House of Commons

Women and Equalities Committee

Oral evidence: Unequal impact? Coronavirus, disability and access to services, HC 386

Wednesday 24 June 2020

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Watch the meeting

Members present: Caroline Nokes (Chair); Sara Britcliffe; Angela Crawley; Alex Davies-Jones; Peter Gibson; Kim Johnson; Bell Ribeiro-Addy; Nicola Richards.

Questions 1–36

Witnesses

I: Fazilet Hadi, Policy Manager, Disability Rights UK; Ayla Ozmen, Head of Research and Policy, Action on Hearing Loss; Edel Harris, Chief Executive, Mencap; Sarah Hughes, Chief Executive, Centre for Mental Health.

Written evidence from witnesses:

- Centre for Mental Health
- Disability Rights UK
- Mencap

Examination of witnesses

Witnesses: Fazilet Hadi, Ayla Ozmen, Edel Harris and Sarah Hughes.

Q1 **Chair:** Welcome to this afternoon's sitting of the Woman and Equalities Committee. Thank you to our witnesses for joining us to take part in this afternoon's evidence session. I am going to start the questioning; my first question will be to Fazilet.

Over the course of the last 13 weeks or so, there have been complaints about the lack of information and guidance that is made available to disabled people. Much of the focus has been on the clinically extremely vulnerable—the shielded group. Which aspects of information and guidance for disabled people do you think have been particularly lacking?

Fazilet Hadi: The underlying problem is that the Equality Act does not seem to have been truly embedded in the thinking of Government or indeed other sectors. That actually gives disabled people some fantastic provisions around accessibility, and the need for policies and practices to be equal and non-discriminatory. To be honest, we have seen it across Government and other sectors.

To come back to your question about examples, there were some high-profile examples that were quite hurtful to the disabled community or sections of it. One of the most famous is the lack of British sign language interpreting on the main Government broadcasts. That has been raised all through the 13 weeks. No one can quite understand why other countries can deliver that, whereas the UK Government could not. Another high-profile example is the Prime Minister's letter that went to all households, yet not much was done around easy-read, large-print, audio versions or other formats.

There have also been examples where communication has not so much been inaccessible, but has not been properly thought through. There are two very prominent examples of that. One is the decision to relax shielding at the beginning of June. People were seeing press releases on the Saturday night, getting text messages, and the guidance was then published on Monday 1 June. That was a very insensitive way of delivering the communication and information to 2.2 million people with health conditions and disabilities.

Another example would be the transport guidance last week on face coverings. That was published on 14 June for implementation on 15 June and has caused some disabled people a great deal of concern, particularly those who are not able to wear the face covering for legitimate reasons that the guidance fully accepts. Because that communication was not handled to show the balance between wearing a face mask when you can but not wearing one when that is difficult for you, it led to confrontation, particularly between members of the public and disabled people.

Q2 **Chair:** Given that you have used an example from 14 June, do you feel that the communications have improved over the course of the pandemic, or is the suggestion perhaps that they have got worse?

Fazilet Hadi: Regarding accessible information and thinking about the needs of disabled people, I do not know what it is, given that the Equality Act was in 2010 and the Disability Discrimination Act was in 1995. I do not want to insult all officials and Government Ministers, etc. I am sure some of them have regard to disabled people, but the feeling from our side is that our needs have not been taken into account as they should have been, all through the period. It has not got better or worse. We always feel a bit like an add-on or an afterthought.

Q3 **Chair:** The publication of the equality impact assessment might have given us some indication right at the outset as to where disabled people had featured in the Government's thinking in planning for how they were going to tackle the pandemic.

Fazilet Hadi: I think everyone in government fully understands that there are a range of disabled people with different impairments—learning disabilities; sight loss; hearing impairments; autism—who all have varying needs for communication. We are 14 million, so we are a fifth of the population. Given that, it should not have been a surprise. Every piece of communication should have had that running through it like a stick of rock: "How do we meet the needs of these various groups and what do we need to do differently?" I saw good intentions sometimes, but I did not see planning.

Q4 **Chair:** You mentioned the lack of British sign language interpretation in the daily press conferences. There is also a vast array of information on gov.uk. How helpful for the hearing-impaired community do you think it would have been if that information had also been in some way conveyed in BSL?

Fazilet Hadi: You have raised a good point about online information. BSL is considered a separate, different language. I know there is another witness who knows a lot more about that than me. Your point is made well. Also, we know that a lot of disabled people struggle with online communication full stop, either because of affordability or due to accessibility reasons. Throughout the period, we saw a real reliance on digital from Government, the NHS and supermarkets. We saw that and it has been brilliant for some disabled people. We have seen some disabled people say, "Thank goodness. This gives me flexibility. I can do things differently." We have seen a lot feeling disenfranchised and abandoned as well.

Ayla Ozmen: I wanted to add to what Fazilet said. I absolutely agree with everything she said. The key problem we are seeing is that these things are really simple to do. We have communicated them to Government from the start and we are not yet seeing any tangible changes. The point about the BSL interpreter on broadcast media is a really crucial issue, but it is just the tip of the iceberg for the BSL community. That was a huge issue. There was no BSL interpreter on the key announcement that the Prime Minister made on 23 March. There has been no interpreter for the press conferences at the beginning. Now, the only interpreter is on the BBC News Channel and we know that many BSL users are not aware there is an interpreter on that channel.

There are also other issues. Like you said, there is key information on the website that is not BSL accessible. It took weeks for there to be a BSL version of the shielding letter. We raised that at the time and there is still no BSL version of the new letter to the shielding community. These changes are all very simple. The frustration is that we cannot really see why these changes are not happening. Besides BSL access, there are issues around subtitling—things going out on social media and on websites with no subtitles. Again, this seems like a very simple thing that can be done.

Regarding contact methods, people are being referred to telephone-only helplines. There is no reference there to the existence of Relay UK, which exists for all communication providers. It is just not mentioned, so people think it is not accessible. That is meaning that people do not have key information that they need. We have heard from people, for example, who have had a test and are not able to get the results because they have been given a telephone-only helpline. That is where our frustrations lie.

Sarah Hughes: My colleagues have spoken beautifully about some of those concerns. From a mental health perspective, one thing we have been struck by is that the messaging has not been psychologically informed consistently. For messaging to be heard by societies, communities and the population, it has to embody that sense of compassion and empathy. To follow on from the point of messages being released at maybe 8 pm on a Saturday night, for instance, that has a massive impact on families. Their ability to take on that information can then be disrupted if there is not a psychologically informed transaction happening.

There is something about the messaging not being just about behaviour and instruction, but about understanding the experience people are having, in terms of making sense of all the instructions that they are getting thrown at them. For our people with mental illness, managing and making sense of all those instructions can be very difficult if they are not within a context of being really careful around the psychological impact on people and trauma. We should all agree that this has been quite a traumatic event for quite a lot of people.

Q5 **Chair:** I am going to quickly go back to Fazilet. There was not enough consultation with disabled people about the measures around lockdown that are having a profound effect. How could that consultation have been better? What would good have looked like?

Fazilet Hadi: This is a refrain we have heard from disabled people's organisations across the country. They feel that they could have helped make information, policies and communication better. They felt that their voices were not heard sufficiently locally, but particularly nationally. That is strange, given that the Disability Unit was just on the verge of launching stakeholder meetings in April across England to engage with disabled people around Government policy. I understand that, in the heat of those first two weeks, the meetings were pulled. I do not understand why, at a time when we needed more engagement with disabled people to show that people were listening, there was just a lot of silence. Even though maybe not all our views could have been acted upon, just being heard would have made a huge difference.

It is not fair to say that no disabled groups were consulted. I think there were groups consulted. How you got on the list was not very transparent. There were a lot of Zoom meetings where there were hundreds of you, so you were being broadcast to. It was not dialogue. It was very much a sort of broadcast mode. We all accept that the speed of change was great and that digital had to be the main mode of communication. We all understood the limitations of that, but we feel that, despite those limitations, a lot more could have been done centrally, by the UK Government certainly, to show that willingness to engage, listen and respond. It builds on what Sarah was saying about that lack of empathy and connection. That has felt like a disconnection over the last three months.

Q6 **Kim Johnson:** I have a very general question around hard-fought-for disability rights and whether you, as a panel, feel that things have gone back 40 years. That is particularly in terms of disabled people being told what they can and cannot do at the moment. Some of your key issues are not being taken on board, particularly around communication.

Fazilet Hadi: In 2017, the United Nations Committee on the Rights of Persons with Disabilities reviewed what the UK Government were doing on equality for disabled people. It had a lot of criticisms around the way the Government were not consulting and engaging with disabled people. It pointed to a lot of areas of life, education, social care and housing where our needs were not being met. It is fair to say that these issues were apparent and obvious. They were evident. The rapporteur of that committee came back a year later. He went and met people across the country and he reinforced all those recommendations in late 2018.

The coronavirus crisis put a spotlight on all those inequalities. It put a mirror to them and showed us all how deep they were. For some of us, it showed how far away we are from being equal members of society. Despite good intentions and maybe goodwill, the value of our lives is not completely embedded in society.

Edel Harris: I echo everything that has been said to date. I am representing in particular work with people with a learning disability, but everything that has been said applies equally. There is the question about good consultation. During this process, there have been some examples of good consultation, for example the consultation around the Care Act easements and the Mental Health Act easements. Although it was a very onerous, time-consuming, exhausting and emotional process—everyone had to work very long hours and there was a quick turnaround—there appeared to be a genuineness about that consultation.

I would reinforce one point. It has already been made, but it is important to reinforce it. Throughout this crisis and indeed today, now, while we are sitting here, people with a learning disability feel very much like an afterthought. Guidance is often produced, distributed and communicated. It is only afterwards—when there is a lot of confusion, and there is reaction from people with a learning disability in their family and organisations such as Mencap—that the reasonable adjustments are made.

Although we have been happy to provide this service, we and other charities have had to do all the interpretation, translation and accessible formatting of Government guidance. It would be wonderful to see a time when it does not feel like an afterthought, with guidance having to be changed once somebody starts to think about the implications for people with a learning disability.

Sarah Hughes: We are obviously saying the same thing, in concert together. From a mental health perspective, we have seen some really positive consultation. The mental health sector broadly works very well together, but there are things that have been very challenging, for instance the NHS volunteering scheme. Initially, people with mental health problems were excluded from that scheme. It took us quite a long time to get them into the scheme. At the beginning of May, we were delighted to have resolved that, but of course the uptake is very small because the information about that is limited. The system and individuals do not have access to information that is enabling them to use the service in the way that we know they need.

There is the opportunity to really learn from this experience around communication before, potentially, a second wave. That is an opportunity to deal with some of these things that not only have been revealed by the virus but also have been an experience for decades. That is around decisions being made and people with disabilities being brought into those already established decisions to see if we can almost put a square box into a round hole, which is obviously impossible to do. There is something here about a culture of embedding disability rights and communication right at the very beginning. Also, what can we learn from this experience that we can take into the future? We have lots of people here now who are willing to share their experience for the good of the rest of society.

Q7 **Angela Crawley:** My first question is to Ayla. You mentioned the simple changes the Government could have adopted, in terms of British sign language, subtitles and communication in other formats. We have heard from other organisations as well that the accessibility of the Government coronavirus communications have fallen short of their equality duties. Could you describe the implications of inaccessible communications during the pandemic, specifically for deaf and disabled people?

Ayla Ozmen: The implications are huge. The first issue is around compliance with the guidelines. A lot of people have lost trust in what the Government are saying as a result of the failure to make communications accessible. I know the BSL community have felt really strongly that their asks have not been listened to. They have been asking for these basic things right from the beginning and there is a feeling that they have been ignored. Obviously that trust is hugely important at the moment and there is a lot of evidence to suggest that trust is what makes Covid responses effective.

This is not a small number of people. There are 12 million people in the UK who are deaf and have hearing loss, so it is in the Government's interest to do this. Then there are the issues around compliance as well. People are simply unaware of the severity of the situation. We have heard from people contacting us, saying whole families are unaware of what is happening until weeks later—until someone has been able to contact them. Then there is what I was saying about the testing information, so specific bits of information that remain inaccessible to people who have been actively trying to get that information.

Of course, there are huge mental health implications, in terms of the anxiety that this causes. Imagine if you are put in front of a screen that you know is vital public health information but you cannot understand a word that is being said. That is what a lot of people felt like, particularly in the Prime Minister's major lockdown announcement on 23 March. It was clear that that was a huge announcement, but it was completely inaccessible. It has a multitude of implications for people.

Edel Harris: It is not just the inaccessibility of the guidance; it is also when the guidance has been issued in a very rushed way. That can have very serious implications. There are two quick examples that fortunately have been put right. In the very early days of responding to this pandemic, whole groups of people with a learning disability were issued with do-not-attempt-resuscitation letters. They were encouraged to sign up to say that, if they did contract the virus, they would not request to go into hospital for treatment, and that they would stay where they were and potentially die.

Also, the clinical frailty score, when it first came out, wrongly, in our view, conflated having support needs with other issues. This caused massive fear and anxiety for people with a learning disability, who were already anxious and worried, and in particular for the families of people with a learning disability. As I say, both those things were put right and corrected, but the guidance was already out there. As a result, some GP practices and health trusts unlawfully, in our view, and inappropriately sent blanket letters around things like do not attempt resuscitation. That is a pretty serious matter, with serious implications.

Q8 **Angela Crawley:** Fazilet, from your point of view, how accessible has the Government communication been for blind people? How could that be improved?

Fazilet Hadi: I wanted to reinforce what Edel has said about that fear that was caused by the clinical frailty scale and the DNAR notices—20 March was the NICE guidance with the clinical frailty scale and then the DNAR notices were the week after. The fact that that happened at a time when the death rate was going up cannot be underestimated. Whether they were mistakes or mis-steps, I do not think the impact of those on the psychology of us, as disabled people, and the feeling that our lives were not valued in the same way, can be underestimated. Maybe we will come back to that issue later.

On blind people and accessible information, you see a huge variety. I have grown up being blind, so I listen to a lot of information through audio. A lot of older people who have acquired sight loss are going to need large print. I did not see any evidence of that being the norm. It is not a big deal with modern technology, as Ayla was saying, to deliver large print. I know that there was no lead in Government until very recently for accessible communication and information. There should have been more large print. On digital, some blind people love it and our lives have been changed by it; others really struggle with it and cannot adapt to new ways of getting information.

In terms of what could have been done, it is the same in a way as with deaf people or people with learning disabilities. Our needs need to have been built in from the beginning. It is not rocket science. It is really not rocket science. Charities should not have had to pick up and do the job of Government.

Q9 **Angela Crawley:** Many charities have had to step in in many ways to support those who needed that kind of vulnerable support at that time. I have a question to all the witnesses. What can the UK Government learn from devolved or overseas Governments about effective, accessible communication with disabled people during coronavirus?

Sarah Hughes: It is about hearing about the impact that information has on people. People have taken the information very seriously. It has deeply affected our lives. There needs to be a real deep understanding that disabled people are not an entirely separate group. They need to have access to that information at the earliest stage.

I would reiterate the point that has been made around the impact of the DNAR information and the letters that went out. I want to come back to that briefly because this is something about the learning for the future. These are things that will do harm. There is something about us having that inquiry about the things that have done harm. We need to attack those quite quickly. This was alongside a narrative that was, at the time, "The deaths are going up and the deaths are going up in people with underlying health conditions". If you are somebody with an underlying health condition and all those messages are coming out, I suspect that you are going to be in quite a fragile and vulnerable position.

To take your question, which was what the UK and the devolved Governments could do, there is something about that learning piece. I am concerned that we are very reactive in nature. We have an overreliance on charities, which is a risk in itself at this moment in time, because we are looking at a 40% decrease in charities perhaps over the next year. It is something about that deep understanding of what has gone wrong and an urgent attempt to rethink that quite soon, because obviously we are not out of the woods yet.

Q10 **Angela Crawley:** My question was also specifically on what the UK could learn from devolved Governments, accepting that other devolved Governments have done things differently.

Ayla Ozmen: There are good examples from other countries. Scotland, Wales and Northern Ireland have all had a BSL interpreter in the room at press conferences, which is something that is being called for here. In Northern Ireland, there are ISL and BSL interpreters on a screen in the room. There are other things that have happening in Scotland. For example, there is an SMS shielding service that was texting people to say how they could access information that they needed if they were shielding. There were BSL videos produced for the website. There was communication with stakeholder groups on how to disseminate information on contact methods that were available. They set up various different new ways of getting in touch, so a chat box and web chat was available.

Those things are all great but they are not revolutionary. As I was saying, these are really quite simple things. Along with a number of other disability charities, we wrote to the Prime Minister. After a month of waiting for a response, we received a response to say, in line with our calls, there has been a named senior leader identified for accessible comms in Government. We had a first meeting with her and issued a shopping list of the simple things that could be done to make communications accessible. We are hoping that can be taken forward. A lot of this has been overcomplicated in lots of ways.

The excuse that things are moving quickly and it is not possible to do those things is not valid. As everyone has said, it should have happened from the start. They should have been built in from the start. It is much more difficult to build in accessibility to something when it has not been thought of right at the beginning. We are hoping that this shopping list can be used for when they need to do things very quickly. They can use that as a basic list.

Edel Harris: I have a couple of quick points. Mencap works in Wales, Northern Ireland and England, not in Scotland, but I have recent experience of working in Scotland. In Scotland, health and social care is integrated, with, really importantly in this context, the third sector as an equal partner in that health and social care integrated system. That means that Scotland had a head start in some of this because of the integrated nature of the way it works and the importance it places on the role of the third sector.

In Wales and Northern Ireland, through our experience at Mencap, there has been more agility in responding to some of the issues that have arisen as a result of the coronavirus pandemic. There has been a much quicker and faster engagement and release of funding where it was needed. There has been much more visibility of the Disability Minister. We have to take our hat off to the Care Minister and others, who have, in my experience, engaged very well with our sector and with the disability charities through this, but I am afraid to say that we have not seen too much of the Disability Minister.

Q11 **Angela Crawley:** Sarah, from a mental health good practice perspective, what is your assessment of the Government's communications with disabled people during the pandemic?

Sarah Hughes: I wanted to reiterate some of what has been said around some good examples of engagement and consultation. We know of some great examples where local authorities are using their ability to convene local communities and organisations. We have seen in St Albans, Leeds and Sandwell some really good examples of local community engagement that has been thoughtful and powerful in terms of getting information and the learning out there and co-producing solutions with local groups.

From a mental health perspective, we would definitely endorse everything that has been said so far. We have been concerned that the information has not always been consistent, timely, psychologically informed and in formats that could be understood by a variety of different groups, particularly those with serious mental illness, who may not be in a situation to translate information that is coming out late in the evening or over weekend periods. Their support teams might not be available to help them think it through. We would be very concerned about that.

We would be very concerned about the information. We have had a lot of conversation in the daily briefings and in the media generally about an awareness of the metal health impacts of the virus. That has popped up fairly regularly. That has been hampered by a lack of really good data that has allowed us to understand the impact as we have gone on. Therefore, our ability to answer some of your questions is problematic because we do not have robust data that can allow us to feed back to you properly.

Emergency powers were created under the Mental Health Act. We are really pleased to say those emergency powers have not yet been used.

We really hope they are not used, but of course the early communication of that was very frightening. We had a lot of very anxious people worried about if we are reducing the number of people who are required to sign off a section, etc. There was a lot of confusion out there about what the new measures would argue for.

Like every other disability domain, it is about that consistency and thoughtfulness. It is about, "We can put this information out there, but how is it going to be received?" That is the issue. A lot of information is going out into the public domain but there is not enough understanding of how individual groups will receive, translate and implement that information into their daily lives. That has been a real challenge.

Q12 **Chair:** Ayla, you mentioned your shopping list to the Government. Have you shared that with the Committee? If you have not, please can you? Can you tell us when that was given to the Government? I hesitate to use the words "progress chasing". How are you monitoring whether those requests are being delivered upon?

Ayla Ozmen: I have not shared that shopping list and I absolutely can do. It arose from a first meeting that we had with the named senior lead in the Cabinet Office for accessible comms, which was about three weeks ago now. We developed this in conjunction with a number of other charities and presented that to Claire Pimm, who is the lead. The plan is to work with her to make sure that is disseminated throughout Government Departments and acted upon. I know that the Government themselves issued some guidance some time ago now, after our initial calls for them to act on this. We saw the guidance and what they were asking for from Government Departments was not very clear. The aim is that this shopping list will simplify things and make it much more straightforward to do these things, which are actually, as I keep saying, very simple. I have a meeting with her tomorrow, so I am hoping that a plan of how we use that shopping list will come out of that meeting.

Q13 **Bell Ribeiro-Addy:** I would like to start with a question to Fazilet about access to food. Access to food has been an ongoing issue since the start of the pandemic. We all saw panic buying early on and that meant many disabled people were not able to access basic food necessities. Supermarkets allocated specific priority slots. I was really shocked to find a survey by Savanta ComRes found that 38% of people who were disabled and vulnerable could not get slots, 46% said they had issues getting essential items, 36% reported long queues that aggravated their conditions and 26% were scared about catching coronavirus while shopping. There is a whole list of issues around it. I wanted to get your opinion on the extent to which you think disabled people are still experiencing these problems with access to food, be it online or going out to physically shop.

Fazilet Hadi: Food became a problem from the end of March. Hats off to supermarket frontline staff who worked through that early period particularly. I must admit that I have no praise at all for the leadership of supermarkets in this country. I will take you through the little vignette of what happened and then come back to your question about what is happening now. It has improved. What happened was a catalogue of disasters, from the point of view of disabled people.

The NHS came out with a priority list of people who were medically vulnerable. That was a top-down list. It had about 1.5 million people on it. Defra then took that list and began to ask people if they wanted food boxes. Meanwhile, tens of thousands of other disabled people felt that, for various reasons, maybe not medical, they could not go out either. It may have been that they were blind or had learning disabilities and felt social distancing would have been difficult. As you said, it might have been because they could not stand in queues for a long time. There are a whole host of reasons. Those who had online delivery slots and had used that as a way of managing their impairment for years suddenly found those slots gone because the supermarkets gave them to the clinically vulnerable list.

Suddenly, large numbers of disabled people who shopped online and in store found themselves completely at sea as to what to do. Maybe no one could have foreseen that situation for the first few weeks. If we had joined up our thinking about who might need supermarket deliveries and not just prioritised one group over another group without thinking it through, we could have avoided that. Government acted with good intentions, but in a siloed thinking approach, which then caused knock-on problems for tens of thousands of disabled people.

The supermarkets' reaction when disabled organisations wanted to talk to them about how things could be put right was, "We are going to take our lead from Defra. Defra is telling us this is the priority group. We might talk to you, but it will only be via Defra". That response from supermarkets has essentially carried on, despite letters from the EHRC to the British Retail Consortium and despite charities publishing open letters to supermarkets. There have been at least two in the last three months. They have actually rejected all direct dialogue.

I know they would say, "We have gone along to Defra meetings and talked to you via the BRC". I do not think that is acceptable. What other industry in this country carries on its conversation and dialogue with disabled people through intermediaries? These very big, multi-million-pound businesses have actually profited during the last three months, and good luck to them, because we all needed them. For them to not talk to us about what reasonable adjustments should be made is appalling.

People are still having problems. We still hear about people who cannot queue. We still hear about people who cannot get online delivery slots. We still hear about blind people who cannot socially distance in the supermarket. We hear about carers who are not believed that they are shopping for more than one person. We have had disabled people being asked for evidence of their disability.

I should say that this is very anecdotal. Because there is no promotion of what supermarkets' reasonable adjustments are, we are all getting very different experience depending on the kindness, helpfulness and training of the staff in our particular supermarket. It has been an appalling catalogue. I understand why there was a disaster in the first couple of weeks, but I do not understand why the supermarkets are failing to take responsibility for their own disabled customers.

Edel Harris: Once again, you have a panel of witnesses here who are nodding when each other is speaking. We have very similar experiences. When the coronavirus first hit, as has already been said, when we or people with learning disabilities and their families had the opportunity to speak to the key workers who work in the supermarkets one to one, they were incredibly helpful and empathetic.

Learning disability is often described as a hidden disability. There is a suspicion almost, and this is something that is now worrying us about the compulsory nature of wearing face masks on public transports, but I am sure we will come to that later. There is the stigma and hostility that people with a learning disability can and do face because it is not always apparent just by looking at someone that they have a disability. In the early days of coronavirus, we found that the supermarkets were not listening to us and were very reluctant to make reasonable adjustments.

Often, if you have a learning disability and are going shopping, depending on the nature of your disability, you need some support. We at Mencap—I know other charities did this, too—had to issue formal letters for all our social care workers, for all our colleagues, to carry with them when they were out shopping with a person with a learning disability, and to show this to the supermarkets. It seems unnecessary and adds to people's anxiety and fear about going out. I echo everything that has been said. We had a lot of calls to our helpline about this issue.

One last point is about the announcement very recently, yesterday, about the national shielding service and the service there around food and medicines. That concerns me, Mencap and other learning disability bodies a great deal. That is one access to food that is being removed from some people.

Q14 **Bell Ribeiro-Addy:** Ayla, in response to a letter from the Equality and Human Rights Commission, Helen Dickinson, the CEO of the British Retail Consortium, said that a community response is essential and urged people to consider picking up food for vulnerable people, disabled or self-isolating neighbours. Through this, we saw all those mutual aid groups, at the beginning about 1,500, and about 20,000 volunteers. I am sure this grew since then, as people were helping. Do you think that the British Retail Consortium and the Government became too reliant on these groups and neglected their responsibility towards the disabled community?

Ayla Ozmen: Those groups were and are inaccessible. The NHS volunteer responders did not advertise the fact that they were accessible via Relay UK and video relay, despite being available through those means. We had a lot of people come to us, saying they had received a text or a voicemail from the shielding service, but had no means of contacting these people who were supposed to be helping them access food. As everyone has been saying, there were similar problems with the hearing loss and deaf community. Supermarkets have abandoned their email contacts and said people can only call them, so there is absolutely no way of people getting on to the vulnerable priority lists if they cannot use the telephone.

Also, to add to that, as people are increasingly going into shops, BEIS has developed guidance for reopening shops with various measures in place—social distancing measures and face coverings, which are very restrictive for people with hearing loss. For people who rely on lip reading, it is absolutely impossible to communicate with someone who is wearing a face covering. That guidance needs to be clear about the reasonable adjustments that need to be put in place for not only the customers who are accessing food, but the staff in those businesses who have hearing loss and are deaf. That is definitely not clear at the moment in that guidance.

Sarah Hughes: I would say the same for people with mental illness. At the beginning, it was incredibly difficult for people with mental illness to access the NHS volunteer scheme. In fact, they were not included. They are included now, but we are not confident in that referral route in. The experience of shopping for people with mental illness can be very difficult in relation to food. It can be hard to get out if you have a certain condition, maybe a phobia or severe anxiety. It can enhance disordered eating.

We know that access to food is closely linked to mental health outcomes. Generally, for the entire population, this will have been psychologically very difficult, hence the hoarding we saw at the very beginning. You cannot underestimate the psychological impact we will have. Our entire response has been quite frantic and fraught.

As a shielded family, we have had a very good experience from our local Tesco—other supermarkets are available. We have had a very positive experience. I am very aware that, if you have the resources and capacity within your family to manage the shielding relationship, you are going to be able to access those resources well. If you do not, the shielding resource might as well be miles and miles away.

From our perspective, we would very much like to see the volunteering scheme expanded to understand the needs of all the vulnerable groups we are talking about today. We would also like the Government to understand the psychological impact of food restriction and access to food on the general population. There is a copious amount of research literature around about the psychological impact of food poverty and limited access to food.

Fazilet Hadi: I want to express my dismay and astonishment that someone from the British Retail Consortium should be telling disabled people to go and use friends, family and volunteers. If I want to use friends, family or volunteers, that is my decision. To say that we have to help out some of the biggest businesses in this country, making the most money, is a bit like telling me that, rather than my bank giving me a braille bank statement, I should go and get someone else to read it for me. I feel absolutely outraged about this because the Equality Act applies to supermarkets. I do not know if they know that, but they act like they do not.

On food poverty, I have heard Emma Revie give evidence from the Trussell Trust. Disabled people and disabled families are, unfortunately, some of the biggest users of foodbanks. Food poverty is a whole other issue, but it affects many disabled people.

Q15 **Bell Ribeiro-Addy:** That takes me on quite well to my next question, which you have half-answered. It is pointing to that same letter from the Equality and Human Rights Commission, which stated concerns about the inaccessibility of websites and telephone lines and the queues, which you have all touched on before, and store layout generally. Do you think that the Government should have done more to enforce reasonable adjustment measures on supermarkets? Following on from that, would you like the Equality and Human Rights Commission to take enforcement against these food retailers?

Fazilet Hadi: In a way, the Government, and certainly Defra, have tried to broker positive relationships, but actually it is almost getting in the way. It was great, because we were so desperate, as disabled organisations, to get food to the people who needed it, and Defra really tried to make some things work that were not working. I almost think they should step back now, because these is a direct relationship between disabled people, disabled customers and supermarkets.

I do not know why we have to be driven to enforcement action, unless the supermarkets think the Equality Act does not apply to them, in which case let us hear that. They are hiding behind the BRC. That is a question mark. Why would they do that? You can normally talk to the banks or other big institutions. It is really unusual to have so little dialogue. Most disabled charities get dialogue. If there is no dialogue, yes, there has to be enforcement action, but that seems a real shame when we know the Equality Act applies to supermarkets and the reasonable adjustments, given their wealth, have to be pretty reasonable.

Q16 **Bell Ribeiro-Addy:** I wanted to ask the question to everybody else, but we are a bit short on time. I will put my final question to Edel. It is about those categorised as clinically extremely vulnerable. We know that there are many people with conditions or disabilities who have been excluded from that list. Many of them have been told to shield but, because they are excluded from that list, they cannot get the priority deliveries and that has caused problems. In my own constituency, we had a tragic report of a disabled man actually starving to death because he was not able to access food essentials. It was so tragic. What do you make of the Government's reluctance to expand the clinically extremely vulnerable list to include more illnesses and disabilities?

Edel Harris: If we had longer, we could have a whole debate about the use of language in the context of disability. Even the definition of extreme clinical vulnerability could be open to all sorts of different interpretations. One challenge, and I am sure that this applies to the other witnesses here today as well, for people with a learning disability is that, first and foremost, they are all unique individuals. There are 1.5 million people in the UK with a learning disability. Not all of them would be described as vulnerable, let alone extremely clinically vulnerable.

I know it is not possible to look at everybody as an individual, but my response to the question would be that we do not just try to approach this in a very black-and-white way. Somebody's vulnerability, however we want to define that, will not just depend on a clinical diagnosis or a diagnosis of a lifelong condition. It will also depend on their living circumstances, their income, the context, the environment and the community. We need a little bit of agility around some of these lists and the ways in which they are interpreted so that the important message is that if you need support and help in one area of your life—in this context we are talking about access to food—you have the right help and support to enable that to happen.

This black-and-white way of trying to divide or describe groups of individuals who are unique but who may have something in common—i.e. a disability—is not helpful. A more agile, flexible individual and community response is what is required.

Ayla Ozmen: The key thing is that this should be in the supermarkets' interests. That was what I was saying. There are 12 million people who are deaf and have hearing loss. They should not need to be on a list or classified as clinically vulnerable. They do not see themselves as clinically vulnerable. It should be something that is done as standard. Lots of private sector organisations see that this is something that is in their interest. There are banks, for example. Lloyds Bank has a BSL version of its website. Supermarkets have been very quick to dismiss that this is a large number of customers that they are talking about here. If they are not listening to their legal duties, they should at least see that it is in their interests.

Sarah Hughes: I would absolutely concur with that. Speaking to Edel's earlier point about a cynicism and a suspicion that people are somehow trying to work the system by declaring a vulnerability, we are past that, in terms of that way of thinking about human beings. This cynicism that we have seen from the supermarkets probably needs to be addressed broadly from a leadership perspective. We have heard very positive stories of what it has been like for people who have been trying to get access to food from people on the frontline. We really need a step change from the supermarkets broadly to step forward, acknowledge and work with disability in a proactive way. This is not just about having accessible doorways. This is about having accessible culture within their supermarket environments.

It also speaks to me around the learning that they could get from other industries. Ayla has talked about the banks. We have seen quite remarkable steps forward in mental health terms from the banking industry and certainly from the City. We have seen remarkable shifts in the way that they treat their customers, seeing them as valuable. You will see the adverts from Lloyds and others about, "We are going to stand by you through this time. If you have a mental illness, come and talk to us. We are going to try to help you through this". That messaging has not been there from the supermarkets. It has all been about, "How can we fill the shelves with toilet paper?" If we had a much more psychologically informed approach, we might be able to address the issues around cynicism and, frankly, discrimination. That is what it boils down to.

Q17 **Alex Davies-Jones:** Thank you to all the witnesses for giving very powerful evidence to us today. My section of questions is primarily on mental health, so, Sarah, they will be addressed to you. If any of the other witnesses want to come in with comments, please do. Sarah, you mentioned that the messaging so far during the pandemic has not been psychologically informed. One of my big bugbears has been the term "social distancing". It should have been coined as "physical distancing" because, at this time, we have all needed that social contact with people. It is something that has kept a lot of people going, these Zoom calls and keeping in touch with people on social media. How concerned are you that the pandemic and the negative psychological effects of isolation and physical distancing may be doing irreparable damage to the mental health of disabled people?

Sarah Hughes: We as an organisation, at the Centre for Mental Health, are being very cautious about talking about a tsunami of mental illness consequences as a result of the crisis, but we cannot underestimate the particular impact this will have on people with severe and enduring mental illness prior to this extraordinary pandemic that has impacted us all. Again I make the point that, from a mental health perspective, the information has not really taken into consideration how that is received.

When you are making changes to the Mental Health Act and the way people will receive their care, that communication needs to be thought about in terms of the implications. It could have an implication that somebody further deteriorates in their mental health, self-harm or other forms of self-injury. The risk of getting it wrong is quite high.

We know that there will be a long-term impact on people with a disability from an isolation point of view. We already know that is a problem. This will be enhanced because of the pandemic. We know that certainly the language around social distancing has been problematic, partly because there has not been a real opportunity to truly understand what that means. Like you, I would have liked to have seen a physical distancing approach. All of this nuanced, thoughtful language makes a difference.

I am sure you are going to have lots more questions in terms of the mental health of the nation in response to the pandemic. It is fair to say that this should absolutely be a priority for Government and I am happy to talk in more depth about that. In this instance, the information coming out has not helped people's mental health in any way.

Q18 **Alex Davies-Jones:** Given that impact, what could and should be done at this stage to lessen the negative psychological impacts going forward?

Sarah Hughes: There are the examples we have given before around that co-producing of information, that drawing in of people with lived experience to make sure we consider how that communication is being received. I know somebody who is saying that every time she listens to a daily briefing she comes away feeling unclear. She needs to talk about it with somebody to try to translate it. It is about making use of community resources, so that there is a real, viable local route to both understand and translate information on behalf of local communities. I do not think you can do this at scale.

Q19 **Alex Davies-Jones:** Yes, I agree. The other big issue we have had during the pandemic is access to mental health services. I have had constituents contact me, saying that they could not go to their group therapy sessions because of the situation. They did not have access to their psychologist or their therapist. Do you think enough is being done to maintain access to mental health services during the pandemic?

Sarah Hughes: We work with a lot of practitioners across mental health, in both public and third-sector environments. Without doubt, the people providing the services are doing their absolute best. I really want to honour them during this time. I know that they have had a very difficult experience as well. The campaign about, "We are open for business," came a bit late in the day. Certainly for the first month, we would very much say that access to services absolutely went down. We were talking about something in the region of a 40% reduction in the access to services that people had been using, but a 42% increase in the number of urgent appointments that the mental health services were dealing with.

It is not entirely true that people have not been able to access services, but it is about what services they are accessing. If you are somebody who has been engaging with somebody for a period of time, that service may have dropped off a cliff. If you are somebody who has needed support during a crisis, you may very well have been able to access support in a quite straightforward way.

The other thing about access to services is the manner in which people were invited to access those services. We are talking about moving all services online. That would be very difficult for some people because they are digitally excluded—they do not have laptops, broadband or the capacity to use those systems. They may not be in an environment where they can have a therapeutic conversation. If you are in the middle of a family home, having a private, confidential one-to-one with somebody would be very difficult. It also sparks safeguarding concerns. If somebody is vulnerable, how will they be able to engage in this service in a positive way?

There are a multitude of reasons why accessing a digital service is problematic for a number of people, not least the people who are delivering that. We know that there are people delivering therapeutic services from their own homes. It is a complex interchange of factors that make access to services very difficult.

Q20 **Alex Davies-Jones:** Yes, absolutely. You are from the Centre for Mental Health and you have told us that Anxiety UK's helplines have quadrupled during lockdown. I know in my own constituency we have had local groups set up and they have been going online. They have been holding Zooms. We have a really good men's mental health group in my own village. How confident are you that our mental health services will be able to cope with demand as we emerge from this pandemic? We know there has been a massive increase. Will they be able to cope?

Sarah Hughes: We are going to relook at this in a couple of weeks' time, but as it is we are suspecting that there may be 500,000 extra people needing mental health services as we emerge from this pandemic. Most areas are working to a 30% surge in the need for services. We know Bristol, for instance, is working to 30% and other areas too.

Before the pandemic hit, we were incredibly concerned, although not about the desire and commitment the NHS has to deliver the services that were outlined in the long-term plan. That is absolutely on track and working closely with Claire Murdoch and others from the mental health team to drive through some of those commitments. The reality is that we do not necessarily have the workforce to deal with those people who we already have in the system and those who are going to need services in the future. Particularly for people with disabilities and long-term physical health needs, often that comes with mental health problems too.

At the moment, we are hoping to come to some clarity about what the surge in demand is going to be, as well as working to understand the needs of particular groups. Those with physical needs are a great worry to us, frankly, because the workforce and interventions are not necessarily there.

Q21 **Alex Davies-Jones:** I would like to talk now about the Mental Health Act and the implications we have seen as a result of the new coronavirus legislation that has been passed. Do you agree with the Royal College of

Psychiatrists that, on balance, the emergency easements of the Mental Health Act should be kept in place as long as they are only ever used as a last resort?

Sarah Hughes: Yes. This is a very difficult area. I worked very closely with Sir Simon Wessely when we were doing the review of the Mental Health Act. We worked very hard to come away from a very restrictive Mental Health Act that had a very negative impact on those people who had experienced it. We are very concerned now that the emergency measures are further away from what we recommended than the original Mental Health Act that we were reviewing. We are further away than ever.

Thankfully, those emergency measures have not been used. We really do not want to see that happen. We understand that, within the system, to ensure the safety of all, these emergency measures need to be available, but we will push with every fibre of our being so that we can help the system resist that for a long as possible.

Q22 **Alex Davies-Jones:** The fact that they have not even been used yet shows that they are unnecessary, arbitrary and should be repealed at the first opportunity.

Sarah Hughes: You could definitely argue that. We have probably been through the biggest time of the crisis and we have not gone to that place. I think the evidence is showing that we will not ever need it. Like probably most people on this call, it is very hard to predict what is going to happen next.

Q23 **Alex Davies-Jones:** On trying to predict what happens next, there are concerns that these new easements could derail the actual important Mental Health Act reform, like you mentioned. Could you expand on your concerns on that?

Sarah Hughes: The review of the Mental Health Act looked at making sure we could increase the balance of power so that it sat more equally with the patient and with those delivering care. We wanted to go for the closest we could to a human rights approach within the parameters that we had. We have come up with a reform that is quite radical, in terms of giving power to the patient. We do not want the Government or the system to think that moving further and further away is a direction of travel that we are all comfortable with. We absolutely would not be comfortable with that. The reform of the Mental Health Act was about giving power back to the patient in the way that it should be and that is ethically right.

Alex Davies-Jones: Yes, absolutely. I suppose that is another argument for removing the easements as soon as possible.

Q24 **Sara Britcliffe:** I am going to talk about healthcare. I know we have already mentioned it. I would like to address my question first to Edel and Fazilet. This is what we have already spoken about, but a more in-depth response. The Equality and Human Rights Commission told us in May that it was satisfied that both NICE and the BMA had responded quickly to concerns about potentially discriminatory guidance to clinicians about who to treat for Covid-19 in hospitals if services became overstretched. We have discussed this, but are you satisfied that your concerns have been addressed effectively?

Edel Harris: Yes and no to this. As I have already said, within a week of each other we had the blanket use of do not attempt resuscitation and the production of the clinical frailty score. It caused huge upset and anxiety, and, as has already been said, made a number of people with a disability feel that their lives were less valued. It caused unnecessary anxiety, particularly for older parents who have a son or daughter with a learning disability who live with them. They were already concerned because of their age profile that they may get coronavirus. They then were of course doubly concerned that, if their loved one with a learning disability contracted the virus, in some way they would not have access to treatment. It was a really serious and very awful thing to have happened.

I know Mencap was not the only organisation by any means that responded strongly to this. To give credit where it is due, NHS England issued letters very quickly to put things right and the clinical frailty score was amended. We had one issue when it was amended. Although it was amended and was on the website, they did not actually communicate with any clinicians that the amendments had been made. We had to push pretty hard for that, because I am not sure that, in the middle of a crisis in intensive care units, consultants were running to look at amended guidance on a website.

Our fear now, and we have a number of live cases in this regard, is that some of these do not attempt resuscitation notices have been left on people’s medical records. It is definitely discriminatory. It is bordering on unlawful. We are giving advice to individuals with a learning disability and their families that they must check and see if these notices are still on medical records. If they are, they must have a conversation with their GP and other relevant clinicians to make sure their wishes are made really clear. Out of the context of a coronavirus pandemic, you may have a different view as to whether you want something like that sitting on your medical records. Going forward, we certainly must not see cause of death ever being described as having Down’s syndrome or having a learning disability. It is not appropriate. Our concern at the moment is that that may still be occurring in some situations.

Fazilet Hadi: I do not think the issues have gone away. I agree with Edel that letters were sent promptly by the NHS leadership. The EHRC got involved and the BMA responded. All those good things happened. Later on, I think at the end of May, there was another personalisation statement produced by the NHS around really emphasising that you had to talk to people about their end of life, etc., not just make blanket decisions.

For me, it leaves a bad taste and my thinking that the NHS does not fully understand and respect disabled people. Those incidents, while they were put right on the face of things, have left me with concerns about what happens on the ground, what training medical people get and what is in the NHS plan around supporting millions of disabled patients to get an equal right to healthcare. I know there is a workforce standard for disabled staff, but it leaves me thinking that the NHS needs to do a lot more work to convince me and other disabled people that we will genuinely get access to equal treatment. On that scale, it literally showed that, if you needed support to live, your life was worth less. I do not think letters do it for me. The fact that that was in someone's head and that it was produced leaves me with a very uncomfortable feeling.

Q25 **Sara Britcliffe:** My next question was what steps you would like to see the Government taking further, but I think you have both answered that question. Would you like to come in on that, Sarah?

Sarah Hughes: I wanted to reiterate that point, but from a mental health perspective. We know that 6% of the people who have died from Covid, on NHS England figures, have a mental health problem. We know there has been an increased death rate from those who are detained in hospital or subject to a Mental Health Act in-the-community order. Many of these are Covid-related and have been confirmed as such.

Access to healthcare for people with severe mental illness is very problematic already. We run a campaign called Equally Well, which is about trying to bridge that gap. We understand that people with mental health problems are very likely to live with long-term physical health needs. Access to physical health checks and being able to access help for their emergency physical health needs is very disrupted as it stands. We are very mindful that, for this particular group, access is very complicated. We already know that people with serious mental illness die up to 15 to 20 years before everybody else does.

I have one final point on access to services and healthcare. I want to remind people that, after the 2008 recession, the most severely disabled people bore at least 15% of the cuts in terms of access to certainly social care and healthcare generally. We are very concerned that will be repeated because of the economic impact. Access to healthcare for disabled people going forward may be impacted because of the economic downturn.

Ayla Ozmen: I wanted to add to the points around access to health services. A major issue for people who are deaf and have hearing loss is the increase in use of remote appointments. Even before this situation, we did some research that showed over 70% of people were leaving GP appointments having not understood the information they were given. All health and social care providers have duty, under the accessible information standard, to find out and meet people's communication needs, and it is absolutely not happening at the moment.

We have heard from people that telephone appointments have been insisted upon, rather than video appointments, which would allow for lip reading with captions. People have been told that they should fill in an online form and then the doctor will call them back because they cannot access a telephone appointment. That is hugely significant now. Our concern is that this remote way of working and remote appointments will become the standard for the longer term. We need to make sure that, if that is the case, people with disabilities are considered and their needs are taken into account in how that is taken forward.

The second issue that is hugely significant at the moment is people who have hearing loss or are deaf rely on lip reading and facial expressions for effective communication, and that is completely masked by PPE. The new guidance means that all hospital staff, visitors and outpatients are wearing PPE, so everyone in a hospital environment is masked, including interpreters. It is impossible to meet people's duties under the accessible information standard while wearing PPE.

We absolutely understand the public health need for PPE, but there are also serious concerns and safety risks if people cannot communicate effectively. The Government need to produce guidance on how to resolve that conflict between those two duties. There also needs to be urgent approval of clear masks, which we know are available for use in the US, for example. They need to be available in the NHS here as well. There needs to be a big awareness-raising campaign around the issues that people with hearing loss are facing at the moment, because there has been absolutely nothing for a long time on this huge challenge in healthcare settings.

Edel Harris: There were a couple of important points on healthcare. I am not sure where your questions are going, but, very briefly, there is an issue for us around data, particularly in terms of the number of deaths of people with a learning disability. The picture is not clear at the moment. The CQC has published data of deaths that have been notified to them by providers, but that is incomplete because it did not start at the start of the pandemic. We also have the data from NHS England on deaths in hospital and we have the learning disability and mortality review. Some of the figures that are coming through are quite shocking, like an 134% increase in deaths of people with a learning disability in the mental health institutions and assessment and treatment units when compared to the same time last year.

As has already been said, I am obviously delighted that the Mental Health Act easements have not been required, but nobody really talked about prevention. For people with a learning disability in their families, right now, for those who are in receipt of social care support, day services are closed. There is no access to respite. Some families do not have support workers coming into the home because of fears of contracting the virus. They might be shielding. There is a real building up of mental health problems for the future. We need to try to reinstate, safely of course, some of these much needed daytime activities. When that is coupled with there still being no guidance around supported living or guidance for the 50% of the social care recipients who are working-age adults in the context of lack of access to services, something needs to happen pretty quickly to prevent additional health problems in the future.

The final point is to do with the transforming care agenda. Yet again, despite goodwill and good intentions, I am sure NHS England has missed its target in terms of people with a learning disability and/or autism being in institutions, often hundreds and hundreds of miles away from their families. Because of coronavirus, I am sure that has had an impact. We are nowhere near meeting any new targets that are set.

Fazilet Hadi: On what Ayla was saying about the accessible health information standard, we need to see that implemented in relation to digital communication, by the NHS or by Government. It is not good enough for everyone to just roll out digital like it is some great new saviour for us all. It is great for some people and discriminatory for others.

On Edel's point about death, I would like to see Public Health England investigate the disproportionate deaths of disabled people. It is not good enough to just brush that under the carpet and move on

Q26 **Sara Britcliffe:** Can I come back to you? You briefly mentioned it then. This is the non-Covid healthcare. Can you describe some of the most pressing difficulties being faced by deaf and disabled people because they cannot access the non-Covid healthcare services that they need during the pandemic? Also, what would be the priority to reopen now, once these announcements have been made?

Fazilet Hadi: The Office for National Statistics has been surveying disabled people. Far more of us are worried about non-Covid treatments and are waiting for them. It goes across the board, across all treatments. I would like to see the NHS consider not just medical priority but also the impact that being on a waiting list is having on your ability to function. If you are waiting with an existing impairment, for whatever the treatment is, it is going to make life much more difficult for you, potentially, than for someone else. It is not a competition, but the prioritisation of the 10 million. You can hardly think about how that is going to be done, but I would like it to be done, as colleagues have mentioned earlier, with sensitivity, personalisation and a real understanding of people's lives, not just through a medical lens.

Ayla Ozmen: In terms of specific services that I think need to be reopened as soon as it is safe to do so, audiology services are obviously vital, particularly at the moment. We know that, in normal times, people with unmanaged hearing loss are at greater risk of social isolation, and that is inevitably being increased at the moment. The ONS data showed that people with hearing loss, of all disabled groups, are least likely to have left their house or visited a green space in the past week. People with hearing loss are most concerned of all groups about accessing essential services.

Hearing aids have been proven to improve not only social isolation but some evidence shows that there are links to reducing the risk of dementia. Hearing loss is the largest risk factor for dementia. As soon as it is safe for audiology services to reopen, not just for those who need their existing hearing aids fixing, but for those who need fitting with hearing aids who had not previously imagined that they would need a hearing aid, but now are realising it when they are relying on using the telephone to communicate with friends and family and it is becoming much more vital, it is really important that those people get access to hearing aids.

We know that all the people with hearing aids are such a small proportion of those with hearing loss. We think that around 9 million people have unmanaged hearing loss. It is absolutely essential that they are reopened. Also, there are opportunities there, which the NHS is not currently taking advantage of—around new and emerging technology that can be used to offer these services remotely and create efficiencies in the system as well. That is not currently being taken advantage of and really should be.

Edel Harris: The annual health checks for people with a learning disability have been suspended. There is no clarity or guidance around when they will be reinstated or how they are going to be carried out. For example, are they going to be carried out remotely? I am sure there will not be one uniform approach to this, but it would be useful, because there is going to be a backlog. They are incredibly important when you think about the inequality in accessing healthcare and good health outcomes for people with a learning disability. We want to see those annual health checks brought back as soon as possible.

Q27 **Peter Gibson:** First of all, thanks to all of the witnesses for their contributions. My first points are directed primarily to Edel and Fazilet. We understand that there are eight local authorities that have taken steps to use the easement for social care. Do you have any data that you are able to share with us of the impact on disabled people in those specific local authorities?

Edel Harris: I do not have any concrete data, unfortunately. It is something that we are trying to gather at the moment. The good news in this respect is that the Care Act easements, which were widely consulted on at the start of the Covid-19 pandemic, have not been used as much as they possibly could have been, which is a good thing. At maximum, I think there are about six local authorities that have used the Care Act easements.

We are seeing activity and support happening in individual local authority areas and in individual family circumstances that result in a loss of support. That can, in some cases, lead to a crisis, which, in those cases, results in all sorts of challenges and problems to the individual and their family. We would be calling for those Care Act easements to be repealed as soon as possible. Fortunately, we are not seeing too many cases where they have been used, although there is an underlying current or conversation around loss of support. There is the point that has already been made about the future, particularly if we go into a period of austerity, and what that is going to mean for the reinstatement of essential support packages around things like respite, support for carers, and the budgets and number of hours that are available for people with a learning disability to get vital and necessary support.

Fazilet Hadi: At Disability Rights UK, we would like to see the elements of the Coronavirus Act relating to switching off rights in the Care Act, mental health legislation and education terminated in September. I find it astonishing that, for parts of the population that were acknowledged to have some of the greatest needs in relation to the crisis, it was felt that we were the ones that had our rights removed. I could not get my head around the logic of that and I still cannot. It was completely unacceptable.

Eight authorities, at various times, switched on the Care Act easements. It was not clear when you asked them why they switched them on. They did not communicate fully with their citizens. It was not clear what triggered the decision. Quite a few of them switched the Care Act on again relatively quickly, but you did not get many answers to your questions if you approached them.

The bigger issue is the levels of fear among disabled people speaking out about Care Act reductions. We have pretty much had stories from across the country of people's care packages being reduced. I think someone who gave evidence to the Health and Social Care Committee last week said that a third of her hours had been taken, which meant a third of her life had been taken. We find that happening. There is a project at the moment that is trying to get people to log their experiences. People do not want to speak out. People do not want to speak to the media. People are in a position where they feel, if they speak out, they might be penalised in some way. It is all really unsatisfactory.

Social care was treated as a second-class service for the first three weeks. It was not until after Easter that the social care plan came out. It was not until the end of April that disabled people receiving direct payments were given guidance from the Government. On 13 March, there was guidance for care homes, which was pretty inadequate. It was about keeping people isolated with the virus, keeping things clean and disposing of waste. Within three weeks, there was the guidance to move people into care homes from hospitals, with or without coronavirus.

The whole way social care was treated in the first month of the crisis showed a disregard for the lives of disabled people. Whether people meant that or not, that is what it felt like. Government knew where we were. We were in care homes, in supported living and receiving care in the community, and we were ignored for quite a long time. The death rates are a testament to that

Edel Harris: That continues to be the case. It has not stopped, unfortunately. I wish I had a pound for every time during this period I have had to remind the civil servants and politicians I have spoken to, and everyone else really, that more than 50% of the social care budget is spent on working age adults. Although of course we all understand the importance of the care home sector and older people in this context, the whole supported living, I do not think there is even a general understanding of supported living.

Everything has been focused on care homes. That meant that when supported living setting managers were calling up, for example, to get access to PPE through the general portals, they were not getting access because they were not registered care homes, but rather registered as supported living settings. There is a whole education piece to do here. Social care does not just equal older people, as important as that is. Even now, we do not have clear guidance for supported living. We have had to interpret the recent guidance that came out to care homes about visitors, for example, for ourselves and use some common sense, because it is really important that people in supported living settings have visitors, now that things are a little more relaxed.

There is a whole range of things, which would take far too long to articulate here. One thing we must do at the end of this crisis situation is not forget the light that has been shone on the social care sector. Although we are not here today to talk about the social care workforce, this has to be an immediate priority: that people who work in the social care workforce are paid on a par with the NHS and genuinely valued and appreciated in the same way that we have talked about people who work in the NHS.

Q28 **Peter Gibson:** Returning to the specific point of my question in respect of the impact on disabled people and the reduction in that social care provision—that easement—is it either of your organisations' intentions to gather specific data from those local authorities there?

Fazilet Hadi: We are in a project gathering evidence from all 152 local authorities in England. We feel that, whether you had an easement or not, local authorities are reducing the care they are providing to people. In a way, you could say that the ones with the easements might have been a bit more transparent. I did not realise this, but you only have to register your easement if it has gone past stage 2 of the guidance. There might be all sorts of authorities out there that are at stage 2, which I think means you have closed various day services, etc. Luckily, the easements are a little bit of a red herring in a sense. The real issue is chronic underfunding of social care and disabled people not getting enough money to do more than survive and nowhere near living full lives in the community.

Q29 **Peter Gibson:** I can see Sarah is indicating an intention to answer, but my next question was for you, in any event. I will give you that and then you can answer the point from the previous question as well. Specifically with regards to those with mental health difficulties, in terms of the easement of social care in that particular sector, do you have any data and information for that particular area?

Sarah Hughes: Like my colleagues, we are in the process of collecting data. Answering some of these questions is very problematic from a data perspective, apart from wanting to give Edel applause earlier on, because I do not think you can understand these easements without putting it into the context of an extraordinarily underfunded social care system. We need to understand that, as Edel said, 50% are working age adults, which includes people with serious mental illness, in terms of support in their homes as well as supported living and residential care.

That context absolutely has brought us into this situation where easements are happening. I think it is right that we probably have more local authorities at stage 1 and stage 2 than we have people who have gone the entire distance with that. We certainly know anecdotally that day centres have been closed. One-to-one services, in terms of supported living, have not been able to be delivered because of lack of PPE and various other reasons. The easements are particularly challenging. I see that only one is using them now. Is that right? We have moved forward.

There is a very real risk that we could, as we approach winter months, re-engage in these easement discussions. It may be a way out of some of the challenges that social care generally faces. As a matter of urgency, we must get a fair settlement for social care. We cannot discuss easements without understanding that context. While I understand the question, the context is really critical. We know that local authorities, from a prevention point of view, have not been able to deliver a prevention agenda that will help social care in the long term. We have a complicated range of factors here and we would be very happy to come back and talk to you about that too.

Q30 **Nicola Richards:** My question was to Edel, and it has been touched upon already, about how concerned you are about the data released by the CQC on deaths of people with learning disabilities and autism in social care. Maybe I can add to that question. Do you think enough is being done to address concerns about personal protective equipment and coronavirus testing at homes registered to care for people with learning disabilities, autism and other disabilities?

Edel Harris: I hope we have made the point around the data that has been collected on the deaths of people with a learning disability. It is incomplete. It is numbers, but it is meaningless in some respects, so we certainly want some more attention paid to that.

The access to PPE has been a roller coaster right the way from the start. Fortunately, I guess because of the size of Mencap as an organisation, we already had good supply chains. We had access to suppliers that I know a lot of other social care providers in the sector did not have. It is a daily challenge, not helped by, in the first few weeks, the guidance changing all the time. I think that was often because the fear was that the social care sector would use up all the PPE that, at the beginning, people felt should go to the NHS.

On Easter weekend, the guidance was changed quite significantly about the type of PPE that should be used in certain settings within social care. We discovered it, quite by accident, on Easter Monday. It was not published or shouted about. There was a constant reaction to that.

We continue to stock up. We have spent over £1.5 million now on personal protective equipment in addition to what we would normally spend. We have had a mixed response from local authorities, to be fair. Some have been very good in covering our additional costs and others less good, but we will continue to look at that.

On the testing issue, there is a void, again in supported living. There is quite a lot of information around testing and priority testing for people in care homes, but we are still waiting on guidance in the supporting living context. We are still waiting for people with a learning disability to be given priority. This is a real issue for us and others. Sadly, we have had deaths from coronavirus, both of colleagues and people we support. We keep calling and pushing for guidance for priority testing for people with a learning disability.

Q31 **Nicola Richards:** Are primary healthcare services continuing to encourage learning disability social care providers and individuals with learning disabilities in social care to consent to do not attempt to resuscitate notices? I know this was touched upon as well. I wanted to clarify, if it is the case, why it is still happening against the clear guidance of NHS England. In your opinion, have the Government done enough to put a stop to this? If not, what should they do?

Edel Harris: As far as I am aware, and certainly from calls to the Mencap helpline and our conversations with other learning disability organisations, it is not continuing to happen, in the sense that there is not an issuing of blanket letters. In our supported living settings, for example, we had everybody who lived in one setting getting a letter because they had a learning disability. That is obviously, as I said before, discriminatory and potentially unlawful. As far as I know, it is not continuing to happen in that way.

As I have already said, the concern for us is that some of these notices are on people's records. There has to be an individual conversation, as we would expect people to have with us if we were facing the same set of circumstances. It is not over by any means as an issue, but it is not as big an issue as it was in the first few weeks of the pandemic, in my experience.

Q32 **Kim Johnson:** Thank you for your contributions today. My question is towards Ayla, Fazilet and Edel. I will start with Fazilet. What more could the Government be doing to ensure that people with communication and support needs and learning disabilities maintain access to education during this pandemic?

Fazilet Hadi: I am sure my colleagues may be more expert than me, but very recently a big survey came out from Disabled Children's Partnership with really astonishing headlines about the abandonment that many families are experiencing. I have heard a lot about back to school planning and whether schools are doing enough on remote learning, but I have not heard enough about how children with disabilities and other special education needs are being supported to be educated in their homes and what the plans are to help them to access alternatives if school is not an option at the moment.

Instead of hearing about those plans, the right to have your education, health and care plan delivered has been turned off under the Coronavirus Act. They were turned off in May and they were turned off for June. It was three days. On Friday 29 May it was turned off for Monday 1 June. Again, we see a bit of a disregard for the needs of families and children with very significant educational needs. I would like to see that group given much more priority, much more clarity about education and life skills while they are at home, and also support therapies that their parents and them are not getting at the moment. There is a lack of respite care. I feel they have not got a strong enough voice. Hopefully, this survey will give them more of a voice, but they have really been forgotten.

Ayla Ozmen: I am also not the expert in this area. The experts on education policy are the National Deaf Children's Society. I know a key issue is around online learning. There are obvious accessibility issues with online learning for people who have hearing loss or are deaf. There is a need for the right technology, making sure that there are BSL interpreters and transcription services for online seminars.

Also there needs to be an awareness of the fact that, even with the right technology, people with hearing loss and who are deaf are at a disadvantage with online learning, in that it can be exhausting following a BSL interpreter or transcription for any length of time. That needs to be acknowledged. There also need to be good catch-ups in place for when people return to schools and universities.

Edel Harris: The main points have probably been made there. Mencap is a member of the Disabled Children's Partnership. The survey that came out very recently said that 76% of families receiving support have seen this stop as a result of the pandemic, and 32% of parents of children with special educational needs are receiving no support at all in relation to their child's home learning. That is obviously quite concerning.

We are calling for there not to be an extension to the amendments to section 42 of the Children and Families Act under the Coronavirus Act when they expire at the end of this month. There is already a gap between children with a learning disability and their non-disabled peers. We see that gap widening at the moment. It is really important, as schools prepare for children to come back, that, in the same way we have said throughout this afternoon, we do not want children with a disability or a learning disability to be an afterthought, but to be centre of all the decision making and plans that are being put in place for the schools to reopen.

Q33 **Kim Johnson:** Going to that question about schools reopening, to the same panel members, should greater effort be made to ensure more disabled students can get back to their specialist schools? What needs to happen to ensure their safety and that there are no risks, in terms of the return to school?

Fazilet Hadi: I think that families and children will feel very mixed about this. There will be some who are ready to go back. There will be some who may feel, due to health conditions or other issues, that they are not ready to send their children back. The main issue is that we see planning for those children, whatever the decision of the family and the school is, and we do not see them abandoned. If they want to be educated from home for a bit longer, the right support package should be put in place—the right educational package, as Ayla says, with the right accessibility. If they want to go back to school, that should be an option, again with the right safeguards. We are not hearing enough about how families are being engaged with this process, whether they decide to stay at home or go to school. There are issues as well for young people in further and higher education. Again, accessibility requirements need to be considered because remote learning may not be as straightforward as for some other students.

Ayla Ozmen: I would echo what Fazilet said. Again, I am not the expert in this area. For more information on education policy, I would recommend going to NDCS.

Edel Harris: For the parents of children with a learning disability, although a school's primary focus is of course education, it is also a form of respite for parents and families. At the moment, there is no respite provision. There is no access to day services. As I have already said, some families are really struggling. There are also the other children in the family, who use school as a form of respite. Please think of this in the context of respite, not just purely education.

Q34 **Kim Johnson:** My final question to you, Edel, is around education, health and care plans. I think you touched on it briefly. Do you know how many authorities have relaxed their requirements? Is there still a case for allowing EHCP requirements to be relaxed, or should the emergency provisions be suspended or repealed?

Edel Harris: Our view is that they should be repealed. They have not been used in the majority of cases although, again, I do not have access to that data, as we have all said that we are still trying to gather it. We need to get back as soon as we can to life before the Care Act easements and the educational changes, so that all children with a learning disability have the same access and rights as every other child.

Fazilet Hadi: Could I add that it is a bit different with education? The Secretary of State switched them off for the whole country. It was not a local decision.

Kim Johnson: Thank you, Fazilet, for clearing that one up.

Sarah Hughes: I have one very small point. One in seven children with serious mental health needs also has a learning disability. We are calling for the re-entry of students to be psychologically trauma-informed, using a whole-school approach, and that we have speech and language therapists a well as counsellors going in. We need to have a really thoughtful, system-wide, whole-school trauma-informed approach, to enable children to get back to school and start learning in a safe way. Current plans do not feel too safe to me.

Q35 **Kim Johnson:** I have one final question. The Government announced the £1 billion catch-up recently. How do you feel that should be used to support the needs of the mental health sector, children with disabilities and others?

Sarah Hughes: It is very much about making sure that investment is not just about performance. All the narrative about that spending has been about getting children to catch up so that their educational attainment stays at a level. We are much more worried about children's health and wellbeing which, ultimately, will have a direct impact on their entire life health and wellbeing outcomes. That will inevitably have an impact on their learning, employment and relationships. It feels to me that there needs to be some consultation to think about how that money could be used to have a much more whole-system, whole-school approach.

Q36 **Alex Davies-Jones:** My question ties really nicely into your last one, Kim. One of my big concerns is the impact that this is going to have in the long term on children's mental health, particularly now as schools re-open. In Wales, the Welsh Government have specifically targeted this with funding for mental health in schools, particularly for children under the age of 11. This is in addition to the £1.25 million that they announced in April for local authorities to deliver counselling services directly in schools. Is this something you would like to see replicated across the UK to help children in all areas of our nation?

Sarah Hughes: Yes, absolutely. In other parts of the country, we have seen great strides to really understand the mental health needs of children and young people during this time. I have to say that we have lacked that focus in England. When we are talking about re-engaging children in a school environment, we must remember that they may have come from quite considerably difficult home environments, where there might have been domestic violence or poverty, or they might have had somebody in the family die. There are all these things, coupled with the stress of going back to school. We must not underestimate the traumatic impact of that. We are calling for the Government to invest very wisely in school environments, but not to focus just on performance. We will create great harm if we do that.

Chair: Can I take the opportunity to thank all our witnesses for the evidence they have provided this afternoon? It has been incredibly helpful and very thorough.