citizens advice York

Aligning Policy and Reality:

how to achieve the aims of sickness and disability benefits reform

York Carers Centre
Free Support for Unpaid Carers

York Disability Rights Forum

York: Human Rights City

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York Foodbank
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York Carers Centre

York Disability Rights Forum

York Foodbank

Healthwatch York

York Human Rights City Network

Older Citizens Advocacy York

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Executive Summary

Over the last fifteen years the levels of support for disabled people with significant but not the highest levels of impairment have been increasingly stripped out of the benefits system. All of our signatory organisations believe that the changes proposed in the Green Paper would accelerate that trend. Worse, they would achieve the opposite of what is intended. They would push those who might be able to work further from work; force many from poverty into deep poverty; damage the physical and mental health and wellbeing of many; and increase health inequalities and homelessness. Although, because of the transitional protection in place, the full impact would not be felt immediately, there would be an insidious creeping increase in poverty and destitution. The benefits system needs to address the reality of people's lives not the distorted picture so often presented.

In the supposed interest of simplification, there has also been a move away from targeted support based on the needs of different individuals in different circumstances. A benefits system that is responds to different needs of different people is inevitably complex but the burden of navigating that complexity should not fall on its users. It is, in fact, a core task of a sophisticated system to manage complexity internally so that, externally, it is simple for people to use.

Some of the language used in the debate is extremely unhelpful and distressing. Many chronically sick or disabled people who would like to work can't find a job. In researching this report we were shocked by how many of the stories we heard began with clients being forced out of work by their employer, even though they could have remained in employment if reasonable adjustments had been made. Increased intervention is needed to ensure employers put reasonable adjustments in place alongside genuinely helpful work preparation support, such as early assessment for Access to Work, for those sick or disabled people who are able to move back into work.

However, retaining benefit support is also an essential part of the package. Cutting benefits will not help people return to work. Instead, it will reduce the financial support that could help them to remain in employment or re-enter the workplace, and it will push those who might be able to work even further from work.

The government's previous claim, that reducing the number of people eligible for the LCWRA element would assist those affected to find work and was not primarily a cost-saving measure was rejected by the High Court. Yet the claim continues to be made that cutting benefits is a "moral issue" to prevent people being "written off". It is not the "generosity" of the benefits system that creates barriers to work; the issues are far broader. The trend of reducing lower levels of support is highly counterproductive for people with significant functional impairments but who could, with additional financial support from PIP and UC, enter and sustain work.

For those who cannot realistically work, the proposals would trap many into deep poverty. There must be a recognition of the value of all people to society regardless of their ability to work.

We also believe, as we set out in more detail in Appendix 1 that several proposals in the Green Paper run counter to, and risk violation of, provisions of the UN CRPD, the Human Rights Act 1998, and the Equality Act 2010, particularly where they would result in significant loss of income for disabled claimants.

We hope that the Timms Review will consider how to transform the support for sick and disabled people within the benefits system so that it reflects the diverse needs and circumstances of different groups. It should create a system that is genuinely simple to use, supports those who can work to enter employment and ensures dignity, an adequate standard of living and proper social protection for those who cannot work.

We are very grateful to those who shared their experiences with us. Names and identifying details have been changed or removed to ensure anonymity.

Recommendations

1. **The structure of the benefits system for sick and disabled people needs to restore different levels of support and support targeted at groups with particular needs**
   - **Personal Independence Payment (PIP) needs a genuine standard level of support** so those with significant (but not high) care needs are also supported.
   - **Similarly Universal Credit should have different levels of support** depending on: how long someone is likely to be unable to work and whether they are likely to be restricted by their impairment or health condition in the amount of work they can do
   - **Passporting** Without lower levels of support in UC and PIP, other organisations who use receipt of a sickness or disability benefit to offer reduced prices or other support will be unable to assist those with significant levels of impairment.
   - **Disabled Persons Work Allowance (DPWA)** People with significant levels of impairment also face additional costs in work that others don't face - the DPWA must be available to them to ensure that if they can do some work they can cover the additional costs they face and so can make work pay
   - **A self care element** Support for disabled people who live on their own or just with dependent children who are often carers but who don't get CA, face much higher costs than those who have someone paid CA or the carers element to assist them. A self-care element at the same level of the carers element should be available
   - **Contribution based benefits must not be time-limited for those who are unable to work because of a health condition or disability**

2. **A joint assessment for PIP and UC health additions could reduce levels of duplication and allow more resources to be spent on accuracy but it is essential that:**
   - **It distinguishes between, and considers separately, the ability to work as well as care needs.** Some people who have only moderate care needs are actually unable to work and face the additional costs associated with being out of work long-term. Others have high care needs and face additional costs as a result but are able to work.
   - **The inaccuracy of health assessments is tackled**

3. **The assessment of the ability to work needs to include a realistic consideration:**
   - **of the impact of generalised pain and exhaustion**
   - **of the impact of the client's diagnosis on the likelihood of he/she getting work**
   - **of the impact of the client's condition, given their age, work experience and level of educational qualifications on the likelihood of he/she getting work**

4. **Particular consideration should be given to anyone over sixty with a serious health condition as to the realistic likelihood of them being able to work again taking all the factors above into account. If they are realistically unlikely to be able to work then they should be given early retirement on health grounds**

5. **The complexity of UC needs to be addressed by looking carefully at the different levels and types of support that different claimants, with differing health conditions and in differing circumstances, need and then ensuring that the route someone needs to take to claim the appropriate level of support is clear, straightforward and adapted to their circumstances.**

6. **It is also vital that alongside any changes to the Benefits System it should be made simpler and easier to compel employers to make reasonable adjustments so that those disabled people who can stay in work are able to do so, and disabled people trying to re-enter the workplace have the same access to a job as others with the same level of qualifications.**

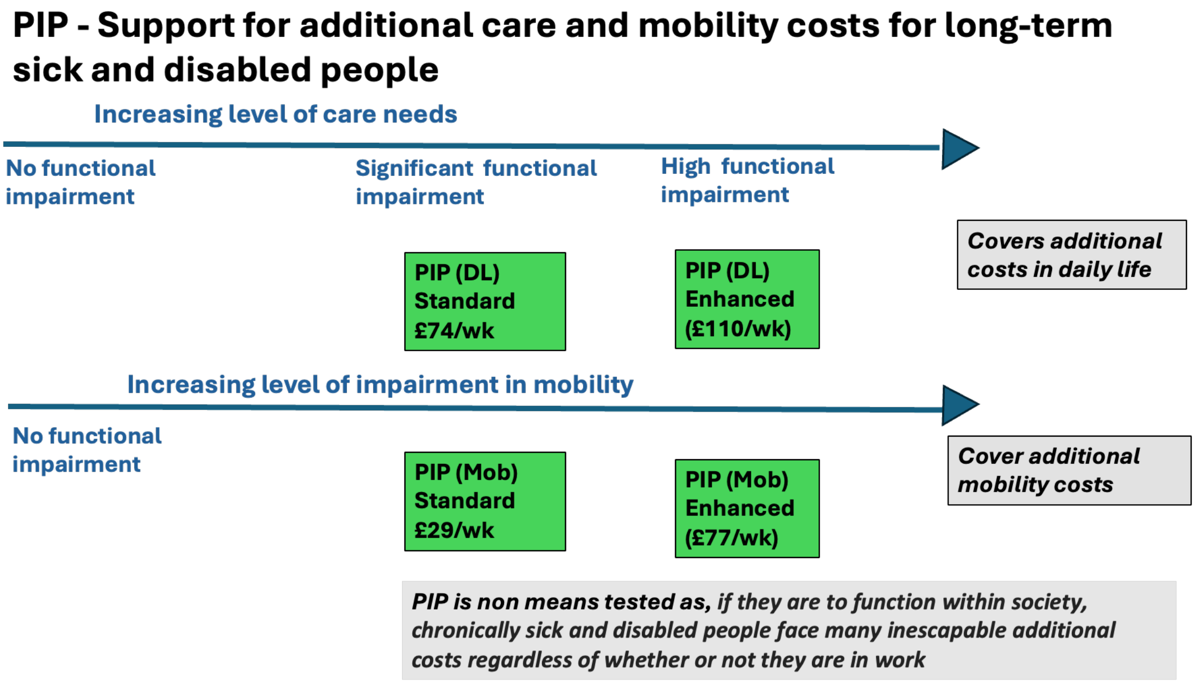
A. The current structure of sickness and disability benefits

Personal Independence Payment (PIP)
Chronically sick and disabled people face inescapable extra costs if they are to play an active part within society. PIP is a non-means tested benefit intended to help such people meet these costs whether or not they are in work.

PIP Daily Living PIP (DL) is based on how impaired someone is in tackling everyday household activities such as washing, dressing or making a meal and in interpersonal activities such as communication or social engagement, and helps with the cost of paying for assistance with these.

PIP Mobility PIP (Mob) covers the additional transport costs for those with limited mobility, including over short distances, and is based on how much help they need in moving around and in planning and following journeys.

Both elements of PIP can be awarded at standard or enhanced rates depending on level of impairment.



PIP - Support for additional care and mobility costs for long-term sick and disabled people

Increasing level of care needs

No functional impairment

Significant functional impairment

High functional impairment

PIP (DL) Standard £74/wk

PIP (DL) Enhanced (£110/wk)

Covers additional costs in daily life

Increasing level of impairment in mobility

No functional impairment

PIP (Mob) Standard £29/wk

PIP (Mob) Enhanced (£77/wk)

Cover additional mobility costs

PIP is non means tested as, if they are to function within society, chronically sick and disabled people face many inescapable additional costs regardless of whether or not they are in work

Universal Credit (UC)

UC is a means tested benefit. The UC total maximum payment to someone with no other income has an amount to cover living costs and an amount for housing costs. The basic living costs maximum has an additional amount (or up to 2017, 2 additional amounts) for those likely to be out of work for longer because they are long-term sick or disabled. This addition reflects the fact that for those on benefits for more than a short time, any savings that have been put aside to cover sudden emergencies will have gone and that there is nothing in basic UC to cover broken household items, repairs to houses, washing machines etc, clothes that have worn out or been outgrown, to say nothing of presents or trips out.

These additions comprise:

The Limited Capability for Work element (LCW) - the additional payment for those in this group is no longer payable to new claimants[1] It was awarded to those who were thought likely to be able to return to work in the medium term.

The Limited Capability for Work Related Activity element (LCWRA) is paid to those in this group – most in this group were assumed to be unlikely to be able to return to work long-term.

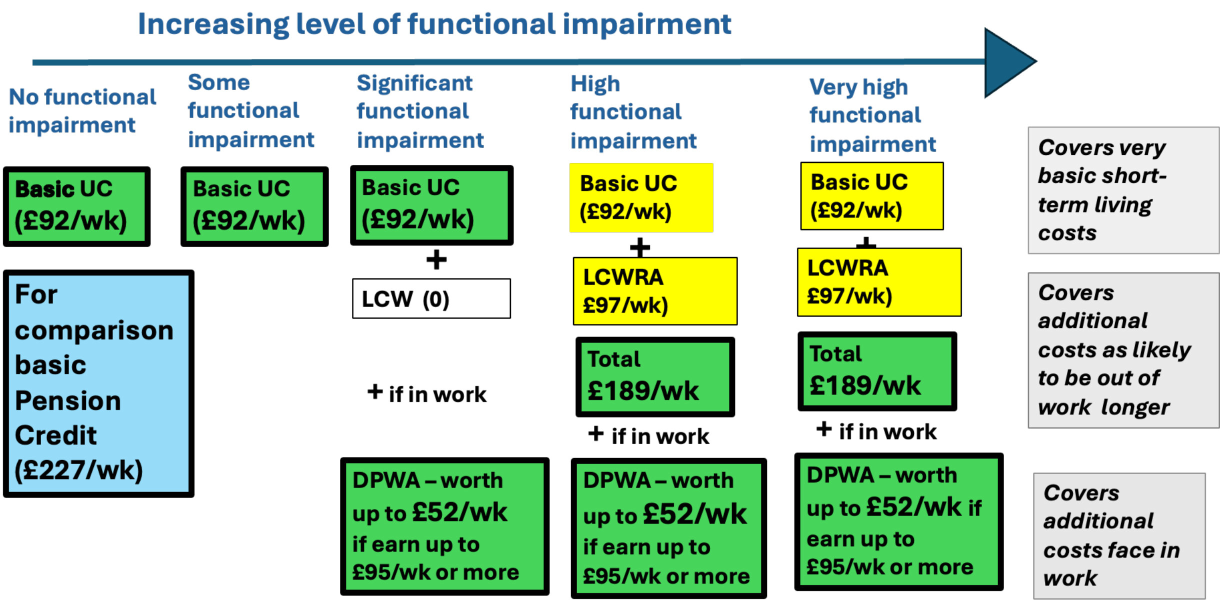
Eligibility for LCW/LCWRA depends on the level of functional impairment affecting work-related activities

When someone is in work the UC they receive reduces (is *"tapered"*) by £5.50 for every £10 rise in earnings, however there is a concession for some chronically sick or disabled people.

The Disabled persons Work Allowance (DPWA) doesn't increase a claimant's maximum UC, but claimants keep the first £95[2]/week of earnings, (before the taper applies) meaning they have about £52/week more than those on standard UC. It helps cover additional in work costs those who aren't disabled don't face and is available to those in the LCW or LCWRA groups who enter work.

The following diagram shows how UC living costs amounts are calculated – housing costs are then added to give maximum amount (current benefit rates for April2025/26).

Living costs support for long-term sick and disabled people in UC



Contributory Employment and Support Allowance (**ESA (cb)**)
Those who are unable to work because of sickness or disability can claim ESA (cb) (now known as new style ESA) if they have paid enough National Insurance (NI) contributions. Those found to have LCW receive the basic £92 /week, those found to have LCWRA after 3 months receive £141/week.

Those, who have no other income apart from their ESA (cb) and so are also reliant on UC, are actually, unlike in the Legacy System, no better off financially as the income from contribution based benefits counts as unearned income so is taken pound for pound off entitlement to UC. However claimants who aren't entitled to any means tested benefits, such as those who have a partner who has earnings or a pension, rely on ESA (cb) to have any income of their own unless they have an occupational pension.

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[1] Stopped for new claimants in 2017

[2] For those with no housing costs in their maximum UC it is higher

B. The revised structure suggested in the Pathways to Work White Paper

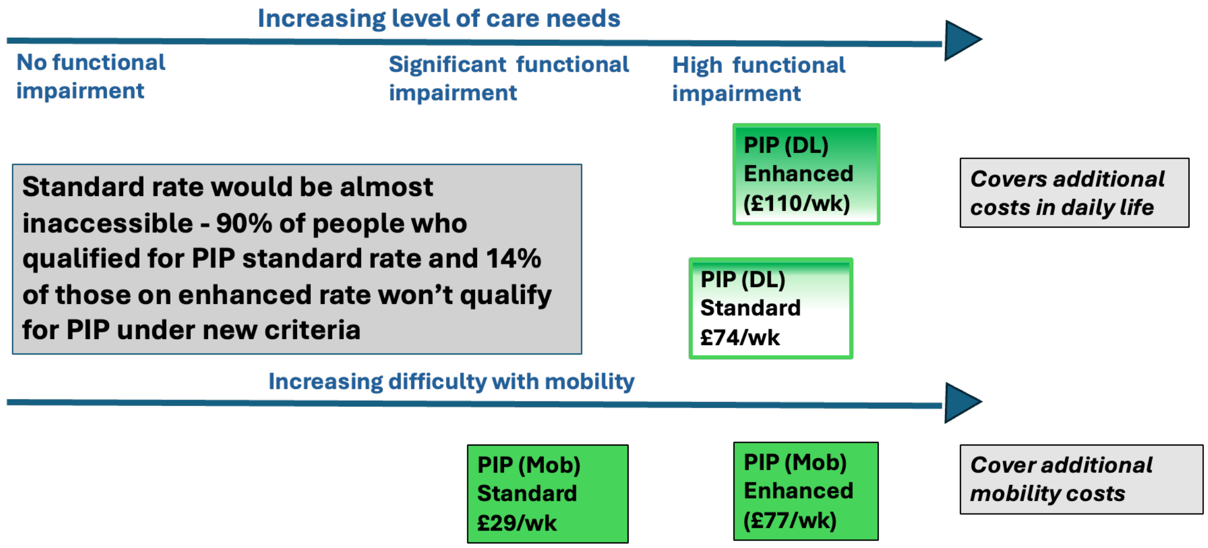
Personal Independence Payment PIP

Currently, PIP is assessed on a person's support needs for basic tasks such as washing, dressing, cooking and communication. Individual tasks are scored between 2 and 12 points depending on level of assistance needed (eg needing assistance to wash your hair is worth 2 points). Currently with a total of 8 points across tasks, a person will get the standard rate and the enhanced rate with a total of 12 points or more. The Pathways to Work paper proposes the same totals but adds the requirement of at least 4 points on at least one task; the same total score spread over two point impairments is worth nothing.

Government estimates suggest that the changes will make 0.8m people lose PIP by 2029/30. But FOI data shows 1.3 million out of the 3.7 million currently PIP do not have any single task score of 4 points and would fail the new rule; **including nearly 90% of those on the standard rate.**[3] Local data shows about 83% of PIP standard rate recipients in York would also lose eligibility.[4] [5].

Losing PIP does not only mean loss of income. Councils and other local bodies use PIP as a passport for many kinds of support essential for fuller social participation.
The following diagram shows current benefit rates for April2025/26 as at time of writing figures for following year have not been announced.

Proposed structure for PIP
for long-term sick and disabled people



Standard rate would be almost inaccessible - 90% of people who qualified for PIP standard rate and 14% of those on enhanced rate won't qualify for PIP under new criteria

Health addition of Universal Credit

Currently those who are likely to be too sick or disabled to work for more than the short term have to undertake the Work Capability Assessment (WCA). The assessment scores impairments (on a scale of 0–15 points) across tasks necessary for work, such as mobility, sitting or standing at a work station, communication, ability to learn new skills, coping with change, and social engagement. Someone with less than 15 points in total is classed as fit for work. To qualify for the LCW group the claimant needs to score a total of 15 points, for LCWRA the claimant needs to score maximum 15 points on one activity or qualify for one of the exceptions such as having a terminal illness or there being a serious danger to them or others if not placed in LCWRA.

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[3] https://www.benefitsandwork.co.uk/news/almost-nine-out-of-ten-standard-rate-pip-awards-fail-new-test

[4] About 1500 people in York Central constituency and 830 people in York Outer are currently receiving PIP DL but didn't score 4 points on a single activity

[5] https://www.jrf.org.uk/uk-poverty-2025-the-essential-guide-to-understanding-poverty-in-the-uk#_-groups-with-unacceptably-high-rates-of-poverty

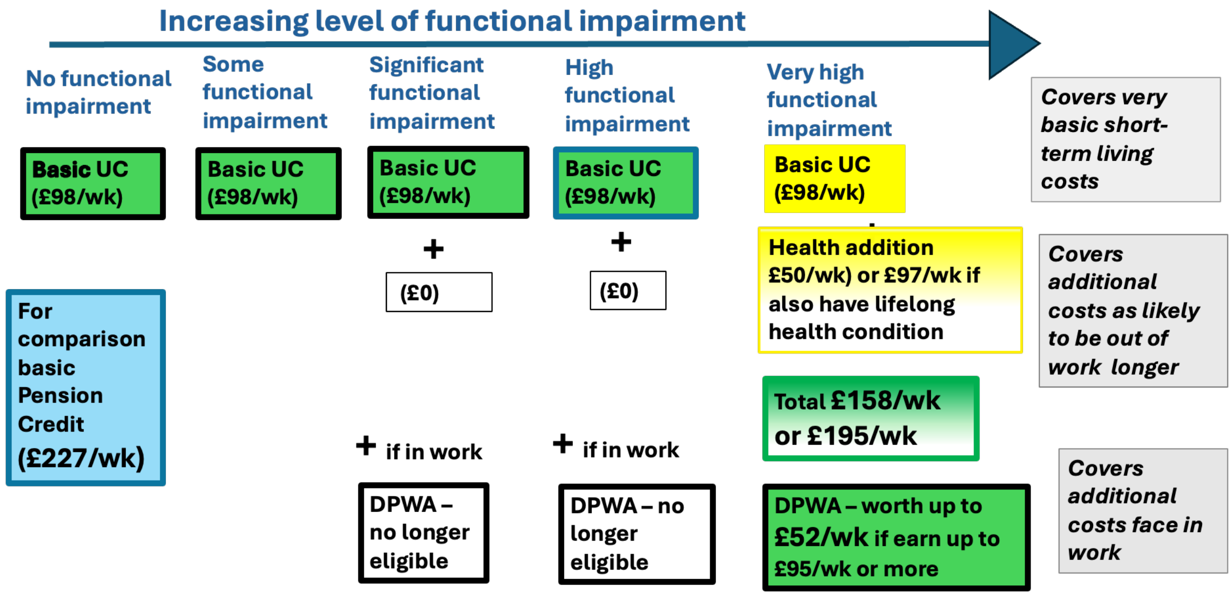
Under the proposals in the Pathways to Work Green Paper there would not be a separate test for ability to work. To qualify for the Health Addition in UC someone would have to qualify for PIP Daily Living. FOI data from the DWP shows that as of May 2024, only 32.1% of UC claimants with LCWRA also receive PIP DL and score 4+ points on one activity, so over two thirds of current recipients would no longer meet this threshold.[6]

This structure has implications for more than the loss of the health addition. There will be many fewer disabled people entitled to the *Disabled Person's Work Allowance* (DPWA) under the proposed structure.

There will also be a loss of *passported benefits*. Many organisations rely on the receipt of a sickness or disability benefit as a way of allocating additional support.

(The benefit rates in the following diagram show the expected new basic rate of UC (£98) and the health addition (£50) for new claimants from April 2026/27. However the basic pension credit rate and the health addition for existing claimants and those covered by the special conditions rules are the existing 2025/2026 rates.)

Proposed living costs support for long-term sick and disabled people in UC in Pathways to Work



Contribution based benefits

The Pathways to Work green paper proposes paying a time limited flat rate of benefit to anyone who has paid enough NI contributions and who is unable to work. The flat rate would be paid at the level currently payable to those in the support group (£141) and would be paid at this rate without a waiting period of 3 months. It would be paid regardless of whether the claimant is unemployed or unable to work because of an illness or disability but everyone would also be limited to the same time limited period.

The higher payment without a waiting period is very welcome as many who unexpectedly have to stop work face a sudden and dramatic drop in income but have spending commitments such as rent that can't be quickly adjusted. If they have had to stop work because of a diagnosis of a serious illness they frequently also face additional costs. During what is obviously a worrying time, adjusting to the financial difficulties adds to the stress so anything that can be done to relieve this is obviously helpful. **However** unless there is a disregard for the extra £49 above the basic living

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[6] https://www.whatdotheyknow.com/request/lcwra_pip_daily_living_allowance/response/2987083/attach/3/Response%20FOI2025%2025575.pdf?cookie_passthrough=1

costs element of £92 in UC, those who are on their own living in rented accommodation and therefore likely to struggle most, won't be helped by the additional support as their ESA **will be taken pound for pound – the additional support in effect coming off the rent part of their UC.**

The most worrying aspect of this proposal is the time limiting to the same period regardless of how long you may need to be out of work. Those who have worked all their lives and paid NI stamps but may well not live to receive any retirement pension will be justifiably very angry that, despite having worked and paid NI for many years, they will, after a set period of time unlikely to be longer than 6 months or a year at the most, have no income of their own if their partner has earnings. The long-term needs of someone who has a serious deteriorating illness and is unlikely to be able to return to work are very different to someone who has lost his job and is looking for work. Simplification is no excuse for disregarding the very different needs and rights of different groups.

The existence of an *indefinite* entitlement to contributions-based income replacement benefit for people who are too ill or disabled to work is a long-standing one – it pre-dates the WWI welfare state and has been a continuous feature ever since. We believe removing it is likely to be legally challenged on a number of grounds, including discrimination and legitimate expectations, as we set out in Appendix 2.

C. Personal Independence Payment – why is it necessary?

In 2024, Scope estimated that households with a disabled person need on average an extra £1,010/month for the same standard of living as a non-disabled household.[7] These costs include needing to spend more on heating, costs of specialist equipment and also maintaining it, additional laundry costs, help with household tasks, special dietary needs, paying for carers, and extra transport costs. Sometimes family members or friends live at a distance so aren't able to assist for enough hours to claim carers allowance, and they may be struggling financially themselves and coming 2 or 3 times a week. PIP allows the disabled person to pay for their travel costs. Some services come with a price premium for disabled people, such as paying for medication and treatments not covered by the NHS.

Yet 1.3m of 3.7m PIP claimants, including nearly 90% of those on the standard rate, don't score 4 points on any activity and would lose out. Citizens Advice see many in this group facing unavoidable additional costs. Without additional financial help they are likely to be trapped in their homes and pushed further from the job market.

Case Study 1

Elizabeth was made redundant a while ago and has been looking for work ever since. However she is in a lot of pain from a health condition which has got much worse over the last year. She takes strong prescription pain killers which make her very groggy. She has struggled to find work and is really struggling to manage financially.

She needs help with many tasks in her home but has no one to assist her – tasks, such as hoovering, lifting or reaching for things, and food preparation, all aggravate the pain. It is so painful to lift her arms to wash her hair that she avoids it when she can but she would have to look presentable for work. She has just been awarded PIP and this will enable her to get some help with these tasks and hopefully will make the pain more manageable and work more possible. However she wouldn't qualify for 4 points on any of the descriptors.

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[7] Scope, *Disability Price Tag 2024: Living With the Extra Cost of Disability,* September 2024, https://differencenortheast.org.uk/wp-content/uploads/2025/01/DisabilityPriceTag2024-LivingwiththeExtraCostofDisability.pdf.

PIP is key in helping disabled people take part in society, through work if possible, or in other ways if not. Those who may be capable of work, are more likely to succeed in finding and sustaining it if they can afford help, for example with getting assistance with tasks that would aggravate their pain, or covering the extra costs needed to engage outside the home , or of being presentable in a work environment. These additional costs are many and varied depending on the person's health condition or disability. They can include additional travel costs when others could walk, having to buy and maintain aids, presentational costs such as having to wash or replace clothes much more frequently than others, having to pay for help with self-care such as hair washing that others can do for themselves, having to pay someone travel costs to come and assist them, and for additional medical treatment that relieves their condition but is not available on the NHS.

Impact on carers

Many of those currently on PIP but who do not score 4 points on any single activity rely, like Peter (Case Study 2 below), on outside help to have any life outside of their home. If the changes remove their PIP (DL), the person helping them will not be able to claim Carers Allowance or the carers element in UC, and the government estimates that 150,000 carers will lose entitlement as a result. Others rely on the support of their children. There have been very many reports[8] on the negative impact on education, health, wellbeing and future prospects of being a young carer. The loss of the severe disability premium created further significant hardship for young carers looking after a sick or disabled single parent. The loss of PIP would make things even worse.

By paying people appropriate benefits it gives them more control, eg to be able to pay travel costs to family members, who are too far away to care full-time , to assist part-time on a regular basis; or to use micro-providers, who are far more adaptable to individual need. This increases the likelihood that the person with a disability or illness may be able to take up opportunities for work (ie not waiting for someone to come and help you get dressed who isn't reliable and doesn't turn up until lunchtime). This then reduces the burden on statutory social care provision and also on unpaid carers - who then also might potentially be more able to work / increase hours etc themselves.

For couples where one has had to give up work because they develop a long term health condition and the other divides their time between part-time work and caring responsibilities, the financial losses are enormous. Currently the couple will be entitled, in addition to their basic UC, to the LCWRA £97/week and the Carer element (£46/week) in their maximum amount of UC as well as PIP (DL) (£74/wk). If they are in rented accommodation and especially if they also have children, the loss to their income, if the carer is unable to work or only able to work part-time is likely to be this amount in full – a loss of about £217/week or £11,300 a year.

Other impacts of the loss of PIP

Organisations wishing to offer reduced prices and other forms of support to disabled people can obviously not do their own medical assessment so use receipt of PIP as a proxy. For example, many disabled people who might be able to improve their health and readiness for work by getting reduced price access to swimming pools, will lose this proof of their special needs.

Loss of PIP can also in some situations reduce housing costs entitlement in UC, remove exemption from the Benefit Cap; remove entitlement to UC as a student, remove carers' benefits and NI credits and remove the disability addition and disabled child element/addition from the UC or PC of parents of dependent children aged over 16. Restricting all support only to the most severely disabled will disadvantage many who, with help, could engage more actively in society, and even return to work.

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[8] https://www.caringtogether.org/news/report-reveals-huge-impacts-of-being-a-young-carer/
https://carers.org/young-carers-action-day-2023/being-a-young-carer-is-not-a-choice
https://www.barnardos.org.uk/sites/default/files/uploads/still-hidden-still-ignored.pdf

D. Universal Credit health addition (currently LCWRA) – why do people need the health addition?

How Universal Credit health additions work currently

When UC was first introduced an additional amount (LCW component) was added to the maximum UC of those likely to be unable to work in the medium term or be limited in the amount of work they could do because of illness or disability and a larger amount was added (LCWRA component) for those likely to be unable to work long-term.

In April 2017 the LCW element was removed so since then anyone placed in the LCW group does not get any more money than those who are unemployed. To be placed in the LCW group you must have been assessed as being too disabled to be expected to look for work for at least 3 months. The shortest period for reassessment is 6 months with some people not being reassessed for 2 years[9]. Many people particularly in manual occupations who are diagnosed with deteriorating conditions such as Parkinsons and are unable to continue in work can be in the LCW group for some considerable time before they are placed in the LCWRA group. Managing more than short-term on the basic UC causes considerable financial difficulty.

Higher cost of not being able to work long term

The additional amounts for those who are sick or disabled reflects at least in part that when someone is out of work more than short-term any savings that have been put aside to cover sudden emergencies will have gone, there is absolutely no spare in basic UC to cover broken household items, repairs to houses or cars, clothes that have worn out or been outgrown, to say nothing of presents or trips out – the longer they are unlikely to be unable to return to work the more difficult this situation will become. The following case study illustrates this. The much higher level of Pension Credit maximum living costs basic amount **(£227)** than Universal Credit **(£97)** surely at least in part is there to reflect this sort of need.

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[9] https://questions-statements.parliament.uk/written-questions/detail/2024-11-13/14050/

Case Study 2

Peter is in his late fifties. A number of years ago he had a serious accident at work, permanently disabling him. He was awarded Industrial Injuries payment. He had been working for the same large firm ever since leaving school, and was keen to return to work in a different role, but the firm refused. He successfully challenged this in an employment tribunal and was reinstated, in a new less physical role.

Several years later, after a fall, he was diagnosed with further conditions which cause extreme nausea and dizziness. At this point he was unable to return to work. His conditions have steadily worsened since then. As a result of his disability and also the dizziness he needs a lot of assistance from a friend. When they are unable to come he sometimes can't get dressed and he relies on pre-prepared food or snacks. The dizziness and nausea are particularly bad several days a week but even on better days he can have a bad attack so he is reluctant to go out unaccompanied. These factors and their unpredictability, the grogginess from strong painkillers, his difficulty sleeping because of the pain, his sheer exhaustion, all make work unrealistic.

Peter had worked hard for many years until it was no longer possible, progressed in his job and was buying a house. After leaving work, he lived on his redundancy pay and savings, which have now all gone. He has had to claim UC and is in the LCWRA group. His industrial injuries payment is taken pound for pound off his entitlement to UC so he is totally reliant on his UC plus PIP. There is nothing to spare for house maintenance and repairs. ***He is very worried about what will happen to his PIP – it is a great struggle to manage currently living long-term on such a low level of income. He is worried he may lose his house.***

Those who are seriously ill or disabled but likely to recover within a year
PIP is only payable if you are likely still to be sick/disabled in a year's time. However currently the LCWRA element in UC is payable after 3 months. Some claimants such as those who have a diagnosis of cancer and are undergoing chemotherapy and radiotherapy but then hope to be able to return to work are not eligible for PIP. However, they may, like those long-term sick, face high additional costs such as high heating bills, even if these apply only in the medium term.

The UC health addition needs to be payable to those who may be out of work less than a year, but who still have very high costs over that period and so are not receiving PIP.

It is crucial therefore that the assessment for the health addition to UC:

- **actually assesses realistically who is unable to work in the long term.**
- **and also includes those whose level of impairment is high but who wont qualify for PIP because they are likely to be able to return to work within a year**

E. Using PIP to determine entitlement to the health element of UC

There would be some advantages to only having one assessment. It would save repetition in both the forms and in the assessment - many of the questions about how their condition affects their daily life will be similar for both benefits. It therefore could reduce claimant stress and save administrative costs. **However there are a couple of essential points:**

i) **The need for the assessment to distinguish between, and consider separately, high care needs and the ability to work**

There is obviously a strong overlap between who needs the health addition of UC and who needs PIP as any functional impairment is likely to create some additional costs and also to some extent affect the ability to find and undertake employment. **However, there are clearly people with significant impairments but who can work (**about 1in 6 PIP claimants are in work). [10]

However there are others with lower care needs but who are nevertheless unable to work as a result of their illness or disability and so face the problem of meeting repair and replacement costs while living long term on out of work benefits. (about 0.6m of those in the LCWRA group did not receive PIP (May 2024) [11] while 0.4m claimants on Universal Credit or income-related ESA were in receipt of PIP or DLA but did not have the LCWRA (or support) component (November 2022).[12])

ii) Tackling the inaccuracy of health assessments

Having one assessment rather than two will make it even more important to properly address the long-term issue of their inaccuracy. Inaccuracies and unwarranted assumptions are distressingly frequent in the reports produced by the health practitioners employed by DWP, as evidenced in multiple reports by, e.g.Citizens Advice, Disability Rights UK, and MIND. Several Government inquiries and efforts to improve the situation have had very little effect so far.

In 2024, Citizens Advice helped more than 50,000 people challenge a PIP decision. Most appeals (68%) that reach a tribunal are overturned in favour of the claimant. In the vast majority of overturned decisions, the tribunal reached a different conclusion based on the same evidence, suggesting poor first-tier decision-making. In the answer to a parliamentary question it emerged that less than 1% of the changed decisions were due to new evidence provided to the tribunal.[13] Reports from organisations frequently quote outrageous examples, but the underlying concern is the high proportion of the reports from the health professionals doing the assessments that contain inaccuracies and omissions, resulting in an incorrect award.

If there is going to be one assessment for both benefits:

- ***the assessment must consider realistically costs associated with the impact of the illness or disability on their ability to work as well as the extra costs of daily living and moving around.***
- ***the long-term problem of the inaccuracy of health assessments must be tackled***

F. What factors need to be taken into account

i) For those who can do some work

a) The need for different levels of support

Over the last fifteen years the lower levels of support for disabled people with significant levels of impairment have been increasingly stripped out of the benefits system. The proposals in the Green Paper accelerate that trend. As has pointed out above this is very counterproductive to any attempts to support people to enter and sustain work. Some support in both PIP and UC is important for those who have significant levels of functional impairment but are able to work.

b) **Almost eliminating the standard rate of PIP is counterproductive**

As shown by Elizabeth in case study 1, PIP is important to enable people with a significant level of functional impairment but who are able to do some work - to get and sustain work. At present about 35% of those on PIP receive the enhanced rate and 65% standard rate. However this will drastically

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[10] https://obr.uk/box/trends-in-working-age-disability-benefit-onflows/

[11] **https://www.whatdotheyknow.com/request/lcwra_pip_daily_living_allowance/response/2987083/attach/3/Response%20FOI2025%2025575.pdf?cookie_passthrough=1 and** https://www.gov.uk/government/statistics/universal-credit-work-capability-assessment-statistics-april-2019-to-june-2024/universal-credit-work-capability-assessment-statistics-april-2019-to-june-2024

[12] https://commonslibrary.parliament.uk/research-briefings/cbp-9800/

reverse if the proposal for the need for 4 points on one activity is enacted – it almost eliminates awards of a standard rate.

Reducing by 90% those eligible for the standard rate of PIP is counterproductive – it will make finding and sustaining work much more difficult.

c) Universal Credit – reducing numbers getting the Disabled Persons Work Allowance DPWA is also counterproductive

The amount of additional costs someone faces as a result of being chronically sick or disabled significantly rises if they are working. Some of these are covered by the Access to Work scheme but there are multiple other costs that are not covered in this way.

The additional costs people experience vary enormously. They may not qualify for help with transport through Access to Work but may still pay extra because they get exhausted by walking more than short distances or pay a much higher proportion of their earnings because they are limited by the number of hours they can work each day.

Those who have conditions that cause them a lot of pain or exhaustion on exertion frequently describe needing to rest and recover after work and the following day. They need assistance with the housework and to use more shortcuts such as ready meals. Disabled parents often report having to pay for longer hours of childcare than others because they need to rest after they have finished work or pay for days they are not working to rest and recover the following day.

Being presentable is important in work; some people who find raising their arms painful will need a regular hair appointment, others may need a carer, who can assist them to get ready for work in the morning – this assistance will help prevent them starting the day exhausted by the pain. Some people need someone to prompt them to wash and dress appropriately so that they can overcome low mood or lack of motivation - this can make a big difference to the sustainability of work. Many need to pay more for medication and other therapies to cope with being in work. Those who are neurodivergent or have a mental health condition may only be able to cope with very limited hours each day, especially at first, if the work is to be sustainable, so travel costs will be proportionally higher. Being able to join in work social activities will be important but If they are only able to work part-time, paying for, and the travel to, them will form a higher proportion of their earnings than of their full-time colleagues' earnings.

On top of this, the disability pay gap is now 17%. Analysis of official statistics shows that over the year to Spring 2024 the earnings gulf between disabled and non-disabled workers widened to £2.35 an hour.[14]

For those without a work allowance any earnings you receive reduces the amount of UC you receive by 55% of your earnings so someone earning £100 a week will have £55/week less money from their UC and earnings combined than if they had a work allowance. However, their earnings will also reduce their Council Tax Support so that will reduce their income still further[15] . They will then face the additional costs as a result of working **– leaving them, if they can only work reduced hours, struggling not to be worse off as a result of being in work.**

The Disabled Persons Work Allowance (DPWA) doesn't increase the maximum amount of UC you receive but it does mean that if you start working the UC you receive each month doesn't reduce straight away. The first about £100[16] per week you earn doesn't reduce your maximum UC.

The DPWA is a key support for disabled people entering work yet received just a passing mention in the Pathways to Work White Paper. In there it confirmed that those who receive the health addition of UC will be entitled to the DPWA. Currently anyone who is in the LCW group as

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[14] https://www.disabilityrightsuk.org/news/disability-pay-gap-reaches-staggering-level-£4300-year?srsltid=AfmBOoprQWgotjUHHBA3Mtz3EtyjED4pnSlNP8Dl4yRuA_NEpcsafNXE

[15] The amount depends on the council – each council uses its own council tax support scheme

[16] For those with no housing costs in their UC maximum amount

well as the LCWRA is entitled to receive the DPWA if they enter work. Clearly far fewer new claimants would be entitled to it. In response to a FOI request DWP revealed that as of May 2024, of those in receipt of the LCWRA element in Universal Credit, only 32% receive a PIP daily living award and scored a minimum of 4 points in at least one daily living activity.[17] A very much smaller percentage of people in the LCW group are likely to have scored a minimum of 4 points entitled to the health element. It is very counterproductive to be significantly reducing numbers entitled to this incentive to work whilst trying to encourage more people into work. The Government say the changes will help the most disabled **but it is those with a significant level of functional impairment but who are not the most severely disabled who are most likely with additional financial support to be able to return to work.**

DPWA is a significant incentive and support to work by covering the additional costs of working disabled people face. There needs to be a lower level of points score in the assessment so that the numbers entitled to the DPWA are not significantly reduced

ii) For those who can't work

a) Impact on health of living in deep poverty

Under the proposed changes many future claimants who can't work, would not get PIP or any addition to the basic UC and will be placed in long term deep poverty. The government has not released evidence to support the assumption that anyone who scores less than 4 points on all the activities in the PIP Daily Living assessment will be able to move into work in the relatively short-term, despite their health condition or impairment.

Professor Kate Pickett, Professor of Epidemiology in University of York noted:

"*Living in deep poverty has profound and enduring effects on health outcomes that persist across the lifespan and generations, as evidenced by extensive UK-based research over many decades.*

The British cohort studies (1946, 1958, 1970, Millennium Cohort Study), landmark studies (such as the Whitehall studies, Born in Bradford and ALSPAC,) and government-commissioned reports (Black report, 1980; Acheson report, 1992; Marmot review, 2010) consistently demonstrate clear social gradients in health, high levels of health problems related to poverty, and intractable health inequalities.

International comparative research shows, again consistently, that the UK performs poorly compared to other high income countries, with higher rates of poverty (especially child poverty) and worse health outcomes.

The longer that individuals spend in poverty, the worse the outcomes

As well as poverty, research shows that income insecurity and volatility have independent negative effects on health, beyond low income. Poverty creates chronic stress that damages physical and mental health through multiple pathways, including exposure to environmental stressors, poor nutrition, overcrowded housing, and limited access to healthcare and other health protecting and promoting services. Childhood poverty, in particular, has lasting and intergenerational effects, with individuals who experienced early socioeconomic disadvantage showing lower educational attainment, worse employment and productivity and poorer health, all of which are mutually reinforcing in negative feedback pathways. A vast and robust body of evidence underpins a picture of extreme poverty becoming "embodied" through chronic stress responses, environmental exposures, and cumulative disadvantage, creating health inequalities that compound across generations."

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[17] https://www.whatdotheyknow.com/request/lcwra_pip_daily_living_allowance/response/2987083/attach/3/Response%20FOI2025%2025575.pdf?cookie_passthrough=1

b) The need for a realistic assessment of who is unable to work based on more than just a functional assessment

The impact a health condition or impairment has on your ability to work and on your chances of securing employment varies enormously depending on your level of qualifications, your work history and skills, your age, your condition, its variability, the medication you need to take, the pain and exhaustion you suffer and the support system you have around you.

It is likely that even if the proposal to change PIP to having 4 points for one activity goes ahead there will be some who will still receive PIP and who can and will work.

However there will be others who won't qualify for PIP who are unable or cannot reasonably be expected to work, because of the impact of their condition on their health, wellbeing, and employability.

Many people who are disabled or have a serious health condition that causes a general level of pain and exhaustion, rather than having a concentrated effect on one key function they can't perform without help, are going to be in this position. Yet it is this very level of general pain, exhaustion and brain fog from difficulty sleeping and the impact of strong painkillers that for many makes work unrealistic.

Case Study 3

Sally had a professional career until fifteen years ago when she became ill. She had post-operative complications; her employer failed to make reasonable adjustments and fired her. She wanted to continue working and seriously considered and explored going to an employment tribunal but was ill and when she looked at what would be involved, she could not face the stress.

Since then, her condition has significantly worsened. She has had numerous operations and has a stoma and a feeding tube. She has lost a lot of weight, and her body struggles to absorb nutrients. She has also developed rheumatoid arthritis which means she is in pain a lot of the time and finds walking very difficult. She has difficulty sleeping. She is exhausted a lot of the time.

Her social life is very limited – any trip out means that she must do nothing for several days before and after the outing.

She would love to work but believes that it is unrealistic. She was doing a small amount of voluntary work but had to give it up because she never knew from one day to the next whether she would have a bad day.

Sally receives UC with the LCWRA component and PIP mobility and daily living. She received 10 points in the PIP daily living assessment but didn't score 4 points for any activity. She is very worried about how she would manage without her PIP and horrified how someone in her position on an even lower income will be expected to manage.

Making reasonable adjustments more attainable and enforceable

Many seriously ill and disabled people who were pushed out of work by their employer when they became sick or disabled, believe they could, with reasonable adjustments, have been able to continue in work. Of the cases quoted in this report Peter (Case Study 2) actually succeeded at employment tribunal. Others, like Sally, got to various stages in challenging their employers but the process is very stressful.

Since leaving work, their condition has significantly worsened to the extent that they believe that work is no longer a realistic possibility but are now being expected to do so. Much more needs to be done to support those who develop a health condition or disability whilst working but would be able to continue working for that employer if reasonable adjustments were made. Currently, if refused their only recourse is to take the employer to an employment tribunal – a difficult and stressful thing at the best of times but at a time when facing a health crisis it is frequently impossible.

Similarly, many long-term sick and disabled people who are actually able and desperate to work find it impossible to find an employer to make the necessary adjustments. In a large-scale study in 2022/2023 fictitious job applications were sent to over 4000 job vacancies, some applicants were indicated as using a wheelchair and others were not. The 2 types of jobs were accountants and financial accounts assistants – jobs where using a wheelchair would have no impact on job performance. Significant discrimination against disabled candidates was found with disabled candidates having a 15% lower chance of callback than non-disabled applicants. The discrimination was even stronger for the less skilled roles.[18] Research shows disabled people apply for a significantly higher number of jobs—around 60% more—than non-disabled jobseekers before finding employment. [19]

Much more needs to be done to make it easier to access reasonable adjustments and to avoid discrimination

c) The need for the system to consider factors other than level of impairment when considering early retirement on health grounds

The severe conditions criteria purports to offer a sort of early retirement on health grounds – albeit at a much lower level of means tested income than a healthy pensioner. However, this requires someone to not only have a serious disability or health condition that is lifelong, the impairment to be constant with any recovery of functionality unlikely ***and also*** that they qualify for PIP daily living component. **These requirements would exclude very many who have no realistic possibility of being able to work again.**

What chance, realistically, of finding other employment does a manual worker in their sixties who is diagnosed with a serious deteriorating health condition and is no longer able to do manual work have, even if they have not yet reached the level of functional impairment required by PIP?

The LCWRA currently contains a descriptor that allows entry to the LCWRA group if you can't mobilise 50 metres without stopping. The proposal to use PIP daily living means that ability to mobilise will no longer count towards the health element. Yet the ability to mobilise will affect people very differently depending on a number of factors.

A 30 year old who following a car accident sustained back and shoulder injuries and is now a wheelchair user clearly needs and deserves a great deal of help and support to get back into work – he or she is also likely to continue to face many additional costs and will and should qualify for PIP mobility and may also qualify for PIP daily living. Many in this situation will have reached the stage when they can return to fulltime work. If they have a high educational level and skills suitable to a desk job their chances of finding work will be increased.

A sixty year old who had worked all his or her life in manual work but now has heart disease and emphysema, may have a lower level of functional impairment – perhaps able to walk 40 or 50 metres but their employability is likely to be low. If their condition is likely to deteriorate further then employers are even less likely to take them on.

Besides, in a society where the majority of the population looks forward to many years of healthy retirement, should those whose functioning has already deteriorated to the extent they can now only walk about 50 metres, get tired very quickly so already have to limit time spent with their grandchildren or going out, be expected to spend their limited energy working or looking for work so a social life is impossible until their health deteriorates to an extent that they can no longer enjoy any social life? Everyone should have the opportunity to have some sort of retirement from work before they become so sick or disabled they are unable to take part in any social activity.

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[18] https://www.cardiff.ac.uk/news/view/2873912-uk-study-exposes-widespread-hiring-bias-against-disabled-job-applicants

[19] https://business.scope.org.uk/understanding-the-challenges-of-disabled-jobseekers/

Even in the USA – not known for having a generous social security system – those who don't automatically qualify for disability benefits because of the seriousness of their health condition or disability may still qualify if they are over sixty. Whether they then qualify is based on a complicated grid system that takes into account many other factors for a given level of functional impairment. Employability varies enormously depending on a whole series of factors such as age, whether they have always been a manual worker in the past, and their level of education. If it is decided that the impact of these factors will mean someone with their level of functional impairment would be unlikely to get work they will be eligible to retire with a disability pension.[20]

Early retirement on health grounds is available to many in the wealthier parts of society – the benefits system needs to offer an equivalent.

d) Impact of low life expectancy on ability to work in later life

Low levels of life expectancy and healthy life expectancy in the UK especially for those in the most deprived areas inevitably lead to a higher proportion of people in their late fifties or early sixties who are unable to work than in comparable countries. It is obviously those in the most deprived areas that are least likely to have sufficient income from a private pension if they have to stop working before retirement age and are therefore reliant on Universal Credit.
In England, average life expectancy for men living in the most deprived areas is 73.5 years and healthy life expectancy is 52.3 years, compared with 83.2 years and 70.5 years in the least deprived areas. Life expectancy for women living in the most deprived areas is 78.3 years and healthy life expectancy is 51.9 years. compared with 86.3 years and 70.7in the least deprived areas.[21] **In Scotland, average life expectancy for men living in the most deprived areas is 68.9 years and in Wales 74.1years.**

(For charts showing life expectancy for UK and comparable countries see Appendix 3)

"*The latest comparisons of health care quality and outcomes in OECD countries show that, overall, the UK continues to compare poorly with comparator countries on many health outcomes. For leading killers such as cardiovascular disease and cancer, the UK under-performs along the whole pathway of prevention through to early diagnosis and treatment. Hence the UK's higher rate of deaths following a heart attack or stroke, poorer cancer survival, and greater rates of avoidable deaths – all of which contribute to the country's low ranking on life expectancy*".[22]

e) Impact on those with Cardiovascular Diseases and Respiratory Diseases

A breakdown of the **cause of the gap between the life expectancy between the lowest and highest 20% deprivation groups for males (2020/21) shows that almost a quarter of it is due to a higher mortality rate from circulatory diseases such as heart disease**, **a further 12% is due to respiratory diseases;** (the corresponding figures for females are 19% and 14%).[23]

Both are conditions that are likely to cause breathlessness and exhaustion. **These groups are very likely to be affected by taking the ability to mobilise out of the assessment criteria for the health element.** (Government estimated that 260,000 people would be excluded from the LCWRA if the ability to mobilise was taken from the assessment criteria[24].) Difficulty mobilising for people with these conditions, rather than a musculoskeletal problem, acts as a proxy for general problems with breathlessness, pain and exhaustion.

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[20] https://silverandsilver.com/social-security-disability-rules-after-age-60/

[21] https://www.health.org.uk/evidence-hub/health-inequalities/inequalities-in-life-expectancy-and-healthy-life-expectancy

[22] https://www.kingsfund.org.uk/insight-and-analysis/press-releases/health-at-a-glance-oecd

[23] https://analytics.phe.gov.uk/apps/segment-tool/

[24] https://www.gov.uk/government/publications/work-capability-assessment-reform-estimated-number-of-claimants-affected/work-capability-assessment-reform-update-to-estimated-number-of-claimants-affected#:~:text=With%20these%20changes%20to%20the,them%20move%20closer%20to%20employment.

However not only do these groups lose out because difficulty to mobilise is taken out of the criteria for the health element. If the proposal to go ahead with the PIP daily living new criteria needing 4 points for one activity then those with Cardiovascular Diseases and Respiratory Diseases are also amongst those most likely to be excluded from PIP (Daily Living) (PIP DL).

Nationally 62% of those with Cardiovascular Diseases and 55% of those with Respiratory Diseases who are currently entitled to PIP DL didn't receive 4 points on any of the activities. (Percentages for those in York at risk of losing PIP DL are similar. 64% of those with cardiovascular diseases and 48% of those with respiratory diseases who live in the York Central constituency and 50% and 54% who live in York Outer currently receive PIP DL but didn't score 4 points on any single activity.) [25]

They are more likely to be generally exhausted and find all tasks difficult rather than rather particular difficulty with one of the activities.

Case Study 4

Mike and his wife Angie are both in their late fifties. Angie works part-time. Mike has recently had to give up work due to COPD and angina worsening over the past year. He has always worked in physically demanding jobs.

They live in rented accommodation. Their savings are now almost gone. They will be entitled to UC and he should qualify for the LCWRA (health addition), because he gets breathless and exhausted walking more than very short distances. He was also advised to claim, and currently should qualify for, PIP mobility and PIP Daily Living. Angie, depending on the hours she needs to spend assisting her husband with everyday tasks that others can do for themselves, would be eligible for the carer element of UC. However he is unlikely to score 4 points on any single activity so couples like them in the future would not be entitled to the health addition or carer element in their UC or to PIP DL.

Those who have worked in manual jobs all their lives but in their late fifties or early sixties develop heart or respiratory problems that affect their mobility, have little chance of finding work. Much has been made of the greater availability of jobs that allow working from home but these are primarily for those with a higher level of qualifications.

Case study 5

Steve is in his late fifties. He did physical work for many years but is no longer able to work. As a result of heart disease and angina he is in pain and becomes breathless when walking short distances. He has had multiple heart attacks and stents fitted. His family have a history of heart disease leading to early death. ***He is concerned about his increasing risk but would be very unlikely on the basis of his heart condition to score 4 points on any of the PIP Daily Living activities. He does qualify for the LCWRA in his UC.***

f) Impact of living on own without a carer

There are factors other than the level of impairment, such as whether someone lives on their own and does not have a carer, that very significantly affect the additional costs disabled people face. **The Severe Disability premium was paid in means tested benefits in the Legacy system to those who received PIP (Daily Living) and who lived on their** own or just with dependent children and didn't have someone receiving Carers Allowance to care for them. **No equivalent was included in the UC system** – instead the savings were spread between all those in the LCWRA group.

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[25] https://www.jrf.org.uk/social-security/where-will-cuts-to-sickness-and-disability-benefits-fall-hardest#_-labours-heartlands-affected-most

All those who have care needs sufficient to qualify for PIP(DL) are likely to face additional costs. However this group obviously face much higher additional costs than those who have a partner or carer, if they have no one to assist with all the day to day tasks around the house such as cooking, cleaning, washing, changing sheets, and small decorating and maintenance jobs. A survey [26]of those in receipt in 2012 (when very few had moved to UC) of those who still received the SDP found that many were concerned that, because they were unable to do the maintenance tasks such as cleaning gutters, small decorating jobs, tidying the garden themselves – and they could not afford to pay someone else to do it – their home was becoming very neglected. Others were having to prioritise paying for some of these tasks, such as having their grass mown, as it was part of their tenancy agreement, but were then left with less to spend on other essentials.Getting out was also in many cases very expensive for this group and many felt they could not prioritise socialising, only going out for essential trips such as hospital appointments.

Some had relatives at a distance and some had friends who lived closer. Where none of these were able to assist for enough hours each week to claim CA, the SDP was used to pay expenses of those who were travelling some distance to help and to buy small presents for friends living nearby in acknowledgement of their assistance. One commented "….. my daughter takes me to hospital, dentist, doctors, shopping or if I want to visit friends. I put around £50/60 in petrol as daughter lives 30 miles from me and also comes to help with showers etc."

Young Carers are a particular concern. Single parents whose children take on the caring role face these costs and more. Children are not eligible for CA but single parents were using the SDP to try to limit the impact the child's role as carer was having on their day to day life. The disabled parent has extra transport costs for essential trips for their children as well as themselves. In the survey they were clearly concerned to try to limit the social exclusion of their children. Many also prioritised paying for cleaning help, so that their children were not faced with having to do the heavy cleaning as well as the personal care.

A self care element paid at the same rate as the carers element for those chronically sick and disabled people receiving PIP (DL) who don't have someone paid carers allowance or the carers element to assist them would be a fair and straightforward way of meeting the particular needs of this group. It is also important in tackling child poverty as families with a disabled adult are more likely to be in poverty. Dependent children acting as carers for a single disabled parent are particularly likely to struggle.

iii) Simplification

A benefits system that is responsive to the different needs of different people is inevitably complicated but the complexity does not need to be apparent to its users. **What is important is that it is simple for people to use, claimants can understand what they need to do to make a claim and very importantly, there are no unexpected consequences. It should not require claimants to carry out complicated calculations to avoid irrational and unfair situations**.

Simplification is not about taking away graduated levels of support or different sorts of targeted help – it is about ensuring that the route someone needs to take to claim the appropriate level of support is clear, straightforward and adapted to their circumstances.

Universal Credit was clearly an attempt to simplify the system and the complex interaction between different systems with different reporting requirements. Whilst there were several changes in the move to UC that did genuinely simplify things for claimants and administrators, such as the removal of having a limit on the amount a carer could earn before losing the carer element of UC, many claimants report the move to UC generally made life more complex.

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[26] https://www.citizensadvice.org.uk.cach3.com/Global/Migrated_Documents/corporate/holes-in-the-safety-net-sdp-report.pdf

Examples of UC complexity

It may appear simple and straightforward to have an assessment period of a month and to decide the claimant's UC that month on the other income including any earnings received that period but this rigid rule with no adaptations to cover differing circumstances has led to many complex, irrational and unfair situations and legal challenges that could have been avoided. For example:

When someone has to leave their job because they become ill they are likely to think they need to claim straight away as they know they will have to live off their final earnings while they wait for 5 weeks from the date of their claim for their first payment of UC. However if their ex-employer pays them their final earnings just after their claim then at the end of the 5 weeks they will find that having lived off those earnings for the last 5 weeks they now need to wait another 5 weeks with no income – ***if they had waited a couple of days to claim they would have received full UC after 5 weeks instead of 10 weeks and wouldn't have lost a month's UC.***

Those who are paid 4 weekly often struggle to manage when their UC payment suddenly stops altogether one month or drops very significantly because for 1 AP each year there are 2 wages paid in (there are 13 lots of 4 weekly payments in a year).

Being paid 4 weekly has an even more disastrous outcome for some. A claimant who is earning the equivalent of 16 hours a week at the minimum wage escapes the benefit cap. However if they have found a job working 16 hours/wk as expected but are paid 4 weekly they will find they aren't exempt from the benefit cap for 11 APs each year.

These are examples caused by just one rigid rule – there are many others such as the problems caused by the system's assumption for simplicity that there are exactly 52 weeks not 365 or 366 days in the year for those who have to pay rent 4 weekly – leaving claimants 1 or 2 days short of rent each year. It is possible to design a system that is simpler and fairer to use because it takes people's different circumstances into account and doesn't leave people losing money compared to others simply because of the way wages are paid or rent payments structured.

It doesn't need to lose targeted support

The severe disability premium was complicated and led to errors but was vital to those who live on their own or just with dependent children. Abolishing it and paying one level of benefit to everyone in the LCWRA group regardless of whether they face many additional costs because they live on their own does not make life simpler for that group of disabled people who now have to find ways to cope with tasks that they could have paid to have assistance with. ***A simpler fairer system would be a self care element paid at the same rate as the carers element to those who don't have someone paid carers element to assist them.***

G. Conclusion - the key factors in structuring sickness and disability benefits

i) What the basic structure needs to cover

a) Consideration of ability to work as well as care needs

There are some advantages to having a combined test for the various sickness and disability benefits. However it makes it **even more important that the accuracy and reliability of any assessment process is very significantly improved.**

The assessment may sensibly have *some* overlap between care needs and ability to work but there needs to be a recognition that this is not sufficient. Part of the assessment needs to assess:

- who because of the impact of their condition faces **significant additional costs in daily life whether in or out of work and**
- who faces the **additional costs of being out of work long-term because of the impact of their condition on their ability to work.**

b) Different types and levels of support

As we pointed out earlier – whilst the greater the level of functional impairment you have the higher additional costs you will face, those with lower levels of functional impairment also need some help with their additional costs or they will be trapped in their homes unable to take part in society and less likely to be able to work. In both PIP and UC there needs to be genuine different levels of support recognising that even low levels of support are important and are noted – perhaps by lower levels of scoring on the assessment.

Passporting Many organisations use receipt of a sickness or disability benefit to offer reduced prices or other support. Even a small amount of money for a low level score would also give recognition and would enable passporting to additional support. It could also be used to passport people to the DPWA (see below). If the only people who can access this additional help are the most disabled then it further cuts off support to those who with help might be able to play a more active role in society or return to work.

c) A realistic assessment of ability to work

The impact a health condition or impairment has on your ability to work and on your chances of securing employment varies enormously depending on your level of qualifications, your work history and skills, your age, your condition, its variability, the medication you need to take, the pain and exhaustion you suffer and the support system you have around you. **The assessment of the ability to work must include a realistic consideration:**

- **of the impact of generalised pain and exhaustion**
- **of the impact of the client's diagnosis on the likelihood of he/she getting work**
- **of the impact of the client's condition, given their age, work experience and level of educational qualifications on the likelihood of he/she getting work**

d) Those who are unable to work for less than a year but have high care needs

In order to qualify for PIP you must have had the necessary functional impairment for at least 3 months and be predicted to have that level of impairment for at least another 9 months. Those whose level of impairment is high but who wont qualify for PIP because they are likely to be able to return to work within a year must still be able to qualify for the health element.

e) Those who don't have a carer

The Severe Disability Premium in the legacy system recognised that disabled people who live on their own or just with dependent children and don't have a carer face a lot of additional extra costs that those who have someone assisting them don't face. However it was complicated both for administrators and claimants and led to frequent under and overpayments as people who were not part of the claim (eg adult children returning to live at home for short periods) moved in and out of households. It did need simplifying - however as those who live in the same household and are caring for the disabled person would now be eligible for the carers premium regardless of their hours of work – **a self care element** paid at the same rate as the carers element would be a simple and well targeted addition. It would just need the criteria of having the care needs and not having someone entitled to CA or the carer element. It would not need the criteria of living on one's own to be efficiently targeted on those who need it most.

f) Those who have additional costs because they are working and are disabled

The DPWA is an important support to enable those who may be able to, to do some work but even a few hours work will incur additional costs. To target it effectively and make a real difference to the numbers who move into work it needs to be available not just to those with the highest levels of impairment. It also needs to come with genuine support in looking for and sustaining work. By enabling just a few hours of work a week to make work pay it can give someone who will never be able to work more than a few hours a sustainable way of staying in work. For others it can give the confidence to gradually increase their hours

ii) Simplification

A benefits system that is responsive to the different needs of different people is inevitably complicated but the complexity does not need to be apparent to its users. Indeed it is part of the job of a sophisticated system to manage complexity internally so that, externally, it is simple for people to use

Any change to the Benefits System needs to start by looking carefully at the different levels and types of support that different claimants, with differing health conditions and in differing circumstances need and then to ensuring that the route someone needs to take to claim the appropriate level of support is clear, straightforward and adapted to their circumstances.

It is also vital that alongside any changes to the Benefits System there is a serious attempt to make reasonable adjustments more attainable and enforceable so that those disabled people who are able to stay in work are able to do so and disabled people trying to re-enter the workplace have equal access to a job as others with the same level of qualifications.

The Timms Review

We are really pleased that the Timms Review Terms of Reference includes in the points it will consider:

> ***"Whether any other evidence should be considered alongside the functional assessment to fairly reflect the impact of living with a long-term health condition or disability, including related to an individual's personal circumstances and environment."***

We are concerned that any lessons learned over many years about ways in which support can be more targeted and nuanced, in so many diverse situations for people with a wide variety of disabilities or health conditions of sick and disabled people, and often in very different circumstances have been gradually lost over the last 15 years.

The Pathways to Work Green Paper accelerates that trend. Hopefully the Timms Review will look in detail at these concerns and put in place a system that genuinely considers the differing needs of disabled people in differing circumstances.

Appendix 1

Deprivation of income and violations of the UN CRPD and the Equality Act 2010

Several of the proposals within the Green Paper run counter to, and risk violation of, provisions of the UN CRPD and the Equality Act, in particular where they result in significant loss of income for disabled claimants.

Article 28 (2) CRPD requires state parties:

> 'b. To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
>
> c. To ensure access by persons with disabilities and their families living situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care'.

Benefit reforms prior to these proposals have already depressed the income of disabled people, and placed the UK in a position of violating the UN CRPD. The UN Committee on the Rights of Persons with Disabilities wrote to the UK government in June 2025, noting that it had received 'credible information that if approved, the Universal Credit and Personal Independent Payment Bill will deepen the signs of regression that the Committee indicated in its 2024 Report'.[27]

In that 2024 Report, **the Committee found that the UK had failed to address its 'grave and systematic' violations of the UNCRPD.[28] The Committee added that 'This failure exists particularly with respect to the State party's obligation to guarantee... an adequate standard of living and social protection (art. 28) in the United Kingdom of Great Britain and Northern Ireland'.**

The Committee calls upon the UK to urgently:

> *'Take comprehensive measures to ensure that persons with disabilities are adequately supported through social security payments, benefits and allowances, including by conducting thorough assessments based on the human rights model of disability, and by reviewing the current Universal Credit system, to ascertain the additional costs of living with disabilities and adjusting benefit amounts accordingly to reflect these costs'.*

In short, benefit cuts had already gone too far in violating the UN CRPD.

This Report had been commissioned as a follow up to the 2017 inquiry[29] in which the Committee found 'grave and systematic violations' by the UK of the UN CRPD, focusing on the effects of austerity measures cutting welfare. This conclusion was based, inter alia, on:

> '(c) The impact assessments conducted by the State party prior to the implementation of several measures of its welfare reform expressly foresaw an adverse impact on persons with disabilities;
>
> (d) Several measures have disproportionally and adversely affected the rights of persons with disabilities;
>
> (e) Measures resulting in a reduction in the support provided to meet the extra cost of disability and denial of reasonable accommodation in assessment procedures and in the realization of the right to employment have had a discriminatory effect on persons with Disabilities'.

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[27] UN Committee on the Rights of People with Disabilities *Follow-up Note verbale to United Kingdom of Great Britain and Northern Ireland,* 23 June 2025, CRPD/2025/JA/ro.

[28] UN Committee on the Rights of People with Disabilities, *Report on follow-up to the inquiry concerning the United Kingdom of Great Britain and Northern Ireland*, CRPD/C/GBR/FUIR, 22 March 2024.

[29] UN Committee on the Rights of People with Disabilities, *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention Report of the Committee*, CRPD/C/15/4, 24 October 2017.

The UK has been invited to report back to the Committee in 2029 on which measures have been taken to address and reverse these violations. As the proposals currently stand, they will not reverse the damage done to the dignity of disabled people by austerity – they will worsen and deepen that damage.

The Equality Act 2010

Several of the proposals risk discriminating against people because of something arising from their disability, contrary to section 15 of the Equality Act 2010. We note the successful challenge to a Council Tax Reduction Scheme in *LL & AU v Trafford MBC*,[30] in which the High Court found the scheme amounted to discrimination under Section 15 of the Equality Act 2010 'because [the claimant] has the protected characteristic of disability and *it treats her differently (in an unfavourable way) on account of something arising from that disability, namely the receipt of a particular benefit*.'

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[30] [2025] EWHC 2380 (Admin).

Appendix 2

The importance of indefinite, contributory benefits

The existence of an indefinite entitlement to contributions-based income replacement benefit for people who are too ill or disabled to work is a long-standing one – it pre-dates the WWI welfare state, and has been a continuous feature ever since. S.8(1)(d) National Insurance Act 1911 provided for 'disablement benefit' of 5s per week, for 'so long as so rendered incapable of work by the disease or disablement',up until the insured person reached retirement age. This was replaced in 1948, by the National Insurance Act 1946, with 'sickness benefit' which was indefinite. The National Insurance Act 1971 then provided for indefinite invalidity benefit, turning sickness benefit into a short-term form of social security. Invalidity benefit was replaced with incapacity benefit in 1995, under the Social Security (Incapacity for Work) Act 1994, which takes us up to the launch of ESA in 2008; contributory ESA for those in the LCWRA cohort is not time-limited.

In short, it is an enduring feature of both the pre-modern and modern welfare state, that those who have made contributions should be socially insured against chronic conditions which prevent them from working for an indefinite duration. It is a form of social security that is indisputably 'property' within the meaning of Article 1, Protocol 1 of the ECHR (*Stec v UK* 65731/01 [2006] ECHR 393), while disabled people clearly form a group capable of invoking the protection of Article 14 right to non-discrimination (*Carmichael v SSWP* [2016] UKSC 58). The ECHR is incorporated into UK law through the Human Rights Act 1998; as a result of section 3, UK judges are required to interpret UK law in line with the ECHR, and to declare when it is incompatible under section 4. Ultimately, challenges on the basis of the ECHR may fall to be decided by the European Court of Human Rights.

Permanent incapacity is a recognised ground for a social security risk in many European welfare regimes

This explains the copious legislative provisions on 'invalidity benefits'; the details on converting invalidity benefits to pensions; and on rights in cases of 'permanent incapacity to work' within the EU legislative framework.

Given the geographic and temporal reach of the key principle – that contributions guard against the social security risk of indefinite incapacity – it is highly likely that removal of this principle, and abolition of indefinite ESA for those in the LCWRA cohort – will trigger an A1 P1 ECHR challenge, on a number of grounds, including that of legitimate expectations. Writing in 2021, Cousins noted that this concept might bring cases within review of the European Court of Human Rights where a person 'has paid contributions towards a pension and changes are made to entitlements before the right to benefit accrues and where the person has a legitimate expectation that these changes should not be made'[31] – the same argument could be made of contributory ESA. In the case of *Béláné Nagy v. Hungary*,[32] the loss of a disability allowance as a result of legislative changes to eligibility criteria, led to a finding in the ECtHR that there was a legitimate expectation of the applicant to an asset. Other cases in which 'legitimate expectations' arguments have succeeded include: *Lengyel v Hungary*;[33] *Baczúr v Hungary*,[34] *Krajnc v Slovenia*,[35] *Saumier v France*,[36] and *Čakarević v Croatia*,[37] in which last case no legal right had already yet accrued.

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[31] M. Cousins (2021) 'Legitimate Expectation and Social Security Law Under the European Convention of Human Rights' 23(1) European Journal of Social Security 24-43.

[32] (Application No 53080/13), [2016] ECHR 1114, 13 December 2016.

[33] (Application no. 8271/15), [2017] ECHR 681 (18 July 2017).

[34] (Application no. 8263/15), [2017] ECHR 232 (07 March 2017).

[35] (Application no. 38775/14), [2017] ECHR 958 (31 October 2017).

[36] (Application no, 74734/14), [2017] ECHR 30 (12 January 2017).

[37] (Application no. 48921/13), [2018] ECHR 371 (26 April 2018).

Potential violations of the ECHR and UN CRPD

The removal of this longstanding principle of social insurance would jeopardise the right of disabled people to live in dignity – a core principle underpinning both the ECHR and the UN Convention on the Rights of People with Disabilities. In particular, those whose life expectancy is lower than the state retirement age, and who are unlikely to be rehabilitated into the job market, will be denied the opportunity to a dignified retirement in the last few years of their life – an opportunity enjoyed by non-disabled people for decades of their lives.

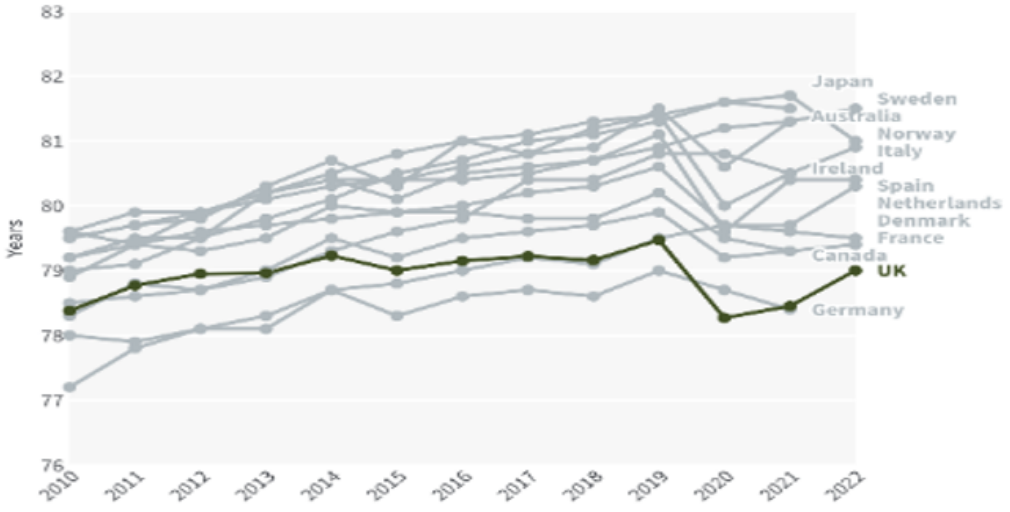
This serious threat to rights protected under the UN CRPD makes it extremely unlikely that the UK will be in a position to reassure the Committee on the Rights of Persons with Disabilities that it has addressed the 'grave and systematic' violations of the Convention *already identified* as a result of austerity measures - but the UK government is required to provide that assurance in 2029. But instead of reversing the damage done by past, regressive measures, the current proposals promise to entrench, exacerbate, and considerably extend that damage.

The threshold to qualify for indefinite rather than time-limited support should not be so high that it is only those who meet the new serious conditions criteria.

Appendix 3

Figure 7 Life expectancy at birth, males

Selected OECD (Organisation for Economic Co-operation and Development) countries, 2010–22



Source: OECD (2023), Office for National Statistics (2024)

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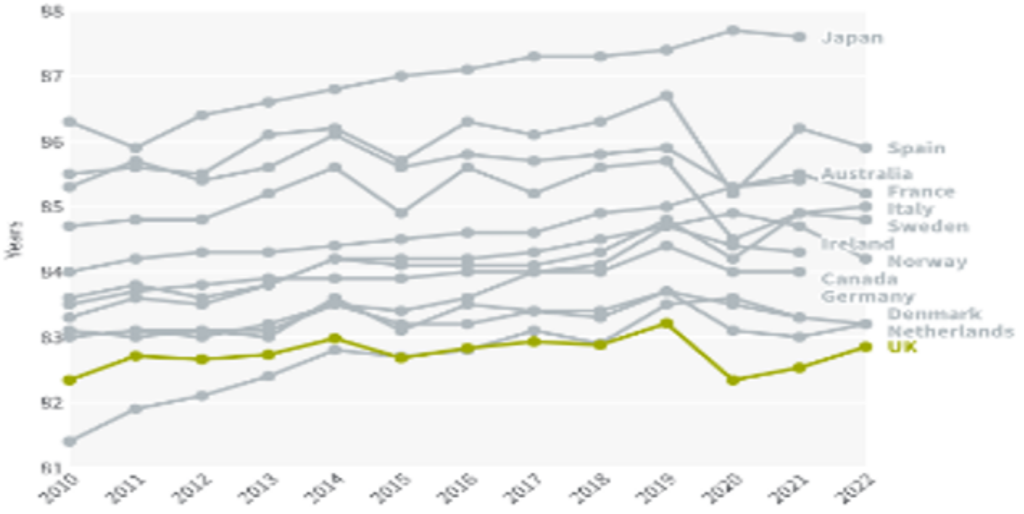
Figure 8 Life expectancy at birth, females

Selected OECD (Organisation for Economic Co-operation and Development) countries, 2010–22



Source: OECD (2023), Office for National Statistics (2024)

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A Flourish chart