



**Disabled People's Organisations Sharing Experiences During
Covid 19**

**Project Report 5 – Disabled Peoples' Organisations Meeting Each
Other**

July 2021



Contents

Executive Summary

Project Introduction

The Findings

Office

- Blended
- Pressure
- Risk Assessment
- Collaborative working
- Unneeded
- Logistics
- Income
- Admin
- Safe space
- Volunteers

Statutory Authorities

- Threatening to DPOs and disabled people
- Crisis management
- Agency
- Don't Bite the Hand that Feeds You
- Added value

Unforeseen Covid Implications

- Clients
- Staff
- Personal Assistants
- Proactive

Service Redesign

- Crisis management
- Rationalise
- Safe management

Funding

- Competition
- Short term
- Time

Sharing/Support

DPO Strength

- Purpose
- Campaigns

Meetings

- Online

Young People

- Recruiting

Wellbeing

- Clients
- Staff

Joy

Conclusions

Appendix 1

Executive Summary

- There is a demonstrable and clear need for a national grass roots Disabled Peoples' Organisation (DPO) infrastructure body led by disabled people
- This pandemic has enabled DPOs to demonstrate their importance in relation to knowledge of their local disabled population, service delivery, organisational agility and their ability to reach traditionally 'hard to reach' groups of people
- Pre-pandemic, many DPOs felt undervalued by the national and local statutory authorities. It is very hard for DPOs to stay afloat financially – there is no core funding available. This reflects the low esteem in which these organisations are held by funders, including Local Authorities
- In spite of this. during the pandemic many Local Authorities relied on DPOs to contact disabled people and people with long term health conditions by –
 - o translating their materials into Easy Read,
 - o delivering food, medicine, PPE and vaccines, to disabled people and people with long term health conditions, particularly those who were shielding, and
 - o maintaining regular contact for individual wellbeing, support and to reduce loneliness, particularly among people who were self-isolating.
- During the pandemic DPOs have –
 - o Worked remotely, mostly from home, at very short notice
 - o Changed their organisation to meet the urgent needs of disabled people and people with long-term health conditions during the pandemic
 - o Created new pandemic-related services
 - o Used technology extensively to hold meetings for the organisations as well as for clients, and
 - o Created Wellbeing services for customers and staff to help isolated individuals to maintain human contact.
- DPOs –
 - o have shown themselves to be very resilient
 - o have shown themselves as natural partners and allies to Local Authorities in relation to their service delivery and reaching disabled people and people with long-term health conditions
 - o can be very nimble, agile organisations, shifting to meet local needs as they are identified, and
 - o DPOs stay afloat by securing precarious, short- and medium-term, project-specific funding. This results in a high turnover of staff, and makes it very hard for the DPO to develop a depth and breadth of knowledge throughout the organisation

Project Introduction

In March 2020 the government initiated the first national lockdown in response to the Coronavirus pandemic. As the death toll rose, with over two thirds of the total mortality figures being disabled peopleⁱ, many disabled people were either told by the government to shield or decided for themselves to do so.

This impacted all sectors of the economy including Disabled People’s Organisations (DPOs). These organisations found themselves at the frontline of service delivery, whilst also having to physically shut their premises to reduce human to human contact.

This was an incredibly difficult time for DPOs, managed, controlled and staffed by disabled people, as workloads were often increasing, staff and volunteers were working from home, and the government was issuing new deadlines about when it would be safe to open and go back to work.

Many disabled people were experiencing increased mental health difficultiesⁱⁱ at this time because of the pandemic, which affected the staff, volunteers clients and customers of DPOs.

I held a series of online DPO meetings over Zoom between February and July 2021, to give the DPOs the time to talk to each other about their experiences during the pandemic. Here I present the key themes that came from these meetings.

Here is a list of the DPO meetings that took place, together with the number of participants at each meeting –

Meeting	Date	Numbers
Trial	8 th Feb	2
1	26 th April	4
2	27 th	3
3	28 th	2
4	29 th	2
5	4 th May	3
6	5 th	3
7	7 th	2
8	11 th	3
9	9 th July	3

DPO Meetings

Although the total number of participants in this list is 27 people there were times when more than one person from a DPO attended, and one person attended three different events in total. This means that in total 24 DPOs participated in this first 'round' of meetings.

The DPOs who met each other were located across England, from the far North West/East, through the Midlands, London and the South East, and down through the South West. There was a fairly uniform distribution, not weighted to any particular geographical location.

These organisations were a range of sizes, with a small number having few, if any employees. These smaller DPOs had a particular organisational focus, such as Disability Arts or Access. One of these organisations would not meet the description of being a DPO (with a governing committee of a majority of disabled people and a majority of disabled employees), as it only had one employee who did not identify as a disabled person.

The majority of the DPOs that took part were pan-impairment, offered a range of services including information and advice, PA recruitment and employment, as well as social and leisure activities.

These meetings were semi-structured where I had some notes to refer to in case there was a break in the conversation between DPOs. However there was rarely a break, and it took some effort to keep us on topic – these DPOs had a lot to talk about! For a list of the questions and the basic structure of the meetings see Appendix 1.

This document presents the themes, grouped by the number of mentions for each theme during the meetings.

I have then delved into each theme and grouped the responses according to a set of sub-headings, which add further understanding to the broad themes that emerged. These are also presented here from the largest to the smallest number of mentions, under each theme.

Of course it is impossible to separate peoples' comments in very strict ways into separate categories, because many people will mention more than one thing in a sentence. It might also be the case that one person is very preoccupied by a particular issue at the time of the meeting, and so mentions that issue many times in a conversation. But in general this seems to work as a way of understanding the key concerns for these DPOs during this pandemic.

The largest theme to emerge from these discussions was that of the buildings, or offices, used by these DPOs, with 49 mentions in total. This is not surprising because one of the questions I asked during the meetings was about their office premises, so it would therefore inevitably be a key topic of conversation during these meetings –

Office

The biggest topic of discussion, with thirteen mentions, relates to how these DPOs are now using their premises in a much more 'blended' way, mixing their real, actual premises with virtual, online, and home-working activity –

Blended

Key to the conversations about office space is the sense of uncertainty in relation to how a DPO uses its office now, compared to how it did so before the pandemic –

We won't be back in the normal way for at least a couple of years, certainly not until we've been through a winter.

This sense of 'normal' has been enormously disrupted during the pandemic for DPOs, as well as for the rest of the entire planet –

After the pandemic we will operate a hybrid of in office or at home.

Anecdotally at least there were many conversations before the pandemic about home working, and how easy or difficult this would be, in a hypothetical sense at least. The sudden break that the pandemic brought made this an absolute inevitability if these organisations were to remain operational –

We were surprised how easy it was to pack up the office and move home.

It's been proved that we can work from home – the organisation carries on perfectly. Will continue to offer this as a mix for staff.

Staff get the job done and do the hours even though they're homeworking.

However the individual feelings about working from home can be different from person to person –

Mental health – some people love being at home while others are hating it. People with families and young children are finding it very difficult as they have the kids at home.

Feelings about home working have also changed over time –

Many people who hated home working at the start of the pandemic are loving it now and want to stay there.

We have a total mix of staff – some are longing to come back to the office while others are very reluctant and prefer working at home.

Some people need to go back to the office for mental health reasons while for some people the opposite is true.

Continuing uncertainty about the pandemic makes planning for the long, or even the short, term very problematic –

We anticipate that we will have to do work apart again in the future, so we are trying to get back to normal in the summertime before we then have to go our separate ways again.

Our office return depends on individuals and the services we are offering – if people are proving they can work well remotely then why not?

DPO Meetings

We planned to get staff back in September but that's not going to happen. If they can stay at home I think they will.

We'll be operating a mixed model for the foreseeable future.

It was clear throughout these conversations the amount of pressure being experienced by all levels of the staff in these DPOs, with at least seven mentions.

Pressure

The different levels and types of pressure at the CEO level became clear in these meetings –

There's a lot of pressure on the CEO – keeping staff safe, keeping business going, making good decisions, etc.

One person talked about how important it was for DPOs, almost more so than for other organisations, to 'get it right' during pandemic times –

We need to be more cautious than everyone else. Our customers are disabled people and people with long-term limiting illness which can have major implications in terms of the virus. Many of our customers don't believe the government but do believe us. If we open too quickly many of our customers might get the wrong idea or the wrong message that everything is.

This sense of caution and of the need to take care of staff and customers ran through all the meetings –

We need to be planning for 5 years of virus and not to keep opening and closing our services so often.

I'm reluctant to move people back into the offices because I think we will have to go back into a lockdown again and many staff still feel very cautious anyway about coming back to a shared office. We made loads of plans during the first lockdown which all came to nothing and which wasted everybody's time. I don't want to do that again.

There is so much uncertainty about everything at the moment and I'm reluctant to move back to the offices.

The stress, waste of time, effort and money, created by having to make plans, change them and then then remake them again is easy to understand. Added to this is the stress of working away from the office for a CEO –

As CEO I am on-call all the time which I don't really like because we are not in an office and not able to sort things out together.

At a very basic level there is an onus of responsibility to make sure that the staff are kept safe from the pandemic –

Staff are tested before going to the office to make sure everyone is safe.

Very much related to the stress, pressure and uncertainty is the need to risk assess everything, including the workplace, the work, the staff and the customers, with seven mentions –

Risk Assessment

We are going to move forward on a risk assessment basis.

We are taking everything step-by-step and conducting relevant risk assessments for every service.

It is clear that opening a DPO cannot be done quickly, and this 'step by step' approach is being adopted by most –

Every service is doing its own risk assessments about how to operate in this new environment.

We are introducing a phased return to our offices by each team to do their collaborative work.

One DPO described how they have formalised their return to their premiss –

We will carry on as we are until September at least. We have a rota system. To make sure the office isn't over occupied.

It has been almost impossible during this pandemic to rely on the government and its information. This is the very nature of a pandemic, as the virus mutates, situations change and government advice changes almost from day to day. This makes planning very difficult if not impossible –

We don't know what's going to happen when the government's rollout dates pass and think will not go back to the office until at least after summer.

However one DPO has noticed an unexpected positive outcome as a result of their organisational monitoring –

We've noticed a huge drop in illness with all the hand sanitisers and temperature checks, so will keep those in place.

One reason why these DPOs liked working from a shared office space, before the pandemic, and with five mentions at least, is the collaborative way of working that this facilitates.

Collaborative working

I feel it's very important as CEO to be able to meet staff and to have space to collaborate/work together.

This importance of being able to work together in a shared space has become very clear in this pandemic –

We are rethinking about what the purpose of an office is. It's not necessarily about sitting behind a desk from 9 to 5 just to get work done, but it is good for collaboration.

We all worked from home initially but are looking forward to returning.

By finally getting everyone together the future looks much more positive.

DPO Meetings

Many of the themes that came up during these meetings can be tied together by the clear idea of wellness, mental health and reducing loneliness, in both staff and customers –

Our office has never been good for customer facing work. Generally the reason people get into a car to drive to our office is for loneliness reasons, so we're tackling this in new ways now.

Having said all that this has been a time to understand just what an office is for, how useful it is, and whether it is still required at all. There were at least five mentions of how offices might not be needed any more –

Unneeded

There were a few different possibilities in relation to DPO office space. As discussed above the majority of DPOs are talking about when and how to return to their premiss.

At least two DPOs are contemplating reducing their office space, while keeping some staff home working –

Getting back to the office is not our top priority – do you stay in the same size space or do we find somewhere smaller?

We rent 6 offices across county, but may reduce this number and continue home working but rent meeting rooms as required

Other organisations are thinking about not going back to an office space at all –

We are not going back to the office but going to meet monthly with staff. We had very few/no clients in office anyway

I heard about one organisation down south that has given up their lease and moved entirely to homeworking.

The pandemic has forced DPOs to think about their office space, how much it costs and what they actually need it for –

We're essentially paying for space to keep our filing cabinets in – it would be cheaper to hire yellow storage. But why are we doing this?

Four people talked about the logistics of getting to and using an office space –

Logistics

A key issue here is the travel to an office, mentioned especially by people in cities –

When we travel round the city is very different – the Tube the bus – which brings people very close together which can feel very traumatic for some people right now.

In London there can be problems meeting up with each other/going to the office because of the public transport is needed to travel the big distances. The Tube and buses are all really crowded.

The logistics of finding and affording an office space came up explicitly once, but also arose throughout the meetings in different contexts –

It's very hard to find premises that are accessible and affordable for small organisations like ours – some small organisations get council premises rent-free.

One organisation described the familiar option of being tied into a fixed term lease –

We have no option with our premises because we are on a 10 year lease but it would have kept it going anyway.

Three DPOs talked about how their inability to be in their office space during the pandemic had affected their income –

Income

We rented buildings/space to other organisations/services which has stopped entirely during the pandemic which has made a big gap in our income.

We rented our building for years when it came up for sale we found half the cash and got the 3 year mortgage so we now own outright. We rent out all the downstairs to get income, though we're not doing this at the moment.

There might also be new opportunities in the future for DPOs with large enough premises –

We know lots of voluntary sector organisations have shut their premises so will rent desk space from us.

One key function of DPO office space is the admin function, mentioned explicitly by two DPOs –

Admin

We deliver very few services through the building but use it for admin – our services are out in the community and in people's houses (information, advice).

We got quite a lot of customers who can't do things electronically so have to go into the office to send out the relevant paperwork.

Two DPOs said how important their office space is as a safe place for some customers –

Safe space

We will keep our building because it's a safe space for people to come to.

We've had to use the building when we needed to put our eyes on someone for safety reasons.

At least one DPO talked about how important the office is to enable them to involve volunteers in the organisation –

Volunteers

It's hard to think about how we'll work with volunteers who need to be in the office environment in order to volunteer.

The next major theme, with at least twenty two mentions, is that of the Statutory Authorities –

Statutory Authorities

Seven of the DPOs talked about the statutory authorities and the way they work as being either a threat to themselves or to local disabled people –

Threatening to DPOs and disabled people

The danger of austerity is always looming in the background which will really hit the local authority which will then inevitably cut services to disabled people very hard again.

The local authority has to balance budgets every year by law and yet there are underfunded by central government who could then come in and instigate special measures.

Over the years there are countless examples of central government 'blaming' a local council specifically, or in more general terms, for what they perceive as local mismanagement.

However this might present an opportunity for local DPOs to campaign on the side of the Local Authority against central government for increased funding at the Local Authority level. This is a very strong case for greater co-ordination at the DPO level nationally, to identify local trends and devise campaign materials for use at the local DPO level, as well as to offer mutual support in difficult times –

DPOs need to support each other to cope with increased number of clients, and to be available to provide support/information sharing with each other

One DPO talked about the direct threat posed by their Local Authority in relation to full cost recovery –

Local authority/health contracts are changing and won't be full cost recovery which is very threatening to DPOs – we are subsidising much of this work as a group from our charitable or fundraised income which is quite illegal.

Another DPO talked about how their LA follows the letter rather than the meaning of DPO language –

Our Local authority has always followed a very tokenistic acceptance of coproduction. They prioritise older people and discharge from hospital – of course. We only ever get crumbs from the table at best.

One DPO talked about the cynicism of their LA during this pandemic –

The Local authority used the opportunity to reassess people and reduce their care packages.

DPO Meetings

One idea that has come up throughout this project is how difficult it can be to establish a good relationship with a Local Authority, and how reliant any such relationship is on the people in the LA –

Relations with LAs are very focussed on/through the individual in the council. If that person moves on the funding might stop

And finally one DPO spoke about how different all local Authorities are from each other, in relation to what they do and how they do it –

There are 33 London boroughs each with very different rules.

This goes to the heart of the DPO/LA relationship. While some manage to create a good local relationship, potentially with funding involved, others don't seem to even get a look in. There is a real place here for a national DPO to help demonstrate the value of DPOs to the statutory authorities.

Six of the DPOs talked about how they had been recognised by their Local Authority in relation to the management of the pandemic –

Crisis management

As the data started to come from the pandemic it became clear that disabled people and people with long term health conditions were being hit the hardest, with over 60% of Covid deaths being disabled people. It therefore became very important to focus attention on this group of people, which proved problematic for some Local Authorities –

The local authority had got rid of its disability register so it relied on us to contact disabled people locally.

We had contact with disabled people who even the Local Authority didn't have contact with even though they were getting direct payments

The local authority has turned to us and admitted they needed help to reach disabled people.

For some DPOs this admission that they needed help to reach this section of their local population has been a turning point in their relationship with their Local Authority and other local partners –

The voluntary sector as a whole 'benefited' from this pandemic – the statutory sector has started calling on us much more. We've had the busiest time we've ever had.

The work required by the council included reaching these groups in the population, including through accessible information –

Lots of work translating documents/information into for example Easy Read.

It was also important to reach the people who work closely with disabled people and people with long term health conditions –

We work with the council to get personal assistants vaccinated along with the frontline healthcare staff.

Four of the DPOs talked about how not relying on the council for funding has increased their organisational sense of agency –

Agency

Freedom from LA funding can increase individual organisational agency as you can do what you want and not what they require

Should we tell the local authority to sod off with their funding; then have more freedom and flexibility to do what is required by our membership.

This organisational agency will include fighting the council when required –

Our role might be much more combative to fight the local authority for the rights of our community.

One DPO expressed their exasperation at having to continually fight for the rights of their members, rather than concentrating on the other aspects of individual lives –

When will the fight ever end? When will we be able to help people make the most of their lives rather than fighting for entitlements/against systems?

Three of the DPOs talked about the constant friction at the heart of any relationship with the Local Authority –

Don't Bite the Hand that Feeds You

'Don't bite the hand that feeds you' – it's a very fine line between what we can and can't say or ask for from our local authority.

We have to be careful what we say and how we say it to government, who can be very suspicious of us and what we do

One DPO described how they had got around this problem, allowing them both to fight for people' rights whilst also delivering local services contracted by their Local Authority –

We set up an arms-length organisation to be to take court cases to challenge the local authority, health, etc. so that it's not us.

To conclude this section about the statutory sector are these comments, relating to the added value of contracting with a DPO –

Added value

The local authority can achieve so much more by giving money to DPOs who can then match fund it to create more and provide continuing added value to service users.

We are all doing a lot without a huge amount of money.

Making the most of scarce resources is a huge issue for both Local Authorities and DPOs in these times of continuing and potentially increasing austerity. Everyone is trying to make the most out of every penny, and the way DPOs can stretch money – often doubling it or more – should make them very attractive partners for Local Authority service delivery.

The next theme the 18 DPOs talked about relates to the unforeseen implications of Covid –

Unforeseen Covid Implications

The biggest category here with 9 people talking about it relates to the DPO clients –

Clients

Worryingly one DPO noticed how Covid has reduced the independence of some of the disabled people they are seeing –

Dependencies were created so people are going backwards in their journey towards independence.

There is a very strong potential role here for DPOs –

There is going to be a really big reablement piece to get people out into the world and interacting with other people again.

At least 2 DPOs talked about how the number of customers they are seeing, and will continue to see, has increased thanks to Covid –

There will be more disabled people thanks to long Covid, which will increase DPO workload/demand

We are seeing a new client group – there are people who couldn't access our services because they couldn't drive or couldn't come to our premises for whatever reason and who we are now in contact with. This helps to reduce their social isolation.

These 2 statements express how it is true to say that the numbers of disabled people are increasing, as well as how the reach of DPOs is changing.

The workload for DPOs will both increase and need to change –

The senses of belonging and connection have reduced during Covid – how do we position ourselves to facilitate a greater sense of connection?

It became clear to one DPO that some of the provision on which some disabled people rely needed to change –

Need flexibility in Direct Payments during Covid

And two of the DPOs talked about how their own provision changed during Covid –

Our social activities have gone but it's too risky to do things indoors. We've done a 5-year plan.

We've had to maintain equipment that we rent out to disabled people and which we currently have to keep in storage. For example we need to keep checking the batteries of the electric scooters.

Four of the DPOs talked about the unforeseen implications in relation to their staff –

Staff

DPO Meetings

One DPO noted how they had been recognised as the frontline workers that they are –

A lot of our staff and volunteers had vaccines early because we're frontline health and social care staff.

One DPO described how the increased cleanliness required during a pandemic has reduced their staff sickness –

Disabled staff are very worried, even those who had the jab, of other viruses that have been suppressed because of all the sanitiser. We've had the lowest sickness absence during Covid.

While this sickness reduction is obviously welcome the negative implications for staff and their mental health could not have been foreseen. For example one DPO lamented the sense of loss experienced by their staff –

We never had time to grieve the old, collaborative way of working, which we really enjoyed before Covid.

Another DPO expressed how they and all their staff had to be more spontaneous during Covid –

You have to live in the moment a bit – forward planning is very difficult.

Personal Assistants were discussed by five DPOs –

Personal Assistants

The first two comments here recognised one of the key discrepancies in relation to the vaccine rollout –

Some personal assistants were also shielding.

Vaccines for PAs were not available, BUT they have been available in care homes for a long time

No Covid advice for PAs

Taken with other factors, this meant that many disabled people who are shielding could not rely on their PAs for the support they needed –

Some disabled people who are shielding had to fall back on relatives therefore losing some of their independence.

One DPO understood how PAs might have felt left out during the pandemic –

PAs need furlough sometimes

At least three of the DPOs described how they had become more proactive as organisations –

Proactive

Previously we were very reactive but became more proactive to ID people who might need help and offering it up front

DPO Meetings

We developed a risk assessment tool for people who used personal assistants which is quite long but very straightforward.

One DPO recognised how –

Business community plans are suddenly very important thanks to the pandemic.

The next theme, that was discussed by 18 DPOs, relates to the way the organisations had to redesign their services during the pandemic.

Service Redesign

Eight DPOs described how they have had to crisis manage during the pandemic –

Crisis management

During the pandemic, as disabled people were isolating and closing themselves away from the rest of the world, it became very clear that the most basic necessities of life needed to be sourced –

Instead of our usual service delivery during this crisis we have had to initially help crisis manage and make sure people have enough food and medicine and later start reinstating our services whenever possible and start to help people on their journey towards independence, employment, or whatever.

The pandemic made planning for any future service delivery very difficult and made dealing with the crisis in the here and the now incredibly important –

We are dealing with the people in front of us right now and the chaos everybody's going through and not planning ahead as we did in the first wave and then had to scrap all those plans. I'm much more relaxed with the idea of waiting until April 2022.

We had to massively change our services for the crisis.

We were part of a massive logistical job to get PPE to personal assistants/people on direct payments.

One DPO described some specific provision they put in place to help their staff and customers during the pandemic –

We set up a new counselling service to help people during lockdown.

One DPO described how they have the support of their senior management team behind them –

The board is behind us working on the present busy-ness.

It is obviously very important to have the support of all levels of the organisation including the governing committee behind the front line staff.

Two of the DPOs described how they have had to evaluate how they deliver their services –

The crisis has 'helped' the organisation to create new ways of working and re-prioritise

DPO Meetings

We've been doing a lot of activities on zoom so we asked them what they want and they're not keen on returning face-to-face, except our autism group who are keen to get back together again, though I'm not sure we want to be responsible for that.

One DPO seems to have benefited from the new pandemic ways of working –

We've proved there are better ways of doing things than the old 'normal'

There are 3 categories here which each had two mentions from the DPOs. The first relates to how the DPO has had to objectively think about itself and rationalise its services –

Rationalise

We've been a lot more rational about the way staff are using their time, especially outreach workers who may not need to go face-to-face for every little thing

We've had to refocus our organisation to a specific impairment group and away from pan impairment as that's where the money is.

This latter comment shows how these organisations can be very reliant on the funding sources they receive for the services they deliver and the actual core focus of the organisation. In many ways this reduces the ability of the organisation to act in a self-directed way, which is an incredibly negative consequence of the Covid pandemic.

2 DPOs described how they had to change their services to make them as safe as possible for everybody concerned –

Safe management

Each project involves creative thinking to get it going again in a safe and secure way.

We have robots – iPads on stilts – to visit people in their homes and see how living. This isn't the same obviously as a home visit but it's quite a good alternative.

And two DPOs describe how they have moved some of their services either outside or online to make them safe during the pandemic –

We are doing walking, yoga, and picnics in local parks/outdoors.

We set up a secure online recruitment system with a local employment agency for personal assistants.

The final comments relating to this service redesign theme each had one mention. The first describes how peripatetic some of their services have had to become –

We are moving our service out to work people are now – for example general practice and local authority buildings.

DPO Meetings

In many ways this element of service delivery might remain long into the future for many DPOs as they are able to reach a greater number, and different type, of customer for their services. One DPO recognised this as an opportunity for themselves as well as other service providers –

Build back better by making everything inclusive.

The volunteers who give up their time to help their local DPO, many of whom are themselves disabled people or people with long-term health conditions, have been hit very hard by the pandemic –

Our volunteers have been slammed by the pandemic and many have left or are shielding.

This will have implications for the organisation and the way they run their services now and into the future. DPOs rely on volunteers who in many ways can help them to reduce their costs in relation to service delivery. This is very important for the present and future involvement of people with lived experience in their organisations.

Running through any meeting with a Disabled People's Organisation is the key issue of funding, where it comes from, and who is giving it out –

Funding

There were at least 17 mentions of funding during these DPO meetings –

Very few/no guarantees for DPO funding

We need to have a conversation with our funder to see if they're happy for us to continue not delivering on their stated outcomes.

The biggest theme here with 4 mentions is that of competition –

Competition

Disabled People's Organisations seem to be at the whim of funders and who they want to give their money to. This can be very threatening, particularly for smaller DPOs, which often find themselves in competition with much larger organisations –

Funding streams/structures are changing to give money to much bigger organisations which is very threatening to our smaller groups. But what we do is much better value and has a much more local reach. This reorganisation of funding streams is very threatening to DPOs.

This report is clearly demonstrating the value of small DPOs in relation to local knowledge and expertise. Some of the smaller organisations can feel very threatened even by their Local Authority –

Some LAs have a set of 'favourite' vol orgs they fund, and no-one else gets a look in.

At the heart of all of this is the increasing competition for ever scarcer funds, as local authorities find their resources stretched ever further, and major funding organisations see the demand for their money increasing –

There is serious competition for funding

For smaller organisations with a narrower focus or specialism this funding situation is increasingly difficult –

Arts funding is going to much bigger organisations which really threatened smaller DPOs like ours – I'm not positive at all about our future.

The short-term nature of much of the funding that was available during the Covid pandemic was talked about by 3 of the organisations –

Short term

Covid funding is very short-term so we are very concerned about the future

We got a very small amount of funding to create the Covid help online with links to relevant organisations and information.

The result of short-term funding streams, even in the best of times, means that projects start and projects close. This has serious implications for the staff that the DPO is able to keep hold of, and those they have to let go –

We lose incredibly good people when we lose contracts/projects, and it's really sad.

The stability of the DPO is very hard to maintain with a high turnover of staff. The depth of knowledge, understanding, and experience that an organisation is able to create and then build upon are all in peril pretty much all the time.

Two of the DPOs described how some of their fundraising activities had to stop during Covid –

Trading activities had to stop – DET - while all other parts of the organisation thrived

We ran a café in the building which attracted a diverse group of people, which had to close and we had to make staff redundant because we didn't know how long we would have to be closed for.

This self-generated income can be very important for the success of the DPO as it represents unrestricted funds, which the organisation can use in any way it sees fit according to the rules of the organisation. This provides some flexibility for organisations to be able to adapt and change in times of crisis.

Core funding is incredibly hard to come by as funders are increasingly attracted to new, shiny projects, rather than the day-to-day running of an organisation –

Just imagine what DPOS could achieve if they had core funding, when we have done this much with so little.

This lack of core funding means that organisations have to constantly find time to find, and then complete, funding applications that are relevant to the organisation –

Are we achieving the outcomes we need by spending so much time chasing contracts/money/delivering local authority services – what are we here for?

DPO Meetings

One DPO which concentrates specifically on disability arts has found the funding situation during the pandemic incredibly difficult –

For Arts organisations everything has stopped. We are disabled people to help them to design and fund their projects in the future. There is no new income or projects on the horizon which has given us space to think about what we want to be doing. Work has been very bleak for artists.

This lack of funding forces many disability arts organisations to shift their core focus, and potentially even their core identity –

Cultural organisations go for the mainstream and move away from the disability arts

Eighteen people talked about the strength that we could gain as a sector if we shared between DPOs and supported each other in more formal ways –

Sharing/Support

At the heart of this theme is the idea that one DPO expressed –

On our own as small DPOs we are quite vulnerable – if collaboration were possible we can explore ideas in a safe space and potentially work together on a much bigger scale.

At least four DPOs talked about the importance of continuing these conversations into the future –

It's been useful sharing experiences and similarities and I'd like to do it again later in the pandemic.

The recovery is going to be more interesting than the pandemic – how we all re-shape and return to our offices, and what our services look like.

There might be potential for DPOs to join forces for funding/projects/etc.

DPOs need to support each other to cope with increased number of clients, and to be available to provide support/information sharing with each other

Being part of a collective is something that several DPOs were interested in looking at –

Being a DPO does feel quite lonely. There is no longer any central co-ordinating DPO/network for us to connect into

I'm interested in hearing what other DPOs are doing.

One of the DPOs recognised the diversity within the sector –

There is a huge diversity in DPO services though there are common threads throughout.

And one of the DPOs talked about how there could be strength in broadening working together beyond the DPO sector –

There is real strength in working together with other voluntary sector organisations to increase inclusivity and come back stronger.

DPO Meetings

During these conversations it became clear that these organisations talk about themselves in different ways. While some describe themselves as DPOs, others use the term DDPOs, while others call themselves DPULOs. One DPO thought that it was time to start a conversation again to create some kind of unanimity –

What is a DPO? We need to decide a definition between ourselves, as it can feel like we're all using a different definition

In order for this work to take place one DPO put forward the idea that we need stronger leadership –

We need some sort of genuine leadership for DPOs – a nurturing and collaborative space for DPO leaders to come together and share ideas – scope and DRUK are not doing this at the moment.

I personally believe that we could understand DPOs as one big national organisation with independently operating local organisations, all running similar/the same services. This is in no way suggesting that DPOs should all amalgamate, or that we all are identikit versions of each other. However there is power in size and numbers, and if we were to begin to calculate the total numbers of people served by DPOs, the total income and expenditure of DPOs as a cohort, and if we were to begin to work more closely together when the opportunities presented themselves, we might be more likely to be seen as having a similar power status to the national big disability charities, with which we are constantly in competition. This might give us more political clout and more ability to negotiate common themes such as the lack of core funding and the lack of any obligation for the statutory authorities to consult with us.

Two organisations described this idea using the idea of a “network”–

Having a network of people doing the same thing will be great.

it's useful seeing different organisations and how they're coping and to network with each other.

Two DPOs recognised the strength of being able to share policies, procedures, and services between ourselves when it was desirable and applicable –

Do an audit of DPO services so we can borrow from each other to avoid making the same mistakes over and over.

DPOs sharing policies where this reduces workload/need to write new ones

Sixteen of the DPOs talked about the theme of the strength of DPOs during the pandemic –

DPO Strength

Five of the DPOs talked in various ways about the sense of purpose that the pandemic had given them –

All the things we've had to do for lockdown are all the things DPOs were built for.

DPO Meetings

Some of the DPOs recognised that their strength and purpose came from their organisational structure, ethos, and ways of working –

If you're in a post where you represent the views of disabled people you have to be a disabled person.

Our organisation employs a majority of disabled people with lived experience.

Our teams have really come together – everyone supports each other. It's been great.

We're very entrenched in the social model of disability.

We are a community response organisation.

Despite all these things one DPO talked about how our organisations are still not often the first port of call for people when they have a new diagnosis –

When people get diagnosed they join their impairment specific organisation rather than their DPO. There is a serious comms issue for DPOs which needs to be the first port of call locally.

This kind of communications issue is the sort of thing that a national network of DPOs could tackle in its very early stages.

One organisation talked about how the pandemic had increased the number of calls they had received –

c.4,000 people calling for support/advice/information

And one organisation sets itself very high goals even though it recognises how difficult it will be to achieve these goals within a limited time span –

We are writing a 5 year strategy even though some things – for example eliminate stigma – are not possible. We at least need to make steps towards these long-term goals

it is this sense of hope and aspiration that underpins the work of many DPOs and which sets a very high bar towards which we are all working.

Five of the DPOs talked, or raised questions, about the campaigns that the pandemic had made them think about –

We thought a lot of the old arguments had been won – poverty, disadvantage, exclusion – but when Covid struck it showed how they hadn't. People with Learning Difficulties were 4 times more likely to die, for example.

The long-standing argument for disabled people and people with long-term health conditions to be able to live independent lives was framed in a new way by two DPOs –

How does life expectancy for people living independently compared to people living in residential care – we need some research into this.

DPO Meetings

Independent living has been much safer during Covid than being in a residential establishment – we need to be shouting about this much more loudly.

Many Disabled People's Organisations have resisted the dominant language that has been used in relation to disabled people and people with long-term health conditions during the pandemic –

We've struggled with the reintroduction of the term 'vulnerable' for all disabled people.

Two of the DPOs referenced the agility of their organisations which was demonstrated during this pandemic in the way we shifted our services, created new services, and worked in new ways –

Because we are small we can be quite nimble.

Our community connecting groups are out and about but were not doing home visits.

This pandemic has shown how at very short notice DPOs individually, and as a cohort, are a very strong group of organisations that can work in new ways to meet new ends. This is recognised by many disabled people who, according to one DPO, trust the DPO and its advice more than they trust the "official" line –

DPOs 'translate' the news given out by the government for local disabled people in terms of what the restrictions are, and what it means for them personally.

Thirteen of the DPOs talked about the challenges of holding meetings during the pandemic –

Meetings

The theme of online activity and connection came up in every meeting at almost every point in relation to every subject we discussed. This is absolutely understandable in relation to how organisations were able to meet and conduct their business during the pandemic –

Online

One of the key issues, mentioned by at least six DPOs is how the use of appropriate technology can bring more people together than was previously the case –

If we get the right technology then we get more people involved.

More people meet now for our trustee meetings than they used to before because it's much easier on Zoom – there's no travel, though some people don't have the technology or Internet access so Zoom isn't possible for them.

Previously I dropped out of meetings as I got too tired to be driving all around the country all the time, but now, without travel, I can do so much more.

Some people who come to our Zoom meetings never came to our real-life meetings, so we are keen to keep that.

DPO Meetings

Teams really works for trustee meetings to bring people together from right across the county.

Our trustee board haven't met for a year – some have never met each other face-to-face, only over Zoom.

This demonstrates how technologies that had previously been largely theoretical have become much more commonplace during the pandemic and much more accessible for many disabled people.

Of course other technology is available to keep people in contact with each other, including emails –

Weekly emails to Trustees, not quarterly reports

Four DPOs talked about how technology has become assimilated with real-life in a blended way for meetings during the pandemic –

From now on meetings will be blended – some people really want to be in the same room while others will be happy joining virtually.

We are looking at blended meetings. I've been able to make contact or go to meetings with people very far away for example in London which is great because of this way of working.

However one DPO expressed a legitimate concern in relation to this new use of technology –

We must be very careful to avoid a new apartheid where it's much cheaper and easier for disabled people to be kept online for future meetings while everyone else is actually in the room.

One DPO recognised how for many disabled people organisational meetings are opportunities to come together and enjoy each other's company –

Some of our board members need actual meetings for company and because they have poor IT skills.

2 of the DPOs talked about how they had managed to maintain a limited number of face-to-face meetings, often unlike other organisations –

All face-to-face meetings in the building has to be booked – no dropping is possible at the moment.

The CAB stopped all face-to-face meetings. We have Face-to-face meetings where possible because some people felt they needed them – for example people with mental health issues – plus our walking for health groups kept going as an opportunity to see/meet other people.

The next theme with nine mentions is that all young people –

Young People

DPO Meetings

Two people talk about the difficulties of recruiting young people to the organisation, and one further person talked about recruitment in general for the board which does not necessarily relate solely to younger people –

Recruiting

We are not getting young disabled people coming into the organisation which is threatening to our future. And I don't know why young people aren't applying for jobs we advertise.

We do find it hard to recruit to our board.

We use the term 'lived experience of disability and long-term health conditions' to appeal to more people who see disability only as wheelchair users.

How can we involve the voice of young disabled people – I've tried several different ways with little success and the people I did manage to get involved didn't stay around for very long.

This is a very substantial issue for all Disabled People's Organisations. If we can't recruit younger disabled people or younger people with long-term health conditions into our organisations at all levels the sustainability of our organisations is in jeopardy.

This ties in with the issue discussed above about making sure our organisations are appealing to all disabled people and people with long-term health conditions in terms of our relevance, the services we provide, and the kinds of things we say and do –

Young disabled people are busy getting on with their lives and don't want to get involved with DPOs and politics. We need to present a new face to attract young disabled people. We've gone into service provision too much which is seen by many young disabled people as very dull. There is also a lot of stigma around disability so why would young disabled people want to come into an office full of disabled people?

This issue of stigma in relation to disability and long-term health conditions is not by any means a new issue. The idea of Disability Pride seems to have very little traction unlike the issues of Gay Pride or being proud of one's ethnicity. There is clearly a lot of work to do in this area and this is something that a network of DPOs could tackle in the future by showcasing the services they offer and the innovative ways they work.

Further to this issue is the fact that there are in fact fewer younger disabled people or younger people with long-term health conditions in relation to some specific impairment groups –

There's also fewer young disabled people now than there were in the past – many young disabled people are screened out from being born anymore for example I went to a school for children with spina bifida and hydrocephalus which no longer exists because there are not enough of us being born anymore.

DPO Meetings

Many of our organisations were established by younger disabled people, who are now obviously much older, and who came together in a collective fight for the rights of disabled people. That sense of having to fight for our rights for full societal inclusion is not as high up the political agenda now as it used to be –

Getting young disabled people involved is difficult because there aren't the same fights that we used to have when we were younger. For example we fought for the disability discrimination act, for access to public transport, and to be able to get into theatres. Now many disabled people think those battles have been won, though there are still much more subtle battles to fight – we might be able to get onto the train but there are only 5 seats.

Young disabled people will come to us in the future when things get tougher for them – and things are going to get a whole lot tougher. We won't become irrelevant but we will in fact become more important.

Two of the DPOs mentioned how their services for younger people have been affected by the pandemic –

Our youth service has been most affected by the pandemic but we've kept it going on Zoom.

The kids/young people want to get back together but their parents are much more anxious.

One of the innovative ways that Disabled People's Organisations worked during the pandemic, changing services that they already provided, or developing entirely new services, was in the provision of well-being services. Despite the lack of any coordination nationally amongst DPOs this seems to have been an area where provision was recognised as important and was therefore provided at very short notice in new and innovative ways –

Wellbeing

Nine people mentioned the well-being services that they provided. This is an area that could do with much more attention as it help keep people safe and secure in their own homes away from the pandemic and away from potential illness and even death –

Feel responsible now for keeping people alive

DPOs offering Wellbeing/Keeping in Touch services, including reaching new people e.g. farmers with mental health issues

DPOs providing low level mental health support – phone calls every 1-2 weeks

Mental health support has been key during Covid.

We need to find ways to mitigate the mental health issues that come from not meeting up.

This identification of new customers as well as the needs of existing customers has helped demonstrate the value of DPOs to staff at all levels of these organisations. In

DPO Meetings

one case the staff on the Disability Information and Advice Line of the DPO came to work every day and phoned up their client list just for an informal conversation and to check they were okay.

DPOs also, of course, felt responsible for their staff as well as for their customers –

We've got four mental health first aiders for our staff and for customers.

We offer tailored support for staff according to what their needs are.

We use NHS mental health helpline for staff support.

The ability of a DPO to tailor support for an individual comes as second nature for an organisation which has a holistic way of working ingrained in the very fabric of the organisation. This obviously applies to the customers as well as to the organisation staff.

An unexpected theme to come from these conversations, with nine mentions, is that of the joy of working for a DPO.

Joy

As one DPO said –

It's about remembering what gives us joy in what we do.

Five people mentioned how much they like working with their fellow workers –

As an organisation we like interacting with each other.

It's brought us closer together.

The people steering DPOs need to be very clear and to create opportunities for informal mixing between staff.

We're running staff picnics in the summer to keep a sense of staff community.

We like spending time together. One of the things we miss is all the fun stuff that comes with collaborative working.

It is the informal mixing, the daily conversations in the office, the team breaks and lunch breaks that are missed by many members of a DPOs staff group. Many of the people who work for a DPO are themselves disabled people or people with long-term health conditions. Some of these people enjoy coming to the office every day for the company they get and for the opportunities to relax in such a friendly and welcoming environment. This has been very difficult for many people during the pandemic when they find themselves on their own, living and working in their own home environment, possibly not seeing any other people except through Zoom –

Teams doesn't allow space for the fun times.

The Friday staff quiz has always been very important as well as time in the pub after work. We make sure we carry on doing these things through Zoom.

We've brought new people into the organisation during the pandemic and managed to help them into the ethos of the organisation including some shadowing over Zoom, with a Friday night quiz.

It has been important for DPOs to create some informal time over the Internet to maintain the strong bonds between staff groups and to help people nurture their friendships.

Three people talked about how important technology has been to their organisation during the pandemic, although this has been a theme that runs through all the meetings in pretty much all of the thematic areas that were discussed –

Our phone service work really well because of problems here in rural areas with Internet/mobile connectivity so we used landlines to contact people.

This whole situation would have been impossible without the technology.

We can monitor the staff who are homeworking throughout the IT system, which has a green light if people are busy or not.

Without the technology that we have today this pandemic would have been a much more difficult situation for these organisations, their staff, and their clients. Although screen time is a poor substitute for actual face-to-face contact, it is still a whole lot better than no contact whatsoever.

Two people talked about the big charities operating in the disability field and how threatening these can be to small, local DPOs –

Suspicious of big disability charities using DPOs to gain credibility at ground level – e.g. Scope, Leonard Cheshire

Big charity is coming to local areas and bidding very low for contracts subsidised by their charitable income. This shuts out local DPOs and threatens our existence.

These big charities operate across the whole country, although some specialise in particular geographical areas. They employ teams of people to scope out local authority contracts which they can then bid very low for as a loss leader to get their foot in the door at the local authority. This undercuts any bid the local DPO could offer, excluding the DPO from a potential source of income at that time and into the future.

Many local authorities see the big charities as reliable, experienced, and dependable service deliverers, over and above their local DPO. This is despite the fact that the local DPO will have much more sense about what works on the ground in that local area as well as the needs of the local population of disabled people and people with long-term health conditions. The value for money is almost certainly located at the DPO level, which has much lower overheads, and much smaller operating costs.

The mission statement for many of these big charities often talks about how they work very hard to empower and increase the independence of local disabled people, while at the same time operating in this very disreputable way against the local DPO community. This is an area of work that urgently requires attention from an infrastructure body which is there to support the growth and development of the DPO sector, which does not currently exist.

DPO Meetings

There were ten mentions from people about what they would like to see from this project. The biggest category here is that of the creation of a national network of benefit to DPOs, serving the needs of DPOs, and not coming in with an external agenda –

We need something organic looking at what DPOs need and can help us, rather than following their own agenda. Some space to explore what people are experiencing in the real world.

A national network to share expertise would be good

A DPO network nationally to share expertise between organisations.

It's a great idea to network nationally with other DPOs – we're so far away from you that we can openly talk about anything. But it's much more difficult to talk as openly with more local DPOs, because we are in competition with each other. I think regional meetings would be a problematic.

Next 12-18 months will be crucial for DPOs, and will be a time when help might be required – going back to offices, opening services, etc.

These are turbulent times and this ability to talk to each other is something that everyone has benefited from –

We can learn what others are doing across the country in terms of local authorities and relationships and gain strength collectively.

It would also be beneficial for DPOs to be able to offer each other wellbeing and befriending support during difficult times –

Wellbeing/Befriending scheme between DPOs

Three people here talked about the benefits they saw from holding future Zoom events, including a national conference –

A national conference would be a good idea

Another set of Zoom events after we have opened up would be good – pull together a Wish List of what DPOs want

I'm interested in keeping this conversation going.

Conclusions

The coronavirus pandemic has highlighted the lack of an existing national network of DPOs in England, able to provide information, advice, and connectivity, between DPOs for information sharing, support, and advice to DPOs. The creation of such a network, led by DPOs, would facilitate inter-DPO communication, collaboration and knowledge, which could greatly strengthen the sector. It would reduce duplication of time and effort, and increase our ability to campaign and work together on issues of importance to us.

DPO Meetings

The DPOs involved in these meetings exhibited great resilience in the way they managed to move their services online, and their workers to be able to work from home at such short notice. They conducted risk assessments at every stage of every process for both staff and customers.

The big question for many organisations remains how they use their buildings/premises. Some have closed entirely, continuing to operate from home into the future, while others will return completely to their offices, but the majority will operate a blended, hybrid model of home and office working.

The ability to provide a safe space for some customers who need to be able to come to third party space, for example to deal with a hate crime enquiry, as well as a space for volunteers to be able to get involved with an organisation, are both key issues for DPOs.

DPO relationships with external organisations, particularly the statutory authorities, have been strengthened for some DPOs as a result of their work during the pandemic. Many local authorities relied on their local DPO to help with their crisis management activities.

For some DPOs however their relationship with their local authority remains fraught. This, together with continuing core funding issues, competition for ever scarcer funds, and the short-term, project-based nature of much of the funding that is out there, means DPOs will continue to face threats to their very existence.

This is despite the fact that DPOs have exhibited great strength and resilience during this pandemic, often experiencing a greater sense of purpose, and understanding the continuing need for their campaign and advocacy work. The wellbeing work undertaken by DPOs to establish and maintain contact with the most marginalised disabled people and people with long-term health conditions is a clear example of the ability of these organisations to identify a need, design a solution, and implement it very quickly.

The recruitment and retention of young disabled people remains a key issue throughout the sector and threatens the longevity of the DPO sector. We need to work together to show the value of the work we do, the joy of working with other disabled people and people with long-term health conditions, and the pride we take in ourselves.

DPO Meetings

Appendix 1

The questions/prompts I used for the meetings are here –

- Introductions
- How this session will run –
 - o 1 hour long
 - o Confidential – I will record Forum events but no names will be linked to any comments or specific Forum events
 - o Only speak one at a time please
- General conversation about DPOs in Covid –
 - o Introduction by me with some key findings from the questionnaire
 - o Questions –
 - How have you been running/coping for the past year?
 - What are they key issues as you see them now and into the future?
 - How confident are you to return to your offices? What about your staff? What will help you return confidently?
 - How do you see this panning out over time – e.g. what will ‘normal’ look like next winter?
 - What about if/when new strains and lockdowns happen?
 - o Do you or any members of your staff, have any training/education needs as a result of this pandemic? Or information from other DPOs?
 - o Is there anything you need or that would help you in these tough times – i.e. what if anything can I organise to help you?
- What do you think about holding an online event to bring together DPOs into a conference style event, e.g. with breakout rooms, etc.?
- Tell everyone about Slack
- How can we build a DPO movement across England?

ⁱ [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)00625-5/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)00625-5/fulltext)

ⁱⁱ [https://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/publications-and-technical-guidance/mental-health-and-covid-](https://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/publications-and-technical-guidance/mental-health-and-covid-19#:~:text=As%20the%20coronavirus%20pandemic%20rapidly,also%20expected%20to%20rise.)

19#:~:text=As%20the%20coronavirus%20pandemic%20rapidly,also%20expected%20to%20rise.