Disabled people and the COVID-19 pandemic: lessons for policy

0:00
Nicholas Watson (University of Glasgow, Chair)
Hello, welcome everybody to today's event, which we hope will be a way of looking both backwards at what's happened to disabled people during the pandemic, but most importantly, to look at developing policy recommendations and ways of ensuring that we can make up for some of the... and make better some of the disadvantage that disabled people have experienced during this pandemic.

We're going to open with talks from four disability organisations across England and Scotland. Tressa Burke is going to speak for Glasgow Disability Alliance, Kirsten MacLean for Inclusion Scotland. Rick Burgess is going to speak from Greater Manchester Coalition and Svetlana Kotova is going to speak for Inclusion London. And then Tom Shakespeare will round up and talk a little bit about our own work on COVID and disability and set the way of going forward.

We're then going to move into, after a short break, we're going to move into breakout rooms. Unfortunately, we've got to change the webinar because this webinar that we're on doesn't allow us to go to breakout rooms. So we've got another link that we'll put in the discussion, the chat room at the side, and you can then come back into that other link where you'll be able to select to go to a breakout room. And we've put the breakout rooms down to different themes. We've got themes around health, around social care, around leisure and recreation and so on.

So just to be able to choose that after the presentations. Can we ask that during the presentations, people don't use the chat very much because I think that interferes with people's screen readers so if we cannot use the chat through them. But if you have any questions, there is a question and answer session down the bottom. So can you please.... so can you please, please put any questions into the question and answer site.

I've just seen that somebody has put up a question about being able to remove the signer from their screen because the sign that can trigger problems. Is that possible? I don't know if you can see that Nat. Can you see the question that's come through?

02:41
Nathaniel Scherer (London School of Hygiene & Tropical Medicine)
Yes, let me look in how to do that.

02:44

Nicholas Watson (University of Glasgow, Chair)

Right, thanks very much. So what we'll do is we'll move. You see, there are signers and so people who need BSL and in the chat rooms afterwards, the signers, we have a particular session that is going to look at the needs of people with sensory impairment, but there will be closed. So if you need to use this, we're hoping that people would be happy using that one.

So if we move on, first of all, to move straight to Tressa, who's going to talk a little bit about experiences from Glasgow Disability Alliance. OK thanks, Tressa.

03:19

Tressa Burke (Glasgow Disability Alliance)

Thanks, Nick. Just get my notes up. So good morning, everybody. It's lovely to be here today and so glad to hear that there's people taking part, including some policy makers and hopefully decision makers amongst you all.

We've been asked to focus on the lessons for the future. So I'm going to do a wee whistle stop tour of what went wrong for over 6000 disabled people in Glasgow during these 15 months of various lockdowns and restrictions. And also what GDA did and what lessons we learnt. As our first report back in August 2020 said, we learnt that we may have all been in the same storm, but we've definitely not been in the same boat. Disabled people have fewer lifelines than many. Some of the lessons learnt are about doing what's worked.

So we engage with over 6000 disabled people and we conducted check-in calls to see how people were doing with no strings, no consultation. It was genuinely checking in. And it wasn't supposed to be a piece of research. Apart from calling 5000 members multiple times we received thousands of calls to our helpline and we spoke with well over 6000 people. We also got 2500 written responses, just a wee bit more than that, through our online survey. So some of the things that happened and then what works and lesson for policy and amongst what I'm gonna say next.

And I will try to fly through it. 41% couldn't get accessible information in the formats they needed. GDA provided what we could through our helpline, through the calls and through multiple mailings. We made accessible films and posters. We translated things into BSL as well as other languages. So what worked there was reaching out using accessible and inclusive methods of communication and information. And also we responded to the fact that we know that many, we didn't really know the numbers, but anecdotally we knew it was high, did not have access to digital devices or WiFi. So phoning and reaching out to them was really important.

80% of those who responded to the surveys were not aware of any local support services and many relied on GDA to provide information and accessible support. So,

what worked here was a flexible, responsive, part information, part informal counselling, sometimes advocacy, sometimes more than just cold referrals rather building trust, building relationships and signposting thousands to our contacts across all of Glasgow's communities and beyond. And we learned that whilst geographical community responses, so in neighbourhoods and small areas where people live, these were heart-warming and heroic at times and very, very effective at meeting local needs. But less so in meeting the needs of disabled people. So, for example, food banks or provision, mainly not delivering food or even food being delivered by shielding services wasn't necessarily appropriate because people had had their social care support cut. So they weren't able to deal with a bag of vegetables, for example, with nobody to help them prepare it.

82% of GDA members surveyed, during the last year, were concerned about isolation. So we moved all of our programmes of learning and support online. We've evidenced the very real need for holistic community support that recognises the barriers a person experiences across their lives and isn't constrained by policy or resource silos. And the lesson here for policy very much is that we need investment in social connections and empowering disabled people in our communities. What worked was listening to our members and taking their steer or we'd have made a lot more mistakes than we did. And we did, we did make a few. I'd never been on a Zoom before March 2020. Another realisation to all of this is the fact that disabled people need opportunities to participate in fun, accessible peer support, to sustain them during challenging times, and also that they need opportunities for learning and individual and collective development.

Over 60% had no devices, broadband or the confidence to use them. And so with extra funds from the government, we set up our connect project to provide devices, connections and extensive coaching, which people would absolutely not have managed without. So the lessons learnt here are when something works and there is a desperate need for it, recognise the evidence and direct resources accordingly. And I'm really pleased to see that the Scottish government did exactly this. They were in calls and meetings with us immediately after the first lockdown, they took (unclear) and directed resources where needed. Obviously, this was at that point and still short term, which brings its own problems for sustainability. So longer term funding would help. Another thing to say about the digital side of things is that digital coaching is really, really needed for disabled people, some of whom may never have held a laptop or iPad in their hands, and they do not understand the language. And doing this sometimes over the phone... We did it in multiple languages. We did it with disabled asylum seekers and refugees. We did it with people who are visually impaired. That is extremely challenging. We were solution focused and found a way around it. And actually we will be producing a report that might be useful.

83% of members said they had previously faced barriers to access and support before COVID. And we know over 1884 social care packages were cut in Glasgow. We used our Future Visions Project to support people with urgent needs, providing peer support,

counselling and urgent supplies. Lamps, washing machines, a cooker, waterproof sheets, PPE and sanitising gel. That was just amongst some of the items. So the lesson is that we need health and social care that upholds rights and equality. We need to find ways around programmes and cut through bureaucracy and if possible, deliver holistic preventative services. So, in name, we need to implement fully in Scotland and embed the UNCRPD into domestic law so that we all mean the same thing by independent living.

I'm trying to fly through this. 90% were concerned about physical and mental health, and 62% about their mental health specifically. We set up a wellbeing project, again using Scottish government funding. And the lesson for policy here is that often disabled people need wellbeing support and sometimes navigation through a web of barriers that accumulate to cause life to grind to a halt, and that was before COVID. Being in crisis, even now with a pandemic with challenges across a whole range of areas, it really does crush confidence, self-esteem and self-belief. So as with our online programmes people need this type of support before they can consider goal setting, like employability measures or even volunteering. And people need to be able to exercise the rights to services that support them. And so much of that was stripped away in relation to social care and health.

Almost half of the people we spoke to were worried about food, about money, about poverty and hardship. We set up a lifeline service providing food to 2600+ people. And we also have a welfare rights project that receive top up funding to bring in money, nearly a million pounds to almost 500 people during the last year. And the lesson is that community responses frequently exclude needs and rights of disabled people. And there's a lesson here too about the Coronavirus Act making things worse, misunderstood at best and seen as a loophole for the public sector to justify halting or reducing provision and assessment for social care as well. And this is all despite disabled people being more vulnerable to actually dying itself. I don't know how much more vulnerable you have to be to get services and priorities directed at you. But we really need focus rights-based responses on the people most affected by COVID. And some of this is covered in Social Renewal Advisory Board recommendations. Alarmingly we became aware that some GP services were calling to ask people about Do Not Attempt Resuscitation notices, which seemed at odds with the extreme lifesaving measures being used for the wider non-disabled public through the pandemic. And this direction of travel is a growing concern with media attention on the Private Members' Bill around assisted dying in Scotland, and we're very concerned about that. So the lesson is that with urgency, the Scottish government should involve DPOs as key stakeholders in any dialogue and deliberation and debate which they have committed to around assisted dying. And we need to self-organise as a movement and hopefully we are doing that.

It's not surprising with all of this, and I'm aware of time, that over 90% of all the people we spoke to want disabled people's voices to be heard in policy, services and decisions

affecting their lives. And that includes decisions about how money is spent for recovery and renewal and how plans are made. To ensure that it's accessible and controlled by disabled people, as in our input, we need DPOs to be funded and recognised as distinct in supporting disabled people's collective voices to be heard. And we draw attention to the UN's General Comment 7. which urges government and local authorities to work with and resource DPOs, because we have a unique role in telling disabled people about their rights, helping them claim these rights and building capacity and supports to share the collective and diverse voices. The lesson overall is to implement all of the recommendations that we already have. In Scotland we have a raft. We've got the Social Renewal Advisory Board and the Human Rights Leadership Task Force and we've got Feeley's independent review of social care and sometimes the DPOs own reports. So implement them all, impressive realisation of human rights. We need to start now and we absolutely need disabled people at the table because if we're missing, then our expertise is missing for more effective policy solutions. Thank you.

13:04

Nicholas Watson (University of Glasgow, Chair)

Thank you. What an excellent start Tressa. Thanks very much. And we're saving, as I said we're saving up questions until the end, if anybody has any questions that they want to ask the meeting, they can put on the question and answer phrase and we'll sort them out and I'll link them together. So if we move straight onto Kirsten, if that's OK, thank you Kirsten from Inclusion Scotland. Thanks.

14:02

Kirsten Maclean (Inclusion Scotland)

Thanks Nick. And hello, everyone. It's wonderful to be with you and thank you for the invitation to be here. And yeah, I was just wanting to put my hand in. I was excited about what Tressa was saying there about that we need to implement them all and we need to start now. So thanks Tressa for that. That's fired me up.

My name is Kirsten and I'm the people-led policy officer with Inclusion Scotland. We are, like GDA and others, a National Disabled People's Organisation or DPO. And my role involves working alongside the people-led policy panel who are a group of deaf and disabled people and unpaid carers or supporters from all over Scotland with experience of using or trying to use adult social care support.

As well as our people-led policy work and adult social care Inclusion Scotland are also doing a lot of work to campaign around remobilisation and renewal, specifically around issues of poverty, employment gap, devolution of benefits and ground-breaking work around climate change and eco-abelism. So I'm going to focus a bit more on the social care support policy area, if that's OK. But I'm really happy to talk to people afterwards if you want to email me and I can put you in contact with colleagues who are working on

other policy areas as well, and please go to our website too to find out about the work that we're doing in these different areas.

The people-led policy panel have been working with the Scottish government and other stakeholders to co-produce the reform of adult social care support policy since 2018, and we've always maintained a direct line of communication with the cabinet secretary. And I think this communication or connection to power is essential for meaningful co-production and for the success of this model of co-production. Of course, all work on the reform programme and co-production just ground to a halt when the pandemic hit. Like Tressa, we moved our meetings online with the PLPP and did our best to support members, to access remote meetings and carried out our surveys. And then later in the year, the First Minister announced the independent review of adult social care support.

The PLPP were the first group Derek Feeley, who led the review, met with, and one of our members was invited onto the reviews expert advisory group after we highlighted the lack of lived experience representation. The review, of course, reported back in February with a key recommendation being the setting up of a national care service, which is now a manifesto commitment of the Scottish government. So I suppose if we are looking at what we think we want to make things better or what we think should happen next. The first thing that I want to say is that I agree with Tressa that we, the PLPP and Inclusion Scotland fully support the findings and all recommendations of the independent review. We feel very much that Derek Feeley listened to us during that process, and we in particular, we want a national care service based on human rights and independent living. And central to this must be accessed independent complaints process, accountability and redress. Linked to this, of course we also want to see direct incorporation of the CRPD urgently, another recommendation of the review. And we are, of course, awaiting the outcome of the Supreme Court hearings at the moment, which will have a big bearing on this.

A key recommendation of the independent review is that the ultimate accountability for social care support should no longer lie with local authorities and instead it should shift with and sit with the Scottish government with a dedicated minister for social care support, which is a bit of a game changer. And this structural change we believe is of critical importance. And nobody undertakes structural change lightly, but we believe it's of critical importance and it can't be watered down regardless of any resistance from powerful vested interests in maintaining the status quo. If the Scottish government is genuine in its commitment to a national care service, that's based on fairness and consistency, human rights and the principles of independent living rather than tight eligibility criteria and limited council budgets, then we think this change is essential. Human rights can never be contingent on local priorities. And if they are, they're not rights at all.

We want to see boldness then and for the Scottish government to deliver all the recommendations, we don't think it's possible to cherry pick certain elements or recommendations. So we're asking for the government and other stakeholders to follow

through on the recommendations of the review in full. We think the review also reflects other key asks of the independent living, such as the re-opening of the Independent Living Fund, scrapping of non-residential care charges, increased advocacy, peer led and brokerage services. And also this phrase that we really liked was a relentless focus on involving people with lived experience and at all levels, including having voting rights on integrated joint boards and on the board of a national care service. Now, this was music to our ears. And although we want to understand, I suppose, better the structures and support that will be in place for making this happen and the role of DPOs within this, many of us here today, have been saying for years, what needs to change. The strategic landscape is littered with well-intentioned and potentially radical policy documents that have never really amounted to actual change in people's lives. And both the independent review of adult social care, which is grounded in the Christie commission as well, principles, and the Social Renewal Advisory Group recognise this need to urgently close the implementation gap between policy intention and the reality of the lives of of disabled people. So the failures we all know of the system are well rehearsed. We know and we've heard there from Tressa about all that went wrong in the pandemic and we need change. None of us can wait any longer. And this change, I believe, can only happen with the meaningful and active participation and ceding of power really to disabled people in our organisations as per General Comment 7. of the CRPD.

So in terms of what we want to see next, we too want a relentless focus on the active and meaningful participation of disabled people and remobilisation and renewal. And as part of that, I just want to highlight the distinctive and key role of disabled people's organisations, as I believe this is of fundamental importance in advancing the rights of disabled people. General Comment 7. says that representative organisations are only those that are led, directed and governed by disabled people and clearly differentiates between DPOs and other organisations are for disabled people, provide services or advocate on behalf of disabled people. It also recognises the history of the disabled people's movement in relation to the duty on state parties to consult with disabled people and therefore situates this debate around participation and involvement with an important and still relevant social movement history. DPOs, although changed a lot from the 80s, we still maintain strong activist roots and the politics of the Disabled People's Movement, the independent living movement, the mental health service user, survivor or mad movements. And this link to the collective, to a movement is, I think, very important. And another aspect of what sets us apart. Tressa talked about continuing to do what works and she gave so many fantastic examples of her GDA, as a DPO, were so well positioned to support the people that they work with. And as DPOs, we know from our history, from our activism, from our work as academics and our lives, our lived experience. And we know from our experience of operating in the invited spaces of policymaking that there's a tremendous amount. We know what works, I suppose, and there's so much that goes on. There's a tremendous amount of capacity building, confidence building, building social connections, movement building, collective learning and politicization really that needs to go on to make participation or co-

production truly meaningful. We have so much to offer in building meaningful, participatory decision making and policy-making spaces. And we know that policymakers and other stakeholders gain a lot from this process too. And it's a mutual learning process. Policymakers learn more about how effectively to work in this way, what's involved, how long it actually takes, and how to genuinely value and give space to lived experience in a policy context. There's so much to do,,, there's so much to learn and so much to dismantle and break down together. But fundamentally, we need to be there at the start and to be able to set the agenda, not just respond or consult to it.

Moving forward then, it's critical that DPOs have a central role. We can draw, we don't need to reinvent the wheel. There's so much existing collective expertise and successful models such as the PLPP and GDA's expert groups and others that are supported by and connected to DPOs. So we really want to see these valued and supported and prioritised. And these models have wider relevance for other policy areas and demonstrate a way forward to genuinely create people-led policy in a wide range of policy areas. And lastly, I just want to say, there can be no denying that it's a matter of life and death, that our voices and our views, our analysis are essential to recovery and remobilisation. But we need to recognise that we all are our lowest ebb, perhaps more now than ever and as a result of this, more care, I think we need to take more care to make sure that we do engagement and participation well and listen to the voices of disabled people and just be patient and kind with each other as we all recover a sense of who we are and how we relate to each other in this new world. So I hope we can keep talking and keep these conversations going. And thanks for having me here today.

24:48
Nicholas Watson (University of Glasgow, Chair)
Thanks Kirsty, that was excellent. Kirsten sorry, that was excellent, and thanks very much. It's great to hear these messages coming through. So if we move to Rick from Manchester Coalition of Disabled People, who will talk about experiences from Manchester and give more of an English perspective.

25:07
Rick Burgess (Greater Manchester Coalition of Disabled People)
Hello. Right, so in Greater Manchester we have an unusual and unique structure set up, the Coalition got a commitment from Andy Burnham before he was first elected in 2017 that he would engage with disabled people across the city region. We developed that idea. We got funding for it, and that led to the creation of the Greater Manchester Disabled People's Panel, which at present is 16 DPOs from across Greater Manchester. And we meet, we have a large online meeting at the moment monthly, and we do a lot of work in between. During the pandemic, we went to obviously a virtual meeting very quickly, in fact ahead of government advice as I think a lot of people did. And we were

meeting weekly. As part of the pandemic response we were involved in the humanitarian aid group, which was a city region wide group of council and combined authority personnel, leaders in public health and welfare assistance. And as part of that, we made sure that our offering of community hubs included a text number, which is something that they kind of neglected at that point. So it wasn't fully accessible. So this gave us a unique, unique structure.

And one of the things as the pandemic developed, we were saying to people, this is happening, that is happening. Sometimes the response was, well, where's the evidence? You know, we've got a lot of pressing needs. And so we were like, well, we know this is happening. 16 organisations know this is happening. But obviously there's a bit of a battle over priorities. So we did the survey and that was 936 respondents, ran for around four weeks between April and May. There was a standard one, an easy read one. And also we made sure that where it was possible, people were assisted to fill it in. We have got input from disabled children, people who aren't online, people with communication impairments. So there's a big report you can go and look at it online, I'm sure we'll share the links, it's fantastic.

We got help with data analysis for it and we were then quite cunning. We said to all the system leaders, right, we want to present to you this report and we're going to present to you a week before we go to the media with it. So if there's any horror stories, you've got a chance to get out ahead of them and say something we're going to do about it. That got a lot of important people to the meeting: council leaders, CEOs, MPs, people from central government. So now I would basically like to go… by the end of the report, we had 13 recommendations. I want to quickly go through those.

Our first recommendation was equality impact assessments. That they're actually done, that they are of good quality and they are listened to. It's not just enough to say we did an EIA. Secondly, digital inclusion. There's quite a good ONS survey from 2019, which found 56% of digitally excluded people are disabled people. And it's certainly the picture, across Great Manchester, it's probably worse than that. So we recommend that, you know, we really need attack this as a priority and we are now doing that. That was a manifesto pledge from Andy Burnham. And we are now in the Digital Inclusion Access Network where over the next four years, the ambition is to get everybody who wants to be, every disabled person, connected. And that includes the whole gamut of services. So getting them a device, getting them data, getting them the learning and the support. You need to do all of those things and then parallel to that make sure the actual digital offerings are accessible. It's going to be a bit of a challenge, but we've got some actual support from communications corporations, technology corporations as well. So money may not be a problem there for once.

Accessible information. Just seems really basic, but the panel recommends that information should be in an accessible format for every disabled person. You know, the format they request. I'm also reminded that most institutions, they already have this policy and they always already promised this and there are legal grounds to ask for this.

So we're really just asking them to do what they kind of pretend they do already, but reminding them they actually have to do that.

The next one is include disabled people in decision making and I will come back to this at the end quickly, but the lived experience and expertise of disabled people and disabled people's organisations, as in the case with the text line number, literally nobody else had figured that out. And I'm not sure the final figures yet, but certainly within a couple of months, they had hundreds and hundreds of contacts to humanitarian aid hubs. So clearly, without that, hundreds of people would not have got the help that they needed. And that was just one example of when you actually include disabled people, when they're funded, when there are structures in place to do that, where the system knows they have to talk to them, they can't ignore it, they can't just do an easy focus group, they can't just tick a co-production box. We have to be in those big important meetings at the very top of things at a strategic level.

OK, isolation, safety and mental health. So we found 90% of disabled people said their mental health had been negatively affected by the pandemic and to be more precise, the pandemic response. So the health crisis we faced, which includes social isolation, anxiety and depression, increased risk of domestic abuse, food insecurity, access to community mental health services and addiction services, urgent priority for that. And we now have established a funded task group that is looking at some of the mental wellbeing work across Greater Manchester. So, again, we got some results there.

Support independent living for disabled people. Article 19 of the UN Convention. You know, very clearly huge deaths in the care home sector because a lot of people concentrated in one place, and the government did a very poor job there. Independent living, as well as a principle we live by, it would have saved lives. So that needs to be said again and again to them. Personal assistants and carers. Now, there was a problem with PPE for a while and equipment and also cover for personal assistants. They had to isolate or they were ill. What happened there, the system was poorly set up for this and we muddled through, but we recommended that in the recovery phase and to improve emergency planning and any future peaks or crisis situations, they need to be more flexible in how they are providing those services, who they provide, who they approved to provide. And also when the disabled person stands up and says, you know, I need this, I need that, not to sort of subject them to form filling and criteria. Go, we're in an emergency, of course you can. That hopefully did happen. Statutory standard social care assessments and health care.

We recommend that disabled people were not subject to unnecessarily onerous assessments, things like that. If they had a working plan, just roll it over, continue it. If they wanted an assessment, of course. But there were instances where social work departments were still doing work on just kind of standard assessments where nothing has changed and everything was fine. It's a waste of their time, and it wasted a disabled person's time. It stressed them. It was silly. The development of more diverse disabled people's organisations... One minute. Oh, my God. OK, more diverse disabled people's

organisations. Disabled person organisation, in each of our ten boroughs. The Good Employment Charter in Greater Manchester has better focus on disabled people. We've been working on that.

Education. Education, health and care plans were neglected. So we need to have a fully supported, inclusive education system. And finally, which links back to the previous thing, utilise the knowledge, insight, and lived experience of disabled people's organisations. And again, that's about, you can have policies, you can have policy recommendations, but you need the structures funded to interface with power at the highest level to follow them through, to make it real, and then to deliver it and commission it in an effective way, in an informed way. And that is what we're pursuing. The rest of England doesn't really have that, although we have had interest from other cities and we're very keen to develop this model across the whole of England anywhere that wants it. We've had a fairly good partner in the combined authority, Andy Burnham. Not perfect, but it's productive. It's positive. And, you know, we're moving forward on that. The one thing I would say is that, you know, the interface with national government where there was one, was not fantastic and it has now broken down. And I think that's an issue that DPOs across England have all had. So I will leave with that. Just basically, we need those structures in place and we need them funded, resourced. And we need DPOs to be funded and resourced to make those policies actually happen. We can't just recommend it. We need to be there to make them happen.

35:21
Nicholas Watson (University of Glasgow, Chair)
Thanks, Rick, that was great. And I think three really interesting talks, both about the inclusion, but also about putting the structures in place to enable that inclusion is really coming through. And that's a really nice common theme emerging. So if we move on for the next presentation from Svetlana Kotova from Inclusion London. So do you want to fire away Svetlana.

35:43
Svetlana Kotova (Inclusion London)
Thanks very much Nick. Thank you for inviting us to talk. And hello, everyone. So Inclusion London is a deaf and disabled people's organisation. We are based in London, but we work a bit on national policy, and we are a second tier organisation, we support over 70 other deaf and disabled people's organisations in London. So we published two reports during the pandemic highlighting experience and kind of summarising our recommendations for policy. I'll put them in the chat after I'm finished with this presentation.

So I wanted to kind of just focus on some general lessons that should be learnt and lessons for specific areas if I have time. So in terms of general lessons, what we saw as

disabled people and me included, and we saw it from people who got in touch with us through campaigns and also through organisations that we support, is that the big lesson that we learnt as disabled people is that our rights are not set in stone. Unfortunately, the rights that we had to fight for many years, that they could be easily removed. So the introduction of the easements to the Care Act, Mental Health Act, to education, to the Children and Family Act, was quite a big shock. And we did spend a lot of time campaigning on the care easements, and that was because we did not believe they were necessary. And now we know that only few local authorities implemented them. But the message that it sends to us as a community was that the support, at a time when many of us needed support the most, that local authority could get away with not providing it. And one respondent to our survey said to us, I was vulnerable enough for my GP to have a conversation with me about putting a DNR note on my file. But I wasn't vulnerable enough to get a priority slot for supermarket delivery. And I think that kind of sums it up how disabled people felt, at least at initial stages of the pandemic. So in terms of lessons from this, there needs to be assessment. Was this really necessary? Was it not better to focus on providing support at the time when people needed most rather than removing our rights?

Second, and Rick spoke about it a little bit, what we've learnt is that Equality Act can be easily forgotten. Equality Act was always in force during the pandemic, but we didn't see equality impact assessments. And we also didn't saw how easily different organisations from public bodies, from high up in Cabinet Office, to GP surgeries and private organisations, from transport providers and supermarkets, forget about their duties under the Equality Act. And those duties are anticipatory. So they have to identify barriers before person comes and tries to access service. So it needs information. So now we ended up in a situation where somehow we have to teach disabled people to quote Equality Act at the receptionist in GP surgery for them to get a face to face appointment without going through an e-consult. And this is not a situation we should be in. So a lesson that Equality Act needs to be strengthened and current existing provisions that are already in place needs to be implemented properly, including equality impact assessment.

We also saw policy that sometimes were meant to help but had unforeseen consequences. So maybe a good example of this, giving supermarkets access to extremely vulnerable register for them to allocate priority slots, which meant that many disabled people who relied on online shopping for years as the only way of shopping were kicked out and couldn't get food. And that happened because of lack of understanding about how it works and lack of engagement and, of course, lack of assessment of potential impact. So everyone talked about engagement. And we believe, and we've seen local authorities in London who engaged with disabled people's organisations, with disabled people directly, did much better. So its Hammersmith and Fulham, for example, Tower Hamlets. They were able to advise people much better. They were able to change their policies to make it easier for people to navigate through the pandemic. Those who didn't did much worse. And we've seen, for example, when

the Care Minister, Helen Whatley, engaged directly with some DPOs and people who use social care, that's when changes were made and some guidance was issued for people who use direct payments because initially they fell through the gap. There was nothing, no guidance, no PPE, no testing, nothing for people who self-direct their support. Because engagement and response was almost always focused on providers, on people who speak on our behalf. So general loss that it's important to engage with us, with disabled people's organisations directly. And it's important to remember that solutions that really changed our lives, like the Equality Act, well the Disability Discrimination Act then, like self-directed support and social care. They all came from disabled people's organisations, from our community. So it's not only international obligation for government to do that. It's also a good thing that leads to solutions that do have an impact.

We also believe that disproportionate deaths of disabled people from COVID and also now there is evidence, for example, that the number of people who just receive home care dying in greater numbers due to not COVID related reasons, that needs to be investigated and understood and obviously addressed. So I wanted to talk about, a little bit about social care. And we hope to see the promised, long promised reform of social care. And we believe some lessons from COVID absolutely need to be learnt in developing this reform. This reform should meet, first of all, and the goal of reform should be to meet the aspirations and needs of people who use social care. So focus and engagement should be with us first in terms of how we want the system to operate, how system could enable us to live a normal life and then kind of look at everything that needs to happen. We also see as a direct result of the pandemic that its exposed how rigid the system is and how it is ineffective to react to change. And even with people who self-direct their support, who use direct payments, it was a scandalous situation where in some London boroughs, people had to wait for weeks for response from social worker to allow them to spend their money on PPE. And this should not happen. And when our government tried to push some flexibility on local authorities for direct payment users, which was the whole goal of this purpose, of this policy intent initially, but it didn't happen. So now we also see local authorities because they try to close gaps in their budgets. They try and make people pay more for care. We see many cases where people have to pay for care that they haven't received or just charges increasing. And that happens at the time when people can afford it the least. And the response to that from the government and from local authorities is that we have minimum standards to make sure that people are left with enough money to live on, while that money to live on is from £3 to £20 a day. And we need to take a step back and think as a kind of society and policy makers and everyone, do we really think that this is appropriate? So we believe that (unclear) must be free and this problem must be addressed immediately, even if there isn't social care reform.

So digital exclusion, people were talking about this. And for us, it's technology skills and money to be able to afford access to broadband. So there needs to be plans related to that. And no one mentioned access to work. And I don't want to say that those disabled

people, those of us who are working and rely on support from access to work also felt how not responsive the system was. And again, support wasn't there when we need it the most. So we also are calling on reform of access to work based on engagement with people who use this service and based on what would help us to do better at work. So thank you very much.

45:09

Nicholas Watson (University of Glasgow, Chair)
Thank you very much Svetlana. Thank you. OK, so I'll move straight to Tom, who will round things up for this session.

45:18

Tom Shakespeare (London School of Hygiene & Tropical Medicine)
OK, thanks, Nick. I would like to say thank you to all our colleagues. It's exactly why we invited you to speak today and these surveys that you presented, and yesterday, the BBC presented their survey, are really useful and worth reading, worth listening to. What we did in the University of Glasgow and London School of Hygiene & Tropical Medicine is in-depth qualitative research. We are funded by the ESRC. We talked to 69 individuals and twenty eight organisations in England and Scotland, and we talked to them twice in- depth. And so what I report today is what they said to us, and we've taken all their findings and tried to analyse them. So three areas. Short-term, medium-term, long-term.

So in the short-term, we heard strongly we need consultation and participation, we need dialogue about social care planning. We need an expert advisory of disabled people and their organisations to Scottish and national government as equal partners. And we felt that we need to set up committees of key statutory actors, DPOs, other relevant partners, to review the pandemic response and make recommendations in all of the areas that I'm about to talk about. Secondly, short-term, we need coordination of services: health, social care, statutory services generally, but also the independent sector, including disabled people's organisations. In this pandemic, DPOs and NGOs did huge amounts to support disabled people, and they need to be part of the response to the crisis in future. Thirdly, we need clarity, clarity of information and messaging. So, for example, just very basically, government communications from Boris Johnson and the Chief Medical Officer and so forth need to be sign language interpreted there and them. We need easy read versions of everything that's published for everybody else so that people with learning difficulties can easily understand it. From the NHS, fourthly, we need responsive and person-centred services, better patient file management, better consistent use of telemedicine and online consultation when there is difficulty with face-to-face consultation. Don't forget social care. Remember social care, that is our fifth message. Bring social care agencies together with health and social care partnerships to

find better social care solutions. We've been so fixated on the NHS that we fail to respond accordingly to people's social care needs. And many of our respondents had their packages cut or they reverted to having their family supporting them, which is not what we want in the 21st century. And sixthly, and related, we need more PPE going into social care to people who use personal. We need transparent masks so that people who rely on lipreading can read what people are saying. When people are in public and shops and so forth, we need either a lanyard or some other identification, plus awareness campaigns because people don't understand the interaction issues that, for example, guide-dog users or people who lip read or people with autism, might have in public. And they need to understand that so that they don't attack people verbally or physically when they can't conform to, as it were the new social norm. When it comes to online support activities, and that has been a plus of the pandemic for children, for disabled people generally, for people with mental health conditions, for people with dementia. All of these platforms have been really useful. But as has been said already, people need support to overcome the digital divide. Disabled people are disproportionately excluded from all of this, but they need it even more. We need better information so that everybody knows what is available and doesn't languish, isolated at home, not knowing what they could log into. We need creative alternatives, like, for example, the Staying Inn for disabled people to make contact with others, because particularly people who are shielding are very isolated. And some people need training in how to use virtual and online meetings and services. So that needs to be made available. And of course, better educational provision for children with special education needs and disabilities. When school was out, when people were learning from home, we found that, as it were, non-disabled children did get their needs met. But it took a long time for children with special educational needs and disabilities. And a lot of caregivers tended to teachers, and had a totally different pandemic, as a result. We've already heard it was only people who had official shielding letters who received priority in online shopping and many other disabled people lost out. Now, we know that you need some sort of certification so that supermarkets aren't judging who is and who isn't acceptable. But what about letting all people who receive DLA or PIP to receive a priority for shopping? These have been assessed. They are disabled people. So please let people who receive PIP get priority, not to have to make special requests and begging letters in order to get into online shopping.

In the medium term, we need to meet all those postponed health needs. There's lots of disabled children and adults who need rehabilitation, who need physio, who need dentistry, who need podiatry. There's all sorts of needs that have been postponed. We need urgently to fund catch up in health. We need to remember and catch up with the educational needs of children with disabilities, including deaf children who need to learn BSL. We need to meet also the play and leisure needs of children with disabilities who have been so excluded. We need to secure the funding of the third sector, particularly disabled people's organisations, and we need to engage with the third sector, who have been so flexible and so effective as equal partners, not as contractors

who are delivering services for fees. We need to tackle the isolation of disabled people that COVID-19 pandemic reinforced, particularly for people with mental health conditions who reported more anxiety, more depression, more isolation. We need equal access for disabled people to work, education and social spaces. And above all, as Michael Marmot has said, in terms of building back fairer, we need to address the long-term poverty and discrimination experienced by disabled people in all areas of life.

Thirdly, let me talk about long-term needs. Firstly, in the NHS, we need training as part of the curriculum for all health care workers on the specialist needs of disabled people and how to respond to them. And we need localised health care hub, so that people with chronic illness or specialist needs can get access to GP. Secondly, we need to make social care as important as health care. It must have a voice. And remember, social care is not just older people. Half of all disabled people are older people, but half are not. Let's remember, disabled people who are younger, who receive social care, home care, who receive personal assistance, and sometimes who live in institutions. Institutions are terrible places for disabled people. Let's help everybody get out now because they're places where people unfortunately die from the pandemic. We need to bring social care agencies together with health and social care partnerships with the NHS in England to find better social care solutions. We need to grow the social care workforce, which might include visas for people with care and support skills to work in the UK. People from Europe who previously worked in the UK. We need to recognise support workers, personal assistants, as a profession and we need to pay them in line with the NHS, not minimum wages. There is so many problems post-2008 with the hollowing out of social care after the crisis, and this has made it even worse. People were not prepared for the pandemic because it had been hollowed out by cuts. We need long-term investment in mental health services, delivered in community settings, delivered online. There's loads of mental health issues that have arisen from the pandemic, as well as the pre-existing mental health issues that people have had. And here social work departments, the third sector can play an important role in providing online or face-to-face supports. Fourthly, long-term, COVID revealed the diversity of disabled communities and how this insight intersects with health needs. We are sorry that today we have a bunch of white people talking about COVID when it affected black and minority ethnic people so much. We are sorry that in our study we were unable to reach enough black and minority ethnic people really to speak about those needs. But we need desperately, definitely need to understand that disabled people are very diverse and we need to look at the impact of COVID on this diversity. And we need more support for third sector organisations, DPOs, that represent and support BME people. Fifthly, we need to ensure the participation long-term of disabled people in their communities. Disabled people volunteered throughout this pandemic as well as benefiting from volunteering. We need to ensure that volunteers understand the rights and the needs of disabled people. And this is all public education. We need to review how volunteer recruitment has worked, including the recruitment of disabled people as volunteers. And there's lots in the third sector we can learn from. I've nearly finished Nick. Sixthly, long-term, we need

awareness of the challenges that disabled people face in managing their pandemic restrictions. We need people to understand what it's like to be a disabled person. So we need public education long-term. Post-COVID in our cities, the use of our urban environment is changing, we need to ensure the access needs of all disabled people, particularly people with visual impairments. We think that we should allow blind people to use the freedom pass on taxis, perhaps for free or subsidised fares. We need to train taxi drivers to include blind people and their dogs. There are lots of inequalities here. And finally, we need blended, that is to say online and face-to-face models for services, for employment. We can't forget what we've learnt about Zoom and teams and all the rest of it. And lots of disabled people have accessed the public and the cultural world more than ever before. We can't put it away. We can't stop this. We need blended models of service provision and employment. So I'll stop there.

That's what our participants said to us and what we're saying to you. And we're really grateful that we can stand or sit alongside all of our colleagues from DPOs, who've done brilliant reports on this, and which you should read. And we can send this recording of all of our presentations to anybody who requests it. Back to you Nick.

56:55
Nicholas Watson (University of Glasgow, Chair)
OK, thanks Tom. That's great and thanks everybody else for such a fantastic opening to the morning. There's a couple of questions come through in the questioning. And I'd just like to ask, because I think one of the central things that has come through all of the presentations has been the need to include voices of disabled people and for disabled people to be part of the conversation. And Jim Elder-Woodward has made the point that organisations like GDA or Inclusion Scotland and Inclusion London are, you know, obviously struggling for money, but relatively well funded. And same with GMCDP. How do we get organisations, other DPOs, how can we bring other DPOs into this sort of meeting, so that we can spread across outside of the areas where we know that disabled people's organisations have impact? And I also think one of the other things that came through our work when we were talking to organisations working with disabled people was how precarious people's funding is, how central these organisations are to going forward and planning. And I suppose one of the key things that we need to think about is, and it relates to the points that both Kirsten and Rick were making, around the need to fund the services, the disabled people's organisations that bring this through. So I suppose just very quickly, if anybody has any comments they want, any of the panel members want to talk about that. How do we broaden out to bring all the DPOs in and to keep them funded?

58:41

Tom Shakespeare (London School of Hygiene & Tropical Medicine)

I think this is a really, really important issue because we've had wonderful colleagues from Glasgow, Scotland, London, Manchester and ourselves, our studies were in western Scotland, in London and East Anglia. But what about all the other places? And we know that there are good and strong DPO's in many, many parts of England, Scotland, Wales, Northern Ireland. But over the years they have been defunded and they've been isolated. And we need more provision for people, particularly in rural and remote areas. Even we had people who were talking to us from the west of Scotland and from the islands and facing really difficult times. And I'm sure that's the case in many rural areas of Britain and Northern Ireland. So we do need to try and fund the services, which really can make a difference to people's lives.

59:28

Svetlana Kotova (Inclusion London)

If I can say one comment. So we see it as a as part of our mission to raise awareness with funders, to make sure they fund DPOs, and we did have some successes during COVID like Community Response Fund, for example, where we managed to route money that was meant to disabled people, to DPOs, and I think some learning could be... we could get some learning from this. But the problem that many organisations have at the moment is that they funded to deliver services, usually by local authorities, so they are in very precarious position of voicing the needs of people who use those services and being dependent on the funding from local authorities. And so we believe that there must be engagement with disabled people's organisations, which should be resourced by those bodies that need us to engage with them. And that's how that should work.

01:00:37

Rick Burgess (Greater Manchester Coalition of Disabled People)

Across Greater Manchester, that's 10 boroughs, originally only six were represented by a specific DPO. That's now up to eight. And we're working on the other two. I do think there's a great need for existing DPOs to get involved in community organising where there are gaps. And once people start getting together and plotting and conspiring together, funding will start to be sought out. It's going to be a hard battle, but we absolutely need to impress on people, on system leaders, on commissioners, that to do their policies well, they need to have these organisations existing and funding.

01:01:35

Nicholas Watson (University of Glasgow, Chair)

Right OK, thanks so much, and I'm conscious that we've gone on for an hour and its always good to have a break. So we're going to stop for a short period now and we're going to come back with... unless anybody, does anybody... I'll just throw it open. Does anybody have any other questions that they want to ask? They could put questions up on the open, on the question and answer or on the chat if people would like to do that, or want to do that, just to see if we have any questions. So what I think because it's always better to have questions, I think, and save the questions for the panels, which is what we were hoping. So if we have a short sort of comfort break right now for 10 minutes, and then we'll return. We have to return to a different webpage. And I think, Nat, have you put... I think that is the zoom link for the next webpage that's just gone up and it will also go into the question and answer pages, because I think that one somebody said that they would have trouble accessing the chat room here, is that right? So we'll cut it across there. And Sabrina will be staying in this web. Somebody will be staying in this webpage. So if you have trouble getting into the next Zoom link, you can come back into this webpage and somebody will be able to help you into the next room if you need to be in there. So we're going to have a complete break and people can have like 10 minutes. It's probably best, if they want, they can zoom into that link now and leave it and go have a cup of tea or get a cup of tea or a comfort break and then we'll come back in 10 minutes. So we'll be back just after quarter past eleven, if that's OK with people. OK, we'll break it down to a discussion. OK, thanks very much. And I'll see you in about 10 minutes.