DEATHS BY WELFARE PODCAST - TRANSCRIPT

Episode 3: 'Death of a Customer'

Intro music by Rosemary Moss, with audio testimonies from the 'Right to Record' action group, collected by Hannah Kemp-Welch:

"If it's a benefits thing, I'm in a terrible state"

"Yeah, I could have cried, and thought, what's the point?"

"They're judging you and..."

"They're just gonna say no to everybody and it's your... down to you, to fight it."

"Don't want him to bring the bad news, after bad news, after bad news."

"I don't need to be in constant fear any minute my support's gonna be taken away"

"The system we rely on to keep us alive, seems to want us dead. We've tried petitions, letters, emails and treaties, protests, road blocks, questions in Parliament to UN reports, countless reports. But they refuse to change the system that puts us in harm's way."

[00:00:44]

CHINA: Welcome to the Deaths By Welfare podcast. This podcast is produced by Healing Justice London, and is part of our wider Deaths By Welfare project, investigating deaths caused by, and linked to, the welfare system, welfare reform, and the violence of state austerity. I'm your host, China Mills. You're listening to the Deaths By Welfare podcast.

From 2012 onwards, local newspapers—and occasionally national newspapers—started reporting on inquests and accounts from families of how their relatives had died after encounters with the UK welfare system. In the summer of 2014, Disability News Service—the UK's only news agency specialising in disability issues—as well as a number of disabled people's anti-austerity campaigning groups, began to question what the government knew about these deaths, and whether the Department for Work and Pensions had a system for recording deaths linked to lethal flaws in the benefits system.

[phone rings]

[00:01:52]

CHINA: It's taken a long battle, largely fought through Freedom of Information requests, to learn more about the government investigations known as Internal Process Reviews, or IPRs, and previously called Peer Reviews.

DWP ANSWERING MACHINE: [repeated and overlapping] "...the Department for Work and Pensions. Your call me be monitored or recorded for legal and training purposes, and to help us improve our services."

[00:02:14]

CHINA: The Internal Process Reviews is important, because it's a government tool, through which to investigate if DWP activity may have contributed to a claimant's death.

This episode is about the fight that has gone into exposing the investigations the DWP does into what it calls the death of a "customer". We'll be joined by John Pring from Disability News Service and Imogen Day, whose sister, Phillippa, took her own life in 2019 as a result of welfare state violence.

—Music—

[00:02:57]

CHINA: In the first few days of January 2021, I plucked up the courage to email John Pring at Disability News Service. I'd been reading John's work for years, and knew that there could be no Deaths By Welfare project without his expertise. John is a journalist, and a disabled person, with over a decade of experience researching the impact of state austerity on disabled people.

—Cuts to interview with John—

What is publicly known about the largely-secretive investigations carried out by the government into people whose deaths have been linked to the welfare system is really, largely, the result of disabled-people's and bereaved-families' campaigning and resistance. This story of their work, and the labour that has gone into exposing these investigations, is rarely told, but I think is so important.

John, you, through Disability News Service, have played such a key role in what has become, basically, a Freedom-of-Information battle to learn more about what the government knows and does about people's deaths. So how did you come learn about these deaths that are linked to the welfare system, and to start investigating them?

IMOGEN: It all started, really, from the activism from disabled people, and user-led research, in the early 2010s. Once the implications of the impact of what was happening under austerity was starting to be felt, disabled people started to realise what was going on—because it was happening to them, and it was happening to people they knew, and their friends.

So there were protests. I think the first protest I went to in 2010. I think it was Mad Pride organised something in London. And then there was research reports from Disabled People's Organisations. It all started to emerge gradually. 2010, 2011, 2012: that's when it really started to pick up. In 2012 and 2013, local newspapers started reporting on inquests and accounts from families of how their relatives had died, often, when left destitute.

Because I was reasonably slow to really picking up on this, and I think it was summer of 2014 that I started to get myself in order, and started to question what the DWP knew about the deaths, what records were kept, how it responded to those deaths. And particularly whether the Department for Work and Pensions had a system for recording deaths that were linked to these lethal flaws and failures in the benefits system. I had a lightbulb went on, and thought, 'Okay, let's see what they do when they get a death; how they record it.'

And they started denying that they had any way of doing it. And I think it was a Lib-Dem minister—I think Steve Webb, who was a Pensions' Minister, so he didn't really have much to do with this, but—the Conservative Minister-for-Disabled-People, Mark Harper, had said, 'The DWP's right to ignore these kind of deaths. We don't keep details; we're right not to do so.'

But then, the following week, at the Lib-Dem Party Conference, Steve Webb insisted that, 'When these cases come up—clearly, when we're aware of cases—they do get looked at.' And it was then that the DWP finally admitted that they did investigate some benefit-related deaths. And then the Freedom-of-Information started with trying to find out how they did this, how many, when, 'Can I see them?'—all those kind of things. And then, that started

that ordeal of trying to squeeze information from the DWP, which is just… I wouldn't recommend it to anybody.

[00:06:34]

CHINA: So I was thinking about, in… I think it was in October 2014; there was a response by the Department for Work and Pensions—and you covered this in Disability News Service—where a spokesperson, and I quote them, said, "Where it is appropriate, we undertake reviews into individual cases, but we do not accept the argument of those who seek to politicise people's deaths by linking them inaccurately to welfare policy."

I was always so struck by that, and also really struck by… And this isn't just my response; I can remember that Pat Onions—the founder of Pat's Petition, which has played a key role in campaigning for the end of cuts that disproportionately impact disabled people—told Disability News Service, "We're very disappointed the DWP would suggest that this politicises peoples deaths, especially for cases where those people have left clear notes, or there's evidence that implies that welfare reform itself is specifically a root cause of their ongoing worries and mental health problems."

JOHN: Yeah, it was just one of the many tactics that the DWP used: suggesting that this is all just a political gambit to get at the Tory party. Which, just—it wasn't.

[00:07:53]

—Narration—

CHINA: DWP internal guidance, made available because of Freedom-of-Information requests, states that the Internal Process Review—the IPR—is a factual account of events without opinion or judgement, and is therefore not, to quote them, "a mechanism to be used to seek out or apportion blame."

In relation to deaths-by-suicide of claimants, the DWP says that, "IPRs do not come to a judgement as to whether benefits-related issues were the cause of the suicide, but instead, scrutinise departmental processes." What makes IPRs a significant focus is that they are supposedly the main tools through which the

DWP investigates the harms of its own policies. And yet they're designed and carried out in a way that systematically invisibilises state accountability.

In an investigation carried out by the National Audit Office in 2020, they found that access to the Internal Process Review reports is restricted to the team handling them, and that recommendations made from IPRs are not tracked or monitored, meaning the DWP doesn't know whether the suggested improvements from the reviews have been implemented. Despite multiple FOI requests, the DWP have never made public any information about whose deaths have been investigated—not even to most of the families of those who have died.

Another important part of this story, alongside the activism of disabled people, has been the warnings from coroners.

JOHN: The first coroner's report was the following year; so it was the Peer Reviews that came first, and then the first coroner's report came in the next year. I think, again, it was just another lightbulb that came on: I thought, "Well, surely coroners are hearing these cases—and what are they doing about them?" And then, I think I tried to get something from the Coroner's Society, trying to find out from them whether there was anything that they were aware of nationally, and again: they just don't don't talk to journalists, really.

But I think there might have been some guidance about prevention-of-future-deaths reports, which were very, very low-key at the time. And then I found this database, that was very low-profile at the time—I think it was on the Ministry-of-Justice website—that had all the prevention-of-future-deaths reports. Or, certainly going back to a certain period. I think I spent a weekend just trawling back through them, over about a year, and found one that was the awful death of Michael O'Sullivan.

And it showed the coroner making what you call a prevention-of-future-deaths report that, basically, is sent to the DWP—was sent to the DWP—saying, "I believe that your actions were partly responsible, and you need to take action to prevent further such deaths." And this was the death of Michael O'Sullivan, which did create some waves when that came out.

[00:11:01]

—Narration—

CHINA: Michael O'Sullivan died by suicide in September 2013 after being found fit-for-work and ineligible for Employment and Support Allowance: ESA. At his inquest, the coroner concluded that the trigger for Michael's suicide was his assessment as being fit-for-work. The coroner wrote a prevention-of-future-deaths report to the DWP, saying that there's a risk that future deaths will occur unless action is taken. At the time, this was thought to be the first of its kind.

JOHN: Later on, it turned out there were some other cases that weren't quite so easy to track down, and it showed that another coroner, several years earlier in 2010—so just before the coalition government started in 2010—another man called Stephen Carré had taken his own life in 2010. Again, the coroner had linked that, at the subsequent, to the Work Capability Assessment, and had written a prevention-of-future-deaths report to the DWP.

So, years before Michael O'Sullivan's death, a coroner had said something very similar to the DWP: "Change this assessment, or further people will die. Make these changes, make this safer, or other people will die." And then, years later, we find out another coroner says exactly the same thing, proving that the DWP... They didn't do nothing, but they did almost nothing. They didn't take measures they needed to take. That was the second element: the Peer Reviews, and then the Coroners' Reports. It's all building up on top of all the activism and disabled people's research; it's all building up into a giant pile of evidence.

Between July 2019 and June 2022, there were 151 IPRs—Internal Process Reviews—completed into deaths and serious harm. Roughly 20-a-year to roughly 50-a-year. And I think that's down to activism. Disabled people have just kept banging on the door, and saying, "Do something about this." They can't carry on pretending that there are only 20 deaths that were linked to their actions. Because they're supposed to carry out an Internal Process Review for every single suicide of a benefit-claimant they hear about. And there are hundreds of suicides of benefit-claimants every year. So it was just completely impossible for them to carry on holding their ground on that.

[00:13:36]

—Interview with John—

CHINA: A lot of what we know about how the welfare system harms and kills people, and the government denial of accountability, like you say John, has come from disabled people, and also come from the campaigning of families who have lost loved-ones.

—Cuts to narration—

[00:13:52]

CHINA: And we're so grateful to be joined in this episode by Imogen Day. In 2013, Imogen's sister, Philippa—Pip—took her own life. Her disability-benefits had been stopped, and she'd been told she had to attend a face-to-face assessment. Despite being exhausted and worn-down, Phillippa fought the system. At her inquest, a recording was played of a phone-call she made to the DWP, saying that she was starving and cold, and that she literally needed a reason to live.

Phillippa's suicide note, which lawyers at her pre-inquest trial implied Imogen had written for political gain, directly implicates the DWP. Phillippa knew the violence she experienced was systemic, and her sister Imogen has continued Pip's fight, coming together with other bereaved families to demand a public inquiry into benefits-related deaths.

—Cuts to interview with Imogen—

[00:14:52]

CHINA: I think at the heart of this battle to learn more about governmental reviews into deaths has been your family, Imogen, and your battle with the system over your sister Phillippa's death. Maybe, before you tell us about this: I'm just really conscious that our podcast, and this wider work, is really focused around people's deaths. And I think a lot of thought has gone into this strategically to try and build solidarity, and push for change, mobilising around people's deaths; but each person's death, obviously, represents a life; and a life of human beings, whose non-negotiable dignity has been systematically challenged by brutal systems.

And so, Imogen, I wondered: would you mind, before you tell us a bit more about Phillippa's encounters with the system, and experiences, and your just-incredible campaigning and resistance afterwards, would you tell us

something about Phillippa, and about her life? Maybe something about what brought her joy?

IMOGEN: [laughs] So many things brought her joy. She was a really, really happy, kind person. She loved her friends; she loved just engaging with different people. She was always the first person to give a homeless person a cigarette, and would sit and chat with them. She cared so much; she had so much empathy for the world. And yeah, she was just a really, really kind person. I think playing with her son brought her the most joy. I've never seen a mum engage with her child in such a playful way before, and it was a true pleasure watching her bring him up.

She always had DLA, because she was a Type-1 diabetic, and she was diagnosed... I think it was either 18- or 21-months with that. So she'd always grown up receiving Disability Living Allowance, and hadn't really had any issues with that until she transferred from Disability Living Allowance to the Personal Independence Payment. And I think the system just broke her heart repeatedly, in so many different ways. She said to her community psychiatric nurse that she just felt like a National Insurance Number.

And during her engagement with them, she was on a mental health ward at the time as an informal patient, for the majority of her assessments, and the majority of the process. And when I would go to visit her, there was one time where she was crying to me, and she just asked me, "This is gonna kill me. This process is going to kill me, and when it does, you need to fight for me. You need to fight for the others."

She was aware that it was happening as a systemic issue, and she just couldn't do anything to stop it; she tried her hardest to engage with them, using both their CPN, her family members; and considering her intense mental health struggles, she called them on multiple occasions. I mean, there was a recording that released in the inquest where she was saying that she had no food, no heating; she was really struggling.

And at the end of the call, she still said thank you. She still thanked the call handler; it just repeatedly broke her in so many different ways. And my sister was an incredibly strong woman. She'd faced a lot of adversity and come out the other side of that. And yeah, this just destroyed her. There were so many different...

The coroner outlined that there were 28 different mistakes in that application in the way that she was treated; and that's her heart breaking 28 times. You can't expect any human being to suffer through that and still try and survive.

JOHN: It was almost: with Pip's experiences, that everything that was going wrong with DWP was encapsulated in what happened to Pip, having gone wrong over the years—that culture of hostility within DWP and its assessors: the poor training, the poor record-keeping; the refusal to make the process safe and accessible; the systemic-

IMOGEN: It was the perfect storm.

JOHN: Yeah. Yeah.

[00:19:00]

CHINA: How did you come to know that a review had been carried out into Phillippa's death, and how did that happen?

IMOGEN: I come from a research background. I did my undergraduate degree in politics, and my Master's in Domestic and Sexual Violence; so when Pip died—and obviously I was aware, anecdotally, that this was a systemic issue—I spent a really long time researching; discovered that Internal Process Reviews existed, but were not published. I happened across most of the information on John's website, to be honest, and through Liberty.

I didn't have legal representation for the first Pre-Inquest Review; me and my parents were having a little bit of a disagreement about whether or not it was needed. During the first Pre-Inquest Review with our wonderful coroner, Mr. Clow, I let him know that there were Internal Process Reviews, and that I wanted to see it. And I don't think that the DWP's legal team were expecting: a) me to be aware of it; and b) to be quite so openly hostile—quite professionally; I still maintained professional boundaries, and dignity, and all of that.

But yeah, it was a very interesting Pre-Inquest Review that led me to get legal representation for the rest of it, because I just knew that, even though I had all of this knowledge, and all of this background, I'm not legally trained, and I needed help to continue to fight this. And that's when Merry Varney of Leigh Day came on-board, and she was absolutely fantastic; I had nothing but love for her, and we still communicate regularly.

The only word I can use to describe it is utterly exhausting, because not only do you have the obvious grief, and heartbreak, and turmoil over losing a loved one, there's also this impossible anger at the fact that: a) it was preventable; and b) that it's a systemic issue that the DWP are more than aware of, and have made very small attempts to correct.

JOHN: And you opened the doors for other families as well, because I'm pretty sure you were the first family to get hold of an IPR; of an Internal Process Review.

IMOGEN: We were; we were the first person to get one. And it was only that previous ones that had all been released were heavily redacted, and there was only one redaction through ours; and we did[n't?] [00:21:20] mind. But yeah, we were the f... And that's in 2020: we were the first family—in fact, it might even have been 2021—to receive an IPR, seven years after the knowledge of them became public.

JOHN: Yeah. And they're now saying, officially—DWP; I had a Freedom-of-Information response—that families should be able to now get them as long as you put that in through... Executor-of-the-will, I think, is the right person to do it, or something. I mean, they're still making it difficult, but they are...

That's the first time they've admitted that that they should be releasing them. And I'm sure that's down to you; and other families, but particularly to your efforts.

[00:22:03]

CHINA: I mean, it's just incredible that it took you to have to draw on those skills and expertise that you already had in research to find out about that, and that's how that happened. I mean, wow! Okay.

And so, can you tell me: How long was it, the process of getting to see that?

IMOGEN: Oh, it was exhaustive: we had our first Pre-Inquest Review in the summer of 2020, and the inquest itself didn't begin until January of 2021, and that was around the time that the IPR was released. [laughs] Because both me and John argued quite heavily for it to be in the public domain.

Yeah, it was an incredibly long process: at least nine months of requesting it; asking for it; informing the coroner that we needed it, and that he needed to see it as well. And it was just absolutely fascinating when the coroner would ask for these different reports, these different things: the lawyers would, firstly, deny their existence; and secondly, say that they couldn't release them without express consent from the much-higher-ups.

Yeah, the entire inquest felt like they were trying to gatekeep what information: a) we as a family could have; and b) what the coroner could have, even though of all the legal rights that he has to see everything.

[00:23:21]

CHINA: What difference did it make to see that? What was it like to see that Internal Process Review, and look at that kind of evidence? I suppose.

IMOGEN: It was painful, but necessary. Because we as a family, we needed to know that there was nothing else we could have done; we needed to know that there were these external forces at play here. So yeah, it was painful, but definitely necessary for my own grief-recovery.

[00:23:46]

CHINA: And presumably, then, so many families just don't even know if one was carried out into their loved-one who's died, right?

IMOGEN: Absolutely. And I can't imagine the pain of that; of having all of those... Having the Internal Process Review silenced my night-time questions, right before I was going to sleep; of, "Could I have done more?" "What would have happened if I had done x?" And I really feel for families that still, obviously, have those going-to-sleep anxieties, and don't have answers.

JOHN: Yeah. Are you saying that's because... it silences those questions because you realised there was nothing you could have done?

IMOGEN: Yeah. Yeah.

JOHN: It was just... DWP was just a machine out of control.

IMOGEN: It made it incredibly clear that we as a family had done everything that we could have done, and that it was a governmental system that had let her down.

[00:24:42]

CHINA: Do you have a sense of what role that evidence, that was in the Internal Process Review, played in the inquest more broadly? Could you tell us a bit about the inquest, and what's come after that? I suppose.

IMOGEN: Yeah. It felt like a battle from-start-to-finish, of being, "We know this information's available; please give it to us, and please look into it." It was just such a long, drawn-out process. It felt like we had umpteen Pre-Inquest Reviews, and there isn't supposed to be more than one—or, maximum, three—to ascertain what information we could have; what information the coroner could have. And it felt like the DWP's legal team was just desperate to keep all of the information themselves, and not distribute it.

Not only is an inquest an incredibly drawn out legal process, it was so emotive; there were so many different feelings that were floating around for, I think, everybody. We all had huge trigger-points of, "This is horrific." And yet, we had to do it; we had to show up for her.

[00:25:52]

CHINA: Can you say a little bit more about Capita, and what the involvement is here, in relationship to them?

IMOGEN: Capita are the DWP's outsourced partners, and they do a lot of the busy work, and some of the assessments; and they handle a lot of the calls that come through regarding payments, and questions that they might have. And there is no communication between Capita and the DWP itself. And that was the main issue in the inquest: was—things are being told to Capita, and then Capita was not informing the DWP of different phone calls that they'd had with Pip's CPN, or things like that.

And that was one of the main proponents of the inquest, was that the communication between them was sorely lacking.

JOHN: And we need to point out, also, that all this applies to Maximus (that carries out the Work Capability Assessments now) and also ATOS (that also carries out other PIP assessments in other parts of the country). And ATOS, in the early years, was doing the Work Capability Assessments that Maximus later took over; and ATOS was right at the heart of all this.

I guess, maybe that's the only accountability that's ever taken place: is that they pulled out of the contract—the Work Capability Assessments—because they'd just done such an awful, terrible, harmful job. It's not really accountability, is it? I guess.

[00:27:14]

CHINA: And some of that internal guidance in documents that have become available through Freedom-of-Information requests to the DWP (many of which have been submitted by you, John), the way that they talk about what Internal Process Reviews are, I think, is quite interesting, their wording of it. So they say things like, "The Internal Process Review is a factual account of events without opinion or judgement; it's not a mechanism to be used to seek out, or apportion, blame; does not come to a judgement as to whether benefits-related issues were the cause of suicide, but instead scrutinises departmental processes."

When we're talking about accountability, there's something really interesting about how the DWP frame their very mechanism for investigating and reviewing.

JOHN: Desperation not to be any accountability.

IMOGEN: Mm.

[00:28:05]

CHINA: Yeah. Like, the design of it is designed not to see that accountability, I suppose, in some ways.

JOHN: Yeah. Also, I know one of the things we've talked about, China, is whether this happened by design or by mistake. And it's not by mistake; they've been told this by disabled people, by coroners, by their own Internal Process Reviews; they've been told it in parliament, on the streets, by activists, by researchers; the warnings and deaths in the 1990s.

God! There was a clinical psychologist, who spoke to me a few years back, who worked on the Work Capability Assessment in the 2000s (so in 2006, or something), and he said at the time that everybody thought that the new Work Capability Assessment would damage people. He said it was barn-door obvious it was never going to work, and it was always going to be very stressful for people. His impression, right from the very beginning, was that the DWP was reckless, and insistent about that direction it was going to take.

It's continued over three decades. That was kind of right in middle of it, but the evidence is all there. And now they're refusing to carry out research into the impact of their policies: they don't want the proof of what they're doing to people.

IMOGEN: Well, it gives them plausible deniability.

JOHN: Yeah. It's indefensible; completely indefensible. This is a department that's built on indefensibility. That's the core of all these problems over the years: is that they've never co-produced anything they do with disabled people. If they'd done that 30 years ago, none of this would have happened. That's the great tragedy of all this: if they'd listened to disabled people 30 years ago, none of this would have happened.

IMOGEN: Yep.

[00:29:33]

CHINA: Something that has really struck me, the more I've delved into some of the internal documents from the DWP, and all of the bureaucracy around this, is that this isn't just something that you can see in retrospect. It isn't just something of, "Well, the privilege of looking back, and seeing that something's going to harm people;" actually, there is evidence of this all the way along. Really early, the DWP's own research-reports, finding that this... Almost a prophecy of the harm that's to come, as well as disabled people forewarning this long before some of the deaths actually happened.

JOHN: Yeah. Absolutely, absolutely. It was all there.

IMOGEN: And that's what breaks my heart: is how preventable all of this was. Every single death was preventable. And not preventable by the families, not

preventable by peer-support, or anything like that; it was preventable by the system.

JOHN: Has there been any accountability for anybody over the last 30 years? A single person: a single senior-civil-servant, outside-advisor, or senior-politician; who has been held accountable for any of these deaths?—None. There's been no accountability ever. Not even a resignation; there hasn't even been a resignation.

[00:30:57]

CHINA: It's like: What would accountability, or could accountability, look like?—for both Phillippa's death, but also the so-many other deaths we've seen.

IMOGEN: So for me, accountability means an apology, an explanation, and proven change; and I think they've failed on all three fronts.

JOHN: There needs to be a public inquiry into all the deaths, going back twelve years; back to January 2010, starting with Stephen Carré's death. Clearly, that's what needs to be done, I think. Some activists have talked about, at some point, (Maybe after a change of government; I don't know. Rick Burgess has talked about this.) the idea of a reconciliation commission, or something, to examine everything; to try and get some kind of clean start; a break.

I mean, I think the DWP is doomed as an organisation. They just can't justify carrying on with all the harm it's caused; there has to be a new department. I don't care what the politicians say, and how difficult it would be—it can't carry on with everything it's done; all the harm it's caused; all the deaths it's caused. It just can't.

IMOGEN: It feels like it's state-sanctioned eugenics of disabled people, because of the amounts of people that have died. We're not just talking about a handful of cases that have gone wrong due to human-error or systems; there's hundreds.

[00:32:15]

CHINA: And it's so much a part of what you're saying, Imogen: this sustained and systematic dehumanisation of disabled people and people who claim, or try to

claim, welfare. I suppose. And that crosses lots of different party-politics, and it goes back a long time, like you were saying, John.

JOHN: And if you go back 30 years, you'll see the same phrases cropped up then, as cropped up under the coalition in the early 2010s: the same attempts to stir up hostility against claimants comes in waves to cut the bill. So there was talk of bogus claims, and sponges, and welfare, being a way-of-life back in 1992.

IMOGEN: This issue comes from the top down. And I think it's incredibly unlikely, but I would like to see, as John said, the entirety of the DWP demolished and built back up from scratch using a model of co-production, and involving disabled people, and involving claimants, in what they would like the system to look like.

[laughs] Don't know whether or not that's realistic, but that, to me, is what justice would look like: demolishing it with the hearts and minds of disabled-people and claimants at the forefront.

—Show's Outro Roll—

[00:33:38]

CHINA: This is the Deaths By Welfare podcast. Thank you so much for listening.

—Outro Roll Ends—

—[00:34:03] End of Transcript—