



Consortium for the Regional Support for Women in Disadvantaged and Rural Areas

Response to: Modernising Support for Independent Living: The Health and Disability Green Paper

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Women's Regional Consortium: Working to Support Women in Rural Communities and Disadvantaged Urban Areas

1. Introduction

1.1 This response has been undertaken collaboratively by the members of the Consortium for the Regional Support for Women in Disadvantaged and Rural Areas (hereafter, either the Women's Regional Consortium or simply the Consortium), which is funded by the Department for Communities and the Department of Agriculture, Environment and Rural Affairs.

1.2 The Women's Regional Consortium consists of seven established women's sector organisations that are committed to working in partnership with each other, government, statutory organisations and women's organisations, centres and groups in disadvantaged and rural areas, to ensure that organisations working for women are given the best possible support in the work they do in tackling disadvantage and social exclusion.¹ The seven groups are as follows:

- ♀ Training for Women Network (TWN) – Project lead
- ♀ Women's Resource and Development Agency (WRDA)
- ♀ Women's Support Network (WSN)
- ♀ Northern Ireland's Rural Women's Network (NIRWN)
- ♀ Women's TEC
- ♀ Women's Centre Derry
- ♀ Foyle Women's Information Network (FWIN)

1.3 The Consortium is the established link and strategic partner between government and statutory agencies and women in disadvantaged and rural areas, including all groups, centres and organisations delivering essential frontline services, advice and support. The Consortium ensures that there is a continuous two-way flow of information between

¹ Sections 1.2-1.3 represent the official description of the Consortium's work, as agreed and authored by its seven partner organisation

government and the sector. It also ensures that organisations/centres and groups are made aware of consultations, government planning and policy implementation. In turn, the Consortium ascertains the views, needs and aspirations of women in disadvantaged and rural areas and takes these views forward to influence policy development and future government planning, which ultimately results in the empowerment of local women in disadvantaged and rurally isolated communities.

1.4 The Women's Regional Consortium appreciates the opportunity to respond to the Department for Work & Pensions consultation on Modernising Support for Independent Living: The Health and Disability Green Paper. **We suggest that the implications of these proposals in the Green Paper will be even more significant in Northern Ireland given the higher levels of disability benefit claimants here. We encourage Government to carefully consider the particular circumstances that exist in Northern Ireland (some of which are detailed in Section 2 of this response) which have not been referenced within the Green Paper.**

1.5 Throughout this response the Consortium has sought to ensure the voices of women are clearly represented. We carried out a number of telephone interviews with individual women as the basis for our comments on this consultation. We also refer to previous research with women we carried out for the Second Independent Review of PIP (2020) where we carried out an online survey and a number of telephone interviews with local women. We believe that it is essential for policy makers and the Government to listen to the voices of these valuable lived experiences of PIP. Their voices and experiences are included throughout Section 3 of this response and we encourage the Department to listen and act on these important contributions.

1.6 The Women's Regional Consortium would like to endorse the responses made by the Women's Policy Group in Northern Ireland and by Disability Action.

2. General comments

2.1 The Women's Regional Consortium is concerned by the proposals contained in this Green Paper and we believe that they seek to remove the dignity of disabled people. Having sufficient income to live a dignified, healthy life is essential for all people and we believe these proposals seek to reduce the amount of money paid out on PIP regardless of the impact on disabled people's lives.

2.2 Scope research shows that life costs a lot more for disabled people including people with mental health conditions. It shows that disabled people need £975 more a month, on average, to have the same standard of living as a non-disabled person.² However, because of welfare cuts and austerity policies disabled people have already lost average benefit payments of around £1,200 a year.³

2.3 A report into destitution in the UK by the Joseph Rowntree Foundation⁴ showed that there are strong links between disability and destitution. This research showed that almost two-thirds (62%) of destitute survey respondents stated that their day-to-day activities were limited because of a chronic health problem or disability. *“There were widespread reports that the process to claim disability benefits, such as Personal Independence Payments, could be long and arduous. Sometimes this had detrimental impacts on interviewees' mental health, as well as very substantial effects on their material well-being.”*

2.4 Research and personal testimonies have shown that the PIP process is already failing disabled people. We believe that implementing the proposals in the Green Paper would make this situation even worse contributing to higher levels of destitution for disabled people. The Women's Regional Consortium are in agreement with colleagues in Disability Rights UK who said: *“The social security system should be an essential public service that ensures everyone has access to the right support when they need it. But after years of dire cuts and reforms, it has been torn apart.”*⁵

² [The Government's proposed changes to Personal Independence Payment \(PIP\) explained. | Disability charity Scope UK](#)

³ <https://www.disabilityrightsuk.org/news/dr-uk-responds-proposed-changes-personal-independence-payment-pip>

⁴ <https://www.jrf.org.uk/deep-poverty-and-destitution/destitution-in-the-uk-2023>

⁵ <https://www.disabilityrightsuk.org/news/dr-uk-responds-proposed-changes-personal-independence-payment-pip>

2.5 A number of reviews into PIP in Northern Ireland (see paragraphs 2.9 to 2.13) have shown widespread concerns about the PIP process and the need for reform. Welfare Supplementary Payments are in place in Northern Ireland which highlight the need for financial support for disability within the social security system. We need to see investment in the social security system to ensure that it provides the safety net of support that disabled people rely on and in the long term reduces the pressure on other services, including the health service, which is so impacted by inadequacies in social security support for disabled people.

Northern Ireland Considerations

2.6 We point the Government to the following statistics for Northern Ireland which provide important considerations around levels of disability, benefit dependency and socio-economic issues. These considerations mean that Northern Ireland is likely to feel the impact of the proposals contained in the Green Paper much more severely.

- Northern Ireland has traditionally had a much higher proportion of people claiming disability benefits than other areas of the UK. Prior to the introduction of PIP in 2016 around one in nine people in Northern Ireland (208,760 people) were on DLA.⁶ At that time Northern Ireland had proportionately twice as many people claiming DLA compared to the rest of the UK. *“This higher uptake in NI remains unexplained, though poorer mental health, possibly resulting from the civil unrest known as The Troubles, might be significant.”*⁷
- 16% of the Northern Ireland population are in receipt of disability benefits.⁸
- Northern Ireland has higher levels of benefit dependency than other parts of the UK with the Consumer Council for Northern Ireland reporting that income from social security benefits is at 71% in Northern Ireland compared to 60% in the UK.⁹

⁶ Northern Ireland Benefits Statistics Summary, Department for Social Development, November 2015 <https://www.communities-ni.gov.uk/sites/default/files/publications/dsd/benefit-statistics-summary-november-2015.pdf>

⁷ https://pureadmin.qub.ac.uk/ws/portalfiles/portal/234059841/SSM_final_.pdf

⁸ [NI: IN PROFILE Key statistics on Northern Ireland \(nisra.gov.uk\)](https://www.nisra.gov.uk/ni-profile/key-statistics-on-northern-ireland)

⁹ Q2 2023 Northern Ireland Household Expenditure Tracker, Consumer Council for Northern Ireland, November 2023

[Q2 2023 Northern Ireland Household Expenditure Tracker | Consumer Council](#)

- Over the last 15 years, economic inactivity in NI has been consistently higher than the UK average.¹⁰ The latest economic inactivity rate is 27% compared to the UK rate of 22.3% and is third highest of the twelve UK regions.
- In February-April 2024, the most common reason for economic inactivity in Northern Ireland among the working age population was 'long-term sick'. There were 126,000 'long-term sick', accounting for 39.7% of the total economically inactive (aged 16 to 64), or 10.7% of the working age population.
- One in four people in Northern Ireland (24.3% or 463,000 people) had a limiting long-term health problem or disability, 40% of which were aged 65 or more (185,300 people).¹¹
- Northern Ireland has the worst hospital waiting lists with half of patients waiting over a year for treatment.¹² In Northern Ireland 21 times more people are waiting over a year for a first outpatient appointment compared with England.¹³
- In December 2022, 500,678 people were on waiting lists - a figure equivalent to 26% of the Northern Ireland population, although some patients may be on more than one list.¹⁴
- Northern Ireland is reported to have the highest prevalence of mental health problems in the United Kingdom, around 25 per cent higher than in England. The higher prevalence levels in Northern Ireland are associated with both greater levels of deprivation and the impact of the 'Troubles'.¹⁵
- 21% of the adult population has a possible mental health problem (identified in the NI Health Survey 2021-22).¹⁶
- Figures for December 2023 show that around 6,500 people are waiting to access a first appointment with psychological therapies. Performance against waiting time targets has also deteriorated with around three-quarters of those on psychological therapies waiting lists waiting longer than the 13-week target time.¹⁷ Without timely treatment peoples' conditions will deteriorate becoming

¹⁰ Northern Ireland Labour Market Report, NISRA, June 2024

<https://datavis.nisra.gov.uk/economy-and-labour-market/labour-market-report-june-2024.html>

¹¹ <https://www.nisra.gov.uk/system/files/statistics/census-2021-main-statistics-for-northern-ireland-phase-2-statistical-bulletin-health-disability-and-unpaid-care.pdf>

¹² [Half of Northern Irish patients wait over a year for treatment \(economist.com\)](https://www.economist.com/health/2024/01/12/half-of-northern-irish-patients-wait-over-a-year-for-treatment)

¹³ [NHS planned care waiting times across the UK - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/health-and-social-care/articles/2024/01/12/nhs-planned-care-waiting-times-across-the-uk)

¹⁴ [Waiting lists: 'Urgent funding needed' to clear Northern Ireland backlog - BBC News](https://www.bbc.com/news/health-67845678)

¹⁵ [00293490 - Mental Health Report_WEB.pdf \(niauditoffice.gov.uk\)](https://www.niauditoffice.gov.uk/00293490-Mental-Health-Report-WEB.pdf)

¹⁶ Ibid

¹⁷ [Report on Mental Health Services in Northern Ireland \(niassembly.gov.uk\)](https://www.niassembly.gov.uk/2024/01/12/report-on-mental-health-services-in-northern-ireland)

more difficult and costly to treat and impacting significantly on the health service. The Public Accounts Committee believes that addressing issues early can often result in better value for money and better solutions.¹⁸

- More than 3,500 people in Northern Ireland are waiting for home care packages and some of the longest delays for full and partial care packages have been up to five years.¹⁹

PIP Claimants in Northern Ireland

2.7 The most recent PIP claimant statistics for Northern Ireland²⁰ are also an important consideration for Government in its work on the Green Paper alongside the appeal :

- The average (median) clearance time, from the date a claim is registered to the initial decision being made during February 2024, was 14 weeks.
- 205,840 claimants were in receipt of PIP on 29 February 2024.
- Of the total claims in payment 54% were made to women and 46% to men.
- 42% (86,260) of claims in payment are awarded the enhanced rate for both the daily living and mobility components.
- 45% (92,500) of claims in payment have a main disabling condition recorded under the highest medical category of 'Psychiatric disorders (Mental Illness)'. The next biggest category is Musculoskeletal disease at 20%
- The average time to process Mandatory Reconsiderations from registration to clearance was 96 calendar days (February 2024).
- During February 2024, 67% of mandatory reconsiderations resulted in no change to the award and 33% resulted in the award being changed.

PIP Appeal Statistics in Northern Ireland

2.8 The percentage of PIP appeals that are successful clearly points to problems with the assessment process for PIP and there have been widespread calls for it to be changed. Figures obtained by our colleagues at Law Centre NI via a Freedom of

¹⁸ Ibid

¹⁹

<https://www.bbc.co.uk/news/articles/c722qd900v4o#:~:text=Care%20packages%20are%20designed%20to,been%20up%20to%20five%20years>.

²⁰ Personal Independence Payment Statistics, Department for Communities & NISRA, February 2024
<https://datavis.nisra.gov.uk/communities/personal-independence-payment-statistics-february-2024.html>

Information request²¹ have shown that success rates for PIP appeals are higher than appeals across all benefits at 66.8% for in-person hearings and 60.3% for remote hearings.

Reviews/Investigations into PIP in Northern Ireland

2.9 A number of reviews into PIP have been carried out in Northern Ireland and the recommendations from these Reviews must form part of the Government's considerations in relation to this Green Paper. The First Independent Review of the PIP assessment process in Northern Ireland was carried out by Walter Radar and published in June 2018 making 14 recommendations.²² In his overview of findings Walter Radar said about the PIP assessment process:

"It is a fragmented process that impacts negatively on both claimants and those who seek to support them. In particular the face-to-face assessment causes fear, anxiety, stress and frustration. This in turn has a knock on impact on the health and well-being of claimants, their family and wider support networks, placing even more demands on already stretched services."

2.10 The Second Independent Review of the PIP assessment process in Northern Ireland was carried out by Marie Cavanagh and published in December 2020 making 12 recommendations.²³ In her foreword Marie Cavanagh said:

"My findings point to the need to improve claimants accessibility to the PIP journey, through the claim process, the type of Assessment carried out and the quality of further evidence used in decision making. They also include Recommendations to broaden the audit process and complaints procedure to increase confidence in the

²¹ <https://www.lawcentreni.org/news/social-security-appeal-statistics-obtained-by-law-centre-ni-reveal-how-outcomes-can-be-improved/>

²² Personal Independence Payment, An Independent Review of the Assessment Process, Walter Rader, June 2018
<https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-independent-review-pip-assessment-process-june-2018.pdf>

²³ [Second Independent Review of the PIP Assessment Process in Northern Ireland - report and response | Department for Communities \(communities-ni.gov.uk\)](https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-independent-review-pip-assessment-process-june-2018.pdf)

process..... This second Independent Review of PIP again highlights the need for assistance and advocacy in completing the complex PIP application journey.”

2.11 The Northern Ireland Public Services Ombudsman (NIPSO), Marie Anderson, announced in 2019 that she had chosen PIP as her first area for investigation under her new ‘Own Initiative’ power – she can investigate if her office suspects “*systemic maladministration.*” She pointed out the high number of PIP decisions which have been overturned at appeal and the significant number of complaints made about the benefit to her office in making her decision.²⁴ The NIPSO investigation examined the availability and application of further evidence in the administration of PIP. It made 33 detailed recommendations²⁵ and in presenting the report, Marie Anderson said:

“Overall my investigation has made a finding of systemic maladministration having identified repeated failures which are likely to reoccur if left unremedied. It is therefore my view that there is more work to be done to improve the experience and outcomes for claimants, the robustness of decision making and public confidence in the system.”

2.12 The NIPSO investigation found that the major problem is that the Department for Communities and Capita (the outsourced provider of the assessments) had systematically failed to collect and use further evidence from claimants health professionals. The Ombudsman found the system relied on claimants challenging decisions through the various stages of the appeal process but many do not challenge decisions given the nature of their health conditions and vulnerabilities.

2.13 In March 2021 the Northern Ireland Audit Office published a report on the Department’s management of the Capita contract and how PIP has been delivered.²⁶ The report notes that in the early stages of the contract Capita missed key targets relating to clearance times and the quality of assessments but more recently performance has improved in these areas. The report stated that it is too early to assess if the implementation of PIP will meet its objectives in terms of value for money

²⁴ <https://nipso.org.uk/site/wp-content/uploads/2019/01/Own-Initiative-investigation-PIP-statement.pdf>

²⁵ [PIP Summary.pdf \(nipso.org.uk\)](#)

²⁶ <https://www.niauditoffice.gov.uk/publications/html-document/management-and-delivery-personal-independence-payment-contract-northern#toc-2>

but it is likely to cost more than DLA.

Impact of the Cost-of-Living Crisis on Disabled People

2.14 Disabled people face higher costs on average resulting from their health condition and have more intensely felt the impact of rising prices as a result of the Cost-of-Living Crisis. Research by the Joseph Rowntree Foundation²⁷ found that low-income households with a disabled person are being hit hard by the Cost-of-Living Crisis with almost 6 in 10 experiencing food insecurity in April/May 2023 (57%), 7 in 10 going without essentials between November and May (71%) and almost half are in arrears with at least one household bill (48%).

2.15 Research by the Resolution Foundation²⁸ found that people with a disability are facing the Cost-of-Living Crisis with lower-than-average incomes. The underlying disposable income gap between the disabled and non-disabled population was 44%. The income gap means that the disabled population are at a heightened risk of experiencing material deprivation, meaning that they are unable to afford everyday essentials. The report finds that people with a disability are almost three times as likely to live in material deprivation than the rest of the population (34% vs 13%). Around two-fifths of people with a disability (41%) said they couldn't afford to keep their homes warm, compared to just over one fifth (23%) of the non-disabled population. Almost one-in-three (31%) people with a disability say they have had to reduce their expenditures on food, compared to 18% of the non-disabled population. The report also notes that people with a disability are far more likely to be poor than the rest of the population. One-in-three (33%) adults in the lowest household income decile have a disability, compared to fewer than one-in-ten (9%) of adults in the highest household income decile.

²⁷ <https://www.jrf.org.uk/cost-of-living/our-social-security-system-must-support-households-with-a-disabled-person-to-afford>

²⁸ <https://www.resolutionfoundation.org/press-releases/44-per-cent-disability-income-gap-makes-people-with-disabilities-more-likely-to-struggle-to-heat-their-homes-and-cut-back-on-food-this-winter/>

2.16 A Sense survey has shown that more than four in five (83%) of disabled people in Northern Ireland say that their financial situation has worsened since the start of the year (2023) and one in two (55%) admit to being in debt.²⁹

Women and the Cost-of-Living Crisis

2.17 Women are more likely to be in receipt of social security benefits, more likely to be in low-paid, part-time and insecure work and also more likely to be providing care either for children or other family members which limits their ability to carry out paid work. This contributes to keeping women's incomes generally lower over their lifetimes and therefore puts them at greater risk of poverty. These existing gender inequalities have been worsened due to the Covid19 pandemic and by the Cost-of-Living Crisis.

2.18 Women often bear the brunt of poverty in the home managing household budgets to shield their children from its worst effects. This means that women end up acting as the 'shock absorbers' of poverty going without food, clothes or warmth in order to meet the needs of other family members when money is tight.³⁰ Research by the Women's Regional Consortium in Northern Ireland on the impact of the Cost-of-Living Crisis on women³¹ found that 91% of women surveyed reported difficulty paying their bills as a result of Cost-of-Living increases, 90% felt that the Cost-of-Living Crisis had impacted on their physical or mental health or both and 78% of the women had felt cold or hungry or both as a result of cost of living increases.

2.19 These structural inequalities expose women to greater risk during times of economic crises and these experiences are compounded for disabled women who are even more likely to live in poverty.

²⁹ <https://www.communityni.org/news/new-research-shows-cost-living-crisis-worsening-disabled-people-northern-ireland-charity>

³⁰ A Female Face, Fabian Society Blog by Mary-Ann Stephenson, Women's Budget Group, February 2019

<https://fabians.org.uk/a-female-face/>

³¹ Women's Experiences of the Cost-of-Living Crisis in Northern Ireland, Women's Regional Consortium, June 2023

<https://www.womensregionalconsortiumni.org.uk/wp-content/uploads/2023/06/Womens-Experiences-of-the-Cost-of-Living-Crisis-in-NI-2.pdf>

Women and Austerity

2.20 The safety net provided by the social security system has been weakened by a decade of welfare reform changes meaning that many people are unable to meet the costs of essential items such as food, heat and clothing and are unable to cope with unexpected life events such as a washing machine breaking down. Welfare reform and austerity policies have disproportionately impacted on women. Research by the House of Commons Library shows that 86% of the savings to the Treasury through tax and benefit changes since 2010 will have come from women.³²

2.21 An intersectional analysis of social security cuts since 2010 by the Women's Budget Group³³ has shown that the cuts and changes to the benefits system since 2010 have had a devastating impact on women on low incomes, women from Black and minority ethnic backgrounds, lone mothers, disabled women and households with three or more children. It showed that disabled women significantly lose out by £2,553 per year on average (11% of their annual net income) compared to £1,952 for disabled men (see graph below).

³² [Estimating the gender impact of tax and benefits changes \(parliament.uk\)](https://parliament.uk/research-and-factsheets/2016/06/estimating-the-gender-impact-of-tax-and-benefits-changes)

³³ [Who-bears-the-brunt_WBG-June-2024-1.pdf](https://www.wbg.org.uk/wp-content/uploads/2024/06/Who-bears-the-brunt-WBG-June-2024-1.pdf)

Figure 3: impact of social security changes by sex and disability. Change in annual net income in cash and percentage.

Disabled women lose on average £2,553 per year



Notes: the definition of Disability is the one used in the Family Resources Survey: "The definition of disability used in the FRS is consistent with the core definition of disability under the Equality Act 2010. A person is considered to have a disability if they have a long-standing illness, disability or impairment which causes substantial difficulty with day-to-day activities. Some people classified as disabled and having rights under the Equality Act 2010 are not captured by this definition, such as people with a long-standing illness or disability which is not currently affecting their day-to-day activities." Disability data tables, Definitions, [Family Resources Survey, financial year 2021 to 2022](#).

Source: Women's Budget Group

2.22 In Northern Ireland an analysis of the impact of the reforms by the Northern Ireland Human Rights Commission (NIHRC)³⁴ showed that across most income levels the overall cash impact of the reforms is more negative for women than for men. It also found that disabled households in Northern Ireland lose more on average from the social security reforms than their counterparts elsewhere in the UK.

2.23 Research by the Women's Regional Consortium in Northern Ireland on the impact of austerity/welfare reform on the lives of women showed overwhelmingly negative impacts.³⁵ Many women were forced to make difficult decisions and to stretch their already tight budgets further and further in order to provide for their children and families. This led to many personal sacrifices on the part of the women with resulting impacts on their health and wellbeing. Northern Ireland tends to be disproportionately

³⁴ [Publication - Cumulative impact assessment of tax and social security reforms in Northern Ireland | Northern Ireland Human Rights Commission \(nihrc.org\)](#)

³⁵ <https://womensregionalconsortiumni.org.uk/wp-content/uploads/2021/04/March-2019-Impact-of-Ongoing-Austerity-Womens-erspectives.pdf>

affected by any changes to social security due to its relatively high levels of economic inactivity and disability, lower average earnings and larger average family size compared to the rest of the UK³⁶ and because women are more likely to claim social security benefits they will be even more adversely impacted.

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https://www.niassembly.gov.uk/globalassets/documents/raise/knowledge_exchange/briefing_papers/series7/simpson060618.pdf

Specific Comments

Chapter 1 – PIP – Overview and assessment reform

Q1. What are your views on an assessment that places more emphasis on condition rather than the functional impact of a condition on the person?

Given that people are all individuals and can be impacted in different ways by different conditions this is a difficult question to answer. A PIP assessment that places more emphasis on condition rather than functional impact would seem to make sense for some conditions where it is clear that support is needed - for those where the condition/disability is chronic, progressive or life-threatening.

For other conditions where the impact of the condition/disability varies from person to person or fluctuates there would still be a need for an assessment. Reviews into PIP referenced in Section 2 of this document highlight significant issues with the quality of PIP assessments in Northern Ireland. It would therefore be important for assessors to be appropriately trained and have an understanding of the specific conditions presented by the claimant (including mental health conditions) to make accurate, fair assessments and to provide trust in the process.

“In some ways it might be useful to base it on the condition but assessors would have to know enough about the condition and how it impacts.”

“It would potentially save money if someone with a diagnosed chronic condition, supported by clear clinical evidence, should not have to suffer the indignity of an Capita assessment.”

“They need to keep some kind of assessment to see how your disability affects you. You could have ten people with the same disability all affected in different ways. Different conditions can affect people differently.”

“I always thought that if you had a chronic condition like I have with no cure (MS) that you should just get PIP. But I ended up having to fight for 4 years to get it. To get them to acknowledge that my MS was life long and chronic. The costs of going through that were awful. But then I would have concerns about people with mental health conditions and things like autism – would they be in or out? Would it be harder for them to get PIP?”

“There would be issues with mental health conditions and depression as one size doesn't fit all for these. People can be depressed and go to work. If they didn't have

work they would be worse. But if you say you go to work I think it goes against you. Little things like getting washed if you have depression – if they didn't have to go to work they may not get washed but if they go to work they have to. Work can help with a condition but the condition is still there. Some assessors have no experience or knowledge of dealing with people with mental health conditions and may not understand all this – the impact of poor mental health.”

“Put claimants in green, amber and red lanes. For those with chronic conditions they should just get put straight through and don't have to fight to get PIP. For others assessments will need to be done to determine eligibility.”

“Capita assessors need to be adequately trained on different conditions such as Cancer and Alzheimer's, etc. They need to be trained and have an understanding of how certain conditions impact on people both mentally and physically.”

“They could actually use assessors that have knowledge on certain conditions. I had a nurse that wasn't even aware of the severe allergies I have and how they restrict my entire life. How is that a fit way to assess my conditions?”

Q2. What are your views on people receiving PIP without an assessment if they have specific health conditions or a disability as evidenced by a healthcare professional?

It should be possible to rely on the evidence of healthcare professionals for specific health conditions or disabilities. If claimants have been under the care of a healthcare professional through to getting a diagnosis, then a professional decision has been made and PIP should be awarded. Automatic eligibility could be applied to conditions which are progressive, chronic or severe without an assessment.

However, we have highlighted in paragraph 2.6 of this document the extreme pressure that healthcare professionals and the NHS are under. There is huge pressure on already stretched services and limited funding. This means that delays and waiting periods are common and some particularly in Northern Ireland are very long. This means that people, often those who are the most vulnerable due to sickness or disability, could be left for very long periods without treatment or diagnosis and therefore without access to PIP if these proposals come into effect.

“I struggled to get PIP. I have osteoporosis and I have to wear a girdle at work, cardiovascular issues with blockages in my legs and COPD. I work and use my PIP to get taxis to work. I was turned down when I applied but with help from an advice centre and representation at appeal, I was awarded low rate.”

“I could have been on PIP a long time ago but I never bothered and kept saying no I’m all right, I can manage. My Rheumatology Nurse encouraged me to apply, she said to me you’re living with this. If it’s bad I’m having to take time off work.”

“You’re frightened off applying for PIP. I didn’t apply for a long time I kept on saying there are people worse off than me. But it really helped me, I was able to get a Motability Car and it has changed my life and meant I’ve been able to get out and about more. I wouldn’t be able to do that without it.”

“People who understand the condition you have should do the assessment. GPs should be trusted and the assessment should be short and simple.”

Q3. What are your views on PIP claimants not being subject to an award review if they have a specific health condition or disability as evidenced by a healthcare professional?

If a claimant’s condition is progressive, chronic or severe with no likelihood of improving then it should not be subject to award review. There are conditions, for example, Alzheimer’s, where there is clearly no prospect of the claimant getting better and it therefore makes no sense to subject them to an award review.

For other conditions which are less severe or which are more likely to fluctuate, affect people differently or improve then these should be subject to review.

“In reality my condition is not going to change, it’s chronic and as I get older it’s going to get worse. It doesn’t make sense to review it if it’s a progressive condition.”

“Longer awards for people with long-term illnesses, my award is 2 years and I have to go through the whole thing again soon and I won’t ever improve.”

“A person with life debilitating conditions that will not improve over time should not be forced to go through the same ordeal again and again, it’s difficult enough accepting many conditions without having to justify yourself over and over, there is no dignity left by end of the process.”

“It’s embarrassing having to fill it in on conditions that aren’t going to improve. Surely they should believe what your GP writes about you. It’s not like they are going to give false information.”

“Assessors should be made more aware of particular illnesses. Why are Reviews being done if the illness is progressive and will last a lifetime without a cure?”

Q4. Do you agree or disagree on making provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP?

Disagree

Q5. In relation to Question 4, please explain your answer and provide evidence or your opinion to support further development of our approach.

There are many people struggling with the impacts of conditions/disabilities without a formal diagnosis. This may be for a variety of reasons including fear, an inability to access services, being unable to get a firm diagnosis, being 'borderline' for conditions or being on long waiting lists for assessment. While there is no diagnosis in these situations the claimant may still suffer considerable impacts from the condition/disability and should not be excluded from access to the help that PIP can provide. Making evidence or formal diagnosis mandatory could exclude some very vulnerable people.

We acknowledge the value of medical evidence and having a formal diagnosis in determining eligibility for PIP but wish to highlight the significant difficulties that currently exist around this. Delays make it unrealistic to rely on diagnosis. As previously raised delays and long waiting times for NHS appointments, referrals and diagnosis mean that many people are coping with conditions/disabilities without the treatment, support and diagnosis they need. Waiting lists and long waiting times within the Northern Ireland health service have often been described as scandalous with some people waiting six years for surgery.³⁷

"You can't argue with what's written down in black and white by a doctor. The minute they see medical evidence they know you're not messing about. If you're seeing your doctor regularly then the issues you have are going to show up in your records."

"It's not always possible to get the evidence, a lot of doctors and consultations won't give evidence for PIP."

"When I got diagnosed with MS I got a letter from my neurologist and I thought that would be enough to say that I had the condition. But for PIP I had to get notes from everyone – my GP, physio, speech and language therapist, etc. I had to get all the notes and it was really stressful having to get them all. The diagnosis letter wasn't enough."

³⁷ <https://www.itv.com/news/utv/2024-05-30/recurrent-and-protected-budget-needed-as-ni-waiting-times-miss-targets-again>

Q6. How could we prevent the provision of evidence or a formal diagnosis by a medical expert from impacting the NHS? Please explain your answer and provide evidence or your opinion to support further development of our approach.

It would be very difficult to avoid impacting on the NHS. If you are proposing to make the provision of evidence or a formal diagnosis by a medical expert mandatory then this will result in an increased workload for NHS staff to provide this information. There are huge and ongoing pressures on the NHS and this would only add to what is an already difficult situation.

Consideration needs to be given to asking the right people the right questions in relation to the provision of evidence. Doctors may be able to comment on the condition/diagnosis but cannot comment on how it impacts on function – this could more accurately be done by Occupational Therapists, Physiotherapists, carers, etc.

If Government are going to ask the NHS to provide this information then they would need to provide training to enable them to do this effectively. Many have no formal training in PIP and therefore do not understand the criteria. For example, they may say a claimant can walk but do not look at things like limping, the use of sticks, how they manage over distance, etc.

The only way to reduce the administrative burden (but would not remove it completely) would be the provision of a standardised form that could be completed to provide the necessary information/diagnosis.

“I can’t see how that can be prevented they are already so swamped. I had to phone my GP three times last week and no call backs were available. I had to end up going to the Bel Doc for an antibiotic.”

“Even trying to get an appointment with your doctor now is shocking.”

“You can’t prevent it impacting on the NHS! If they just used the information from whoever has given the diagnosis that might take some pressure off the system? Could PIP not have used my diagnosis letter and once that was provided that should have been enough? Instead they made me gather evidence from all the health professionals involved with me. At the point of diagnosis a letter could be produced by the consultant and that letter should be enough as proof as surely you had to have the symptoms to get to that point? Surely that proves that you went through the system to get a diagnosis?”

Q7. Do you agree or disagree that eligibility for PIP should be based more on condition?

Disagree

Relying entirely on condition would be very unfair leaving all those without diagnosis without access to this important help. As previously stated there should be consideration of automatic eligibility for certain conditions which are progressive, chronic and severe. However, for other conditions which impact people differently, are variable or fluctuation or have a likelihood of improving there is still a need for an assessment.

Q8. How could we determine eligibility for the following conditions?

- **Conditions that fluctuate**
- **Conditions that vary in severity**
- **Conditions that might be cured, or have access to better/new/novel treatments over time**

Please explain your answer and provide evidence or your opinion to support further development of our approach.

People are individuals and many are affected differently by the same conditions. It is hard to see how to determine eligibility for conditions that fluctuate, vary in severity, might be cured or have access to better/new/novel treatments over time without an assessment. We think that for these type of conditions an assessment may be the best way of determining eligibility for PIP.

What is vitally important in relation to conditions that fluctuate, vary in severity or may improve is the training, knowledge and understanding of assessors. Improvements are needed in relation to capturing the information from claimants around their good and bad days rather than just a snapshot on the day of the assessment.

“I have mild COPD but yesterday I ended up in hospital with it. My son has schizophrenia and he is different every day. Maybe they should do a bit of both – take into account the condition and also how it affects your everyday living.”

“I’m bipolar and have a personality disorder. I go through so many emotions in a day and every day is a battle. People are not getting a fair shot at assessments. Some are done over the phone and as much as face to face is daunting at least they get a better idea of what’s going on with you when it’s face to face.”

“There are days I can get up and clean the house from top to bottom and I’m fine and the next day I can’t get out of bed. No two days are the same.”

“There are some people who will need to have an assessment. People with chronic, progressive conditions should get a green ticket straight through into PIP without an assessment. Those people who have variable conditions may need to be assessed. It might help to take the pressure off the system if chronic conditions were taken out of it.”

“More awareness is needed around fluctuations in symptoms. Just because I can walk up the road on one day doesn’t mean that it then doesn’t impact on my energy levels for the next two days and make me bed bound. I kept getting asked how far I could walk - no idea, it changes with how my symptoms are presenting but they kept pressing for a definitive answer which then undermined and invalidated my condition.”

Chapter 2 – PIP – Eligibility reform

Q9. Do you think the need for an aid or appliance is a good/bad indicator of extra ongoing costs and why?

The need for aids/appliances can be an indicator of extra ongoing costs as it help to illustrate the severity of the impact of a condition/disability on a person’s day to day activities. However, pressures and delays within the NHS and social care have implications for access to the necessary aids/appliances for some people meaning they are having to manage for long periods without them. Women spoke to us about delays in even getting to see their GP to get a referral to Occupational Therapy, etc. In these instances PIP claimants should not suffer a detriment because they do not have access to the aids/appliances that they need.

It is also important to note that not all aids help a person complete an activity safely and that assumptions are being made that the person can use the aid and use it safely and repeatedly. It’s also important to note that the need for an aid/appliance may change over time so that for example, someone who has arthritis in their hands may no longer be able to use a grabber if their hands become worse. Therefore, it is not just about having an aid/appliance but about the use of it – can the person use it safely and complete the activity with the use of the aid.

“It went against me that I had no aids or adaptions. I don’t have any but I’m still impacted by my condition. I’m in a Housing Executive house and it has a really long

front garden and I've no handrail. I've asked for one but I've been waiting and you could be waiting a long time. I still need it but because I don't have it then it goes against you."

"This is the only way to get mobility, it's the only way I got it. I have handles in the shower and on the stairs, a bed rail, commode upstairs and a Zimmer frame. Without giving evidence of these I wouldn't have got it – 100% I wouldn't have got high rate mobility."

"I have arthritis in my hips and need to use crutches. There's a 6 month wait to get crutches, I'm having to use my son's old ones."

Q10. Do you think the need for prompting is a good/bad indicator of extra ongoing costs and why?

As has been highlighted by the women we spoke to prompting is really important particularly in relation to mental health conditions. Without prompting many people with mental health conditions would not fulfil many basic daily activities and therefore this can be an important indicator of ongoing costs.

"Prompting is really important for mental health. I have to prompt my son who has schizophrenia all the time. I have to tell him to wash his hands, remind him to eat, take a bath, there's a lot of prompting every day. I just told him to have some toast and cheese for lunch and if I hadn't said he wouldn't have done it."

"Prompting is important, if I'm having a bad day I can lie in bed all day and not move, it takes someone coming in and telling me to get up."

"I think prompting should have points. Some people need it but don't have someone to prompt them – they have the need of it but are not necessarily getting the prompting they need."

"My daughter has mental health issues and she needs to be prompted. If she's not thinking about her hygiene and physical appearance I know there's a problem. I prompt her all the time, it's very important with mental health conditions if you don't prompt them they let themselves go."

Q11. Do you think people who accumulate low points across activities have the same level of extra costs as those who score highly in one or more activities?

This is very dependent on the individual circumstances and also makes assumptions that the assessment is correct. A person may accumulate low points across a range of activities and this would indicate that their life is affected by the condition/disability in multiple ways. While another could score highly in fewer activities and may be particularly affected in one area of their life but not in others. It comes down to the

individual circumstances therefore it is difficult to answer this question but for some people it is incorrect to say that those who accumulate low points across activities have lower levels of extra costs than those who score highly in one or more activities.

“If they have some level of difficulty across a whole range of things then it’s likely to affect a big part of their day.”

Q12. Do you think any of the PIP activities measure similar functions and could be merged?

Women told us that they found the PIP process very repetitive asking the same questions over and over again. It was suggested that the first few activities around basic needs could be merged and the activities around preparing food, eating and drinking could be merged.

We support the assertion made by our colleagues in Disability Action that the best way to change the PIP activities should be by co-producing the application system with disabled people.

“You’re repeating yourself a lot in the application form. It feels like they’re asking the same thing over and over.”

“They keep asking the same questions but in different ways.”

“I think preparing food, eating and drinking could all be merged as they all go hand in hand.”

“I think the first few activities around basic needs could be one question.”

“I think there should be three areas of questions – on basic needs, mobility and brain functions and the questions could be merged under these.”

Q13. Do you think any of the PIP activities should be removed or re-written and why?

Please see answer to Q12.

Q14. Should we consider adding any new activities? If so, which activities should be added and why?

Some of the women highlighted to us that night time activities were not part of the PIP assessment and this included things like toileting at night time and managing sleep. For some people this is really important as they have considerable needs at night time and

the difficulties they may experience at night may then have further implications for them during the day. It was also felt that there should be more around planning around the activities – this included planning for making meals and planning for shopping.

There was a general view that the PIP assessment did not cater as well for mental health conditions as it did for physical health conditions so there is a need to strengthen the activities around mental health.

We support the assertion made by our colleagues in Disability Action that the only way to add or change the PIP activities should be by co-producing the application system with disabled people.

“There’s nothing specific for night time – asking about the needs for help during the night including going to the toilet.”

“There should be more on the ability to plan your day like going out to get shopping to make meals. It’s not just about making the meals it’s about planning and shopping. My son is not going to do that if I wasn’t there – he would just buy a Pot Noodle and a packet of Monster Munch and that would be it.”

“There should be an activity for night time including toileting and managing sleep. There is no mention of sleep.”

“I don’t think the assessment is strong enough on the impact of mental health on both you and your family. If you have a physical condition they only take into account how it affects you physically not how it impacts on your mental health too. A lot of conditions affect your mood/anxiety/depression but there is very little on that.”

Q15. Do you think the current entitlement thresholds levels are set at the right levels to define the need for Government financial support and why?

In general the women we spoke to felt that achieving the entitlement thresholds in PIP was difficult and there was a suggestion that the eligibility for the standard rate is set very high.

“It’s very arbitrary. I think the points needed for the standard rate should be half of the enhanced rate so 6 and not 8. The bar is set very high for the standard rate.”

“Getting twelve points is very hard to reach.”

Q16. What are your views on changing the length of the current three-month qualifying period for PIP which is used to establish that the functional effects of a

health condition or impairment have been present for a certain time period before entitlement can start?

We do not see a need to change the current three-month qualifying period for PIP.

Q17. What are your views on retaining, removing, or changing the length of the current nine-month prospective test which is used to determine if the functional effects of a health condition or impairment are likely to continue long-term?

It is possible that some people suffering from some conditions could be severely impacted by that condition for shorter lengths of time, for example, cancer. The person may suffer severe impacts over a matter of months which result in high levels of need. We do not believe that they should be excluded from access to PIP. If changes are to be made to this test they must be carefully examined taking into account the views of disabled people.

Chapter 3 – PIP– What do we provide support for?

Q18. PIP provides a contribution towards extra costs. Which extra costs incurred by disabled people are the most important for a new scheme to address? Please rank the following options in your order of importance:

- **Equipment and aids**
- **Medications and medical products**
- **Personal assistance (costs arising from hired physical and/or emotional support within and outside the home, eg. help with household tasks or assistance with transportation)**
- **Health and personal care (including physical therapies, talking therapies, massages, etc. Also includes greater spending on personal hygiene or appearance)**
- **Extra transport costs (from reliance on taxis or accessible taxis, hospital parking fees, vehicle adaptations, etc.)**
- **Additional energy and utility costs arising from disability or health condition (including digital access)**
- **Additional food costs arising from disability or health condition**
- **Additional spending on clothing, footwear, and bedding items arising from disability or health condition**
- **Higher costs of insurance**
- **Additional housing costs arising from disability or health condition, including home adaptation costs**

This question is impossible to answer given that each person is an individual and people are often affected in different ways by different conditions resulting in different needs for support. What is important to one person may not be important to another. What is needed is a much more tailored approach to how people are affected by their condition.

Q19. In relation to Question 18, please explain your answer below and tell us about any other important kinds of costs not listed above.

See our answer to Question 18 and what women told us in relation to this:

“This depends on what condition you have and what extra costs are most significant to you. I use PIP to help with transport getting taxis to work and to the doctor. That’s what applies to me but for other people it could be different things and they’re important to those people.”

“Really difficult to say. Each person is an individual. Someone can suffer from really bad incontinence and need new bedding/clothes or have really bad anxiety and be unable to leave the house and need to pay someone to do their shopping, etc.”

“All the money I get goes on bills – electricity, petrol, car, food. 90% on my bills and maybe sometimes 10% for a massage if my arm and leg are not good. Most of the time the money goes on keeping my house. Money for equipment or carers would mean nothing to me.”

“Money from PIP allows me to work part time so I don’t have to kill myself in a full time job and make my condition worse. When I was working full time I was taking 4 relapses a year. I couldn’t afford to come out of work then I took ill and had to come out. PIP allowed me to go down to 21 hours/week, to stay reasonably well and to be able to pay my bills. If I hadn’t got PIP I wouldn’t be working as I would have ended up coming out of work sick or I would be in thousands of pounds worth of debt. Getting PIP has allowed me to be able to manage my MS and stay relatively well and be able to work.”

Q20. What are the benefits and disadvantages of moving to a new system for PIP claimants?

A catalogue/ shop scheme

- **Benefits**
- **Disadvantages**
- **Other**

Please explain your answer and provide evidence or your opinion to support further development of our approach.

The Women's Regional Consortium opposes all of the four proposals of support put forward in the Green Paper. We believe in a cash-first approach which provides dignity, choice and control for disabled people. The proposals outlined are humiliating and remove the dignity and autonomy of disabled people. The proposals also remove the flexibility of PIP to meet disabled people's needs, they remove choice and disempower disabled people from maintaining their independence. We also believe that all of the proposed options would only add to the administrative burden of both disabled people and the Department.

"This just sounds like a lot more work for the person who has got the condition or disability. I couldn't do it – applying for things, paperwork, etc. It doesn't suit everyone. All these options just complicate things for people who already can't cope at the best of times."

"I don't think this would work, everybody's needs are different, a catalogue scheme wouldn't work for everyone. If you have cash you can use it for whatever you need it for."

Q21. What are the benefits and disadvantages of moving to a new system for PIP claimants?

A voucher scheme

- **Benefits**
- **Disadvantages**
- **Other**

Please explain your answer and provide evidence or your opinion to support further development of our approach.

The Women's Regional Consortium opposes all of the four proposals of support put forward in the Green Paper. We believe in a cash-first approach which provides dignity, choice and control for disabled people. The proposals outlined are humiliating and remove the dignity and autonomy of disabled people. The proposals also remove the flexibility of PIP to meet disabled people's needs, they remove choice and disempower disabled people from maintaining their independence. We also believe that all of the proposed options would only add to the administrative burden of both disabled people and the Department.

“I think it’s stupid. Only the person knows that their needs are and vouchers won’t cover everyone’s needs. They’re trying to do away with cash altogether and you need to have cash. I would rather have cash.”

“It could end up costing them more money giving vouchers if they are contracting certain companies when people might be able to get things cheaper elsewhere.”

“Vouchers wouldn’t work for me, in these days when we haven’t enough money as it is!”

“This is awful, I don’t agree with any of these options.”

“I would need a voucher for every one of my utility bills. I don’t agree with this.”

“Government gives cash to those on Universal Credit and on the state pension. Why would you do this to the most vulnerable the sickest in society? Why would you do that? It’s discrimination.”

“I think these proposals go against human rights for disabled people. It goes against any rights I have giving me vouchers or using receipts instead of providing cash.”

Q22. What are the benefits and disadvantages of moving to a new system for PIP claimants?

A receipt-based system

- **Benefits**
- **Disadvantages**
- **Other**

Please explain your answer and provide evidence or your opinion to support further development of our approach.

The Women’s Regional Consortium opposes all of the four proposals of support put forward in the Green Paper. We believe in a cash-first approach which provides dignity, choice and control for disabled people. The proposals outlined are humiliating and remove the dignity and autonomy of disabled people. The proposals also remove the flexibility of PIP to meet disabled people’s needs, they remove choice and disempower disabled people from maintaining their independence. We also believe that all of the proposed options would only add to the administrative burden of both disabled people and the Department.

“I can’t read or write, I wouldn’t know how to do all that with receipts. I couldn’t be annoyed with all that, it would be a lot of work especially if you have a mental health condition going on like I do.”

“This would be a nightmare to administer. You’d need receipts for all your bills and what if you forget something or forget to get a receipt. Part of my condition is that I forget to do things. They are not thinking of people with these conditions who would struggle to cope with all this. Managing this whole process would be so stressful – how would anyone with a mental health problem manage this?”

Q23. What are the benefits and disadvantages of moving to a new system for PIP claimants?

One-off grants

- **Benefits**
- **Disadvantages**
- **Other**

Please explain your answer and provide evidence or your opinion to support further development of our approach.

The Women’s Regional Consortium opposes all of the four proposals of support put forward in the Green Paper. We believe in a cash-first approach which provides dignity, choice and control for disabled people. The proposals outlined are humiliating and remove the dignity and autonomy of disabled people. The proposals also remove the flexibility of PIP to meet disabled people’s needs, they remove choice and disempower disabled people from maintaining their independence. We also believe that all of the proposed options would only add to the administrative burden of both disabled people and the Department.

We agree with colleagues in Disability Action that adaptations and large scale purchases should be addressed through a system outside PIP.

Q24. If PIP could no longer be used to determine eligibility to passport to other benefits and services, what alternative ways could service providers use to determine disability status?

We do not believe there is an alternative and PIP should continue to be used to determine eligibility to passport to other benefits and services.

Q25. If PIP could no longer be used as the eligibility criteria to additional financial support in Universal Credit, what alternative ways of determining eligibility should we use?

We do not believe there is an alternative and PIP should continue to be used as the eligibility criteria to additional financial support in Universal Credit.

Q26. Are there specific groups of people whose needs are not being met by the current PIP provision and have a need for a greater level of support? What form should this support take (eg. help with specific extra costs, access to improved healthcare such as mental health provision or enhanced local authority support such as care packages and respite)?

There is a general feeling among the women we spoke to that the PIP assessment is inadequate for those with mental health conditions. In our previous research for the Second Independent Review of PIP in Northern Ireland 70% of the women who provided responses to the online questionnaire felt that the PIP assessment was ineffective for mental health conditions.

Government proposals around social care packages, talking therapies and respite care as better alternatives to benefit payments are simply unworkable given the current state of the NHS and social care sector. We have highlighted a range of problems with the health service and in social care at paragraph 2.6 which are particularly acute in Northern Ireland. Long waiting lists and much needed reform in the health and social care sectors which have yet to be delivered means that for many people access to alternative forms of support are simply not available when they need it. Pushing further demands onto a fragile and over-burdened health and social care sector is simply not workable and would leave many vulnerable and sick people without access to the help and support they need.

“The process is not great for mental health issues. It needs some adjusting as not one question fits all people. Even with mental health it does have a physical element but it’s hard to explain that. In the assessment all they want to know is if you can walk a certain distance and while that might be possible physically on the flipside you might not go out very much due to mental health issues.”

“A lot of people are really worried about these changes particularly women who have autistic children. They’re worried sick about losing their money. These changes go against disabled people’s human rights and I think they would make a lot of people stressed and unwell.”

“I don’t think the PIP process is good for mental health. I deal with depression and anxiety and that doesn’t stop me walking up and down the street and speaking to people - it is not good for more hidden things.”

Q27. Instead of cash payment, are there some people who would benefit more from improved access to support or treatment (for example, respite care, mental health provision or physiotherapy)?

Access to support and treatments such as talking therapies, respite care and social care packages should be available in addition to PIP not instead of it. As previously stated the demands, waiting lists and delays for these services are huge and growing particularly in Northern Ireland. Large scale reform and investment is needed within the health and social care sectors. We disagree with this proposal which could mean that vulnerable sick and distressed people face the possibility of having no access to help and support whatsoever. These supports and treatments are not a replacement for cash which is provided to meet the everyday additional costs of having a condition or disability. People will continue to need cash payments to support them in managing their condition or disability and in providing them with independence.

“No it wouldn’t be better. It’s just better getting the money and then you can decide what to do with it.”

“There’s nothing there for people with mental health problems they’re just put on medication and left with it.”

“There is no quick fix for mental health stuff. All the counselling in the world isn’t going to make my mental health issues go away especially when it’s been caused by trauma in the past. I was with a counsellor for 18 months and with a therapy group and I still have issues.”

“Everything is already under so much pressure how would this help?”

Chapter 4 – PIP– Aligning support

Q28. Do people already receive support from local authorities or the NHS with the need/costs that come with having a disability or health condition?

Some people may receive small amounts of support, for example, with energy costs for life saving equipment and local councils in Northern Ireland do not provide support with the costs of disability.

Q29. In relation to Question 28, please explain your answer and provide evidence or your opinion to support further development of our approach.

Local councils in Northern Ireland do not provide support with the costs of disability. Other supports are very limited. Support can vary considerably across geographic areas and between health trusts.

We have highlighted throughout this response the issues with resourcing, lack of funding and delays within the health and social care sectors. Local council support and NHS services are over-stretched with many people not getting the help and support they need or having to wait a considerable length of time for it.

Women have highlighted to us time and time again for this consultation and for many others the huge issues they have accessing health and other public services. Public services across the board are under huge pressure and we hear day and day daily about the huge budgetary pressures that exist in Northern Ireland the need to reduce public spending and find savings within Departments.³⁸ Therefore this should not be considered until there is adequate funding and investment in public services. It is impossible to align support with health and social care services in their current state where it is often described as 'collapsing'.

"I can't even get an appointment with my GP at the minute so I can't even get referred on to anyone else."

"There are long waiting lists for mental health support and people are ending up killing themselves because they can't get the services they need. How are they going to fix that?"

"The money isn't there in local Councils to give the help people need and if they do have it they're only going to give the bare minimum. Sometimes the help is discretionary so not everyone will get it either."

"There are long waiting lists for Occupational Therapy – it's 2 years plus. Waiting times are a real issue."

"The services they want to align with are overstretched and bureaucratic. If you have to go to your GP they are overstretched and you struggle to get an appointment. How long would you then have to wait to get a referral to an OT? You just end up buying the things you need yourself."

³⁸ <https://www.bbc.co.uk/news/uk-northern-ireland-68446689>

Q30. Which of the following do local authorities or the NHS help with?

- **Equipment and aids**
- **Medical products**
- **Personal assistance (eg. help with household tasks)**
- **Health services**
- **Social care**
- **Respite**
- **Transport**
- **Utility costs**
- **Other**

Support can vary considerably across geographic areas and between health trusts and in Northern Ireland local councils do not provide support with the costs of disability.

Q31. In relation to Question 30, please explain your answer and provide evidence or your opinion to support further development of our approach.

We have highlighted throughout this response the issues with resourcing, lack of funding and delays within the health and social care sectors. Local council support and NHS services are over-stretched with many people not getting the help and support they need or having to wait a considerable length of time for it.

“It’s not easy to get mental health counselling, a lot of it is through charities and there are long waiting lists. There is not enough funding for these services and there is huge demand for mental health counselling.”

“If they want to support mental health issues in local areas then they need to fund it.”

“This is a stupid idea, some local councils have been declared bankrupt due to lack of money and they don’t have enough funding especially in this Cost-of-Living Crisis.”

Q32. Which needs/costs that come with having a disability or health condition could local areas help with further?

- **Equipment and aids**
- **Medical products**
- **Personal assistance (eg. help with household tasks)**
- **Health services**
- **Social care**
- **Respite**

- **Transport**
- **Utility costs**
- **Other**

We do not believe that local areas could help further with the needs/costs that come with having a disability.

Q33. In relation to Question 32, please explain your answer and provide evidence or your opinion to support further development of our approach.

Councils in Northern Ireland have different functions than other parts of the UK. We have highlighted throughout this response that the NHS is already under-resourced and overwhelmed by demand and would therefore not have the capacity to help with this. See also our answer to Q34.

Q34. If we align the support offered by PIP into existing local authority and NHS services, how could this improve things for disabled people and people with health conditions?

There are widespread issues with funding, resources, waiting times and delays in accessing a variety of public services. The Cost-Of-Living Crisis has seen enormous additional demands for help and support on systems that were already struggling to meet need. This means that local councils and health services may struggle to provide support and services to those that need help. In addition, people can miss out on their rightful entitlements because they don't know about the services/support provided by their local councils or health services and sometimes this information can be difficult to find out especially for those who are more vulnerable. The bureaucracy involved in administering any such local council schemes could result in barriers to access to disabled people and variability in schemes offered across different council areas.

"I don't know what services my local council even offers it's the last place I'd think of going to. I have never gone near my local council for anything to do with my MS."

"You can't get respite care now since Covid. It doesn't exist!"

"Most services haven't returned to what they were pre-Covid – respite, day care, etc."

"How are they expecting to supply extra services when they can't even supply what they're supposed to at the minute?"

“The services are just not there at the minute so asking them to do more is just not going to work. They say they’re going to support this, that and the other but in reality it doesn’t happen, it’s just words.”

“You can’t ask others to pick up things when they don’t have the resources to do it.”

“If the services are not there it’s not good enough it just makes people worse and then they have no money either.”

Q35. Do you think aligning PIP with local authority and NHS services could reduce the number of assessments a person with a disability or health condition would have to undergo? Would this help to reduce duplication?

No. Please see our previous answers to the Questions asked in Chapter 4.

Q36. What disability support services in your community are the most important services or support to deliver?

This question is impossible to answer as all disabled people are different, are affected differently by conditions and have their own specific needs. This means that different services will be more important to different people according to these needs.

Q37. How much flexibility should local areas have to decide their priorities in supporting people with disabilities and health conditions?

This is a moot point. We have repeatedly made the point that it is impossible to align support with health and social care services in their current state.

Q38. What capacity and capability would be required to better align PIP with local authority and NHS services?

As previously stated we believe there are significant reforms and investments needed in local authority and NHS services and these are long-term. We therefore don’t believe that there should be any attempt to align PIP with local authority and NHS services.

“It would need huge investment as the waiting lists are so long for everything. There’s no help with mental health issues, it’s non-existent, how are they going to improve that?”

“They don’t have enough money to do what they need to do now. The system is too broken now, it needs fixed before they try and do this.”

“It’s unrealistic given the current state of the Health Service. You can’t even get a doctor never mind a specialist. People are put on waiting lists and waiting years.”

Compulsory question

Q39. Are you an individual or an organisation supporting claimants applying for PIP?

Yes. Many local Women's Centres provide advice on social security benefits including PIP and can also provide signposting to advice centres for more complex issues and advocacy work. Consortium members also send out information updates from the Department for Communities on benefits including PIP and will signpost people to welfare rights organisations for help and support on making claims and appealing decisions.