Inclusion Gloucestershire & Barnwood Trust Disability Benefits Consultation 2025

Full report

Background

In March 2025, the Government published a green paper, Pathways to Work: Reforming Benefits and Support to Get Britain Working, detailing 22 proposed changes to the benefits system. These changes would mean that some disabled people would lose some or all of their Personal Independence Payment (PIP) benefits. Ten of these proposed changes are currently open to consultation. The Government's consultation process includes several virtual and in-person meetings, as well as a lengthy and complex survey that was not accessible to many people.

After the proposed changes were announced, Inclusion Gloucestershire received calls from concerned members of the community and reached out to Barnwood Trust to work in partnership to support disabled people to contribute to the consultation. The aim of the work was to understand how these changes would impact disabled people living in Gloucestershire by asking those who will be affected by them to share their views and experiences. Inclusion Gloucestershire and Barnwood Trust felt that the proposed changes would make life harder for disabled people and that it was imperative to give disabled people in the county a voice on this issue. Information about both organisations can be found in Appendix 1.

We began this process by holding a workshop with members of Inclusion Gloucestershire and Barnwood Circle, a group of disabled people who are Experts by Lived Experience. The aim of this workshop was to co-produce five questions that would encompass the key parts of the green paper that are open to consultation. These questions were designed to be more accessible than the 17 questions in the Government's survey. These new questions were used in an online survey that was distributed through participating organisations. The questions were also used as a guiding structure for focus groups led by these organisations. Each question was accompanied by a short statement which detailed the areas of the consultation the question was referencing. A list of the questions, with the contextual information, can be found in Appendix 2.1. A table showing the questions from the Government's survey and the co-designed questions can be found in Appendix 2.2.

The survey was conducted from May 2nd to May 30th, and focus groups were held during the same period. The survey data was collected from individual respondents, while the data from the focus groups was provided by a facilitator who took notes during the discussions. The data from the survey and focus groups were analysed separately, allowing for a distinction to be made between the responses provided by survey respondents and focus group participants. For some questions, the most common themes were the same in both the survey responses and focus group data, so the findings from both sources of data have been included within the same section. Where there were differences in the most common themes, the findings from the survey and focus groups have been presented separately. Please note that when the term "respondent" is used, it is in reference to data from the survey, and when the term "participant" is used, it is in reference to data from the focus groups.

This report is structured by first examining the key findings from all the data collected from both the survey and the focus groups. Following this is a breakdown of the themes per question. Please see Appendix 3.1 for a full list of themes that were identified in this data.

We have an immense amount of gratitude for all the people who participated in this work. We appreciate you trusting us with your voice and allowing us to communicate your lived experience. We hope that our report has done your involvement justice, and you feel seen, heard and validated in your lived experience.

Summary of findings

The data presented in this report comes from the responses of 38 individuals who participated in our survey and the discussions of people participating in 8 focus groups, with 52 participants overall. Both the survey respondents and focus group participants highlighted the negative impact the proposed changes to disability benefits would create in different areas of life. The impact people spoke about most frequently was a negative impact on the community of disabled people, negative impact on an individual's or family's wellbeing, and negative impact on an individual's and their family's finances. Respondents and participants also spoke about the support they might need if these changes go ahead, such as support with work and a need for greater disability awareness.

> "Until you find yourself living with a disability (which can be anyone of us tomorrow) I don't think people are ever fully aware or understand the extent of how that disability impacts every aspect of your life. The financial, social and emotional impacts of disability are often not visible to others. Many disabled people would do anything to be able to live without the extra barriers they have to face on a daily basis. Disabled people would perhaps not be as reliant or require as much in the way of benefits, if society was structured differently and better understood the barriers for disabled people. Having this understanding and a long term approach would achieve greater economical gains for disabled people and society, unfortunately the proposed changes won't address this". – Survey respondent

Negative impact on the community of disabled people

Many people in the focus groups and the surveys spoke from a place of concern for the impact on all disabled people, not just themselves or someone they know. People worried that some disabled people would fall through the gaps of this new system and go without any form of support. Anxiety was expressed around the lack of clarity concerning who would be affected and who would be negatively impacted by the changes. People spoke about disabled people who would not be eligible for Personal

Independence Payment (PIP) under the proposed eligibility requirements, despite not having any “good days” or already having unmet needs.

When discussing the change in points needed for PIP and the change in age for receiving PIP, there was a question around why different groups of disabled people were viewed to be more deserving of support compared to others: If you do not score high enough on the PIP assessment, then you aren't disabled enough for support; if you are between 18 and 21 years old, then you are not disabled at all. It was highlighted that these changes would not only target the community of disabled people – they would disproportionately affect specific groups of people within that community.

> “Why pick on those of us that have long term illnesses or disabilities - I fully understand that some disabled [people] can and do wonderful things - but those with long term debilitating life changing illnesses need care and a bit more understanding of our conditions…” – Survey respondent

Survey respondents and focus group participants stated that they wish to be understood, validated and supported to live alongside everyone else. They expressed a desire to see a government that supports them to better their lives and validates that the system is already disabling them.

> “Nothing about us without us. More and more we see governments think they have the magic wand that can mend the welfare system but every time they prove that isn't the case. Ministers for the DWP have come and gone and most seemingly are oblivious to the struggles many disabled people have to endure on a daily basis. A think-tank of disability charities and organisations should be in the room when plans are being finalised for the changes”. – Survey respondent

Negative impact on individuals and their families

Wellbeing and mental health

People expressed fear, anxiety, stress and concern for their wellbeing. It was highlighted that the type of support people would need to combat the expected decline in mental health would be far-reaching, but necessary to avoid additional damage.

> "I am so worried about the changes, I have been suicidal at the thought of losing my independece [sic] and ability to get aids, go out the house and have money to take social trips out, afford transport like taxis, buses and trains, I know changes are needed, I know my health wont get better and would love it if it was just a light touch review every 10 years, I get so scared filling out forms and flustered I don't know what to write. then the assessments are awful, they lie and try to make it sound like your [sic] better then [sic] you are so they don't have to give you pip and they can get their bonus. they don't know what it is like to have my health problems and I am worried that I will end up in a really bad place again." – Survey respondent

Within the survey responses and data from the focus groups, the word "cruel" was used repeatedly. Survey respondents and focus group participants said that they feel the choices made by the Government are targeting disabled people, and as a result, they feel demoralised and degraded. People expressed that they are already struggling to get by without the additional burden from these changes.

People spoke about how these changes would reduce their quality of life, worsen their physical health, restrict them from gaining skills or confidence, create social isolation and further alienate them from their community.

Finances

Respondents and participants mentioned several ways these changes will have a negative impact on their finances or the finances of their family. A focus group participant stated that they currently rely on their overdraft, and the money that does come in isn't enough. They explained that even if there is some money, they still need to afford different types of support to live their life, such as a Personal Assistant (PA). They explained that if they cannot afford a PA to support them to live, they would have to ask to be put into care.

People were concerned about the impact these changes would have on their finances, and some mentioned concern around the long-term impact on their ability to support themselves. It was highlighted that disabled people face additional costs compared to other members of the community, which need to be factored into their finances.

> "Medication, PA costs, extra equipment and adaptations, extra travel costs for hospital appointments, MH [Mental Health] counselling, private physio appointments, gym memberships - all these additional costs don't go away when a disabled person goes to work, but having the support with these additional costs enables disabled people to remain in work for longer, which achieves far better outcomes for individuals and healthcare services in the long term." – Survey respondent

Some people also mentioned that some of these changes would not only affect someone's ability to afford to live but could put a whole community in poverty.

> "It will put a lot of people into poverty. I'm completely reliant on my parents at the moment, I cannot afford to live alone but with the changes in the benefits, I won't be able to afford to even help contribute to my parents. It will put people in vulnerable situations and easily exploited. People will be in poverty…" – Survey respondent

Participants in the focus groups also expressed this concern for the future and the increased risk of poverty. One focus group discussed the lack of employment options for people who are currently claiming benefits. They might not be able to improve their income in any way and will fall further into poverty. They mentioned this could lead to an increased reliance on charitable support, an increased amount of debt, worsening health, and deteriorating social outcomes.

Types of support needed

Support with work

Survey respondents and focus group participants both spoke about the need for support with work. This included a need for support in obtaining work and support in getting the skills needed for employment. People also described the types of adjustments a potential employer would need to make for work to be accessible.

People explained they would love to work and have no problem with the idea of working; however, there needs to be the right support in place for that to be possible. They mentioned there needs to be more flexibility in available jobs, and more accessible job opportunities.

> "There needs to be very supportive employers who do not just pay lip service to reasonable adjustments. There needs to be more suitably qualified job coaches to give long term support to a person trying to get into work, and there should not be the risk of losing a benefit or having to go through a lengthy reapplication process, should the job not work out. Disability friendly companies need to fully understand what this means and other employees need to know how to support a disabled person in the work place..." – Survey respondent

A number of survey respondents and focus group participants expressed the need for benefits to remain in some form while disabled people are beginning a new job. Additionally, they emphasised that benefits should be reinstated immediately if any issues arise during their employment and they are no longer able to continue with that job.

> "Often having flexibility of working hours and tiered payments offered with a stepping stone approach, so benefits aren't just immediately stopped or cut off until the individual has established what working hours can be achieved. Often mentoring and training to build confidence when returning to work is essential and much needed but comes at a cost - so free training or mentoring would help support people." – Survey respondent

One focus group, made up of participants who are all currently working, felt that not being in work is not the reason that some people claim PIP, and that claiming benefits and working should not be mutually exclusive. They felt there needs to be more accessible workplaces and employers need to be more proactive around offering support to disabled employees.

Greater disability awareness

Alongside the need for support with work described above, there were many respondents and participants who expressed a need for greater disability awareness and understanding. Some people stated that the Government needs to have a better understanding of disabled people regarding work and seeking employment.

> “A greater understanding of all sides. Most people want to work, whether it's full or part time. Businesses would benefit just as much as employees if all parties had better support” – Survey respondent

Focus group participants mentioned a need for employers to be accepting of disabled people as well as flexible and understanding regarding the needs of disabled people.

People expressed that assessors doing Work Capability Assessments (WCAs) and the Government need to have a better understanding of disabled people and the experiences they have.

> “Try understanding the problems disabled people face before making ridiculous decisions. Help the people that need help and stop putting them down.” – Survey respondent

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> “Assessments should not be driven by targets or performed by people who have little to no knowledge of the reality of learning disabilities. Too often anything said in assessments is taken at face value and doesn’t represent the real problems people with disabilities face. Do not make the process even more demeaning to people with life time disabilities!” – Survey respondent

A focus group participant stated they hope MPs will really examine the documents sent in through this consultation and view disabled people as human beings and not just as numbers. They wanted those in power to understand the impact these changes will have and see that disabled people are worth something and their voice is valuable in this consultation.

Breakdown of data by question:

Question 1:

The first question posed in the survey and to the focus groups was: "If you (or someone you know) stopped receiving PIP, what would you need to make you feel supported?".

Survey results

There were 36 survey responses to this question. Of the different types of support that participants mentioned would be needed, respondents most frequently mentioned having support needs regarding finances and needing support from services. Respondents also mentioned the negative impact this would have on their lives, especially regarding finances and quality of life.

Types of support needed

Financial support

Responses reflected disabled people's need for additional financial support if they would no longer be able to access PIP due to changes to the eligibility requirements. People expressed a need for financial support to pay rent or housing costs, purchase food, afford health care, access mental and physical support, acquire mobility aids (or other specialised equipment), and afford transportation.

> "It took 6 months of waiting until I received my PIP assessment and 1st payment. Losing PIP now would be financially upsetting and have major impact on being able live with sight loss. I would be cancelling essential trips by taxi (buses being unreliable), buying fresh food and any travel away from home. As I found out previously, there is no support available apart from friends & family who have their own struggles". – Survey respondent

One respondent described the effect the proposed change would have on her daughter, who has a learning disability and is dependent on the money she receives from PIP:

> "…[my daughter] needs this money to try and enable her to build in some enrichment into her life, with the odd trip to the cinema or theatre with a volunteer buddy. She has enough hurdles in her life to get over, without financial hardship being another." – Survey respondent

Support from services

The responses indicate that people would need more support from services, including services provided by the Government. People said that support from services would need to be easier to access and free if they, or someone they knew, stopped receiving PIP. Some types of support that respondents stated they would need from services include a care or support worker, access to a care facility, specialised support services, financial advice, and mental health support.

> "I would need to be taken into a secure 24 hour care facility as I don't have any family to care for me and I could not pay for the care I now get" – Survey respondent

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> "I use my PIP to pay for activities which enrich my life, teach me life skills and connect with others. So without it I would need services to be free." – Survey respondent

Negative impact on individuals and their families

Finances

Where respondents spoke about the negative impact this change would have on their finances, they often highlighted the knock-on effect this would have on other aspects of their life, such as wellbeing and quality of life.

Respondents highlighted how detrimental the lack of PIP would be to their finances and lives. Some people expressed that there was no form of support that could be provided that could make up for the loss of PIP.

> "I am unsure what, other than actual money would help anyone. Most people on PIP have to use the money they receive to help pay for rent, food and bills. If this was to stop then many people

> would be put at risk and potentially lives might be lost as a result." – Survey respondent

Quality of life

Some respondents stated that no longer receiving PIP would have a negative impact on their quality of life or the quality of life of someone they know. A person's quality of life directly relates to their perception of being able to live a full and meaningful life. Respondents spoke about how these changes would make them feel less supported or able to live.

> "I wouldn't be able to manage on to maintain a reasonable standard of living without PIP. I know when they tried to reduce my PIP a few years ago day to day existence became very difficult" – Survey respondent

A higher quality of life could include the ability to access activities that make people feel happy and improve their well-being, such as meeting up with friends and engaging with the community. Respondents spoke about how these changes could make these opportunities completely inaccessible.

> "PIP payments are essential to my daughter to live a meaningful life as they help to enable her to access activities that enrich her life. Therefore there would need to be additional funding to provide these opportunities for her and others" – Survey respondent

Focus group results

The participants in the focus groups spoke about the need for support from services and financial support, as well as other forms of support, if they or someone they knew no longer received PIP. They also spoke about the negative impact this would cause, focusing on finances and well-being.

Types of support needed

Support from services

Participants mentioned a need for support from services to be free or cheaper in order to make the support they need accessible without benefits.

Types of support mentioned included cheaper care support or social care, low-cost therapy, and access to an advisor to support with getting information. One participant mentioned that there would need to be better infrastructure support for services in order to make care easier and more effective. They also mentioned that the money to do this type of infrastructure change could also just be used to maintain people's benefits.

A number of participants in focus groups mentioned the need for support for services regarding information provision. Participants stated that if these changes were to go ahead, they would need support in accessing information on how to deal with these changes and other places they can go to for additional support. One participant expressed the need for additional support from organisations like Citizens Advice to help identify other benefits they might be eligible for, compensating for potential income loss.

One participant spoke of the different types of support they need to live, including getting dressed, "drying", and cooking. They explained the council only provided them the support they needed for three hours a day, and they use PIP to fill the gap and obtain extra support to feel physically safe. These changes would mean they would no longer be able to get the support they need.

Financial support

Participants spoke of a need to replace the financial impact with another form of financial support in order to fill that gap in their income. Participants mentioned that disabled people might need support in meeting the costs they have to take on. One participant explained that PIP is what gives disabled people the ability to meet these costs independently.

Participants in one focus group emphasised the need for financial support that people might need if they cannot access PIP due to insufficient income, and the worsening effects of limited, suitable, and accessible employment opportunities. They explained that getting a job is only an option to fill the financial gap left by PIP if people are able to get work that is suitable and supports them. They would need to be able to get a job that has the right number of hours, supports them with reasonable adjustments, supports their condition, and is within the skill level of the disabled person. They mentioned it would be good for the Government to make support available for people who would be impacted but acknowledged that they have not been clear about their plans for support.

Other support

The focus groups mentioned a number of other types of support that would be needed if they, or someone they knew, stopped receiving PIP. This included diverse types of therapy; addressing barriers to services that provide diagnoses such as Attention Deficit Hyperactivity Disorder (ADHD); mobility aids and other equipment; transportation; and support with physical activity.

Negative impact on individuals and their families

Wellbeing and health

Participants spoke about how these proposals bring a lot of anxiety and fear around how the changes will impact each person. There was a perception that there would be people who would fall through the gaps of this new system and suffer because of it. One participant felt that these proposed changes would make people feel worthless, and that the Government doesn't care about them. Another participant felt that losing PIP would also create a loss of personal identity and self-worth, as well as social isolation. This could eventually lead to people having exacerbated mental health struggles and increased strain on local services.

Overwhelmingly, people feared for their mental wellbeing. This fear was not isolated to themselves: their concern encompassed any disabled person living in fear of these changes.

Finances

The focus groups discussed how these changes would lead to a negative impact on their personal finances or the personal finances of others. Participants spoke about how they would be left with a lack of any alternative financial support. People would be unable to pay for rent, health care, transport, or therapy. One participant mentioned they would be evicted from their home if these changes went through, as they would no longer be able to afford their house, even though they have been a model tenant.

There was an acknowledgement of what people use PIP for, and how the financial impact will lead to a lack of support in other areas of their lives. Many participants spoke about how PIP is often used to meet the additional costs associated with their disability. This could be paying for medical care, mobility aids or equipment, therapy or physiotherapy. This could also be paying for opportunities to decrease isolation, such as meeting friends or engaging with the community. Losing this financial support would be detrimental to people's ability to live holistically. A number of participants mentioned the benefits they receive as the reason they are able to leave their homes at all and not be completely isolated.

One participant explained that their finances are so tight, they have already had to sell belongings as they struggle to afford the things that bring them joy. The type of activities that were mentioned regarding enrichment or fulfilment were being able to see friends, engage in physical activity, or just being able to leave the house. Another participant stated that if they did not have the support of receiving benefits, they would not be able to leave the house. They explained how badly this would affect their wellbeing, and being able to see people is what keeps them from feeling worse. They question how they are meant to live their life if they cannot work a full-time job and cannot access benefits to cover their bills.

Question 2

The second question posed in the survey and to the focus groups was: “If the age for claiming PIP and the health element of Universal Credit is changed to 22 years old, what might the impact be for you (or someone you know)?”.

Survey results

There were 35 survey responses to this question. Of the 35 responses, 26 described the anticipated impact of this change on the respondent or someone they knew, and 9 responses indicated the respondent would not be impacted by this change. The type of impact respondents most frequently stated was a negative impact on the community of disabled people, followed by a negative impact on finances, and a negative impact on wellbeing.

Negative impact on the community of disabled people

Many respondents expressed that this change could delay the independence of young people and impact their mental health and financial security. There were also many responses expressing confusion about the Government's decision to impact a specific age group.

> "This is ridiculous. It will be devastating for persons 18 to 22 and cause even greater poverty than we have now. At 18 you are an adult, but this will force disabled people to remain living with family (if indeed they have or get on with one) whether that family can afford it or not, potentially forcing their family into poverty or greater poverty." – Survey respondent

People expressed concern that this change would further young people's dependence on their families or the system, lead to poverty and homelessness, and increase social exclusion.

> "The many 18-22 yr olds who are suffering from mental health issues and physical injuries, cancer and other illnesses could become homeless. Suicide, especially amongst young men is likely to increase. At the beginning of adulthood young people need all the help they can get to get back to studying and working and leading a successful happy life." – Survey respondent

Respondents also questioned why people over the age of 18, who are legal adults, have access to fewer services and support than people aged 22 and over. Many people wanted clarity from the Government on the decision process for this change and rejected the idea that just because a person is young, they could not be considered disabled.

> "This is ridiculous, to say that a person only qualifies for a disability benefit once they turn 22 is like saying everyone under 22 simply can't be disabled." – Survey respondent

Negative impact on individuals and their families

Finances

Many respondents expressed concern around the financial impact on a young person losing PIP or the family supporting a young person losing PIP. Young people will need to stay with their families for longer, increasing the financial strain on a family.

> "No financial aid for the support and items that enable my family members and friends who need this to live. This means they will have less money to put towards essential items like rent of food." – Survey respondent

Some respondents expressed a need for further financial support for 18-22-year-olds. There were concerns around young people going into poverty, becoming homeless and not being able to afford education if access to PIP was removed.

> "If this is implemented you are likely to get fewer disabled people able to afford to go to university and further their education. Between the age 18yrs and 22yrs is a crucial transitioning point from student to adulthood. Without PIP support during these years many people living with a disability or long term chronic health condition may miss their window of opportunity to further their education, hence making them more dependent on additional funding and state support in future." – Survey respondent

People explained how they would be even more financially dependent on their parents and how this would lead to further social isolation and increased vulnerability.

> "I wouldn't have been able to claim initially and I would have financially struggled. I'm already dependent on my parents but it would have made me very vulnerable" – Survey respondent

Wellbeing and mental health

Some respondents expressed concern about the mental health impact on a young person who genuinely needs support and would no longer be eligible to receive it. The mental health impact would be compounded by other concerns mentioned, such as the financial implications and the negative effect on quality of life.

> "Both my children -17 and 18- relieve [sic] a PIP. Not getting it would reduce their quality of life significantly. It would limit the places they were able to go and reduce social links and impact their mental health." – Survey respondent

Focus group results

Regarding impact, the focus group participants also heavily focused on the potential negative impact on the community of disabled people, a negative impact on an individual's quality of life, and a negative impact on an individual's finances.

Negative impact on the community of disabled people

Participants discussed how this change would be detrimental to young people, leading to inequalities between different age groups of disabled people. Participants questioned why some disabled people would be considered to be more deserving of support than others, and why 22 is the cutoff point to be considered disabled. Some participants spoke from experiences of receiving PIP between 18-22 and how damaging it would have been to not have had that financial support. One participant highlighted that, under these new rules, someone would be considered disabled until 16 and could apply for Disability Living Allowance; and then would not be considered disabled from 18-21; and then would be considered disabled again at 22. This would not only be confusing but also frustrating for young people to be seen and acknowledged for their disability, and then arbitrability no longer supported because they have turned 18.

Participants also spoke about the pressure and financial strain this would put on the community of carers and family members who care for young disabled people. Some participants spoke as parents of young people who would no longer be eligible for support. They feared for their children and what this would mean for their family.

Participants felt there should be more support for young people, especially around skills building, gaining confidence and support getting into the workforce without benefits being removed.

Negative impact on individuals and their families

Quality of life

There was a concern among participants that this change would lead to further dependence on family or services. Young people would be forced to move home, become more reliant on family and forego important milestones that others their age would be experiencing.

> "Young people need to socialize and be part of society and PIP could enable this by funding transport, carers, food and any other attendance charges, or to allow participation in groups, attend the gym to build strength and stamina. support for those with higher needs." – Focus group participant

Participants expressed fear that, without PIP, young people would no longer feel able to attend higher education or support themselves to gain skills for their future. Students would feel forced to quit school and potentially lose qualifications that would support them to find work. Young people need these skills and support.

Finances

A number of participants state that the cost of living for disabled young people would not be radically different from that of any other disabled adult. They need to access things like specialist physiotherapy, counselling, and medication, which will not be different at 22. There is a risk that many young people will go without the care they need without financial support.

There were a few participants who mentioned the unique impact this will have on young disabled students. Participants worried that if students were to lose the financial support they get from PIP, they would feel they could not continue with their education. Participants in one focus group felt being able to access PIP while attending education or higher education was useful and made them feel supported. Another participant states that this change would put disabled students at a higher risk of poverty due to their higher cost of living. The risk of young people going into poverty or becoming homeless in the future was mentioned by multiple participants.

Financial impact was also mentioned regarding the families that would need to support their children for longer if they could no longer access benefits. Many participants spoke of young people being dependent on their parents. Participants were also concerned about what would happen to the young people who do not have a family to financially support them for 4 extra years. One participant expressed that, for those who have no family support, young people would be on the street, and as the cost of living rises, there will be even more challenges for them to face.

Question 3

The third question posed in the survey and to the focus groups was: "If you (or someone you know) had to do more Work Capability re-Assessments (WCA), what might the personal impact be?". The survey and focus group results have been presented together, as the two most highlighted types of negative impact were the same.

Survey and focus group results

There were 36 survey responses to this question. Of the 36 responses, 35 describe the type of impact this change would have on the respondent or someone they know, and one response did not include information regarding impact. The type of impact respondents most frequently stated was a negative impact on wellbeing and a negative impact on the community of disabled people.

Negative impact on individuals and their families

Wellbeing and mental health

Most respondents expressed that Work Capability Assessments had a negative impact on their well-being. This was either in relation to the possibility of more frequent assessments or having the assessment in general. People mentioned that these assessments have already given them extreme stress and anxiety.

> “Suffering mental and physical issues is hard enough, but to compound it with the ongoing assessment process, this can only cause more anxiety at different levels for each person.” – Survey respondent

One respondent stated that the assessments are so draining that they are left bedridden for days, and having more frequent assessments would require them to have full-time care. Respondents also highlighted the impact of constantly focusing on their disability and what they cannot do has on their wellbeing.

> “More unnecessary stress leading to more illness flare ups mentally and physically. I don’t get better/only worse and having that reminder/constant pressure of proving it will lead to more anxiety, suicides etc. Life is hard enough already just getting through the day.” – Survey respondent

The focus group participants also spoke about how difficult the assessment process is to go through, and the stress that comes from having to constantly prove to someone the impact of your disability. One participant spoke of their brother, who was told they were lying in their assessment. The impact of the stress and anxiety from this process was enormous. They explained that if these assessments became more regular, their brother could not do them and would, in turn, end up on the street. Participants spoke about the difficulty of advocating for themselves and the stress of having to focus on the worst days of their lives to validate their support needs.

> "My worth as an individual was tied to an assessment done by someone over the phone who doesn't even know what my condition is." – Focus group participant

Many participants described feeling that the assessment was trying to trick them or catch them out. People have felt humiliated, belittled and completely disregarded.

> "It's worse with hidden disabilities, because people can't tell that you have a disability. You're just dismissed. They think because you can work, you're alright. I need to work. People don't get that and they don't care." – Focus group participant

Many respondents expressed confusion and frustration about why multiple assessments would be needed if someone has a lifelong, chronic disability. The assessments are not viewed as compassionate or conducted with empathy and can lead to people feeling invalidated and degraded.

> "When you have a disability that is never going to go away such as a learning disability, it is very degrading to have to have repeated assessments. These assessments batter self esteem. The focus has to be on all the negative aspects of a persons life, as there is a tendency to view any slight bit of positivity as a sign all is ok and there is the risk that the assessor rejects the application for continued support. A life long condition or a deteriorating long term condition should not be subject to repeated reassessment - it is distressing for the applicant and a waste of money for the system." – Survey respondent

Negative impact on the community of disabled people

Some respondents shared their views from the perspective of the family or carer of a disabled person, or views on the community of disabled people. People shared compassion and empathy for disabled people and people with mental health conditions who would be subject to more frequent assessments and repetitive stress.

> "…I understand that checks need to be in place. However, lots of people are living with debilitating, long term conditions which are not going to go away. It must be very difficult knowing you

> are dependent for the rest of your life, without having it reinforced annually. Doctors understand the medical condition, once diagnosed, disabled people should not be repeatedly made to feel as if they are second class citizens." – Survey respondent

Many respondents believed that assessments should recognise that a person's disability can have different types and severities of impact on their lives at different times. The way someone appears during an assessment is not necessarily reflective of the full range of their day to day experience. If someone has a good day and is able to do more, that does not mean they need less support in life.

The focus groups discussed what this change would mean for disabled people trying to get support and feeling disadvantaged. People spoke about how the system is confusing and not supportive for people trying to access care. One participant explained they needed to go back and forth to the Job Centre and their GP six times in order to get the correct sick note approved. A few participants questioned why a doctor's note or a medical diagnosis is not enough to prove their disability.

Alongside how difficult the process is to access or work within, there is a distrust in the outcome of the process, and fear about being turned down.

> "It's a process of grinding people down, because you do it enough and people would rather not get benefits and avoid the process."- Focus group participant

Question 4

The fourth question posed in the survey and to the focus groups was: "If you (or someone you know) would like to begin working, what would you need to feel supported to work? Support could mean financial, emotional, social, or physical support". The survey and focus group results have been presented together, as the most frequently mentioned types of support needed were the same for both groups.

Survey and focus group results

There were 37 survey responses to the fourth question, which is the most responses of all the questions. Of the 37 responses, 33 described the type of support the respondent or someone they know might need in response to the proposed change, and four responses indicated the change did not apply to the respondent. People most frequently mentioned a need for support with work, followed by a need for greater disability awareness. However, many people responded saying they could not work due to their disability and that there is no support that could change that.

Types of support needed

Support with work

Many respondents answered this question by explaining exactly the support they would need to be able to start work or to make work more accessible to them. While not all the support needs were the same, there were a few ideas and initiatives that were common. One of the most common ideas for support is related to a person's access to benefits once they are employed. Some respondents explained they would feel supported if they knew they could immediately access benefits again, without having to wait or be re-assessed, if the job did not work out.

Respondents also mentioned that they would need more flexibility in their work, specifically around hours required to work and the ability to work from home. People felt they would need employers to be flexible in the number of hours they would be expected to work, as they couldn’t possibly do any more. However, people also expressed that they would still need to be paid a wage on which they could live.

> “The ability to flexi work whilst still being paid enough to live for a whole month. The problem with trying to get those with disabilities into work is that the system does not allow for days where it’s not possible to work, and the lack of pay for these days means someone will do themselves damage (mentally as well as physically) so that they can pay rent or buy food.” – Survey respondent

Many people also needed jobs to be accessible to them in terms of the job description, type of work or the qualifications needed for the work.

Focus groups also spoke about what they would need from potential employers in order to get into, or back into, the workforce. There were a lot of similarities in what the survey respondents mentioned, such as a system where people are able to retain or regain their benefits in order to support someone's ability to safely try work. One participant mentioned that a system like this would need to be co-designed with disabled people and properly advocated for.

Participants also mentioned the need for employers to have more flexibility and types of support available to disabled people. Many disabled people want to work, and they want to feel valuable at work; therefore, an employer would need to be flexible about the number of hours someone can work and allow them to work from home. Participants also spoke about the need for more reasonable adjustments at work, which is particularly important given that employers are currently legally required to provide reasonable adjustments under the Equality Act 2010.

> “People have different needs and different levels of disability. Multi-disabilities means it takes a long time to get ready, has low energy and varies significantly daily meaning work would not be possible.” – Focus group participant

Focus group participants specifically mentioned the need for Access to Work reform in order to make reasonable adjustments more accessible. Participants mentioned that employers need to be more willing to support reasonable adjustments and take advantage of Access to Work grants.

One participant mentioned that when trying to access “Access to Work”, the wait time for an assessment can be 6-12 months. When people are able to get an assessment, they are expected to know exactly what to ask for, compared to the assessor offering reasonable adjustments that could be beneficial to them. Participants mentioned that without getting reasonable adjustments in a timely manner, disabled people are not able to show their employer the best they can do in the workplace or highlight their skills within a role.

Greater disability awareness

Respondents who mentioned the need for support with work and other practical support often also referred to a need for greater disability awareness in the workplace. People want employers to value the work disabled people can do and utilise the skills they already have.

> "Make employers value the work that my daughter can do rather than have a CSR policy[3] that pays lip service to the values rather than puts it into practice. Too often the only criteria to be considered useful in the workplace is "how quickly" something can be done." – Survey respondent

Many people expressed a wish to work and a strong desire to do something valuable with their time. It was highlighted that work needs to be achievable and allow people to succeed.

> "…Disability friendly companies need to fully understand what this means and other employees need to know how to support a disabled person in the work place…" – Survey respondent

Focus group participants talked about the need for employers to address the expectations put on disabled people. There was also a strong desire for employers to have jobs available that are appropriate for disabled people and support the skills and qualifications they have. People discussed the need for suitable opportunities for disabled people, especially regarding jobs that require qualifications which many disabled people do not have the same opportunities to acquire as non-disabled people.

Running congruent to the conversation around different types of support needed was the acknowledgement that disabled people should not be consistently expected to know all of the support they need. One participant spoke about the drain in energy and physical toll they experience trying to research all the different ways they need support. There was fear around

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[3] A Corporate Social Responsibility (CSR) policy defines a business's commitment to operate ethically and sustainably.

asking for support that would be denied, and not knowing enough about the options available to them in order to ask for the right form of support.

Other forms of support

Respondents also mentioned other practical forms of support they would need. Some people mentioned requiring accessible transport, or a "driveability scheme"[4] so they can transport themselves to potential employment. Some people mentioned they would need a work coach, or someone who could support them with the work, such as a PA.

> "Personal work coach, who helps to find suitable work, speak to employers and help with transport, find ways of helping to improve skills and qualifications." – Survey respondent

Some respondents also highlighted a need for financial support to cover expenses during the transition to work.

> "I currently work part time and have a degree and have worked full time since I was 16. However trying to get back into work after a period of mental health was really hard and felt almost impossible at first. So a good support system, financial support to start off as part time so the person doesn't crash and then have to stop work completely, and help with any practical barriers to work." – Survey respondent

The focus group participants spoke a bit more about the additional types of support someone would need in order to work. However, these were consistent with the support opportunities mentioned by survey respondents. Participants discussed the need for developing skills and gaining confidence in the workplace. For example, one participant stated that it could be useful to have specific training programmes to support disabled people to gain experience and the necessary skills for work. This was also mentioned alongside the need for more job coaches and higher-quality job coaching.

Participants also identified having a PA to support them with work, receiving support in learning to drive and more suitable shift/work patterns as

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[4] "Driveability scheme is the language used by the respondent. This could be in reference to the Motability scheme.

support that would help them to work. There were also a few participants who spoke about the need for financial support if they were required to start work again. This support would be used to ensure they are still earning a living wage, despite only being able to work part-time hours.

Question 5

The fifth question posed in the survey and to the focus groups was: “Is there anything else you would like to say about the plans to change disability-related benefits?”. The survey and focus group results have been presented together, as the most frequently mentioned type of support needed was the same for both groups.

Survey and focus group responses

There were 35 survey responses to this question. Of the 35 responses, 34 included information regarding the changes being proposed and the impact of the green paper, and one response did not include information from this respondent. The focus group information presented in this question is from 45 focus group participants, as one focus group, with 7 participants, did not submit a response to this question. Most respondents and participants focused on the impact these changes will have on people's lives. The areas of impact that were most highlighted were a negative impact on the community of disabled people and a negative impact on wellbeing.

Negative impact on the community of disabled people

Many individuals expressed concern for the wider community of disabled people who would be negatively affected by these proposed changes, as well as the potential impact on themselves individually. Often, people stated that if any of these changes went through, it would be catastrophic to people’s health and wellbeing. There needs to be more understanding of how disabled people live with the resources they currently have, and what the impact would be if those resources were removed. There are currently limited options for support, and accessing what is available is difficult.

Respondents wanted there to be more support, and more options for support, made available for disabled people.

> "We should be looking at making funding and support available to more people not less. If we removed the hoops people who are actually in need would get support which would in turn benefit the whole of our society. The current system prevents many people who need support for asking for it. The new proposed system would make this worse not better." – Survey respondent

There are clear concerns about what this would do to people's physical health, mental health, quality of life, independence and financial circumstances.

> "It is cruel and demoralising. We suffer enough each and every day with our disabilities without extra financial burdens" – Survey respondent

Some survey responses specifically focused on the effect this would have on the families of disabled people and carers. There would be a huge financial impact on families and carers, and they would struggle to support their loved ones. Focus group participants also questioned why people with lived experience of being disabled were only being consulted now, and why decisions are not being made by the people who would be affected.

The focus group participants shared similar views on how these changes will impact the wider community of disabled people. Participants felt they deserved better, and the Government is not acknowledging the knock-on effect that these changes would have on people and those who care for them. They expressed confusion about why the Government has chosen to target disabled people and stated that there should be more of a focus on supporting people. One participant expressed a desire to be positive about supporting disabled people with employment, but felt the reality of the situation would just further disadvantage people. People felt there was an assumed expectation that there would be suitable employment opportunities for people who would no longer be receiving PIP, but there is minimal or no evidence to show this would be the case.

> "Benefits need to change to ensure those with disabilities are fully supported. Those non-genuine claimants need to be identified. Those with lesser disabilities that wish to work an [sic] be valued should be supported. However, those more disabled, such as having learning disabilities and being partially sighted (PS) that cannot work because daily life is stressful enough, should be left alone, without Re-assessments, due to unmanaged pain and having chronic disabilities at birth." – Focus group participant

Negative impact on individuals and their families

Wellbeing and mental health

With all the risks and expected consequences, it was highlighted that these changes would cause immense stress, anxiety and poor mental health.

> "When my PIP was reduced after a review in 2023 I had to rely on support from my family, both financial and emotional to be able to just exist. Doing anything or going anywhere was just not possible financially and having to go through the long process of appealing the decision causing [sic] me stress and anxiety. I felt unable to live my life, improve my condition. I couldn't see what the future would be like…" – Survey respondent

Many people have explicitly said that these changes are cruel, but even more so than the current system is already cruel. When applying for PIP or being assessed on their condition, there is already a huge impact on someone's mental health. This will only get worse for people seeking support.

> "I worry and have sleeples knights [sic] worrying about, 'when the time comes 'how I prove myself again that I'm not a layer [sic] that I am telling the truth about my problems…" – Survey respondent

The participants in the focus groups shared similar concerns for well-being and mental health. Poor mental health and a negative impact on a person's wellbeing underpinned many of the discussions in the focus groups and responses to the survey. Participants did not feel the proposed changes are fair to them and felt that marginalised communities are being targeted.

One participant explained that if PIP were to be removed, they could barely exist. They questioned why everyone else is afforded the right to live but disabled people are not treated the same.

Overall negative impact on an individual's life

Many people spoke from a place of upset and confusion, but some responses were more focused on worry and concern for their vulnerability and safety. There was concern that being so dependent on other people, even more so than before, would create more opportunities to be taken advantage of. Many people expressed worry about what the lack of financial support would do to their ability to stay out of poverty. People stated that they were fearful that losing access to financial support would cause their health to decline and worsen their quality of life.

> "Under the proposed plans, I would lose my PIP. My health would decline, and there is the serious risk that I could die if this is the case" – Survey respondent

People also felt that these changes would have the opposite effect to what the Government intends. If the goal of these changes is to increase a disabled person's ability to find and keep work, many people believe this would do the opposite.

> "…I am all for those who can or want to work being helped into employment, but experience tells me to have little belief in the fairness and reliability of the DWP and other government organisations full stop. I see very vulnerable and sick people failing work capability tests and being forced into employment they ultimately cannot manage and end up dropping out of, most likely with sanctions and condemnation…" – Survey respondent

Participants in the focus groups felt that these changes would make it even harder for people to ask for support, and it would increase the vulnerability of a group that is already vulnerable. They expressed fear for the future and the unknown impact. Participants also discussed a need for things to be individualised, and for more people to be recognised and considered in their circumstances. There was fear and concern for the services and already stretched support systems in place if these changes were to go ahead. Participants expressed that more people will be reliant on charitable support and social services; the financial impact will be moved from the national government to more county councils and local charities.

Appendix:

1. Organisational information

Inclusion Gloucestershire

Inclusion Gloucestershire is a Disabled People Led Organisation, working to create an inclusive society that values, respects and includes disabled people. We work alongside disabled people, through offers like advocacy, peer mentoring and Hubs, to ensure that we are empowered and have rights and opportunities. We also work with organisations and society more widely to remove disabling barriers, providing services like training, accessible information and access audits. Registered charity number: 1171559

Barnwood Trust

Barnwood is not your typical funder. We drive forward change so that disabled people and people with mental health conditions have choice of opportunities, access their rights, and are included where they live.

We bring people together for a different conversation and explore big ideas. Through learning and collaboration, sharing research, and looking for better ways to fund, Barnwood makes a difference in Gloucestershire. Registered charity number: 1162855

2. Co-designed questions

2.1 Full questions with an explanatory statement

The first four questions had a few sentences to act as an explainer for the question and why it was being asked. Below is a list of all the questions with the small paragraph explainer that was put to the survey respondents and focus group.

1. There is a plan to change the conditions someone must meet to receive PIP. People will now have to score at least 4 points on one area to get the daily living part and a total of at least 8 points. This would mean that it would not be enough for a person to score a small number (less than 4) of points on a few areas to make up a total of 8

points, and so some people will no longer receive PIP.

If you (or someone you know) stopped receiving PIP, what would you need to make you feel supported?

2. There is a plan to change the age at which people can apply for the health element of Universal Credit (UC) and PIP from 18 to 22. This would mean only people aged 22 or older would get PIP or the health element of Universal Credit.

   If the age for claiming PIP and the health element of Universal Credit is changed to 22 years old, what might the impact be for you (or someone you know)?

3. There is a plan to require people claiming the health element of Universal Credit to have Work Capability re-Assessments (WCA) more often. A Work Capability Assessment involves checking whether their disability makes it harder for them to work, and by how much.

   If you (or someone you know) had to do more Work Capability re-Assessments (WCA), what might the personal impact be?

4. There is a plan to use the benefits system to support people who are not currently working, due to disability, and would like to try to work. Support could mean financial, emotional, social, or physical support.

   If you (or someone you know) would like to begin working, what would you need to feel supported to?

5. Is there anything else you would like to say about the plans to change disability-related benefits?

2.2 Government consultation questions mapped to co-designed questions

Original questions from the government survey	Question co-designed with the BWC group
2. What support do you think we could provide for those who will lose their Personal Independence Payment entitlement as a result of a new additional requirement to score at least 4 points on one daily living activity? 3. How could we improve the experience of the health and care system for people who are claiming Personal Independence Payment who would lose entitlement? 12. Do you think 18 is the right age for young people to start claiming the adult disability benefit, Personal Independence Payment? If not, what age do you think it should be?	There is a plan to change the conditions someone must meet to receive PIP. People will now have to score at least 4 points on one area to get the daily living part and a total of at least 8 points. This would mean that it would not be enough for a person to score a small number (less than 4) of points on a few areas to make up a total of 8 points, and so some people will no longer receive PIP If you (or someone you know) stopped receiving PIP, what would you need to make you feel supported?
11. Should we delay access to the health element of Universal Credit within the reformed system until someone is aged 22?	There is a plan to change the age at which people can apply for the health element of Universal Credit (UC) and PIP from 18 to 22. This would mean only people aged 22 or older would get PIP or the health element of Universal Credit. If the age for claiming PIP and the health element of Universal Credit is changed to 22 years old, what might the impact be for you (or someone you know)?

8. How we should determine who is subject to a requirement only to participate in conversations, or work preparation activity rather than the stronger requirements placed on people in the Intensive Work Search regime. 9. Should we require most people to participate in a support conversation as a condition of receipt of their full benefit award or of the health element in Universal Credit? 10. How should we determine which individuals or groups of individuals should be exempt from requirements?	There is a plan to require people claiming the health element of Universal Credit to have Work Capability re-Assessments (WCA) more often. A Work Capability Assessment involves checking whether their disability makes it harder for them to work, and by how much. <u>If you (or someone you know) had to do more Work Capability re-Assessments (WCA), what might the personal impact be?</u>
1. What further steps could the Department for Work and Pensions take to make sure the benefit system supports people to try work without the worry that it may affect their benefit entitlement? 4. How could we introduce a new Unemployment Insurance, how long should it last for and what support should be provided during this time to support people to adjust to changes in their life and get back into work?	There is a plan to use the benefits system to support people who are not currently working, due to disability, and would like to try to work. Support could mean financial, emotional, social, or physical support. <u>If you (or someone you know) would like to begin working, what would you need to feel supported to?</u>

3. Themes explored in this analysis

3.1 Table of the themes and descriptors used in this analysis

Theme	**Description of theme**
Health (negative impact)	Respondent or participant mentioned that the proposed change will have a negative impact on their physical health
Wellbeing (negative impact)	Respondent or participant states that the proposed change will have a negative impact on their mental health and well-being
Support system (negative impact)	Respondent or participant states the proposed change will have a negative impact on their support system, such as family or carer
Finances (negative impact)	Respondent or participant mentioned that the proposed change will have a negative impact on their finances
Quality of life (negative impact)	Respondent or participant states the proposed change will have a negative impact on their quality of life and ability to engage with life outside their disability
Loss of independence (negative impact)	Respondent or participant mentioned the proposed change will have a negative impact on their independence
Negative impact on community	Respondent or participant mentioning the proposed change will have a negative impact on the overall community of disabled people and people with mental health conditions, wider impact
Overall negative impact	Respondent or participant stated this change would be an overall negative impact on their lives or the lives of others.
Financial support (Support need)	Respondent or participant mentioned that financial support would be an opportunity for support through the proposed change
Support for family/carers (Support need)	Respondent or participant mentioned that extra financial support would be an opportunity

	to support them individually through the proposed change
Support from services (Support need)	Respondent or participant mentioned that extra support from services (government) would be an opportunity to support them individually through the proposed change
Support with work (Support need)	Respondent or participant mentioned that extra support around gaining and keeping employment would support them individually through the proposed change
Services funding (wider support need)	Respondent or participant mentioned that additional funding for services would be an opportunity for wider community-based support through the proposed change
Support other	Respondent or participant mentioned other forms of support not related to other themes.
Disability awareness wider support need)	Respondent or participant mentioned that more disability awareness would be an opportunity for wider community-based support through the proposed change
Positive impact (individual)	Respondent or participant believes the proposed change is good and will have a positive impact on them
Positive impact (wider)	Respondent or participant believes the proposed change is good and will have a positive impact on the wider community
No support needed (N/A support)	Respondent or participant states they need no support in this area, or it does not apply to them
No impact to them (N/A impact)	Respondent or participant states this change has no impact on them
No support possible	The area applies to the Respondent or participant, but no support is possible
Other	Anything other