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"There's a lot of learning that can be done if you open your eyes and ears up to people with lived experience"

Lived Experience of Deaf and Disabled People During the COVID-19 Pandemic

Foreword

It is vital for the COVID Inquiry to consider Deaf and Disabled experiences separately from the general population, due to the inequalities Deaf and Disabled people faced before the pandemic. We need to evidence how this has worsened for those people who are most in need of help and support. Additionally, it is essential to understand why this is and, if a pandemic or national crisis should happen again, what has to happen across the UK. From the start of the COVID pandemic, Deaf and Disabled people, together with their unpaid carers, received less support than others. It is essential to have Deaf and Disabled people involved in reports such as this, because they are the experts in respect of their circumstances, and reports need to be relevant to communities, not just policy experts.

I hope the lived experience narratives that have been collected to support the COVID Inquiry will be shared publicly. As a professional co-producer, I am still dealing with the impact of basic health and social care systems that did not function effectively during the pandemic. Whole communities were affected. The videos should be used as a primary evidence source to show the impacts on those accessing services and their carers. Even those of us who access services regularly and co-produce policy felt excluded and ignored during the pandemic and had to be resourceful. Many of us had loved ones who died, because Deaf and Disabled people's needs were forgotten.
Now it's time for the COVID Inquiry to remember and recommend how to involve Deaf and Disabled people as part of co-producing a pathway that does not ignore what happens to them. Currently, numerous blind spots exist in both health and social care systems. From my work and lived experience I know professionals learn more from a patient's journey than they do from reports.

In the future, if we face global challenges on the same scale as the COVID pandemic, Personal Assistants working with Deaf and Disabled people must be given more credit and pay in the workforce. They saved so many lives in the pandemic and have largely been ignored. Often, they risked their own lives to look after others when family members could not. Additionally, power needs to be given to communities. They regularly demonstrated how to pull together and don't need permission to solve problems. Nevertheless, leaders at national and local levels continue to dictate and seem not to understand how to produce pathways that will be effective and reflect the needs of Deaf and Disabled people.

The Inquiry must ensure that people affected by COVID have their voices heard, particularly in respect of how we co-produce health and social care. We can't get our loved ones back, but lessons need to be learnt at a strategic level and apologies need to be made.

Keymn Whervin

Introduction

"We realised very quickly that although people said we were all weathering the storm, we weren't in the same boat. … people were frightened. They felt frustrated. They thought that no-one cared"

The above quote from a health and social care activist is echoed in the experiences of many Deaf and Disabled people relating to the COVID-19 pandemic. Whilst aspects of the Coronavirus Act 2020 and its implementation did seek to support society through this challenging time (e.g. the furlough scheme and amendments to tenants' rights), such support and security was not always felt by the Deaf and Disabled community. The lived experiences of Deaf and Disabled people show that longstanding laws, which should have protected them, were overridden. Consequently, the rights and freedoms of Deaf and Disabled people were curtailed, which often affected their ability to live safely and with dignity. Furthermore, Deaf and Disabled people believed they were not valued as much as other members of our society.

This report explains these experiences and seeks to give a platform to Deaf and Disabled people so that their voices are not ignored as society recovers from the pandemic. People's Voice Media has worked in partnership with Disability Rights UK to gather 22 lived experience stories from people identifying as Deaf or Disabled from across the UK. Furthermore, this project includes the lived and living experiences of parents/carers of people who cannot communicate verbally, covering both the parent/carer experiences and those of the people for whom they care.

The lived experience stories[1] were gathered through online dialogue interviews, conducted by a Peer Researcher (also known as a Community Reporter), between October 2022 and March 2023. An additional 165 stories, which included those of Deaf and Disabled people, from a previous project (COVID Conversations) that had gathered a broad range of people's experience of the pandemic during 2020 and early 2021 were also utilised. In these conversations, themes included DNR (Do Not Resuscitate[2]) decisions, living life in lockdown and supporting children with autism were covered. Furthermore, an online sense-making session was held with 13 of the lived

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[1] The lived experience stories can be found at https://communityreporter.net/disrupt-covid-19-enquiry, https://www.youtube.com/playlist?list=PL1vtHOjD7gN0_xzrQVwDiXbA4oktqBF42 and https://peoplesvoicemedia.co.uk/covid-conversations/

[2] Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders were placed on the medical files/notes of Disabled people without their consent during the Covid 19 pandemic.

experience storytellers to support the identification of the key points and themes from across the lived experience stories.

The lived experience stories gathered identify how prevailing discriminatory attitudes impacted on decisions and actions that directly and negatively impacted (sometimes catastrophically) Deaf and Disabled people's lives during the pandemic. This work's core aim is to disrupt the narrative by collecting the lived and living experiences of Deaf and Disabled people so their voices are not lost, overlooked or side-lined as society rebuilds post-pandemic.

As a society, we must learn from these experiences and ensure we do not repeat harm in the future. Working with Disability Rights UK, we will feed this learning into the forthcoming COVID-19 Inquiry and into the services and institutions that work with Deaf and Disabled people. We want this work's findings to contribute to repairing the damage that has been done, and to ensure that Deaf and Disabled people's voices are heard and have influence on society's recovery from the COVID-19 pandemic.

"The DNR orders were deeply shocking." - Confusing and frightening information

The tone of official communications was often frightening and confusing, which made people feel more vulnerable than they were because of the 'disability' label. In many of the narratives, people referred to Do Not Resuscitate (DNR) decisions that came via official advice. This was explained by Baroness Brinton:

> *"One of the most shocking things about that first email was [being asked to] think about whether you want to go to hospital at all or not, or what you want to happen in the event of you catching COVID. Essentially, people were told to consider, do you want to have treatment? Unfortunately, a very small number of doctors decided, probably misunderstanding the rules, that in a crisis they were able to do that. But that was stopped, and it was stopped pretty quickly once it was discovered."*

How this information was given by official sources has been reported in the narratives as conflicting, incorrect, untimely and morally unacceptable. Baroness Brinton explained further:

> *"We had actually had a debate in the Lords, the previous year, about how they [DNR orders] worked, what was ethical, what wasn't ethical. And to be fair, ministers didn't have anything to do with this. This was from some misguided people in areas, mainly GPs, who were struggling under the weight of things. But the problem is, it wasn't stopped fast enough and I think it was appalling that anybody could just start applying DNRs without reference to the individuals or, if they didn't have competence, their families, automatically."*

Whilst Baroness Brinton acknowledges that this decision was stopped, nevertheless it created immense fear for Deaf and Disabled people. As Eleanor, the mum of a non-verbal young woman who has autism and learning difficulties puts it, "*If she had become ill, my fear was with all the things that had happened in the NHS and hearing the horror stories in the news about DNR, how would it affect us?*" Another mum, Sally speaks of her daughter's experience and the fear it instilled:

> *"Hannah has a severe learning disability and we were terrified that a DNR order would be given to her and we were determined to keep her out of hospital. Healthy people died because of the DNR decision. When Hannah broke her leg, the first doctor didn't want to mend it because she is a wheelchair user. They didn't ask if she could walk before she broke her leg (she could) they didn't value her - but that didn't surprise me. I believe that the government would have rather saved a 20-year old without a disability than a 20-year old with a learning disability. Putting a DNR on someone with a learning disability demonstrated this. I would have fought for a DNR not to have been forced on Hannah."*

For many, this fear has continued because decisions around DNR orders and the Frailty Index[3] illustrated the value that was placed on the lives of some members of society, that is, who people in authority felt were worth saving and who were not. Miro, an academic in the field of Disability Studies explains:

> *"The political response (in the UK and globally) considered what would be best for the majority of people. That leads to making decisions about which life is most important and deserves to be saved. The clinical frailty score made this happen. The utilitarianism approach doesn't work and it reinforces a eugenicist approach - the pandemic is an example of that because it was accepted that some lives did not matter. The political response was considered eugenicist by many Deaf and Disabled people as it failed to recognise disability as a political issue."*

Consequently, this "eugenicist" approach understandably led to increased stress and anxiety for the parents and carers of Deaf and Disabled people, and some have the lasting impression that the government was trying to get rid of people who were perceived as draining the system.

The prioritising of people in hospitals, in addition to DNRs having been applied without consent, shows that within society it's ingrained that people with a disability or impairment are worth less

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[3] Guidance from National Institute for Health and Care Excellence (NICE) on which coronavirus patients should receive intensive care treatment was released early on in the pandemic 2020. It said that all adults should be assessed for 'frailty' when admitted to hospital, and that 'comorbidities and underlying health conditions' should be taken in to account.

than others. The point was made, in many of the lived experience stories, that government and the whole of society need to understand this as a matter of urgency because Deaf and Disabled people believe it is systemic – that some people's opinions are valued more and, as a consequence, some people's chances of surviving are more / less than others. It was extremely frightening for people with a disability that if they ended up in hospital, they would not be a priority.

Furthermore, communication with and from statutory services and the government was criticised for being either insufficient or confusing. Some Deaf and Disabled people found the government gave mixed messages and it was difficult to ascertain what was current and accurate. Many families with Deaf and Disabled members were distraught and tried to work together to make sense of the information. Eleanor says how the information she received through the post made no sense so she *"ended up spending time with friends on the phone, going through the paperwork, to see if I'd understood what I was reading."* The overriding feeling is that neither national nor local governments understand personalisation and personalised care in terms of respecting people and giving them information about what will happen; much greater transparency is required. This is highlighted by Jo, who recounted that *"many in the community were absolutely terrified of the DNR information that was received. We tried to get a straight answer from health boards [in Wales]. It was quite messy, and we weren't given straight answers. So, it was a massive fear."* Another storyteller, Hazel, described the government advise as *"flimsy, to say the least, and confusing,"* while Mark called the letters *"gobbledygook"*.

Another comment was that the official shielding information came too late and when it did come it was confusing. For example, vulnerable people or someone with COVID were advised to live separately from other people in the house. Often that was not feasible, because many people live in small properties and only have one bathroom. Another point raised was that often people had no support and when they received information, it made no sense to them. In contrast, people who had more resources and more power, or more social capital (friends or family who were able to help explain the information), had a different way of managing the pandemic and lockdowns.

There were accessibility differences between the UK nations in terms of how Deaf people could receive official information. Frustration occurred because BBC News required Deaf people had to switch to a different channel to access sign language, but not all Deaf people had access to that channel; it depended on the TV service and channels they had. All official updates should have had a sign language interpreter as standard, and the information needed to be clearer:

> *"There was a lot of confusing information that was conflicting. You really just needed simple bullet points, and not just for Deaf people, but for all hearing people, for them to try and understand what was going on. For me, it was really difficult trying to actually understand. In Scotland they provided an interpreter. The Scottish COVID news was very clear about what was going on in Scotland. Again,*

in Wales they had a very clear interpreter, for every meeting and every news update; there was nothing in England."
(Amanda a British Sign Language teacher)

Overall, the sense from those sharing their stories was that the information was confusing, unclear and inaccessible at best, and outright frightening and traumatising at worst, highlighting deep-rooted systemic issues. Lessons need to be learned to ensure better communication with Deaf and Disabled people on all matters going forward.

In their lived experience stories, Deaf and Disabled people often reported that they could not abide by all the COVID rules because they knew these would not be appropriate for them or their carers in terms of risk. *"There was no conversation with disabled people about their needs and no trust in their knowledge about what would work for them,"* points out Andy. Instead of telling people what to do, it would have been better for people to have had conversations with Deaf and Disabled people so they could have made choices and explained consequences to others. There were some very confusing and stressful times as a result of this, and sometimes there was confusion about the rules. For example, the shielding guidance told people in the shielding group that they had to be very careful, but the support mechanisms were not in place for them since they might usually live alone but have carers attend a few times during the day. Alternatively, they might only have had contact with their partner or parents if personal assistants were not able to attend during the pandemic.

In respect of shielding people[4] and the decision-making process, particular groups of people were affected. Often, people who were not shielding or who do not have disabilities stopped thinking that reasonable adjustments were required. There was also a breakdown in communication between the NHS and social care in terms of meeting the needs of Deaf and Disabled people.

Even people who work for disability rights campaigning organisations reported that some of the COVID restrictions and rules were unworkable for Deaf and Disabled people. Some Disabled people did not know how direct payments could be used flexibly to purchase different services. *"I found it difficult to get PPE [e.g. from retailers],"* says Sally. *"But I found out by accident (after a few months) that I could have ordered it by phone from my local council from the start of the pandemic via a COVID PPE line. I needed PPE to keep PAs safe. The inflexibility of the system meant that direct payments couldn't be used to buy PPE".*

Many of the Disabled people who receive direct payments reported feeling they always had to ask permission and are expected to be grateful, e.g. when making amendments or changes to their

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[4] The shielding information applied to people who were considered clinically extremely vulnerable, e.g. immunosuppressed, immunocompromised, and having respiratory conditions.

support. During the pandemic, some decided not to ask permission because they knew what would be best for them and made their own decisions in order to survive. Campaigners and academics who understood the system reported they were transparent and accountable when not following the rules, telling the relevant people what they were going to do, rather than asking for permission. For example, some full-time wheelchair users reorganised their support, with the aim of protecting their personal assistants (PA), their partner becoming a paid PA, or PAs moving into their house.

The lack of coherent information and rules that were not sustainable for Deaf and Disabled people is symptomatic of systemic issues which flow from inflexible systems that are unfit for purpose, which will be explored in the following section.

"We were left to our own devices, within the constraints of 'you have to abide by our rules still'." - Inflexible and unrealistic systems

There was very little flexibility around how people could use their health funding and social care funding. Currently (and during the lockdowns) it is highly controlled, which led to people not being appropriately supported because of inflexibility by those authorising the direct payments. Said Sally of the situation: *"[With Direct Payments] We were left to our own devices, within the constraints of 'you have to abide by our rules still'."* Often, Deaf and Disabled people did not understand information from their local authorities who control the direct payments. There was guidance, but often councils or local authorities did not share that with people in receipt of direct payments. Consequently, Deaf and Disabled people felt they were not being supported, or supported very poorly.

When people did feel supported, it was because they had a good relationship with their social worker before the pandemic, and trust had been built. Some people either obtained permission to use direct payments flexibly, or decided that they would make the changes they needed in order to live safely and with dignity. Nevertheless, Deaf and Disabled people experienced fear of breaking the direct payment rules. Furthermore, many Deaf and Disabled people felt that clearer and fairer guidelines were required. For example, paid personal assistants/carers were given 2 monetary bonuses (one of £650 and another of £1000). However, unpaid carers (e.g. parents with a disabled child) only received one payment of £500. One such parent noted that if all unpaid carers were to refuse to provide care, the system would collapse: *"Furlough pay and self-employed grants made me upset and frustrated because without me, my son would cost the state thousands of pounds. It is frustrating because I know that what I'm doing is best for my son, but unfortunately, it's not best for me."*

"The government guidelines for carers during COVID was to write a back-up plan for when things go wrong, to support your family member… I still can't do that because there isn't

anyone. It's like the system wants me to write a plan that if Maddie's dad and I are run over by a bus, or are poorly, these are the people you can call who will sort it out. We haven't got anybody. For me that's a massive gap that the system hasn't dealt with. And my fear would be that Maddie would get carted off by social services or a social worker to some awful place." (Kate)

Many Deaf and Disabled people reported that social services seemed to be more concerned about spending money, rather than the welfare of individuals. When discussing direct payments and other financial support, there was a prevailing opinion that social services want to retain the money, rather than giving it to Deaf and Disabled people and that decisions are made from a financial perspective rather than considering what Deaf Disabled people want to achieve or what they need. Direct payments can be used flexibly but the government was late in giving official confirmation e.g. for communication devices that people would need. This meant many Deaf and Disabled people were confused and disadvantaged because their social workers had advised direct payments could only be used for specific people or equipment.

COVID and the lockdowns highlighted how Disabled people, or those with additional support needs, are largely 'done to' and never 'done with'. Those who gave their lived experience stories reported that power is rarely shared or understood by people who provide services for Deaf and Disabled people. Some even reported they would never ask social services for help and that the services are inadequate. For example, in parts of the UK, Deaf and Disabled people do not have specific social workers, there might be a phone number to call and they speak to a duty social worker, which means every time they have to explain their situation. It was also reported that at times people would feel 'hounded' by social workers. During the lockdowns, many Deaf and Disabled people reported they had no contact from social services. Donna, for instance told us that *"I couldn't get hold of my social worker. He completely disappeared……social services didn't even talk to me. Didn't give me a call to find out if everything was all right. In fact, I remember calling my social worker to find out if HE was all right because I was worried."* Kate, meanwhile told us that she had no support from social services until vaccinations were available and PAs could be vaccinated. She continues, *"I don't feel social services are interested in my family's circumstances, we're a case or a cost number to the local council. I don't trust them to have my daughter's best interests at heart."*

"In Essex, it was very difficult to get any kind of support via the council or local government - there was no central place to call and ask for help. I found the government guidance very difficult to understand. I did receive help from the voluntary sector and friends so that I could participate in online circles to help navigate the systems. Within those groups people set up their own systems for exercising or having a cup of tea together and that was a space to say to others that I was drowning and I wouldn't be judged - that was important." (Eleanor)

In many of the lived experience stories, there was little surprise that information was unclear, systems were inflexible and that they were ignored by statutory services. Thos was because, as Isaac says, *"Deaf and Disabled people being marginalised and restricted happened before COVID, but COVID magnified what happens to them."* Deaf and Disabled people having felt they had no voice, no choice and no control over their circumstances during the lockdowns was the most frequent comment made by the lived experience storytellers. Numerous examples exist of choice being taken away from Deaf and Disabled people or their carers. Furthermore, Disabled people and their carers were often not listened to as experts in respect of their daily needs. Consequently, Deaf and Disabled people, together with their carers, felt that they were in a situation of the system versus the individual.

When the COVID Act came into force, much of the legislation meant to protect Deaf and Disabled people appeared to be overridden. Disability rights' campaigners, who have full understanding of the legislation, reported that both the Care Act and the Equalities Act seemed not to exist, even though the Equalities Act 2010 was still in force there was no regard for it. The COVID Act seems to have been interpreted by local authorities that if they were short of staff and money that they could remove essential services from people in the community who needed them. Whilst it is acknowledged that some services had to close due to public health safety, the fact that the COVID Act and the government allowed Deaf and Disabled people's basic rights to be removed is a huge concern. One storyteller, Kamran, says: *"The local authority only seemed to be interested in my financial assessment. I had free care for 6 weeks and after that had to fund it myself. I did what I could to protect myself but had to accept that there were things beyond my control."* This experience suggests, again, that Disabled People and/or their carers were seen by local authorities and government as little more than numbers and drains on the economy. Highlighting this further, at one meeting with her local authority, a mother who cares for her son heard an official say: *"Unpaid carers are economically inactive and they need to get back to work."*

Furthermore, in some lived experience stories, people reported that the day services they had pre-COVID have not yet been reinstated by local councils and there is a sense that local authorities have used the COVID Act to deliberately reduce the level of resources needed to support Disabled people to live good lives. As Sally puts it: "*They [the council] were using COVID as an excuse for absolutely everything, they are still using COVID as an excuse for everything."* While it can't be denied that COVID has had lasting impacts, restoring services for Deaf and Disabled people (that never should have been removed) should be a priority, not something at the bottom of the list.

When these lived experience stories were gathered, one question asked was: What would you like the COVID Inquiry to know?

Most people responded that the Inquiry must hear directly from people with disabilities and impairments because they are the people who were disproportionately affected by the pandemic. Furthermore, the root causes of why they were disproportionately affected was because of systemic inequalities that existed in our society and across health and social care before COVID. As Kamran puts it:

"COVID shone a light on the inequalities we always said existed and how frail some of the systems in place are, whether they are at breaking point or just not there at all…. It's highlighted the inadequacies of the welfare benefit system to a wider range of people who had never had to engage with it."

Accessible and safe spaces need to exist. The problems have been identified, but opportunities and a taskforce are required to explore the possibilities of change. We all need to take responsibility for change, with Deaf and Disabled people being well-placed to do this, but they often find their voices are not listened to. Changes are needed in health and social care because, when crises occur, systems have to be able to respond, and the COVID pandemic has shown that this response was not achieved in respect of Deaf and Disabled people.

It appears the current systems that are supposed to support Deaf and Disabled people are ineffective, and during COVID there was an expectation that Deaf and Disabled people would cope because they are in the system; this did not happen. *"We felt we were left behind,"* says Clenton. Moreover, the impact of the pandemic or its ramifications are on-going and are a product of what happened pre-COVID. Concern exists that for the people who were most affected by the pandemic there will be some who are immediately forgotten about, because people want to move on and focus on the next generation. Consequently, change is needed, but change cannot be made using a flawed, inequitable system.

"Every time I had to engage with clinical professionals there were communication barriers because of masks or people not thinking about alternative ways of communicating. This was a problem prior to COVID but the pandemic did highlight the problem and exacerbate it." (Amanda)

"Normality / normalcy is toxic and deeply harmful to Disabled people." - Ableism and the value of Deaf and Disabled lives

From the lived experience stories, it appears society has an ingrained view of what it is to be productive, to have value and to be successful. This is coupled with what it means to be a good individual, and is often linked to self-sufficiency, individual responsibility, and aggressive competition with others. These principles are returning in post-pandemic society. Such attitudes are highly likely to compound the situation for Deaf and Disabled people, as many regularly face challenges and difficulties in daily life, with tasks that the wider society may consider easy, normal or manageable. As Miro puts it:

"In the post-pandemic society, the dominant voices are saying 'go back to normal'. However normality / normalcy is toxic and deeply harmful to Disabled people - it doesn't work for everyone because it doesn't allow for different ways of being or participating. Chasing normal is a form of ableism"

The work of the Inquiry and any response to the Inquiry has to be done in recognition that Deaf and Disabled people feel they are failed in times of disaster and humanitarian crisis. For example, during the pandemic, Deaf and Disabled people's families were not prioritised and emergency services were not geared to protect all lives. As discussed earlier, the DNR decisions angered and frightened Deaf and Disabled people. However, they were not surprised that decisions about medical care were made based on who was most likely to benefit and that older or Disabled people were not at the top of the list. Kamran summarises:

"In our professional work we talk about dignity and value and human-centred approaches. Then to experience how it feels when it's not like that at all, and you're just seen as this object that we've got to get out somehow and who cares how it happens, it's only afterwards that emotion comes out. Is that who I am or is that how I'm seen? What value and worth do they place on who you are?"

Within the lived experience stories, there was agreement that Deaf and Disabled people are not seen as an equally important part of society, or valued as much. Comments were made that they feel like easy targets to ignore, because they are not heard much in the media and do not have strong voices. Thus, they feel local and national governments deem them less of a political risk, an unimportant part of society, who can be treated less equally than others. Baroness Brinton underscores this when she says, "*Peers who are COVID deniers, who thought the vaccination was unnecessary, said 'well, you know, we're going to lose some people if they're vulnerable, if they're disabled. That's just life', and I thought, they're talking about me, they're talking about me."*

"We are not a useless commodity. We put into the system with our abilities when we are able. We have contributed to this country. We are still people in our own right. We are not a nonentity." (Eleanor)

"Deaf and Disabled people know how to be strong. They want to remain independent and manage their own lives, not just for their own interests but for their community as well. Disabled people also care for others and it is important for them to be included and

participate in mainstream society. Despite having disabilities they still have a lot to offer." (Banane)

"How can we live in a community where we are a minority, but more of that minority are dying? That's inequality." (Keymn)

Regarding inequalities, the primary concern was racism. The examples given by contributors included how people were treated in NHS hospitals and reports of age inequalities were given. There were also inequalities in terms of how carers were treated, depending on whether they were carers from within the family, unpaid carers or regular carers. Inequalities and the harsh reality of racism in practice meant that Disabled people from black and minority ethnic groups frequently had to rely on their communities for help, and often received poor treatment from health and social care services.

In one lived experience story, an activist who cared for her mother for over 20 years reported that an assumption was made as soon as an elderly, black woman with long term conditions went into hospital. The hospital knew what was going to happen. There was no information, no power share. Clinical staff were rude to her when she tried to obtain information about her mother and the hospital did not know what time her mother had died; however she was also informed someone was holding her mother's hand when she died, which is conflicting information. Overall, it was felt that the experiences of Black and Minority Ethnic communities were particularly poor during the pandemic, with people being adamant that this shows the level of systemic racism within our society, particularly in health and social care.

Additional inequalities occurred when Deaf and Disabled people were amalgamated into or labelled as one category. Furthermore, using the word 'vulnerable' to describe people led many Deaf and Disabled people to feel an additional inequality was being assigned to them. Examples were also given when people who could have been considered vulnerable were ignored, for example people with mental health diagnoses who were emotionally vulnerable, or polio survivors with reduced lung capacity. Often, clinical professionals made assumptions about what a Deaf or Disabled person might require, rather than asking that person what they needed or wanted. This was illustrated by Deaf people who had assumptions made about their communication needs. As Mark puts it:

"The inquiry needs to understand the voices of individuals. For some the isolation was severe, they were distressed and their voices were silent. It seemed as though identifying people as vulnerable would help them be protected, but that did not work. Some people still got COVID but others did not. Also, there were people who were extremely vulnerable in terms of mental health but were not classified as vulnerable."

Furthermore, digital exclusion was reported, along with other aspects of financial inequality. For example, although the furlough pay of 80% was helpful to people who have a good salary, 80% of the minimum wage felt very unequal and insufficient to manage on. People from ethnic minorities or from disability groups are often in lower income brackets, thus the inequalities had an additional negative impact on those who were already experiencing financial hardship.

It was acknowledged by some participants that progress had been made, pre-COVID, to support Deaf and Disabled people's rights with legislation. Nevertheless, it was commented that "We often have rights in law, but we don't enjoy them in practice".

"Throughout the whole pandemic, at no point did any of my professional medical people say you should be isolating… I was never on the clinically vulnerable list." (Kamran)

"Trying to manage without support caused my mental health to deteriorate." - Isolation and the mental health impact of COVID

Whilst it is understood that social distancing was essential during the pandemic lockdowns, the impact of isolation on Deaf and Disabled people had numerous consequences that cannot be ignored. In addition to isolation having led to depression and anxiety, other aspects of the lockdowns impacted negatively on Deaf and Disabled people's mental health. Donna tells her story:

"Trying to manage without support caused my mental health to deteriorate, especially having an emotionally unstable personality disorder, which made me not want to be alive. I found listening to the news very depressing. Rules and guidance seemed to change constantly and the fact that people in government broke the rules made other people fucked off and that made some people stop wearing masks. I think it would have been better if the government had admitted they did not know what they were doing as that would have been honest."

Eleanor, meanwhile, discusses how mental health issues are not often perceived as a disability because they are generally invisible:

"It traumatised me more mentally than physically. Even though people were helping me, I no longer appreciated the help. It was all about cleaning and making things safe. Why is it so hard to accept that none of us are in a linear state, all of us are individuals, all of us have disabilities or needs. And some of us may present as if we understand because of how we look, we don't have to end up completely in a wheelchair to be identified as disabled. There are mental health issues that are not visible."

This is echoed by parents and carers of people with autism reported that the post-pandemic world is problematic because test kits have to be bought. One parent explained that her son is obsessed with testing and his mental health deteriorates when he cannot do a COVID test. The post-pandemic world is difficult for him and his mental health has been in deep depression, which has a significant secondary impact on his mother's well-being.

The pandemic and lockdowns also led to some neuro-diverse people experiencing mental health challenges through not having contact with others and not being able to communicate electronically. Post-pandemic, such challenges have continued because not all day services have re-opened and some people with profound learning support needs have now become accustomed to not seeing other people and need support to re-learn how to socialise or to manage their fears and anxieties about going out.

> **"We lost a lot of people with disabilities and long term conditions during the pandemic, not because of COVID but because services were not designed, or developed or changed during COVID to support Disabled people, and that caused a lot of deaths. Going forward, we need to put people with disabilities at the heart of a situation like a pandemic and prioritise people with disabilities. We need to provide support so their health doesn't deteriorate. We need a system in place so carers know how to look after their loved ones who have disabilities or long term health conditions." (Hameed)**

"If it wasn't for the outside help I sourced from the voluntary sector, without them I couldn't have survived this." – The agility of the voluntary sector

There was substantial gratitude expressed in numerous lived experience stories for local and community initiatives, which proved to be able to respond to the crisis in a more agile manner. As Eleanor states, "*If it wasn't for the outside help I sourced from the voluntary sector, without them I couldn't have survived this." Hameed takes this further:*

"COVID was extremely difficult and challenging, but one thing that has come out of it is that we do have care in the community and when I say care I mean informal care. … We've shown the government that we can come together as communities and we can get through difficult times. … Some services were set up, not by government, or local government or the statutory, or the NHS but by communities rallying round…. This was done by the goodness of faith communities, cultural communities, local, informal people, doing things for others and that could have been more nicely organised, if there had been a bit more communication between these communities and the government."

One parent-carer, via the charity she helped set up, had meetings with her local council and arranged to have a weekly multi-agency meeting. Within this group were health, local authority, child social services and education, all in one room every week. The organisers put together frequently asked questions and obtained the answers at those meetings to help share the information with other parent-carers so they could have accurate, timely information. Other examples of community initiatives were community centres distributing food and friends helping each other with food parcels – “real heroes,” Andy calls them.

Nevertheless, sometimes assumptions were made that were not accurate, for example that all Deaf and Disabled people required food parcels or meals to be delivered. This meant some people received food that they did not require, although they were able to pass it on or share with those who could benefit. This is significant to the report and its recommendations because it illustrates points made above, about seeing Deaf and Disabled people as a homogenous group, in addition to demonstrating the resourcefulness shown in resolving challenges and not wasting resources. This will be discussed further in the Recommendations’ section.

Key learnings

This report has demonstrated how individuals’ lived and living experiences have common themes from which many statutory bodies, healthcare professionals and members of parliament must learn. The narratives collected show how discriminatory attitudes and decisions had negative impacts on Deaf and Disabled people’s lives during the pandemic, with the following key learnings emerging:

1. **Confusing and frightening information from national government and local authorities.** This needs to be addressed with future information co-produced with Deaf and Disabled people. Government needs to understand that there is a genuine benefit and value to engaging with Deaf and Disabled people. Currently, there is not a genuine commitment to co-production.

- **COVID highlighted and exacerbated existing systemic problems and Inequalities (including racism, ageism and ableism) within statutory services,** resulting in unwelcome labels of vulnerability and even involuntary DNRs. The government was not ready and this has been going on for a long time. Opportunities to reimagine health and social care – which do exist – must be taken in co-production with Deaf and Disabled people, with our statutory services and systems being redesigned from the ground up to form equitable services.

2. **Little understanding exists about Deaf and Disabled people’s needs**. Politicians, together with health and social care decision makers, need to live in our world. Few have really experienced what it is like to be a disabled person. It should not be about Deaf and Disabled people fitting into society. Instead, the

experiences of Deaf and Disabled people should be used to reimagine an alternative way of organising society which values everyone's participation and to champion accessibility and inclusion.

Recommendations

"We've got the potential to really radically overhaul what we've done previously and think about what is much more preferable and possible for Deaf and Disabled people to have accessible spaces to organise their lives around the things that matter to them, and things that are best for their health and wellbeing." **(Miro)**

As a starting point to restoring justice, co-production of new systems, legislation, education and social values is important and the Inquiry is asked to consider the following recommendations, based on the key learnings to emerge from this insight report.

Learnings	**Recommendations**
Confusing and frightening information from national government and local authorities.	A National Deaf and Disabled Strategic Committee should be formed, made up of Deaf and Disabled People as well as carers. With the right support, numerous challenges and struggles could have been easier to deal with during the pandemic., with Deaf and Disabled people often felt dictated to, rather than discussed with. A Strategic Committee would not only plan for future crises to ensure there are person-centred processes and policies in place, but also campaign for reform and redesign to make positive change to the everyday lives of Deaf and Disabled people. This Committee could also be mirrored at regional and/or local levels.
	Involve Deaf and Disabled people from the offset. There is evidence to show that organisations representing Disabled people struggled to get access to government ministers and decision-makers. The committees within and outside government

	did not have a proportionate level of representation of Deaf and Disabled people at a political level. In future crises, Deaf and Disabled people should be involved in decision-making from the start and there needs to be Government commitment to this policy.
COVID highlighted and exacerbated existing systemic problems and Inequalities (including racism, ageism and ableism) within statutory services.	There needs to be conversations between Deaf and Disabled people, Ministers, NHS chiefs, and other statutory services about how we can have a society that brings everyone together. Who and what do we value? How can we build that and protect it in law?
	We need to build a more caring society, to care about each other and to consider the language we use around inequality, disablism, racism because at the moment it’s like a them and us situation which is dehumanising and that starts with the language we use to describe people, for instance, labelling people as vulnerable.
	Working with Deaf and Disabled groups or individuals will enable solutions to be found through co-production. The private sector has been working with people to make improvements and it should be the same within statutory services. This is because Deaf and Disabled people and/or their carers know what works and what does not. They know how to save money.
	The pandemic showed that it is very easy to lose hard fought for rights with The COVID Act having overridden other legislation. The worry for Deaf and Disabled people is that when support and services are removed it becomes very difficult for these to be reinstated. In

	particular, when people are deemed to manage with a reduced level of support, that then becomes their new or normal level of support. The rights of Deaf and Disabled people need to be enshrined in law in such a way that an emergency solution such as the COVID Act cannot override them.
Little understanding exists about Deaf and Disabled people's needs.	Local pre-pandemic services for Deaf and Disabled people that have remained closed need to be reopened as a matter of priority, with additional funding provided by central government to assist this.
	Where such services need to be rethought or redesigned, this should be done in co-production with local Deaf and Disabled people.
	There needs to be a commitment to co-production with all marginalised communities – not just Deaf and Disabled people – by the Government, with formal guidelines set out – and enshrined by policy – pertaining to the creation and redesign of systems and services. After all, people with lived and living experience will tell you what is difficult. They will not always tell you what you want to hear, but if you engage with them, they can be part of a positive solution

The request is for the Inquiry to recognise the details and oversights explained in this report and to challenge the government to not forget about the voices that have gone. Deaf and Disabled people must be considered in a much more meaningful way so their voices are at the forefront of these conversations, not in a reactive way, but proactively.

Closing remarks (Kamran/DR UK)

Disabled people paid with their lives during the pandemic, due to structural inequality in our country. 6 out of 10 people who died from COVID-19 were Disabled people. Figures released in

February 2021 showed the unequal impact of the pandemic. We, Disabled people, were once again the hardest hit, as we were during austerity and today during the cost of living crisis.
We were not part of the Government's response to the pandemic. We were forgotten, not thought about and not heard. We must learn from these catastrophic mistakes so that this never happens again. For the UK, June 2023 marks 15 years since it became a signatory of the United Nations Convention on the Rights of People with Disabilities (UNCRPD). A central aim of the treaty is to require state parties to engage with their civil society, through Disabled Peoples Organisations (DPO). To have Disabled people at the table to inform thinking and planning. To bring lived experience into the work of national and local governments. The UNCRPD committee criticised the government in 2017 for not demonstrating engagement with DPOs. The pandemic demonstrated the importance of engagement.

This joint work between People's Voice Media and Disability Rights UK captures the voices behind the figures. The individuals and families that were impacted on during the pandemic and continue to be now. Their voices must be heard. People have shared their pain, trauma and sense of injustice with us. This must be a turning point where governments listen and take action. I am grateful to all those who took part in the interviews, for being open and for sharing their experiences.

ABOUT DISABILITY RIGHTS UK

Disability Rights UK's response to the Covid-19 Inquiry reflects our commitment to ensure that something worthwhile emerges from the suffering and trauma which has been inflicted upon so many both by the Covid-19 pandemic itself and by the decisions and actions taken during it which proved catastrophic for so many.
To ensure that nothing like this happens again requires this Inquiry to take both itself and those called before it into some profoundly uncomfortable spaces. How, for example, did we ever get to a place in which requiring Disabled people to, in effect, sign their own death warrants was considered acceptable? What beliefs and assumptions about the worth of Disabled people guided this eugenicist way of thinking?

Deaths of Disabled people in and out of care homes, lack of access to food shopping and PPE for Disabled people isolating and/or requiring personal care did not happen by accident. They were the result of long-standing policies and a series of political choices based on a discriminatory view of Disabled people.
Disability Rights UK & People's Voice Media have partnered to gather 21 lived experience narratives/ insights to ensure that the COVID-19 Inquiry hears the experience of Disabled people who lived through the pandemic and ensure that these voices are central to the Inquiry's exploration of the challenges that people face during the pandemic.

People's Voice Media has already collected a number of stories in relation to the experience of those with living and lived experiences and/or multiple disadvantage during the COVID-19 pandemic, These lived experience Insights will add to the learning of this partnership and provide a greater depth of knowledge and insight into the challenges faced during the pandemic.

We aim to support people to have a voice and share their lived experience of the COVID19 pandemic. We will endeavour to ensure that we have a diverse group of lived experiences of the Covid pandemic to enhance our knowledge of the particular challenges that individuals and communities faced. We are committed to the less-often heard voices being reflected in the Inquiry.

Find out more at: https://www.disabilityrightsuk.org/

ABOUT PEOPLE'S VOICE MEDIA

People's Voice Media is committed to creating a just world in which people's lived experience is heard, valued and has influence. We use storytelling as a tool for social change. Our work uses lived experience stories to inform services, research and policy in a bid to change institutions, systems and society for the better. Our core strategic objectives are to:

1. Enable people's lived experience to be heard and provide platforms for marginalised voices
2. Support people, communities and organisations to use lived experience to address inequalities and injustices
3. Inform and influence services and policies so that they better meet people's needs and enable people to live well

Our core values are:

- Learning and Evolving: These values represent our organisation's overall approach – we are open to change and this supports us to develop, innovate and adapt in changing contexts.
- Collaboration and Equity: These values represent our way of working – we connect with others to create social change, creating platforms via which people have their voices heard.
- Authenticity and Integrity: These values represent our behaviour – we live out our values in all that we do, allowing space for honesty and openness in our work.
- Optimism and Joy: These values represent our mind-set – we seek to find hope in all situations and bring a positive, solution-focused approach to all that we do.

Find out more at: https://peoplesvoicemedia.co.uk