**Police emails show dodgy data was used to sell ‘unsafe’ mental distress scheme to NHS**

Emails released by a police force show how “hugely inaccurate” data was used to persuade NHS trusts across England to sign up to a mental health scheme branded unethical, unlawful and unsafe by disabled activists.

The emails were secured from Hampshire police through [a freedom of information request](https://www.whatdotheyknow.com/request/integrated_recovery_programme_20), and then shared publicly by a mental health activist, who tweets under the name of [@Sectioned\_](https://twitter.com/Sectioned_).

The release of the emails appears this week to have led to the former police officer who devised the Serenity Integrated Mentoring (SIM) scheme, Paul Jennings, closing down the network he set up to promote the programme and telling Disability News Service (DNS) that he was now “moving on with life”.

The Hampshire police emails show how unnamed figures within the force raised repeated concerns about the way that inaccurate data about how well it worked was being used by Jennings to promote the SIM system.

Critics of the system, which is now widely used across the NHS, believe it puts people in severe mental distress at risk of being denied vital support.

Under the leadership of a police officer and a mental health professional, SIM puts pressure on users of mental health services – often those at high risk of suicide and self-harm – who have not committed a crime but are seen as “high intensity users” of emergency services.

This can involve withholding assessment and treatment, and it gives police officers a key role in making clinical decisions when service-users are in crisis.

Following pressure from campaigners and SIM service-users, NHS England has already written to mental health trusts across England, calling on them to review their use of the scheme.

But disabled activists from the [StopSIM coalition](https://www.stopsim.co.uk/) have called on NHS England to “halt the rollout and delivery of SIM with immediate effect” and order an independent investigation into its use.

The emails released by Hampshire police were all written in 2018, and refer to a pilot scheme, the Integrated Recovery Programme (IRP), which was trialled on the Isle of Wight by Jennings, then a sergeant with Hampshire police, in 2013 and 2014.

The results of this pilot, which was renamed Serenity Integrated Mentoring (SIM), were later used by Jennings to promote and market the SIM system to mental health trusts and police forces, with support from the [High Intensity Network (HIN)](https://highintensitynetwork.org/), which he co-owned with his wife.

The network was believed to be working with 23 of 57 mental health trusts in England when Jennings shut it down this week.

Campaigners have been concerned for several years about SIM and its rapid rollout across the NHS in England, including the lack of quality research into its impact on mental heath service-users, but those concerns became much more vocal this spring.

Now the Hampshire police emails have shown that inaccurate results from the pilot – exaggerating its effectiveness – were apparently used to sell SIM to mental health trusts across the country.

The IRP pilot appears to have worked with just six women, but one email from Hampshire police says that two of them were removed from the trial results, even though one of them left the process and then died and the other was admitted as a mental health inpatient.

Another woman left the scheme at the end of the first year, but the trial reported that she made zero demands on services throughout the second year, even though police records actually showed a “significant number of calls to Police from her throughout that year”.

The email adds: “All of these incidents have been removed from the data giving a grossly distorted set of statistical outcomes.”

Another Hampshire police email five months later says: “He is still representing data around the country that we know to be completely inaccurate when compared to both Police and NHS data, as well as being formulated in a way that is just not ethical.”

The next day, apparently in an email to Jennings – although all names have been redacted – he is warned: “This does seem to me as a method of unfairly bringing pressure on other trusts to join the network in an aggressive sales pitch, and I do see that suggested in some of the communications that you send out.

“I don’t think this is appropriate, and I do not want us to be any part of this.”

The Hampshire police email then tells Jennings that “the way in which you have then used that erroneous data to produce various charts and graphs is misrepresentative and not ethical”.

The email adds: “You have left out whole swathes of data that do not support your findings, and even worse you have submitted a ‘0’ response across all categories for one patient who you know actually did make many calls to services in that period.”

Despite these warnings, the inaccurate data was apparently still being used four months later, as another email from Hampshire police on 24 November 2018 says: “I have significant concerns about the data being used to sell SIM around the country.

“The raw data is not remotely accurate in a number of ways, and is then being presented in a way that is just not ethical.

“I have had to make it very clear that Hampshire Constabulary cannot have any connection with SIM in the way it is being presented around the country.”

In a statement issued this week, after being asked about the emails, Jennings denied any wrongdoing.

He told DNS: “We have done absolutely nothing wrong and I have not in any way been dishonest at any time about data or any other matter.

“There is a very complex back story involving former colleagues at Hampshire Police which has been going on for years and has been the subject of a review by the Hampshire Police Professional Standards Department for several weeks now.

“I can’t say anything more at the moment.

“We are just about to turn off our network emails as the stress has become too much.

“The network as far as we are concerned is closed. All our teams have had their portals turned off – the website is closed and we are moving on with life.

“Whether individual organisations continue this line of work is now down to each of them... they will ironically be less transparent, less accountable, less measured and less safe outside of a national programme... so if this campaign thinks it has won, it hasn’t.

“We are good people trying to make the world a better place. We have served the public for over 20 years each and have not lied once whilst at work.

“When we get our energy back, we will carry on being these people, operating with these standards.”

But one disabled woman on a SIM scheme who has spoken to DNS this week said she found the police emails about the inaccurate data “really distressing” and “really shocking”.

She said: “I feel totally betrayed, totally violated.”

She said the SIM scheme bullies women in vulnerable situations, and she added: “It’s based on discrimination and stigma. I think it’s horrendous.”

She was also critical of Jennings’ actions in shutting down the network, and said: “He’s trying to hide and run away and not allowing himself to be accountable.”

She backed calls for a proper investigation into the use of SIM schemes across England.

The activist who helped publicise the freedom of information release, @Sectioned\_, told DNS today (Thursday) that she was concerned about the impact on those under SIM schemes of HIN’s sudden closure.

She said: “The whole model of care needs to be reviewed so people receive proper care rather than coercion and denial of potentially life-saving care – not just pulling the plug on the network overnight.

“It seems to be that, as soon as the evidence base for SIM, and its ethos and legality, began to be seriously called into question, the owners shut up shop.

“That seems highly irresponsible, especially given the vulnerable service user group targeted by SIM.”

She added: “A key priority for me is that, while NHS trusts review their SIM programmes, all threat of police sanctions should be removed.

“Some service users live in fear of arrest or prosecution for being in mental health crisis, which puts them at risk of harm because they are not asking for needed help.

“The need for help doesn’t go away just because someone is threatened with arrest or prosecution for asking for help; they may just stop asking for help.”

A Hampshire police spokesperson told DNS that SIM had been developed and piloted in the county in 2015 but was discontinued in 2017 after a review of the data and its findings, when “it became apparent there were inaccuracies in the way some of the data had been recorded”.

She said: “The SIM model was developed in partnership to help people in crisis with the specialist support needed from the right agency, reducing the use of detentions under section 136 [of the] Mental Health Act.

“Regrettably, the police data that was used to show the effectiveness of the system in reducing police demand contained some inaccurate data and its use was stopped.

“We informed other agencies regarding our concerns, and made it clear that our data should not be used as part of any further development of the programme.”

She added: “We have constantly sought to amend our approach to those who present to police when mentally unwell.

“The fundamental principle has always been to seek the best support for that individual at that point in time.

“We know that more often than not the police are not the right agency to respond. High intensity patients can span a broad definition and our work in this area was not, and is not, limited to the SIM model.

“Where individuals frequently present in crisis to police we will work with mental health trusts to develop plans to manage their needs and the demand.

“It isn’t for Hampshire Constabulary to comment on any subsequent evaluation of this delivery model nor on previously employed individuals who have voluntarily left policing.”

NHS England spokesperson had failed to comment by noon today (Thursday).

The two NHS organisations linked to the original pilot scheme and the police emails, Isle of Wight NHS Trust and Hampshire, Southampton and Isle of Wight Clinical Commissioning Group, had also both failed to respond to requests to comment by noon today.

**3 June 2021**

**Minister for disabled people refuses to criticise disablist comments of Tory peers**

The minister for disabled people appears to be condoning the behaviour of four Conservative peers who aimed discriminatory and disablist comments at disabled members of the House of Lords.

The Conservative party has also refused to take any action over the comments made by Lord Farmer, Lord Howard of Rising, Baroness Noakes, and Viscount Trenchard – [reported last week](https://www.disabilitynewsservice.com/tory-silence-after-four-peers-aim-disablist-barrage-of-attack-on-disabled-colleagues/) by Disability News Service (DNS) – [during a debate](https://hansard.parliament.uk/lords/2021-05-20/debates/1A303224-207C-4131-96B2-4A07DE9CF3D8/HouseOfLordsRemoteParticipationAndHybridSittings) on the continuing use of remote participation and “hybrid” sittings in the Lords.

They were all arguing that the Lords should quickly return to “normal” and end the adjustments that have allowed disabled members and those shielding from coronavirus to vote and take part in debates from their homes during the pandemic.

One of the peers argued that “personal infirmity should not provide grounds for exemption from normality”, while continuing the adjustments post-pandemic would be “extending the logic of equality beyond reason”.

Another suggested that those members who “cannot or will not” attend the Lords should retire as peers, while a third said it was “inconceivable that those who aspire to take part in the governing of this nation should not make the effort to attend parliament, whatever the difficulties”.

Disabled campaigners reacted with horror and anger to the comments this week.

[People First (Self Advocacy)](https://peoplefirstltd.com/) told Justin Tomlinson, the minister for disabled people, that failing to act on the comments would make it “much harder” for him to implement his policies.

[Ben Wilson](https://twitter.com/BenjaminEWilson), co-artistic director of Brick Wall Ensemble, said on Twitter: “The quotes from the Tory Peers in this article, although not surprising, are devastating.

“How can there be any hope for us disabled people who just want a fair chance to live our lives when those in positions of power treat us with such scorn and disrespect.”

The disabled Liberal Democrat peer [Baroness [Sal] Brinton](https://twitter.com/SalBrinton), who took part in the Lords debate, said it had been “horrible being on the direct receiving end of this from fellow peers”.

But she also said that all those found to be “clinically extremely vulnerable” to COVID-19 – including herself – had received repeated letters and emails from government ministers “telling us to continue to work from home if at all possible”, which made the comments of the four peers “even more ridiculous”.

Freya Papworth, co-chair of the Women’s Equality Party’s [disability caucus](https://twitter.com/WEPDisability), said she was so appalled by the comments that she had been unable to finish the DNS article.

She said: “The utter disdain these Lords clearly feel for disabled people is disgusting.

“No wonder we live in a country that is committing human rights abuses against us that no-one cares about.”

Disabled composer [Amble Skuse](https://twitter.com/AmbleSkuse) said on Twitter: “And just as quickly as the barriers came down, they start going back up.

“And we thought people might learn from a pandemic...”

[Steve O’Hear](https://twitter.com/sohear), until recently a journalist with TechCrunch and now a senior executive with a tech-based start-up, said: “The prejudice displayed in this piece is shocking.

“If the company I work for didn’t support hybrid working then I couldn’t work for them.

“And if TechCrunch hadn’t been remote I wouldn’t be in this industry at this level at all.”

Another disabled campaigner, [Natalya Dell](https://twitter.com/natalyadell), described the peers’ comments as “disgusting, disablist, outdated and inflexible ideas”.

Despite the widespread anger, the Conservative party has refused to answer questions about the comments made by the four peers, or to say if it believed they were disablist and discriminatory, or if the party would take any action against them.

Justin Tomlinson, the minister for disabled people, refused to say if he believed the comments were disablist and discriminatory, and failed to pledge to ask his party to take action against the four peers.

Instead, he issued a statement that appeared to condone their comments.

He said: “Whilst I understand the strength of feeling of tradition held by many of long service, we must always be mindful to review and adapt, as the Leader of the House has already set out.

“This government is committed to removing barriers for disabled people from all backgrounds so that everyone can contribute, [and] the House of Lords is no different.”

In the debate, the four Tory peers all argued that the Lords should quickly return to “normal” and end the adjustments that have allowed disabled members and those shielding from coronavirus to vote and take part in debates from their homes during the pandemic.

Lord Farmer, a former treasurer of the Conservative party, said that extending hybrid arrangements post-pandemic would be “another example of extending the logic of equality beyond reason”.

He said that “for the sake of the public who are paying our way, personal infirmity should not provide grounds for exemption from normality” and that “parliamentary participation is for those able to bring vitality to proceedings”.

He said that “if infirmities of mind or body make that vital contribution impossible, any permanently lowered bar to participation serves peers’ interests, not those of the public.

“The previous norm should be reinstated: those of us who cannot come to the House cannot contribute.”

His colleague, Lord Howard of Rising, called for the Lords to “resume our usual proceedings at the earliest possible opportunity” and said it was “inconceivable that those who aspire to take part in the governing of this nation should not make the effort to attend parliament, whatever the difficulties”.

Baroness Noakes called for the Lords to “get back to normal as soon as possible”.

She told fellow peers that there were “no good reasons for hybridity in future” and that “those who are ill or otherwise unable to attend for periods of time can take leave of absence”, while those who “cannot or will not, for whatever reason” attend in person can retire instead.

A fourth Tory peer, Viscount Trenchard, made it clear that he did not believe that “those with disabilities, in poor health or pregnant should be allowed to continue to participate remotely”.

He said it was “an unfortunate fact that if a noble Lord’s condition or circumstances prevent his or her attendance and ability to participate fully, it is hard to argue that that member is fully capable of exercising his or her functions as a legislator”.

He added: “I welcome the fact that it has become easier for those with disabilities to participate fully, but exceptions to physical attendance requirements should be minimised.”

**3 June 2021**

**Anger over ‘horrifying’ slow pace of government’s post-Grenfell action**

The government has failed to act to protect disabled people from the risk of fire in high-rise and other residential buildings, nearly four years after the Grenfell Tower tragedy, say campaigners.

Disabled campaigners and allies have shared an open statement – calling for urgent and long-overdue action – with the home secretary, Priti Patel, and the housing, communities and local government secretary, Robert Jenrick.

Organisations including [Disability Rights UK](https://www.disabilityrightsuk.org/), [Claddag](https://twitter.com/claddag), a leaseholder disability action group, and the [Grenfell Next of Kin](https://twitter.com/GRENFELLNEXTOF1) group, say the government has failed to implement crucial recommendations made at the end of the first phase of the Grenfell Tower Inquiry in October 2019.

And they warn that disabled lease-holders are [living in fear of losing their homes](https://www.disabilitynewsservice.com/disabled-high-rise-leaseholders-are-living-in-post-grenfell-fear-of-fire-and-financial-ruin/) because of the high cost of removing dangerous cladding from residential buildings.

The Grenfell Tower fire, on 14 June 2017, led to the loss of 72 lives, including many disabled residents who died after [public bodies failed to plan how they would evacuate their homes](https://www.disabilitynewsservice.com/disabled-grenfell-residents-were-repeatedly-failed-in-years-before-fire-inquiry-finds/) in the event of a fire.

In October 2019, [the inquiry recommended](https://www.grenfelltowerinquiry.org.uk/phase-1-report) that owners and managers of high-rise residential buildings be legally required to draw up evacuation plans, to be given to the fire and rescue service and also stored in an information box in the building.

It also recommended that they should prepare personal emergency evacuation plans (PEEPs) for all residents who may find it difficult to “self-evacuate”, and to keep up-to-date information about these residents and their PEEPS in the information box.

The new open statement calls for these two measures to be “urgently” implemented.

But it also says these measures should be applied to all disabled residents living on the upper floors of residential buildings, and not just those in high-rise buildings, while such buildings should have to be provide equipment that would enable disabled residents to evacuate independently and safely.

Sarah Rennie, co-founder of Claddag, said: “The pace at which the government is reviewing evacuation planning is horrifying, particularly when many disabled people are living in buildings known to be riddled with fire defects.

“The message is clear: our lives are deemed less valuable. ‘Stay put’ is not deemed safe so why is it ok for us?”

Fazilet Hadi, Disability Rights UK’s head of policy, said: “It is now over 18 months since the Grenfell Tower Inquiry recommended that building owners and managing agents should have a legal duty to prepare personal emergency evacuation plans for disabled residents unable to self-evacuate.

“It is completely unacceptable that thousands of disabled residents continue to live in fear of fire.”

[The new statement](https://www.disabilityrightsuk.org/sites/default/files/word/Protecting%20Disabled%20People%20from%20Fire.pdf) also calls for government action on the “distress and hardship” being caused to disabled leaseholders facing the high cost of removing dangerous cladding from residential buildings, and the costs of continuing to live in dangerous buildings.

Some disabled leaseholders are being harassed by other residents over the cost of equipment that would enable them to escape from a fire, it says.

Hadi said it was “unjust that disabled leaseholders should fear losing their adapted homes or be asked to contribute to bills for remedial works that they can’t afford and that aren’t their responsibility”.

Among other organisations signing the statement are disabled people’s organisations [Disabled People Against Cuts](https://dpac.uk.net/), [Greater Manchester Coalition of Disabled People](https://gmcdp.com/), [Disability Sheffield](https://www.disabilitysheffield.org.uk/), [Inclusion London](https://www.inclusionlondon.org.uk/), [Spinal Injuries Association](https://www.spinal.co.uk/) and [Sisters of Frida](https://www.sisofrida.org/).

Asked to respond to the statement this week, a government spokesperson said: “We are doing everything in our power to implement the Grenfell Inquiry phase one recommendations in the most practical, proportionate and effective way to ensure such a tragedy can never happen again.

“We continue to work with disability groups to improve accessible housing and to develop improved guidance for evacuation.

“Our £5 billion funding will protect those in the highest risk buildings from unaffordable costs, but does not absolve building owners of the responsibility to ensure their buildings are safe.”

The [latest detailed update](https://www.gov.uk/government/publications/quarterly-thematic-update-on-progress-against-the-grenfell-tower-inquiry-phase-1-recommendations#history) on the government’s progress in implementing the inquiry’s recommendations was published in April.

Ministers have said they will publish revised statutory guidance on evacuating disabled people and will seek further views on PEEPs, although it is not yet clear when this will happen.

[The government said in February](https://www.gov.uk/government/news/government-to-bring-an-end-to-unsafe-cladding-with-multi-billion-pound-intervention) that it would “fully fund the cost of replacing unsafe cladding for all leaseholders in residential buildings 18 metres (six storeys) and over in England”, while a new scheme would guarantee that no leaseholder in a building between 11 and 18 metres in height would have to pay more than £50 a month towards the cost of removing unsafe cladding.

**3 June 2021**

**Philippa Day’s sister pledges to continue fight for justice, after DWP’s PIP changes**

The sister of a disabled woman whose death was caused by widespread flaws in the benefits system has vowed to continue her family’s fight for justice, after the Department for Work and Pensions (DWP) announced changes in response to the tragedy.

The Courts and Tribunals Judiciary has published DWP’s response to a coroner’s report that [called earlier this year](https://www.disabilitynewsservice.com/philippa-day-flawed-pip-system-led-to-young-mums-death-says-coroner/) for urgent changes to the personal independence payment (PIP) system to avoid further deaths.

In January, assistant coroner Gordon Clow highlighted 28 separate “problems” with the administration of the PIP system that helped cause the death of 27-year-old Philippa Day, from Nottingham.

It had taken Clow more than two hours to read out his conclusions and findings, after a nine-day inquest that uncovered multiple failings by both DWP and its private sector contractor Capita in the 11 months that led up to Philippa’s death in October 2019.

He had concluded that flaws in the benefits system were “the predominant factor and the only acute factor” that led to her taking her own life.

And he issued what is known as a [prevention of future deaths (PFD) report](https://www.judiciary.uk/publications/philippa-day/), which calls for action from organisations linked to a death to prevent further such tragedies.

The report was addressed to both DWP and its PIP contractor Capita.

Clow called for action to address concerns around the training of DWP call handlers; how information from calls was recorded; the sending of a misleading letter to Philippa; and the flaws in the system which prevented incorrect decisions about the assessment process from being changed fairly and easily.

All these flaws helped lead to her death, the coroner concluded in January.

Now DWP and Capita have responded to his PFD report, announcing a series of changes they have already made, and promising others that they will soon implement.

Although both organisations express condolences to Philippa’s family in their responses, only Capita apologises for its mistakes, while DWP merely acknowledges “the tragic nature of this case” and says it is “determined to learn” from Philippa’s death and “takes the Coroner’s concerns very seriously”.

Philippa’s sister, Imogen, told Disability News Service yesterday (Wednesday) that the fight for justice – which includes a legal case against DWP and Capita for breaches of human rights and negligence – would continue.

She said: “I made a very sincere promise [to her sister, to secure justice for her if she died as a result of her PIP claim] and regardless of what that looks like, I have to carry that promise to the end.

“I still continue to take that promise very seriously.”

She said this promise was about securing both “justice and accountability” at senior levels of DWP for what happened.

Part of the fight would be to change DWP’s “culture of disbelieving claimants and the lack of empathy”, which was “a huge problem” and had not been addressed in the PFD response, she said.

Imogen said she was pleased that some changes were being made because of the inquest and the PFD report, but she said it did not make her “feel any better” about DWP.

She contrasted the department’s “very disappointing” behaviour with that of Capita, which has agreed to a meeting with the family, has acknowledged its failings and has apologised.

She said: “Apologies are important because they admit and accept wrongdoing, and that’s not what we have got here [from DWP].”

She said a meeting was important. “It’s not going to bring her back but I still want to sit and talk about what happened, so it doesn’t happen to other people.

“I want a meeting. I want to sit down and discuss why this happened. It is incredibly important to me and I am going to get it.”

Among the changes it has made in response to the PFD report, DWP says it has improved mental health training for new staff working on PIP and employment and support allowance (ESA) claims; and is issuing new guidance to PIP and ESA staff on accurate note-making; and is improving the process of checking the quality of PIP and ESA decision-making.

It says it is also introducing a new way to pause the PIP process even if an assessment has been booked, to allow for additional information to be gathered or the type or location of the assessment to be altered.

Among other changes, DWP says it has made alterations to the “scripts” used by call handlers when dealing with new PIP claimants who may need extra support; and has improved guidance for case managers and call handlers in dealing with those who may need more support.

And it says it has changed the PIP computer system to ensure that a new “watermark” is shown on the first page of a claimant’s records to show that that they have, or had, additional support needs.

In its own response to the coroner’s PFD report, Capita says it is altering the way it deals with requests to change a PIP assessment route – for example a request for an assessment to be carried out in the claimant’s home, rather than at an assessment centre – including pausing the claim while the request is being reviewed.

Among other changes, it says it is working with DWP to “further review the tone and language used in any written communications with Claimants”, partly to ensure “that they do not cause any unnecessary distress, anxiety or upset” to those going through the PIP process.

**3 June 2021**

**DPOs take control after Tomlinson ‘shuts down his own forum’**

Disabled people’s organisations (DPOs) across England have set up their own national network after the minister for disabled people apparently shut down his advisory forum of DPOs after just three meetings.

The government’s DPO Forum has not met since last October, despite the imminent publication of the government’s long-delayed national disability strategy.

[Launched only last July](https://www.gov.uk/government/news/disabled-peoples-organisations-dpos-forum-launches-this-month), the minister for disabled people, Justin Tomlinson, said at the time that it would “play an important role in bringing the voices and expertise of disabled people into the heart of government policy making”.

He added: “I am looking forward to working with this new DPO Forum as we develop the National Strategy for Disabled People, the DWP Green Paper, and beyond.”

But following the repeated cancellation of meetings, some of the forum’s members have now set up their own replacement, DPO Forum England.

Among their continuing concerns, they believe the government is preparing to launch its new cross-government disability strategy without any meaningful consultation with DPOs, in breach of the UN Convention on the Rights of Persons with Disabilities.

Four disabled people have already been granted legal aid for a judicial review of the government’s “disrespectful” and “unlawful” approach to seeking their views on the strategy.

Members of the new forum include the [Greater Manchester Disabled People’s Panel](https://gmdisabledpeoplespanel.com/), the [Reclaiming Our Futures Alliance (ROFA)](https://www.rofa.org.uk/), [Inclusion London](https://www.inclusionlondon.org.uk/), [The Alliance for Inclusive Education](https://www.allfie.org.uk/), [Equal Lives](https://www.equallives.org.uk/), [Disabled People Against Cuts (DPAC)](https://dpac.uk.net/) and [Disability Positive](https://disabilitypositive.org/) in Cheshire.

Mark Harrison, from ROFA, said the government’s forum – which he said was not a DPO forum at all because some of its member organisations were not led and controlled by disabled people – had not met since its third meeting last October.

He said: “We decided to carry on as a DPO forum in our own right, so we took control.

“We wanted to have a much more powerful voice for DPOs in England, not only speaking truth to power but holding power to account.”

He said he hoped the new forum’s work would back up other strategic actions by the disabled people’s movement in England, including direct action by organisations like DPAC, the legal challenge to the disability strategy, and campaigns around independent living and care charging, including the push for a new [National Independent Living Support Service](https://www.disabilitynewsservice.com/labour-silent-on-why-kendall-ignored-disabled-led-social-care-plans-in-major-speech/).

Harrison said that Tomlinson had told members of the government’s DPO Forum that its future was under review, with further meetings cancelled until further notice.

He said this “smoke and mirrors” approach was “what we have come to expect from the government”.

Harrison said Tomlinson appeared to have shut down the forum after a request from members for it to be run with proper terms of reference, with a disciplined approach, a work programme and a strategic approach to disability.

He said: “There was no discipline to it, no notion of co-production with the agenda.”

He added: “When people don’t agree with their world view, [the government] just shut it down and move on. That’s what they did with the DPO Forum.”

The other leading DPOs that have joined the new forum so far are [Breakthrough UK](https://breakthrough-uk.co.uk/), [Greater Manchester Coalition of Disabled People](https://gmcdp.com/), [Disability Rights UK](https://www.disabilityrightsuk.org/), [Choices and Rights Disability Coalition](https://choicesandrights.org.uk/), [Disability Stockport](http://disabilitystockport.co.uk/), [West of England Centre for Inclusive Living](https://wecil.co.uk/) and [Sisters of Frida](https://www.sisofrida.org/).

The government’s Disability Unit had not commented by noon today (Thursday).

**3 June 2021**

**New disabled people’s panel inspired by ground-breaking projects**

Disabled people’s organisations (DPOs) in Cheshire hope a new disabled people’s panel will allow them to work in co-production with the public sector across the county, after being inspired by ground-breaking projects in Greater Manchester and a London borough.

Five DPOs in Cheshire – [Cheshire Disabled People Against Cuts (CDPAC)](https://twitter.com/CheshireDpac), [Deafness Support Network](https://dsnonline.co.uk/), [Disability Positive](https://disabilitypositive.org/) (formerly known as Cheshire Centre for Independent Living), [Dial West Cheshire](https://dialwestcheshire.org.uk/), and [Disability Information Bureau](https://dibservices.org.uk/) – have set up the new Cheshire Disabled People’s Panel (CDPP).

Although the panel is unfunded so far, its members hope to act as a new collective voice for disabled people in Cheshire, and to work to ensure that disabled people’s rights are understood and upheld in the county.

They were inspired by [a similar panel in neighbouring Greater Manchester](https://www.disabilitynewsservice.com/panel-seeks-dpos-for-pioneering-partnership-with-mayor/), as well as the earlier work of the [Hammersmith and Fulham Disabled People’s Commission](https://www.disabilitynewsservice.com/disabled-residents-play-ground-breaking-co-production-role-in-major-development/).

Although there is not yet any commitment from the public sector, the panel will host a meeting next month with senior representatives from local councils, emergency services, the local NHS clinical commissioning group and MPs, where members “hope to secure their commitment to working with the panel”.

The panel will hold virtual meetings every month and will initially prioritise accessible transport, health and social care and “embedding the social model of disability”.

They also hope that other DPOs in Cheshire will join the panel.

CDPAC and the Greater Manchester Disabled People’s Panel first approached Disability Positive about the idea of creating a panel in Cheshire last year.

Lynne Turnbull, chief executive of Disability Positive and CDPP’s chair, said the idea had “fitted in perfectly with Disability Positive’s strategic aims to work in partnership and amplify the voice of people with lived experience of disability and long-term conditions in Cheshire”.

She said: “Too often, there are no disabled people in the room when key decisions are made that directly affect the lives of disabled people.

“This is an outdated way of doing things.

“Disabled people’s organisations in Cheshire have seen new and inspiring ways of working in Greater Manchester, which we need here.”

She said the panel now wanted to work in co-production with “public sector decision-makers at the highest levels”.

The new panel has received backing from the Labour mayor of Greater Manchester, Andy Burnham, whose office funds the Greater Manchester Disabled People’s Panel.

Burnham said: “It’s great to see that the Greater Manchester Disabled People’s Panel has provided a model for our colleagues in Cheshire.

“The panel was the first of its kind and, from the beginning, was developed in partnership with disabled people’s organisations here in our city-region.

“They’ve been a powerful voice in vital conversations about inequalities and accessibility, and the work of the panel shows our continued commitment to working with disabled people to bring about transformative change to our public institutions, environment, and transport systems.

“I am proud that here in Greater Manchester we are leading the way on tackling inequalities and adopting pioneering approaches to democratic engagement and policymaking with people in our city-region.

“I wish our colleagues in Cheshire all best in their work.”

Helen Rowlands, who co-founded the Cheshire panel, said: “From my work with Cheshire Disabled People Against Cuts and disability rights campaigners across England, I know the discriminatory impact and distress caused by unfair social care charges, and the frustration disabled passengers experience at the lack of access to our rail network.

“The CDPP offers co-production opportunities to senior public sector decision-makers in Cheshire to deepen their understanding of the rights of disabled people and the barriers disabled people routinely face in dealing with public organisations, environments, and public transport.

“The CDPP’s work will focus on the increased engagement of disabled residents in Cheshire’s local democracy.

“This approach has brought about inspiring, transformational changes to the lives of disabled people in Greater Manchester and Hammersmith and Fulham.”

Keith Roper, chief officer at Dial West Cheshire, said: “As a disabled people’s organisation with a mission to empower disabled people to live sustained, independent lives, we are delighted to have the opportunity to work in partnership with like-minded organisations as part of the CDPP.”

*\*For more information about the panel’s work, email* [*cheshiredisabledpeoplespanel@gmail.com*](mailto:cheshiredisabledpeoplespanel@gmail.com)

**3 June 2021**

**Disabled people largely ignored in response to pandemic, says new book**

Disabled people and others who have been most severely affected by COVID-19 have largely been ignored by those in power who drew up policies and plans to respond to the pandemic, according to a new book.

The e-book, published by Policy Press in two volumes\* and available free to download, argues that the failure to adopt more “collaborative, diverse, and inclusive” responses to the health and social care challenges created by the crisis has increased the fatal toll of the pandemic.

It also explores how disabled people and others have continued to be “ignored, disempowered, and discriminated against” in health and social care research, policy, and practice.

And it argues that greater use of co-production – where service-users, professionals and decision-makers work together as equal partners in planning and policy-making – could reduce the toll of both the current pandemic and future health emergencies.

Those particularly impacted negatively by the pandemic, it says, include disabled people and those with long-term health conditions; black, Asian and minority ethnic groups; people living in deprived areas and poor housing; and older people.

But these are the groups who have largely been ignored in developing responses to the crisis, and as a result have been “further detrimentally impacted by it – in many cases fatally”, according to the e-book’s introduction.

“Disabled people with vast experience of social isolation could have made valuable contributions to ‘shielding’ policies and social care provision and yet typically were not invited to contribute to decision-making processes,” it adds.

The collection of chapters by a range of authors, including leading disabled campaigners, calls for marginalised voices to be better heard through co-production.

In his chapter, Professor Peter Beresford, chair of [Shaping Our Lives](https://www.shapingourlives.org.uk/), compares the pandemic efforts of frontline NHS health workers with the “arbitrary and sweeping decisions” of senior NHS managers to “clear out thousands of older, long-term patients” into care homes and domiciliary services, which “then caused the infection to spread on a massive scale”.

He says that the NHS’s actions, which used “social care as a dustbin for COVID-19 casualties” were made “doubly dangerous and discriminatory by the appalling state of social care in England”.

Beresford was first approached by Policy Press to write a book on co-production in the pandemic and then worked with other service-users and researchers as co-editors.

He says that one of the many disasters of the UK government’s response to the pandemic has been how it has ignored both “old-stye experimental research” and “new user-led and co-produced approaches”.

He says that little if any effort was made to involve those groups most at risk in the pandemic in developing policy, practice, or research.

He says in his chapter: “This was despite their requests to do so and although the experience of many, from living a life routinely ‘locked-down’, could have offered very helpful insights into developing evidence-based policy and practice to combat resulting mental distress and other damaging effects.”

Beresford adds: “It was as if the thinking was that this crisis is too urgent, there just isn’t time to listen to people in the firing line, however much we recognise the value of that in normal times.”

In their chapter, disabled activists [Ellen Clifford](https://twitter.com/EllenClifford1) – author of [The War on Disabled People](https://www.bloomsbury.com/uk/the-war-on-disabled-people-9781786996640/) – and [Mark Dunk](https://twitter.com/mark_dunk) argue that governments have “widely failed to consult disabled people or to consider the impacts of their strategies on the most disadvantaged in society”.

They say that the scale of the disproportionate impact of COVID-19 on disabled people –about three-fifths (59 per cent) of COVID-19-related deaths in England during the pandemic have been of disabled people – has “not been reflected in the response to the crisis”.

Clifford and Dunk are due to speak at [a launch event for the book](https://www.eventbrite.co.uk/e/book-launch-talk-covid-19-and-co-production-in-health-and-social-care-tickets-151625705567) on 22 June.

*\*COVID-19 and Co-production in Health and Social Care Research, Policy, and Practice:* [*Volume 1: The Challenges and Necessity of Co-production*](https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care)*; and* [*Volume 2: Co-production Methods and Working Together at a Distance*](https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care-1)

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**News provided by John Pring at** [www.disabilitynewsservice.com](http://www.disabilitynewsservice.com)