

London Covid Narratives

The experiences of older people and disabled people of the
Covid19 pandemic



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Amplifier

The Covid-19 pandemic has given rise to many heroes. Those caring for the sick and stocking up our supermarkets have been operating in plain sight and celebrated widely. With this study, we shine some light on a group that has been more hidden, but nevertheless has also had to be especially resilient. Disabled and older people had to be great problem-solvers to cope with everyday life whilst all around them the government's Covid-19 response disproportionately affected them.

The Covid-19 pandemic has also highlighted many aspects of our pre-Covid lives and the ways in which society discriminates against disabled people. It is an amplifier of a city and a society in which disability is already hidden. Changes to our 'normal' has temporarily made disability more visible in all its invisibility.

These stories illustrate how re-thinking our new normal can be an opportunity to realise a more inclusive society in which people with disabilities are part of conversations as they happen and not after the fact.

Social rules and behaviour

Disabled people are disproportionately affected by the emergency measures made by the government during the Covid-19 pandemic. Shopping, walking, and meeting friends have all changed the social fabric of everyday lives. While occasionally it has made some aspects of life more accessible, our research uncovers that disabled people are faced with having to make greater personal sacrifices.

[Click here](#) to listen to and read all the Social rules and behaviour 'postcards' online



Seven Salads

I always get the same things, so like seven salads for each day of the week. But buying in bulk was no longer allowed and I could not get hold of any online shopping slots because I am not classed as vulnerable, even though I have these problems and feel disabled because of my autism. While I have social anxiety, that means I have to go out more often. But then I found a supermarket that was letting people in with disabilities so that was good. That did feel a lot easier than before, because I don't have to struggle with people walking around in different ways. It's less busy, less sensory.



How might we enable supermarkets to improve their infrastructure for people with disabilities based on lessons from the Covid-19 pandemic?



Space

I was already in the wheelchair space.. and Transport for London policy because of COVID is that if there is somebody in the room, if there is somebody occupying the wheelchair space, and they say they don't wish to share the space, the driver should respect that. So what happened was a buggy, a mother and a buggy got on. And I said to the driver, there is no space. And he still let her on, and I said, there is no space again. He then got out this cabin and came down to me without wearing a mask. He said, why are you being difficult? And I say, because of COVID. That is my preference. And I'm allowed to do that. And he just said to me: Why'd you fight everybody? All I wanted to do was to travel on the bus. And this was the bus driver.



What might help transport companies to develop and communicate guidance effectively so people in wheelchair spaces feel safe when people are urged to social distancing?



Roadworks

Roadworks on my route have been delayed because of COVID and they're doing them all at the same time now. So that reduces the overall amount of spaces on the road that can be parked in and if I don't have a lot of space for my tailgate to let my wheelchair out, I can't park. I can't get out of the car. I have a big van because it needs to take the wheelchair. So when I move my car from one of the parking spaces outside my house, I'm worried that there will just be no space for me to park. It stops me from leaving the house.



How might councils and construction companies be enabled to consider the needs of wheelchair users in their local area when planning for and carrying out roadworks?



Lifeline

I work for an organisation that supports people with sight loss, and the number of calls to our telephone line and emails to our mailbox has increased significantly. We find that individuals or organisations seeking to help often cannot get in contact with the Council's Sensory Services. Many of our callers don't have computers to use Zoom or Teams and many people feel lonely and feel isolated. We have been able to provide another outlet and lifeline for them to talk to someone who has experienced some of the same issues in coping with their loss of sight.



How might councils and community organisations be enabled to quickly increase peer-support for people with disabilities during times of crisis without excluding those without internet access?



Unpredictability

Before I used to not really want to go outside anyway, but I had to go outside so I would. And even that was scary using public transport to get places. I knew that I would always have staff around me. I knew the rules to follow. And I could follow them. And now that has all changed. I didn't know what rules to follow, when to follow them how to follow them. And they were changing them enough every day, it seemed. Like, I don't know what you're supposed to do on buses now. How is that supposed to work? When I got on the bus, people still seem to be sitting next to each other. So knowing when to follow the rules or when not following the rules is a big issue. It made the world very scary to go out. Unpredictability was everywhere, which meant I was too scared to leave the home.



How might we enable government and private sector organisations to communicate changes in social rules so that people with Autism are able to 'find the flex' ?



Spontaneity

I miss the interactions with local people and staff when sitting in Costa Coffee and everyday interactions at the bus stop, at the shops and in my local library. I no longer “bump into people”... all my journeys and walks have an intention, they are deliberate. There is no spontaneity.



How might we foster 'serendipity' in local communities and create online and offline intersections for people to meet and interact spontaneously during times of crisis?



Pole

Because I've always gone into the shop wearing a mask shop assistants have led me around the store pretty much as normal. But with members of the public, it's more a mixed picture. In theory, they reintroduced sighted guiding on the tube now, so that if you're wearing a mask, then you can grab someone's arm, and there should be no problem. But sometimes, I get into little arguments. Some people offered non-verbal guiding and then other times people have even tried to improvise and brought a two-metre-long pole out and got me to hold one and then they've held another.



How might we enable non-disabled members of the public access and navigate changes in guidance on how to assist people with disabilities (such as visual impairments)?

Stay Safe
Leave Space
2m
(6ft 6")

Queue

I can't take the cold in my bones, it makes me very ill so I can't actually wait outside in the queue. So before, when I go to the shops, usually the security guard will let me in straight away. But now with the queuing, lots of people kind of end up looking at me like, why does she get special concessions to go in first? You might see elderly people in the queue and mothers with babies... And I feel really bad. So I'm wondering what to do, because I need some shopping. And I don't want to have to wait, because sometimes I do have to wait. Sometimes they don't let me in. And also, I don't want kind of bad looks from people who are not happy that I've been let in as an exception.



How can we enable stores to enable those with hidden disabilities to skip a queue when they need it without feeling guilty or being judged?

Digital inclusion

The experience of disabled people during the Covid-19 pandemic restrictions shows technology as a powerful amplifier of vulnerability. The shift to a socially distanced society has created greater isolation of disabled people with the blind and partially sighted being especially affected.

[Click here](#) to listen to and read all the Digital Inclusion 'postcards' online



Outside

I used to be a person... my company was outside. So I didn't really have the people coming to me or in that way I used to go out to engage with people. So the fact that I'm not going out to engage and have to do it on a phone. When you're communicating with somebody on a phone, for example, that person has to have the time to talk to you at that given time. Or they say, can I call you back later? Or they say, I'm busy today, I'll call you next week. Whereas when you used to pop out, as it would be and you see the person, you could have a 20 minute chat, and you come back home, or you could meet them somewhere. You could have a conversation, and you could come back home.. I wasn't so reliant on the phone. Now I'm having to learn to become reliant on technology and the phone and Zoom and all the rest of it .. It's taking me a while to adapt. But it has highlighted that I do live quite a lonely life.

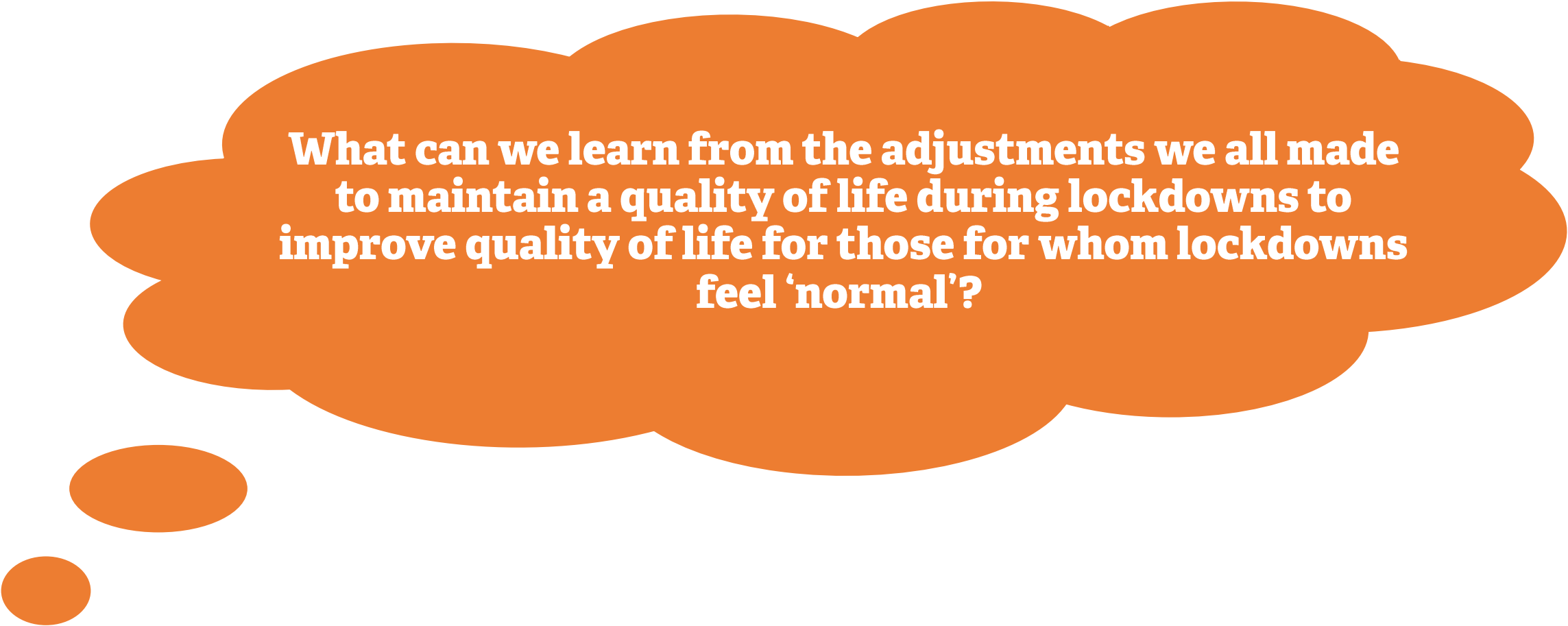


How do we help communities identify and offer support to those among their communities who might feel lonely?

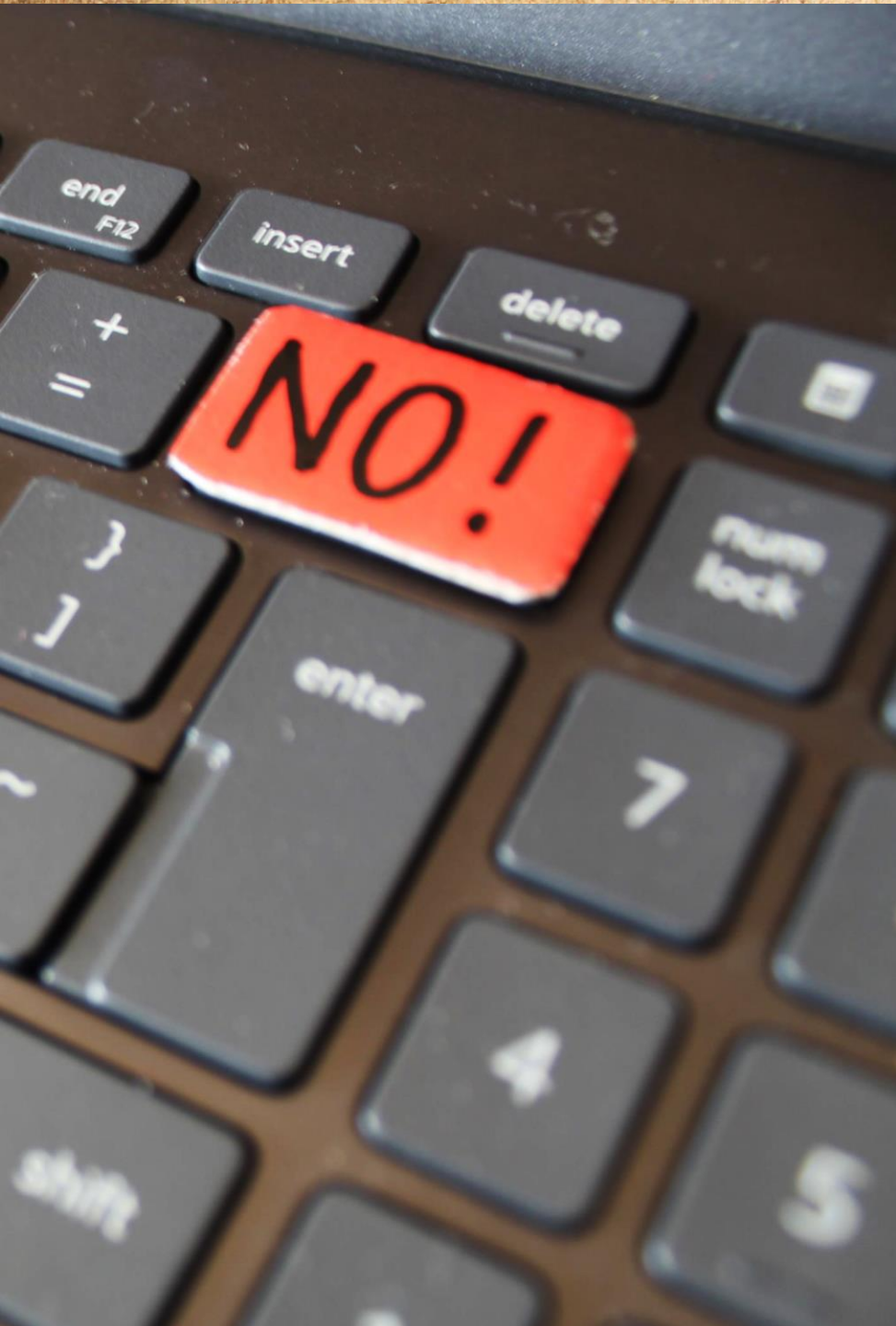


Online

I haven't found this any different to my non-covid life. Most of my social life is lived online, whether through Facebook or WhatsApp. However, all of my support groups have moved online which makes it a lot easier to attend.



What can we learn from the adjustments we all made to maintain a quality of life during lockdowns to improve quality of life for those for whom lockdowns feel 'normal'?



Not for them

I had to relay some details of a workshop to get elderly people digitally savvy to my group the other week. And it actually said, for details, email so and so. And then when I made a complaint that actually, in order to get on the workshop, you have to email the person. They said 'Oh, well they'll have to go to another service. Perhaps this isn't for them'.



How do we meet people without basic means or skills at their level to help them broaden digital infrastructures?



Broadband

People like myself who are on Universal Credit, it's not just free to make telephone calls beyond the internet, we have to measure how long and how much data we've got. So for me, the internet is a luxury. At the beginning of lockdown I didn't have broadband or a laptop at home, I had to purchase one. Because I was used to going to the library. And I was used to doing everything, you know, in internet cafes and stuff. So, you know, we take for granted the luxury of broadband data, a good signal and everything. But actually, there's a lot of digital poverty. And especially people whose first language isn't English as well... I just find it very distressing.



How do we identify and prevent the atrophy of essential offline infrastructure while ensuring that free and accessible offline spaces remain so as key aspects of our infrastructure migrate online?



Card reader

I've had problems understanding shopkeepers because they are behind thick plastic screens and I can't hear them. I have also had problems accessing my bank because they cut their hours, and they say you have to do everything online. But to make a transfer online, you need to be able to use a card reader, which I can't use because it's not accessible to me.

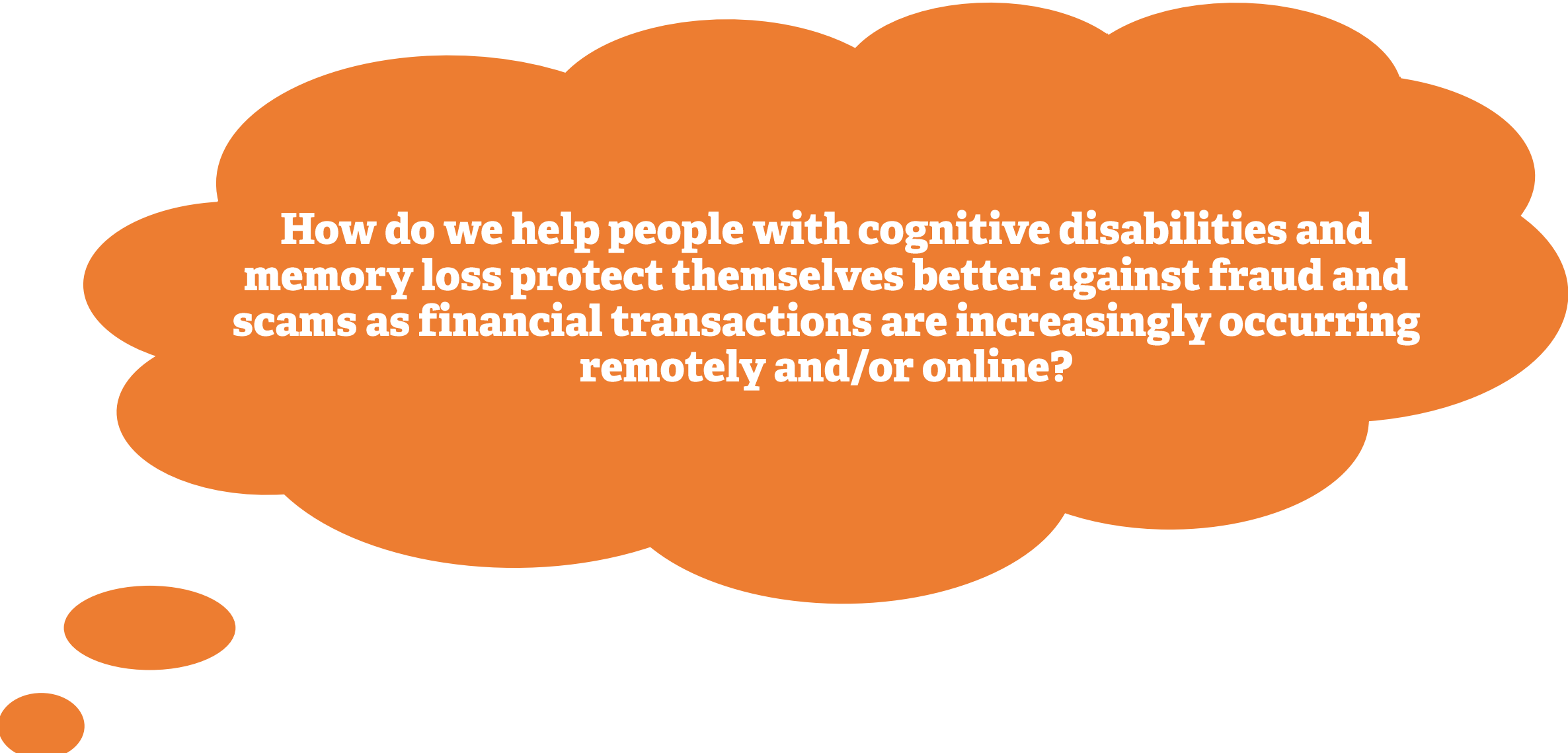


How do we enable essential services like banks to have plans in place to ensure accessibility isn't compromised when changes are made to services?

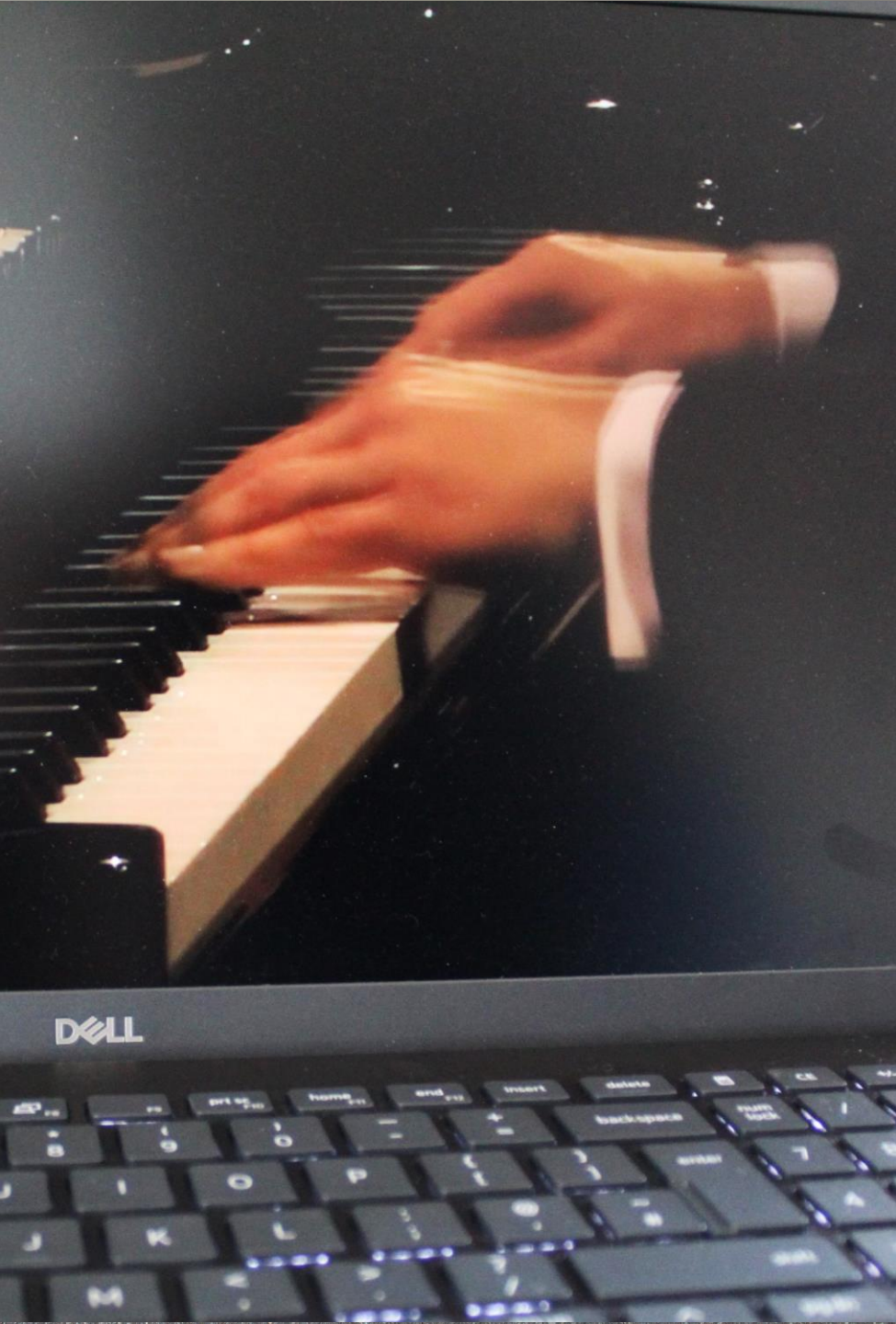


Notebook

I have problems with internet at home. So I needed to go to my bank to set up my online banking app. I normally go down to a bank and put my card into the machine for a statement to see what's going in and out of my account. It was a bit of a challenge because of course, I needed a notebook to write things down and a pen. It's the only way I could do it. I just hope that banks don't close because people with cognitive problems like me, I constantly can't remember my pins and passwords and all of that jazz. And I lose my notebook. If my notebook got stolen, I'd have to start again. I'm worried about security.



How do we help people with cognitive disabilities and memory loss protect themselves better against fraud and scams as financial transactions are increasingly occurring remotely and/or online?



Jazz

I obviously think it's awful that we've got this pandemic and that people are dying of Coronavirus. For me, it's actually changed my life for the better. Because as well as my partial sight, I've got walking difficulties. And so I have difficulty getting out of the house, and going to the wonderful gigs in jazz clubs that I used to love to go to. But now because of the pandemic and because of lockdown they stream these gigs live. And I can watch wonderful gigs that I once had to go all the way to the West End in a taxi for, someone to help me out the steps are down the steps, then I've got to struggle out and you've got to struggle to the loo halfway through.. And instead I can just sit down comfortably, and on my lovely iPad and going through my lovely Bluetooth speakers is a wonderful jazz concert that I can see even more clearly than I can at the club. My favourite is when the pianist is playing, they go right up to his fingers and the camera is right on his fingers... And you can see the fingers moving. And it's just such a thrill for me.

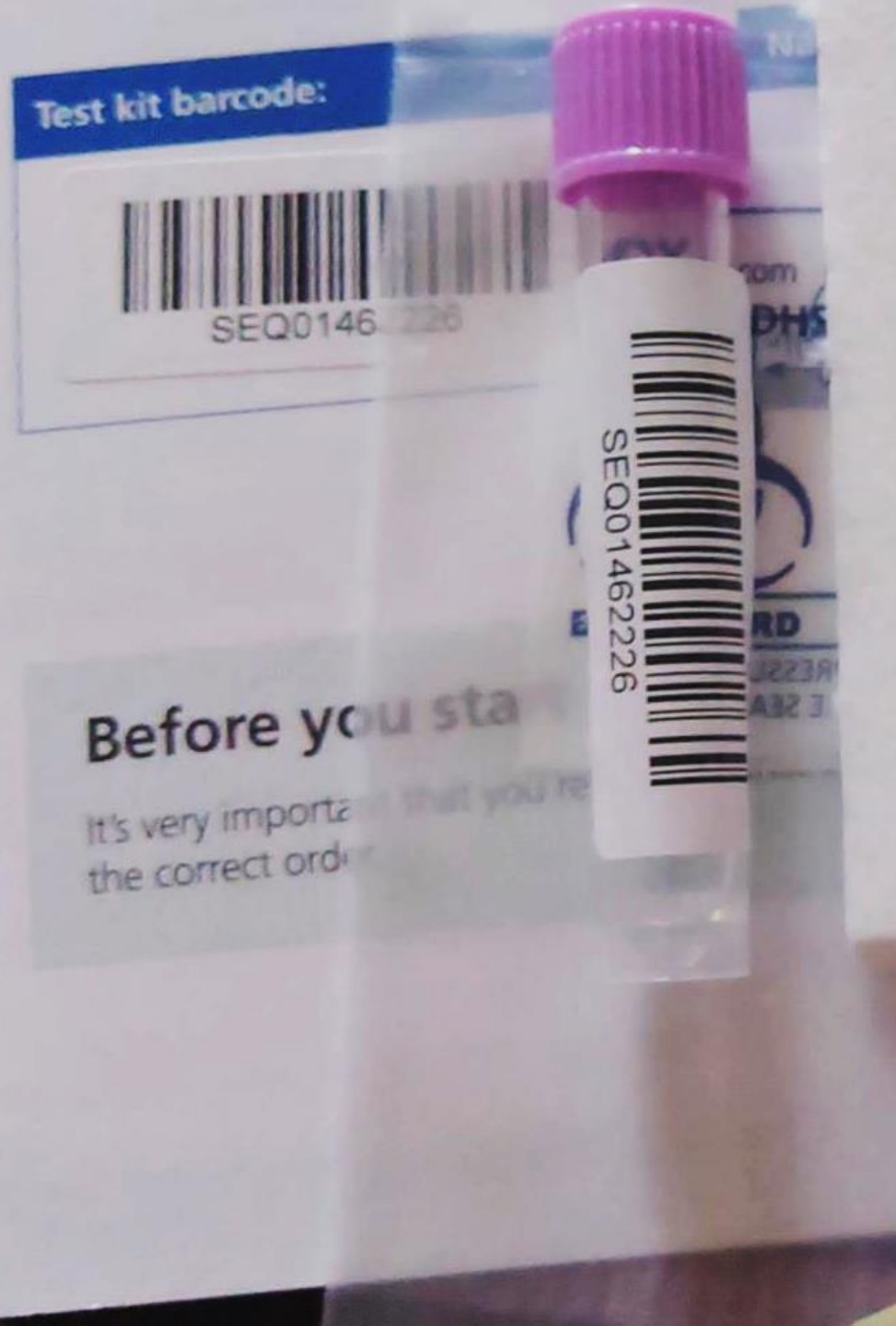


How do we support the event industry to integrate lessons on digital infrastructure more permanently when live productions are possible again whilst also improving the accessibility of venues?

Bottom of the list

National emergency measures amplify vulnerability. Disabled people are considered last as part of fast-paced disaster control measures. Measures tend to place disabled people at greater risk whilst making their disability more hidden.

[Click here](#) to listen to and read all the Bottom of the list 'postcards' online

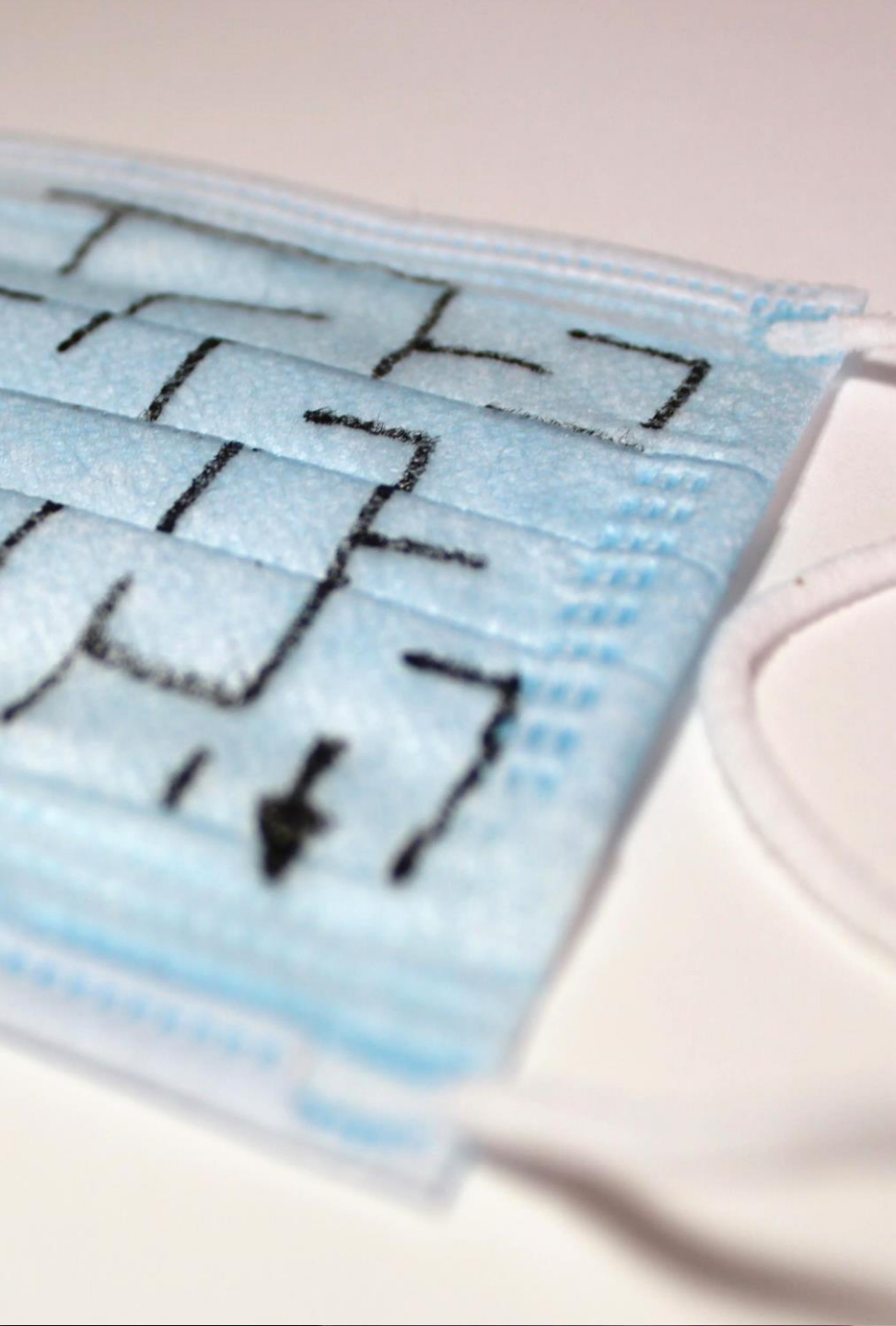


Isolating carers

A few months ago one of my carers decided not to continue in the role because of the required travelling on public transport through London. They didn't want to put themselves at risk of contracting the virus, a lot of my carers are getting sick, and if not them getting sick, members of their households are getting sick, meaning they have to self-isolate. And especially as there's already a reduced number of carers as it is, and it's the Christmas period - people wanting time off and annual leave and that kind of thing... It's proven to be really difficult now to get care cover, and I'm not sure what I'm gonna do. For the time being, my family can definitely help for the Christmas holidays because everyone's off work and school, but help is not kind of, you know, working 12 hour shifts.



How do we enable essential service providers to rapidly increase service provision in times of emergency?



Roaming concierge

In Westfield they used to have this thing called the roaming concierge. You could go to the front desk, and they would get someone to take you to the shop. For a short visit they would wait with you or if it was a longer visit, you rang the security people again and they picked you up. Now, this service is still not running. So when I got there, I basically had to fend for myself. I knew the shop I needed was on the right-hand side about halfway down. So I went roughly the right kind of distance, but I had to ask in three or four shops. I really hope this isn't an excuse to remove the service. It was something that they brought in at Westfield to do it in all the country as far as I know. And I hope that they aren't now going to use this as an excuse to get rid of it forever.



How do we help chains and shopping centres to make sure accessibility is considered when changes are made to their services?



Car park

I was in hospital for four weeks, and family members weren't allowed to come and see me. And obviously, I couldn't go out into the car park or anything like that. So it was pretty frustrating because everyday was like a month or a year for me. And being in the hospital, obviously you're really scared to get the virus. Because the nurses and doctors, obviously they kind of go around to everybody. I said to them, I also have a learning difficulty. So my family was speaking to the doctors and seeing if it's okay if my mum could stay with me, but she couldn't and it was really frustrating. Because I was going through treatment and tests that I've never done before. That was a big, big anxiety for me as well. Facing the machineries and stuff like that.



**How do we make sure rules that keep all safe don't
come at the cost of the safety of some?**

A white sign with black text that reads "SEE ♥ YOU". The sign is divided into three horizontal sections. The top section contains the words "SEE", a heart symbol, and "YOU". The middle section contains "12TH". The bottom section contains "APRIL".

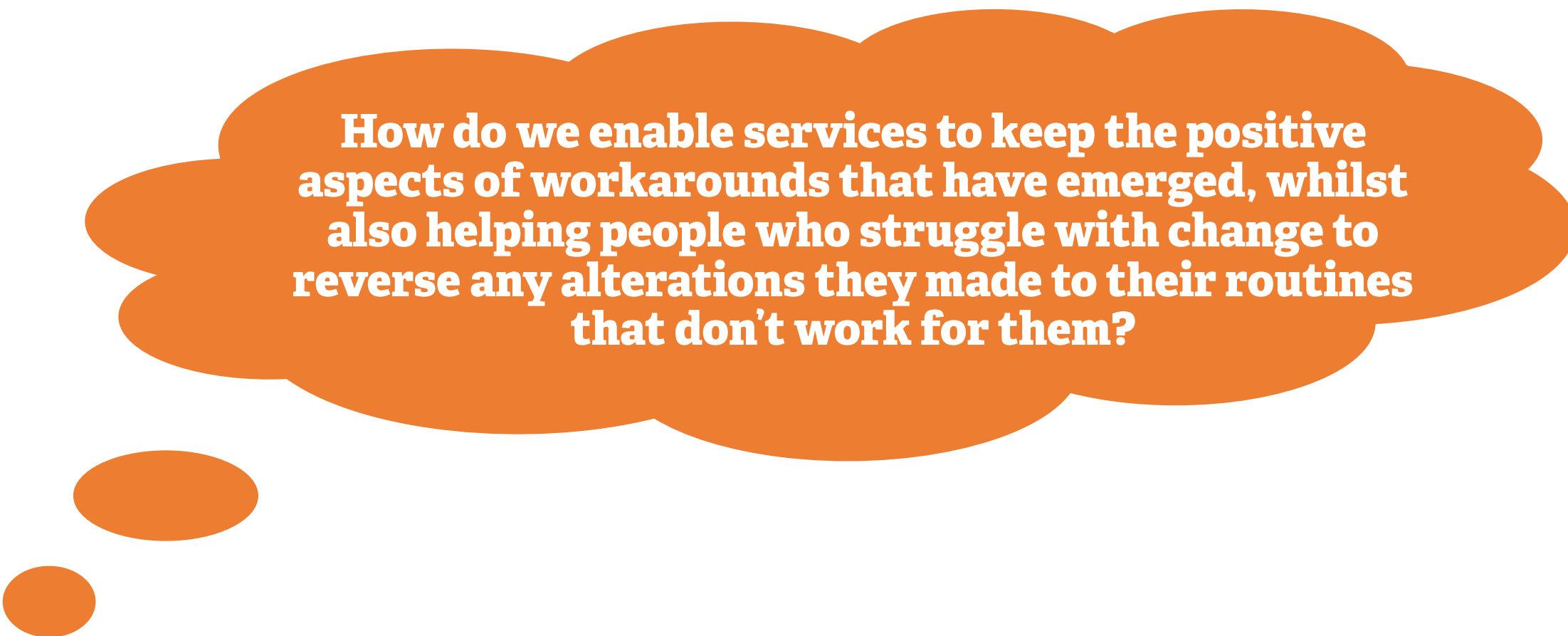
SEE ♥ YOU

12TH

APRIL

Hidden

In some ways the situation is ideal for autistic people, for me anyway. It means you have to go out less to see or talk to people. Like, the other day, I needed to see my doctor. It was also easier to communicate over the phone than face to face, although it was harder to describe stuff... But it also means that my disability is less recognised. It's more hidden. I might stick to some of the changes that happened or that I have been forced to take. Either because they are easier or I am now used to them. Because it will be harder for me to change back again to the way things used to be. I think Covid has uncovered more of my disability. The things I can't do have been highlighted to myself.



How do we enable services to keep the positive aspects of workarounds that have emerged, whilst also helping people who struggle with change to reverse any alterations they made to their routines that don't work for them?

Helping the helper

Peer to peer support networks reflect the important role of 'communities of need'. These networks are fragile and need constant support to maintain.

[Click here](#) to listen to and read all the Helping the helper 'postcards' online



Painkillers

Two weeks ago, I was told to shield, then the following week I got an infection from my first jab. I got my prescriptions delivered and British Gas suggested using the NHS volunteer service to help me top up. The WRVS took my details and said they would put me as “high priority” on the database, as I was in emergency, to volunteers in my area and someone would ring from a withheld number, but nobody has rung. Three days later I just had enough electricity, dosed myself up with painkillers and antibiotics and went to the shop to top up. Ironically, I’ve been doing community advocacy assisting older people during the pandemic and I have worked in my local community paid and unpaid for over 15 years...



**How do we help companies become both aware of -
and accountable - when inaccessible services result
in an increased burden on essential service
providers and increased risk for their customers?**



Closer

I find it hard that if my friend is on their own and in distress I can't meet up or give them a hug. I can't take a train journey across London to visit a relative. But even though most of my family live miles away, I have become closer to them. They have had more time to message and speak on the phone. We've also had family bereavements which has brought us a lot closer. I still feel uncomfortable using Zoom for close family and friends. But I have made new friendships over Zoom by doing training, conferences and joining organisations.



What initiatives could help those with mobility issues who feel isolated as a result of family members living far away?



Cold

The thing is, helping people has been very therapeutic for me. So it's actually made me forget about my own isolation, because I've been able to help people or elderly people within the Zoom groups and within our over 50s forums. And I've also been able to assist an elderly person in my support bubble who's partially sighted. So that's helped me. But with this second lockdown, the most striking thing is the weather. Because I met up with someone, about month ago, we sat in the park and it was so cold. It's not something I can do again. And so I think that is the real difference, that we are going to be forced to actually stay at home.



How might we support people more vulnerable to harsh weather conditions so they are not excluded from socialising and access public spaces outside?



Dog

My friend takes out my dog very regularly. So I see people. And even when we weren't really allowed to see people, she would stand at the bottom of the stairs, and the dog would run down the stairs, but we would also have a conversation. And I would go out for a walk every day with the dog, just me and the dog, so I was very fortunate. Because if you went at the right time, people weren't having picnics in the park and stuff.



In the event of a future pandemic, knowing what we know now, how could we ensure a safe degree of distanced interaction between people to prevent isolation?

Enabling curious conversations

In order to develop sustainable solutions that work for everyone we need to be able to reflect and map both challenges and new ideas. We took a first step in creating two canvases and a [Miro-board](#) designed to reflect on the insights from stories and solutions from older and disabled customers. Did you find them useful? Let us know at @RIDC_UK or email us at research@ridc.ok.uk

Temporary measures

Things we started doing that we want to stop again

Innovative measures

Things we started doing that we want to do more of

New

How accessible were our temporary measures?

Accessible for SOME

Accessible for ALL

Old

How accessible were our old practices?

Obsolete activity

Things we stopped doing that we realise we can do without

Stop

Start

Paused activity

Things we had to pause and realise we need to restart

1. Populate the framework with old practices stopped and new practices started as a result of the pandemic (see RSA guidance)
2. Reflect on the accessibility of these practices for some vs all by populating the cloud in the middle
3. Reflect on how and which accessible practices can be moved outside of the cloud and from the left to the right of the canvas

*Tip:
print me
on A3!*

This framework is adapted by RIDC from the RSA framework for future change
www.thersa.org/approach/future-change-framework

Impact

Why not test if these are desirable right away?

Lets get these on the agenda..

That sounded great but, let's think that one through some more...

Cost/Effort

1. Use the questions in this deck to brainstorm about insights and ideas that could improve the accessibility for disabled customers
2. Reflect on the impact of these practices for disabled customers verses the cost or effort required to implement them
3. Reflect on practices in the cloud on the right. Could small actions be taken? Could those be placed in the cloud on the left?
4. Don't disregard practices in the bottom field right away: what was it about them that felt exciting?

*Tip:
print me
on A3!*