

Understanding the needs of Disabled people's organisations in England.



Easy read summary

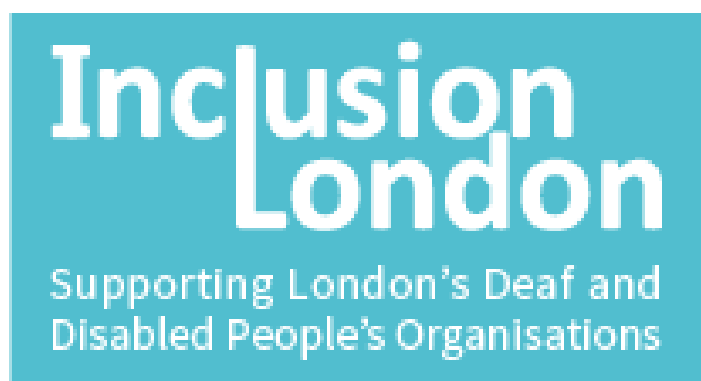
Introduction



This is the easy read summary of understanding the needs of Disabled people's organisations in England.



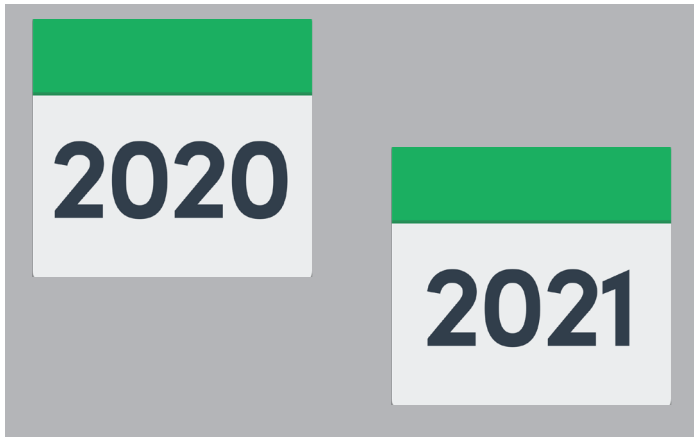
This research is to understand the challenges and needs of disability equality organisations in England.



The report is by Inclusion London. It was written by Mark Harrison and Tracey Lazard.



It was funded by the National Lottery Community Fund.



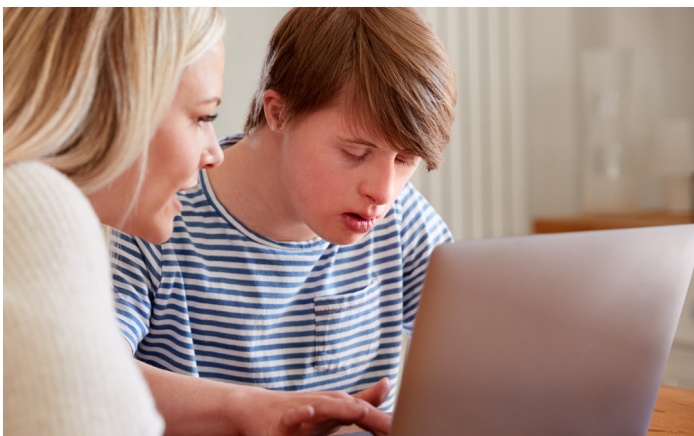
This report shows a snapshot of the state of Disabled People's organisations in England in 2020 - 2021.



In this summary we call Disabled People's organisations DPO's for short.

Different DPO's all across England helped us with the research.

They all received funding to support being involved with this work.



You can see a copy of the full report by clicking here: [Understanding the needs of DDPOs in England | Inclusion London](#)



The report talks about the good things that DPO's do.



It also talks about issues and challenges that they face.



It then sets out the things that DPO's need in the future.

This will help them to be stronger, work together and be able to support more disabled people.

What is a Disabled People's Organisation? (DPO)



DPO's are run and controlled by disabled people. They work to make sure that disabled people have the same rights as everyone else and that they are treated equally.



Some of the work they do includes:

- Giving information and advice
- Advocacy
- Personal budgets and direct payments
- Peer support
- Befriending
- Aids and equipment
- Training



Most DPO's in our study work locally in the area that they are based.

Some work right across their region.

About DPO's and their needs



Many DPO's have an income of under £500,000 per year. This is a big difference to some of the big disability charities who have incomes of over £100m.

An income is how much money you have coming in.



Lots of the DPO's we spoke to said their income had stayed the same in the last 5 years, some said their income was now less.

We also found out that some DPO's had closed down.



The main issues that disabled people face in most areas are:

- Accessing services and support
- Loneliness and mental distress
- Poverty
- Not having enough benefits or money



Here are some of the things we found out from our research.

What Disabled People's organisations do



Over the last 40 years DPO's have led the way in bringing about lots of social change.

They have helped to make new laws and transformed the lives of many individual disabled people and continue to do so.



DPO's run a range of different services including advocacy, advice and support. They are user-led which means they bring added value to the services.

Added value is all the extra things they do.



Some of the added value includes

- They have a greater understanding of disabled people's needs and of the issues they face
- Peer support and disabled people supporting each other
- High quality support that meets people's needs and is easy to access
- Helping people to use mainstream services

DPO's across the country



At the moment there is not a DPO that covers the whole of the country.



There is an urgent need to bring DPO's from different areas of the country together to be the national voice of the DPO's.

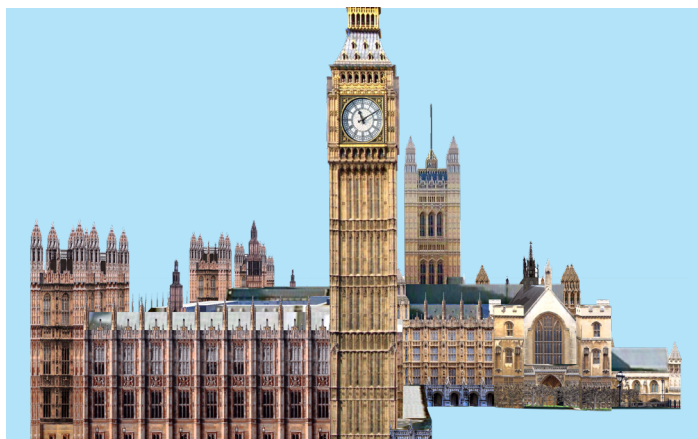


There are only 2 DPO's that are funded to provide infrastructure in their regions. Infrastructure is the name for support and training to help organisations run well and keep going.



There are large areas of the country that have no DPO's.

Issues faced by DPO's



In 2005 the Prime Minister published a plan called Improving the life chances of Disabled people.

It said that every area in England should have a DPO. The plan was never put into action.



There were lots of other things that also led to areas not having a DPO.

This includes the financial crash in 2008.



Our research showed that lots of DPO's that were led by people with learning difficulties have closed, including People First groups.

This has meant that organisations that are not user led have taken over the work.

Intersectional Issues



Intersectional is when a person may face different discriminations, for example black disabled people.

Many DPO's said they needed to better reflect the diversity of the communities they work in.



They want to meet with other DPO's in their regions to work and learn from each other so they can better address these issues.



Funding is needed to help do this.

Funding issues



Funding was one of the biggest issues for almost all of the organisations that took part in the research.



In our survey we asked about the closure of DPO's over the last 5 years.

Lots of DPO's knew there had been closures in their areas.



Only a couple of people we spoke to said they didn't know of any that had closed.

Many people that answered said they didn't know if there were closures or not.

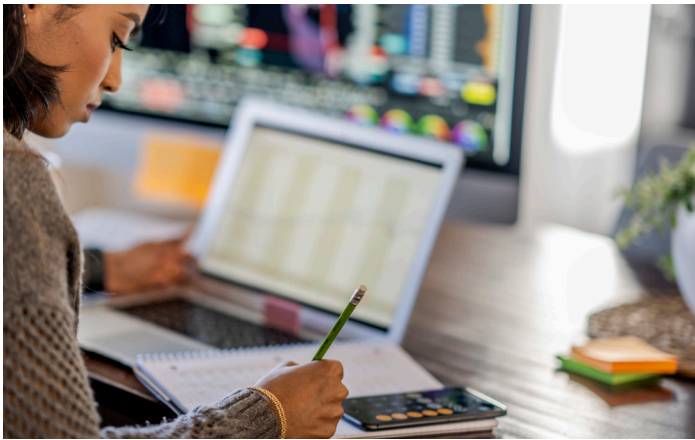


This shows that DPO's are not working together and are isolated from each other.

Other funding problems that were reported are:



- Many local authorities have ended contracts with DPO's and are doing the work themselves



- Funders don't often understand the extra work (added value) that DPO's give



- Big charities often have fundraising teams which makes it easier for them to win contracts meaning smaller organisations miss out



- Lots of DPO's struggle to get core funding. This is funding that pays for things like salaries, rent, bills and so on.

More demand and less resources



DPO's said that there was more and more demand for their services.

They also said that disabled people who had more complex needs were coming to them for support.



The main things that people need support with are:

- Social care and housing advice

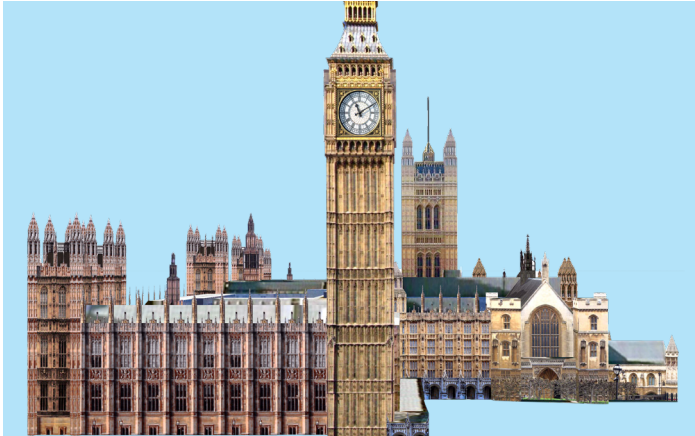
- Welfare benefits advice

- Advocacy services for people with mental distress



- Covid related issues.

Marginalization from Decision Making (Being left out of decision making)



We can see from our research that many DPO's feel that they are not seen as important by the Government.

At the moment the Government don't engage with any DPO's.



There also isn't anywhere for organisations to take part in engagement and co-production.

All of these are government duties that are required under the UN Convention for the Rights of Disabled People.



Many DPO's say they don't feel important to their local councils or other organisations like the NHS.

They said that councils are wanting more work for less money.

Some DPO's have said that their local councils have become unfriendly to them.

Some have even lost contracts because they have challenged the council's policies.

Internal issues (Issues inside organisations)



Many DPO's said they have problems recruiting disabled staff.



There are lots of different reasons for this including:

- No training or support budgets
- Having no work experience
- Disabled people having no confidence
- Problems with access to work.



Other internal issues are not being able to support current and future leaders and not being able to reach out to younger disabled people.

Covid-19 Disabled People and DPO's



Covid-19 has made a big impact on DPO's. It has increased and changed the needs of their service users.



Digital exclusion was highlighted as a big concern.

This is people not having access to or being able to use the internet, iPads, tablets, phones and so on.



This was an important way of people being able to stay in contact during the lockdowns.



Generally DPO's had a huge increase in what they did during the pandemic. In many cases they became the provider of lots of statutory and critical services.

These are services that should be provided by the NHS and local council.

One DPO in South London provided some of the following services during the pandemic:



- Helped people with their benefits and direct payments
- Arranged emergency care for people
- Delivered shopping, medication and so on to people across the region



- Arranged vaccinations for thousands of people who were giving care to disabled people
- Developing digital support peer groups for isolated disabled people



For many disabled people Covid-19 made them more isolated especially if they were living in residential care and not being able to see their loved ones.



The impact of Covid-19 has included councils and other funders cancelling on going and planned work with DPO's.

There is a worry that things will never go back to how they were before. This will leave disabled people without their voices being heard.

A new vision for DPO's.



A vision is what we want to see happen. We want to reclaim our power as DPO's and as a disabled people's rights movement.

We will build a strong network of regional DPO's that will last in to the future.



Some of the things the DPO's will do are:

- Provide support networks (infrastructure) so local DPO's can support disabled people in their area
- Engage with decision makers as valued partners that are respected. Work with them to develop ways to solve the problems that disabled people face
- Empower and give new skills to our communities. Bring young disabled people into our movement who can be our future leaders
- Make change in our communities and in local, regional and national policy making.





We want a need to create a society where policies and decisions about disabled people are made by involving disabled people and our organisations.



We want DPO's to be viewed as the place to go and people to work with on any issue about equality, community, wellbeing and social justice.



We want all public organisations such as local authorities, NHS services, adult social care organisations and more to make it their mission to take down the barriers and stop discrimination that disabled people are faced with in everyday life.

Our recommendations



Some of our recommendations to support DPO's are:

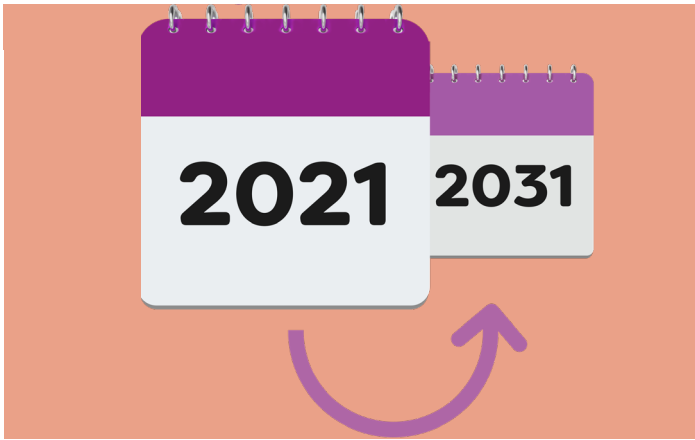
- Set up regional peer networks where staff and trustees can meet and share ideas
- More training on issues including planning, funding, supporting staff, modelling services and so on
- Resources so DPO's can be set up in areas where there aren't any



- Support to build relationships with funders and policy makers
- Support to research and develop new ways of recruiting more disabled staff
- Set up and provide long-term funding and support to groups for people that face more than one discrimination such as BAME, LGBTQI and women's DPO's



The full list of recommendations are in the original report which you can see by clicking here: [Understanding the needs of DDPOs in England | Inclusion London](#)



We estimate that 8 to 10 years of funding is needed to deliver the full range of recommendations.



We think it will cost between £10 - £18 million. We know this is a very large amount of money but we believe it is needed.



It will tackle the deep inequalities and discrimination that millions of disabled people face.