**Coronavirus: ‘Long delayed’ data on disabled people’s deaths to be published**

Official figures showing how many disabled people are dying due to coronavirus will finally be published next month, Disability News Service (DNS) can reveal.

The Office for National Statistics (ONS) has told DNS that it recognises the importance of providing the figures and will publish them “as soon as is possible”.

The data is likely to be published for the first time towards the end of June, which would be about four months after the UK’s first recorded death from COVID-19.

One grassroots group of disabled activists told DNS yesterday (Wednesday) that the failure until now to produce figures on how many disabled people have been dying due to coronavirus “simply reflects the lack of value placed on our lives by this government”.

The ONS plans were revealed as four campaigners\* launched a legal action against the government and various public bodies over their failure to publish “accurate and reliable” data on how many autistic people and people with learning difficulties are dying from COVID-19.

They have sent a “pre-action” letter to NHS England; health and social care secretary Matt Hancock; NHS Digital; the UK Statistics Authority; and the Care Quality Commission (CQC), arguing that this failure is both “irrational” and “discriminatory”.

They say it is a “stark” contrast to how published data on COVID-19 deaths is broken down by ethnicity, age and sex.

And they fear the absence of data could make it impossible to ensure that autistic people and people with learning difficulties are safe and can access appropriate healthcare, and to monitor whether they are dying “prematurely and preventably” from COVID-19.

[Funding for the case is being crowd-sourced](https://www.crowdjustice.com/case/every-death-counts/) as part of the #EveryDeathCounts campaign, with legal support from solicitors Rook Irwin Sweeney and barrister Steve Broach.

Although NHS England has, in the last week, started to publish new data sourced through its “[learning disabilities mortality review](https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/)”, the #EveryDeathCounts legal team has described these figures as “partial and incomplete”.

Meanwhile, the new ONS figures should – from next month – show whether deaths of disabled people from coronavirus have occurred in hospitals, care homes and private homes, and should also be broken down by age, sex, ethnicity and occupation.

It has proved difficult so far to publish such figures – according to ONS – because death certificates do not state whether a person is disabled, although conditions are mentioned if they were a cause of death.

ONS has instead been working to link records from the last UK census in 2011 – where people reported whether they considered themselves to be disabled – with health records and death registrations.

An ONS spokesperson said: “We are prioritising work to analyse the impacts of COVID-19 on different communities and groups and have already produced one article focussing specifically on the social impacts on disabled people during lockdown.

“We appreciate the importance of this information and will publish as soon as is possible.”

But the government’s failure to keep track of the impact of the pandemic on disabled people has frustrated and angered disabled campaigners.

Mike Smith, the former disability commissioner of the Equality and Human Rights Commission and now chief executive of the east London disabled people’s organisation [Real](http://www.real.org.uk/), said the figures were long overdue.

The focus on disabled people was “months behind” other groups, he said, as it had been throughout the crisis, such as with [the publication of government guidance](https://www.disabilitynewsservice.com/coronavirus-pa-guidance-is-finally-published-five-weeks-late/) for disabled people using direct payments to employ their own personal assistants.

Smith said the new data would be important because it could be used to drive policy and practice locally and nationally, and to check whether younger disabled people were disproportionately more likely to die from the virus.

He said he hoped the figures could also show whether there had been an impact – even subconsciously – on the NHS treatment received by disabled people as a result of discriminatory guidance issued [by both the National Institute for Health and Care Excellence (NICE) and the British Medical Association](https://www.disabilitynewsservice.com/coronavirus-joint-action-from-disability-movement-secures-nhs-treatment-pledge/).

Smith added: “At the moment, disabled people feel ignored by the government, devalued by the medical profession, and forgotten by people planning the relaxing of the lockdown.

“We are not able to access restricted public transport, take long walks or cycle or even get to the shops safely, and are fearful that our care and support arrangements might be cut too. People feel isolated and unsupported.”

Smith said he hoped the ONS figures might help disabled people – particularly those seen as “at risk” but not extremely clinically vulnerable to coronavirus – make an “informed decision” on when and how it was safe for them to “re-engage in society” after lockdown.

But he said numbers needed to be “backed up with a proper review of what people in our situation should be doing”, and “much more comprehensive guidance and support nationally and locally to stop us from being the forgotten minority who are languishing at home for the next year”.

He said: “We do need to know this information, but we also need to know that it is used by policy-makers and decision-makers to appropriately target resources to help us maintain our freedom and human rights.

“The numbers alone are not the goal. It is what is done with the numbers.”

Professor Peter Beresford, co-chair of [Shaping Our Lives](https://www.shapingourlives.org.uk/), said: “From early on, we knew who COVID-19’s victims were most likely to be.

“They were older people, people with long-term and underlying conditions and compromised health and immunity. That includes many disabled people.

“As a group recognised under equalities legislation, it is shocking that information has not so far been collected on deaths among disabled people from the pandemic and it is crucial that the ONS expedites its work to rectify this omission as soon as possible.”

He said there was also a “much broader failure to collect full and accurate information about the consequences of COVID-19 in the UK”, which he said was “essential to combat it”.

He added: “But then the political sub-text has long been that this is a public health war that has been fought on spin and distraction rather than implementing the essentials long established for countering pandemics.

“I strongly doubt that disabled people have even figured in government reckoning until we have forced ourselves on to its attention.”

Svetlana Kotova, director of campaigns and justice for [Inclusion London](https://www.inclusionlondon.org.uk/), said: “It is extremely concerning that so far the data on COVID-19 deaths does not show how many of those people were disabled.

“It is vital that ONS collects and publishes this data as soon as possible, so that the true impact on disabled people can be assessed.

“We know already that disabled people feel they were abandoned and sacrificed during this crisis with many left fearful for their lives and wondering whether or not they will get the treatment and help they need if they become ill.

“This data can help to shine a light on what disabled people are going through during this pandemic.”

Linda Burnip, co-founder of [Disabled People Against Cuts](https://dpac.uk.net/), said: “The lack of stats on the number of deaths of working-age disabled people is not surprising and simply reflects the lack of value placed on our lives by this government.

“There is little difference between these unnecessary deaths and the many thousands we’ve all witnessed over the previous 10 years.

“Being unproductive to capitalism, we are all expendable.”

Ian Jones, from the [WOWcampaign](https://twitter.com/WOWpetition), said: “Yet again this government refuses to measure the impact on disabled people of their policies.

“It is important to assess the impact this virus and all other viruses in future have on disabled people to identify where society has failed to protect those people it should be protecting and put that right for the future.

“Who decided it would be a good idea to discharge patients from hospitals into social care with the impact of seeding COVID-19 into the homes of elderly and disabled people?”

He compared the government’s actions on coronavirus with the thousands of deaths that have been linked to the government’s welfare reforms and the actions of the Department for Work and Pensions.

Asked about the current gap in statistics on coronavirus-related deaths of working-age disabled people, and the legal action, a DHSC spokesperson said: “Any death from this virus is a tragedy and we are working incredibly hard to protect the nation’s public health.

“We are committed to transparency, and publishing robust, quality assured data. We want to ensure that any data we publish is as accurate as possible before publication.

“We are working with arms-length bodies and stakeholders to improve our data reporting, and to better understand the impact of this virus on people with disabilities and those who are clinically vulnerable.”

She said DHSC had received a letter from Rook Irwin Sweeney but could not comment on it for legal reasons.

Asked about the current gap in statistics on coronavirus-related deaths of working-age disabled people, and the legal action, a CQC spokesperson said: “Supported by ONS we are doing further work on our care home deaths data so that we can better understand the impact of coronavirus (COVID-19) on specific groups of people, including people with learning disabilities.

“This will form part of our reporting moving forwards. We are also identifying the best approach to capture the impact on autistic people as part of this.

“This work is a priority for us and will be published as soon as possible.”

*\*Disabled activist* [*Simone Aspis*](https://www.simoneaspis.co.uk/)*, who is campaigning to reduce the high levels of deaths of people with learning difficulties; Mark Neary, who took* [*a ground-breaking Court of Protection case*](https://www.disabilitynewsservice.com/council-that-kept-man-in-care-for-a-year-breached-his-rights/) *in 2010 relating to the unlawful deprivation of liberty experienced by his son Steven; Dr Sara Ryan, who has fought for justice for* [*her son Connor Sparrowhawk*](https://www.disabilitynewsservice.com/teenagers-death-was-institutional-disablism/)*, who died a preventable death in an NHS institution in 2013; and open justice campaigner Dr George Julian*

**21 May 2020**

**Net closing on government departments that refuse to publish deaths reports**

The government is facing calls to publish two coroners’ reports that link the Department for Work and Pensions (DWP) with the deaths of benefit claimants.

New information shows that the missing reports were written by coroners in 2015 and 2016, but neither of them have ever been published.

Both “prevention of future deaths” (PFD) reports warned DWP that more disabled people could die if the department failed to act.

But both DWP and the Ministry of Justice (MoJ) are refusing to release the reports, so it is unclear whether work and pensions ministers took any action to protect other benefit claimants.

Labour’s new shadow minister for disabled people, Vicky Foxcroft, called on the government to publish the two reports, and described its reluctance to do so as “worrying”.

The two PFD reports were written by coroners and sent to DWP, and they were also passed to the chief coroner for publication on the MoJ website.

Following a series of reports, freedom of information requests and ministerial answers to written parliamentary questions – including two from Foxcroft – Disability News Service (DNS) has now been able to confirm that one of the reports was written following an inquest that was held in 2015, while the other followed an inquest that took place in 2016.

One of the reports related to the death of a benefit claimant who took their own life, while the other cause of death has not been revealed.

The existence of the two unpublished reports was [first revealed by DNS in March](https://www.disabilitynewsservice.com/dwp-refuses-to-release-two-reports-by-coroners-into-deaths-of-benefit-claimants/).

The chief coroner of England and Wales, Judge Mark Lucraft, who receives all PFD reports from coroners and publishes them on the official website of the judiciary, has so far been unable to explain why he has not published the two missing documents.

[But guidance issued by his predecessor](https://www.judiciary.uk/wp-content/uploads/2013/09/guidance-no-5-reports-to-prevent-future-deaths.pdf) makes it clear that there is a “a presumption of publication” for such reports.

MoJ, in a response to a DNS freedom of information request, has resisted requests to search for the two missing reports, suggesting that it would be impossible to do so because PFDs “are filed under a limited number of categories but these do not include reference to the ‘DWP’”.

Only about 500 PFDs are written by coroners every year.

[A written response this month to Foxcroft](https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2020-04-28/41123/) from Justin Tomlinson, the minister for disabled people, showed that the missing PFDs were written by coroners in 2015 and 2016.

[He had earlier told her](https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2020-04-28/41124/) that DWP “considers the information confidential and it is the chief coroner’s decision whether to publish these reports”.

Foxcroft told DNS: “The government’s reluctance to release these reports is a worrying move that it should immediately reconsider.

“A key focus of prevention of future deaths reports is to understand past mistakes and ensure they do not happen again.

“The public has a right to know what changes have been made to avoid future deaths, and many will wonder what it is trying to hide.”

**21 May 2020**

**Coronavirus: ‘Greater clarity needed’ over mayor’s COVID-19 transport plans**

Accessible transport campaigners in London are continuing to fight for greater clarity around sweeping measure announced by the capital’s mayor as England begins to ease its coronavirus lockdown.

Sadiq Khan [has announced plans](https://www.london.gov.uk/press-releases/mayoral/car-free-zones-in-london-as-cc-and-ulez-reinstated) to create what he has called one of the world’s largest car-free zones in parts of central London, as a way to “create more space for social distancing when walking and cycling”.

The mayor promised that access for disabled people “will be maintained” as part of his [Streetspace for London](https://tfl.gov.uk/travel-information/improvements-and-projects/streetspace-for-london) plan, although he is yet to explain how that will be achieved.

[He originally announced](https://www.london.gov.uk/press-releases/mayoral/statement-from-the-mayor-of-london-regarding-tfl), separately, that free travel at peak times would be temporarily suspended for disabled people with a [Freedom Pass](https://tfl.gov.uk/fares/free-and-discounted-travel/freedom-pass) and older people with [60-plus cards](https://tfl.gov.uk/fares/free-and-discounted-travel/60-plus-oyster-photocard), many of them key workers.

The Labour mayor said the Conservative government had insisted that [emergency funding for Transport for London](https://www.gov.uk/government/speeches/transport-for-london-extraordinary-funding-and-financing) – which has been hit hard by the pandemic crisis and lockdown – would have to be accompanied by the suspension of free travel for the two cards at peak times.

Friday’s announcements, particularly on the suspension of Freedom Pass use at peak hours, caused concern and threats of legal action from disabled people on social media.

[Transport for All (TfA)](https://www.transportforall.org.uk/), the user-led charity which campaigns on accessible transport in London, said it was “extremely concerned” about the Freedom Pass announcement and “appalled” that the concession might not be valid at peak hours.

It said the pass existed “to redress societal and structural barriers that reduce physical access and economic opportunity” and was “not a favour bestowed upon disabled people and should not be treated as such”.

But the government has since confirmed that working-age disabled people will after all be able to use their Freedom Passes at peak hours, although it is not yet clear what the situation is for those with 60-plus cards.

TfA said there was uncertainty across the transport sector, including within TfL and bus and train companies, with “mixed messages” being sent to disabled people, and that the picture was changing rapidly.

TfA said it was talking to TfL and the mayor’s office in an attempt to “iron these things out” and to ensure that the “disabled person’s perspective” was heard and “to get answers that work for everybody”.

Alan Benson, TfA’s chair, said: “The problem at the moment is the uncertainty, not only what the new rules are but what services are currently out there, and what restrictions are out there.”

He said that car-free streets would mean less pollution and noise, which would benefit disabled people, but that disabled people would still need to be able to access those areas of the city.

Benson said: “I don’t believe anybody is out to stick us. They are just in a world that they have not been in before and they are working it out as they go along.

“I don’t believe it is creating enormous difficulties at the moment but over the next two or three months if they don’t get those messages sorted out, it will be an issue.”

Meanwhile, Transport for All is developing ideas on how the transport system in the capital should adapt to the pandemic to take account of the needs of disabled people and ensure that the impact of COVID-19 “does not regress the rights, opportunity and perceptions of disabled people who travel in and to London”.

Its ideas include providing accessible “hotspots” at stations and platforms, which only disabled passengers would be able to use as they waited for support; accessible and safe spaces such as priority seats and wheelchair spaces to be more “stringently enforced”, like blue badge parking spaces; and clear, accessible guidelines to be shared with disabled passengers on what they can expect from passenger assistance during the pandemic.

A spokesperson for the mayor said: “City Hall and TfL are still working through the details around temporary changes to the Freedom Pass, 60+ Oyster card and children’s travel in London, as required by the government as part of the funding deal agreed last week.

“Once these are agreed TfL will be fully communicating them to passengers before they are implemented.

“TfL will follow all of its statutory requirements and its policy of taking care of vulnerable passengers.

“As confirmed by the government in their [written ministerial statement on Monday](https://www.parliament.uk/business/publications/written-questions-answers-statements/written-statement/Commons/2020-05-18/HCWS240/), there will be no changes to the disabled persons’ Freedom Pass.”

But he said today (Thursday) that there was “no further update on the Streetspace elements at this stage”.

**21 May 2020**

**Coronavirus: Supermarkets and government must act on ‘food crisis’, MPs hear**

The major supermarkets and the UK government must do more to solve the “food crisis” that is still affecting millions of disabled people months into the coronavirus crisis, MPs have heard from a national disabled people’s organisation.

The environment, food and rural affairs committee heard that the coronavirus crisis had turned into a food crisis that had “swept away the careful arrangements that disabled people had made for getting their food”.

Fazilet Hadi, policy manager for [Disability Rights UK](https://www.disabilityrightsuk.org/) (DR UK), told the committee – as part of its inquiry into COVID-19 and food supply – that the government’s scheme to provide support for those who are seen as particularly vulnerable to infection had been welcome, but had also caused knock-on problems for many disabled people.

Many of those who previously shopped online because of sight, physical or other impairments, lost their ability to book deliveries because they were not placed in this “clinically vulnerable” group.

At the same time, millions of others who had previously shopped in-store “found themselves completely without the ability to shop in the usual way”.

This week, Tesco became the first supermarket to be threatened with an urgent legal injunction as part of a class action being taken against the UK’s biggest supermarkets by 320 disabled people – many of them taking action against two or three supermarket chains – who say they have been discriminated against during the coronavirus crisis.

Joanne, the disabled single mother taking the case against Tesco, with the support of solicitors [Fry Law](https://www.frylaw.co.uk/), is on the government’s list of extremely clinically vulnerable people, and hers is seen as one of the most urgent among the 320 cases.

She has multiple health conditions which currently leave her unable to leave her bed while she recovers from surgery she underwent in late March.

Although Joanne has regular delivery slots through Tesco, the supermarket is refusing to deliver her shopping at a time when her care workers are there to accept and clean it.

Fry Law yesterday (Wednesday) sent a letter to Tesco asking it to act urgently to make a reasonable adjustment for her under the Equality Act by promising to deliver her shopping at a time when her care workers are with her.

If it fails to do so within five days, Fry Law will make an application to the county court to order temporary “relief” through a court order until the case can be heard in full.

A Tesco spokesperson said: “We are aware of this claim, and have offered to engage with this customer’s representatives about her needs.

“We are continuing to do everything we can to support our most vulnerable customers, and are confident that we are fully compliant with all relevant laws and government guidance.

“We have more than doubled the number of online slots available since the start of the crisis, to 1.3 million slots this week, and are currently supporting more than 530,000 vulnerable customers with priority access.

“We would encourage any customers facing similar issues to contact us directly.”

Hadi told the Commons committee last Friday that the pandemic crisis had impacted the ability of millions of disabled people to secure food.

Surveys still show about 45 per cent of disabled people struggling to secure the food they need, she said, down from about 60 per cent in early April.

Tory MP Derek Thomas told her that 45 per cent was “a colossal number of people who are not getting the food they need”.

Hadi said the UK government had failed to speak soon enough to groups that knew about the needs of disabled people, preventing a “more joined-up response”.

She said: “They were acting very quickly [at the start of the crisis], but we could have acted quickly as well.

“The fact we weren’t at any table until a bit later on in the crisis has resulted in maybe more problems than there needed to be.”

She said there had been “silence” from the Department for Environment, Food and Rural Affairs (DEFRA) for the first few weeks of the crisis, and officials had only begun to talk to DR UK about the support needs of disabled people from mid-April.

But even now, she said, “we are not sitting down with DEFRA and the supermarkets and talking about the big plan” and asking “who are the groups who are really affected, who are struggling to access food because of the coronavirus situation, what’s our strategy and what role is each of us playing”.

Hadi also told the committee that supermarkets needed to think more about their duties to make reasonable adjustments for their disabled shoppers under the Equality Act.

Among the problems facing disabled people who want to shop in-store are difficulties with signage, with social distancing, wheelchair-users unable to reach higher shelves, and others who are forced to stand for long periods in queues.

Hadi said it was time for supermarkets to take part in discussions with DR UK and others “about what we need to put in place over the next few months, the next year, that allows disabled and older people to shop safely and independently”.

She said: “I do think this situation is going to go on for a long time with people not getting the online slots, not getting the support they need in-store, so I’d really like to see us ‘sit round the table’ with supermarkets and government and the third sector.”

She also called on the major supermarkets to “lead the way” on introducing reasonable adjustments for their disabled customers, to show smaller shops what could be done.

And she said the priority was to find solutions that allowed disabled people to shop independently – with the support they needed – and then find local “safety net” solutions for those who might still need them.

Hadi, who herself has no sight and so is currently unable to shop safely in person in a supermarket, said: “We just need to think through what that looks like for disabled people because I don’t want to be under house arrest for an unlimited period just because I can’t social distance, just because I can’t have some support.”

**21 May 2020**

**Bus company forced to act after campaigner’s wheelchair space victory**

A disabled campaigner has secured an “important victory” that has forced a transport company to bring in new measures to protect the rights of wheelchair-users to use buses.

Wheelchair-user Nina Grant, from north London, began legal action against Arriva after repeatedly being left on the pavement by drivers who made no attempt to ask parents to move their buggies so she could board the bus and use the wheelchair space they were blocking.

This was a breach of principles established in a legal action taken by fellow disabled activist Doug Paulley, which resulted in [a ground-breaking Supreme Court victory in January 2017](https://www.disabilitynewsservice.com/we-must-keep-banging-the-drum-says-bus-campaigner-after-five-year-fight-for-justice/).

That case established that bus companies operating a “first come first served” policy on the use of their wheelchair spaces were acting unlawfully.

But more than three years on, many wheelchair-users believe too little has changed, that parents with buggies often refuse to move from the wheelchair spaces, and bus drivers often refuse to make any attempt to persuade them to do so.

Grant managed to obtain CCTV footage from onboard cameras which showed one driver failing even to open the doors when she wanted to board a bus.

The driver said there was no point opening the doors because there were buggies in the wheelchair space and the parents would not move.

But the Paulley court victory established the principle that disabled passengers have a right to priority access over the wheelchair space on a bus, and that a driver must do more than simply ask a non-disabled passenger to move.

Now Grant – with assistance from solicitor Chris Fry, of [Fry Law](https://www.frylaw.co.uk/), and barrister [Cathy Casserley](https://www.cloisters.com/barristers/catherine-casserley/), from Cloisters chambers – has secured a court order that will hold Arriva’s drivers to account for their actions.

Arriva has made a legally-binding pledge to improve accessibility and ensure “comprehensive” disability equality training for all new drivers and refresher training for existing drivers, with all drivers having to reach a basic level of competency before being allowed to drive a bus.

At the end of each shift, every driver will have to file a record of each occasion when they refused access to a wheelchair-user.

The legal case was supported by the Equality and Human Rights Commission (EHRC), [as part of a project launched last year](https://www.disabilitynewsservice.com/watchdog-to-launch-project-to-fund-legal-actions-on-transport-discrimination/) to provide funding for disabled and older people to take legal action when they have faced discrimination on public transport.

Grant said the court order was about holding Arriva accountable to disabled passengers and would ensure the company policed how priority access for wheelchair-users was being applied on its buses.

She said: “Drivers need to know that their behaviour matters and will be scrutinised at the depot.

“I am grateful to the EHRC for their support in bringing this case. Without their help I could not have taken the risk of bringing the claim.”

Paulley welcomed the “important victory”.

He said: “I regularly heard (before the pandemic) of buses leaving disabled people at stops because the spaces are occupied by non-disabled people’s prams, without the driver even asking the occupants to move.

“This is clearly discriminatory and has a massive effect on the people left behind, both practical and emotional. It shouldn’t happen.

“Bus companies should be doing more to make sure that space is available for disabled people.

“Drivers must comply with their obligation to request and instruct non-disabled people to vacate that space if needed by a disabled person, as established years ago in the First Bus case.

“It’s a disgrace that this happens so frequently, that it happened this time, and that it’s down to individual disabled people taking legal action to enforce their rights.

“I hope this case causes bus companies to reconsider.

“Well done to Nina, Cathy Casserley and Chris Fry for taking this on, seeing it through and refusing to let it go unpunished; and for achieving a positive result that should make a major difference for disabled people.”

Fry said: “This agreement shows that Arriva is committed to tackling the ‘garage culture’ where drivers believe that there’s simply no point in challenging people to move from the wheelchair space.

“There needs to be a way for bus companies to find out what’s happening at street level and to better support drivers.

“This mediated outcome shows what can be achieved without expensive and lengthy litigation.”

Rebecca Hilsenrath, EHRC’s chief executive, said: “Equal access to transport is still a very major issue for disabled passengers, despite the progress made over the recent years.

“We expect all bus companies to take proactive steps so access to wheelchair spaces becomes a reality for disabled passengers, improving the everyday lives of disabled people for the long term.”

An Arriva spokesperson said: “Arriva is committed to ensuring that its bus services are fully accessible to disabled [people] and wheelchair-users.

“Our driver training, internal policies, on-bus signage and conditions of carriage have for many years made clear the legal priority which wheelchair-users have over designated wheelchair spaces and the standards we expect of our employees in providing assistance to wheelchair-users.

“Any complaints from wheelchair or disabled users are treated with the utmost seriousness, promptly investigated and, if a breach of policy is identified, we do not hesitate to take action to address this including, where appropriate, disciplinary action.

“Despite these existing measures, the service experienced by Ms Grant on this occasion clearly fell short of our high standards and as a result we were happy to agree the measures described to provide her and other wheelchair-users with further assurance that we take the accessibility of our services extremely seriously.”

**21 May 2020**

**Project set to bring 50 years of disabled people’s movement to life**

A new five-year, lottery-funded project is set to bring to life the history of the disabled people’s movement over the last half-century.

The user-led disability arts organisation Shape has secured £142,000 from the National Lottery Heritage Fund (NLHF) for the development stages of a project that should eventually see a website, an e-learning site and a physical home for artefacts from the movement.

These artefacts could include banners, publications, tee-shirts, photographs, badges and video footage from some of the iconic protests of the last 50 years.

Shape hopes eventually to secure further funding of £840,000 from NLHF to complete the five-year project.

The plan is to focus on the years leading up to the passing of the Disability Discrimination Act in 1995, but the project will also tell the story of the campaigns, actions and battles that spun off from that milestone over the last 25 years.

The idea for the National Disability Movement Archive and Collection (NDMAC) grew from another major heritage project led by Shape, the [National Disability Arts Collection and Archive (NDACA)](https://the-ndaca.org/).

Last year, in the culmination of a project that had its origins more than 30 years earlier, [Shape launched the NDACA archive](https://www.disabilitynewsservice.com/visitors-to-new-wing-will-feel-the-power-of-the-disability-protest-movement/) and learning zone at the High Wycombe campus of Buckinghamshire New University, featuring more than 3,500 pieces of artwork, most of which was stored in digital or physical form in an archive repository.

Shape’s new project is set to mirror that work, which was also funded by NLHF.

NDMAC already has some historical documents, photographs and other artefacts that did not fit into the NDACA project.

Alex Cowan, NDMAC’s head of archives and collections, who was also NDACA’s archivist, is now [looking for stories and objects](https://www.shapearts.org.uk/blog/the-launch-of-ndmac) that tell the story of the two decades that led up to the passing of the DDA in 1995.

He said: “I am not expecting it to be a collecting mission without controversy.

“We are interested in every possible take on what went on.”

For example, he wants to hear from both sides of the persistent argument over whether the DDA was a significant step forward for the movement or served only to frustrate demands for a genuine disabled people’s civil rights bill.

Cowan told Disability News Service: “We will be going to potential depositors, working out what is out there to tell the story.

“Just like NDACA, the National Lottery Heritage Fund are not interested in dusty boxes on shelves; they are interested in narratives and stories, both individual and collective.”

Among the items Cowan is keen to source are original videos and films of direct action protests, including those of disabled activists who chained themselves to buses in the early 1990s.

He said: “Modern audiences particularly are much more likely to come along if there is something visual as a starter. It is a powerful draw.

“Protest ephemera, such as the banners made by Disabled People Against Cuts… works particularly well for younger audiences.”

The physical home of the archive and collection will be at Shape’s offices in an accessible building in Peckham, south London

Cowan said: “There will be a fully-functional website, with lots of stuff available digitally, and there will be the physical repository where fragile, valuable or non-digitisable objects can be stored. It will double up as a study centre.”

NDMAC’s home will be a place that disabled people, academics and others can visit to see some of the historical artefacts of the movement.

Cowan said the project had been given added importance by the pandemic crisis.

He said: “I think it’s important, given the austerity from the past 10 years and the new austerity narrative that I suspect will come back after coronavirus, which is always biased against disabled people.

“It is this type of heritage story of politics we will be trying to capture and re-tell.

“There is also the general dissatisfaction with politics at the moment from many disabled people, after Brexit and the last general election.

“Referring back to previous disabled people’s movements and times is an important educational process and allows people to think about their relationship with society and inclusiveness.

“I think it’s an important reminder that agitation and political campaigning do yield results – and that is the heritage story we want to capture.

“They are never perfect, but it doesn’t mean you shouldn’t strive for them or be cynical about them when you succeed. It just informs the next level of struggle.”

**21 May 2020**

**Coronavirus: Pandemic crisis has entrenched social isolation, research finds**

New user-led research has highlighted how the coronavirus crisis has entrenched social isolation among many disabled people.

More than three-fifths (61 per cent) of the disabled people questioned by [disAbility Cornwall & Isles of Scilly (DCIS)](https://www.disabilitycornwall.org.uk/) said they felt socially isolated, while three-quarters (74 per cent) were not receiving any support from charities, the NHS or their local community.

Many were concerned about a lack of clarity over their responsibilities as an employer of personal assistants (PAs), while more than a third (35 per cent) said they had had problems obtaining the personal protective equipment (PPE) they needed to keep themselves and their PAs safe.

DCIS heard from 83 disabled people between 17 and 24 April after asking how they had been affected by the pandemic.

The survey findings were summarised by partners in [The Inclusivity Project](https://www.ecehh.org/research/inclusivity-project/), an initiative led by the University of Exeter and funded by the European Union’s European Regional Development Fund.

The findings are included in the latest of a series of reports that have been submitted by disabled people’s organisations to the [Commons women and equalities committee’s inquiry](https://committees.parliament.uk/work/227/unequal-impact-coronavirus-covid19-and-the-impact-on-people-with-protected-characteristics/) into the impact of the COVID-19 crisis on disabled people and other groups protected under the Equality Act.

One of those who took part in the Cornwall research said: “Personally I have not been supported by charities in my local community despite the fact of living alone.

“There are many like me that’s fallen through the cracks. We are really socially isolated due to our complex health conditions, but even more so now.”

Sharon Kilty, a wheelchair-user who also responded to the survey, said: “As usual I feel invisible when it comes to the government handling this situation.

“I don’t know what we have to do to be seen and treated as an equal part of society. We have to get on and manage things for ourselves as best we can.”

Many of those who took part – particularly those with high support needs and invisible impairments – told DCIS they believed disabled people had been forgotten during the crisis, in comparison with the NHS, key workers and older people.

Disabled people who were not living with family members said they felt a strong sense of isolation, depression and anxiety because of being cut off from family or from local activities and supportive organisations.

Many spoke about the lack of access to healthy, affordable food, even some of those who were on the list of those the government viewed as particularly vulnerable to the virus.

One of those questioned said: “I have been unable to get shopping in as I’m unable to get a delivery and can’t go out for it.

“I have no access to my support networks. I can’t have an appointment with my therapist. I’m struggling a lot more than usual.”

Another said: “Whilst self-isolation is nothing new when much of society is still inaccessible and ignorant of the needs of disabled people, in many ways disabled people feel more marginalised, vulnerable and discriminated against than at any time during the last 30 years.”

Among the demands of those questioned by DCIS were for care workers and disabled people to be tested regularly for COVID-19; for greater access to PPE; for more support from health professionals and GP surgeries; for access to emotional support for mental health issues; and for advice on how to cope if social care packages are discontinued.

Another respondent highlighted the level of anxiety caused to many disabled people by the coronavirus lockdown.

They told DCIS: “I’m worried that I’m not going to be able to get any shopping at all.

“I’m worried I’m going to end up hurting myself or someone else.”

Jane Johnson, chief executive of disAbility Cornwall and Isles of Scilly, said: “The lack of timely information and support, lack of COVID testing for care staff, and poor provision of inclusive information has caused considerable fear and confusion for many.

“Some people’s stories are truly heart-breaking; more can and should be done now to alleviate further suffering.”

Among the report’s recommendations for immediate action are for more accessible information about the crisis for those without internet access.

It also calls for the government to collaborate with disabled people and their organisations to produce and share a clear plan for how the needs and priorities of disabled people will be met as lockdown restrictions are eased.

**21 May 2020**

**Round-up: International action call, BBC’s DAN drama, and DNR letter for Hancock**

**Two international disability rights groups say governments and health authorities are putting the lives of disabled people at greater risk during the coronavirus pandemic because of their failure to take “concerted action”.**

[International Disability Alliance](http://www.internationaldisabilityalliance.org/content/ida-members) (IDA) and [International Disability and Development Consortium](https://www.iddcconsortium.net/) (IDDC) have launched a campaign to prevent discrimination against disabled people.

They described the situation as a “hidden crisis” for disabled people, and have written to the UN and the World Health Organisation.

They want the two organisations to send a stronger message to governments that disabled people must be included in measures to contain and treat COVID-19.

They also want to see public health information and communications around COVID-19 to be fully accessible.

They have asked the UN and its agencies to make their own daily briefings and any supporting documents on COVID-19 fully accessible.

Ana Lucia Arellano, chair of IDA – whose members include the European Disability Forum, the World Federation of the Deaf and the World Network of Users and Survivors of Psychiatry – said: “Life-saving information is not being made in accessible formats, which is leaving huge swathes of the population in the dark.

“The UN has now committed to a number of changes to ensure its information is more consistently accessible.

“We believe this will show governments and international media outlets that inclusion is possible and indeed necessary to reach all audiences.”

**A woman has sent a second legal letter to health and social care secretary Matt Hancock, calling on him to provide clarity on how “do not resuscitate” (DNR) decisions are made.**

Kate Masters sent the letter to Hancock following an “unsatisfactory” response to a previous “pre-action protocol” letter.

Masters is the daughter of the late David Tracey, who brought a [successful judicial review in 2014](https://www.leighday.co.uk/News/2014/June-2014/Landmark-judgment-in-resuscitation-case) which established that his late wife’s human rights had been breached after a DNR order was placed on her medical notes without her being consulted.

Masters fears that – due to the current pandemic – “blanket” DNR notices are being imposed on many people, and due to ongoing health problems she feels at significant risk herself of a DNR notice being imposed on her without full information in advance and proper consultation.

She said: “I feel it is clear that the health service needs some national guidance on DNRs to ensure that patients’ rights are protected.

“Not only that but I remain greatly concerned about my own situation and that of my family’s due to ongoing health problems – I want to make sure that what happened to my mum does not happen to anyone else.”

Her solicitor, Merry Varney, from [Leigh Day](https://www.leighday.co.uk/), said: “This case is about alleged systematic breaches of patients’ human rights through the way in which do not resuscitate decisions are being taken, and our client believes that the secretary of state has a duty to take action to prevent these widespread violations and ensure her own rights are protected.”

**BBC Two has commissioned** [**a factual drama**](https://www.bbc.co.uk/mediacentre/latestnews/2020/independence-day) **based on the story of how disabled activists** [**Barbara Lisicki**](https://www.disabilitynewsservice.com/dan-sends-message-to-coalition-we-are-coming-for-you/) **and** [**Alan Holdsworth**](https://www.disabilitynewsservice.com/crescendos-first-tour-for-13-years-will-pay-tribute-to-movement/) **met, fell in love, and became the driving force behind the Disabled People’s Direct Action Network (DAN) in the early 1990s.**

The drama has been commissioned to mark 25 years since the Disability Discrimination Act became law in 1995.

It has been written by the multiple BAFTA-winning disabled writer Jack Thorne, and Deaf actor-turned-writer Genevieve Barr.

Thorne said: “DAN changed the world through their actions, and they have never been properly celebrated for it; in this film we want to do that in a way that lauds their true punk spirit.”

[**A survey by the Benefits and Work website**](https://www.benefitsandwork.co.uk/news/4226-what-pip-telephone-assessments-are-really-like) **has raised concerns about how some telephone assessments for personal independence payment (PIP) – replacing face-to-face assessments because of the coronavirus pandemic – are being carried out.**

More than 250 PIP claimants have responded to the survey so far.

Among concerns raised are respondents being wrongly told that they failed to answer their phone when their assessor called, and others being given no notice of their assessment, while 12 per cent of those who responded said their assessor did not have a quiet and confidential place from which to carry out the assessment.

One survey respondent told Benefits and Work: “Could hear other people laughing and making comments in the background. Then someone saying sshhh.”

Another said: “Her husband was in the vicinity and I was on speaker phone.”

**The user-led charity Buckinghamshire Disability Service (BuDS) has worked with Thames Valley Police to help autistic people and people with learning difficulties who have found it difficult to follow social distancing rules.**

Some may also have additional or particular exercise needs, such as needing to exercise more often than others, or to exercise in a particular way or place, which could cause conflict with other people and lead to possible trouble with the police.

They can now obtain a letter from BuDS that explains their situation, and which is recognised by Thames Valley Police.

Andrew Clark, chair of BuDS, said: “The letters are a way for people to instantly explain their situation to others who may not understand why people are behaving differently or in a way which seems unusual.

“Disabled people have to have confidence that they can go out without unnecessary conflict arising from people’s lack of understanding, and these letters will help build that confidence.”

The letters [can be obtained free from BuDS](https://buds.org.uk/contact/).

**21 May 2020**

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