



Crisis, Challenge and Change

Reflections from Deaf and Disabled people's user-led organisations about the impact of COVID-19 on their work in 2020.

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Foreword

In June this year, Shaping Our Lives was awarded a grant by the National Lottery Community Fund to carry out and complete research into the impacts of COVID-19 and national and regional lockdowns on Deaf and Disabled people, Deaf and Disabled People's Organisations (DDPOs) and Patient Participation Groups.

DDPOs are not-for-profit organisations which are user led, run by and for Deaf and Disabled people. They provide a range of peer-led accessible services that support Disabled people to access services and entitlements, challenge discrimination and exclusion and have choice, control and independence.

This report reflects on the experiences of 20 DDPOs all working in England, in over 20 different local authority areas from early March until late September 2020 as they responded to working during the COVID-19 pandemic.

Shaping Our Lives convened two online round table discussions with 20 DDPOs attending at the end of September 2020. An outline of this process is in the Appendix. The discussions were facilitated by Joanna Matthews (National User Group member of Shaping Our Lives) supported by Becki Meakin (General Manager Shaping Our Lives). The quotes in this report come from those discussions (unless otherwise indicated) and the views expressed are those of the participants. We knew the identity of the 20 senior staff representing organisations but have kept their identity and where they work anonymous.

Thank you to all of our participants. We appreciate your willingness to share your experiences and your candour.



The other three COVID-19 reports published by Shaping Our Lives, December 2020 are:

Behind Closed Doors: The longer-term impacts of COVID-19 on independent living for d/Deaf and Disabled people.

Locked In or Locked Out? d/Deaf and Disabled People's Experiences of using Remote Technologies during COVID-19.

Engaged or Ignored? Reflections from patient participation groups about practice during COVID-19.



Glossary

ATW **Access to Work** - a central Government scheme to provide funding for additional equipment and support for Disabled people in employment

DPs **Direct Payments** - a payment made by a local council or trust to a person, enabling that person to choose and purchase necessary services to help with their support and/or care needs (as assessed by the local council/trust) instead of receiving the support arranged by the local council/trust.

EIA **Equality Impact Assessment**

Equality Act 2010

- The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society.

Hate Crime

- term used to describe a range of criminal behaviour where the perpetrator is motivated by hostility or demonstrates hostility towards the victim's disability, race, religion, sexual orientation or transgender identity.

PA **Personal Assistant** - a paid worker supporting a Disabled person to live independently

PPE **Personal Protective Equipment**

PSED **Public Sector Equality Duty** – requires public bodies to have due regard to the need to eliminate discrimination, advance equality of opportunity and foster good relations between different people when carrying out their activities.

Support Worker

– an employee who provides support to a Disabled person in work (often funded by ATW).

UNCRPD United Nation Convention on the Rights of People with Disabilities.



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Executive summary

- The first few weeks of the pandemic created a high demand for support services from DDPOs. This demand did not continue at the same intensity as 2020 progressed, but the type of support need changed for Disabled people. These changes have presented new challenges for DDPOs.
- DDPOs found themselves at the frontline, ensuring that Disabled people in their communities had access to food and other daily essentials including PPE.
- Inclusion of Disabled people in the services of public and commercial organisations was not universal. DDPOs had to fill the gaps to make sure Disabled people could continue to live independently.
- Because there was a lack of coherent and clear advice from both central and local Government about many aspects of the pandemic. DDPOs had to both source accurate information and disseminate it to many in their community, not all of whom are online. This included vital advice about Direct Payments and the employment status of PAs.
- Loneliness has increased for many people during lockdown(s). DDPOs have a vital role in combatting this, finding innovative and imaginative ways to deliver activities and events.
- Home working through IT was a challenge for some staff teams and required additional investment. Barriers to using technology and getting online was a big issue for many Disabled people and DDPOs had to step in to help.
- Alongside practical service delivery DDPOs worked to ensure the voices of Disabled people were heard by gathering evidence of problems and raising awareness with local and central authorities. DDPOs who are hate crime reporting centres contributed to the body of evidence that disability hate crime increased in 2020.
- There is concern about the significant number of Disabled adults in residential care who DDPOs are not in direct contact with. They lack an independent voice and are isolated.



- DDPOs had additional funding to meet extra demand for their services. There are significant concerns about what happens when this emergency funding stops and needs still exist.
- Staff teams rose to the challenge working from home and delivering reconfigured and new services. There is fatigue and stress caused by dealing with the pandemic.
- Many staff are also Disabled people so had to manage their own challenges to daily living. Some were isolating at home as well as running organisations.
- Volunteers, a valuable element of DDPO delivery, were not always able to be fully part of the team because of concerns about their risk of exposure to COVID-19 and reconfiguring services to be delivered from home.
- Collaboration between local agencies increased, building good relationships for the future. However, the pandemic exposed both gaps and duplicated effort. Where local infrastructure was poor it often continued to be so.
- Some DDPOs were pleased to have built good relationships with existing and new funders; there was a change in how funders responded to need. DDPOs were cautiously optimistic that this new outlook might continue into 2021 and beyond.
- Disabled people's rights were not evident in the central Government response to COVID-19. This created more work for DDPOs, providing practical and emotional support.
- There was a call from the DDPOs who attended both Round Tables for national representation for Deaf and Disabled People's Organisations and significant, sector building, financial investment to enable DDPOs to meet the needs of Disabled people.



Key Actions

- Raise awareness with businesses of the everyday living needs of Disabled people and the impact of disrupted services and support networks in getting what they need.
- Increase understanding of central and local Government of the needs of Disabled people living independently for equipment and medical supplies and ensure this is resourced to prevent disruption in future emergencies.
- Ensure the provision of accessible, timely and accurate information:
 - to all Disabled people in receipt of Direct Payments from Adult Social Care to enable them to make informed decisions for independent daily living.
 - for all official announcements.
 - from central Government to Disabled people as employers, employees and recipients of benefits, about any legislative or policy changes in response to this pandemic or future emergencies.
 - uniformly across a nation, disseminated to all Disabled people who need it without an unfunded cost to the user-led sector.
- Increase understand in the wider helpline/befriending sector about needs of specific communities and how they are additionally impacted by both COVID-19 and by isolation.
- Address the barriers Disabled people face with all forms of technology. This should include training in the general UK workforce to ensure Disabled people can access communications in all medias.



- The Disability Unit in the Cabinet Office, the Minister for Disabled People, Health and Work and the Minister for Patient Safety, Suicide Prevention and Mental Health to understand that:
 - Disabled people are specifically at risk of exclusion during the continued COVID-19 pandemic.
 - Central Government has a crucial role in ensuring the legal and institutional processes that are in place to protect Disabled people are adhered to, for example: the Equalities Act, a Public Sector Equality Duty and EIAs, and that measures taken by the government are compliant with the UNCRPD.
 - It is crucial Disabled people are continuously involved in these processes.
- Ensure that the direct voice of Disabled people in residential care and detained in institutions is heard and acted on, so that their human rights are protected.
- For central and local Government to take steps to ensure Disabled people are not once more 'the hardest hit'.
- For central and local Government and grant making trusts and foundations to recognise the value of strategic investment to build the capacity of the user led sector.
- For the Disability Unit in the Cabinet Office and the Minister for Disabled People, Health and Work to put in place a strategy for tackling attitudes to Disabled people give rise to inequalities.
- Establish a national voice for DDPOs who collectively represent the diverse community of Disabled people.



DDPOs and Disabled people

DDPOs support Deaf and Disabled people, people who face barriers to their full inclusion and participation in society. As organisations they work to the Social Model of Disability. The Social Model states that people have impairments, an inevitable aspect of the human experience, but that the exclusion and discrimination people with impairments face is not an inevitable consequence of having an impairment but is caused instead by the way our society is run and organised.

The Social Model of Disability holds that people with impairments are 'disabled' by the barriers operating in society that exclude and discriminate against them. When these barriers are removed, Disabled people can be independent and equal in society. Disabled people have the right to have choice and control of everyday activities and to apply strategies to overcome those barriers to be able to do things independently.

Disabled people are a diverse community, estimated to be about 20 per cent of the UK population and represented in every class, race, sexual orientation, marital status, age group and family relationship. However, as a community we face specific challenges which unite us and cause us challenges in daily living, income, employment, access to technology and our social life. The Equality Act 2010 defines Disabled people as people with: sensory, cognitive, neurodevelopmental conditions, learning disabilities or physical impairments, mental health issues and people with long term health conditions.

DDPOs work to support Deaf and Disabled people with the challenges we face. They do this through direct service delivery, advocacy, signposting to other support agencies, raising awareness, campaigning and challenging breaches of existing legislation or influencing new legislation which improves the lives of Disabled people. As user led organisations DDPOs are uniquely placed to anticipate failures in systems and process caused by COVID-19 that have or will impact on Disabled people in 2020 and beyond.



Shaping Our Lives surveyed Disabled people in 2020, asking them to comment on how the pandemic had affected them. This is a key finding:

“More than half of the respondents feel that COVID-19 and lockdown has had a long-term negative impact on their ability to live independently. Four fifths of Disabled people responding to this survey agreed that COVID-19 and lockdown measures have reduced the choice and control they have as a Disabled person. ”

Behind Closed Doors, Shaping Our Lives 2020.

At the start of the pandemic central UK Government identified a cohort of the population as ‘clinically extremely vulnerable and at very high risk of severe illness from coronavirus if they either have one or more specific conditions or a clinician or GP has added them to the Shielded Patient List because, based on their clinical judgement, they deem to the person be at higher risk of serious illness if they catch the virus.’ ([UK.Gov Advice on shielding](#)) Many Disabled people met the requirement for shielding and were told to stay at home at all times from mid-March until the end of July 2020. However, many more Disabled people were not put on the Shielded Patient List but like those on the list they too faced many barriers with getting help and support but with no formal status. DDPOs supported Disabled people regardless of their status.

The 20 participants that we interviewed in two Round Table discussions work for organisations based in England. Between them the DDPOs cover more than 20 different local authority areas (nine county councils and five unitary authorities plus two regional organisations who between them represent Disabled people living in 43 local authorities). Of the 20 DDPOs four are national organisations who represent specific communities of Disabled people; adults living with mental distress/trauma, adults with learning disabilities and the LGBTQ+ community. One organisation supports Disabled people who work in the arts sector. Three of the 20 organisations are infrastructure organisations: not supporting individuals directly but raising awareness through policy and campaigning work and supporting DDPOs who provide front line services.



A. What organisations did to support Disabled people

One organisation summed up the experience of many:

“We had a horrendous six weeks early March through to mid-April, swamped with calls from PAs and their employers wanting information that nobody had, wanting guidance that nobody could give us, on where to get PPE, information on shielding, ‘what do I do about furlough’. It felt relentless and endless.”

Meeting basic needs

By early March worry about the impact of the pandemic specifically on essential supplies and concern about an approaching lockdown was prevalent in the general population, resulting in shortages of some foodstuffs and household items. For Disabled people relying on supermarket home deliveries, they suddenly found there were no delivery slots available, and no system in place to give them priority.

DDPOs reported delays in statutory health authorities informing people that they should be shielding (because of specific health conditions) so there was confusion for some about whether they could, or should, leave their homes to shop. Disabled people who knew their health put them at risk but were without an official letter to prove ‘shielding status’ found it difficult to get food and other essentials. Many turned to their local DDPO for help; these organisations saw an increasing demand for existing services while also working in new ways to meet needs they had not encountered before.

“We put together packs for people with things like soap, cloths, deodorant - because we found people often didn’t have basics because they didn’t have support to get into the shops and pick up the basics.”

“We set up meal service for people who were vulnerable to impact of COVID but didn’t get official shielding status.”

“We distributed food parcels to those who could not get shopping.”



In addition to direct service delivery DDPOs worked with other existing voluntary agencies, developed new partnerships in their locality or a combination of both.

“We were part of a partnership providing up to 5,000 meals a week [in a large metropolitan area], to make sure Disabled people didn’t get missed out.”

DDPOs identified one of the biggest challenges facing Disabled people was a lack of awareness of the needs of Disabled people, specifically around access to everyday goods and services. The everyday systems that Disabled people had in place to live independently were very disrupted.

“There is more work to be done with supermarket chains. They think they have adapted but we have evidence to show they haven’t really.”

Disabled people living on their own needed additional support, as did specific communities. For example, LGBTQ+ Disabled people are less likely to have supportive families to provide informal care and support therefore are additionally disadvantaged.

- **Key Action** - Raise awareness with businesses of the everyday living needs of Disabled people and the impact of disrupted services and support networks in getting what they need.

PPE and other specialist equipment

During lockdown 1 there was a national shortage of PPE and a lack of comprehensive information about supply. Reported as a “massive challenge” by our participants, from the small local independent DDPOs to those contracted by local authorities covering larger geographic areas, they were either constantly trying to find reliable information about PPE sources or sourcing and distributing PPE themselves. This was so they could distribute PPE to individual members who were unable to access any for their personal assistants (PAs) and informal carers. For DDPOs who run PA agencies they needed PPE for



their own support staff, or risk exposing staff and vulnerable clients to infection.

“We were trouble shooting for individual members, providing a bespoke service responding to individual need – food, PPE and immediate issues with care.”

Some reported fielding calls on help lines constantly, others picking up problems in a weekly round of contacting members and physically distributing PPE themselves.

“PPE was a massive challenge for people. We were providing a PPE delivery service from my house.”

This particular DDPO did secure funding from their local authority to manage the logistics and support volunteer delivery drivers, moving storage and delivery to/from their office. By late September they were serving about 100 people with regular deliveries of PPE, about 30 plus deliveries a week, though reported demand increasing as cases rose locally.

Although sourcing PPE was a major feature of early pandemic response, by September there were reported improvements in distribution.

“It took time to sort but now have got good relationship [with their local authority] were we can request PPE for Disabled people, and that has worked really well”

However, this major challenge has left organisations questioning what significant logistical issue will arise the next time there is a national emergency.

- **Key Action** - Increase understanding of central and local Government of the needs of Disabled people living independently for equipment and medical supplies and ensure this is resourced to prevent disruption in future emergencies.



Direct Payments and employment of PAs and other support staff

All front line DDPOs experienced an upsurge in calls about managing daily living care and support funded through direct payments (DPs) from local authorities. Quite often local authorities were giving unhelpful or contradictory advice.

“Direct Payment users were badly served throughout this [pandemic]. We lost our DP advice service when the contract was given to a larger agency, but still have a lot of clients on DPs and so we had a lot of interaction because that organisation sent out no communications. DP users were coming to us for help and advice about things like statutory sick pay and PPE. We have had quite a few battles with the local authority about getting good information to this group.”

This case study was echoed by organisations all over England. At a time when Disabled people managing their own care needed accurate and urgent advice as employers none was forthcoming from national or local statutory bodies. One example of confusion was whether PAs could furlough and still get paid through the client’s direct payment income.

Disabled people were very concerned about their own daily living care, recruitment and retention of care staff (which is a challenging marketplace at the best of times) and there was no single source of public information, therefore DDPOs spent their resources pulling this information together.

“We haven’t had a DP advice service in our city that was funded [for a long time]. We had always picked up bits and pieces [pre-pandemic] anyway through our advocacy service. When COVID-19 came we were flooded with calls as the City Council had no support in place for people on DPs and then the Council realised they had a massive gap in providing support. So we ended setting up an emergency PA register and providing support alongside that. There was not much information coming out [from local or national government] so we had to pull that together.



This DDPO did secure funding from their local authority for a part-time worker to support people on direct payments, although reported this post is already overstretched.

Other DDPOs that provide PAs as part of their services faced similar issues with a lack of statutory information which made their role difficult in supporting this workforce, vulnerable both to increased risk of catching COVID-19 but also to issues with employment and therefore income. DDPOs faced an increase volume of work as they had to carry out additional risk assessments, advise about furlough (with scant information initially available), find replacement PAs when workers got COVID-19 or had to isolate because of contact, and of course source PPE for their workforce.

“PAs were the abandoned workforce in the pandemic.”

In spring 2020 there was quite rightly a national focus on enabling the NHS to function, and to get them adequate supplies. However, personal assistants and family carers are front line workers too, some working for clients with conditions which make them very vulnerable to COVID-19.

- **Key Action** - Ensure the provision of timely and accurate information to all Disabled people in receipt of Direct Payments from Adult Social Care to enable them to make informed decisions for independent daily living.

Information and advice

Provision of accurate, timely and accessible information and guidance to Disabled people is a crucial role that DDPOs undertake all the time, but it became vital during the pandemic. The volumes of contacts went up quickly and a greater number of service users had more urgent enquiries; already busy advice phone lines needed to be matched with a fast turnaround of help in the context of DDPOs themselves adjusting to working from home and online.

For some groups that meant quickly collating and interpreting information, constantly updating their own websites.



“The local authority are directing most of their enquiries to our website, which we are keeping up to date. Not much information is available, so we are very quickly having to pull things together. ”

For others that meant pointing out to their council their statutory role and lobbying (sometimes with others in forums and networks) to ensure Disabled people in their locality were kept informed. Year on year budget cuts means provision of specialist information and advocacy is now unfunded.

“We had quite a lot of battles with local authority getting them to get information out to people. Their Direct Payment users were badly served. We have been picking up where other, funded, organisations should have been providing.”

Others recognised there were groups that were not being reached with information at all; for example, adults with autism and other learning difficulties adversely affected by a sudden lack of support structures.

“We’ve been able to contact, connect with isolated individuals, linking [them] in with local and national self-advocacy services [so that they get support].”

For organisations used to providing information, advice and advocacy support one-to-one and face-to-face, they recognised this ‘new communication normal’ required both staff and their clients to adjust. Among their concerns is that face-to-face interaction provides a better service when working with clients through the complexities of benefits advice.

Local authorities and central government not providing information was a common theme. Another issue was DDPOs being expected to be a conduit for the provision of statutory information to Disabled people with no additional resources. For example:

“Generally we have a good relationship with our local authority, but they wanted us to send out 650 questionnaires to all Disabled people in receipt of a direct payment as they didn’t have the staff to do it but thought we did!”



The pressure caused by the pandemic to provide timely accessible accurate information has not let up as changes to Government guidance has had to be assimilated and shared. This is particularly true if information has not been translated into different formats:

“There was no easy read guidance we could find.”

Several organisations provide infrastructure support (information, guidance and access to funding) regionally or nationally and their work levels have increased in support of their membership. Some of this has been because local DDPOs have been getting additional funding to deliver more and/or new work, and consequently need support to implement change.

- **Key Action** - Provide accessible information for all official announcements.
- **Key Action** - Ensure that, where information will be applicable across a nation, it is provided uniformly at the same to all Disabled people and disseminated to all who need it without an unfunded cost to the user led sector.

Combatting loneliness and isolation

This was an issue for many people during lockdown and a great concern because of the impact on people’s mental health. Of Disabled people surveyed for *Behind Closed Doors* in the summer of 2020, 79% said they had become lonelier or more isolated during the pandemic. For Disabled people shielding on their own there was an additional pressure as they were advised not to leave home (initially not even to go outside). Although replacing the informality of drop ins and community cafes has not been easy, DDPOs took their social clubs and activities programme online, reporting a good take up and in some cases more participants online than would come to a live event. However, this wasn’t always the case; access to online technology is not universal (see below) and gatekeeping (accidental or deliberate) can prevent access.



DDPOs with memberships were proactive in tackling loneliness– connecting with members using online meeting software and the phone. Others experienced increases to advice line volumes, often without a specific query.

“An awful lot of people have contacted us just for a chat.”

Some organisations tackled meeting ‘basic’ needs first but then shifted to a bespoke service to meet the emotional and social needs of each caller. Another combined proactive well-being calls with signposting to other sources of help and support as needed. Not all well-being support was one-to-one:

“We’re running a COVID-19 action support group for self-advocates once a week, up to 35 members. We look at what support needs people have and their lived experiences.”

Another organisation reminded us that although meeting tech is free (although there an internet bill and additional outlay on hardware) phone calls on landlines have a unit charge; they found that this excluded some people from longer activities.

Once lockdown#1 finished another adaptation happened; groups met outside. However, for some individual Disabled people the fear of leaving home to expose themselves to COVID-19 was too great. On the whole, organisations did not return to full time working from an office anticipating lockdown#2. One organisation provided a blended service:

“We have had a different online activity or discussion group each day, led by a Disabled person. If someone wants to take part by phone or even SMS they have been sent a kit in the post so they can feel part of it.”

A couple of organisations were able to access additional funding through the Community Fund and other local charities to fund ‘COVID-19’ workers – people employed specifically to increase befriending and well-being offers. There was a recognition that although the activities themselves might vary, the impact of “galvanising a sense of community” (whether



through an art club or an e-bulletin) really mattered to people who were lonely.

- **Key Action** - Increase understanding in the wider helpline/befriending sector about needs of specific communities and how they are additionally impacted by both COVID-19 and by isolation.

Employment

In the early days, before the Government schemes kicked in, organisations were fielding helpline enquiries from Disabled people facing redundancy, worried about income during lockdown or losing income as freelance contracts dried up. A big concern for DDPOs is increased competitiveness in the job market as the recession hits; Disabled people have higher rates of unemployment and lower incomes than the general population. Some employment sectors have been hit much harder than others:

“We are part of alliances designed to amplify our voices [in the theatre industry]. A lot of disabled freelancers rely on that work – so what it means to be an artist, on tour, etc, is going to have to substantially change. It difficult to know where to start, with advice, to provide safe and inclusive spaces. How can we continue to really support these artists, beyond taking everything digital – how do we support career development?”

Others found that newly unemployed Disabled people wanted support understanding what benefits they might be entitled to, meaning either people could not find the statutory information they needed, or it wasn't accessible to them.

Many Disabled workers use the Access to Work scheme to pay for their support workers. It is a paper-based system relying on the collection of monthly data on forms and signatures, and the postal service. With required signatories no longer working alongside claimants, the inevitable delays to post and office closures holding up post opening, some DPOs reported that there were problems with people being able to pay support workers and processing new claims.



“Access to Work’s perennial and multiple problems have been put in a harsh light. At beginning of lockdown Disabled people were still expected to leave their homes to go to post office. Although after lobbying some adjustments were made to reduce the reliance on paper. “

- **Key Action** - Provide comprehensive, timely and accessible communication from central Government to Disabled people as employers, employees and recipients of benefits, about any changes in response to this pandemic or future emergencies.

Access to technology

The world of work went online in March. Online meetings and remote home working meant all our participants could carry on delivering a service (to Disabled people who could get online) although many services had to be re-designed and re-configured.

“As a volunteer led local group we found we could provide ‘a night out while in’ we have been running our monthly quizzes online.”

In some instances, DDPOs were able to offer new activities and reach more people. Many agreed that new IT skills would continue to be a benefit.

“Increased digital confidence is a positive. In the past people told me we can’t have digital conferences or meetings and now we can.”

There was also agreement that for some Disabled people there was no such thing as the ‘new normal’; tech solutions have always been used by a cohort of Disabled people facing barriers to getting out and about.

However, some services were hard to reconfigure online; advocacy services were given as an example of this. All round table participants reinforced that going online is not possible for all Disabled people they work with. Barriers to digital inclusion are documented in our report Locked In or Locked Out? (compiled summer 2020 from a survey of Disabled people); in summary most of these technologies require people



to have access to appropriate equipment and a reliable internet service, which may be cost-prohibitive for many Disabled people.

“We have kept in regular communication [with members] and not relied on remote/digital communication – it doesn’t really work for everyone and raises its own accessibility issues.”

Alternative points of entry to online meetings (e.g. using landlines with Zoom) have an additional cost, as one group reminded us, as their members had been alarmed by large increases to phone bills. Other issues experienced by their client groups were a reliance on support worker visits to access technology; LGBT+ members not being out to carers so not wanting to participate unless they were on their own (a problem if in a shared space); and in one case a Disabled person being denied access by a support worker.

To tackle some of the issues caused by digital poverty, some DDOPs have secured funding to get clients online and ensure they can take part in their activities:

“Our most in demand service is called Tech to Community Connect. It gives people a device and matches them with a volunteer Tech Angel who teaches them how to use the device and then how to access a virtual programme of social activities and forums.”

Others invested resources in upskilling members to use new digital tools or invested in staff resources to ensure access; for example, employing a specialist typist for live streamed events. Simple solutions were always found largely through phones, sometimes simply ringing people one-to-one, other times using conference calls or other mobile phone apps.

“We wanted to set up a phone group conference. Took four months to find a system that could operate from phone rather than using broadband. Lots of our participants don’t have broadband.”

DDPOs involving volunteers in their infrastructure (governance) had to make sure they had their own houses in order, remembering that access requirements have to be resourced in



the same way as offline meetings. This involved time spent on coaching.

Organisations reported previously good practice (hard fought for) sliding backwards as local authorities only provided an online portal during lockdown or stopped providing a minicom service for deaf service users.

“In our city we can see how reliant emergency services are on a digital framework. That excludes many Disabled people from an emergency response.”

DDPOs are frustrated at this lack of awareness about digital access in the wider community, specifically other voluntary sector organisations, the public sector and companies. One person summed it up by calling digital exclusion:

“a persistent, immovable issue that has not been properly addressed”.

The impact on DDPOs is that they faced increased pressure on their services, during the early stages of the pandemic, enabling Disabled people to overcome the technology barriers that other institutions create.

- **Key Action** - Address the barriers Disabled people face with all forms of technology. This should include training in the general UK workforce to ensure Disabled people can access communications in all medias.

Representation

During 2020 DDPOs were even more concerned that the voices of Disabled people were getting lost, ironically when their ‘vulnerabilities’ were almost a daily mention in the news. Advocacy, gathering evidence of need, raising awareness, campaigning – all these rights-based activities continued alongside meeting individual needs, sometimes encountering barriers:



“It’s hard to maintain a rights-focussed framework, we’re all forced into emergency mode. Emergency mindset [from external agencies] views engagement, rights etc as nice-to-haves, things you can leave behind.”

At least one third of the organisations had carried out surveys in their locality and used the findings to change their service provision, raise awareness of need and lobby central and local Government. DDPOs raised awareness with other voluntary, public and commercial agencies of access problems with over reliance on, or even exclusive use of online technology.

Three organisations were involved in the distribution of COVID-19 specific funding to smaller user led organisations; they reflected on how the pattern of funding requests had changed over the six months as small local organisations responded to need in innovative and imaginative ways, and how COVID-19 had revealed structural inequalities.

“There has been a huge burden carried by groups led by people of colour throughout the pandemic. What we are seeing now is a lot of money being funnelled towards those groups [from other funders] but without the infrastructure support which has always been lacking.”

There has been a nationally documented increase in disability hate crime in 2020. Several organisations are hate crime reporting centres for their locality. One organisation ran a regular survey during 2020 to collate hate crime reporting statistics across their region and report on the increase of in-person and online hate crimes towards Disabled people. A CEO from another organisation reflected on one of the many reasons why disability hate crimes might continue to increase:

“What is concerning me for the immediate future, is the rhetoric in the media and from central Government saying, ‘we need to do this [restrictive COVID-19 measure], to save vulnerable people’. I think that there is a real risk that the public will feel more and more resentful toward people who are seen as vulnerable people”.



Two organisations recorded how they were able to identify, contact and connect with new communities of specific interest who were now looking for support because of lockdown (including adults on the autistic spectrum who are not connected to statutory services), enabling them to raise

awareness of a specific need with statutory services. A self-advocacy group linked up in new ways because of the pandemic and shared the learning with the NHS, informally training that institution on better meeting their needs. Organisations ensured their monitoring stats informed not only their own work, but could be of benefit in shaping a national picture:

“We [have been] liaising with Skills for Care and TLap [national infrastructure agencies] feeding in our problems to inform their response.”

A good understanding of legislation pertaining to Disabled people is key when framing policy responses. One rights-based organisation collected evidence to demonstrate how the international UNCRPD’s COVID-19 declaration was not being adhered to in the UK. For UK legislation pertaining to people with protected characteristics, DDPOs had evidence where this was clearly being ignored. For example, the impact of the increase in summer outdoor dining in town and city centres:

“A number of our streets are now inaccessible to Disabled people, and difficult to address due to administration change in region. Public Sector Equality Duty has become farcical - EIAs [Equality Impact Assessments] are being written without consultation. ”

Other examples of how elements of the Equality Act 2010 were not being adhered to include an apparent lack of EIAs on Test and Trace systems and no provision of changes to statutory information in alternative formats including BSL and Easy Read. Provision for people whose first language is not English was also a concern.



- **Key Action** - The Disability Unit in the Cabinet Office and the Minister for Disabled People, Health and Work to understand that:
 - Disabled people are specifically at risk of exclusion during the continued COVID-19 pandemic.
 - Central Government has a crucial role in ensuring the legal and institutional processes that are in place to protect Disabled people are adhered to, for example: the Equalities Act, a Public Sector Equality Duty and EIAs.
 - It is crucial Disabled people are continuously involved in these processes.

Protection and representation for Disabled people in residential and institutional Care

DDPOs are very aware of adults who are in residential care (not just older Disabled people) or detained under the Mental Health Act. They may not be getting any representation other than determined support from parents and family members.

“For people who have been detained under the Mental Health Act, the death rate has doubled in the pandemic. [The death rate is] Especially heavy for Black, Asian, minority ethnic groups [over-represented in detainees].”

The focus in the mainstream media is on the isolation of older people in care homes, a very important issue, but not on the impact of isolation on adults of working age who are similarly isolated and just as vulnerable, to unreported abuse as well as the impact of the lack of family contact.

“Do we even know the stats for the adults of working age getting ill or dying in care homes compared to people in own home with direct payments. What research could we do?”

While the pandemic has prevented face-to-face quality check visits by local authority adult social care staff, there is a concern about how adults vulnerable to abuse in residential care are being protected.



“I questioned our local commissioners about what they were doing now having cancelled all quality checking visits. I was told they were talking to relatives instead. But that isn’t the voice of the individual always. They need to be more inventive about protecting this group but seem to have fallen back on using the pandemic as an excuse.”

- **Key Action** - Ensure that the direct voice of Disabled people in residential care and detained in institutions is heard and acted on, so that their human rights are protected.

B. Infrastructure

Staffing – paid and volunteers

We spoke to DDPOs at the end of September and after six months of responding to the pandemic, some of it in lockdown. They all reported on staff teams that were physically tired and emotionally drained. There was the challenge of keeping to an eight-hour working day because the demands felt overwhelming, compounded by no home/office divide and because the activity of taking a holiday had been upended by the impossibility of travel, staff were not having breaks from work. There were understandably issues with burn out with the potential impact on service delivery.

Workforces across the country experienced these issues. Uniquely for DDPOs a high percentage of their staff and volunteers are Disabled people and depending on the nature of their impairment/condition have to face and manage to the same challenges with the disruption to daily living, household supplies and transport as their client group, in parallel to delivering much needed services.

“About 70% of our staff are disabled, now shielding. If they want to come into the office, they can’t.”

The need to provide an immediate service to many clients meant that DDPO managers had to adapt very quickly in March



to working in lockdown. This included supporting staff to get online at home, delivering adaptive technology and specialist equipment from office to home and transferring systems for ensuring helplines were up and running without an interruption to service. For many Disabled staff creating a home office which was accessible was not straightforward.

Delivering new services meant changes to staff roles, and their terms and conditions. In some instances staff had to have additional training to access IT at home (without the support of an office team).

Disabled and non-disabled people volunteer for DDPOs. Many DDPOs had to let their volunteer workforce go in the pandemic because of concerns about providing a safe working environment for them, and because the projects they work on cannot be carried out through home working. A big issue was services that had been cost effective because they were resourced by volunteer hours, and not always getting additional funding to cover paid staff.

“We’ve had to stand down our volunteers because we can’t really support them, which has impacted on me – I am the advice service at the moment.”

Part of the attraction of volunteering is that it provides opportunities for socialising and camaraderie:

“We have a strong volunteering team - about 80 of them. They have been massively impacted, because the social aspect of it has disappeared.”

Some spoke of how their staff and volunteer teams were fearful of what the autumn would bring (at the time there was a lot of national anxiety about ‘a second wave’ of COVID-19), knowing how hard the first wave had been for their client group and the knock-on emotional impact on staff. Senior staff experienced being pulled in different directions by both the number of different aspects of the pandemic which had to be tackled, as well as the failure of statutory and commercial agencies in meeting the needs of Disabled people. The confused communication from central Government contributed too.



The world of work online did cause issues for staff interacting with other agencies who did not always address access requirements so that all meeting attendees could join in equally. We have provided more in-depth analysis of this issue in Locked In or Locked Out?.

Benefits for staff teams were noted too. The upside to the initial struggles with home working is that the IT skills learnt will be a long-term benefit. Responding to a crisis could be motivational:

“Our staff have felt they can be more innovative and together [as a team] than ever before.”

Another CEO pointed out the irony of being excluded from job applications before because of the excuse that flexible working or home working was not possible and the speed with which a nation could suddenly do it. She felt this ‘new normal’ would benefit Disabled people getting employed in the future.

For people with chronic illness causing fatigue the lack of commuting was a huge boon. It was a benefit to their health but also to their working day, as they ‘arrived at their desks’ with a full complement of energy. Travelling long distances is no longer an issue for networking either.

“It’s great to be able to connect virtually. To attend meetings like this. I wouldn’t have had the time before [for a face-to-face meeting which is not local]. It has pushed a greater connection [with other organisations].”

Interacting online had another unexpected benefit for staff representing their organisation; on a computer screen it isn’t possible to see if someone has an impairment or condition. Some Disabled people described this as a benefit – they thought they were no longer experiencing unconscious (or perhaps conscious) bias.

“They can’t see my wheelchair in a Zoom call, they don’t treat me any differently now.”



Collaboration and involvement

Strengthening existing relationships and building new ones was something the majority of DDPOs agreed was a positive outcome from 2020. Some shared resources (such as training) if they were delivering similar services or delivered work with others to build capacity; one securing new funding to build a COVID-19 information hub with other organisation in their region. One DDPO was ahead of the curve in their locality with their plans for virtual services so was able to open out their online groups to many other residents in their county, working in partnership with other voluntary and community sector organisations.

In another county a DDPO formed an alliance with other agencies to campaign about digital exclusion and then built on that:

“In a county which is 80 miles long with challenging transport we welcomed collaboration through a voluntary emergency response [online] forum with 15 other organisations meeting twice weekly, able to share information and develop ideas. We raised awareness of the needs of Disabled people with other agencies and so many activities are coming on the back of that for example a local authority consultation on what the future for good collaboration could look like”.

Another DDPO was also pleased that new collaborations in 2020 had galvanised their City Council: their City Mayor has announced a commission for Disabled people to enable Disabled people to feed into future policy. Other DDPOs also reported that their relationship with the local authorities had grown stronger, evidenced not only by specific funding requests being met but also recognition of their organisation’s role. A City Council has invited one DDPO to be part of a COVID-19 Prevention Board with a remit to tackle inequalities in communities including Black and Asian communities and Disabled people. Another reported their County Council had a similar initiative but there was a frustration that it had limited impact:



“We want to be on the Board making the decisions rather than the one deciding the communications.”

However, inter-agency collaboration was still challenging and the specialist knowledge of DDPOs ignored; one participant reported that the metropolitan authority she worked within was offering support to a new organisation rather than recognising the DDPO on their doorstep. Another said that they now had a tense relationship with their local administration, compounded by a change post-local elections; they reported still renegotiating their place in this new infrastructure. They had concerns about what they had been invited to join “as window-dressing”, wary of being seen to endorse initiatives they had had no say in designing. Others reported no attempt of local Government to involve the community:

“COVID Recovery Planning is leaving out Disabled people in [our major city], there is no concern for the impact on [the disability] community.”

Raising awareness of the needs of specific communities with other non-specialist partners can still be met with a lack of understanding. This applies between the disability sector and general providers (so COVID-19 response services got set up with no disabled voices informing them), and within the disability sector:

“We have found consistently that the LGBTQ+ community hasn’t wanted to know about its disabled members. There is a huge discomfort about being gay and disabled.”

Gaps and duplication

DDPOs identified gaps in their localities both in direct service delivery to Disabled people and in the infrastructure (co-ordination and communication). They reported that this had directly impacted on Disabled people in a variety of ways (as identified above). One example of this is, confusion about who was responsible for informing people about shielding once central Government had issued instructions for vulnerable people to shield; there were delays in informing individuals that



they should shield, and then delays in offering support with shopping and meeting basic needs for people shielding. There was also duplication (people getting contacted more than once with the same information).

Some of the challenges with infrastructure were to do with existing weaknesses in systems which, not surprisingly, were exposed by the pandemic; many years of austerity budgets have seen both statutory and voluntary services cut so there is no slack in the system to respond to a crisis of this size.

“A lot of us have come to this pandemic already gasping for air.”

Signposting between agencies could have been better in some localities and there was duplication of services which confused people in the community. In some localities DDPOs themselves were initially confused about who was responsible for what. Confused messages from central Government made decision making locally harder and led to patchy responses to Disabled people’s needs.

“Information out there is so mixed and it depends on who you speak to, to what information you get. For Disabled people information has been misleading and continues to be.”

After the initial response to the pandemic a clearer picture of roles and responsibilities emerged, with most DDPOs reporting that the local authority response to meeting need in their area had generally got better, albeit with ‘lockdown fatigue’ of front-line statutory staff. Not everyone was convinced that all Disabled people were getting the services they needed:

“There is a process now established, but we are worried that Disabled people are [still] falling through the cracks.”

However, in some localities DDPOs reported there was more to be done with co-ordination of responses, particularly as the pattern of transmission of the virus means that further lockdowns are inevitable.



Governance

Despite COVID-19 internal process did have to continue alongside additional pandemic related delivery. This included preparation of regulatory reports, AGMs, recruitment of new committee members (volunteer) and strategic planning. Working online did cause some issues for some volunteers.

“ Our committee all tend to be older people, so we faced a challenge in the recruitment and revitalisation of the committee. Normally we would meet new people in an informal way and then invite them to think about joining. Harder to do that virtually.”

Some experienced a challenge in keeping senior volunteers involved; like their staff teams they were managing their own health conditions, concerned about shielding and attending to their own daily living needs. Committee members needed support to access technology, which is yet another demand on staff time. However, there were also opportunities in lockdown to catch up on housekeeping (updating policies, space to step back and review) and if committee members were furloughed they wanted to be kept busy; they found the daily routine helpful.

Funding

At least half the organisations that came to the round table had got COVID-19 specific funding (mostly for additional work caused by the pandemic but for some to offset loss of revenue from public fundraising and other sources); several were able to create new part-time posts (as described above). On the whole it was felt that funders had responded positively and in a helpful timeframe to meet new needs quickly. Welcome too was the level of funding being awarded over such a short period of time from both voluntary and statutory funders.

“NHS funding was easier to access than normal. Definitely got some things funded that we wouldn't have done before.”

There was some frustration at a lack of recognition by funders of the need to fund a specific area of work, even though the organisation could provide evidence for it, or a funder's



assumption that in awarding a grant to a general local provider of voluntary services that Disabled people's needs would be met. There was also acknowledgement that there would be specific communities missing out because of a lack of capacity to bid for funds.

"We are doing a lot of critical friend work with funders to get them to prioritise user-led and grassroots organisations, tackling structural inequalities."

As the initial crisis receded, local authorities needed to progress work that had been put on hold and wanted to involve DDPOs in doing that. However, for DDPOs getting involved in those conversations takes time which needs to be funded and they had no spare capacity while they were still dealing with the longer-term impacts of the pandemic on their client group.

What is needed is core funding to recognise need, for example: simply to cope with the increase in volume of demand for an existing service; or switching to different types of working; or paperwork (e.g. risk assessments, new homeworking policies). What is of concern is what will happen at the end of this financial year when the statutory books must be balanced, and the recession will start to bite into public giving and the resources of grant making trusts.

"We worry that money coming in now will hit a cliff-edge in March and disappear. There is a lack of strategic, long-term funding for our sector to maintain services at the current level. We need strategic investment."

C. Looking ahead – fears and hopes

We asked DDPOs to look a short way into the future and anticipate what might be in store for both Disabled people and user led organisations in 2021, based on what happened in 2020 and their considerable knowledge and understanding of the lived experience of Disabled people and disability organisations.



Fears

Funding Cuts

Anticipating the Government autumn 2020 Budget Statement it was predicted that cuts to statutory budgets would be made to pay for COVID-19 spending.

“We have [published] evidence from the austerity measures taken post-2008 that Disabled people are disproportionately affected by cuts to public services. We have no reason to think that this will not happen again.”

All the participants were fearful that there would be large scale cuts to statutory budgets that would have an impact on voluntary sector services, including their own. They anticipated that the needs of Disabled people would once more be forgotten with the assumption that if the worst of the pandemic crisis were passed then everyone’s lives could get back to normal, not understanding that Disabled people will continue to be disadvantaged as a community.

“[with cuts] people won’t know where to go to get service. Disabled people and people with long term health problems won’t be out of it by next financial year even if everyone else is.”

- **Key Action** - For central and local Government to take steps to ensure Disabled people are not once more ‘the hardest hit’.

Lack of infrastructure support

Several participants identified past lack of investment in both local infrastructure organisations (who meet the needs of front-line voluntary sector organisation) and an investment in the infrastructure of the disability sector as having a significant impact on the COVID-19 response in 2020. They were pessimistic that this would be addressed going forward.

There is also a fear that there will be a continued lack of recognition from central Government and significant national funders that the disability sector needs long term investment, not funding that is annual with no strategic planning.



- **Key Action** - For central and local Government and grant making trusts and foundations to recognise the value of strategic investment to build the capacity of the user led sector.

Negative perceptions of Disabled People

There were several elements that put together created a huge concern about how Disabled people continued to be perceived as a community of less worth by some in the general population, local and central Government, and the print and broadcast media. DDPOs were concerned that the pandemic had heightened these problematic attitudes, and these would persist in 2021.

DDPOs are worried that the increase in disability hate crime will continue and this causes long term harm to individual Disabled people directly affected and to the erosion of confidence and well-being of Disabled people as a community.

The changes to legislation made in 2020, for example the Care Act 2014, were for some a worrying indicator of how the independence of Disabled people could easily be eroded. The imposition of blanket DNRs and the pressure felt by some individual Disabled people to consider a DNR if they contracted COVID-19 and the use of the phrase 'underlying health condition' when reporting on daily death statistics in the early stages of the pandemic were all offered as further evidence about perceived lesser value of Disabled people's lives.

"We're being systematically excluded and ignored. ONS figures showed six out of ten people dying of COVID were Disabled people. And how has that been recognised? It hasn't."

- **Key Action** - For the Disability Unit in the Cabinet Office and the Minister for Disabled People, Health and Work to put in place a strategy for tackling attitudes to Disabled people give rise to inequalities.



Hopes

“ It’s [response to the pandemic] positioned us well for the future to make sure things are user led. My aspiration? That the relationships and networks and confidence we built around different ways of working will continue and grow.”

New investment

- Building on good relationships with funders new to an organisation.
- Building on increased understanding of funders of the sector’s needs.
- Building on increased organisational confidence from getting funding for specific projects.

Solution focussed collaborations

- Building on the solutions Disabled people found for themselves and collectively working together.
- Building on the greater understanding and appreciation of the value of each agency’s value in a locality.
- Building on greater use of online technology to reach further with service delivery and in partnership working.

A greater voice for Disabled people

- Building on an increased determination from adversity to make a difference to Disabled people.
- Building on new collaborations to link more Disabled people together to have a voice.
- Building on the enhanced reputations of DDPOs to increase representation for Disabled people locally and nationally.
- **Key Action** - Establish a national voice for DDPOs who collectively represent the diverse community of Disabled people.



Appendix

Methodology

The opportunity for DDPOs to join one of two round tables (29th September and 1st October 2020) was promoted to Shaping Our Live's membership and subscribers to our e-bulletin through targeted mailings, via third party mailing lists (South East Network of Disabled People's Organisations and Inclusion London) and through specific invitations to ensure we had a good geographical coverage of the whole of England. Twenty CEOs/senior staff members participated.

An engagement fee of £30 was offered to organisations who did not have funding to cover attendance.

Organisations targeted ranged from unfunded voluntary groups to larger organisations with paid staff teams. Many DDPOs are pan impairment organisations but others work with a specific community. We did invite user-led organisations from the Deaf community to attend, however, we didn't have a representative. No organisations specifically supporting Black Disabled people or people from other ethnic minority communities were able to attend.

Question framework

1. Introduction - which one of your services has been most in demand **or** what has your organisation done most of during lockdown?

2. Discussion point: COVID-19 – before, at the beginning and now

What are you doing that is different because of COVID-19 – service delivery (not operational processes)?

NB thinking about beginning of pandemic and now, has there been a change in delivery? Different phases?

What can you not do, but have identified a need?

What is stopping you doing this – funding and other resources, or the operational logistics or both? Something else?



3. Discussion point: Human resources

Have staff and volunteers been able to work? Impact on them as Disabled people.

How have you resourced your services since March – staff, volunteers? Recruitment?

4. Discussion point: In the context of your locality (local or national or community of interest)

Services/activities for Disabled people (voluntary and statutory sector) - has there been duplication or co-ordination?

Collaboration?

The impact of how the locality has responded on Disabled people - what has got better and what has got worse for Disabled people receiving support or not (not general life)?

Have you been able to find out?

Statutory authority relationship to you (and the voluntary sector you are part of) (prompt – funding, support of sector) - better or worse?

5. To end – Organisationally, what is your greatest fear going forward? What is the most positive change, large or small?

The round tables were designed to take about 1.5 hours each and facilitated to ensure each participant was able to contribute.



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