



Ending the Activity Trap

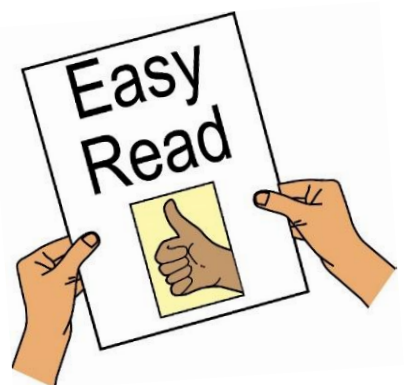
Easy Read Report

(The original name for this report is
“Dismantling the **Activity Trap**”)



Activity Trap: Disabled people want to be active, but they are scared they will lose their benefits if someone sees them being active. This is called the Activity Trap.

The benefits system stops Disabled people from being active. We say what needs to change.



What is this report about?



Disabled people want to be active, but they are scared they will lose their disability or health benefits if someone sees them being active. This is called the **Activity Trap**.



In this report, we explain how the benefits system stops Disabled people from being active.

And we say what we think needs to change so they don't have to be afraid of being active.



8 out of every 10 Disabled people are afraid of losing benefits if they are active.



When Disabled people apply for or get benefits:



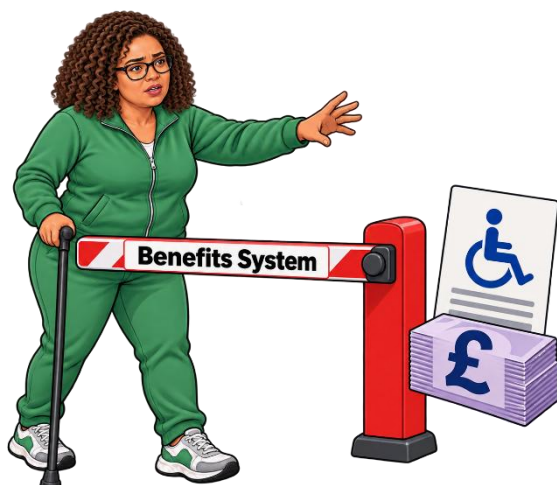
- Only 1 out of 5 people is happy with how physically active they are.



- Over 1 out of 4 people has lost benefits or financial support because they were active.

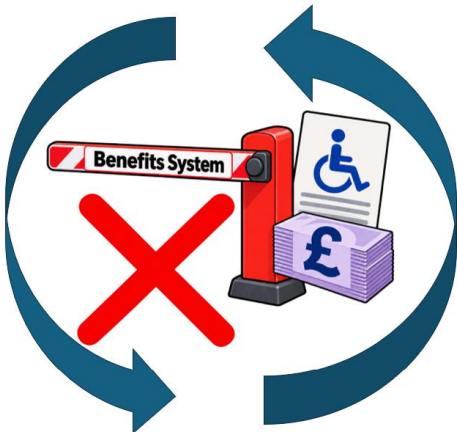


- Nearly 3 out of 4 people would probably be more active if they knew their benefits were safe.



The current benefits system does not work well. It makes it hard for people to get the support they deserve.

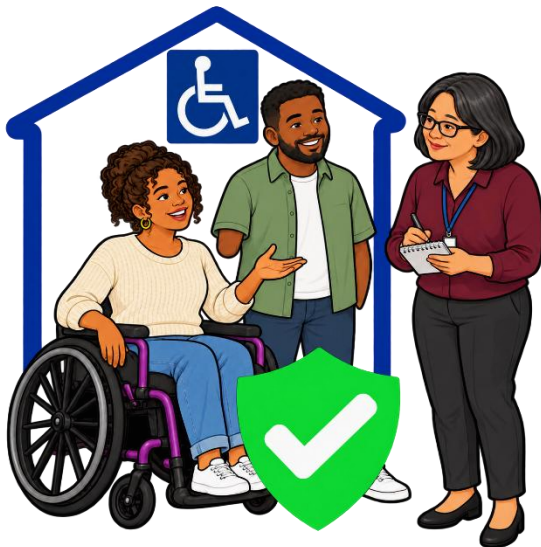
To end this activity trap, we want to:



- Change the current disability benefits system.



- Make applications and **assessments** more supportive.
- Give Disabled people fair, independent advice and support.



- Better understand Disabled people's lives and needs.
- Work with Disabled People's Organisations (DPOs) to reduce unfair treatment and harm.



Assessments are checks to decide who gets benefits.



Disability Rights UK and Durham University led this research using co-production. This means we did the research together equally with Disabled people.

Disabled people are afraid of losing benefits unfairly



Being scared of losing their benefits means Disabled people can stop being active. This harms their health and wellbeing and makes other problems worse.



Below are some quotes that people told us in our research. The pictures of the people are made by a computer.



"I've got a constant fear when I go out in the morning of somebody coming up and saying you've got PIP, how are you able to do these things?"



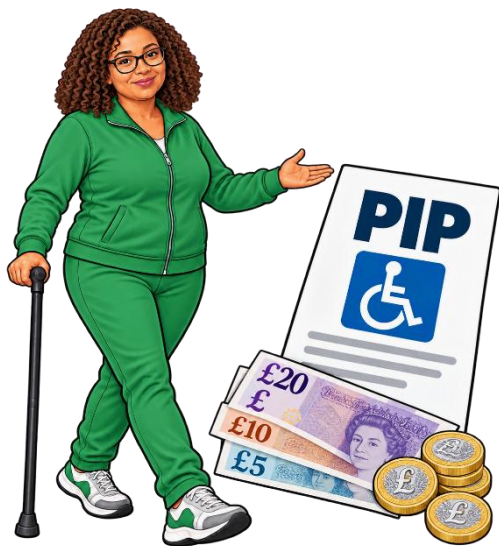
"You're frightened you might go out... have a dance, enjoy a gig... thinking, if somebody sees me, they're going to report me."



"I would love to go to the gym, everyday, but I don't dare because I would be seen as being too physically fit... I'm worried I'll lose my benefits."



Over 1 in 4 Disabled people we spoke to had benefits refused or taken away because they were active.



Personal Independence Payment (PIP) helps adults with disabilities or long-term health conditions.



UK law says people can only count as able to do an activity if they can do it:



- reliably - in a way they can depend on
- repeatedly - over again, not just once or twice
- safely
- within a reasonable time



We found that **assessors** wrongly thought that:

- People with disabilities cannot be physically active.



- Their disability, pain levels and physical ability never change.



- Doing something once means they can do it often.



Assessors are people who carry out **assessments**, like PIP.

Assessments are formal checks to find something out.



This means that assessors did not follow the UK law.



People lost benefits even though they could not do activities safely or often.



This puts Disabled people off from trying to be active and improve their health, enjoying life and taking part in society.

Problems using the Social Security system



The social security system gives out benefits. Disabled people face unfair barriers and **discrimination** at every stage of the benefits process.



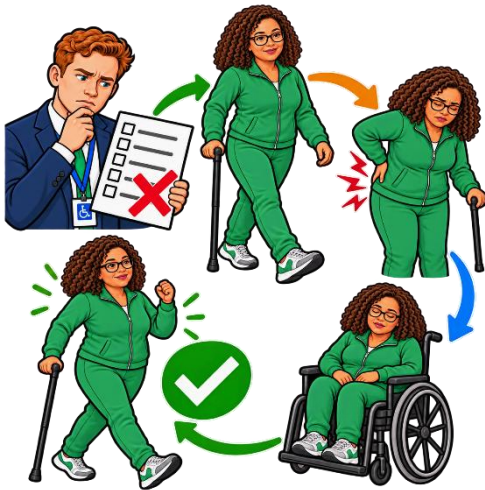
Discrimination means treating someone unfairly because of a part of who they are. For example, because someone is Disabled or because of their race or culture.



Disabled people face problems when using the social security system, including:



- Applications are hard to understand and use.
- They are not given enough time to apply and get help to apply.
- There is not enough information about benefits, how to apply for benefits and people's rights.



- Assessment rules miss how disabilities really affect people and how activity helps, especially when they have a long-term health condition that can change.



- Where assessments take place can be inaccessible. And they do not give the support Disabled people need, like **reasonable adjustments**.



reasonable adjustments are changes or support that help a person with a disability take part equally. For example, providing Easy Read.



Some of the problems Disabled people face using the social security include (continued):



- Assessors don't really understand Disabled people's lives and so can't make good decisions.
- Assessors are often **ableist**. This goes against UK law.



Being **ableist** or **ableism** means favouring people without disabilities.



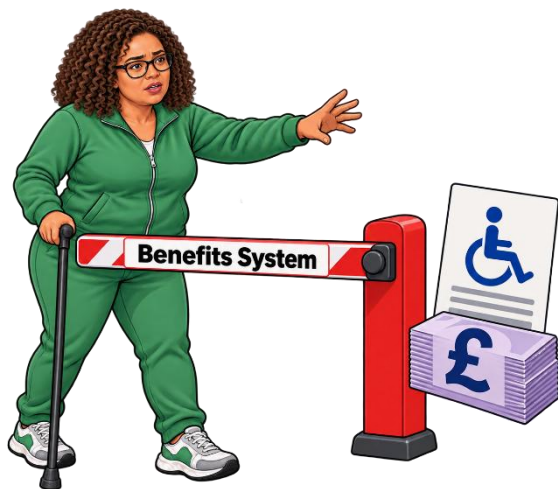
- Assessors think their own judgement is better than Disabled people's own words and medical evidence (proof they are Disabled).
- Assessors see people who speak up for themselves as difficult.



- The processes for applying, assessments and **appeals** take too long and are not clear.
- People may get no benefits while applying or appealing. This makes them struggle for money and get into debt.



An **appeal** means asking for a decision to change.



All these barriers make it very difficult for Disabled people to apply for benefits and then to appeal if they are taken away because they have been active.



This harms Disabled people's physical and mental health. They can get anxious and feel powerless.

Disabled people are also scared that if they lose their benefits because they have been active, they will have to go through this whole process all over again.

The social security system does not work properly



The current social security system is:

- **Dysfunctional** – This means it does not work properly. The system stops Disabled people from applying for and getting money they need and deserve.



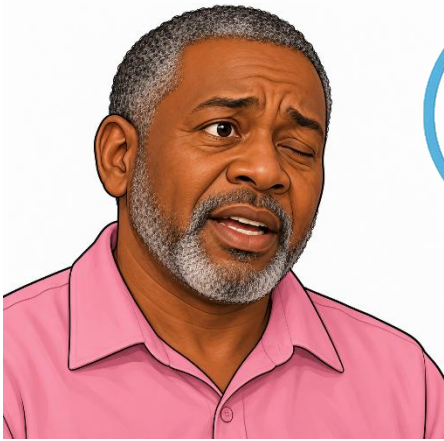
- **Discriminatory** – This means it treats Disabled people unfairly. The system's processes are not accessible and it does not use UK law correctly.



- **Damaging** – The system causes anxiety, money problems and poor health.



Below are some quotes that people told us in our research. The pictures of the people are made by a computer.



“It feels like in assessments they’re holding you to a standard or environment that just doesn’t exist...”



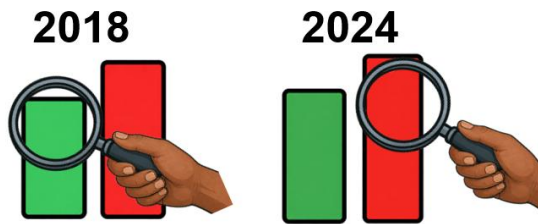
“I had difficulty in performing what she was asking of me, and certain movements I just couldn’t do it. And yet, when she rejected my claim, she said I was not cooperative.”



“The process of PIP... is the most demoralising thing you will ever have to do.”



“I’m still struggling with the mental effects of it... We got into terrible debt because what else was I supposed to live on?”



We compared Activity Alliance's 2018 research with ours from 2024. The problems are getting worse.



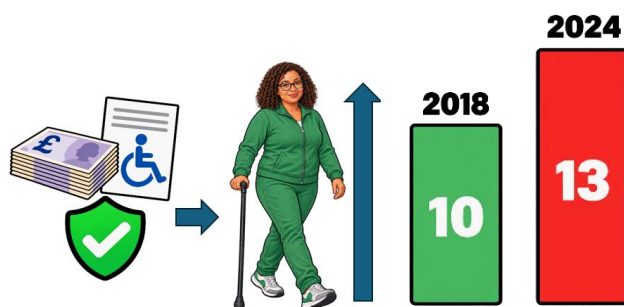
For every 10 people reporting each of the issues below in 2018, the number in 2024 has gone up:



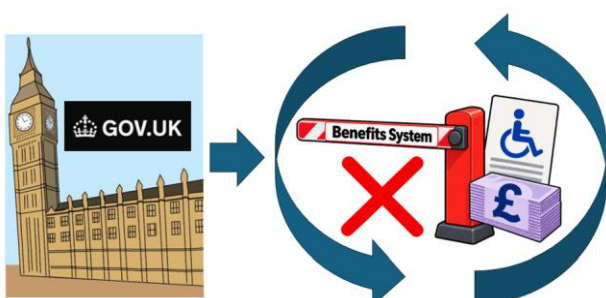
- fearing that activity could mean losing benefits – now 17 people



- finding applications difficult or very difficult – now nearly 15 people



- saying they would be more active if their benefits were safe - more than 13 people



The government must commit to changing the benefits system to fix these problems. Otherwise things will get worse.

The social security system needs to change



Simply encouraging Disabled people to be active will not work. They will still be afraid of losing their benefits.

So, we need these changes:



1. Work with Deaf and Disabled People's Organisations (DDPOs) to redesign the social security system. These organisations are led by people with disabilities. The benefits system needs to:



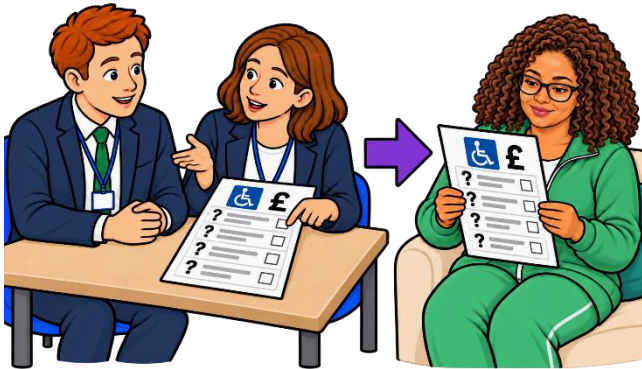
- a. Accept medical reports. Give benefits with no end date for lifelong conditions or conditions that get worse.
- b. Adapt assessments to each person. Give assessors more time to check claims.



- c. Set a deadline for government staff to do all assessments instead of private companies.



2. Make applying, assessments and appeals more supportive, accessible and clear:



a. Tell assessors which questions they can ask.
Give the people applying the questions beforehand.



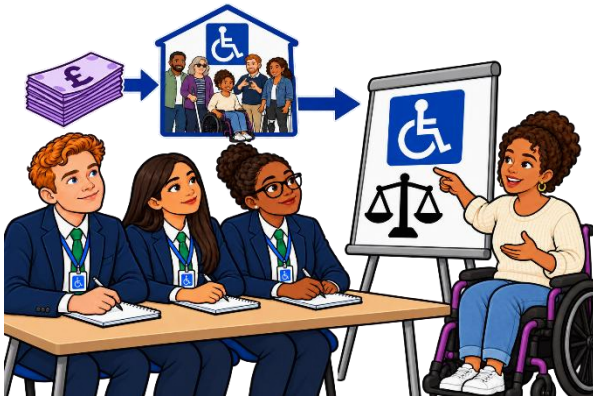
b. Use accessible places for the assessments.
Provide reasonable adjustments.



c. Tell people applying about other available support.



3. Train assessors and decisionmakers to understand and respect Disabled people's lives and needs:



a. Pay Disabled People's Organisations to train all assessors about disability equality. All assessors must do the training.



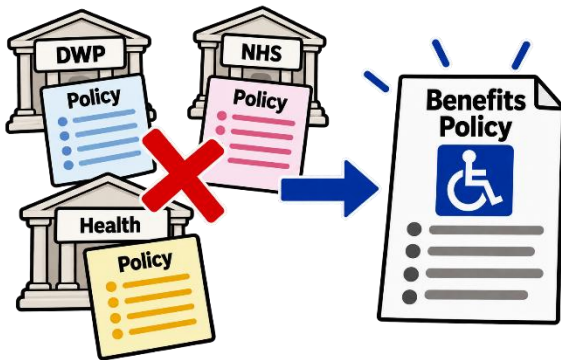
b. Train assessors about Disabled people and physical activity. Use advice about activity from the Government – from the Chief Medical Officer and Office for Health Improvement and Disparities.



c. Only use assessors who know the Disabled person's condition well or have experience of it.



4. Government departments and Deaf and Disabled People's Organisations must work together to reduce unfair treatment and harm:



a. Avoid having different policies so departments can better tackle inactivity and inequality.



b. Improve communication. Explain how disability, benefits and activity connect.



c. Encourage Disabled people to be active and make it clear that it does not affect benefits.



5. Create a National Advocacy Service to give independent advice and help Disabled people speak up.



a. Let someone join assessments to help the Disabled person take part and give emotional support.



b. Work with Disabled People's Organisations to help Disabled people apply for benefits, especially those with mental illness or distress.



c. Leave at least 5 years between assessments, unless medical evidence shows a condition will last for a shorter time.

How we did the research



Research often misses Disabled people's views and experiences.

This means it sometimes does not really show what Disabled people think or what their lives are like.

We included Disabled people in our research in the following ways.



Co-production

Co-production means doing research together with the people we are interested in learning about. It tries to make sure everyone can take part equally.



Our co-production group included:

- Disabled experts on policy and benefits
- Disabled people who had used the benefits system
- Researchers from different subjects

Different accessible ways to get information



Research often excludes people with different needs for movement, thinking, seeing or hearing.



Our co-production and advice groups helped make our research as easy and accessible to take part in as possible. For example, we made our questionnaire shorter and used easier language.

We used:



- A questionnaire about activity and benefits, answered by over 200 Disabled people. People could add their experiences.

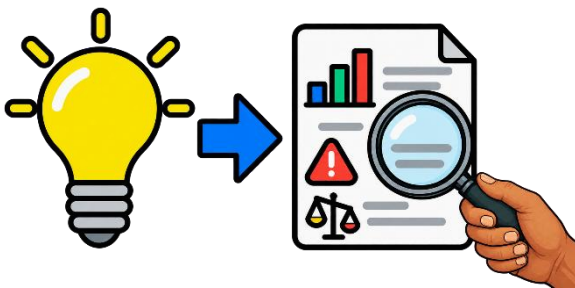


- Group discussions with over 30 Disabled people. Our co-production group designed questions. Some groups focused on just one thing, like applying for benefits or physical activity and benefits.



- A study of UK benefits law and court decisions. This helped explain the activity trap and showed unfair decisions.

Useful Terms and Ideas



The ideas listed below helped us understand experiences, spot patterns and find problems. We explain what we mean by each term below.



Physical Activity

This means any movement, including daily tasks, leisure activities, travelling and work.



Ableism

Ableism means favouring people without disabilities.



Disablism means treating people with disabilities unfairly.



Even if they do not act unfairly, people may believe that being healthy or having no disability is better or more normal than being sick or disabled.



We found people believed that Disabled people should support themselves and their families despite disability or pain.



These beliefs cause Disabled people to feel shame and encourage false claims about 'benefit scroungers'. Disabled people then fear being reported for being active.



Institutional ableism means organisations have rules that stop Disabled people getting what they need.

Epistemic Injustice



Epistemic Injustice means believing some people more than others because of who they are, instead of what they know.



Assessors may:

- question or ignore Disabled people's experiences
- dismiss medical evidence
- record assessments wrongly.



Assessors put their own judgement above Disabled people's knowledge of their disability and daily life.



Administrative Violence

Administrative Violence means that organisations design and run their processes to cause harm to Disabled people on purpose. It is a built-in part of the system, not an accident.



Examples of administrative violence are long delays and no reasonable adjustments. These everyday things stop Disabled people getting the benefits they deserve.

This document was put into Easy Read by the Empower Team at People First (Self Advocacy):

www.peoplefirstltd.com

Information is Power!

People First
a voice for people with learning difficulties