

# OPUS2

Scottish Covid-19 Inquiry

Day 14

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1 Wednesday, 22 November 2023  
 2 (10.00 am)  
 3 THE CHAIR: Good morning. Now, Mr Gale.  
 4 MR GALE: Good morning, my Lord.  
 5 The next witness, indeed the only witness today, is  
 6 Tressa Burke. She is a representative of the  
 7 Glasgow Disability Alliance and what she is presenting  
 8 us with today is an organisational statement on behalf  
 9 of that organisation. The reference to her statement is  
 10 SCI-WT000862.  
 11 MS TRESSA BURKE (called)  
 12 THE CHAIR: Now, Ms Burke, in you come and make yourself  
 13 comfortable or as comfortable as you can. Mr Gale is  
 14 going to ask you some questions.  
 15 Mr Gale, when you're ready.  
 16 MR GALE: Thank you, my Lord.  
 17 Questions by MR GALE  
 18 MR GALE: Hello, Ms Burke. Your full name is Tressa Burke?  
 19 A. Yes.  
 20 Q. Your personal details and your contact address are known  
 21 to the Inquiry and you're here today as the CEO of  
 22 Glasgow Disability Alliance?  
 23 A. Yes.  
 24 Q. How long have you been the CEO of that organisation?  
 25 A. I've been at Glasgow Disability Alliance for 17 and

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1 a half years.  
 2 Q. I think we know that it was formed over 20 years ago.  
 3 A. That's correct.  
 4 Q. I think in 2001, as you say in your statement. I will  
 5 ask you a little bit about the aims and the nature of  
 6 the organisation in a moment, but before we do that, you  
 7 provided the Inquiry with a statement and I've just  
 8 given the reference to it. You've also recently  
 9 provided the Inquiry with some further information which  
 10 is very helpful to the Inquiry because I think within  
 11 that further information you've given us some further  
 12 details of -- and in particular surveys that your  
 13 organisation has carried out and also you've provided us  
 14 with a number of quotes from members of your  
 15 organisation that bring home the impact of the pandemic  
 16 on disabled people; is that right?  
 17 A. That's correct.  
 18 Q. Now, in order that we get all that information before  
 19 the Inquiry, what we are proposing to do is that the  
 20 Inquiry team, together with yourself, will revise your  
 21 statement in the next few weeks and produce a revised  
 22 version of your statement which will then be published  
 23 to all core participants and be made available more  
 24 generally. We will wait obviously until that is done  
 25 before general publication. But at the moment and for

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1 today's purposes, we will utilise the statement that  
 2 you've given and that has been circulated. But as we go  
 3 through it, I'll ask you occasionally to add some of the  
 4 material that you've given in -- the material you've  
 5 provided to the Inquiry so we have some of that in  
 6 context as we're going through it.  
 7 You've also, as an organisation, responded to  
 8 a Rule 8 Notice from the Inquiry and we obviously have  
 9 the information that's contained in that and, on behalf  
 10 of the Inquiry, we're really grateful to your  
 11 organisation for the work that you've put in with the  
 12 Inquiry and we are also aware that your organisation is  
 13 not legally represented so we realise that it is very  
 14 much falling on you principally to do this, so we are  
 15 very grateful to you.  
 16 Right. Can you tell us a little bit about GDA?  
 17 I'll just call it "GDA". We know who we're talking  
 18 about.  
 19 A. Yes.  
 20 Q. Tell us a little bit about it. You say in your  
 21 statement at paragraph 5 that it's run by and for  
 22 disabled people, and then in paragraph 6 you say:  
 23 "GDA is a thriving disabled people led organisation  
 24 with in excess of 5500 members across Greater Glasgow.  
 25 [It was] formed in 2001 [and] is the biggest membership

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1 groundswell of disabled people in Scotland."  
 2 What are your aims?  
 3 A. Well, our aims are that disabled people get to  
 4 participate and lead their own lives with the support  
 5 that they need and with choices equal to other people,  
 6 other non-disabled people, and the way that we think  
 7 that we can do that is by promoting and supporting  
 8 equality rights and social justice. So the kind of  
 9 nature of the work that we do is we provide individually  
 10 holistic services. It was originally, historically,  
 11 built around learning and development, so we built  
 12 people's confidence and capacity to take part in things.  
 13 We raised people's -- working with them, raised their  
 14 aspirations to try things and be more involved in their  
 15 own lives and decisions that affect them. So we did  
 16 that, the learning and development programme. Added to  
 17 that, we offer welfare rights advice and representation  
 18 so that people can maximise the income they're entitled  
 19 to through benefits.  
 20 We also provide digital support and coaching --  
 21 that's something that was added during the pandemic --  
 22 and we provide support for people to build their voices  
 23 collectively so that they can speak out about the things  
 24 that affect them and decisions that affect them and  
 25 influence policies and service design as well.

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1 We also provide well-being, so again that was  
 2 something added during the pandemic. It's always been  
 3 an issue for disabled people because there's  
 4 a correlation between experiencing not just impairments  
 5 and conditions, but the barriers that disabled people  
 6 then face as a result of that, and mental health,  
 7 there's always been that correlation, but the tsunami of  
 8 mental distress and unwellness that people have  
 9 experienced, the increased suicidal ideation, has been  
 10 awful, so the GDA well-being team supports people by  
 11 giving one-to-one support on the phone. They also run  
 12 group sessions for people who can take part either  
 13 online or in person. So that's the kind of individual  
 14 things.

15 We've also got a research project funded by the  
 16 Scottish Government at the moment, and that's looking at  
 17 how disabled people can help shape the National Care  
 18 Service. So we help people navigate social care support  
 19 and services connected to that as well, which is really  
 20 important, and have a voice through our social care  
 21 expert group.

22 So those are the things that we do at an individual  
 23 level.

24 Collectively we work to support disabled people to  
 25 build their voices and their collective priorities and

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1 work together with service providers to be able to  
 2 design services that better meet their needs, so it's  
 3 about amplification of their voices and the issues and  
 4 the human rights that disabled people should have, but  
 5 don't have in reality. Then we collaborate with the  
 6 Government, with local authorities, the NHS, public  
 7 sector and third sector as well, sharing the evidence  
 8 and the insights that we've got from disabled people and  
 9 doing it all with disabled people. I think that's the  
 10 important thing.

11 So when anybody asks me about Glasgow Disability  
 12 Alliance, I think the really key thing that I would  
 13 stress is that we are disabled people ourselves. So I'm  
 14 a disabled person, my board are disabled people, more  
 15 than half the team are disabled people, so we are  
 16 working to the needs of disabled people, and we're run  
 17 by our members which is over 5,500, as you mentioned.

18 I think being a disabled-person-led organisation  
 19 during the pandemic and all of the time is so important  
 20 because there are so many people in the landscape who  
 21 provide services to disabled people that then sometimes  
 22 seek to speak for us, and it's really important that  
 23 disabled people get to speak for themselves through  
 24 organisations that we control and manage ourselves. So  
 25 that's kind of in a nutshell what GDA does and who we

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1 are.

2 Q. I'm glad that was a nutshell.

3 Now, in a perhaps more precise nutshell or  
 4 a confined nutshell, you set that out in paragraph 10 of  
 5 your statement. Can I just understand the range of  
 6 disabilities that you cover because obviously, at a very  
 7 simplistic level, one can identify obviously types of  
 8 disabilities, but what sort of disabilities do you cover  
 9 within the organisation?

10 A. Pretty much it's the full range. So we work disabled  
 11 people who experience barriers, and that's the common  
 12 collective thing that we're identifying and working with  
 13 people on. So it might be people with physical  
 14 impairments, mobility impairments, long-term health  
 15 conditions. It might be disabled people who have  
 16 learning difficulties or learning disabilities. It  
 17 might be disabled people who have hearing impairments or  
 18 visual impairments or blind and deaf people, as  
 19 sometimes people identify with those names rather than  
 20 the impairments. It might be people who have head  
 21 injuries or survivors of stroke, people who are  
 22 neurodiverse, who are on the autistic spectrum. So it's  
 23 the full range. I might have missed out some, but it's  
 24 the full range of impairments, and the important thing  
 25 is that people are united by the barriers that they

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1 experience so we're not specialists in any one area.

2 Our area of specialism is supporting disabled people to  
 3 tackle the barriers.

4 Q. That's really helpful. The groups that you have access  
 5 to and can inform the Inquiry about, are there specific  
 6 groups within the population that you have access to  
 7 that you can tell us about?

8 A. Yes.

9 Q. And they would be ...? Who would they be?

10 A. Right. So it's diverse disabled people, and by that  
 11 I mean people who experience even more marginalisation,  
 12 so not just disabled people who are white, middle class.  
 13 We've got usually people facing quite extreme poverty  
 14 and disadvantage; we've got black and minority ethnic  
 15 disabled people; we've got lesbian, gay, bisexual,  
 16 transgender disabled people; we have disabled women's  
 17 networks; we have disabled young people in particular;  
 18 older disabled people. So we have a range of networks  
 19 that are what we would call the "intersectional  
 20 networks", not because the people are intersectional --  
 21 they may have more than one protected characteristic  
 22 under the Equality Act -- but actually because the  
 23 barriers and the oppression that they experience is  
 24 intersectional and exponential, you know, in relation to  
 25 that.

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1 So the more protected characteristics you have, the  
 2 more barriers usually people face. So we get evidence  
 3 from them and insights from them across a range of  
 4 experiences and policy areas and service areas, and  
 5 obviously one of those areas was COVID and the pandemic  
 6 and how that affected people.

7 Q. I think one of the groups I think you also mentioned and  
 8 I know from the information you've recently given the  
 9 Inquiry, you also have information from the refugee and  
 10 asylum seeker community.

11 A. Yes, that's correct.

12 Q. Okay. One of the points you've raised with the Inquiry  
 13 is that, as a disabled persons' organisation, it's  
 14 important because it means that there is accountability  
 15 and direction of the organisation which remains with  
 16 disabled people themselves and I think you have  
 17 a mantra -- or you call it a mantra -- which is "Nothing  
 18 about us without us". Can you just explain what that  
 19 mantra reflects?

20 A. It reflects I think historical oppression that disabled  
 21 people have experienced and the kind of well-intended  
 22 paternalism of the way services have been designed for  
 23 disabled people rather than with them and, by  
 24 consequence of that, the number of organisations and  
 25 people who speak for us about what is best for us rather

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1 than asking disabled people themselves. So often very  
 2 well-intended services. Often before there were  
 3 disabled--people--led organisations, those were the people  
 4 who knew and they certainly do have a stake in what  
 5 happens to disabled people and how services are  
 6 provided, but they do not speak for disabled people any  
 7 more than white people speak for black people or  
 8 straight people speak for lesbian, gay, bisexual,  
 9 transgender people. And I think that we're in a loop  
 10 where we're not quite able to move forward from that,  
 11 partly because of how hard it is for disabled people to  
 12 self-organise.

13 So disabled--people--led organisations came about  
 14 during the 60s and 70s, when disabled people staying in  
 15 long-term institutional care started to ask questions  
 16 about the nature of their care, the nature of their  
 17 oppression, and the social model of disability developed  
 18 from that and it was an emancipated way of looking at  
 19 their circumstances that said, "Actually is it me and my  
 20 condition that's actually stopping me from going out and  
 21 having a life and being able to go to university or  
 22 socialise with my friends or is it the fact that I'm in  
 23 a care home and bedtime is 7 o'clock? Are those the  
 24 things?". And that's where all that comes from. So  
 25 "Nothing about us without us" is an international slogan

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1 for disabled people and our movement and GDA very much  
 2 adopts that as well.

3 Q. I think one of the ways you also phrase this is that --  
 4 I think you've said that for a long time disabled people  
 5 have been done to rather than people doing things along  
 6 with you.

7 A. That's correct.

8 Q. That sums it up, doesn't it?

9 A. That sums it up and that directly relates not just to  
 10 disabled people's lives generally but specifically in  
 11 relation to services like social care, so people not  
 12 having a say in the nature of the care that they need  
 13 and get means that they don't get to live the life that  
 14 they want to be able to live.

15 Q. And in your statement you set out at paragraphs 15 and  
 16 your vision and your mission. Perhaps you would  
 17 just -- again from the point of view of summarising  
 18 things, perhaps you could just read both 15 and 16 for  
 19 us, please.

20 A. Yes.

21 "Our vision is a world where disabled people  
 22 participate fully and lead our own lives with the  
 23 support we need to do this, with our human rights  
 24 upheld, connecting with peers and opportunities,  
 25 contributing to families, communities and wider society

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1 on a full and equal basis alongside non-disabled people.

2 "Our mission is to promote equality, rights and  
 3 social justice with and for disabled people."

4 Q. Right. Can I just ask about the way in which you  
 5 conduct your work? Clearly, as an organisation, you  
 6 will have contacts and connections and make  
 7 contributions to decision-making and, in that context,  
 8 so far as GDA is concerned, who do you collaborate with  
 9 in that context?

10 A. We are approached and respond to many opportunities.  
 11 So, for example, with the Scottish Government and the  
 12 NHS, with the Social Work Department in Glasgow, with  
 13 third sector organisations, but we also seek out  
 14 opportunities where disabled people raise issues that  
 15 are important to them. So the issues that came up for  
 16 us during the pandemic, we recorded them at the time and  
 17 we then fed them back to structures that set up, like  
 18 the Social Recovery Taskforce in Glasgow; the Social  
 19 Renewal Advisory Board at a Scottish Government level;  
 20 we're collaborating on the National Care Service at the  
 21 moment; we're collaborating on a minimum income  
 22 guarantee being designed for Scotland; we're involved in  
 23 the Poverty and Inequality Commission, which is very  
 24 new. That's just happened this month; and the First  
 25 Minister's Advisory Council of Women and Girls. Those

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1 are areas where we feed in disabled people's priorities ,  
 2 so the latter one is specifically disabled women and  
 3 girls , but obviously disabled people across the board,  
 4 so we work with the full range of people that we can  
 5 within the resources that we have.  
 6 Q. Now, I'm conscious of the fact that your organisation  
 7 has been going for over 20 years. One of the issues  
 8 that this Inquiry is going to be looking into in due  
 9 course is what is generally called "pre-pandemic  
 10 planning" and the sort of policies and possibly  
 11 arrangements that were put in place or had been put in  
 12 place in anticipation of a pandemic. Were you involved  
 13 in any of that prior to this pandemic hitting Scotland?  
 14 A. The simple answer is: no, we weren't involved in  
 15 pandemic planning or disaster planning or anything like  
 16 that. We've been involved in planning for services and  
 17 policies but not specifically that kind of planning.  
 18 Q. Yes. With the benefit of hindsight, do you feel that  
 19 you should have been?  
 20 A. Absolutely, yes. One of the things that we reflect on  
 21 at the time and since then is that disabled people  
 22 really need to be involved in all of these things. If  
 23 you look at disasters all around the world,  
 24 Hurricane Katrina, the war in Ukraine, disabled people  
 25 fare very badly in these situations and not being

13

1 involved in the planning for them means that the actions  
 2 that really need to be taken with speed don't happen --  
 3 they either don't happen or they don't happen fast  
 4 enough and lives are lost as a result .  
 5 Q. Okay. I'm not going to ask you what -- if you had been  
 6 involved in that planning, what your contribution would  
 7 have been to it because that's probably -- that's a day  
 8 and a half in itself , I imagine, but it is interesting  
 9 to note that you feel you should have been and you  
 10 weren't.  
 11 A. Absolutely.  
 12 Q. Okay. Now, you tell us a little about your funding  
 13 base, and that's really not for present purposes  
 14 anything we need to go into in any great detail , except  
 15 I would like you to go to paragraph 20 of your statement  
 16 and I think there you say that:  
 17 "During the height of the pandemic, funding flowed  
 18 and worries about how to meet needs were removed."  
 19 Then you go on to say:  
 20 "However, this reverted to more 'normal' and  
 21 draconian practices which disadvantages [disabled  
 22 people's organisations] because of a lack of  
 23 understanding of the additional supports disabled people  
 24 need and related investment required to enable this."  
 25 Now, can you explain what you're getting at there?

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1 A. What I'm getting at here is that during the pandemic  
 2 there was trust between the Government and the local  
 3 authorities and public partners and communities  
 4 themselves, communities of place and communities of  
 5 interest . There was an understanding that they couldn't  
 6 fix it on their own, that they couldn't reach the people  
 7 even just in relation to the vaccine, which came a wee  
 8 bit later , but in relation specifically to shielding at  
 9 first , and that trust engendered the ability for us to  
 10 be able to access funding that came from the  
 11 UK Government via the Scottish Government directly into  
 12 communities. And we were trusted that we were gleaning  
 13 the issues by speaking to the people and there was no  
 14 question that that was the case. We were able to  
 15 evidence it very, very easily and we were able to apply  
 16 for the funding to do what needs done. And as further  
 17 we have got from the pandemic, that trust has been  
 18 eroded, so sometimes -- or it's more dissolved, as  
 19 though it hadn't happened.  
 20 Sometimes there's a sense of, "Well, how do we know  
 21 that that's true?", and you feel like saying, "Well, why  
 22 did you trust us during the height of the pandemic if  
 23 not now?". I think that we've just reverted back to  
 24 normal where funding is constrained -- and that is  
 25 a consideration for us as a country. I understand

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1 that -- funding is constrained, there's competitiveness  
 2 about how you apply for and get that funding, and  
 3 specifically in relation to disabled--people--led  
 4 organisations, because there's not an understanding of  
 5 the multiple barriers and the levels of oppression that  
 6 that causes for disabled people, there is similarly not  
 7 an understanding of the actions and steps that need to  
 8 be taken to remove those barriers.  
 9 So when you ask for funding for things like access  
 10 facilitation , it's not understood and it seems that your  
 11 bid or your proposal is more expensive than it needs to  
 12 be. It's certainly not as competitive as organisations  
 13 that are applying for funding to do similar things, but  
 14 not with disabled people, for example. So that's really  
 15 what I mean by that.  
 16 Q. Okay. One of the points you made earlier, Ms Burke, is  
 17 that -- you use the word "barriers" for disabled people.  
 18 If we're looking at the barriers that existed pre the  
 19 pandemic, what were those barriers for disabled people?  
 20 A. I think pre-pandemic the barriers were always around  
 21 poverty, deep, deep poverty, and we're seeing evidence  
 22 coming out now that's confirming that from  
 23 Joseph Rowntree, academic evidence. All sorts of  
 24 evidence backs that up; and barriers to accessing the  
 25 services and supports that disabled people need to be

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1 able to live their lives, so particularly around health  
2 and social care; barriers to employment, and that can be  
3 that sometimes disabled people don't have the same  
4 access to education and learning opportunities, so they  
5 can't get on to the rung to get into the level of  
6 employment that they need. When they do get the  
7 employment, they tend to be in low-paid jobs.

8 Employers don't always know how to make adjustments  
9 or support disabled people. There aren't progression  
10 opportunities for disabled people, so at the outset of  
11 the pandemic, there was a precarity for disabled people  
12 who were in certain types of employment, and that was  
13 very evident. People who had really struggled, had  
14 17 interviews to get a job, and I remember one woman  
15 with three degrees telling me — and she was on  
16 a probation period and in the end that just didn't  
17 continue. I just think that employers need support so  
18 employment is another area.

19 Transport is a major barrier, so transport isn't  
20 always accessible or disabled people can't afford it.  
21 Things that are — you might imagine should be quite  
22 routine, getting a blue badge so that disabled people  
23 who do drive or have access to a car can park in spaces  
24 near where they need to go, that's actually full of  
25 barriers to even get that badge. Getting access to the

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1 supports that people need to be able to get into work,  
2 so the employability supports, tend to be more focused  
3 on disabled people who are nearer job-ready.

4 So there are a range of barriers and none of those  
5 things are touching on the stigma and the discrimination  
6 that disabled people face just in general from the  
7 public, who I think don't understand disability, don't  
8 understand the barriers and the solutions that are  
9 needed, and are also fuelled by quite a right-wing  
10 political ideology and a media that jump on that and  
11 that denote disabled people as benefit cheats and  
12 scroungers.

13 So before the pandemic there was a lot — the  
14 United Nations had declared it a humanitarian  
15 catastrophe in 2017. They'd spoken about the grave and  
16 systematic violations of disabled people's rights, so we  
17 knew all of this going into the pandemic and then  
18 obviously things — the inequalities were supercharged  
19 at that point.

20 Q. I think again one of the points you've made in that  
21 answer is that, in your view, there's an almost inherent  
22 discrimination against disabled people; is that right?

23 A. That's correct.

24 Q. Yes. And how understandable is that? It may be very  
25 obvious to you, but how understandable is that? How

18

1 acceptable is that approach?

2 A. Is your question, "Do people understand the barriers  
3 disabled people face?" Is that what you mean?

4 Q. Yes, well, or do you think it is — is it inevitable  
5 that this discrimination exists?

6 A. So two things. One, I think people don't understand and  
7 I think it's hidden away, and that's partly because  
8 disabled people are hidden away. I think that that same  
9 lack of understanding and insight is built into  
10 institutions and organisations, including the NHS,  
11 including Social Work departments and integrated joint  
12 boards that are delivering health and social care  
13 integration and all the services around us, and I think  
14 it's not inevitable. I think that it is no more  
15 inevitable that disabled people experience poverty and  
16 inequality than that we have poverty in the first place.  
17 It's a result of political choices. It requires  
18 a political ideology to shift. It probably requires us  
19 to look at taxation as a country, and that's maybe for  
20 later down the line, in my evidence, I mean, and I think  
21 it requires resources that we currently have and choices  
22 that we make to be prioritised to the people who need it  
23 most, and disabled people are surely amongst that group.

24 Q. Right. Let's have a look at what happened when the  
25 pandemic hit. Paragraph 22, you tell us that you were

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1 contacted by the Scottish Government at the start of  
2 lockdown and because, as you say, "we are a strategic  
3 partner of Government, funded partly through Government,  
4 they approached us", and you personally were "asked to  
5 take part in a number of meetings due to GDA's  
6 connections to thousands of disabled people who were  
7 vulnerable and likely to experience heightened  
8 inequalities and problems".

9 Now, was that reassuring for you at the start of the  
10 pandemic, that there was that apparently outreach to you  
11 as an organisation by the Government?

12 A. I think it was reassuring, very much so, because we are  
13 very used to disabled people being thought of as an  
14 afterthought. So as an upfront gesture, it felt  
15 reassuring and it felt that we were immediately  
16 connected with people who would be making decisions. We  
17 didn't know what those decisions were going to be, we  
18 were all kind of experiencing it as it was evolving and  
19 rolling out, but it did feel reassuring that the  
20 Scottish Government was in touch.

21 I was in touch on a weekly basis with the  
22 Equality Unit, feeding intel in. They knew that we had  
23 recruited lots of people and we were contacting  
24 thousands of people. They wanted to know what people  
25 were saying, what their experiences were, and that

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1 changed. It wasn't the same. You know, each week was  
2 a snapshot in time, but there were changes over that  
3 period so it did feel reassuring and it did feel that we  
4 had a route directly not just to officials but also to  
5 Government ministers as well, which was incredibly  
6 helpful.

7 Q. And I think we see that you had -- well, you mentioned  
8 the Scottish Government Equality Unit in paragraph 23  
9 and you also say from the middle of March,  
10 16 March 2020, you had numerous conversations with  
11 the -- I imagine that unit -- "to share insights and  
12 concerns of disabled people's experiences of the  
13 pandemic". Obviously the pandemic was very early at  
14 that stage.

15 A. Yes.

16 Q. What were you able to impart to that unit at that time,  
17 given that it was so early?

18 A. I think that's a very good point. Yes. At that time  
19 the main issues, which of course I had noted, we had  
20 noted as an organisation, as we were going along -- so  
21 I've been able to look back at all these notes -- and  
22 those concerns at that point were confusion, lack of  
23 information, lack of understanding, not knowing which  
24 set of rules applied.

25 So in those very early weeks there were obviously

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1 the four nations broadcasting and people weren't 100%  
2 sure of which rules to follow or indeed even having  
3 access to the information. Some of our members didn't  
4 have access to a TV or a phone. They were listening on  
5 the radio. So people were getting limited information.  
6 People didn't really know where to turn for support, so,  
7 ultimately, in our research -- which wasn't conducted as  
8 research at the start. It was conducting as well-being  
9 check-ins -- but what we discovered was that 80% of  
10 people didn't know where to turn in their communities.

11 So I think the lack of knowing, confusion,  
12 bewilderment, a sense of panic, some people weren't that  
13 bothered because they didn't think it was going to carry  
14 on, so there was the opposite. There were some people  
15 saying, "I'm fine, hen, I'm absolutely fine. I'm  
16 watching the telly. It will pass", and that kind of --  
17 that spectrum of reaction which obviously changed over  
18 the period.

19 Q. One of the things the Inquiry is hearing about -- and  
20 it's a point you make subsequently in your statement,  
21 particularly in relation to the surveys that you've  
22 carried out -- is the isolation that people have  
23 experienced through lockdowns. Obviously I appreciate  
24 it's the very early days of the pandemic. Was that  
25 a concern to you at that time or had that focused as

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1 a concern in the very early days?

2 A. It emerged immediately, and the reason is because  
3 disabled people are twice as likely to be socially  
4 isolated than non-disabled people in the first place.  
5 They're also disproportionately reliant on services and  
6 those services all stopped, so it became an issue much  
7 quicker than you might think because of that, because if  
8 somebody had services and supports going in and either  
9 those services were withdrawn or they themselves asked  
10 for them to be stopped out of fear, then they were  
11 suddenly isolated -- not just isolated and lonely but  
12 with no support and frightened. So it was enhanced, it  
13 was exaggerated because of that, so it wasn't the  
14 pandemic of social isolation that it became but it was  
15 absolutely apparent even from the outset.

16 Q. Yes. In your discussions with Government, was that  
17 concern about isolation in particular -- was that, as  
18 far as you were aware, understood from the outset?

19 A. I think the things that we were focusing on at that  
20 point was setting up a helpline to give people the  
21 information and the support that they needed, making  
22 sure people had access to benefits advice, making sure  
23 people had access to well-being support. We were very  
24 quickly discovering that people didn't have access to  
25 food and I think the isolation thing wasn't as apparent

23

1 at that time amongst the weeks that emerged. You know,  
2 the first weeks is what I mean by that. But we were  
3 raising it as an issue, that social isolation was coming  
4 up as an issue in relation to the mental health distress  
5 that people were experiencing as well.

6 So one of the ways that we tried to tackle that was  
7 by getting people digitally connected and by moving all  
8 their programmes online, which I can maybe say a bit  
9 about later, but social isolation was there right from  
10 the start.

11 Q. Can I take you -- I should have said earlier that  
12 obviously we have your whole statement and your whole  
13 statement will be taken into consideration by the  
14 Inquiry and we will get a revised version of your  
15 statement, so, again, that will be taken into account,  
16 so please don't think, because I'm moving forward to  
17 different paragraphs in your statement, that certain  
18 things are being ignored. They're not. But if I could  
19 take you on to paragraph 29. This is at the end  
20 of March 2020. You're talking about a meeting that you  
21 had with the Cabinet Secretary for Social Security and  
22 Older People and also the Minister for Older People and  
23 Equalities.

24 You met with "other CEOs and staff from  
25 community-based [organisations] to think through and

24

1 plan for meeting [the] needs of communities across  
 2 Scotland". Now, obviously that tends to suggest that  
 3 that was at a fairly high level in terms of what was  
 4 being planned; is that right? It would be --  
 5 A. It didn't feel like that because it was a telephone  
 6 conference so it didn't feel high-level, but it  
 7 obviously was with people in the Cabinet.  
 8 Q. I'm sorry, what I mean by "high-level" is that it was  
 9 very general in terms of its planning --  
 10 A. Oh, yes, yes.  
 11 Q. -- rather than specific.  
 12 A. Yes.  
 13 Q. You say in paragraph 30 that you were invited to let the  
 14 ministers know about the needs identified, et cetera.  
 15 You say that:  
 16 "It was reassuring for GDA members to be informed  
 17 that we were speaking to the ... Government at the  
 18 highest levels and passing on their concerns ..."  
 19 A. That's correct.  
 20 Q. And I perhaps should have asked you this before: you  
 21 obviously report back to your members?  
 22 A. Yes.  
 23 Q. And how were you -- even in the early days of the  
 24 pandemic, how were you reporting back to them?  
 25 A. So in the very first weeks of the pandemic we spent

25

1 a lot of time trying to get people online who had access  
 2 to that. As the weeks moved forward, we were needing to  
 3 get devices and access to MiFis, which is a thing that  
 4 connects people to broadband if they don't have  
 5 broadband, which many people don't, so we were moving  
 6 all their programmes online. But in the very, very  
 7 early days, we were having telephone conversations with  
 8 people and then we were having -- so with -- for  
 9 example, we've got a Drivers for Change Network, which  
 10 is about 200-plus members who are actively involved in  
 11 the kind of almost campaign, the influence and change  
 12 side of the work that we do, and we were having meetings  
 13 online with them or those of them who had access to  
 14 that, where we were getting everybody else ready and  
 15 getting them all online, which happened in the following  
 16 weeks and months. So we were feeding back to members in  
 17 that way straightaway.  
 18 I mean, the very first week, at the very --  
 19 I think -- would it have been Friday, the 20th? -- so it  
 20 wasn't the first official week of the pandemic but we'd  
 21 gone home towards the end of that week -- my team went  
 22 home at the start and myself and my office manager went  
 23 home at the end, having tried to get everybody devices  
 24 because we weren't set up to work from home. I reported  
 25 to my board that Friday evening to say, "Here's my plan,

26

1 here's what we're doing, here are the steps we're going  
 2 to take in the coming weeks". So accountability --  
 3 that's what I'm talking about -- about being a DPO.  
 4 They're disabled people, they wanted to know, "What are  
 5 you doing for our members? What's the plan? How can we  
 6 help? How can we all be involved in this?".  
 7 So straightaway the accountability was built in and  
 8 straightaway I was able to say, "We're speaking to the  
 9 Government, we're feeding back concerns", which became  
 10 really useful at the point that people were being  
 11 approached about the DNRs because we had that direct  
 12 route into Government to be able to tell them about  
 13 that. I can maybe touch on that later as well.  
 14 Q. Yes, we'll come to DNRs in a little.  
 15 Just looking, again if we can, at the early days of  
 16 the pandemic -- we can all remember it. I don't think  
 17 any of us knew what was happening -- but in those very  
 18 early days, what was the -- I don't know whether there  
 19 was an overwhelming or a dominant feeling amongst your  
 20 members at that time. What were they particularly  
 21 concerned about?  
 22 A. So by the point that I had the meeting with the  
 23 Cabinet Secretary and the Minister for Equalities, we  
 24 had spoken to over 500 people because we basically  
 25 turned all our resources to phoning everybody or texting

27

1 if it was people who were deaf and hearing impaired or  
 2 emailing -- mainly phoning -- and the things that were  
 3 coming out were people being very concerned and anxious,  
 4 people not knowing where to go for support, information  
 5 not being available in accessible formats, people not  
 6 having access to digital supports, which they were  
 7 becoming increasingly worried about if that was going to  
 8 be something that GDA was doing, because we were looking  
 9 to get people online so that we could run things --  
 10 people not having food -- that was a major, major  
 11 concern to them -- and people not having access to the  
 12 services that they needed, so social care and health.  
 13 So I remember specifically one woman who had been  
 14 diagnosed -- in fact this was not just one person, there  
 15 was a few people that I can think of -- who had been  
 16 diagnosed with cancer, somebody else with diabetes, just  
 17 at the outset, and the treatment stopped, the  
 18 communication stopped. People with severe mental health  
 19 illness and distress, somebody who had been sectioned  
 20 seven times and who was bipolar, no access to the  
 21 psychiatrist, no access to the CPNs, phones ringing off  
 22 the hook. So those were the concerns in the first days.  
 23 And food. Food was becoming an increasing concern for  
 24 thousands of people.  
 25 Q. Two points if I can take from that. Can I suggest to

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1 you, just for your comment, was there an element of fear  
2 within the disabled community at this time?

3 A. Yes, absolutely. People were terrified because the way  
4 that things were being talked about, people knew that  
5 they were — "vulnerable" was the word that was being  
6 used — people were vulnerable and shielding was  
7 starting to be spoken about and people thought that if  
8 they caught it, they would just absolutely die.

9 Many, many of our members, even in those early  
10 days — I remember my team feeding back to me and me  
11 speaking to people as well — saying that they were  
12 worried that if they died — not just — the fear wasn't  
13 just if they died, the fear was that, because they were  
14 so isolated in their lives before the pandemic, that  
15 nobody would find them and nobody would know because we  
16 were the only people in touch with them. So that was  
17 a real fear for people. Some people were absolutely  
18 terrified.

19 Q. Yes. The second point — just again going back and it's  
20 something you've mentioned several times and I think it  
21 is something you obviously wish to emphasise — the  
22 question of access to food. I suppose one — we can all  
23 envisage it, but for a disabled person living on their  
24 own in Glasgow, without perhaps access to a car, without  
25 access to other people to do things for them, how

29

1 serious, in your view, was the concern about getting  
2 access to food?

3 A. It was gravely serious, much more than we could have  
4 thought. We're not a food provider, that's not what we  
5 do, and we found ourselves providing food to over 2,800  
6 people over the period. And the issue with food is that  
7 disabled people who weren't shielding didn't qualify for  
8 the way supermarkets were doing things, couldn't get the  
9 delivery slots, and that would have obviously involved  
10 them having enough money to order over a certain amount  
11 to get the free delivery anyway, so they couldn't  
12 qualify. Not all the people that should have been  
13 shielding were, not all the people that were shielding  
14 were getting food that was appropriate to their diet or  
15 to their needs, given that many had their social care  
16 cut.

17 So people described getting things like — I mean,  
18 there was a lot of laughter when we got the online  
19 forum, so people describing two bags of root vegetables  
20 turning up, and it was people who couldn't use their  
21 hands or didn't have access to their kitchens because  
22 these things — all these cumulative interrelated  
23 barriers make disabled people more disabled. It's not  
24 just the conditions or the impairment.

25 So the social care being cut, the house not being

30

1 accessible in the first place, the types of things that  
2 were being delivered and then nothing being delivered if  
3 they weren't on shielding. Food banks were great and  
4 are wonderful but they don't deliver — they mainly  
5 don't deliver and disabled people couldn't get there.  
6 They couldn't get there safely. They didn't have their  
7 own transport. You know, you couldn't safely get people  
8 to go and they would have needed support anyway.

9 So there was so, so many things, so we decided quite  
10 early on that we were going to set up a response and try  
11 and provide — it was a lifeline response — food and  
12 resources, cleaning products, sanitary products,  
13 continence products to people who really needed it. And  
14 we thought it would be small numbers and it ended up  
15 being thousands of people — we just couldn't have  
16 imagined it — and it's not what we had skills or  
17 experience doing, I have to say.

18 Q. Obviously there was a prevalence of online banking under  
19 now an increasing absence of a cash culture. Was that  
20 a problem?

21 A. That was a massive problem. People were terrified about  
22 not being able to pay their bills and being cut off.  
23 They couldn't access their own cash. Some disabled  
24 people don't have credit cards or cards with the debit  
25 function. People just not being able to go out and

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1 access their own money, that was a major, major problem.  
2 So we were delivering food not always because people  
3 couldn't get the food but sometimes because they  
4 couldn't get the cash. That was in smaller numbers but  
5 that was a feature as well.

6 Q. As you increased the range of services that you were  
7 offering — I should have asked this of you earlier —  
8 I think you mentioned that effectively you closed down  
9 in the sense that you closed down your offices and  
10 started to work from home.

11 A. Yes.

12 Q. How many people did you have working for you?

13 A. At that point we had 15.

14 Q. And during the course of the pandemic, did that number  
15 stay the same or did it increase?

16 A. Well, it was a changing picture a lot of the time, but  
17 at the height of things we had 45, and that was when we  
18 were phoning. So there was a point at which we were  
19 phoning, phoning, phoning and only phoning, but then we  
20 were logging all these things and then we were trying to  
21 respond. So we started at a point probably within the  
22 first couple of weeks or after the first couple of weeks  
23 trying to set up the responses, so getting all the  
24 online offers, which were the learning and development  
25 programmes, the voice-related activities, the collective

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1 voice, "What are we wanting to tell the Government about  
 2 what's happening to us just now?", the welfare rights.  
 3 That was mainly provided by phone but there were some  
 4 online things, and I think that's partly because the  
 5 people accessing the welfare rights didn't have and  
 6 couldn't afford broadband and were often in chaos as  
 7 well because of poverty. So we were getting all the  
 8 existing things online and then we were responding to  
 9 the new things, which -- the newly enhanced or made  
 10 worse, exacerbated mental health and well-being issues.  
 11 That was one thing.

12 The lifeline was a major, major thing, started up by  
 13 our fabulous office manager, who got everything set up  
 14 and turned our big training room into a food store and  
 15 recruited personal assistants who were already working  
 16 with us to either change what they did and do that or  
 17 get new people to do that because we really wanted  
 18 people with cars so that people were safer as well.

19 So we were doing lifeline, we were doing well-being  
 20 and then the digital offer, which was us working with  
 21 the Government, with connecting Scotland, to try and get  
 22 a hold of devices, MiFis which connects people to  
 23 broadband, and then coach people who had never seen  
 24 a device, who didn't know what a mouse was, who didn't  
 25 understand, you know, what "swipe" meant, these types of

1 basic, basic things, and that took a lot of intense  
 2 support.

3 So we were still phoning people, still conducting  
 4 a survey, which by that point -- I think weeks in we put  
 5 it online to Survey Monkey. That was completed by  
 6 almost 2,500. And then there was obviously all the  
 7 spreadsheet information we had as well. So we had  
 8 a massive repository of insights and evidence with lots  
 9 of case studies and action points for people who were  
 10 then referring into all the services as they were being  
 11 either transferred online or set up from scratch.

12 Q. Okay. At paragraph 33 of your statement you talk about  
 13 you being appointed in June 2020 to the  
 14 Scottish Government Social Renewal Advisory Board,  
 15 "which sought to capture the human experience of  
 16 Covid-19 by listening to and learning from lived  
 17 experience". I take it this was another aspect of the  
 18 work that you were doing --

19 A. Yes.

20 Q. -- that you were obtaining -- you were not merely giving  
 21 practical advice to people but you were obtaining  
 22 information from the disabled community so that you  
 23 could feed that back into the Government; is that right?

24 A. Yes, yes, absolutely. That's something that we always  
 25 do. That's always been one of our aims from the day

1 that we set up. So we really set up to combat social  
 2 isolation and loneliness and to be a collective voice,  
 3 almost like a union for disabled people, feeding that  
 4 into decision-makers, and that came really to fruition  
 5 and to its most usefulness at the height of the  
 6 pandemic. That was one example of where we fed the  
 7 information.

8 Q. Now, this is slightly out of order, but can we go to  
 9 paragraph 71 of your statement, please? I think here  
 10 you set out some of the information that you  
 11 collected -- and this obviously isn't at the very early  
 12 days of the pandemic -- but you provided us there with  
 13 research that has shown that of 6,000 disabled people  
 14 spoken to, there were certain matters that repeatedly  
 15 came up. Perhaps you can just take us through those,  
 16 please.

17 A. Absolutely. So 82% were worried about social isolation  
 18 and loneliness; 62% were worried about mental health;  
 19 92% were worried about both physical and mental health;  
 20 57% were worried about money and hardship; 47% were  
 21 worried about having access to food; 80% were unaware of  
 22 any local support services they needed and/or were  
 23 unable to access these supports; and 41% were unable to  
 24 get information in the formats they needed, and this  
 25 became more confusing as TV broadcasts meant people

1 hearing slightly different approaches being taken by the  
 2 four devolved nations.

3 Q. Right. I don't know precisely when that data point was  
 4 taken from --

5 A. Five months. After five months. We were able to  
 6 analyse all the data at that point.

7 Q. Thank you. Obviously that was the data at that point --

8 A. At the end of August.

9 Q. Was that in your view an accurate reflection of the  
 10 concerns you were hearing?

11 A. Absolutely. I would say the one that absolutely got  
 12 worse as it continued was the food thing and the social  
 13 isolation and loneliness. The 80% being unaware of  
 14 local support services was up on research we'd conducted  
 15 I think the previous year or the year before that, where  
 16 it was 71% weren't aware of how they could get support  
 17 in their communities or didn't feel that they could be  
 18 involved in their communities. So this has been  
 19 a long-term pre-pandemic issue which was just  
 20 exacerbated by the pandemic.

21 Q. I think I should say to you, Ms Burke, that the Inquiry  
 22 has commissioned some academic research on the  
 23 availability of social care support during the pandemic  
 24 and the changes that occurred during that. That is  
 25 going to be published, in fact I had a meeting about it

1 on Monday. That will be published in the not too  
 2 distant future so we will ensure that that is sent to  
 3 you and we would obviously welcome your comments on it  
 4 when you receive it.

5 A. Thank you.

6 Q. Can I deal with a rather darker issue, and that's deaths  
 7 from COVID. You provide some information on that in  
 8 paragraphs 35 to 37. You give a figure in paragraph 35  
 9 of the number of members that you feel -- that you are  
 10 aware of or suspect died during the pandemic. I think  
 11 you can update that.

12 A. Yes, that's right. So in planning for giving the  
 13 evidence, we worked really hard -- my team worked really  
 14 hard to pull together as much as we could about how many  
 15 members had died, and when I met with the Inquiry back  
 16 in June, I had stated at that time that we had notice of  
 17 114 GDA members dying at that point, between March 2020  
 18 and the end of March 2022, which is just obviously  
 19 outwith the scope of the Inquiry by a few months. Since  
 20 then we've had it confirmed that at least 215 members  
 21 have died, and this is because we find out information  
 22 from letters returned ongoing, sometimes a long time  
 23 after the member dies. We know from families, if there  
 24 are families, that many of these were COVID related but  
 25 we certainly don't have confirmation in every case and

1 we suspect that the figure might be higher, quite a bit  
 2 higher, as we've lost touch with a number of members  
 3 during the pandemic.

4 So some of our members lived in care homes. Some of  
 5 the care homes have actually gone, so we've got no way  
 6 of tracing the people. Some members moved away to live  
 7 with their families and we've simply not been able to  
 8 trace them, despite repeated efforts on our part. And  
 9 I would just like to say that each person was a valued  
 10 member of GDA and, you know, many people did have family  
 11 and friends and loved ones who cared about them and they  
 12 all -- all of the GDA members had GDA who cared about  
 13 them and it has just had untold human costs.

14 Q. You go on in your statement to talk about the start of  
 15 the pandemic, and I think obviously we're familiar with  
 16 many of the difficulties that your organisation faced  
 17 and indeed other organisations faced with the  
 18 abandonment of face to face contact, et cetera. You in  
 19 fact had to cancel all face-to-face advice that you were  
 20 being -- able to be given -- giving to your members,  
 21 I think; is that right?

22 A. Yes.

23 Q. This takes us on -- and, again it's slightly out of  
 24 order -- but one of the things you've been mentioning on  
 25 a number of occasions has been the digital support. How

1 did you transfer from what was your pre-pandemic mode of  
 2 operation to the way in which you had to do it  
 3 digitally?

4 A. Yes. Well, I think being small makes you more nimble  
 5 and more able to respond in a more rapid way, so I think  
 6 we had that privilege, and we also had the resources  
 7 available. We had the connection with the Government,  
 8 we had the partnership with Connecting Scotland as well,  
 9 so we had access to the equipment. So I think it's  
 10 important to own that all upfront.

11 What we did was we basically -- I mean, you know,  
 12 I think I say -- I don't know if I say in this version  
 13 of the statement or the revised one, but we are in no  
 14 way IT experts but we are participation experts, so what  
 15 we were doing was making sure that disabled people could  
 16 participate in the only way that was available at that  
 17 time.

18 So we got access to devices, we got access to MiFi,  
 19 we had to get -- I mean, it's such a process. You would  
 20 think you could just give these things out. In order to  
 21 give out an iPad, you need to register an Apple ID, you  
 22 need to set up an email account for the person, you need  
 23 to download all the apps that you might be taking them  
 24 through to train them and use them, and I'm not a person  
 25 that had done any of this training. So it was Hannah

1 who was our digital inclusion manager who led this up.  
 2 That wasn't her job before the pandemic but that's her  
 3 job now. And working with a couple of really good  
 4 people that had come on board to help us who just had  
 5 really good communication skills so that we were able to  
 6 do the check-in calls and compassion. And those people  
 7 together set about getting all these devices ready --  
 8 some of them were iPads, some of them were just laptops  
 9 and other devices -- and getting them out.

10 So we had what was somebody who was our previous  
 11 personal assistant helping people with support needs  
 12 during the courses and events that we ran. He was then  
 13 delivering these things out to people in a safe way and  
 14 getting them set up and then they would be coached over  
 15 the phone. And, you know, now, looking back, we can  
 16 hardly believe that we managed to do it. They were  
 17 coaching people who had never seen a device, never  
 18 touched a device, didn't really necessarily always want  
 19 a device but we'd persuaded them to try, had been told  
 20 they were too stupid to learn or too old to learn, had  
 21 been turned down by other people who had got devices  
 22 because they were too disabled to be taught and maybe  
 23 the three sessions that were budgeted for by other  
 24 organisations because that's all they had. So we had  
 25 a no time limited approach to supporting people. We

1 coached some asylum seekers and refugees and people  
 2 whose first language wasn't English, I think we coached  
 3 in six different -- six or seven different languages.  
 4 We had a blind coach working with us that we brought  
 5 on to coach our visually impaired members and it was  
 6 just a process. And the way they did it was about  
 7 finding out what was important to each person. So it  
 8 was very much person-led learning and working out what  
 9 they really wanted the device for. We hoped that it  
 10 would be to connect with GDA and all our programmes and  
 11 offers, but it was often also about or sometimes only  
 12 about connecting with family because everybody was  
 13 separate from their family at that time. Shopping might  
 14 have been a thing but it was mainly the family and then  
 15 being able to contact GDA and being able to attend our  
 16 online courses and events.  
 17 Q. Just a couple of points, perhaps going on from that,  
 18 paragraph 44, and again it comes to your team switching  
 19 to homeworking, you list there what in numerical terms  
 20 you were able to do and we can read that. In  
 21 paragraph 49, you say that, "In the first year [of the  
 22 pandemic] ...", and you list what you were able to  
 23 achieve during that period. And quickly and clearly it  
 24 is a very considerable effort that was made on behalf of  
 25 your organisation.

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1 A. I have a brilliant team and they were extremely driven.  
 2 As I say, more than half of them are disabled people,  
 3 but they are all equally committed to the cause of  
 4 trying to make sure at that point that we weren't  
 5 letting anybody slip through the cracks. I mean, we  
 6 felt that we were privileged, we had a mission, we had  
 7 the resources and, you know, it actually kept us going,  
 8 to be able to do these things to help people as well.  
 9 So it was just a fantastic privilege on our own part to  
 10 be able to lead the team and be amongst them, but they  
 11 were just outstanding.  
 12 Q. Just one other point before -- I think we'll take  
 13 a break in just a few minutes. Just one other point, if  
 14 I can go to paragraph 52, please, you say there that  
 15 your organisation "adapted our Rights Now Welfare Rights  
 16 project, Learning Programme and Future Visions support  
 17 to be delivered remotely online and by phone".  
 18 Then:  
 19 "Over 2020 and 2021, events and programmes were  
 20 almost entirely online with face to face returning  
 21 tentatively at the start of 2022."  
 22 So I suppose one of the points you make later in  
 23 this statement is a return to normality, so in early  
 24 2022 things were starting to return to normality for  
 25 your organisation?

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1 A. That's correct.  
 2 Q. I think we see some of the assistance that you were able  
 3 to give, I think in the various bullet points in  
 4 paragraph 52:  
 5 "497 individual clients secured arrears payments of  
 6 [over £205,000] as well as projecting financial gains  
 7 ... [again] achieved by [the] Rights Now Service.  
 8 "465 people were supported by us to get online to do  
 9 online learning, courses and peer support.  
 10 "128 people were supported by Future Visions for  
 11 Social Care programme and hundreds more were supported  
 12 with dealing with distress and being signposted when  
 13 social care had been cut."  
 14 A. That's correct.  
 15 Q. So those were some of the things you were doing?  
 16 A. Yes.  
 17 MR GALE: My Lord, can we pause there for a few moments?  
 18 THE CHAIR: 15 minutes?  
 19 MR GALE: 15 minutes would be fine.  
 20 THE CHAIR: 11.15, please, everybody.  
 21 (11.02 am)  
 22 (A short break)  
 23 (11.18 am)  
 24 THE CHAIR: Right, Mr Gale. When you're ready.  
 25 MR GALE: Thank you, my Lord.

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1 Hello again, Ms Burke. Can I focus on something you  
 2 say in paragraph 55 of your statement? This is around  
 3 the engagement that your organisation carried out, and  
 4 it "uncovered a massive spike in mental ill health and  
 5 distress accompanied with much support being withdrawn  
 6 from services", for example, community nurses, community  
 7 psychiatric nurses and access to psychiatry. Can you  
 8 tell us a little bit more about that, please?  
 9 A. Yes, as I kind of touched on before, I suppose the fear  
 10 that people were experiencing combined with the support  
 11 being withdrawn, so across the board social care as we  
 12 know, the near-collapse of the whole system in certain  
 13 parts of Scotland anyway, but also access to health  
 14 services like CPNs and access to psychiatry. So our  
 15 well-being service was set up to deal with what we  
 16 thought was going to be low-level preventative, keeping  
 17 people well, but it was quite overwhelmed with suicidal  
 18 ideation, people in extreme distress, people who perhaps  
 19 needed to be seen by the psychiatrist and maybe even  
 20 hospitalised in some cases and it has become  
 21 increasingly challenging.  
 22 What we found in the time since -- I mean, the  
 23 pandemic is over, as in, the height of it, but the fears  
 24 around COVID are still very live for some disabled  
 25 people, who either don't have protection from the

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1 vaccine or have mental distress and -- or who don't have  
2 the practical support, the social care support, to be  
3 able to get ready to go out. So for all sorts of  
4 different reasons, people are stuck in and they're  
5 lonely and they're isolated.

6 So what we hoped was we were going to be dealing  
7 with those low-level preventative things, but what we've  
8 ended up dealing with is becoming almost a service in  
9 itself, which was not the intention and it's very  
10 difficult to sustain. It's very difficult to actually  
11 get the funding to keep it all going.

12 Q. I think you say that what initially started as check-in  
13 calls developed into a specialist well-being service,  
14 and you say that well-being work was supporting  
15 529 disabled people in the first year.

16 A. That's correct.

17 Q. And that was presumably something that you could not  
18 have anticipated?

19 A. We couldn't have anticipated it. I mean, when you set  
20 up a disabled-person-led organisation, because of all  
21 the barriers and gaps and challenges people face, you  
22 could choose to set up doing a number of things. We  
23 chose to set up bringing disabled people together and  
24 reducing isolation and helping build their individual  
25 and collective voices and trying to make services

1 better, but what has happened is we've ended up stepping  
2 in to fill the gaps of some services and well-being and  
3 mental health are among those. That's just where we are  
4 and the problem continues.

5 Q. Can we move on to shielding, please? This is in  
6 paragraphs 56 and following. I think one of the  
7 problems that you highlight is that not all people who  
8 one might have anticipated would have been shielders  
9 received communications to that effect; is that right?

10 A. Yes, that's absolutely right. So there was a lot of  
11 confusion. I remember speaking specifically to people  
12 myself, mainly at the online meetings and events, who  
13 said, "Because I had a respiratory condition and I'd had  
14 a virus that had resulted in a head injury and I was in  
15 a coma and I had all these different comorbidities,  
16 I assumed I would be on the shielding list. I phoned my  
17 GP multiple times. Nobody got back to me". So that  
18 comment about "Many 'did not make' the list but were  
19 extremely high risk and vulnerable due to  
20 co-morbidities", it's still outstanding in relation to  
21 access to treatment, but it was very much a gate-keeper  
22 of people getting access to support through shielding at  
23 that time; a very, very big concern.

24 So people -- a particular friend and colleague of  
25 mine at the time who has nearly died a number of times

1 because of respiratory considerations, again not been  
2 put on the shielding list, and I think that just wasn't  
3 taken into account. So it seemed that they had  
4 a rationale, it would have been evidence-based, they had  
5 a list, but rather than refining it and developing it,  
6 it seemed to stop at a certain point so people just  
7 didn't get the support that they needed because it was  
8 cut off.

9 Q. And I think having access to the information you've  
10 provided us with -- you have a number of quotes from  
11 members, and I'm not ignoring these at all, Ms Burke,  
12 but just for time pressures, when you prepare the  
13 revised statement, we will incorporate all these  
14 quotations into there so that we do have them.

15 I think you summarise the situation at paragraph 62  
16 and you use the expression "lessons must be learned",  
17 which is obviously a matter for this Inquiry. Can you  
18 just tell us what you think are the lessons that should  
19 be learned in relation to shielding?

20 A. In relation to shielding? Well, I think the  
21 communications was one part of it. I think how they  
22 determined who was on the list should definitely take  
23 account of comorbidities. We know much more about the  
24 virus now than we did then and I think we have known  
25 a lot for some time and it didn't seem that the list was

1 changed. There was a specific issue around disabled  
2 children not getting access to the vaccine and maybe not  
3 considered in the shielding category. I'm not 100% sure  
4 of that but there was an issue about that. But I think  
5 it's much more about the comorbidities, how the  
6 decisions were taken, involving disabled people's  
7 organisations, not necessarily in determining the  
8 science, of course, because that's not an area of  
9 expertise that we have, but at least helping to  
10 communicate the messages so that we could share them  
11 with our constituents, with our members, which cover  
12 hundreds of thousands of people in Scotland between us.

13 Q. The next section of your statement is about digital  
14 exclusion and this is -- a lot of what you say there is  
15 something we've already touched on. I know, again, it's  
16 a matter on which you have some quotations from your  
17 members and again we will be -- you will be providing us  
18 with that.

19 You do mention -- and it's really about, I think,  
20 the first time you do mention it in the statement though  
21 we'd looked at it earlier -- at paragraph 68 that you,  
22 as an organisation, were never involved or never invited  
23 to be involved in pre-pandemic planning. We've heard  
24 your views on that. I think you've identified that this  
25 issue around digital exclusion should -- could or should

1 have been foreseen and there should have been "more  
 2 effective and meaningful planning" that could have taken  
 3 place. When you say that it "could have been foreseen",  
 4 was it obvious to you?  
 5 A. Yes, it was obvious to us that disabled people were  
 6 digitally excluded before the pandemic. Reports had  
 7 been written on this, so it was obvious to everybody,  
 8 but no notice was necessarily taken of it when resources  
 9 were being directed or actions were being planned around  
 10 it. So it was an obvious thing, and still we have the  
 11 situation where MiFi devices that give people access to  
 12 broadband are now being stopped for disabled people. So  
 13 we're scrambling around, trying to find funding to keep  
 14 people connected and not take off them the access to  
 15 broadband and the web that they've had over the last few  
 16 years since we've been supporting them.  
 17 Q. Can we move on to DNACPR that you talk about in  
 18 paragraph 74 and following? We've heard a little bit  
 19 about this as a subject in the context of care homes  
 20 that we've been looking at. You may well have become  
 21 aware of that.  
 22 So far as your cohort of disabled people are  
 23 concerned, what was being disclosed to you in relation  
 24 to do not resuscitate notices and what were the concerns  
 25 about that?

1 A. It wasn't apparent at first but it became apparent as we  
 2 continued the well-being check-ins but also just the  
 3 engagement that we were having around providing supports  
 4 and programmes and services to the disabled people we  
 5 were supporting. What people were describing was being  
 6 contacted by their GPs and being asked kind of almost in  
 7 passing if, you know, you wouldn't want rigorous  
 8 efforts, heroic efforts, to be made, almost persuading  
 9 them not to -- to say "No" to that. A lot became  
 10 apparent to us online as well, through Twitter. So we  
 11 were being copied into Tweets where people were being  
 12 approached and were being alarmed by this as well. Some  
 13 people were finding out because their GP surgery were  
 14 approaching them; some people were finding out because  
 15 they discovered it when they were in hospital or, when  
 16 something had happened to them, they discovered it in  
 17 passing.  
 18 So people were absolutely terrified and felt that  
 19 the lives of disabled people were being devalued. Even  
 20 the way that it was being described when people were  
 21 dying, but they had a pre-existing condition, as if that  
 22 somehow rewrites -- or writes off their life and  
 23 devalues it and we should just expect all the disabled  
 24 people to die anyway and they're not that worth saving.  
 25 There were obviously -- coupled with this, there were

1 the experiences of people being told they wouldn't be  
 2 taken to hospital if they got COVID, if they became ill.  
 3 If they were, they wouldn't necessarily be given access  
 4 to ventilators.  
 5 So there was a lot of fear, a lot of hype, a lot of,  
 6 you know, genuine -- people genuinely distressed and  
 7 terrified because of this, and the DNRs compounded it to  
 8 such an extent that myself and my friend and colleague  
 9 who ran another DPO, Inclusion Scotland, wrote to the  
 10 Government and we managed to get her on to the clinical  
 11 advisory group to advise them of this, to try and sort  
 12 some of this out, because I think things were being done  
 13 with good intentions but they weren't being thought  
 14 through and it had unintended consequences.  
 15 Q. One of the things that we've encountered so far in the  
 16 Inquiry has been, where there is a do not resuscitate  
 17 notice, then that should at least be prefaced by an  
 18 informed discussion with either the individual about  
 19 whom it relates or their family and then an informed  
 20 decision can be made about it. But you're indicating  
 21 that, so far as a lot of your members are concerned,  
 22 that wasn't happening and what was being created was --  
 23 I think you describe it as fear and a level of hysteria.  
 24 A. Yes, that's absolutely true. I think when you consider  
 25 that the people being approached that we were speaking

1 to were people who were attending our learning events  
 2 online and our activities, these were people not at  
 3 near-end-of-life stage. It wasn't appropriate to be  
 4 having those conversations out of the blue with them on  
 5 those occasions that it was happening.  
 6 I remember one woman reporting to me that her mum  
 7 had received a phone call, had agreed because she  
 8 thought that's what the receptionist wanted her to  
 9 agree -- it was the doctor's receptionist that had  
 10 phoned her -- and she herself was a physio and her and  
 11 her sisters had to speak to her mum and explain there's  
 12 a lot between resuscitation and, you know, care that you  
 13 can be given and just saying "No" to all care is not  
 14 necessarily what you would want to do. So she was  
 15 supported by her daughters to call her surgery back and  
 16 have that changed, which we checked up to make sure that  
 17 that had been done and it had been done. But how many  
 18 people were persuaded or just went along with it, not  
 19 fully understanding what they were being asked to do?  
 20 And I think the thing about it being inappropriate at  
 21 the stage of life that it was being discussed at or the  
 22 types of conditions people had. There was an example of  
 23 somebody deaf -- this was on Twitter, this wasn't  
 24 somebody known to me -- but somebody deaf having it on  
 25 their file because they were deaf, and that just doesn't

1 seem to make much sense at all.  
 2 Q. Presumably a lot of your disabled members wouldn't  
 3 necessarily have been frail and elderly?  
 4 A. That's correct.  
 5 Q. Okay. Intersectional barriers is a section you discuss  
 6 briefly but I think it's probably for us, important.  
 7 Perhaps you would just explain — because you talk about  
 8 the "Triple Whammy" — explain what that is.  
 9 A. The Triple Whammy is a report — actually I wrote the  
 10 report but it was very much a team effort — where we  
 11 engaged with disabled people, with disabled women, on  
 12 their specific experiences, and it actually spanned two  
 13 years, so just before the pandemic started we had our  
 14 first engagement and it ran right up until the end  
 15 of March 2022.  
 16 It basically found that if you are disabled and  
 17 a woman and experienced COVID, it was a triple whammy of  
 18 barriers, so all the things that make disabled people's  
 19 lives less equal in the first place make it even more  
 20 less equal if you happen to be a woman as well and then  
 21 COVID on top of that supercharged the barriers and the  
 22 life chances and the outcomes for disabled women.  
 23 Q. We go on to "Future Focus", which I think is obviously  
 24 a very significant section of your statement, and  
 25 I think, having seen what you also wish to bring to the

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1 attention of the Inquiry, there is more material  
 2 which — when your revised statement is produced, there  
 3 will be quite a lot more within there.  
 4 But I think, so far as what you've said in your  
 5 statement that is before us at the moment, it  
 6 encapsulates a lot of the issues that you've discussed  
 7 with us today. I think — from our point of view,  
 8 I think it would be useful if you would just read  
 9 through from paragraph 80 to the end of paragraph 88,  
 10 please.  
 11 A. So:  
 12 "GDA has drawn on the lived experience of over 6000  
 13 disabled people to consider lessons learned.  
 14 "GDA was able to step in when all other support  
 15 failed or could not be found in a range of  
 16 circumstances. On top of supports already mentioned  
 17 other support included:  
 18 "sourcing and supplying white goods for people whose  
 19 appliances had failed;  
 20 "organising the bulk removal of rubbish causing  
 21 health and safety hazards in the homes of disabled  
 22 people;  
 23 "providing a portable ramp [in one case] to someone  
 24 unable to access their parents' home where they'd moved  
 25 [in] in order to receive personal care that had been

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1 removed by the local authority;  
 2 "sourcing and providing commodes;  
 3 "organising laundry pick-up and return services for  
 4 people whose home help services had been removed,  
 5 including someone living with incontinence."  
 6 Q. Please continue. Just read on to the end of your  
 7 statement, please.  
 8 A. Thank you.  
 9 "Disabled people were not ready for a pandemic. No  
 10 specific consideration had been given to disabled people  
 11 in planning for a pandemic. We want disabled people to  
 12 be involved in future planning, and also in planning for  
 13 recovery and renewal after this pandemic.  
 14 "We wish ..." —  
 15 Q. I'm sorry, having asked you to read on, can I just pause  
 16 you there?  
 17 A. Sure.  
 18 Q. So far as involvement of disabled people such as your  
 19 group in future planning, how would you see that  
 20 operating? What form would you see that taking?  
 21 A. I think it would need to be at a national level with  
 22 Scottish Government but also at local authority level as  
 23 well. So there's people in every area in Scotland who  
 24 are on stand-by for disasters and planning in  
 25 communities, and I think if disabled people were

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1 involved in those conversations, explaining some of the  
 2 considerations they need to think about, it would help  
 3 them with their plans and their strategies and the  
 4 actions that they would need to take early on in  
 5 responding to these crises.  
 6 Q. I take it that's something that you personally would be  
 7 willing to participate in?  
 8 A. Absolutely, and I think the disabled people's  
 9 organisations across Scotland would be. I can say that  
 10 with confidence.  
 11 Q. Okay. Please go back to paragraph 83, please.  
 12 A. "We wish inclusive, accessible communication for all,  
 13 involving disabled people in communications planning, so  
 14 that disabled people can access information on an equal  
 15 basis.  
 16 "Disabled people fall through gaps in almost every  
 17 policy area and always have done, and that's just what  
 18 happened here. Even though shielding was supposed to be  
 19 targeted to them, it did not serve all of those in most  
 20 need and we would wish the shielding list to be extended  
 21 if this were ever to happen again. At the very least we  
 22 would ask to be involved in dialogue, deliberation and  
 23 to influence decision-making about such approaches based  
 24 on our lived experience during Covid-19. We, as an  
 25 organisation, had to do far more than we should ever

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1 have had to do. Although we are proud of our  
2 organisational response and the part we played in  
3 supporting disabled people, I firmly believe that the  
4 wider response just replicated the general exclusion,  
5 stigma and discrimination which disabled people face  
6 based on a lack of understanding about disabled people's  
7 lives, barriers faced and solutions needed."

8 Q. Keep going.

9 A. "It was inevitable that mistakes were made and there is  
10 now an opportunity for these to be acknowledged and for  
11 us to learn the lessons on which we can build for the  
12 future.

13 "My ongoing concern is that the aim of the majority  
14 has been to get back to some kind of normal — and  
15 NORMAL never worked for disabled people in the first  
16 place because the world was designed without us in mind.  
17 We've known about disabled people's inequality and  
18 eroded human rights for many years. Books and theses  
19 have been written on the subject.

20 "At the outset of the pandemic, I outlined concerns  
21 to the Scottish Government that history has shown that  
22 when major disaster hits — [whether that's] austerity  
23 and crisis — disabled people are very much shuffled to  
24 the bottom of society. Wars such as Ukraine and natural  
25 disasters [like the] climate emergencies like Katrina in

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1 New Orleans are examples of where disabled people fare  
2 worst, being missed out of evacuation procedures yet  
3 again. I stated GDA's intention to make sure this  
4 didn't happen again and our commitment to working with  
5 Scottish Government and others towards the best outcomes  
6 for disabled people. Despite this, disabled people have  
7 experienced amongst, if not above all, the worst  
8 outcomes — dying in the highest numbers as shown by  
9 various reports including the National Records of  
10 Scotland's 'Deaths involving Coronavirus in Scotland'  
11 24th March 2021. 'Disabled people were more likely than  
12 non-disabled people to have died with COVID-19  
13 between March 2020 and January 2021 ... Deaths of  
14 disabled people accounted for almost 6 in 10 (58%)  
15 deaths involving COVID ... in the study population [and  
16 then it says] (4,333 of 7,490 deaths)'."

17 That's a quote.

18 "Disabled people need now more than ever to be  
19 prioritised in policies and actions to tackle the  
20 pre-existing inequalities which were supercharged as  
21 well as the new ones created. We must ask ourselves as  
22 a country, what is our motivation, what is our capacity  
23 and what are the opportunities for change? Much of this  
24 will depend on political leadership and resources and if  
25 we can make progress on the motivation factor, the rest

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1 will follow. This will depend on building understanding  
2 of disabled people's lives and working with disabled  
3 people and our organisations to build services and  
4 supports which ensure that disabled people are never  
5 again left behind, fearing for our very lives — not  
6 only because of a deadly virus but because of how  
7 devalued and dehumanised we are by society. This might  
8 seem dramatic and I'm afraid that is because it is."

9 Q. Okay. One of the points you made earlier in your  
10 statement, Ms Burke, was about funding. Obviously we  
11 appreciate from your statement that GDA is funded. Is  
12 there a requirement — it's rather a rhetorical  
13 question. Is there a requirement for additional funding  
14 for organisations such as yours?

15 A. Absolutely. There should be an organisation like GDA in  
16 every part of Scotland. Each of the 32 local  
17 authorities and the national organisations are needed as  
18 well for the policy work they do and the advice they  
19 give Government and the Parliament as well.

20 I have a couple more things to add, if that's okay.

21 Q. Yes, please do.

22 A. So I think in terms of the lessons learned, I was  
23 thinking about this in a wee bit more detail. I think  
24 kind of five things are what really need to happen. We  
25 really need to look at what went wrong and build on what

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1 worked and there's lots of evidence of what worked from  
2 GDA and others. We need to involve DPOs in the plans  
3 and actions that are made and we need to invest in them,  
4 and that does require investment, unapologetically.  
5 I think the return on investment is massive and has  
6 saved lives in this instance.

7 We really need to invest in public services,  
8 particularly health and social care, and we need,  
9 I know, as a country to look at affordability. I think  
10 that's a matter for politicians but it does concern us  
11 all and there are great ideas that have been suggested  
12 around progressive taxation that have come from the  
13 Accounts Commission and the Scottish Fiscal Commission,  
14 the Poverty and Inequality Commission as well. So we're  
15 not starting from scratch with these ideas. Disabled  
16 people certainly want to be and are willing to be  
17 involved in helping shape up these ideas because  
18 affordability is what's always thrown back. But if we  
19 don't invest in the services of health and social care,  
20 we're going to be in a much, much worse position, and  
21 the Accounts Commission has just warned of this as well  
22 as the Fiscal Commission as well.

23 We need to build understanding of why the investment  
24 in public services are needed, why we need to look at  
25 progressive taxation, and I think we need to build

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1 understanding of the reality in our case of disabled  
 2 people's lives , of the poverty and inequality and the  
 3 kinds of solutions that are required.  
 4 Then the fifth thing -- it's probably hard to  
 5 separate all those things, but the fifth thing is that  
 6 we need an action plan. We need actions that embed  
 7 disabled people's rights. One of those things needs to  
 8 be about incorporation of the United Nations Convention  
 9 on the Rights of Disabled People and we need to  
 10 incorporate the stand-alone rights like Article 19, the  
 11 right to independent living, Article 9 about  
 12 accessibility , and all the other rights that disabled  
 13 people don't have in the Equality Act or in any other  
 14 acts that we have. So that's something, and we need  
 15 a plan.  
 16 And there are opportunities, so we're working with  
 17 the Government just now on an immediate priorities plan.  
 18 We're looking at a range of actions about tackling  
 19 poverty and inequality, about accessible welfare rights  
 20 provision, the adequacy of disability benefits and  
 21 a whole range of other things, and we really need to  
 22 come up with that pretty fast if it's to be an immediate  
 23 plan. And the National Care Service obviously gives us  
 24 some hope as well because that is about health and  
 25 social care, and that's one of the major areas we need

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1 to look at. So that's kind of the end of my thinking  
 2 about what needs to be done, but there's a long list .  
 3 Q. Thank you. I can respond at least to one point on the  
 4 UN Convention on the Rights of Disabled People. That is  
 5 something that is discussed at some length in the  
 6 academic research that we've had so you may be  
 7 interested in looking at that.  
 8 A. Definitely .  
 9 MR GALE: But subject to that, Ms Burke, thank you very much  
 10 for your evidence. We're very appreciative of it and we  
 11 will be in touch with you for two things: one, to get  
 12 a revised version of your statement, which will  
 13 incorporate a lot of the other material that you would  
 14 like us to look at, and we will also be in touch with  
 15 you to ascertain if there are any members of your group  
 16 who might be interested in giving direct evidence to the  
 17 Inquiry.  
 18 A. Thank you. Thanks, Mr Gale. Thanks, my Lord.  
 19 THE CHAIR: Thank you.  
 20 Very good. Tomorrow morning, Mr Gale?  
 21 MR GALE: It is indeed tomorrow morning, my Lord.  
 22 THE CHAIR: Very good.  
 23 (11.44 am)  
 24 (The hearing adjourned until  
 25 Thursday, 23 November 2023 at 10.00 am)

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