"We're just numbers to them" – The DWP's failure to investigate death and serious harm.

March 2022

Trigger warning: self-harm and suicide

This report discusses self-harm and suicide, which readers may find upsetting. At the end of this report, you will find links to sources of advice and information, as well as where you can find crisis support organisations.



Although the stories are real the images accompanying them are posed by models.

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"When you're struggling with your mental health anyway, for someone to almost call you a liar is really hard. It was a horrible experience."

"It made me feel worthless - I was treated like a criminal. It made my anxiety and paranoia so much worse." Chris

"I just felt really worthless, and there was a point where I wanted to take my own life." Rochelle

> "It makes my life a rollercoaster." Maria

"It made our lives a living hell. It was so traumatic to see someone you love go downhill so fast." Stuart's partner

"My fear of a brown envelope dropping through the letterbox is still so strong that I have panic attacks." Charlie

"He mentioned his benefits in a suicide note, which was left next to a stack of letters from the DWP." Mark

"I spiralled down really fast, became suicidal and attempted to take my own life."



Foreword

From Brian Dow, Deputy Chief Executive of Rethink Mental Illness and Co-chair of the National Suicide Prevention Alliance.

When we wrote '*Tip of the Iceberg? Deaths and Serious Harm in the Benefits System*' in July 2021, we wanted to highlight the tragic circumstances endured by many vulnerable people claiming financial support, including those living with severe mental illness. We also wanted to throw a spotlight on the Department of Work and Pensions' (DWP) lack of accountability in investigating these events. **Seven months on, this report finds little has changed to address our concerns.**

As self-harm, mental health crises and suicide attempts are more common than suicide, we were not surprised that the vast majority of the cases reported to us (in the survey that forms the basis for this report) were of serious harm, rather than death. Yet since July 2019, only 21% of the Internal Process Reviews (IPRs) conducted by the DWP have investigated serious harm. This suggests that the DWP's internal investigations have a vacuum where most of their work should be.

Time and time again, we see opportunities for transparency and honesty missed. From the failure of the DWP to publish any analysis of deaths or serious harm, to the lack of clear route for professionals or claimants to report incidents, and the fact that claimants and bereaved families are not routinely told if their case is subject to an investigation. The strong association between suicide attempts and eventual death by suicide means that **the DWP's failure to investigate these cases risks undermining the government's suicide prevention strategy.**

Yet for all the talk of the processes required to improve the benefits system, it is vital to keep the focus on individuals and families harmed by failings that will affect their lives for years to come. We want to express **our gratitude to everyone who shared their experiences with us, and particularly to Amanda, Charlie, Chris, Jane, Maria, Mark, Rochelle and Stuart whose stories are featured in this report**. They have endured often appalling treatment and are channelling those terrible experiences into making the system better for others.

We are confident that the benefits system can be improved to work far better for people living with mental illness. A crucial first step is for the DWP to be open and honest in understanding what has gone so badly wrong.

Executive summary and key findings

Many people, particularly those with existing mental health problems, find the experience of navigating the benefits system difficult and distressing.¹ This can make people more unwell, sometimes to the point where they feel compelled to harm themselves or try to end their lives.

The Department for Work and Pensions is supposed to conduct an Internal Process Review (IPR) whenever their actions may have played a part in someone dying (such as by suicide) or experiencing 'serious harm'. The DWP has opened at least 289 IPRs into such cases since 2012.² These internal investigations are intended to review processes and practice, and identify any recommendations for change where there has been a death or 'serious harm' that may be linked to the DWP's actions.

In July 2021, our report '*Tip of the Iceberg: Deaths and Serious Harm in the Benefit*

System' examined data on IPRs as well as evidence from cases reported in the media. To explore these issues further, for this report we conducted a survey to find out more about the harm people have experienced as a result of their interactions with the benefits system, and how the DWP responded to them. This report is based on the responses to that survey and detailed interviews with eight survey respondents. Of the 122 survey responses we analysed:

- Five cases involved the suicide of a friend or family member.
- There were 54 cases where a suicide attempt or self-harm was mentioned (incidents that are specifically named by the DWP as constituting serious harm). Around a third of these respondents said that the DWP had been made aware of what had happened.
- There were 63 cases involving a significant deterioration in someone's mental health,

often to the point of individuals having suicidal thoughts.

¹ Money and Mental Health Policy Institute (2019) <u>The Benefits Assault Course: Making the UK benefits system more</u> accessible for people with mental health problems

² Combined figure sourced from: BBC News (2021) <u>DWP sees 'sharp rise' in benefit death reviews</u>; UK Parliament (2021) <u>DWP Response to a Written Parliamentary Question - 3rd December 2021</u>

Key findings from our survey and interviews:

- 1. Cases of death and serious harm related to the benefits system are a current issue, not just a historical one. Almost three-quarters of incidents where a date was provided occurred in the last five years. Experiences related to applications, assessments and appeals were the largest cause of harm.
- 2. The number of cases of serious harm we were able to identify through our relatively small survey sample suggests that the **DWP is not instigating IPRs as often as it should be.**
- 3. In particular, the DWP is failing to investigate cases of serious harm that do not involve a death. Suicide attempts and self-harm occur much more frequently than deaths by suicide. The proportion of serious harm cases compared to deaths reported in our survey suggests there should have been many hundreds of serious harm IPRs since July 2019, compared to the 31 that the DWP instigated.
- 4. Many cases of serious harm do not get reported to the DWP because of a lack of awareness about the process and a lack of trust in the department. As well as claimants not reporting cases, there is no adequate process for professionals outside the DWP who support claimants, such as clinicians or social workers, to report suspected incidents of serious harm investigation.
- 5. The definition of serious harm used by the DWP is not clear for example, it's not set out if a mental health crisis that does not involve self-harm or a suicide attempt should trigger an IPR. This is made worse by a lack of published guidance or official analysis of cases, trends and IPR recommendations, which adds to the impression that the process is opaque and unaccountable.
- Cases where people's negative experiences may fall below the DWP's threshold of serious harm nevertheless raise wider concerns about the adverse mental health impact of the benefits system and whether enough is being done to address this.

Introduction

While writing Tip of the Iceberg we were struck by how few IPRs investigate serious harm, as opposed to deaths. The most recent data shows there were 31 IPRs relating to serious harm between July 2019 and December 2021, out of a total of 145. This means there were almost four times as many IPRs focused on deaths compared to serious harm.³ This report investigates this overlooked issue of serious harm.

In recent years, there have been a series of high-profile cases in which interactions with the DWP have played a role in people's deaths, most often by suicide.⁴ Yet while only a relatively small number of cases have gained national media coverage, there is growing evidence that many more cases of death and serious harm are linked to the actions of the DWP.

This research builds on our July 2021 report, *'Tip of the Iceberg? Death and Serious Harm in the Benefit System'.* The recommendations from that report called on the government to:

- 1. Establish a full public inquiry into benefit related deaths and cases of serious harm.
- 2. Set up an independent body to investigate future cases of death or serious harm in the benefits system.



The *Tip of the Iceberg* recommendations were based on four key findings:

- 1. The DWP conducted 124 IPRs between July 2019 and June 2021 - an almost threefold increase compared to the period of February 2012 to July 2019.
- 2. There is a wide range of issues across the benefits system that have resulted in deaths, as well as causing suicide attempts, self-harm and mental health crises.
- 3. Benefit deaths and serious harm reported in the media or investigated internally by the DWP may be the tip of the iceberg, with gaps in the way that cases are identified.
- 4. The DWP's current process for investigating cases of death or serious harm are not independent. They lack external oversight, and it is unclear whether they have recommended, far less delivered, systemic policy or culture change.

³ UK Parliament (2021) <u>DWP Response to a Written Parliamentary Question - 3rd December 2021</u>

⁴ Not all deaths linked to the DWP have been by suicide. For example, Errol Graham died by starvation in 2018 after his benefits were stopped.

We know that there are many more suicide attempts than deaths by suicide, and many more people experience suicidal thoughts than attempt suicide.⁵ The sort of distress that can lead to suicidal thoughts and suicide attempts can also lead to people self-harming without suicidal intent, or to mental health crises that are serious but that do not include self-harm. And while the focus of this report is on mental health crises, there are other forms of serious harm - such as homelessness or severe malnutrition - that should also trigger IPRs.

The causes of deaths and incidents of serious harm are complex. There is no single reason why a person may choose to end their own life or experience a mental health crisis, with a range of factors playing a role. However, suicide is preventable and the DWP can play a vital, unique role in suicide prevention. This includes improving its practices, how incidents are investigated and the systemic drivers behind tragic cases of death, self-harm and mental health crises.

This report explores the experiences of over 120 people who responded to our survey about death or serious harm related to interactions with the DWP, and the stories of eight individuals who we interviewed. We reflect on what these experiences tell us about how the benefits system is impacting people's mental health and how the DWP responds when people have been pushed to the point of crisis. Building on these insights, we make recommendations for changes to DWP policy and practice and suggest issues that should be addressed by an independent public inquiry.

What is 'serious harm'?

In order to establish why so few IPRs have been taking place into incidents of serious harm, it is critical to understand what the term means to the DWP. In June 2021, the department stated that IPRs are conducted when:

"There is a suggestion or allegation that the department's actions or omissions may have negatively contributed to the customer's circumstances, or cases in which the department may be able to learn about the operation of its processes, AND a customer has suffered serious harm, has died (including by suicide), or where we have reason to believe there has been an attempted suicide".⁶

This answer suggests that serious harm sits as a separate category to attempted suicides, but a footnote to the same response suggests that "Serious Harm includes the categories self-harm, serious harm, attempted suicide and 'other".⁷

Either way, this tells us that incidents of attempted suicide or self-harm, where the DWP's 'actions or omissions' are alleged to have played a role, should lead to an IPR. It also makes clear that other incidents that do not involve attempted suicide or self-harm but do cause other forms of serious harm are also in scope for an IPR.

What might constitute such serious harm - other than self-harm or suicide attempts - is not defined in more detail. In this report, we have focused on harms around mental health crises. Nevertheless, it is important to note that the DWP's published definition appears to be broad, and could include homelessness, starvation, and a range of other possible harms.

In practice, the lack of transparency around IPRs means that we do not know how the DWP identifies cases that might warrant an IPR or how they decide whether the incident meets their definition of serious harm. This is an issue we will return to later in this report.

⁵ NHS (2016) Adult Psychiatric Morbidity Survey: Survey of Mental Health and Wellbeing, England, 2014

⁶ UK Parliament (2021) <u>DWP Response to a Written Parliamentary Question - 28th June 2021</u>

⁷ UK Parliament (2021) DWP Response to a Written Parliamentary Question - 28th June 2021

Our research

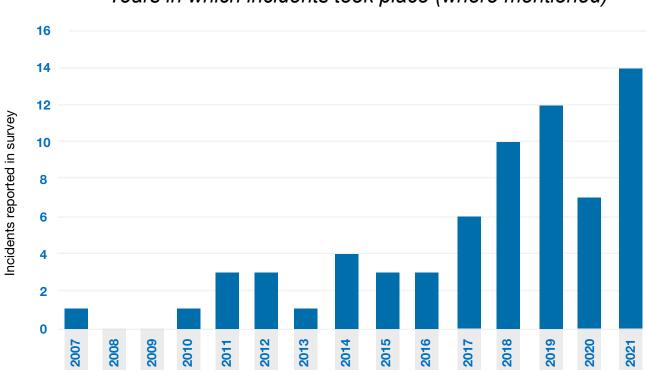
Chart 1

Between July and November 2021, we ran an online survey asking people to share examples of the serious harm they, or a family member or friend, experienced as a result of the DWP's actions. We received almost 300 responses but have based this report on the 122 responses that contained enough qualitative information for us to include them in our analysis.

Of these 122 responses, just over half indicated the year that the incidents being reported took place, as set out in *Chart 1*. Almost three-quarters of the reported incidents that included an indication of the date had occurred within the last five years. It seems likely that those responses that didn't include a year were broadly reflective of this distribution. This suggests the evidence we have gathered is indicative of current problems with the benefits system rather than historical issues that may have since been corrected.

The year 2020 is a notable outlier in the trend that survey respondents tended to report more recent incidents. It seems plausible that this may be linked to the wide-ranging temporary changes made to the benefit system during 2020 because of Covid-19, such as conducting benefits assessments remotely, pausing reassessments, and suspending benefit conditionality and sanctions.

This survey is not the only research looking into death and serious harm. A survey conducted for Channel 4's Dispatches programme found 450 people said that their interactions with the benefit system had caused a suicide attempt. Additionally, 1,154 people said it had caused them to plan to take their own lives and 2,158 said it caused them to have suicidal thoughts.⁸



Years in which incidents took place (where mentioned)

8 Channel 4 Dispatches (2021) The Truth About Disability Benefits.

The constant threat of being called back in to have my integrity questioned again just felt so distressing.

Charlie's story

Charlie reluctantly sought support from the DWP due to her mental and physical health conditions. After a cycle of benefit reassessments and constantly feeling under suspicion from the DWP she made numerous attempts on her life.

Charlie has experienced depression and anxiety for as long as she can remember but had never sought support from benefits. However, in 2012 when she was 27, she also developed physical health problems: "I'd recently lost my job due to my health and so my hand was forced to some extent, but with a physical condition it somehow felt ok to ask for help."

After applying for Employment and Support Allowance (ESA), she was asked to attend a Work Capability Assessment (WCA). Even though she had mentioned her mental health in her application, she was not asked about it in the assessment: "It was entirely focused on my physical health, even though I was clearly having a panic attack in the room at the time. There was no acknowledgment of the distress I was experiencing."

Although Charlie was awarded ESA, the experience of this first assessment set the tone for her relationship with the DWP going forward: "Every interaction with them felt so begrudging, as if they were saying 'you should be grateful for any help you're getting'". She was reassessed frequently, sometimes as little as six months after her previous WCA: "It felt like at any moment this support could be taken away from me." Some of these subsequent assessments did focus more on her mental health, but this was almost worse than having the subject ignored: "When you're experiencing mental health problems, you're often struggling to understand yourself. The invalidation of trying to justify yourself to someone else when you already feel unsure of yourself is terrifying."

This cycle of reassessments had a significant impact on Charlie's mental health: "The constant threat of being called back in to have my integrity questioned again just felt so distressing." On a number of occasions, soon after one of these assessments, Charlie's distress became so intense that she made attempts to take her own life.

Charlie told the DWP many times about the damage this process was doing to her: "I'd say 'you do realise what happened after the last assessment?'. Sometimes they would say 'I'm sorry that happened' but it never seemed to be logged in a meaningful way. On one occasion I was told 'well you do have mental health problems - that's part of the challenges that you're living with', so it was excused as just part of my life experience."

Charlie has now managed to build a career for herself, working in wellbeing and mental health: "I'm on a low income and would be eligible for support from the DWP, but I don't feel able to call on this because of the trauma of my experience with them. My fear of a brown envelope dropping through the letterbox is still so strong that I have panic attacks when I receive post from the DVLA or HMRC."

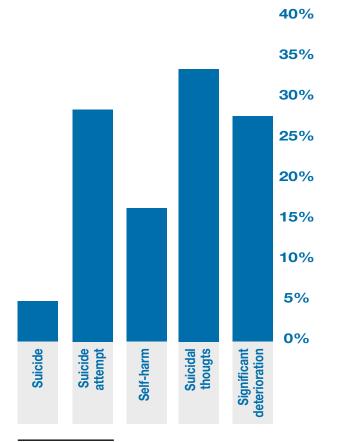
The types of incident that occurred

There were five responses to the survey from people who knew someone who had died by suicide, where their interactions with the DWP seem to have been a significant contributory factor. When negative experiences of the benefits system are pushing significant numbers of people to the point of having suicidal thoughts and attempting suicide, deaths by suicide are the inevitable, if tragic, consequence. We have included an account from one of these respondents among the reallife stories highlighted in this report.

Mindful of the unresolved questions around how serious harm is defined, we categorised the remaining responses by the type of harm that had occurred. As shown in *Chart 2*, these categories included suicide attempts, self-harm and suicidal thoughts.⁹ We also created a category for significant deterioration in someone's mental health without specific mention of suicide, a suicide attempt, self-harm or suicidal thoughts.

Chart 2

Types of incidents reported



Whether incidents met the DWP's definition of serious harm

Based on the type of incident that was reported, we then categorised the responses according to whether they seemed to meet the DWP's definition of serious harm. This is an inherently imprecise task given the lack of clarity around their definition and how it is applied. As such, we erred on the side of caution and only categorised responses as constituting serious harm where suicide attempts and self-harm were mentioned, as both of these are explicitly stated to constitute serious harm in the DWP's definition. We also subdivided responses based on whether it was suggested that the DWP was aware of the incident.

As Chart 3 shows, 46% of the responses we received mentioned a suicide attempt and/or incident of self-harm, and therefore clearly met the DWP's definition of serious harm. A third of this group believed that the DWP was aware of the incidents in question.

The remaining 54% of responses involved a significant deterioration in people's mental health but did not include specific mention of a suicide attempt or self-harm. In over half of these cases, respondents stated that they thought the DWP was aware of the harm that had been experienced as a result of interactions with the department.

Because of the ambiguity around the DWP's definition of serious harm, we cannot be sure whether these incidents would meet their threshold to trigger an IPR. However, it is clear that those affected, experienced serious mental health crises, often to the point of them having suicidal thoughts. Although the DWP's definition of serious harm specifically mentions suicide attempts and self-harm, it is not limited to these. We would argue that, under any reasonable definition, many of these cases are likely to constitute serious harm.

⁹ In general, responses were given a primary category based on the most serious incident that occurred, i.e., if a suicide attempt was reported the response would only be placed in this category. However, where self-harm was reported alongside suicidal thoughts, the response was placed in both categories as it would be inappropriate to state that one was inherently more serious than the other.

Jane's story

Jane's benefits were stopped in 2021 after a DWP administrative error which caused her mental health to deteriorate and resulted in Jane attempting to take her own life. The DWP marked her as 'vulnerable' but Jane does not know if an IPR took place.

Jane lives with Dissociative Identity Disorder caused by severe early childhood trauma. She had been receiving Personal Independent Payment (PIP) for many years in recognition of the additional costs she faces but last year, at age 55, her benefits suddenly stopped.

She was told that she had failed to return a review form by the deadline date. Jane had received this form while she was detained in hospital under the Mental Health Act after a suicide attempt: "I'd struggled to get any support to complete the form and had to ask for an extension from the DWP. Eventually I managed to get some help from a social services support worker, and they'd sent the form off with plenty of time to spare."

The letter informing her that her PIP had stopped arrived on a Saturday: "There was nothing I could do about it that day - I was unable to get hold of anyone for support. On the Monday I also got letters from the council saying my council tax support had stopped as a result. Then later in the week, I got a letter from Motability saying I had to return my adapted car."

This was all immensely distressing for Jane, and it had a devastating impact on her mental health: "I spiralled down really fast, became suicidal and attempted to take my own life." It turned out that the DWP had received Jane's review form but, because they had a threeweek backlog of forms to process, they had not seen it before her PIP award ended: "They knew they were running three weeks behind, but rather than checking the backlog for my form they just stopped my benefits."

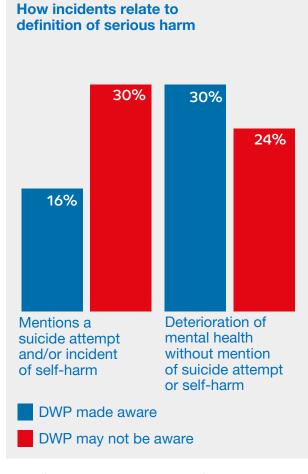
Fortunately, Jane had support to help rectify the situation: "My advocacy worker called the DWP and told them they had nearly caused my death. After a long conversation they looked at my form and agreed that my award should remain as it was."

The DWP did seem to acknowledge that the situation should not have played out the way that it had: "They said they would now mark me as a 'vulnerable claimant' so that my benefits wouldn't be stopped without me being contacted, but they already knew that I am easily destabilised and at high risk of suicide."

These events have had a long-term impact on Jane's confidence and wellbeing: "It rocked my security of knowing that I'd be ok because of the support from benefits. My PIP award gives me access to my adapted car and means I can afford to care for my dog. These two things are completely essential in my ability to stay alive and not be permanently in hospital."

I spiralled down really fast, became suicidal and attempted to take my own life.

Chart 3



Even if we accept that some of these cases do not meet a reasonable threshold for serious harm, it is concerning that significant lower-level harm is not seen as warranting the DWP's attention. This seems to reflect an acceptance, even an expectation, that the benefits system is difficult and stressful for people to interact with, to the point that it has a significant detrimental impact on many people's mental health.

Many accounts described the cumulative impact of negative interactions with the DWP, alongside anxiety about future interactions and their ongoing eligibility for benefits:

"It is always hanging over my head like a guillotine, as they can reassess at any time, despite my illness being long-term."

"Over a four-year period on benefits I was caused untold trauma, distress and was treated like a second-class citizen."

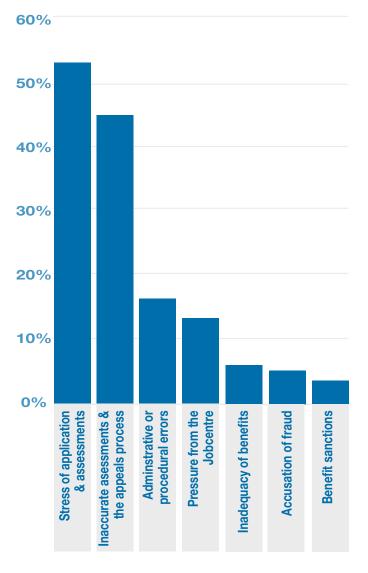
"I've had to use the benefits system over many years due to recurring mental health problems. I've always found it frightening, confusing and stressful."

Problems with the DWP that led to incidents of harm

We categorised all the responses we received by the type of problems people were experiencing in their interactions with the DWP that led to a negative impact on their mental health. Many responses involved two or more of these issues in combination, and so the percentages in *Chart 4* represent the proportion of responses that mentioned each issue, rather than that issue being the only or primary cause of distress.

Chart 4





I nearly died because of this.

Chris's story

Chris was wrongly accused of fraud in 2019 which led to his mental health crisis. The DWP were made aware but it's unknown if an IPR was conducted into his case.

Chris receives Employment and Support Allowance (ESA) because his mental health makes it hard for him to work. In 2019, when he was 37, his ESA suddenly stopped: "I'd not had a letter to say why. I only realised when I checked my bank account and saw I had not received any payments for over a month."

When he contacted the DWP he was told they could not see a reason for his benefits being stopped, but they told him there was a note on his file saying he needed to call a specific member of staff: "I contacted her and she told me there was a fraud investigation going on and until it was resolved all my benefits would be stopped. And that was it."

Chris then realised that other support such as his Housing Benefit had also been stopped. He then received a fine for 'lying' about his eligibility for free prescriptions. When he queried this, he was told to call the same member of staff. "This time she told me that I had over £30,000 in savings that I'd hidden from the DWP and I'd be facing a prison sentence."

Chris had to send years' worth of bank statements to try to demonstrate that he did not have anywhere near that amount in savings: "They wouldn't tell me anything more about the money I supposedly had but expected me to prove I didn't have it." The situation took a huge toll on Chris's mental health: "I'd got to the point where I was getting suicidal. My psychiatrist had sent a letter to the DWP to say, 'you need to sort this out because he's very unwell and you could cause a death', but there was no response."

A month later, Chris still wasn't receiving any benefits and had not been given an update on the fraud investigation. He was having to use what little savings he had to survive. Eventually, after making more phone calls to the DWP, they told him that someone with his name and date of birth had £30,000 in a Post Office account. "I said I'd never had an account with the Post Office, and I wouldn't be claiming benefits if I had £30,000!"

Chris was told he needed to prove that the Post Office account wasn't his, but it took many more difficult phone calls to eventually achieve this and get his benefits reinstated.

Chris put in a formal complaint: "I said the first thing I want is an apology - no one's apologised to me throughout this whole process". He was offered £70 in compensation: "I almost said to them 'you can have it back, that's an insult - I nearly died because of this'."

The whole experience had a lasting impact on Chris's mental health: "It made me feel worthless - I was treated like a criminal. It made my anxiety and paranoia so much worse. I couldn't leave the house. I'd made so much progress before this and it's taken a huge amount of work to get back to where I am now." The most commonly reported issue related to the stress of having to complete applications and assessments, such as the Work Capability Assessment (WCA), in order to access or continue to receive benefits. The impact of this was particularly stark when people were facing these processes on a frequent basis:

"Feeling I need to prove my illness messes with my head – I swing from believing I am disabled and entitled to this help, to feeling like a fraud."

"During assessments I would be distressed enormously by panic attacks, knowing that in the coming days I would harm myself, hearing the words they said, how they said them and how they called into question the validity of every single aspect of my experience."

Receiving inaccurate or inappropriate outcomes from these assessments, which for many people led to them appealing this decision, was also a key cause of distress.

"Every WCA that I have had has been grossly misreported and information given omitted, not one report has taken into account the fluctuating nature of my illness, as in not being able to do anything repeatedly and reliably. It has taken a year, nearly every time to be able to appeal the decision."

"I received the assessor's decision which was to decline my application mainly on the grounds that if I travelled by train then I couldn't have anxiety. Ditto coping with the crowded waiting room, with no mention of my panic attack (witnessed by reception staff)." Administrative and procedural errors that led to problems such as people's benefits being stopped or overpaid by mistake and the pressure that people experienced at the Jobcentre both came up as sources of stress in over 10% of the accounts we received:

"It took me 10 weeks to get Universal Credit, leaving me unable to pay rent for two months. I had to seek help from a number of charities and my housing association to find out that the DWP had not told me about other benefits I could be entitled to."

"The Jobcentre expected me to prepare and look for full-time work. I couldn't cope with what they were asking me to do and had not been told that I could ask for them to decrease the load, despite the fact that they knew I was mentally ill and had never even worked part-time in my life, let alone full-time."

The final three types of issues with the DWP, which a smaller number of people reported as being a driver of poor mental health, were the general inadequacy of benefits, accusations of fraud made against them, and experiences of benefits being sanctioned:

"I was left coping on £64 a week, with serious disabilities and mental health issues."

"I got the letter saying I'd been reported for fraud and would need to have a telephone interview with a case worker. I was extremely scared and upset. I worried I would be sent to prison, so I was self-harming and feeling suicidal."

"I once missed a phone appointment with them due to being in the middle of a panic attack, and despite explaining and pleading that there was no chance I could have participated at that time, I was sanctioned for it."

The stories shared in this report provide a fuller picture of how these types of problems can impact someone's mental health to the point of serious harm occurring.

Mark's story

Mark's brother, John, shared how his brother took his own life after being sanctioned by the DWP. Even though the impact of his interactions with the DWP were mentioned in Mark's suicide note, it is still unclear whether the DWP conducted an IPR.

In 2011, following a Work Capability Assessment, John's younger brother Mark was unexpectedly declared 'fit for work'. He had been on unemployment benefits for many years but had not been expected to work because of his severe depression: "He suddenly had to start going to the Jobcentre for appointments and show he was trying to find a job."

Mark was very private about any problems he was experiencing, always wanting to sort things out on his own. However, John could see he was struggling: "I knew he was having problems with his benefits, and he'd asked to borrow some money, which I lent him. But he kept everything that happened afterwards to himself, until he died by suicide. He was 43 years old."

After Mark's death, John and other family members tried to piece together what had happened: "We discovered that he'd been sanctioned because he hadn't attended an appointment at the Jobcentre. That led to him and his family having nothing to live on and he had taken loans out."

It seemed that Mark had tried to challenge the sanction before he ended his life: "As far as I can tell, he must have contacted them because there was a letter in response from the DWP asking for proof as to why he didn't attend the appointment. I can't know for sure why he hadn't attended but I would suspect it was because he wasn't well enough."

I've attempted to end my own life and have been detained in hospital after becoming really unwell from having to go through DWP application and assessment processes.

John has no doubt that these issues with the DWP contributed to his brother's death: "He mentioned his benefits in a suicide note, which was left next to a stack of letters from the DWP, bank statements showing how overdrawn he was, and an eviction notice from his landlord."

The coroner at Mark's inquest agreed that the DWP had played a part in his suicide, and John expected this to lead to a response from the department: "I think they were supposed to do some sort of review, but if this happened, they didn't involve anyone from the family."

John has long-standing mental health problems himself, and has had to rely on benefits for most of his life. He knows only too well the type of stress and pressure Mark must have been feeling: "I've attempted to end my own life and have been detained in hospital after becoming really unwell from having to go through DWP application and assessment processes."

Although John understands why Mark might have found it hard to ask for support, he wishes he'd had the opportunity to help: "If I'd known, I would have tried to sort it out for him. When you're struggling with your mental health, it can be so hard to get on top of things, and the benefits system is such a hostile and harmful environment."

How the DWP responds to incidents of harm

Of the five respondents who reported a suicide of a loved one, only one suggested that an IPR may have taken place. Three of the respondents stated that an inquest had taken place following the suicides. It was reported that two of these inquests made no mention of the DWP. In the third case, it was reported that the DWP was mentioned in the evidence, and the respondent said it may have been suggested at the inquest that a review should be carried out. However, the respondent was not aware of any action taken following this.

The National Audit Office (NAO) has previously raised concerns about suicides not always leading to IPRs, due to issues with communication between coroners and the DWP, and a lack of clarity in DWP guidance to staff about when an IPR should be instigated.¹⁰

Of the 19 respondents who disclosed an incident involving a suicide attempt or self-harm that they thought the DWP knew about, none were aware of an IPR taking place as a result. Of the 10 incidents where a date was provided, four occurred between 2019 and 2021.

Another 35 respondents reported incidents that may have met the DWP's broader definition of serious harm but which did not mention a suicide attempt or self-harm, and where the respondent believed the DWP was made aware. None of these incidents were reported to have led to an IPR. Of the 16 incidents where a date was provided, five occurred between 2019 and 2021.

Our survey therefore identifies at least four to nine incidents that occurred between 2019 and 2021 that should have triggered an IPR but appear not have done so. Around half of our respondents did not provide dates for the incidents they reported – if these reflect a similar spread of time to those where dates were provided, there may have been up to twice as many such incidents during this period. These findings are based on sample of 122 respondents, drawn from a relatively small pool of people who are in contact with Rethink Mental Illness, had a relevant experience to share and wanted to do so. In comparison, the DWP, which overseas millions of benefit claims, conducted 31 IPRs related to serious harm during this period – fewer than three times the number of incidents we identified.

Given the scale of harm reported in our survey, it is simply not credible that the DWP is only finding approximately one case of serious harm per month (based on the current average of IPRs) that warrants investigation. The majority of respondents who thought the DWP was aware of the harm they had experienced reported little improvement in their treatment following the incidents:

"The response was always the same: they have their rules they must follow, and if that means they have to cause you immense damage then so be it."

Where positive changes were reported, these included benefits being reinstated, face-toface assessments being suspended, and notes being added to people's DWP profiles to encourage more careful treatment in the future because they are 'vulnerable'.

¹⁰ National Audit Office (2020) Information held by the Department for Work & Pensions on deaths by suicide of benefit claimants

The stress of the assessment on top of what was already going on in my life was too much.



Amanda's story

In 2016 Amanda found her Personal Independence Payment (PIP) assessment extremely traumatic and as a result attempted suicide while waiting for the outcome, but she does not believe that the DWP knows what happened to her.

Amanda has experienced difficulties with her mental health since she was a teenager. In 2016, when she was 26, she was having a particularly difficult time with anxiety and depression, as well as the chronic pain condition fibromyalgia.

Amanda's mental health nurse suggested she apply for PIP as her mental and physical health were creating additional barriers in her day-to-day life, including causing her difficulties with her job that were leading to her work hours being reduced. PIP could help her address the financial impact of these barriers.

Amanda hadn't realised when making the application that she would have to attend a face-to-face assessment: "I had no idea about the benefits system – it was all new to me. I had to travel across the county when I was already in a mental health crisis."

Things got worse during the assessment: "The assessor didn't seem to listen to anything I said. I felt like she had already decided I was making things up. I became more and more distressed and upset as I realised what she was doing - discounting everything I said and asking questions in a way that skewed the answer in an unfair way. I began to cry." Amanda felt her integrity was being questioned: "When you're struggling with your mental health anyway, for someone to almost call you a liar is really hard. It was a horrible experience."

Despite Amanda's obvious distress the assessor pressed ahead with her questions: "She clearly just wanted to get me out of her office, and she promised to get me a cup of tea when we were finished. As soon as she got me back into the waiting room, she left me to cry on my own. She never brought a cup of tea."

Waiting for a decision on her PIP application, Amanda's mental health spiralled: "The stress of the assessment on top of what was already going on in my life was too much. I tried to take my own life less than a month later and ended up in hospital for a week."

It was while in hospital that Amanda heard back about her application: "I received a text to say that I had been granted the lowest level of PIP. It was too late then though – I had made a serious attempt on my life and had thought I was going to die."

Amanda does not think the DWP knows the details of what happened to her, but she isn't convinced that, under the current system, it would have made much difference to tell them: "At the moment it seems that's just the way it is, and everyone knows that this is the impact it has. And it feels like - whether it's true or not - they don't care."

Why the DWP is often not made aware of incidents of harm

In over half the incidents of harm reported to us (63 out of 122), the respondent did not think the DWP was made aware, including 35 incidents that mentioned a suicide attempt and/or self-harm.

Our survey responses and the stories shared in this report strongly indicate that many people do not believe it is worthwhile raising concerns with the DWP as they fear they will suffer negative consequences:

"I have not made an official complaint because it is too stressful and often leads to nothing."

"I'm too afraid of further retaliation to say anything."

We asked the respondents we interviewed whether health and social care professionals who supported them during their mental health crisis had raised with the DWP the harm that they had caused, but most did not think this had happened. We are not aware of any formal reporting mechanisms for health and social care professionals to easily raise concerns with the DWP about incidents of serious harm.

It is clear from our research that many incidents of serious harm are not being picked up by the DWP and are therefore not investigated. This seems partly due to the lack of integration with other services as well as a lack of faith among those affected that raising concerns will lead to any meaningful action from the department.

The DWP has not offered clarity about what constitutes serious harm and has done little to publicise the existence of IPRs. Nor has it shown to claimants, families or those professionals who support them how concerns raised through the IPR process can lead to meaningful improvements in practice. It is therefore not surprising that many cases go unreported, which means that opportunities to learn lessons are also missed.

Rochelle's story

Rochelle was told that she had to pay back thousands of pounds to the DWP after their own errors resulted in her being overpaid Universal Credit. She tells us how this experience caused her to have a mental breakdown and feel suicidal.

Rochelle was receiving Universal Credit when, in 2016 at the age of 22, she applied to study an undergraduate course at university. She informed the DWP through the Jobcentre that she would be studying full-time and would be in receipt of student finance: "They should have reassessed my claim and adjusted it according to the income I would be receiving."

However, a few months after starting her course, she was told that there had been an error in her payments: "I received a letter from the DWP informing me that they had overpaid me by around £2,000. After making further enquiries about why this overpayment had been incurred, it turned out they had not adjusted my claim for my changed circumstances."

This came as a huge shock to Rochelle, especially as she had queried the amount of Universal Credit she'd been receiving when she started the course: "The advisor I spoke to at the DWP said I was receiving the correct amount." She was told the overpayment would be deducted from subsequent benefit payments in instalments, even though it had not been due to her doing anything wrong.

However, the situation got even worse the following year, when she heard from the DWP again: "I was advised I had been overpaid again by approximately £10,000. This overpayment was due to the DWP losing paperwork I had shared with them, and not communicating that the original overpayment had increased by roughly £8,000."

With this huge debt hanging over her while she tried to complete her studies and support her three-year-old son, Rochelle's mental health suffered: "My doctor had written a letter to them to tell them how much I was struggling but they didn't take that into consideration. I just felt really worthless, and there was a point where I wanted to take my own life."

With the support of her university and her local MP, Rochelle did manage to get the DWP to acknowledge that the overpayment was their fault. However, she only received £100 in compensation, and was still required to repay the outstanding debt: "Irrespective of who caused the overpayment, the law says that the person who received it has to pay it back."

Although Rochelle managed to complete her degree and start a job, she was still living in the shadow of the DWP: "They put me under increasing pressure to pay back the debt, which had now increased to £13,000. A few months later, they took £244.00 directly from my wages, leaving my son and me financially destitute and having to stay with family. My mental health deteriorated, and I made a threat to end my life."

Four years on, Rochelle eventually managed to get the DWP to waive part of the debt, but she is still paying back the remainder, and managing the longer-term impact on her mental health: "My confidence has really been knocked, and my willingness to reach out for help."

My confidence has really been knocked, and my willingness to reach out for help.

Conclusions from our research

The evidence from our research supports the conclusion of our previous report, '*Tip of the Iceberg? Deaths and Serious Harm in the Benefits System*', that there are likely to be many more incidents of serious harm, and even death, that the DWP is not investigating.

IPRs are the main tool at the DWP's disposal for investigating incidents where their actions may have caused harm. However, it is unclear when IPRs should be triggered, whether clear cases of serious harm have resulted in an IPR, and how effective the process is at addressing issues that are uncovered.

Claimants, their families and professionals are often unaware that the IPR process exists. There is no clear route to request an IPR and when IPRs do take place their existence and findings remain secret, including from the people directly affected.

The consequence of these failures is that opportunities to prevent deaths by suicide as well as other severe consequences are almost certainly being missed.



Six conclusions from our research:

Cases of death and serious harm related to the benefit system are a current issue not a historical one. Almost three-quarters of those who provided dates said that the incidents occurred in the last five years. While respondents mentioned a range of interactions with the DWP that caused harm, problems around applications, assessments and appeals were by far the most common cause.

Our survey provides further evidence that the DWP is not instigating IPRs as often as it should be. Our relatively small sample found more than 50 cases that met the narrowest reading of the DWP's definition of serious harm and many other cases that could reasonably be considered as serious harm. Almost half of respondents said that the DWP was aware of the harm they experienced. That a department with almost 100,000 staff members, supporting millions of individuals, found only 31 serious harm cases to investigate between July 2019 and December 2021 suggests that existing systems for identifying and investigating cases are insufficient.

3 In particular, the DWP is failing to investigate cases of serious harm that do not involve a death. While five respondents to our survey related to a friend or family member who had died by suicide, more than 10 times that number reported harm that meets the narrowest reading of the DWP's definition of serious harm. This is in line with what we know about the wider incidence of mental health crises, self-harm and attempted suicide compared to deaths by suicide. Yet, between July 2019 and December 2021, there were almost four times as many IPRs focused on deaths compared to serious harm. The proportion of serious harm cases compared to deaths in our survey suggests there should have been hundreds of serious harm IPRs over this period rather than the 31 that the DWP conducted.

Many cases of serious harm do not get reported to the DWP. Although almost half of our respondents believed that the DWP were aware of the incidents they reported to us, the majority had not notified the department. This was often because they did not think it was worthwhile to do so, with few aware of the IPR process, and in some cases because of a fear of victimisation. As well as claimants not reporting cases, there is no dedicated route for other services, such as the NHS, to report relevant incidents of serious harm to the DWP investigation.

The definition of serious harm used by DWP is unclear. Many of the incidents reported to us involved a significant mental health crisis, often to the point of the person feeling suicidal. Because of the DWP's unclear definition of serious harm, we cannot be sure how decisions are made about when an IPR should be triggered under the current process.

There is nothing wrong in principle with a broad definition of serious harm that can cover a wide range of individual circumstances. However, when combined with a lack of published guidance or official analysis of cases, trends, recommendations or improvements delivered to processes, it adds to the impression that the IPR process is opaque and unaccountable.

Lessons should be learned from incidents that do not trigger an IPR. Incidents reported to us that may have fallen below the DWP's threshold of 'serious harm' often involved the benefits system having a sustained negative impact on people's mental health. Whether or not IPRs are the right response in such cases, these cases raise wider concerns about the mental health impact of interactions with the benefit system and whether enough is being done to address this.

Implications for a future public inquiry

While significant work will be needed to develop the terms of reference for any public inquiry into benefits related deaths and serious harm, the findings of this report suggest some questions that could be investigated around the DWP's processes:

- How have IPRs been used and how have relevant cases have been identified and selected?
- Have IPRs led to meaningful changes in the DWP's practice?
- How does the DWP define serious harm and apply this definition in practice?
- How has the DWP responded to incidents that do not meet the definition of serious harm but involve a significant deterioration of someone's mental health?
- How have incidents of serious harm and more general deterioration of people's mental health been monitored and reported and how this could be improved?
- How has the fact that the DWP does not consider itself to have a statutory duty of care to claimants shaped its policies and practices?

The horrible irony is that the DWP decided that trying to take my own life was enough proof that my condition hadn't improved, so I was allowed to stay on the same benefits.

Maria's story

While struggling to stay in work during 2018, the DWP decided that Maria should be reassessed for her benefits. The possibility of losing her financial support resulted in Maria attempting to take her own life. While the DWP were aware of this, it is still unknown if IPR took place.

Maria was on Universal Credit and was not required to look for a job but she wanted to work and kept trying to find suitable employment: "I'd be in a job for about nine months or so and then the wheels would just come off and I'd end up with a catastrophic crisis and find myself back in hospital."

In 2018, Maria was 28 and working in a coffee shop when she began to struggle with her mental health again: "The cracks were starting to show and I was thinking I needed to cut down my hours". At the same time, the DWP decided to assess her health again and called her in for a WCA.

Maria became terrified that the DWP would declare her 'fit for work' just as she was feeling she needed to step back from working: "I was faced with what seemed like an impossible dilemma - I can't work because I feel too unwell, but I'm worried I'll be seen as not unwell enough to stay on my current benefits."

Worried that she would be left destitute, Maria tried to take her own life: "I don't have any contact with my family so the state is my only safety net. I couldn't cope with the prospect of having that one bit of security ripped out from underneath me."

Due to this this suicide attempt, Maria was in hospital when she was due to have her Work Capability Assessment: "The horrible irony is that the DWP decided that trying to take my own life was enough proof that my condition hadn't improved, so I was allowed to stay on the same benefits".

Looking back now, Maria feels that better communication from the DWP could have helped to avert the crisis she experienced: "Having a specific point of contact in my local area, from a team of people who understand mental health would be a godsend. I've had good interactions with some individual members of staff, but there's no consistency."

Maria feels the constant threat of a difficult interaction with the DWP undermines her efforts to improve her mental health: "I'll be making good progress and then even just getting the brown envelope through the letterbox or an alert on my Universal Credit journal can make it feel like that progress is thrown out the window. It makes my life a rollercoaster."

Maria thinks the system is not flexible and understanding enough to provide the support and security she needs: "I want to work but it seems like I'm in this all or nothing situation where I'm either expected to work full-time and be fine or prove that I'm too unwell to work at all."



Recommendations for the DWP

The evidence presented in this report strengthens the view we set out '*Tip of the Iceberg*' that **the government must:**

- 1. Establish a full public inquiry into benefit related deaths and cases of serious harm.
- 2. Set up an independent body to investigate future cases of death or serious harm in the benefits system.

After many years in which information about serious harm and deaths has only come to light because affected families have taken cases to the courts and the media, a public inquiry is vital to reveal the truth of what has happened, give justice to those affected and establish the lessons to be learnt. Similarly, when we know that many people affected by these issues do not trust the DWP to investigate them, only an independent body with a remit to review future cases can truly provide the confidence for those affected and wider society.

This report has identified **six immediate changes below** that the DWP should make to improve the effectiveness of the IPR process, to improve the experience of people who report incidents, to increase transparency and accountability and to drive wider change to the way the benefits system works. While these recommendations should ultimately shape the remit of the independent body to investigate future cases, we have framed them here as changes that could be immediately delivered by the DWP to ensure there can be no excuse for inaction.

Six immediate actions required

- The DWP should inform claimants, their appointees and where there has been a death the next of kin about whether an IPR is taking place. They should also inform them of any recommendations they make and progress on delivering those recommendations.
- 2 The DWP should publish annual reports on the IPRs that it has conducted. These should include statistics on the characteristics of the cases examined and the people affected (including the type of harm experienced, and the aspects of the benefit system associated with the harm), anonymised case histories, analysis of issues and trends in incidents of death or serious harm, a list of the recommendations made by IPRs and an assessment of the extent to which previous IPR recommendations have been delivered.
- The DWP should establish a simple process by which incidents of suspected death or serious harm associated with the benefits system can be reported. This includes reporting incidents online, by telephone or in person at Jobcentres by claimants or by their family, friends, appointees or professionals working with them. This system must inspire confidence that incidents will be investigated effectively, and lessons learnt, without fear of recrimination for those who report cases.
- Once a new reporting process has been set up, the DWP should write to all to claimants and professionals who work with people supported by benefits, setting out the IPR process. They should show the value of reporting cases of death or serious harm that may be linked to the DWP for learning lessons. This information should be communicated routinely with claimants, including when a new claim is made. While it is particularly important that those who mention potential harm to the DWP are told about the process, it is vital that this information is widely available since we know that many claimants do not currently report harm.
- 5 The DWP should provide a clearer definition of what constitutes 'serious harm'. They must strengthen and clarify guidance for their staff about the nature and process of cases that should be referred for an IPR. Where cases later come to light in which it is found that earlier opportunities to instigate an IPR were missed, this should be considered a serious and potentially disciplinary matter for the staff or services in question.
- The ratio of cases should be monitored as an indication of how effectively relevant incidents are being identified, as it is reasonable to expect there to be many more investigations into serious harm than deaths.

The Covid-19 Mental Health Recovery Plan shows that ministers understand that supporting people living with mental illness is a task for the whole of government, not only the NHS, just as there is a role for all of us in creating a society where people living with mental illness can thrive. However, it clear that in too many cases, the way in which the DWP interacts with those who need financial support works against that goal.

We are confident that that benefits system can be improved to work far better for people living with mental illness. A crucial first step is for the DWP to be open and honest in understanding what has gone so badly wrong.

Stuart's story

Stuart was given zero points at his health reassessment in 2012 despite the fact that he was unwell. This had a devastating impact on his mental health and resulted in a suicide attempt. While the decision was overturned at appeal, Stuart says it has caused him long-term damage.

Stuart has experienced depression and anxiety since he was a teenager. More recently, he has also been given a diagnosis of autism. In April 2012, when he was 34, he was asked to attend a WCA to decide if he was still eligible for ESA.

The assessment was conducted by a physiotherapist, rather than someone with mental health expertise. Stuart felt that he did not get the opportunity to explain why his mental health made it difficult for him to work, and that his words were being twisted: "I felt like they were committed to misunderstanding me from the very beginning."

A couple of months later, Stuart received the outcome of his assessment - he had scored zero points and had been declared 'fit for work', despite additional evidence provided by his consultant psychiatrist and his GP: "It was a huge shock and it took me a long time to process. But once it sunk in, my anxiety went off the scale and my depression came back really badly. I'd lie on the sofa every day and cry for hours."

Stuart used diazepam to control his anxiety: "My partner doesn't live with me but she was scared to leave me alone in case I did something dangerous". On one occasion he took an overdose and ended up in A&E. Although Stuart's psychiatrist and GP knew about this incident, he doesn't think the DWP were made aware: "They've never understood the impact of all of this." Stuart asked the DWP to reconsider the outcome of the assessment, but they stuck with the original decision. He had to take the case to a tribunal, but this did not take place until November 2013, causing a long and uncertain wait.

Stuart's partner, Kat, remembers the day of the tribunal: "It was obvious that Stuart had quite severe difficulties with things like communication and everyday tasks. The tribunal quickly awarded him over 40 points." Although this was a huge relief, it also highlighted how unnecessary the previous 18 months of distress had been: "It made our lives a living hell. It was so traumatic to see someone you love go downhill so fast."

Fortunately, Stuart has had support from advice services with subsequent reassessments and has not had to appeal the outcomes. However, his experience back in 2012 has had a lasting impact: "I'm still angry to this day it's had a knock-on effect for years. Before the assessment I was studying and doing well - without this experience I would have been able to stay in education and work towards a qualification. They've pushed me away from work."

Even though he now feels better able to navigate the assessment process, he believes it is inherently damaging: "It assumes that you're lying. You have to try to prove that you're not well, and that feels so degrading."

Before the assessment I was studying and doing well - without this experience I would have been able to stay in education and work towards a qualification.



Please see below for to sources of advice and information, as well as where you can find a list of crisis support organisations.

- Relating to suicide: rethink.org/suicidalthoughts
- Relating to self-harm: rethink.org/self-harm
- If you are currently in a crisis or know someone who is, please visit our crisis support pages to find out which organisations can provide the most appropriate support depending on your circumstances: rethink.org/helpnow
- Advice on benefits: visit our Mental Health & Money Advice service for practical support if you are experiencing issues with welfare benefits. You can find out what financial help is available and how to make a claim or appeal: mentalhealthandmoneyadvice. org/en/welfare-benefits/
- If you have had a similar experience please let us know at campaigns@rethink.org

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Leading the way to a better quality of life for everyone severely affected by mental illness

For further information on Rethink Mental Illness

Telephone: 0300 5000 927 Email: info@rethink.org

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