



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

**Project Report 6 – Stage 2: Key Findings**

November 2021



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## DPO Conversations

### **Executive Summary**

- Many DPOs continued with great resilience running their services with or without premises during the Covid pandemic;
- The pandemic has brought to the fore and highlighted many issues with which DPOs have been struggling for a very long time;
- The framework within which DPOs operate means that these organisations exist in a very precarious situation because of a range of factors including –
  - Local Authority relationships –
    - There is a need to strengthen and formalise the relationship between Local Authorities and DPOs to capitalise on the strengths of each organisation;
    - Constantly changing Local Authority staff and relationships with external organisations means that many DPOs struggle to maintain meaningful and beneficial relationships;
    - The government could write DPOs into local authority regulations and guidance to ensure these relationships prosper to the benefit of local disabled people;
    - National recognition of DPOs and their strengths and importance in the lives of disabled people would be very welcome.
  - Funding –
    - Short-term, project specific funding does very little to maintain organisational stability;
    - There is no/very little core funding available for these organisations;
    - Competition for scarce resources is always increasing.
  - Buildings –
    - There are ongoing difficulties post pandemic with maintaining safe spaces within which DPOs can operate;
    - Holding meetings for staff as well as customers can be problematic because of the space required to do these things safely;
    - A lot of people who work for these organisations will remain working from home despite government guidance to the contrary
    - Securing funding and training for the technology required for vulnerable people to continue to work remotely is problematic;
    - Many DPOs still do not feel confident to fully open their premises.
  - Covid –
    - There are still very big mental health issues for many disabled people and people with long-term health conditions in relation to the pandemic. This can include DPO staff and clients;
    - Many disabled people are still experiencing an ongoing fear in relation to leaving their own house;

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- Many people with long-term mental health conditions feel as though they are expected to ‘get better’ along with people whose mental health issues arose as a result of the pandemic.
- At the present time all of these factors and more can combine to make it very difficult for DPOs to continue to operate.

### ***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 people<sup>i</sup>, 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.

On the 19<sup>th</sup> July 2021 the UK Government lifted all restrictions on what was called ‘Freedom Day’. People were encouraged to go back to the office, shops and businesses reopened, and indoor social life resumed. Many DPOs returned to their premises, and their staff repopulated these spaces, while many DPOs also remained closed, or partially open.

This report is not intended in any way as a representation of the broad DPO sector. It is however a bringing together of some of the key themes that arose during a series of meetings with a small number of DPOs. These themes may well be indicative and illustrative of the issues that other DPOs are experiencing in these difficult times.

### ***Method***

In September 2021 I held a series of small meetings bringing together DPOs to talk about specific issues that had been identified during the previous set of meetings in spring 2021. This 2<sup>nd</sup> round of meetings was based around 5 specific themes to give small groups of DPOs the opportunity to talk about these issues in depth. Here is a list of the meetings, when they took place, their subject matter, and the number of attendees –

<b>Date</b>	<b>Subject</b>	<b>Attendees</b>
6/09/2021	Offices	3
7	LA Relationships	3
8	DPO Issues	2
10	Wellbeing Services	3

### DPO Conversations

Date	Subject	Attendees
14	LA Relationships	3
15	DPO Issues	1
16	Funding	2
<b>Total</b>		<b>17</b>

Eleven DPOs were represented at these meetings, some of which attended more than once, and some of which had a different member of staff attending different meetings.

DPOs are incredibly busy at the best of times but during this time of pandemic they are stretched to the maximum. This meant that several of the meetings were quite well booked in advance but on the actual day of the event some of the individuals were unable to attend at the very last minute. This helps to account for the low numbers of attendees at these meetings.

The organisations which did attend found the meetings very useful and welcomed the opportunity to talk about specific DPO issues in depth with each other. There are very few, if any, other opportunities for DPOs to share their operational experience with each other.

Here I present some of the key topics of discussion during these meetings. I have grouped the comments these people made into the dominant themes that emerged, and although the meetings were themed several of the topics stretched from one meeting to another. Consequently some of the themes outlined in this document were not solely discussed during one meeting alone.

The biggest theme, and the reason for these meetings in the first place, was to provide these organisations with opportunities to talk about things which affect them particularly as DPOs.

#### ***DPO Issues***

The value of being run by/employing disabled people is so that disabled customers know they have someone like them to talk to. It breaks down barriers and provides a fast-track way in for people. When a disabled customer realises that the person on the other end of the phone is also a disabled person it really does set them at ease.

This quote is at the heart of what it means to be a DPO. This is the reason these organisations exist and the reason they continue to exist and to provide such valuable services to disabled people across the country. This is the grand unifying theme of all of these organisations.

## DPO Conversations

We will see how this pandemic has increased the workload for these organisations for a variety of reasons –

We have got very busy because of Covid and its impact on disabled people. It would be weird if we hadn't got busy!

This is a time of great uncertainty for DPOs, disabled people, and the country as a whole. It is proving very difficult to be able to plan for the short, medium, or longer term future of an organisation at the moment –

How can you put contingency plans in place for 6 or 12 months into the future in a time like this – who knows where we be from day to day let alone that far ahead?

It feels like a waiting game at the moment with people doing very little until things get back to how they used to be.

Several people spoke in different meetings about their organisational premises and the challenges these manifest at this time –

### *Premises*

DPOs have organisational challenges relating to disabled people both as staff and as customers during this pandemic –

Many disabled people are still very frightened to go back to the office due to the physical implications of Covid, and mental health implications that this brings on.

One of the people I spoke to expressed her desire to continue working at home on an occasional basis –

I'll go back to the office once a week or once in a fortnight but not full-time ever again.

However other people spoke about the need to reconnect with their colleagues and the people with whom they work –

Working from the office – it's nice to be somewhere that is not your spare room all the time.

As a wheelchair user my activity level has dropped dramatically. At least going to the office can be active.

Working from home makes me feel more lazy because I don't go out nearly as much just because it's so much easier to work from home.

We shouldn't feel bad about being lazy.

Several DPO staff commented about how their activity levels have dropped during the pandemic. For many disabled people this homeworking (as we shall see below) is on the one hand very convenient whilst on the other has physical and mental health implications that come with it.

The majority of DPOs talked about how the return to office working is on an occasional, rather than a permanent, basis –

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Staff are working together a few days a week but not permanently.

The closure of DPO buildings has implications both for the staff as well as for customers. Much DPO work is based around the notion of bringing disabled people together to offer peer support as well as company, and specific services –

We closed our building and most services are based on bringing people together. We did some services online including the information and advice provision which we streamed, and it seems to work better, so there are some things we will continue doing in that way.

This pandemic has given the opportunity to think about new ways of providing services, including online (see below). For some disabled people with access to the relevant technology and equipment this can work very well.

The idea of bringing people together within DPO buildings is a key ‘selling point’ for many of the volunteers in the organisation –

Volunteers like coming somewhere rather than working from home. It’s a social activity for them which helps to get them out of the house more. So it’s problematic now that everyone’s homeworking and it’s difficult to keep the volunteers involved.

In fact the closure of DPO buildings has resulted in the loss of volunteers, many of whom are themselves disabled people –

Lots of our volunteers have stopped or gone to other jobs so we need to recruit new volunteers now.

There seem to be 2 kinds of DPO in relation to how buildings are used. The first kind of DPO uses their premises mostly for admin or for the staff –

Our building is not used by clients anyway – it’s not very public.

The second kind of DPO building is a much more public space used both by disabled people as well as other groups of the local population –

Our centre has a lot of footfall including for example every taxi driver in the city needs DET, so we have lots of taxi drivers coming through here.

As well as having their own premises some DPOs use other buildings –

We use lots of other buildings for various activities which is now a very difficult thing to do due to the extra cleaning and Covid security.

There is a group of DPOs which uses its premises as a means of generating income, including by renting space to other organisations.

### *Renting space*

We rent our building out a lot and that provides lots of income for our core costs. This obviously stopped during the pandemic, causing a huge deficit in our income.

By generating their own income in this way the unrestricted money can be used for any purpose that the DPO decides. This can be a way of generating core income for

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the organisation which is – under normal non-pandemic circumstances – a great way of creating the funding for the core services of the organisation, which are otherwise very difficult to fund.

We will run as a hybrid model. We can get some income from renting space to others, but we have a long-term lease which we can't get out of at the moment. This could be a big opportunity to rent out hot desks to organisations that require them.

There will be other voluntary and statutory sector organisations that have made a decision not to keep their premises open following the pandemic. This can be an income generation opportunity for DPOs if they have the space to rent to these organisations –

Our building is fully accessible which is very unusual around here unfortunately, so lots of organisations use us for example for PIP assessments.

The ability to navigate through this pandemic has been easier for some DPOs than for others –

Some people embrace change while others do not. This is a time of constant change so it suits some people much better than others.

One of the key reasons that DPOs have premises in the first place is to provide space for the meetings required to run their services as well as to run the organisation.

### *Meetings*

People don't want to meet up at all face-to-face – they are very nervous, especially vulnerable people.

Over 60% of the people who died during the Covid pandemic were disabled people. This obviously has enormous implications for the way that disabled people now move about in and around the world as the pandemic recedes. At the present time (November 2021) the numbers of people contracting Covid are still over 30,000 people per day. This does nothing to reduce the nervousness that is felt by many disabled people and people with long-term health conditions.

It's not only the meetings themselves which are problematic for many people but the actual moving about in the world and getting to and from these meetings, especially in cities –

In the city it's packed everywhere as if it's all over and there is no more pandemic – it's business as usual again. Lots of disabled people feel concerned and vulnerable – there is no social distancing especially on public transport.

Many disabled people are still shielding although there is no official guidance to do this, and therefore no support and less money to do so. Disabled people still feel very vulnerable.

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One of the implications of this vulnerability for disabled people and people with long-term health conditions is that DPOs are providing new services to help and encourage disabled people to get back out into the world again –

Quite a lot of disabled people are afraid to go out still. One of our roles now is to help people come out again after the pandemic. This is particularly true for people with long-term health conditions. We will operate a hybrid model for disabled people for a very long time.

There are examples of disabled people needing a chaperone/buddy service to support them to get back out into the world and give them confidence for example going to groups of people, going swimming, etc

By providing services such as these DPOs can help disabled people and people with long-term health conditions to feel more included in their local communities, confident that these are safe spaces to re-inhabit. However this can have implications for the confidence of disabled people and people with long-term health conditions to do these things on their own again –

One drawback of this can be that once people find us they won't let go and increase their reliance on the DPO especially as this pandemic ends. What we really want is for people to be able to live as independently as possible rather than to become dependent or too reliant on us.

It is very difficult for some people to imagine how we can ever get back to the situation we were in before the pandemic arrived. This has implications for the way that DPOs deliver services and the services that they deliver –

Pre-covid we had up to 30 people who came to our peer support network meetings along with 6 or 7 professionals to support them. Now we have only 6 people who want to come so therefore there is very little peer-to-peer interaction during or after meetings. A lot of people found this informal peer-to-peer networking very useful in terms of managing their own situations.

During the pandemic, and continuing for the near and medium term futures, meeting size has to be restricted in the numbers of people who can be present –

Real-life meetings have to be minimum occupancy with lots of space rather than rooms filled to capacity.

Many DPOs are offering some of their services in blended or hybrid ways, with people in the room as well as other people at a distance over the Internet –

it is still problematic trying to navigate blended meetings for some DPOs with some people in the room and others virtually attending while keeping everyone included.

However there are large cost implications for the DPO in terms of equipment as well as the technical support, and there are training, cost and technical implications for any disabled people wishing to take part in these meetings –

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Expensive equipment/tech is required to run blended meetings effectively. It can be possible to use the equipment/tech of other organisations if we are going to their meetings rather than holding our own meetings.

Now that many organisations are returning to their premises and to the pre-pandemic ways of working there are time implications for going to external meetings

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There's new frustrations with real-world meetings – travel etc takes time, so you can only have one maybe 2 meetings per day whereas with Zoom you can fit in up to 10 meetings in a day.

Because people were not meeting in the same ways as they used to meet before the pandemic it has been less easy for DPOs to promote themselves and the work that they do.

### *Marketing/Promotion*

At the heart of effective marketing and promotional activity is the ability to build strong and lasting relationships with other organisations –

It is very important to build relationships with the local authority and the voluntary sector and to go to events to give out information about the DPO, all of which can raise the profile of the DPO.

Obviously during the pandemic the number of opportunities to take part in events has been significantly reduced –

DPOs haven't held/been involved with some local events and activities held by other organisations, for the first time in ages, which has upset some people who have been to these events and who were expecting them to be there. This has reflected badly on the DPO.

One organisation recognised that –

Some DPOs need to invest in marketing and promotion to reach new people who don't even know that they exist.

This is going to be very difficult at a time when financial resources are already very stretched and when some sources of income have been reduced or made entirely impossible.

The situation to which we are all returning is not the same as the situation that we left behind at the start of the pandemic –

Pre-Covid events/support groups are not coming back in the same ways with anything like the same numbers of people which means that DPOs need to find people in other ways.

The reason why many events, meetings, and DPO buildings are so sparsely populated is because so many people have been working from home.

### *Homeworking*

Staff mental health became a real issue very quickly including with the trustees, and some DPOs had weekly meetings online and now they are back

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in the office are having more regular staff meetings in real life. The online pandemic situation identified an issue that was always there but which was previously unidentified.

Like other issues relating to the whole world in which we live this pandemic has foregrounded issues that have been there for a long time but which have either gone unnoticed or have been manageable on a smaller scale.

A few DPOs have decided not to return to the office at all, recognising that they can save huge amounts of money by not renting premises and by creating new ways of working with staff located in their own homes –

We're thinking about the pay per hour office model, but most of our staff are not really bothered – our office is for admin not for clients. We meet clients out in the community anyway just like we've always done. Working from home is just as productive.

We closed our office space because all our services are out in the community anyway, but we rent an office space that is much smaller so that people can come together every now and again. But currently everyone is homeworking.

For organisations that already work from home/remotely this (situation) is nothing new.

Some people find it problematic working from home due to the distractions that are all around –

I'm more focused in the office than I am at home where I get diverted by little things for example putting the washing out.

And staff management is more difficult from a distance than it is in a shared office environment –

There is a need to check in regularly with staff and volunteers to see how their work is going, if they have enough work, or too much.

Any return to the office is not going to happen overnight but will be a gradual process –

We are slowly going back to the office but mostly homeworking still.

Working from home seems to have been more of an issue for people who are new to a job role within the DPO than it is for people who have been working there for a long time already.

### *New Staff*

When I started it did feel like a gap in my knowledge about this organisation would never be filled – I had to go to homeworking 2 weeks into my induction. It was quite overwhelming and I was in at the deep end but we did work through it.

One new member of staff commented about how there are things that you can only learn by sharing space with other people who work for the same organisation –

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As a new member of staff I learn much more just being in the office with other people and having informal chats with other staff about what goes on and how the organisation does things. Working from home means this organisational learning is very much more difficult, or even impossible.

Part of this organisational understanding comes from the development of good relationships with other members of staff who work there –

As a new staff member it's difficult building relationships with the other staff plus I had no official handover because the offices were closed and now we're all at home and working from a distance.

We have new staff who've never met each other and therefore have never had informal conversations across the office. Although we run the quizzes online it's impossible to force people to come along and impossible to make people have fun!!

In response to these issues some DPOs make more effort to be available to new staff members whenever required –

We put in an effort to be as available as possible to new staff. We run a 'no question is a stupid question' policy.

With staff working from home and staff working in the office at the same time the social connections and social side of work can be very hard to maintain.

### *Social*

The social side of work has gone. Working remotely makes it impossible to talk to each other across the office and to have informal chatter, and we don't know how to overcome this. People are really missing this aspect of work.

One person talked about how they tried to build some social time into the online, rather than in person, meetings that the pandemic has forced them to hold –

Online meetings are very business focused and there is no social interactions during the meetings like there are in real life. We set up a 10 minute window before Zoom meetings begin so people can interact with each other.

Some organisations build informal virtual meetings into their daily routines to facilitate opportunities for staff to get to know each other better –

Every day at 11 AM we have elevenses where everyone can join if they want some informal time with each other. This seems to be disappearing a bit lately.

It can be possible to hold an informal coffee in the morning which is entirely voluntary but in the diary every week if people want to drop in for an informal chat with each other.

We run online quizzes and outdoor picnics for social reasons, to bring our staff together.

In order that staff are able to work from home there are implications in terms of the equipment that is required to make this possible.

## DPO Conversations

### *Equipment*

It's a bit more challenging to get the equipment that people need for homeworking to them.

One DPO recognised a gap in their knowledge and ability to provide this equipment and so –

We outsourced our IT to another organisation including if people need new equipment. It is delivered to the office where they can come and collect it.

This has also presented new learning opportunities for DPOs –

Working from home has helped identify digital exclusion issues in our clients.

All aspects of the pandemic and current situations can have implications for the mental health of everyone involved in the DPO from the staff who work there to the customers who use the services.

### *Mental Health*

This pandemic showed the importance of work for good mental health especially for people who are clinically vulnerable and/or socially isolating.

Some services absolutely rely on face-to-face contact and peer support –

Our Mental Health Advocacy service is very keen to get back to the office because of the complexity of their casework – there is a big need for peer support in this area which is currently very difficult to achieve remotely.

For some people the long period of isolation and social distance has made it difficult to consider going back to meeting other people indoors. For other people this isolation and social distance has made them much more keen to meet up with other people once again. This can make it very difficult for a DPO to run the services that they used to run, particularly for certain groups of people –

For DPOs it's very hard to keep a distance from clients experiencing mental health issues, for the staff and their own mental health.

For some people this pandemic has highlighted the areas of commonality between different sectors within the disability world –

There is a lot of potential crossover between the mental health world and the DPO world.

The pandemic has also highlighted how some sectors within the disability world have lacked infrastructure and infrastructure support for smaller organisations –

The lack of infrastructure support in the mental health world has become really clear during a pandemic – especially the 'less palatable' elements of mental health.

During the pandemic itself, and for many organisations on an ongoing and continuing basis, the need to be very proactive in relation to service provision became very apparent –

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Many DPOs became very proactive rather than reactive with their telephone services.

See below for a fuller discussion of the Wellbeing services offered by some DPOs.

For some people their mental health worsened as a result of the pandemic. For other people their mental health condition is a long-term issue that arose entirely unrelated to the pandemic. However one DPO which focusses on mental health issues noticed that –

People with long-term mental health issues are expected to get back to 'normal' along with everyone else.

The pandemic has made mental health a priority in terms of the new people experiencing it, but not people who have lived with mental health for a long time already. Other mental health conditions seem to have been ignored.

Closely related to the theme of mental health is that of the wellbeing services created by many DPOs.

### *Wellbeing*

Lots of DPOs designed well-being services which included a whole range of activity such as befriending, providing food, shopping including medications, hot meals, linking people to other services, information, social activities including having someone to talk to, signposting to other services, and a range of other provision aimed at reducing social isolation during the pandemic.

Many of the DPOs who provided these services did so entirely independently of each other and of any central coordinating network. This was a clear demonstration of the way that DPOs responded to need at the ground level. The uniformity of provision and the similarities between the various services that sprang up across the country, all entirely independently and responding to very local needs, demonstrated the similarity of experience that disabled people were encountering across the country.

The pandemic has lasted for such a long time that we have experienced spring, summer, and autumn. During these seasons DPOs were able to capitalise on the better weather in the operation of their services. Many Wellbeing services are dependent on having some outside space for certain activities for example walking and talking activities. Therefore many rural DPOs found such activities easier than urban DPOs –

Meetings outside are not good in bad or cold weather so coming into winter this will be much more difficult.

One person noted how the numbers of disabled people in care homes who perished as a result of Covid running rampant through these establishments, certainly in the early stages of the pandemic, might encourage other disabled people to remain living independently in the community for as long as possible –

The pandemic might make people demand that they live at home rather than in residential care establishments which had a very high mortality rate when they got hit by Covid.

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The range of Wellbeing activity clearly demonstrates the value of a DPO – reaching people in new and specific ways that meet individual needs in ways that other organisations were not doing.

Running throughout all conversations that we held is the theme of the technical issues experienced by both Disabled People's Organisations as well as individual disabled people.

### *Technology Issues*

At the heart of these new ways of working is the fact that disabled people represent the poorest section of the community. This can often mean that disabled people do not prioritise having the tech required to participate in the range of online activity that has grown during the pandemic –

Zoom/online is still very unusual for lots of disabled people who aren't used to it especially if they have not got the equipment they need, the data, or an Internet connection, plus people need training in order to be able to use it at all.

It's very hard to train people about Teams using Teams.

Several organisations talked about the negative aspects of meeting online as compared to meeting face-to-face. For example some statutory services are still operating online –

Annual health checks/GP services are not going back to normal yet but staying digital which means that many disabled people are not able to access these services.

There are also limitations when trying to move services online –

Lots of face-to-face doesn't work well on Zoom.

One DPO noted the disparity between the different software that is used –

Teams versus Zoom – organisations like Teams, individuals like Zoom.

Staff working remotely, technological limitations, well-being and mental health issues can all combine in negative ways with which many DPOs are still struggling –

How can we improve staff morale? It's very hard to know what people are thinking when we are dealing with each other so much over Zoom.

It can also be very difficult to set up a new organisation from scratch while we are all maintaining social distance –

It's very difficult for new organisations or people to try to set up a new DPO because people haven't been able to meet due to the Covid restrictions.

Setting new things up during a pandemic such as organisations or projects is very difficult to get the involvement/bandwidth of other people.

Underpinning everything that DPOs do is the funding that is available to make these things happen.

### **Funding**

For many DPOs the first port of call for funding can be the local authority (LA). However some DPOs steer away from providing council run services and try to remain completely independent of the local authority in order to be able to do exactly what they want to do.

*Don't bite the hand that feeds you*

I always feel like I'm walking on eggshells with them and that maybe they might 'stab us in the back'.

This idea is very tied to the broader theme of Local Authority relationships (see below), but the dilemma central to accepting any funding from the local authority is –

How to walk the fine line between challenging the LA while not jeopardising the funding?

It can be hard to challenge the LA when they fund you. This challenge might affect DPO funding.

Local authority funding can be problematic for these reasons as well as for a whole range of other reasons, such as –

LA funding is very dependent on knowledge of the LA staff and their funding policies which can change from moment to moment.

The way local authorities shift from one way of providing funding to another can also be problematic –

LAs move from providing grants to contracts and tenders all of which require more work. By moving from providing a grant to voluntary sector organisations like ours to a situation where we are in competition with each other and national providers for local authority contracts means that we might lose that contract and therefore a lot of money. We have therefore decided to diversify our income streams which has increased our sustainability and reduced our reliance on the local authority.

The reasons why local authorities would invest in DPOs in the first place is to help the LA to meet their own targets and government dictated outcomes –

LA funding can be KPI/outcomes focused where we sometimes have to do certain things or go to certain meetings where we would not necessarily normally think of going or our members may not prioritise, rather than necessarily doing our own business or following our own direction.

Some DPOs noted that other big providers can come into local areas and bid lower than the DPO would ever find possible. One DPO that had a very good relationship with their local authority said that –

The LA can make contracts more likely for DPOs to secure by doing relatively simple steps such as zero weighting the costs/finances, or scoring highly for local organisations in the tendering process. Some local authorities across the

## DPO Conversations

country actively try to keep contract delivery as local as possible to the benefit of their communities.

A good relationship with the local authority can therefore be very positive for both sides of the relationship. Having a good relationship with the local authority can help to avoid the building of a seemingly positive programme of work which might in reality, without proper consultation, end up having a negative effect on small local organisations –

Social prescribing programs see big organisations funded to refer people to the help they require which often means referring them to small unfunded organisations which then can't cope with the influx of new clients.

During the pandemic many local authorities, as well as other potential funders, operated short-term funding programs to meet immediately identifiable needs. Many DPOs successfully applied for this short-term funding.

### *Short term funding*

There's been specific covid funding to deal with emergency pandemic things but this is all short-term and coming to an end already.

Much of the short-term funding, especially from the local authorities, was identified and targeted to meet very specific immediate goals. One DPO noted how it is only natural that this type of funding would come to an end –

We are not having to firefight anymore like we did last year so it's natural that the funding will reduce.

However there are enormous implications for the size and shape of an organisation if they successfully secure this short-term project based funding. DPOs expand and contract according to the funding available which means staff come and go, so the organisation then loses staff with a depth of knowledge and understanding of the work of the DPO.

This short-term funding is a characteristic of the DPO sector, and has been for many years. Finding any sources of core funding is very difficult –

A big thing for the DPO sector is to develop and maintain core funding which is very hard to find.

The experience within the DDPO sector as well as with individual DPOs is the same everywhere – very threatening to our existence individually and as a sector because of the lack of core funding.

The Covid pandemic has brought to the fore and highlighted many issues that have been present for a very long time. This lack of core funding and the difficulty organisations find in securing any long-term income streams is one such issue. This issue is incredibly threatening to these organisations and does nothing to provide a sense of stability on which the organisations can depend.

An unexpected outcome of securing short-term funding to run local projects was described by one DPO –

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Short-term funding might disadvantage smaller organisations which are then perceived as being bigger than they really are. This can restrict their ability to apply for other bits of money because they are seen as being too big by the funder.

This same DPO also identified how the short-term funding for the short-term projects might actually be better suited to being longer term funding to help combat enduring issues –

A lot of the mental health work will need to continue into the future but a lot of the funding is very short-term and much of it has already stopped.

Several organisations talked about trust funding as another source of potential income for DPOs.

### *Trust funding*

As an activity, applying for funding from trusts, of which there are many across the country, can be very frustrating and incredibly time-consuming –

Applying for trust funding is problematic because you very seldom have a reply back if you are not successful. You don't know whether to reapply in a year or not, you don't know why you were not successful, and it might be simply down to the fact that there were too many applications rather than the fact that your application did not meet their criteria.

Several DPOs commented how it did not seem that there was an awareness of the time and effort required to commit to these processes –

Funders don't seem aware of the impact they have on the organisation in terms of the time taken to apply for monitoring and evaluating projects which can detract from the organisation's main work.

This can be in spite of the fact that trusts, as well as other funders, almost seem to entice DPOs to apply by using attractive language and sentiments in their calls for funding –

The language used by the funder can be very attractive to get people to apply and then when they do it turns out their application does not meet the funder's needs.

One DPO suggested that there was a space waiting to be filled to bring both sides of this relationship together –

Is there some way of bringing trusts, funders and foundations to hear our voices as well as vice versa?

Securing funding from many trusts, in similarity with securing funding from local authorities, can be very reliant on building relationships with them –

Trusts/foundations are very relational and creating good relationships can mean funding lasts a long time as the relationship develops.

One DPO suggested that this is an ideal organisational position for the involvement of suitably qualified volunteers –

## DPO Conversations

DPOs could get volunteers with fundraising experience to put in applications for the DPO.

Of course the entire funding landscape, whether that be with local authorities, trusts, grant giving organisations, or other funding bodies, is filled with organisations competing for scarce resources.

### *Competition*

In the first instance even holding a meeting attempting to bring DPOs together to talk about funding can be problematic, because this could increase competition for specific pots of money and therefore reduce individual chances of being successful. In the meetings we held we resisted talking about specific funders and concentrated on the broader themes of the funding landscape.

As has already been noted big, national charities, are often in direct competition with small local DPOs for local contracts –

Big charities swoop in on LA contracts to the detriment of local DPOs. This can also be true for local voluntary sector organisations which are not disability specific for example local CVS.

One DPO noted that –

Sometimes it seems as if other organisations bid against us for local contracts even if they have no experience with disability issues. They seem to pocket large amounts of money and do a less good job than a local DPO would do.

The local authority, or other funder, as well as other organisations, need to recognise the skills and expertise of the DPO in relation to disability specific issues. In recognising where the true skills and abilities lie both parties should understand that the needs of disabled people will be best met if the services were provided by a DPO rather than someone less qualified.

Several issues relating to local authorities arose in different meetings that we held.

### ***Local Authority***

Good practice is where the LA/DPO goals align more fully and where the LA is more flexible and less outcome focused.

There are opportunities for the local authority to work with DPOs to demonstrate the local need of disabled people to the national government. We can speak up and do campaign work while the local authority can't do this.

LAs need to make the most of us. We can really help them and we really do which can end up saving them a lot of money.

At the end of the day the local authority and the DPO both have the same set of goals and interests in relation to their local disabled population. Both organisations want to increase the confidence, independence, and well-being of all disabled people living in their local area. However the methods that each organisation uses to achieve these goals are very different.

## DPO Conversations

Most DPO contact with LAs is with the social services department even though disabled people use all local authority services, along with the rest of the local population. This can mean that many local authority services are not as accessible for disabled people as they should be.

One way to help overcome this problem could be to become involved with the LA at the senior management levels to try to get disabled people recognised across all local authority services.

One DPO stated that –

Other local authority departments can get in contact but it feels very much like a box ticking exercise and that they use our name to show they've made contact with disabled people which can reflect very badly on us if what they end up doing is not fully accessible.

The individual relationships between the local authority and the DPO were discussed by several people.

### *Relationships*

The pandemic has helped relationships become more trusted in some ways because the LA and others have witnessed how well we've performed under the pandemic pressure.

Where a DPO can build a trusted relationship with the local authority this can benefit everybody involved –

We get involved in specific cases to help resolve things without having to go to the press and are recognised as a good critical friend to the local authority.

However the relationships between the local authority and the DPO are by no means always positive –

It can be very difficult to get the local authority to facilitate communication and connection between ourselves and local disabled people. This means that many disabled people may not know that there are services available in their area and they may know nothing about us (their DPO).

It is a key challenge for this sector to increase the visibility of DPOs with local authorities, because, at the end of the day –

DPOs make local authority processes much easier for both sides – the local authority and the disabled person. We get some recognition for this from the local authority but this depends on individual staff members.

Building good relationships with the local authority can be difficult because of the high staff turnover levels –

LA staff turnover is very high. These seem to be quite unstable organisations.

Staff turnover at the local authority can make it very hard to maintain relationships and therefore contact including with frontline staff many of whom often remain unaware of what the local DPO can do for the local population of disabled people.

## DPO Conversations

Internal communication within the local authority often appears to be very difficult, or even impossible –

The left hand of the council doesn't always know what the right hand is doing. For example one part of the council might be working very well with their local DPO which is providing very good services to the council, while another part then commissions a national organisation to provide exactly the same services in direct competition with the DPO. The question is how to stop this from happening when the staff changeover rate is so high.

Several DPOs talked about the difficulties and problems with maintaining good relationships with the local authority.

### *Hard Work*

It can be hard as the DPO to speak up and say things without being seen as a difficult person all the time.

The amount of time and effort required to keep a good relationship with the local authority was described by several DPOs –

How can we engage with the local authority – this seems like such a difficult job requiring constant work and attention even though the reality is that it benefits both the local authority and local disabled people.

Managing LA relationships/contracts/partnerships is an ongoing and time-consuming process of uncertainty and constantly shifting parameters.

LA relationships are complicated for a whole set of different reasons. Merely maintaining these relationships is a full-time job as staff move on and change positions within their organisations.

It can also be questionable as to exactly why the local authority wants the involvement of the DPO –

It does sometimes feel like we may be there to rubberstamp something from the LA perspective.

Often the LA only consults when they want to hear something specific, and they might only go to the 'usual suspects' to hear things they want to hear.

The pandemic/austerity might force the local authority to work more closely with us to save money, but they must understand that what we do is not free!

Running an effective consultation exercise requires time, effort, and money, all of which can be in short supply –

Often the LA does not give us enough time to do an effective consultation, which might involve writing and printing documentation, getting it to people, and hearing back from them.

The actual services provided by the local authority can be below expectations no matter where you live. Local authorities across the country appear to be underfunded to meet the needs of disabled people –

## DPO Conversations

Even southern England has problems with LA provision – it's not solely a North/South issue.

Several DPOs talked about trying to formalise relationships with the local authority to put things on a stronger footing than being solely dependent upon individual members of named staff.

### *Formalised Relationships*

Three methods were talked about to help formalise relationships between these 2 bodies. These methods were a memorandum of agreement

A local Voluntary Action is trying to create a **memorandum of agreement** to formalise the relationship between the voluntary sector and the local authority.

A service level agreement

We managed to get a **service level agreement** with the local authority which can help and could pay for a worker.

We do training for frontline LA staff on direct payment procedures at our local authority level, and have now made ourselves indispensable to our local authority.

And a compact agreement

We are working with the local authority and the voluntary sector to create a **compact** with the voluntary sector based on the government Home Office model, and we have 6 monthly meetings or even more often which brings us more direct contact with frontline teams, including our staff meeting with their financial assessment staff.

Creating a compact is not a legally enforced agreement so therefore it is not enforceable and either side can decide not to follow it any longer as the whim dictates.

Each of these methods is useful in different ways and for different purposes, but each has the same underlying purpose of trying to set the relationship onto a firmer footing that is not dependent solely on named members of staff getting on well with each other.

One DPO talked about the lack of national presence and how this makes it difficult to build a strong case for the local authority sector to trust and build relationships with DPOs –

DPOs haven't got the national presence we need or national representation unlike the situation 15 years ago. We need a central point of contact which is well coordinated and able to give our voice to government and the press, and to collect local stories to use as evidence to back up our case. The national organisations should speak to each other more often so that local DPOs know we are all singing from the same hymn sheet and not all in competition with each other.

## DPO Conversations

Historically some local authorities created organisations that later went on to become DPOs, entirely independent of the local authority –

Our DPO was created by/in the LA and has since floated off to become independent.

One DPO talked about engagement with local health bodies and how confusing that can be as they change shape yet again –

How to engage effectively with health is an entirely different matter especially as they change between CCG, ICP, and whatever other structures they are inventing.

### **Conclusions**

The DPOs that have been involved in this project talked about how useful it was to be able to compare their own experiences with other organisations like theirs –

It's quite nice to know it's not just us and not just here that is experiencing these problems. It's good to understand what else is going on and what other organisations are going through in the pandemic.

The subjects that we spoke about in their specific meetings all related to each other with so much crossover from one meeting to another that this commonality really did come to the fore.

It is important to think about how best to continue to meet this need into the future. There needs to be a way of building the case for the work the DPOs do across the country all acting individually and yet all with very common themes and common ways of working.

Without the existence of the DPO sector many hundreds of thousands of disabled people would live in isolation, unaware of their rights and entitlements, and unaware of local provision that had been created to meet their needs. All this in turn would lead to feelings of loneliness and social exclusion both of which have very negative impacts on individual mental and physical health.

There is a case to be made at the very basic level that the existence of DPOs increases individual confidence, independence, and more fulfilled lives, all of which reduce the need for intervention by statutory health and social care provision. This in turn saves many millions of pounds to the taxpayer, and to central government.

It remains a question as to how best to bring these voices and organisations into some form of coherent sector that can thrive now and into the future.

This pandemic has foregrounded the way the DPOs work and has demonstrated the skills and expertise of the sector to meet the needs of disabled people in ways that the statutory sector and other voluntary sector organisations would have found impossible. For a start many disabled people remain unknown to the statutory authorities and other local agencies and as such are effectively invisible.

## DPO Conversations

Disabled People's Organisations work hard to increase the visibility of all disabled people, and yet remain underfunded, often unrecognised, and rarely consulted.

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<sup>i</sup> [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)