Set up to fail:

How the social security system can be reformed to work **for people severely affected by mental illness.**

Rethink
Mental
Illness

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Images used in this report are for illustrative purposes only and are not of the people who participated in our engagement activities.

About us

Rethink Mental Illness is the charity for people severely affected by mental illness. They are at the heart of everything we do.

Online, over the phone and face-to-face, we provide services that support and empower people to live and thrive independently in their communities. Every day, we help thousands of people to learn more about specific mental illnesses and treatments, understand their rights and access support that focuses on their wider physical health, financial, housing, work and volunteering needs.

We also provide local peer support groups across the country to help people living with mental illness and their carers support each other, grow in confidence and take greater control of their lives.

We campaign on a local and national level to ensure people severely affected by mental illness are listened to, treated fairly and have easy access to the health and social care services they need.

And we work with a wide range of organisations, including other charities, private businesses, the NHS, and local authorities, to create communities that genuinely care for the wide range of people we support.

Informing and shaping all our work are people severely affected by mental illness. They are the ones who know best what they need and what must change.

> “I couldn’t take it anymore, was in tears and smacked my head on the desk. I was told not to make a scene.”

Executive summary

This report proposes a series of ideas led by the voice of lived experience, to transform the social security system into one that is fair, accessible, and recovery-oriented. Drawing on insights from six sessions we held with twenty-eight people severely affected by mental illness, revealed that the social security system is often ill-equipped to address the complexities of mental health and can be actively harmful, hindering recovery and reducing quality of life. It examines the shortcomings of the Department for Work and Pension's (DWP) Work Capability Assessment (WCA) and Personal Independence Payment (PIP) processes, as well as counterproductive approaches to getting people into work such as sanctions. The following key issues emerged from our lived experience sessions:

- **Processes designed without people with lived experience**: Many policies and practices have been designed seemingly without meaningful insight from people severely affected by mental illness, resulting in processes that are often inaccessible, unfair, or unsafe.
- **Unreasonable burden placed on claimants**: People are expected to collect and submit evidence to supplement their assessments, even when they are unwell or without support. This process is fraught with issues, including delays caused by NHS clinicians, evidence being lost in the post, and the overwhelming need to advocate for themselves when they are not in a position to do so.
- **Inaccurate and harmful assessments**: Assessments often do not reflect people's realities, and this is seen in what is being assessed, how assessment interviews are conducted, and in the notes recorded by assessors. This leads to people being unfairly denied adequate financial support or being pushed into inappropriate work-related activities. Many assessments are conducted by people who lack mental health expertise, which results in retraumatisation, flawed outcomes, and a deepening sense of mistrust in the DWP.
- **Inaccessible and unsupportive processes**: People often go through these processes alone and without proper support, left to navigate confusing and complex systems. Forms are inaccessible, assessment times and locations are inflexible, and there is little clarity about what is expected—increasing their distress due to the ambiguity they face in the processes.
- **Sanctions and inappropriate work activities causing harm**: Many people have been subjected to sanctions or mandated work-related activities that do not align with their mental health needs. These punitive measures often worsen mental health, create financial insecurity, and prevent people from recovering. Additionally, the fear of losing benefits hinders people from attempting work, as re-entering the system is lengthy, stressful, and financially damaging if work proves unsustainable.

These failures in the system have caused extensive distress and hardship for people severely affected by mental illness, highlighting the urgent need for reform. There is a clear opportunity to improve the WCA and PIP, as well as the DWP's wider approach to supporting people into work, to make these processes fairer, safer, and more effective. By working closely with people with lived experience and adopting accessible, supportive, and trauma-informed practices, the DWP can take meaningful steps towards a model that prioritises care and dignity. The findings in this report offer valuable insights to inform these changes, enabling people severely affected by mental illness to not only navigate the system but also build fulfilling and sustainable lives.

Welfare and employment solutions shaped by lived experience

1. Co-design Assessment Criteria with Lived Experience Involvement
2. Co-design Accessible Forms with Lived Experience Involvement
3. Implement a Fair, Efficient, and Transparent Evidence Collection Process
4. Introduce Choice, Sensitivity, and Flexibility in Scheduling Processes
5. Introduce a Multi-Agency, Panel-Based Approach
6. Co-design Quality, Official Guidance with Lived Experience Involvement
7. Proactively Facilitate Access to Specialised, Designated Support
8. Exempt People Severely Affected by Mental Illness from Sanctions and Provide Recovery-Oriented Pathways
9. Build a Stronger Safety Net to Explore Work
10. Transform Jobcentres as Gateways to Specialist, Wraparound Support

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Contents

Introduction

This report is based on the articulated experiences and thoughts of people with lived experience of mental illness and welfare. Social security is intended to provide financial protection and support during times of need or vulnerability. However, many people living with severe mental illness have experienced harmful challenges within our social security system, often with devastating consequences.

Focusing on functional health assessments: the WCA, PIP, and the impact of conditionality and sanctions in people's lives, this report highlights how the social security system frequently fails to address the complexities of severe mental illness, and proposes ideas on how to address them, which have been identified by people with lived experience. These gaps result in inappropriate outcomes, compounding harm rather than providing the support needed.

Through lived experience engagement with people severely affected by mental illness, supported by Lloyds Bank Foundation for England & Wales, this report gathers invaluable insights into what works, what has not, and what could pave the way for a better system. At the heart of this report is a simple but transformative idea:

Building policies around the experiences of those who rely on them makes welfare systems fairer, more effective, and easier to navigate. Listening to lived experience is key to fostering trust and delivering real, positive change.

The importance of lived experience in policy and practice

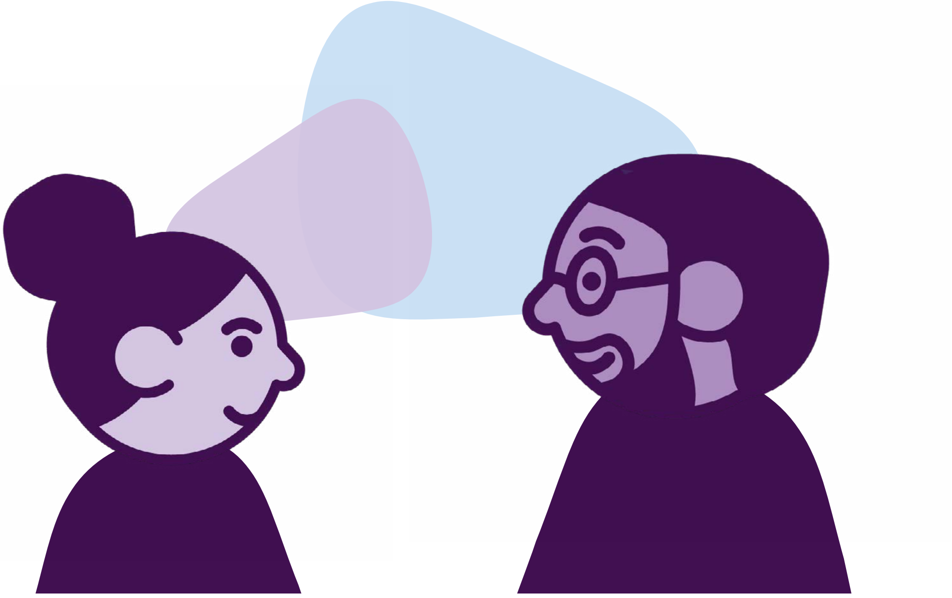
Policy and practice work best when they are informed by the insights of those who experience the system firsthand. People with lived experience, including families, friends, and carers, provide unique perspectives on the real-life impact of policies, revealing gaps and suggesting practical improvements.

This approach has already proven essential in health and social care, where services are legally required to involve people and communities in commissioning decisions (Health and Care Act, 2022). "To reinforce the importance and positive impact of working with people and communities, NHS England, ICBs [Integrated Care Boards] and trusts all have legal duties to make arrangements to involve the public in their decision-making about NHS services." Voluntary, Community and Social Enterprise (VCSE) organisations like Rethink Mental Illness work closely with ICBs to recruit and support people in participatory activities, such as reshaping services and co-chairing meetings in partnership with NHS teams. These collaborations have strengthened decision-making, improved access and experience, and reduced inequalities.

The case for lived experience in welfare reform

A social security system designed with lived experience at its core is less likely to produce harmful errors or flawed decisions, reducing financial costs and reputational risk to government, as well as preventing harm to vulnerable people relying on these systems. Policies informed by real-world needs are more likely to be considered as fair, transparent, and trustworthy, enhancing public confidence in the DWP.

To achieve this, the DWP could draw inspiration from health and social care by investing in lived experience engagement and commissioning insights to help shape welfare policy. This report demonstrates the potential for this approach, offering tangible recommendations to build a system that better reflects the needs of people severely affected by mental illness. The DWP has an opportunity to embrace this approach, creating trust, security, and meaningful impact in its policies and practices.



Our approach to lived experience involvement

Engaging with people severely affected by mental illness requires a thoughtful, inclusive, and co-produced approach to ensure meaningful participation. For this project, we built on our extensive experience in lived experience involvement. Our approach followed key principles: prioritising accessibility, safeguarding psychological safety, and ensuring diversity and representation. In total, we engaged with twenty-eight people across a series of remote engagement sessions, representing a wide range of lived experiences.

We began by co-designing the engagement process with a group of expert-by-experience leaders, who helped shape the design, agenda, and facilitation of the sessions. This ensured that the engagement was accessible, comfortable, and relevant. Recruitment was intentionally inclusive, involving people from diverse backgrounds and experiences through our networks, social media channels, and advisory boards. Insights were gathered through detailed notetaking and anonymised for inclusion in this report, ensuring that people's contributions were fully respected and secure.

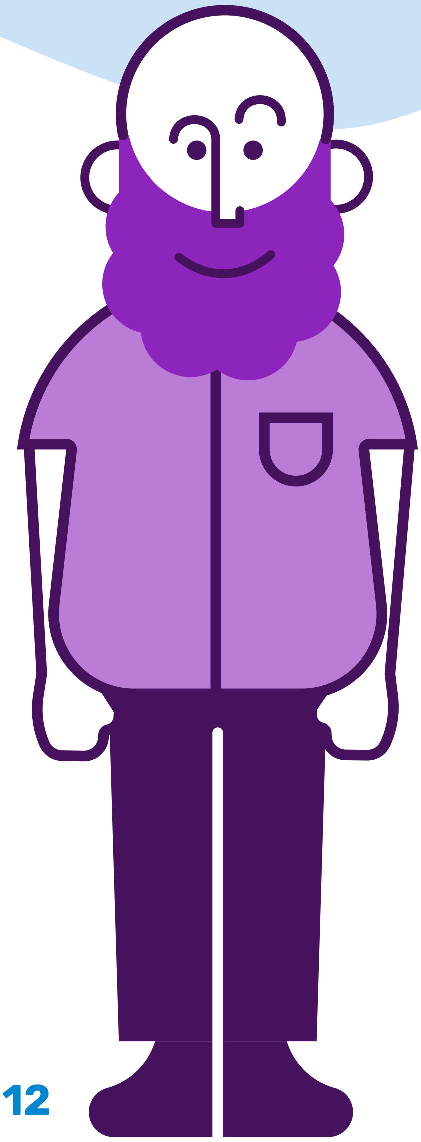
To support accessibility, we used small breakout groups and offered optional pre-meetings and debriefs after discussions of sensitive topics, ensuring people felt prepared and supported throughout. We established group agreements that prioritised safeguarding and psychological safety, and we sent relevant pre-reading and resources ahead of the sessions to help people feel prepared to share their thoughts and experiences. All participants were offered remuneration in line with our reward and recognition policy, and any concerns about benefits or accessibility were addressed transparently.

This approach reflects a commitment to inclusivity, trust, and collaboration, ensuring the voices of people severely affected by mental illness shape the future of social security policies in meaningful and practical ways. As a result, we received positive feedback about the space we created, with people expressing gratitude for the opportunity to share their insights in a safe environment and feeling a sense of purpose in contributing to something meaningful.

> I went into it blind, I had no idea or any type of guidance on what to do. It’s self-led. I had no one who I could follow up with and ask questions.

How could assessments be safer, more accurate, and fair?

This section explores how to make the WCA and PIP assessments safer, more accurate, and fairer. Drawing on insights from people with lived experience, it highlights the key challenges they face and offers recommendations for reform.



1. How the WCA and PIP overlook the realities of mental illness

Participants told us, the current WCA and PIP activities and descriptors (from this point being referred to as 'criteria') often fail to reflect the lived realities of people living with mental illness who have complex needs. The people we engaged with highlighted the following critical shortcomings in the existing criteria based on their lived experience:

- **Overemphasis on physical health**: The criteria disproportionately focuses on physical health, overlooking the complexities and fluctuating nature of mental illness. A previous study also revealed this theme, finding that current functional assessments emphasise physical health and leaving claimants underserved and unfairly assessed.[2]

> "They are very pinned to physical health questions. For example, for myself with eating disorders, there are questions on being able to eat, and I have the ability physically, but mentally, because of my eating disorder, I can't do that."

- **Failure to understand varying presentations of mental illness**: The narrowly defined criteria prevent people from accurately conveying how mental illness impacts their lives including living costs and work capability. This oversimplification often leads to misclassification, undermining the assessment's purpose of fairly determining support. People felt their experiences were largely overlooked in the assessments as a result. A previous study has also demonstrated that they often fail to account for the fluctuating nature of mental illness, leading to undue stress for claimants.[3]

> “Presentation of mental illness looks different for different people. What one person looks like when they feel anxious won't match what someone else looks like and there is no typical presentation of any of these things either.”

- **Difficulty assessing the right level of support**: Many described feeling they were unfairly placed in the Fit for Work (FFW) or Limited Capability for Work (LCW) groups, rather than the Limited Capability for Work and Work-Related Activities (LCWRA) category. The same was said about accessing both parts of PIP by some people in the sessions. This left them without crucial financial support and under undue pressure to engage with requirements to seek or prepare for work when they were not ready, or the activities were not suitable. Even those ultimately placed in the LCWRA group or receiving both parts of PIP, reported having to fight relentlessly to prove their eligibility within these narrow criteria, despite being severely unwell. They highlighted the significant burden of having to heavily advocate for themselves throughout the process, an overwhelming task for those already managing the challenges of mental illness that not everyone can do in their situation.

Solution:

Co-design assessment criteria with lived experience involvement

To ensure assessments are fit for purpose, the DWP would find value in collaborating with people with lived experience of mental illness and other health conditions or disabilities, to co-design assessment criteria, ensure assessments are approached holistically and ultimately that they are fit for purpose. The people we engaged with spoke about co-designing a more holistic model that would:

- Move beyond the binary focus on physical or mental health, to create adaptable, inclusive criteria that assess all health conditions and disabilities fairly, including fluctuating and enduring mental illnesses.
- Recognise that mental illness is not static or the same for everyone; symptoms may fluctuate, while still having significant long-term effects. The assessments' criteria must reflect this reality.
- Design criteria that accommodate people with multiple, overlapping needs including neurodiversity, ensuring no aspect of a person's experience of long-term health and disability is overlooked.

2. The challenges of WCA and PIP forms for people living with mental illness

Assessment forms used for the WCA and PIP assessments[1] reflect the assessment criteria. This makes the process of filling the forms out stressful as people find it difficult to relate their experiences living with mental illness to the criteria.

> “More recently, completing the paper form – I actually put lines through quite a few questions saying ‘not appropriate’ because they were just physical things. It was completely not relevant, because he (their son) has mental illness. He can dress himself, but it has no bearing on anything.” **(Carer)**

In addition, the forms were described as confusing because they are **overly technical, lengthy, and jargon-laden**. People in our sessions spoke at length about not understanding certain sections due to the terminology used or not understanding the difference between certain questions because they were too similar to others.

Solution:

Co-design accessible forms with lived experience involvement

To ensure the forms align with reimagined assessment criteria, the DWP could gain from engaging with people who have lived experience of mental illness and the assessments, throughout the design process. Key improvements suggested in our sessions include:

- Allow people to express the full scope of their experiences in their own words in the forms, ensuring a more comprehensive understanding of their needs from the outset and empowering them to share what they need. This should include dedicated optional space to describe their whole experience, regardless of the criteria.
- Offer both paper and digital versions of the forms to accommodate varying levels of digital literacy and accessibility needs.
- Use clear, everyday language, removing jargon wherever possible or where this is not possible, providing clear and concise in-text explanations.

> “[The entire form] needs to be improved and broken down into everyday language”

By embedding these reforms, the assessment process can shift from confusing and exclusionary to inclusive and empowering, ensuring it reflects the diverse realities of the people it is designed to support.

3. Barriers in evidence collection for WCA and PIP assessments

The current evidence collection process for WCA and PIP assessments is overly burdensome, fragmented, and opaque. The people we engaged with identified numerous barriers that hinder their ability to provide timely, sufficient, and relevant evidence, which impacts the fairness and accuracy of decisions.

- **Financial costs**: Many people spoke of facing out-of-pocket expenses to obtain medical evidence or sending it via post, creating additional financial strain for people already experiencing financial difficulties.
- **Delays in NHS responses:** Responses to requests for medical evidence are often delayed due to capacity challenges in over-stretched health services. People in our sessions reported having to chase clinicians to respond to requests, despite knowing that those clinicians faced considerable challenges managing demand on their time due to pressure on the health system.
- **Insufficient or undervalued evidence:** Some people, particularly those not currently in contact with health services, struggled to provide comprehensive evidence. According to NHS data, 229,084 adults with a diagnosis of serious mental illness were still waiting for treatment from community mental health services in the three months ending October 2024.[4] While the people we spoke with recognised the value of medical evidence and understood they could send evidence from other sources (e.g., social worker), they did not feel DWP decision-makers placed enough value in the evidence provided, including the medical/clinical evidence, but particularly other forms of non-clinical evidence such as a letter from a service that is supporting them.

> “I had to get a letter from my doctor. My post is very slow. It would be easier if they used email & my doctor could send it straight to them, or me to forward to them. I’ve known DWP say they’ve not received mail, when I’ve paid extra to get it signed.”

- **Reliance on traditional mail**: The DWP’s dependence on postal submissions results in frequent delays to process their case and loss of evidence. Even when people pay for tracked delivery, mail can go missing, adding further frustration.
- **Lack of transparency**: People described situations where they submitted evidence on time only to later find that it was not adequately considered in decision-making on their claim. They talked about this as something that particularly impacted on their ability to trust the process and the department.
- **Duplicated efforts across assessments**: People in the sessions shared how they had to gather the same or similar evidence repeatedly for the WCA and PIP assessments, duplicating efforts, and costs, which added to their distress.

Solution:

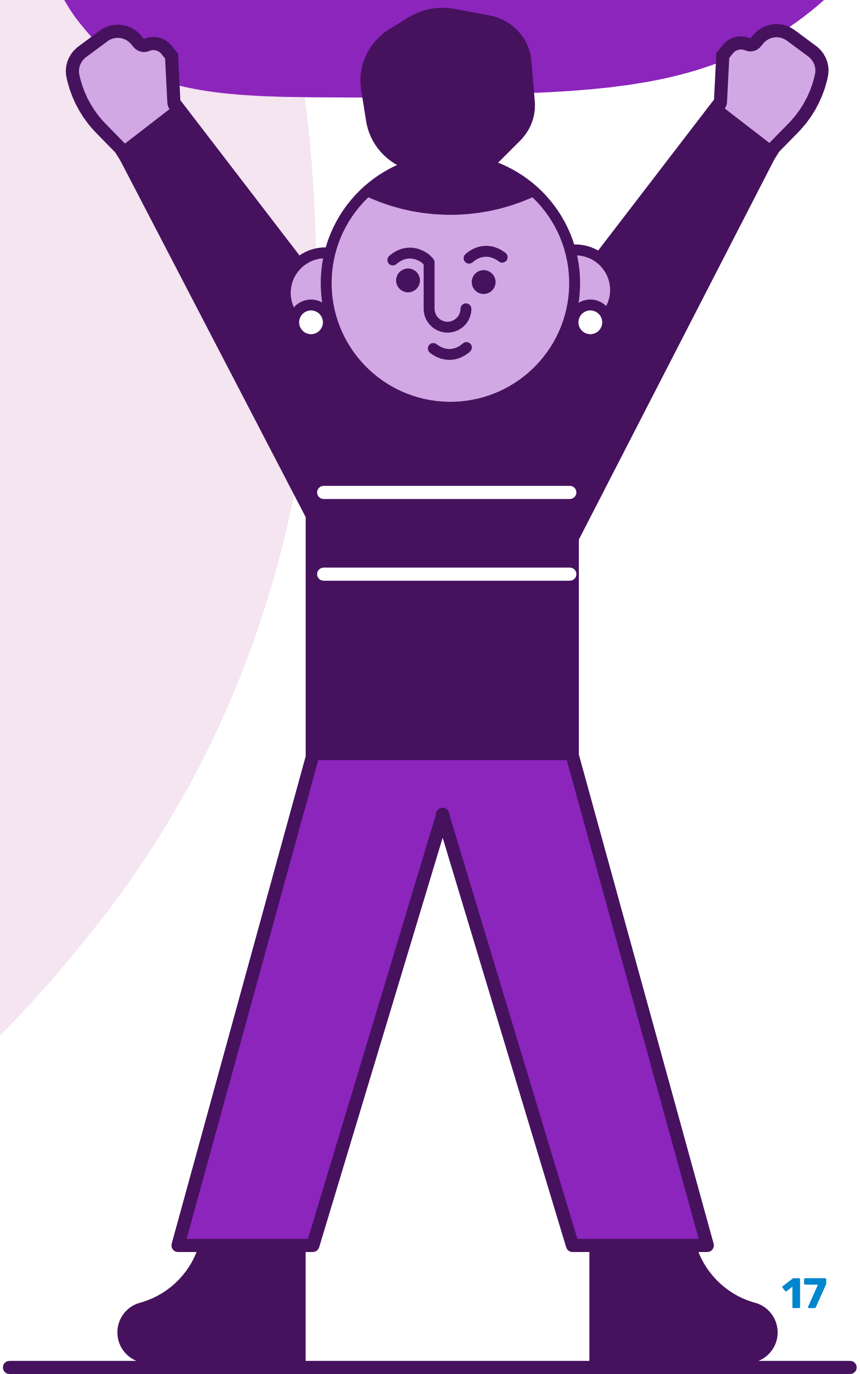
Implement a fair, efficient, and transparent evidence collection process

The people we engaged with identified key principles to reform the evidence collection process, ensuring it is fair, streamlined, and reduces burdens on claimants:

- **Free for claimants:** They stressed that people should not face any costs during the evidence collection phase. They already require financial support, and placing this additional financial burden on them is counterintuitive at best.
- **Valuing distinct types of evidence:** While medical evidence remains critical, non-medical evidence from appropriate sources, such as housing authorities or social care services, should also be actively considered in the decisions. This approach would ensure people without recent medical records are not disadvantaged and allow those who know the claimant best to contribute to the process. It would also allow the DWP decision-makers and assessors to gain a fuller understanding of a person and their circumstances, allowing them to make a fair and accurate decision at the first time of asking.
- **Informing decisions:** All agencies requested to provide evidence could include a clear recommendation on the type of support the claimant needs from the DWP.
- **Shift responsibility:** The administrative task of collecting evidence could more appropriately be managed by the DWP and relevant agencies, reducing the burden on claimants. Claimants should be empowered to provide consent and specify which agencies the DWP may need to contact, while the coordination of this process could be managed by the DWP to ease the burden on claimants.
- **Increase accountability:** It was highlighted that since this evidence collection determines a person's financial situation, with severe consequences for the person if not executed well, then evidence collection must be undertaken with urgency and create ways to ensure the DWP and agencies take responsibility for and are accountable for its collection.
    - *Collaboration with the NHS and VCSE services:* Ensuring timely submissions of evidence is crucial not only for meeting deadlines but also for minimising stress and anxiety for people living with mental illness. Delays often exacerbate symptoms of mental illness due to the stress experienced, risking adding pressure on people already suffering with their mental health and the services that support them. Mechanisms must therefore hold both the NHS and the DWP accountable. Suggestions included prioritising WCA and PIP evidence requests over other non-urgent evidence requests. Another way to resolve this issue is by involving VCSE health and care services as intermediaries between the DWP and NHS. These services, integrated within local health systems (e.g., Integrated Care Systems), could facilitate digital evidence transfers, reducing delays without further burdening clinicians.

- **Repurpose evidence:** The DWP should adopt an integrated system that keeps a claimant profile, allowing the DWP to reuse relevant evidence in different assessments (WCA and PIP) where appropriate. This could help streamline the process, reduce duplication, and minimise stress for claimants.
- **Secure digital system**: The DWP could benefit from modernising its approach – implementing a secure digital system for submitting evidence, which has the potential to reduce delays, prevent lost documents, and improve overall efficiency.
- **Transparency in decision-making:** Decision letters must clearly outline how submitted evidence was used to reach a conclusion. If any evidence is discounted, the reasons should be explicitly stated. Additionally, claimants should have the right to review the evidence provided by external agencies, such as the NHS or a service provider.

Fair, efficient, and transparent evidence



4. The effects of inflexible scheduling

We heard from people in our sessions that the current scheduling process for WCA and PIP assessments lacks flexibility and sensitivity, creating significant challenges for claimants severely affected by mental illness. The people we engaged with shared key concerns about the rigidity of the system and its negative impact on their experiences:

- **Limited rescheduling options:** Interviews are typically assigned with fixed dates, times, and locations, leaving little room for individual circumstances. While rescheduling can be possible, people noted the process is not as flexible as it could be. This creates significant barriers for those with unavoidable commitments, such as medical treatment or caregiving responsibilities.
- **Discomfort with assessment settings:** While people scheduled to have an assessment interview can share their preference for it being remote or in-person, our participants spoke about how those preferences were not always honoured. People whose preferences were not honoured often found the assessment setting, whether by telephone, video or in person, stressful or unsuitable for their needs. It was clear that the lack of choice in settings made the experience more difficult. Telephone and video assessments could feel unfamiliar and intimidating for some due to lack of digital skills, but also the act of sharing deeply sensitive stories in a less personable setting. While in-person assessments could often be inaccessible and required long, complex travel arrangements, making the experience logistically difficult and distressing. For example, this can be particularly difficult for someone experiencing agoraphobia.

These challenges underscore the urgent need for a scheduling process that is flexible, accommodating, and sensitive to the diverse needs of claimants, ensuring a fairer and less distressing experience.

Solution:

Introduce choice, sensitivity, and flexibility in scheduling processes

To improve the WCA and PIP assessment experiences, people in our sessions proposed key changes that prioritise flexibility, accessibility, and individual needs in the scheduling process:

To avoid conflicts with critical commitments, such as medical appointments, claimants should be offered multiple options for dates and times across different days. If these options do not work, additional alternatives must be provided. People in the sessions suggested introducing a digital booking tool to allow claimants to choose their interview at a convenient date and time. However, it was strongly emphasised that this should not be the only method to schedule interviews, ensuring accessibility for those without adequate digital access or digital skills.

By introducing these changes, the DWP can create a more flexible and inclusive scheduling process that respects the needs, safety, and dignity of claimants who are severely unwell. This approach would reduce unnecessary distress, build trust, allow people to share their story in a suitable setting for their needs, and ensure assessment interviews are conducted in a fair and supportive manner.

5. The consequences of inadequate expertise in assessments

The people we engaged with consistently expressed concerns about the qualifications, approach, and understanding of the healthcare professionals conducting WCA and PIP assessment interviews.

- **Lack of mental health expertise**: Assessment providers often do not match healthcare professionals' qualifications with claimants experiencing the health condition or disability they are qualified in. Everyone we engaged with lives with a mental illness but 96% were matched with assessors who were not qualified as mental health clinicians. People stated that assessors were ill-equipped to engage meaningfully with people severely affected by mental illness, leading to interview notes that were inadequate, distressing, and often harmful. This gap often resulted in assessments that failed to capture the full impact of their conditions. They shared that this lack of expertise often left them feeling dismissed, unheard, and emotionally destabilised, fostering mistrust in both the process and the DWP.

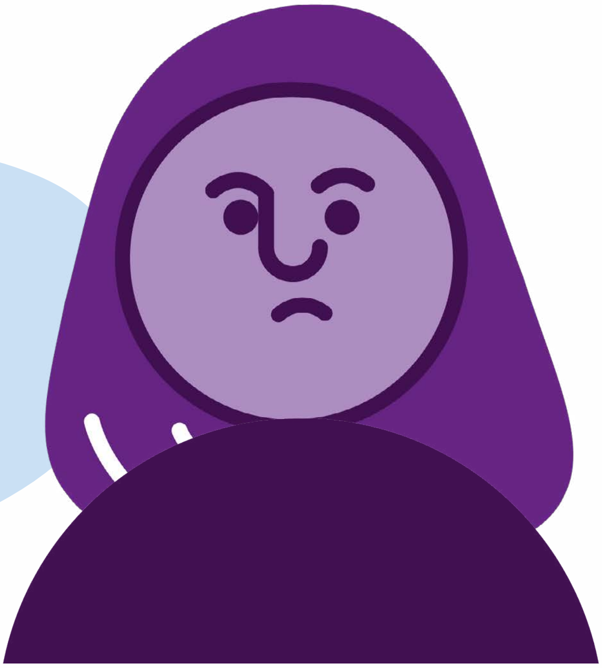
> “The assessor said [in their note] that I expressed myself articulately, and said I can get the bus to work, but the assessor didn't ask me about the social stuff – where I had crippling experiences of anxiety, not being able to leave the house.”

> “I always come away from it thinking they have not listened to me and feels destabilising.”

- **Overlooked reasonable adjustments:** While some noted they were able to indicate their preferences before the interviews, these were not always honoured during the assessment interview. Many highlighted the assessment provider's failure to proactively inquire about reasonable adjustments that could have made the interviews safer for them, such as adjustments for managing anxiety, trauma responses, or respecting cultural needs. The lack of such adjustments led to particularly harmful outcomes for some people. For example, one person living with PTSD recounted requesting a female assessor due to past trauma, only to be assigned a male assessor, which triggered their symptoms. It was also emphasised that assessors should have been better informed about previously requested adjustments and more sensitive in their approach, adapting their interactions to ensure a safer experience during the interview.

> “I couldn't take it anymore, was in tears and smacked my head on the desk. I was told not to make a scene.”

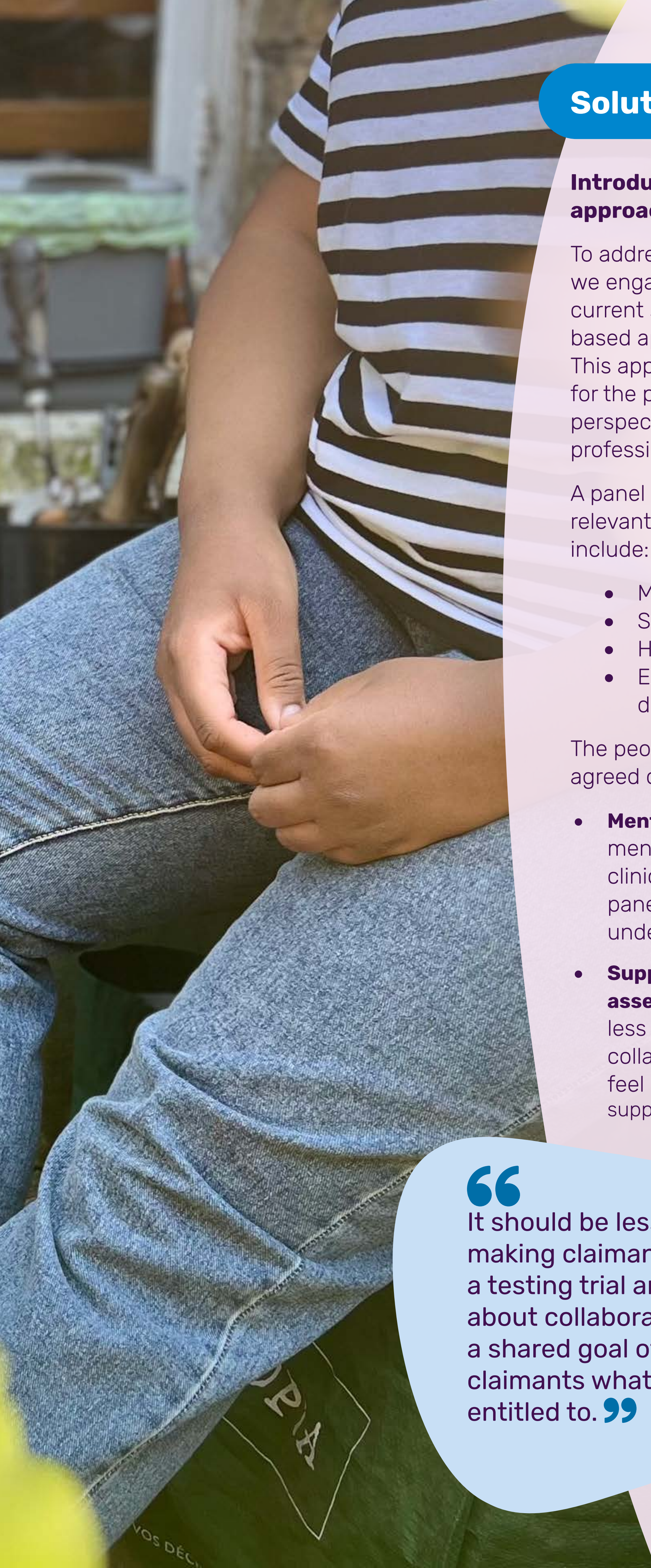
> “In terms of emotional safety, I did not feel I was in an emotionally safe space. I did not trust the assessor or the process.”



- **Misrepresentation in notes**: Many people reported significant discrepancies between what they shared during assessments and how it was recorded. Many felt their experiences were misrepresented or oversimplified, undermining their ability to access the support they need.
- **Challenges for people who identify as neurodivergent**: They noted that assessors often failed to provide clear, explicit communication, leading to misunderstandings and further frustration.
- **High-stakes, single-assessor model**: Entrusting significant power to a single assessor, who often lacks the necessary expertise, was described as precarious and unreliable. People expressed unease about the subjective nature of these assessments, particularly in complex cases involving co-occurring conditions or disabilities together with mental illness.

> “Your life is in their hands based on how they are feeling and based on one meeting. You cannot get the full picture from one meeting. Every individual is different, where one assessor may see it in one way and the other assessor views it in a different way there is no uniformity.”

These experiences reveal an urgent need for a more robust, specialist-led approach to assessments that ensures fairness, accuracy, and sensitivity to the complexities of people’s needs.



Solution:

Introduce a multi-agency, panel-based approach

To address these challenges, the people we engaged with called for a shift from the current single-assessor model to a panel-based approach involving more people. This approach would provide a framework for the provision of specialist insights and perspectives from a multi-disciplinary panel of professionals.

A panel of professionals with expertise relevant to the claimant's circumstances could include:

- Mental health clinicians
- Social care providers
- Housing professionals
- Experts in other health conditions or disabilities

The people we engaged with unanimously agreed on two essential safeguards:

- **Mental health clinicians**: In cases involving mental illness, a qualified mental health clinician must be part of the assessment panel to ensure appropriate expertise and understanding.
- **Supportive, non-adversarial assessments**: Assessments must feel less like interrogations and more like collaborative evaluations, where claimants feel emotionally safe, listened to, and supported.

> “It should be less about making claimants endure a testing trial and more about collaborating towards a shared goal of getting claimants what they are entitled to.”

This approach aligns with the report's other recommended improvements, such as adopting holistic WCA and PIP assessment criteria and enhancing evidence collection methods. These proposals prioritise a comprehensive understanding of claimants' lived experiences. In cases where multiple professionals are involved in care or other kinds of support, their combined insights would enable more accurate evaluations of how intersecting health conditions and disabilities impact a person's daily life and work capability.

Learning from existing multi-agency models

This solution, which was identified by participants of our lived experience sessions, has strong parallels with similar multi-agency processes in comparable holistic evaluations, such as:

- **Section 47 Enquiries (Children Act 1989)**: These involve professionals from local authority social work teams, health services, the police, and other agencies working together to assess a child's welfare. These assessments work best when involving multiple and varied professionals who share key information with each other, in order to make informed decisions.
- **Special Educational Needs and Disability Panels**: Multi-agency panels review evidence from families and schools to determine the level of support and resources a child requires with their education.

We recognise that implementing a multi-agency panel for every WCA and PIP assessment might not be feasible or necessary in all cases. For example, routinely involving clinicians in all assessment would place a considerable additional pressure on an already overstretched workforce. However, a targeted approach could balance resource constraints with the need to ensure fairness and accuracy, as well as potentially being more efficient by reducing the need for mandatory reconsiderations and appeals at independent tribunals.

Implementing the improved evidence collection process recommended on pages 12-13 would ensure that robust and relevant evidence from trusted professionals is gathered efficiently and increase paper-based decisions, potentially saving time and resources elsewhere in the system.

- People who have robust and relevant evidence showing the impacts that mental illness has in their lives, entitles them to the highest level of support without the need for an assessment interview.
- It is crucial that people would not unfairly lose out on support at this stage on the basis of insufficient evidence, as there could be valid reasons why evidence could not be collected, such as not being in recent contact with health or social care services. If claimants have insufficient evidence, then they should not be denied support but instead asked to join a multi-agency, panel appointment to better understand their situation and needs.

This approach would reduce the need for unnecessary assessment interviews while enhancing the quality of those that are conducted.

6. A lack of clear guidance increases distress

The people we engaged with highlighted significant challenges in navigating the WCA and PIP assessment processes, pointing to a lack of clear, accessible, and practical guidance. Without reliable information on what to expect or how to prepare, many felt unprepared, unsupported, and overwhelmed, particularly those without access to support from welfare advice services or family, friends, and carers.

- **The burden on claimants:** People described how the responsibility to navigate the process fell entirely on them, yet they felt *"set up to fail."* Barriers to accessing clear information were compounded by the effects of mental illness, neurodivergence, and other intersecting health conditions and disabilities, making it even more difficult to understand or follow instructions when mentally unwell.

> “Unless you've got a support worker who's got this information with you, no it's not readily available.”

- **Inadequate information from the DWP:** People consistently reported receiving little to no guidance from the DWP to help them prepare for what they were about to go through. When information was provided, it was often inaccessible for a variety of reasons including unclear language and jargon, which was particularly challenging for people living with mental illness who also identify as neurodivergent.

> “I've never had information shared, there's never any information sent or clarity on terminology.”

- **Fragmented and overwhelming resources**: Some turned to welfare advice services for information, but many were unaware of these services or could not access them. Those who accessed non-DWP guidance described it as fragmented and scattered across different websites. This left them feeling anxious, overwhelmed, and uncertain of which sources to trust or follow.

The absence of quality, centralised guidance, combined with inaccessible language and fragmented resources, has left people struggling to navigate highly complicated processes and systems. This lack of clear and practical information significantly amplifies their stress and reinforces feelings of being unsupported and set up to fail.

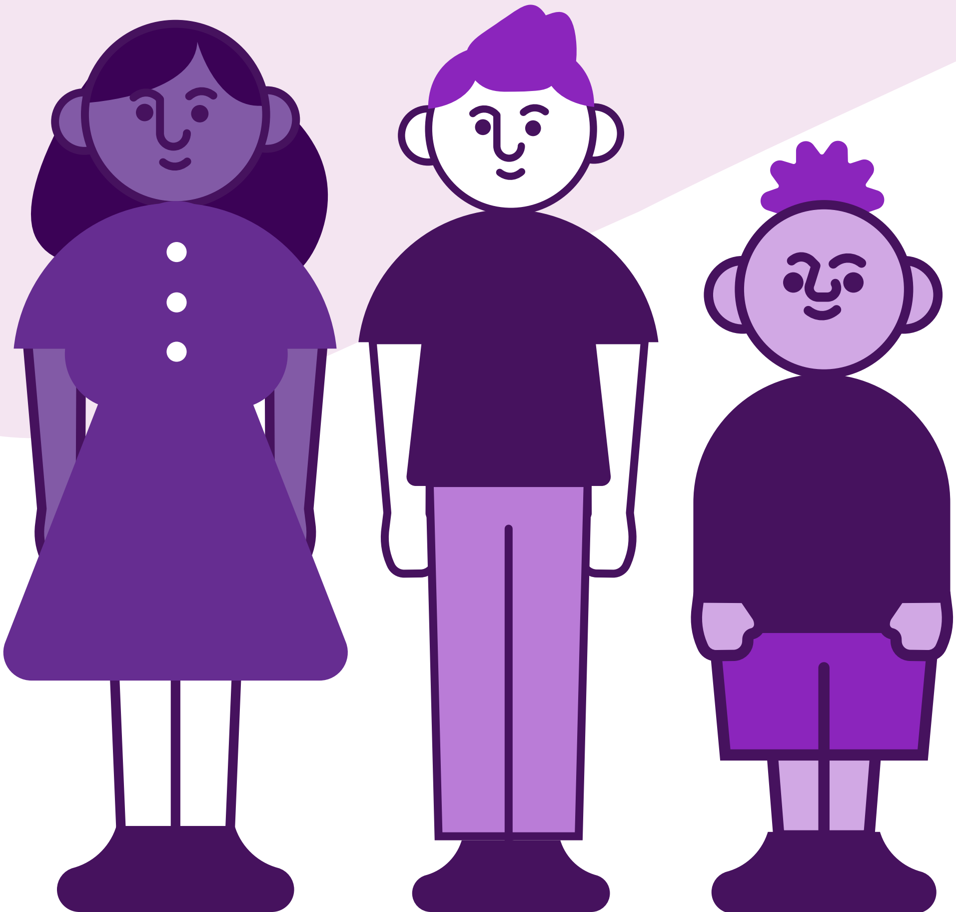
Solution:

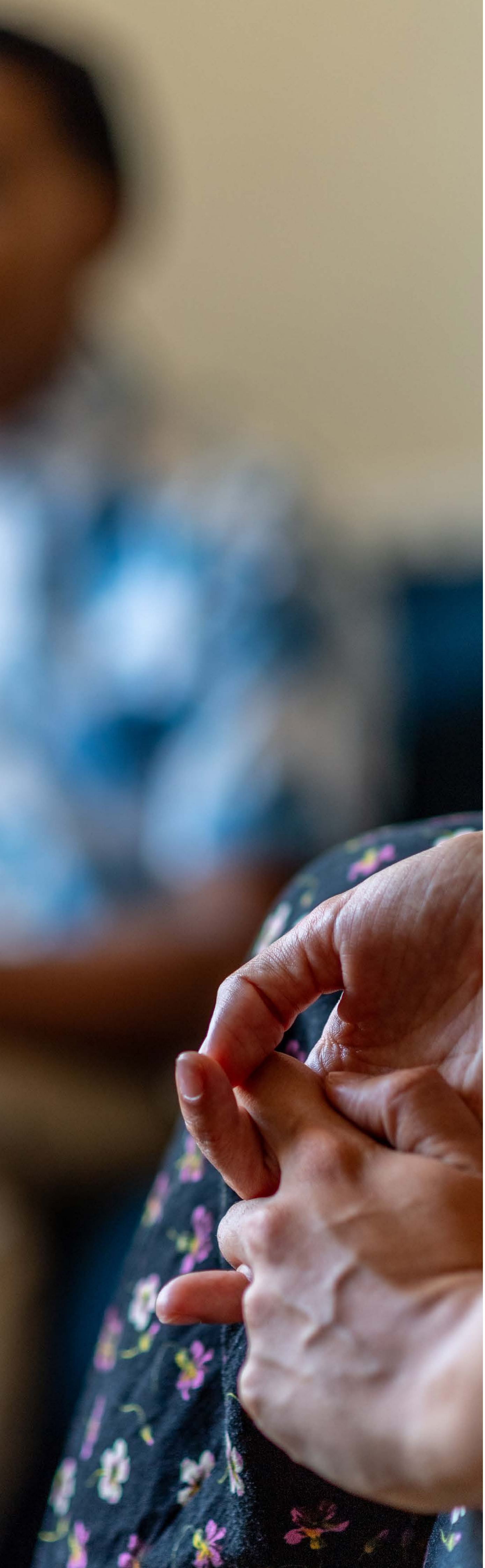
Co-design quality, official guidance with lived experience involvement

To help claimants navigate the WCA and PIP processes more effectively, people in our sessions suggested that the DWP co-design comprehensive guidance in collaboration with people who have lived experience of the reformed assessments, mental illness, neurodivergence, and other complex needs. This collaborative approach would help ensure the guidance is practical, accessible, and tailored to the needs of those it serves. It is important that this guidance is designed and evaluated with input from people with lived experience, so it reflects real-life challenges and is genuinely accessible for those who need it most.

Key features of effective guidance were briefly discussed in our sessions, including:

- Clear, step-by-step explanation about the WCA and PIP processes, from initial application/referral to decision outcomes.
- This resource is easy to follow, written in plain, everyday language and avoiding jargon.
- Provides examples, FAQs, and scenarios to help claimants understand what the panel may ask and how their responses will be considered.
- Guidance should be provided at key moments such as when a claimant is notified that they need to complete a WCA or when they start a PIP application.
- Guidance should be included in all correspondence related to the assessments.
- The guidance should also include information on relevant support people can be referred or signposted to.





7. Isolation caused by a lack of quality, relational support

The people we engaged with identified a major gap in the WCA and PIP processes: the lack of accessible, high-quality relational support facilitated by the DWP to help people navigate these complex systems. Without this support, many felt isolated, overwhelmed, and left to manage the process alone.

- **Reliance on personal connections**: Many people were able to lean on family, carers, or friends for help. However, even with this support, navigating the process was often an insurmountable challenge. For those without relevant personal connections, the experience was even more isolating.

> “I went into it blind with what to expect I had no idea or any type of guidance on what to do. It’s self-led. I had no one with I could follow up with and ask questions.”

- **Lack of awareness, signposting, and referrals**: While independent advice services, such as Mental Health UK’s Mental Health and Money Advice, do exist, many people were unaware of them during their experiences or struggled to access them. People also reported little to no signposting or referrals from the DWP, even when they explicitly expressed a need for help.

These issues are compounded for people living with mental illness, neurodivergence, or intersecting health conditions and disabilities, making the process particularly daunting without clear guidance or specialised support. The lack of proactive assistance leaves people feeling abandoned, amplifying their distress during an already challenging time.

Solution:

Proactively facilitate access to specialised, designated support

To address the lack of support and reduce the isolation people experience, participants in our sessions proposed that the DWP invest more in expanding access to specialised services, including designated mental health advocates, peer support workers, and welfare advice services. By increasing funding for these services and facilitating quicker, easier access, people would receive the support they need to navigate processes effectively, reducing systemic distress and preventing their mental health from worsening. This investment could play a vital role in preventing relapses, fostering stability, and ultimately improving people's chances of returning to work in the future.

Key features of designated support discussed in the sessions included that:

- It should be high quality, including being staffed by people who have a good understanding of both mental illness and the WCA and PIP processes as well as skills in delivering advocacy, advice, and support.
- It would work with claimants wherever they require assistance with the process, providing practical guidance, answering questions, and helping them navigate the different stages of the process.
- It would follow a case management system, ensuring continuity of care between the same worker or volunteer throughout and thereby avoid the inefficiency and potential retraumatisation that results where people are required to repeat their stories repeatedly.
- Whereas it would probably need to be funded by the DWP, it would need to be delivered by explicitly independent organisations, free from any perceived conflict of interest. This independence is critical to building and maintaining trust.
- It should be proactively and routinely offered to claimants living with mental illness by DWP staff, with people referred if they opt for this support.

> “There should be a support line – independent support which people could call any time during the process to get advice. If it was available from the beginning, even if they can't help you directly, they could signpost you.”

While designated support is essential, improving the clarity, accessibility, and fairness of the assessment processes would reduce the need for external assistance over time. By making the changes recommended in this report, the DWP could minimise the challenges claimants severely affected by mental illness face, ensuring fewer people reach the point of crisis.

How to safely support people into work or recovery-oriented activities

Through our engagement, we identified significant barriers to work and other activities arising from DWP processes, as well as the substantial impact of inappropriate decisions and procedures. For some people, the severity and enduring nature of their mental illness may mean that work is not a realistic or appropriate outcome, either permanently or for an extended period as they focus on recovery.

However, fully voluntary, recovery-oriented activities can play a crucial role in supporting their recovery, while gradually building skills and confidence for future employment opportunities. For those for whom work is a realistic and appropriate goal, prioritising long-term, person-centred, and holistic wraparound support that understands the complexities of mental illness is essential.

The following case study illustrates the severe consequences that can arise when these distinctions are misunderstood or overlooked, and when the system fails to provide the appropriate level of support.

Case Study:

Harmful consequences of inappropriate work requirements

One of the people we engaged with who lives with severe mental illness, Charlie, was placed in the **Limited Capability for Work (LCW)** group following a WCA. Despite their mental illness severely limiting their ability to engage in work-related activities, the assessment failed to fully account for the impact of their illness.

As a result, they were assigned to the LCW group, where they were expected to participate in work preparation activities, rather than being placed in the **Limited Capability for Work and Work-Related Activity (LCWRA)** group, which would have exempted them from such requirements.

Upon placement in the LCW group, they met with a **Jobcentre work coach** to agree on a Universal Credit Claimant Commitment. During this meeting, they explained in detail how their mental illness made it difficult, and at times impossible, to engage in certain activities including going outside and travelling from place to place. However, the work coach appeared to dismiss their concerns, offering only vague reassurances, and advising them to sign the commitment, with the promise that adjustments could be discussed later if needed.

Shortly after, they were instructed to attend an **in-person course**, requiring five days a week of attendance over two consecutive weeks. Recognising the detrimental impact this would have on their health; they immediately contacted the work coach to request an alternative and explained that:

- Attending the course would significantly worsen their mental health.
- Leaving their home consistently for five days a week was not feasible due to their condition.

Despite repeated attempts to advocate for themselves and request a remote alternative, their concerns were dismissed. The work coach responded that “others come from further away,” – a response the claimant described as lacking empathy and understanding. They were further told that unless they were actively at risk of suicide, they would have to attend the course or face **sanctions**.

Unable to meet the course requirements due to their health, they were sanctioned – **losing six months of financial support**. This outcome left them in an extremely vulnerable position including:

- **Financial Impact**: They were left without the income they depended on, creating financial insecurity and additional stress.
- **Emotional Harm**: The sanction caused significant emotional distress, leaving them feeling trapped, powerless, and deeply unsupported by the system that should have accommodated their needs.

Reflecting on the experience, they described it as “extremely damaging,” both financially and emotionally. The lack of flexibility and understanding not only failed to support their recovery but actively worsened their situation.

8. Negative impacts of sanctions on mental health

The people we engaged with described how the constant threat of sanctions for those not placed in protected groups such as the UC LCWRA groups or the ESA Support Group, created an overwhelming atmosphere of anxiety and fear of the future. For people severely affected by mental illness, the pressure to comply with conditionality requirements was immense and distressing, as the risk of financial penalties compounded their existing vulnerabilities.

The ever-present risk of sanctions caused ongoing anxiety, forcing people to comply despite it not being safe for them or experiencing financial hardship which makes their situation worse overall. People in the sessions described feeling trapped in a cycle of distress, where sanctions not only undermined their ability to recover but actively worsened their mental health and physical health. Research confirms that conditionality and sanctions exacerbate mental health issues and reduced long-term employment outcomes.[5] Instead of supporting recovery or pathways into work, they exacerbate harm, hindering mental health recovery, and create additional barriers to progress into good work and make it harder for people to not have to rely on the social security system.

Solution:

Exempt people severely affected by mental illness from sanctions and provide recovery-oriented pathways

The government faces a critical challenge: striking a balance between protecting taxpayer money, supporting people into good work, and ensuring that those unable to work receive adequate financial support to live with dignity. This balance is essential to breaking the harmful cycles of poverty and exclusion while fostering a system that enables recovery, stability, and long-term contribution to society. Instead of engaging in practices that inadvertently keep people out of work, we need to create a virtuous cycle where people are empowered to grow and succeed, without fear of financial insecurity or unsuitable activities. To break this harmful cycle and create a more supportive system, people called for the following key changes:

- **Exempting people at risk of harm:** People living with mental illness should be exempt from the sanctions regime. Removing the constant threat of financial penalties would allow people to focus on recovery, stability, and personal growth.
- **Recovery-oriented pathways:** Instead of the current system of conditionality and sanctions, the DWP should explore how to provide recovery-oriented pathways that support people based on their needs, capacities, and circumstances. This approach would prioritise recovery by gradually increasing confidence and skills through meaningful activity such as volunteering, before considering steps towards appropriate paid employment. People would feel more comfortable with participating in productive and meaningful activities like this if they felt safe from the risk that it would trigger reassessments. Guaranteeing this security would help foster trust and reduce fear of engaging with the DWP.

9. When the system becomes a barrier instead of a safety net

A pervasive culture of distrust underpins many experiences of the current system, where disabled claimants often feel distrusted by the DWP and agencies, and in turn, lack trust in those institutions. While some acknowledged that the DWP could, in theory, play a supportive role in helping people into work, people felt this potential was unattainable under existing processes.

> “The system is not set up to help people with mental health into work.”

Many people were reluctant to express interest in work, volunteering, or skill-building activities due to concerns about being reassessed by the DWP. They feared this could lead to reduced financial support, pressure to take on unsuitable roles, or losing access to benefits.

For those who would like to start work, the possibility of a relapse in their mental illness and the subsequent financial and emotional hardship of navigating the burdensome process to reclaim benefits deterred them from taking the risk. As a result, many felt it was safer to remain within the social security system than to attempt employment.

The current system was widely viewed as a trap rather than a safety net, leaving people uncertain about whether they would receive support if work proved unsustainable. Experiences of rigid processes and insufficient understanding of mental illness contributed to a pervasive culture of distrust. Instead of feeling supported, people often avoided discussing work opportunities as a form of self-protection.

Solution:

Build a stronger safety net to explore work

To address this issue, people suggested the creation of a safety net that would enable people to explore work, volunteering, or other meaningful activities without fear of not having access to financial support if work does not work out.

Key elements of this approach could include:

- Introducing a fast-track system to allow people to reclaim the same benefits package they previously received if they need to leave work due to a mental health relapse or other health-related challenges for example. This would provide reassurance that they can return to the system seamlessly without facing financial hardship or administrative delays.
- Acknowledging that recovery is not linear, and providing the flexibility for people to pause or adjust their engagement based on their health needs.

This solution is not only led by the people we engaged with but is also echoed by a growing number of organisations, including the Joseph Rowntree Foundation,[6] who have called for similar reforms to create a supportive and flexible social security system that empowers people without fear of losing their safety net.

10. The absence of tailored support in helping people sustain meaningful work

People have consistently reported not receiving the comprehensive, wraparound support they need to enter and sustain work when they feel ready to work. Interactions with Jobcentre work coaches were frequently described as coercive, dismissive, and unhelpful, leaving people feeling unheard and unsupported. Rather than fostering collaborative discussions, these engagements reinforced the perception that the system prioritises compliance over meaningful assistance.

- **Rigid and unrealistic commitments**: UC Claimant Commitments were often experienced as inflexible directives rather than agreements tailored to individual circumstances or capacities, particularly mental health needs. People felt pressured into unsuitable paths with little opportunity to suggest alternatives or negotiate terms.

> “They tell you what to do and you just have to accept it, no kind of conversation.”

- **Dismissal of individual goals**: Suggestions for more appropriate work options, such as self-employment, were often dismissed outright. This lack of openness to personalised solutions left many feeling frustrated, demoralised, and unsupported in pursuing sustainable pathways to work.

> “[My] work coach didn’t tell me about the Access to Work scheme.”

- **Lack of practical support**: People highlighted a significant gap in practical guidance on managing finances, understanding entitlements, or accessing schemes like Access to Work which are essential resources for people living with mental illness and other complex needs.

> “[My] limited experience of them [was that they were] unhelpful as I was told to ask them for support with managing money, yet they just said at your age do it yourself, so they are useless.”

These experiences demonstrate that many work coaches fail to provide the tailored and practical support necessary to help people living with mental illness access and sustain meaningful employment. Without adequate guidance and flexibility, people are left feeling disempowered and distrustful of the system, making it even harder to explore and thrive in appropriate and sustainable work opportunities.

Solution:

Transform jobcentres as gateways to specialist, wraparound support

People proposed a shift in the role of Jobcentre work coaches, moving from punitive enforcers to supportive facilitators. Jobcentres are not currently equipped to provide the specialised, holistic support needed to help people living with mental illness into work, remain in work, or recover if the job does not work out. Instead, they should function as a central hub in local areas, focused on signposting and matching people with the right, high-quality services that are tailored to their specific needs. This approach would ensure people with complex and specific needs, like mental illness, receive the right support at every stage of their employment journey.

Key elements to this new approach could include:

- Ensuring people are fully informed about all available employment support schemes, such as Access to Work, and actively facilitating their access to these resources.
- Proactively identifying and matching people with appropriate specialist services, for example, referring people living with mental illness to services such as the Individual Placement and Support (IPS) scheme[7] or Mental Health UK's Into Work Programme[8]. If a person is interested in taking part in these programmes and schemes, their work coach could set up an initial meeting with the service worker to explore options and build trust.
- Ensuring all referrals voluntary and free from the threat of sanctions, empowering people to engage with services at their own pace and without fear.
- Providing targeted training for work coaches to build trust, understand mental illness and trauma, and ensure people feel safe at the Jobcentre.

> Joined up working, joined up reports – that’s my plea.

Concluding Thoughts

By exploring the ideas for improvement outlined in this report, the WCA and PIP assessments and approaches to work could become fair, effective, and safer for people severely affected by mental illness – and in ways that have been identified and articulated by people with experience of both mental illness and the current system. At Rethink Mental Illness, we are committed to working with the government to not only highlight the problems within the current system but also to co-develop practical solutions. We believe these solutions must be driven by the voices of those with lived experience, ensuring that policies and practices are shaped by the people who are most affected by them.

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We are the charity for people severely affected by mental illness, no matter what they’re going through.

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