to maintain day-to-day outgoings, even though caring responsibilities may continue. Because the majority of recipients of PIP and Carers Allowance are women, they will face the additional risks of financial hardship. Eligibility for passported entitlements should be retained, including child benefit for children and young people, to minimise household disruption and financial hardship.

It is therefore surprising that in the partial EQIA published as part of the consultation document, no analysis of the ‘28-day rule’ in relation to women has been done. The impact of the ‘28-day rule’ on men in prisons has however been examined and is acknowledged within the proposals the Scottish Government has put forward. It is also unclear why policy would differ between age groups. The EQIA must be completed and published at the earliest opportunity so that the Scottish Government’s policy outputs reflect the experience of women.

**QUESTION 42**

Do you agree or disagree with our proposal to provide entitlement to Disability Assistance for Children and Young People to clients aged 0-18 years?

Agree.

**QUESTION 44**

Do you agree or disagree with our proposal to extending eligibility, for those in receipt of Disability Assistance for Children and Young People before the age of 16, to age 18?

Agree.
QUESTION 48
Do you agree or disagree with the proposal to make a £200 Winter Heating Assistance payment to families in receipt of the highest rate care component of Disability Assistance for Children and Young People?

Agree.

QUESTION 50
Do you agree or disagree with our proposal to use a points-based system to assess eligibility in relation to Disability Assistance for Working-Age People?

Disagree.

QUESTION 51
If you disagreed, please could you explain why:

Engender recognises that there are both positive and negatives to a points-based system. On the one hand, introducing more complex and fundamental change would add to disruption for claimants who have already had PIP introduced relatively recently and the other changes associated with devolution of payment, the point-based system provides an objective standardised methodology for claims to be processed with as little disruption as possible. However, the rigidity of the structure does not work well for those with mental health or fluctuating conditions.\textsuperscript{13} Furthermore, while the assessment process is intended to be gender-neutral the subjective assumptions held by assessors about men and women’s social roles and capacities cannot be appropriately measured and there is evidence that these differential assessments are a detriment to women.\textsuperscript{14}

Although we understand the desire to move quickly and that more complex changes will delay implementation, we are concerned that not enough research into the gendered impacts of PIP has been done since it was introduced by the Welfare Reform Act 2012 for us to fully conclude a gendered analysis of the application of the existing points-based system.

While work to undertake a gender analysis of incapacity benefits has been undertaken over the years, we are not aware of similar analysis of PIP assessment criteria. Jackie Gulland’s research into the gendered history of ‘incapacity benefits’ demonstrates that the patterns of awards punished women for undertaking household labour because it was viewed as potential work activity for women,

\textsuperscript{13} See the Health and Social Care Alliance Scotland.

\textsuperscript{14} See the work of J. Gulland, including Gullund, J., (Forthcoming) Gender, Work and Social Control: A Century of Disability Benefits, Palgrave MacMillan.
while men would not be considered to have breached the rules for doing the same domestic tasks.\textsuperscript{15}

While they may appear gender neutral, the daily tasks outlined continue to overlap with highly gendered patterns of household labour. Time use data for example shows that women in Scotland spend more time on housework (123 minutes a day c.f. 57 minutes) and household management (40 minutes c.f. 30 minutes) than men.\textsuperscript{16} This data also shows that disabled women spent an average of 298 minutes per day unpaid work (including housework; shopping, services and household management and care among other activities) compared to the average of 219 minutes per day spent by disabled men on the same activities. It will not be possible to conclude how ‘can’ and ‘does’ are interpreted by every applicant and every assessor, which is a fundamental flaw in applying an objective, points-based system, but it should be considered how the performance of gender roles is reflected. A more open-ended approach to collecting data which asks qualitative questions may be more effective at assessing individual need and experience.

Engender is generally concerned that the Scottish Government’s plans for data collection and analysis will not assist efforts to conduct this kind of analysis, contrary to the principles of continuous improvement and equality and non-discrimination. The current trend to familiarise resource data to household level does not tell us how and where additional needs must be met.

**QUESTION 53**

Do you have any comments on the full list of descriptors (provided at page 36) currently used to assess claims for Personal Independence Payments?

Evidence shared throughout this consultation process has underlined that the descriptors do not work for those with fluctuating conditions and would support the evidence from the Health and Social Care Alliance relating to the descriptors. In line with the social model of disability and a social model of capacity, the descriptors should ideally reflect what people can do, through a person-centred approach.

Thorough and in-depth research must be carried out into the gender sensitivity of current assessment process before any decision is taken as to the suitability of a points-based system is made and the descriptors articulated.

It is not merely the way in which daily living tasks are articulated, but also the way in which they are assessed, by whom and the standard of review each individual is

http://dx.doi.org/10.18061/dsq.v37i4.6088

exposed to. Little gender disaggregated data relating to PIP decisions is gathered and published, and there is limited analysis of case law, none of which that we have been able to find adopts a gendered approach. However, we have been able to find examples where women’s child care responsibilities have been used to reject their claims relating to the PIP daily living component:

- In *SB v Secretary of State* [2016] a 24-year old women was found not to fulfil the ‘dressing and undressing’ descriptors because she was able to regularly dress and undress her daughter.\(^\text{17}\)
- In *SC-v-SSWP(PIP)* [2017] the statement of reasons given said that the applicant prepared and cooked a main meal for her son daily, whilst her mother would prepare a meal for the two of them.\(^\text{18}\)
- In *ML v SSWP (PIP)* [2017] fact that the applicant took her child to leisure activities was used as evidence that she could get dressed more than 50% of days.\(^\text{19}\)

We found no examples where a man’s care responsibilities were referred to in rejecting a PIP application. Experience-data from the CPAG Early Warning System also suggests that care has been a factor in applying the descriptors:

- *CPAG Client who is receiving carers allowance received a decision refusing her PIP application on the basis that she is a carer. It would appear that the fact that she is a carer has been used as evidence that she can look after herself. #7448\(^\text{20}\)

Given the highly gendered nature of child care responsibilities, the way in which the descriptors are configured should reflect the additional responsibilities and coping mechanisms primary caregivers have adopted to adapt their activities which are not demanded of those with no care responsibilities. An applicant’s position will depend on not only their capacity, but the technology, support and demands external to them. How this is interpreted will be crucial, but the descriptors selected if a points-based system is pursued must be rigorously analysed for gender impacts. Otherwise, there is considerable risk that gender inequality will be baked into the assessment framework.

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\(^{17}\) SB v Secretary of State [2016] UKUT 0219 (AAC). Retrieved from: https://assets.publishing.service.gov.uk/media/5786358340f0b66bda00013e/CPIP_3573_2015-00.pdf

\(^{18}\) SC v SSWP (PIP) [2017] UKUT 0317 (AAC). Retrieved from: https://assets.publishing.service.gov.uk/media/598ab9ace5274a7377b7a1b3/CPIP_0663_2017-00.pdf

\(^{19}\) ML v SSWP (PIP) [2017] UKUT 0171 (AAC). Retrieved from: https://assets.publishing.service.gov.uk/media/5915b45ae5274a4550000059/CPIP_3760_2016-00.pdf

\(^{20}\) See the Child Poverty Action Group Early Warning System.
Currently, data in relation to PIP shows that while women make up a small majority of PIP awards (54%) men are more likely to receive an ‘enhanced’ award (57%) and women are more likely to receive no daily living component (51%).\textsuperscript{21} \textit{Taken with the case-law review above, there is a clear need to understand the gendered nature of application of objective descriptors before any further action to replicate PIP assessments, and this should be a thorough part of the full EQIA a matter of urgency.}

Research carried out by Engender through Our Bodies Our Rights has highlighted the severity of concerns that disabled women with children hold around seeking help in relation to judgements about their ability to parent. To penalise women who do seek support, whether from the social security system or elsewhere, to go about their daily lives for managing parenting responsibilities is wholly inconsistent with their rights as parents.

\textbf{QUESTION 55}

\textit{In relation to assessments, what are your views on acceptable distances to travel?}

This should take into account the availability of public transport and women’s additional reliance on public transport systems,\textsuperscript{22} as well as their childcare responsibilities and any additional costs this presents. Assessments should be delivered as close to the individual as is possible and within realistic public transport hubs.

\textbf{QUESTION 56}

\textit{What other circumstances should the Agency take into account?}

Care responsibilities.

\textbf{QUESTION 57}

\textit{In relation to assessments, how many times do you think an individual should be able to reschedule, or fail to attend, an appointment?}

- Don’t know.

\textbf{QUESTION 58}

\textit{In relation to a missed assessment, do you have any comments on what should amount to exceptional circumstances (e.g. hospital admissions)?}


\textsuperscript{22} Engender, (2017) \textit{Gender Matters Roadmap}.
Childcare issues and disruptions should not be penalised. The Agency should also be cognisant of the way that perpetrators of domestic abuse routinely prevent women from attending appointments that would facilitate their financial autonomy, as part of financial abuse.

**QUESTION 64**

If you have any further comments you would like to make relating to Disability Assistance benefits not covered by this consultation document, please provide them below:

**Carers and the relationship with carer’s entitlements**

Eligibility for Carers Allowance is contingent on the daily living component of Personal Independence Payment, and therefore any changes that increase or decreases entitlement to Disability Assistance payments will also impact those that provide care. Women are more likely to be receipt of disability assistance payments and more likely to provide unpaid care for a disabled person – around 75% of unpaid carers are women and 72% of carers allowance payments are paid to women. Additionally we know anecdotally that that women – partners, mothers, daughters – are more likely to help a family member navigate the PIP application process. The complexity and time-consuming nature of application processes will therefore place further demands on women’s time and increase stress. **Changes to disability support must not negatively impact carers’ entitlements even in the short term ahead of a more thorough review of carers support.**

**Equality and Non-Discrimination**

The partial EQIA published as part of the consultation document does not consider women’s specific circumstances. The necessary research and gender analysis should be done at the earliest stage so as not to reproduce gender-blind policies and processes which further entrench gender inequality, such as the 28-day rule.

Concerns have been raised at international human rights institutions about the intersection of gender and disability in UK social security policy. As poverty is highly gendered, measures which decrease eligibility to assistance programmes or services invariably affects women at severely disproportionate rates. Disabled women face additional further disadvantages. Most recently the UN Special Rapporteur on

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Extreme Poverty has expressed further concern about the situation of disabled women, who suffer from a double discrimination linked to their special living conditions, and recently (May 2019) recommended that the UK should “Review and remedy the systematic disadvantage inflicted by current policies on women, as well as on children, persons with disabilities, older persons and ethnic minorities.”

It is therefore vital that the EQIA is completed and resources as directed towards a gendered analysis of PIP before criteria and processes are replicated. The partial EQIA notes the potential positive impacts of increasing entitlement in a cursory manner and does not consider how changes could be made to ensure women who need disability support receive it at the most appropriate level.

Engender is generally concerned that the Scottish Government and Social Security Scotland’s approach to data collection and analysis will fail to deliver continuous improvement and meet equality and non-discrimination requirements. There must be robust processes embedded into the application and administration systems which systematically collect and disaggregate data by protected characteristics. Gender-blind household level data will not inform necessary analysis to ensure the specific needs of women are met and risks embedding further unfairness. Current indications from the Best Start Grant suggest that data is being gathered on an optional basis which is seriously unlikely to meet legal requirements in the Public Sector Equality Duty.

FOR FURTHER INFORMATION
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ABOUT US
Engender is a membership organisation working on feminist agendas in Scotland and Europe, to increase women’s power and influence and to make visible the impact of sexism on women, men and society. We provide support to individuals, organisations and institutions who seek to achieve gender equality and justice.