

Towards a new partnership between disabled people and health and care services Getting our voices heard

**Deborah Fenney**

**Fazilet Hadi**

**Dan Wellings**

**Emily Lennon**

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# Key messages

* 60 per cent of those who died from Covid-19 in the first year of the pandemic were disabled. The health inequalities disabled people already faced were made worse by the pandemic and a decade of austerity. In this context, it’s vitally important to include disabled people in designing and planning health and care system responses.
* Health and care services need to understand the broad diversity of disabled people’s identities and experiences, and adopt a social model approach to disability, understanding that people are disabled by barriers in society, rather than by impairments or health conditions.
* Health and care professionals need to value disabled people’s expertise through properly recognising the value of lived experience and ensure disabled people’s voices are central to any plans right from the start.
* Disabled health and care staff are potential partners in this work, with their perspectives of both using and delivering services.
* Disabled people’s organisations (DPOs) can strengthen their impact by working with other local DPOs and user-led organisations, understanding which parts of health and care systems they can best influence, and supporting health and care organisations to meaningfully engage with disabled people.
* Both health and care organisations and DPOs need to improve their understanding of how people’s multiple identities shape their experiences, and embrace diversity of voices, opinions and challenges as an opportunity to think differently.
* Ensuring disabled people’s voices are heard requires constant attention. While there are some examples of good practice, we many stories we heard where involvement wasn’t happening or felt tokenistic.

# 1 Introduction

During the first year of the Covid-19 pandemic in England, [60 per cent of those who died](https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020#overview-of-covid-19-related-deaths-by-disability-status) from Covid-19 were disabled. People with learning disabilities were [eight times](https://www.bmj.com/company/newsroom/people-with-learning-disabilities-extremely-vulnerable-to-the-effects-of-covid-19/) more likely to die of Covid-19 than the general population.

These numbers are truly shocking. But what is also shocking is that, for many disabled people, this is not a surprise. These statistics reflect multiple inequalities that disabled people have faced and continue to face in British society.

The inequalities experienced by disabled people are [well-documented](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2021). Disabled people are more likely to live in poverty, have less access to education and employment, and experience poorer ratings of personal wellbeing compared with non-disabled people. Disabled people are among those who have been [disproportionately affected](https://publicmatters.org.uk/all-party-parliamentary-group-for-health-in-all-policies/) by a decade of austerity and major reforms to the welfare system, which have increased the risk of poverty and, in turn, affected people’s health. The number of disabled people’s organisations (DPOs) in England has also declined significantly in recent years – [as result of funding cuts and related challenges](https://www.inclusionlondon.org.uk/uncategorised/understanding-the-needs-of-ddpos-in-england/) – reducing their capacity to tackle the structural inequalities facing disabled people.

When the Covid-19 pandemic hit in early 2020, health and care services needed to reprioritise patients, restrict access and delay care for millions. People across all parts of society faced additional barriers and poorer experiences in terms of accessing health and care but disabled people were [hit](https://committees.parliament.uk/work/320/unequal-impact-coronavirus-disability-and-access-to-services/publications/) harder than others. Inaccessible public health communications, cancellations of regular health and social care services and inappropriate use of ‘do not attempt resuscitation’ notices [all reflected and exacerbated longer-standing inequalities](https://committees.parliament.uk/work/320/unequal-impact-coronavirus-disability-and-access-to-services/publications/).

But despite these challenges, disabled people continue to make valued contributions to family, communities and wider society. And good, equal access to health and care is possible. With this access, people can live in their own homes, take part in their local communities and lead ordinary, valued lives.

Alongside evidence of the barriers disabled people face, is [evidence of how to remove them](http://www.bristol.ac.uk/sps/gettingthingschanged/finalreport/). Many disabled people, researchers, policy-makers, and charities have posed solutions, and yet disabled people continue to die [avoidable deaths](https://leder.nhs.uk/), and many more experience [unfair, poor outcomes](https://www.kingsfund.org.uk/publications/what-are-health-inequalities). Behind these statistics are our family members, our friends, ourselves. Disability inevitably touches all our lives – we all have a stake in ensuring that things improve.

The need to actively involve disabled people in planning and design of policies has been long recognised by disabled people and DPOs through the slogan ‘[Nothing about us, without us](https://www.un.org/development/desa/disabilities/international-day-of-persons-with-disabilities-3-december/international-day-of-disabled-persons-2004-nothing-about-us-without-us.html)’. Key to this involvement is health and care services understanding and valuing the expertise people with lived experience hold. Speaking to non-disabled led charities, or only to family and carers, is not an adequate substitute. This means services and the people using them can come together to ensure that solutions start with people themselves, rather than what the system thinks will work.

There are [many benefits](https://www.kingsfund.org.uk/publications/health-care-system-people-and-communities#why-do-services-need-to-listen) to listening to and learning from people and communities. Services can start to address inequalities by understanding the barriers that people face to accessing health and care and co-designing person-centred, effective, sustainable solutions. And co-creation doesn’t end there – once services are in place, it is the people using those services who are best placed to know what is working and what could be improved. While there are good examples of [disabled people](http://www.bristol.ac.uk/sps/gettingthingschanged/finalreport/) being involved, there are still questions to ask about how well this is [currently being done](https://qualitysafety.bmj.com/content/25/8/626) across the health and care system.

**Who is disabled?**

Understanding the diversity of disabled people is vital to knowing who to engage with. Disabled people make up [approximately 22 per cent of the British population](https://www.scope.org.uk/campaigns/disability-perception-gap/), and up to 45 per cent of those of state pension age. People from all ages, genders and ethnicities, and all walks of life experience disability. But in 2017, [more than a third of people in](https://www.scope.org.uk/campaigns/disability-perception-gap/) Britain said they didn’t know anyone who was disabled, and 60 per cent of people underestimated the number of disabled people in Britain.

So who ‘counts’ as disabled? The [most commonly used](https://www.gov.uk/definition-of-disability-under-equality-act-2010) definition in the UK is from the Equality Act 2010, which states:

*You have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities.*

In [national datasets](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/improvingdisabilitydataintheuk/2019#:~:text=To%20define%20disability%20in%20this,ability%20to%20carry%2Dout%20day%2D), the definition used is:

*…a person who has a physical or mental health condition or illness that has lasted or is expected to last 12 months or more, that reduces their ability to carry-out day-to-day activities.*

In this work we’ve taken a broad approach so that anyone who identifies as disabled or who would be considered disabled under these definitions is included.

## About this work

There is an urgent need to improve disabled people’s experiences of health and care services. When researching this project we found a series of reports The King’s Fund had previously published on disability issues. From the [1980s to the early 2000s](https://onlinelibrary.wiley.com/doi/full/10.1111/bld.12454), ‘an ordinary life’ was a key theme for supporting disabled people moving from long-stay hospitals into the community. And in 1995, The King’s Fund published reports on developing services for disabled people, [written by disabled researchers and campaigners](https://archive.kingsfund.org.uk/catalog?f%5Bcreator_sim%5D%5B%5D=Living+Options+Partnership+%28Development+Centre%2C+King%27s+Fund%29&locale=en). The issues described, such as the impacts of disablism and racism and the intersections between the two, are still being felt by too many people. And the message that service users and user-led organisations want to work with commissioners on how services are planned and purchased because it ‘determines the quality of their lives’ is still equally needed today, a quarter of a century later.

The work of [integrated care systems](https://www.kingsfund.org.uk/audio-video/integrated-care-systems-health-and-care-act) (ICSs) and place-based partnerships offers real opportunities to ensure disabled people’s voices are heard, listened to and acted on. The Health and Care Act 2022 includes a new duty on NHS organisations to focus on the ‘triple aim’ of promoting health and wellbeing, improving the quality of services and making efficient use of resources. This incorporates an explicit focus on addressing health inequalities, reinforcing the opportunity to improve services for disabled people. However, this can only be achieved by understanding what is going to make a difference to people’s lives, so the first step has to be listening to and learning from people and communities.

Lessons from what has and has not worked in the past need to inform how ICSs do this. Doing this will also support many of the challenges the health and care system is facing – because ensuring health and care services are accessible to disabled people will mean people get the support they need more efficiently. This will in turn facilitate improved health and wellbeing and reduce the need for more intensive interventions.

In this context, this work, by The King’s Fund and [Disability Rights UK](https://www.disabilityrightsuk.org/), centred on hearing from disabled people who have been involved in co-design and co-production of health and care services. More than 50 people contributed their insights and experience. This included people with lived experience of disability, representatives from 15 DPOs, disabled people working in health and care, and NHS and local authority representatives, across a range of ages, ethnicities, genders and sexualities. We describe our methods in detail at the end of the piece.

Here we set out what we found about how disabled people are currently involved in health and care system design, and what good might look like. We’ve organised our findings into three sections.

* What do health and care organisations need to do?
* What do disabled people’s organisations need to do?
* What’s the work everyone needs to do?

We hope that this project will provide inspiration and impetus to focus on disability equality, whatever your context. But this is not a box-ticking exercise, or something to be done once. Equality work requires constant attention, until it becomes a habit. Crucially, this first requires a deep understanding of why it’s important. Throughout this project, we heard stories of poor experiences of health and care, from missed appointments to serious harm – experiences that might be avoided if disabled people were involved in service design. These experiences ripple out into disabled people’s wider lives – the untreated health condition that means losing a job, the lack of adequate care support that means losing your social life.

**What is a disabled people’s organisation (DPO)?**

[Disability Rights UK](https://www.disabilityrightsuk.org/) sets out the key features of disabled people’s organisations.

[A DPO] *is governed, led and directed by Disabled people for and with Disabled people. DPOs work to uphold the human rights of Disabled people and the Social Model of Disability. The Social Model says that it is societal factors that create the barriers that stop us from living our lives with full choice and control.*

DPOs distinguish themselves from other organisations and charities that work with disabled people by this clear commitment to disabled people’s leadership and ownership, using a rights-based model.

**What do we mean by involving people?**

The people we spoke to used lots of different words to describe activities to listen to and learn from people. This reflects other findings about how [people use different terms](https://www.kingsfund.org.uk/publications/health-care-system-people-and-communities) – consultation, engagement, involvement, participation, lived experience and voice – often interchangeably, and don’t always agree about the exact meanings or how they are different from each other. This can be confusing, and sometimes it slows progress where there is disagreement.

While all forms of listening and learning from users have value there is an important question about at which point users are involved. Feedback and consultation are about seeking views on services that are already in place or on decisions that have already largely been made. If services are to reflect what matters to disabled people, then these voices need to be heard from outset. Disabled people should be involved in planning, commissioning and designing those services and too often this is not happening.

An increasingly commonly used term is co-production. This is defined by [Think Local Act Personal](https://www.thinklocalactpersonal.org.uk/co-production-in-commissioning-tool/co-production/In-more-detail/what-is-co-production/) as:

*A way of working, whereby everybody works together on an equal basis to create a service or come to a decision which works for them all.*

Co-production is not a ‘thing’ that you do. It’s an approach that recognises that services don’t hold all the answers, so ‘working with’ people rather than ‘doing to’ is vital. It’s about sharing power between people using services and people delivering them. There is no one way to do this, but co-production recognises that partnership working and sharing power is likely to lead to more effective outcomes. Whatever words people used, these principles around sharing power and equal value came through strongly in this project. Moving beyond definitions, any work with people and communities should be judged by the intent and commitment behind it and what is done as a result, rather than the term used to describe it.

# 2 What do health and care organisations need to do?

To properly acknowledge and involve disabled people in developing services, health and care organisations need to listen to disabled people. Applying a social model approach, supporting staff, valuing disabled people’s expertise and prioritising disabled people’s involvement are all part of this.

## Adopt a social model approach

Throughout this project, we heard how people had poor experiences when treated as just a particular condition or seen as only one aspect of their identity by staff (a medical model), both in terms of accessing health and care, and taking part in engagement. They contrasted this with experiences when they felt seen as a ‘whole person’ in the context of their life. We heard that in health and care contexts, professionals often start from a medical model – looking at an individual, their condition and how to ‘fix’ it or adapt themselves to fit in better with their environment. This is not necessarily wrong in a health context such as the NHS, where you might need a specific treatment or intervention, but it is not sufficient. The [social model of disability](https://www.disabilityrightsuk.org/social-model-disability-language) shows how the challenges disabled people face are caused by the way the world around us – our environments – are designed, rather than by a person’s impairments or health conditions. Environments and processes are often designed implicitly for people who aren’t disabled – this is [ableism](https://www.scope.org.uk/about-us/disablism/). Ableism can lead to people experiencing disablism: prejudice and discrimination that comes in the form of disabling barriers.

The social model is a helpful lens to use when thinking about access to health and care. If someone is unable to communicate with their GP surgery, is it because they can’t hear, or because the GP can only be booked by telephone? If someone can’t wait in a health service waiting room, is it because they are autistic, or is it because the waiting room is overly crowded, noisy and bright?

### What does a social model approach involve?

Health and care organisations need to use the social model of disabilityto fully involve disabled people in health and care service design. It means thinking about how situations or environments could be adapted or changed to enable a person to live the life they want. It’s crucial that people working in the health and care sector value disabled people’s perspectives as much as they value their own.

A social model approach would also mean health and care organisations working with other sectors, for example housing, to get a better understanding of people’s lives. ICSs provide an opportunity to do this, but only if partners listen and learn together.

## Support staff

When health and care organisations plan engagement work, they need to ensure that they create spaces where disabled people feel heard, and feel that sharing experiences will make a difference to how services are designed and delivered. For this to happen, staff working in health and care organisations need to listen and have the permission and resources to respond meaningfully to what is shared.

Experiences with staff, both good and bad, were central to the stories of involvement that we heard in this project. Staff who ‘get it’ were hugely valued, but also rare. More often, we heard about staff who don’t understand, don’t have time, or don’t value disabled people’s voices. The ongoing workforce crises in [health](https://www.kingsfund.org.uk/projects/positions/nhs-workforce) and [social care](https://www.lgcplus.com/politics/workforce/widespread-workforce-shortages-revealed-16-02-2022/) are contributing to this lack of time and resource.

It’s also important to recognise that there is lots of experience to draw on from inside health and care organisations. Many disabled people work in health and social care. There isn’t a clear divide between ‘disabled people who use services’ and ‘staff who are not disabled’. Slightly more than 20 per cent of NHS staff indicated ‘they have a disability’ in the latest [NHS Staff Survey](https://www.england.nhs.uk/publication/workforce-disability-equality-standard-2021-data-analysis-report-for-nhs-trusts-and-foundation-trusts/). However, the [Workforce Disability Equality Standard](https://www.england.nhs.uk/publication/wdes-2020-data-analysis-report/) (WDES), which measures and compares the experiences of disabled and non-disabled NHS staff, found that most disabled staff don’t share this information at work. There is a common perception (and sometimes reality) that disclosing disability will lead to negative consequences at work, including barriers to career progression. [Barriers to accessing training (and lack of visible disabled representation in the workforce)](https://www.bma.org.uk/advice-and-support/equality-and-diversity-guidance/disability-equality-in-medicine/disability-in-the-medical-profession) can mean disabled people don’t join the workforce in the first place.

### What does supporting staff involve?

It’s not a big, onerous piece of work to get [staff] to understand the value of engagement and partnering.
NHS England deputy director

**Understanding disability**

Staff at all levels – from administrative staff and clinicians to commissioners and leaders – need to have a deeper understanding of disability.It is everyone’s business. Staff training and development needs to include what disability is and what disabled people’s rights are, what the social model is and how they can bring lived experience to their work. Alongside understanding disabling barriers, disabled people’s strengths also need to be recognised – and staff need to take time to properly get to know the people they work with, both colleagues and those involved in engagement work. Crucially, any new training should be designed and delivered in partnership with local disabled people’s organisations and span across the career pathway; through inductions and ongoing continuing professional development (CPD) elements.

**Leadership**

Health and care leaders need to model a compassionate and inclusive approach that recognises the importance of a broader view of disability. Leaders also have a role in enabling staff to use their learning to work in different ways to make a difference to people’s lives.

A vital part of this is recognising and promoting the role of disabled staff, ensuring that disabled staff are visible, heard and recognised. Disabled health and care staff have a unique perspective, bringing both lived experience and professional experience to the table. Disabled staff networks are an important source of insight for involvement work. For NHS organisations, the [WDES](https://www.england.nhs.uk/about/equality/equality-hub/wdes/) data is a useful tool to understand the issues facing disabled staff and to create a more inclusive workplace. The NHS Disabled Directors Network is newly formed, but is already starting to give senior disabled staff more of a voice in the health sector.

Disabled staff, they generally have experience of using our local services as well, so as well as being a valued member of staff, they've got experiences as service users as well.Equality, diversity and inclusion lead, NHS trust

## Value and prioritise disabled people’s expertise

Fundamental to better partnership working between disabled people and health and care services is understanding why it is important to listen to disabled people’s voices and the [value of disabled people’s contributions](http://www.bristol.ac.uk/sps/gettingthingschanged/finalreport/). Throughout the project, this was at the core of the issues people described. Lived experience expertise is [not given the same status](https://www.kingsfund.org.uk/publications/joined-up-listening-integrated-care-and-patient-insight) as formal expertise. And this sits within a wider societal context where disabled people aren’t valued equally with non-disabled people. Ableist and disablist attitudes [are all too common](https://www.scope.org.uk/campaigns/disability-perception-gap/), and so it was unsurprising to find multiple examples of poor attitudes to disabled people in health and care contexts both from previous research and in this project. This included professionals patronising or disbelieving individuals, which people in our group discussions put down to a lack of understanding about how disability has an impact on different people in different circumstances.

We have one lady who's stopped engaging with the local authority now, because she [says] it's just a tick box exercise.
Discussion group participant

Not valuing disabled people’s voices has multiple negative impacts. People who do not feel listened to may withdraw from future engagement opportunities. Poor engagement also leaves people feeling excluded and can have an adverse effect on their wider wellbeing. One of the impacts of ableism and disablism is that some people feel ‘less than’:

We can't underestimate the levels of oppression in society that make us, as disabled people, feel less than, or like second-class citizens. That makes us feel invisible. That makes us feel that we have no right to be at the decision-making table, even when its decisions being made about our own lives.Local authority co-production lead

Health and care professionals need to ensure disabled people’s voices are central to any planning right from the start – to understand the problem as well as to design the solutions. If this doesn’t happen, then the resulting services may be poorly used, or need re-developing to make them accessible.

We heard lots of examples where this hasn’t happened, and people’s experiences of being involved felt tokenistic, or staff didn’t view it as a priority. We heard examples of decisions about a project being made when people with lived experience were not ‘in the room’, which is not truly sharing power. Participants told us that engagement could feel like a ‘nice to have’ rather than essential part of the decision-making process, or simply a waste of time for participants, when views did not seem to influence decisions.

And I know full well, [they’re] going to go away from this, put this document in the bin, and carry on as usual.
Discussion group participant

### What does valuing and prioritising disabled people’s involvement mean?

Genuine partnershipand involving disabled people from the start should be the first step in any work. How local health and care systems hear from and work with communities should be seen as central to how they address inequalities, not as separate strands of work. And who ICSs hear from matters. As ICSs develop their strategies around how they work with people and communities, particularly in tackling health inequalities through initiatives such as [Core20plus5](https://www.england.nhs.uk/about/equality/equality-hub/core20plus5/), leaders need to explicitly consider how disabled people can input at all levels, from governance to frontline services. This is particularly important on topics that disproportionately affect disabled people, such as health inequalities.

Health and care systems need to apply the principles of co-production, recognising that the answers to the challenges people face do not lie in the system. Meaningful involvement is key, and one way of achieving this is working with disabled people’s organisations who can support individuals to ensure their voices are heard. Awareness raising and capacity building are important parts of this support. Understanding the social model of disability can be a gamechanger for disabled people:

There are lots of disabled people that are that have never heard of the social model who experienced the sense of internalised oppression… So there is a piece of work to be done that really helps disabled people wherever we are in our lives, or in our understanding of disability as a social construct, to say ‘look disability is a positive identity. It's a political identity. It is society that makes you feel terrible about who you are.’ And only then can disabled people really have a sense of their right to be at the table.
Local authority coproduction lead

For example, one person in our discussion groups described their experience of internalised disablism, feeling that ‘nothing I did was worth anything’*.* But being involved in a meaningful co-production project changed their perspective:

The work I'm doing as co-production, it helped me regain my confidence… And so I've actually managed to be stimulated by this. It has actually been my job, I've put on my CV… I've done really well for myself and I feel a lot better about myself... I feel like I have so much more agency now.
Discussion group participant

Understanding and identifying shared aims between providers and people using services can really benefit the work. For example, it can be a helpful way for professionals to rethink how they include people who they might otherwise view as ‘challenging’ if they understand that challenge to be coming from a place of wanting to improve services:

I tend to be extremely critical. But hopefully it's to get to a better place, I come with solutions, not just the problems. But I live in the real world with the real problems and hark back to things people have said about bad outcomes for people. That's why I got involved in the first place.Discussion group participant

This approach to involving people also means reckoning with power. To be able to meaningfully contribute, disabled people’s power needs to be recognised by everyone working in the system. This means hearing from and working in equal partnership, not tokenism. The structural power imbalances between people working in health and care organisations and people representing DPOs and their own lived experience need to be fully recognised, with those holding more power proactively working to reduce these imbalances. People need equal recognition – both pay and acknowledgement – for equal work. And there may be limits to the power a particular project can influence – and so being honest and transparent about those limits is also important.

Finally, it’s important to keep track of any impacts these changes are having. Progress cannot be taken for granted. Local systems need to have the right data and measures in place that capture disability to track progress, understand variation and assure themselves of the progress they are making. For example, a review of routine collections including waiting list data could ensure that disability is being coded correctly and uniformly.

If disability is part of what is measured, and disabled people considered as key stakeholders, this will act as an incentive. As one NHS chief executive described:

What gets measured does have a huge impact… what my board responds to, in terms of where we put our priorities, is partly around what is measured. But it is also around the multiple of stakeholders to whom we have to respond.

Again, partnership with disabled people’s organisations is vital to review what is collected, how these measures are constructed, what is captured and what could be improved, as well as ensuring there is consistency in how disability itself is defined.

## When it works: everyone benefits

If services value disabled people’s expertise, and work with people and communities to design and plan access in the first place (rather than addressing individual access needs each time they arise) this can have positive impacts.

For individuals, when people do feel valued it can be transformative:

[Involvement] changed my life so much for the better. Because for several years before that I'd gone to a day centre. And I'd improved a little bit because of that. But when I stopped going to the day centre I stopped improving. And then… once I was taking part in that project everything, my confidence, my abilities, my self-esteem, everything just skyrocketed.
Discussion group participant

There is also a potential economic value or business case for this work when a service gets it right first time. As a disabled non-executive director described:

[Disabled people’s group]were consulted on quite a few projects and what was being proposed was not accessible for disabled people, and we said, ‘if you go ahead with this, it's going to cost you money once you've done it, to redo it, to make it fit for disabled people’. So if you engage with us at the development stage then you might save money, so that was actually an easy win.
Non-executive director

Ensuring disabled people’s voices are heard can also benefit staff. Providing services that truly meet the needs of disabled people can mean better interactions between staff and people using the service, and therefore playing a part in reducing the pressures staff are currently facing in all parts of the health and care system.

Finally, we heard how it could be transformative for health and care professionals without lived experience to partner with disabled people on projects. As one NHS England deputy director described:

[When involving a person with lived experience] they have a set of eyes and opinions and perspectives that I will never ever have. I need somebody alongside me who could not just empathise with [the topic], but who might have some really valuable data set. Killer questions – that's what I called them. And boy did I learn from that. So without those people as allies and partners to [the project], we wouldn't have garnered the information we did. We wouldn't have been able to make the recommendations that we did for people’s future.

# 3 What do disabled people’s organisations need to do?

While much of what we heard about in this project was how health and care organisations could better acknowledge and involve disabled people, we also heard ways disabled people and DPOs are already working to support their local health and care systems. And, we heard about ways DPOs could work most effectively to make involving disabled people in health and care a priority.

We heard about the work still to do among the wider voluntary sector to understand disability rights and the importance of user-led organisations:

[non-user-led voluntary organisations*]* can't really represent the voice of the people in the same way.
DPO chief executive

And local DPOs can also work together to strengthen their impact. One DPO chair told us about how his organisation and several others had come together as a group, and were therefore able to build better local relationships in their health and care system: ‘it’s a stronger voice’. Some of the more established DPOs we spoke to were also either collaborating with other equalities groups, or actively trying to make these links and work in an intersectional way. This is something the wider [DPO sector has already identified](https://www.inclusionlondon.org.uk/uncategorised/understanding-the-needs-of-ddpos-in-england/) it needs to improve on. We discuss the importance and opportunities of an intersectional approach in the next section.

DPOs are well placed to advise health and care systems and staff on using the social model approach and how to meaningfully engage with disabled people**,** as well as often having good local grassroots networks. And DPOs also need to develop their own strategic knowledge of where and which levels in health and care systems to target their influence, and work with other organisations with similar goals to maximise impact. Part of this is learning from other DPOs across the country at different phases of the work.

Rather than… bashing the local authorities over the head with a stick saying ‘you've got to do this’, we’re trying to take them on a journey.
DPO representative

We heard examples of disabled activists and DPOs working with local system leaders – including local authority commissioners and politicians – to educate them about the social model and about disabled people’s human rights that are in law. In areas where DPOs and their representatives described making the most progress, this was built on decades of work by activists. It had involved difficult, and at times adversarial, relationships with statutory organisations. But over time, through getting their priorities on to the agendas of local politicians, these DPOs had developed positive relationships that were starting to lead to positive change. Thanks to the work of these activists, there are ways of working we can point to for how DPOs in other places might engage with their local health and care systems.

## When it works: disabled people leading change

The [Greater Manchester Disabled People’s Panel](https://gmdisabledpeoplespanel.com/) is made up of representatives from local disabled people’s organisations and was established in 2019 as a joint initiative with the Mayor of Greater Manchester. Its remit covers improving disabled people’s involvement and representation in all aspects of public life. Its officers described being able to use their position on the panel to draw attention to issues facing local disabled people during the pandemic and get support to address these. A key strand of the work is supporting local politicians and decision-makers to understand disabled people’s rights, framed by the United Nations Convention on the Rights of Disabled People. The panel has also helped to drive a broader ‘equality lens’ approach in the region, joining up with other minoritized groups to co-ordinate their work.

The panel is convened by [Greater Manchester Coalition of Disabled People](https://gmcdp.com/), an established DPO with a 40-year history of grassroots organising, which means it has strong links with its local community and can negotiate the balance of being trusted and respected by people inside and outside the system. However, while the officers described good relationships and being heard by local health and care system leaders, this didn’t always translate to necessary substantial, systematic change to policy or approach. There were also barriers to ensuring consistency across the different local authorities within Greater Manchester, for example, in relation to issues of social care. The work of the panel was one of the most positive examples we came across during this project, but it highlighted that progress can be slow – this work takes time.

# 4 Disability is not a standalone issue: what’s the work everyone needs to do?

The previous two sections have focused on the role of health and care organisations and of DPOs. One issue came through the work that both need to make progress on to get disabled people’s voices heard: prioritising solidarity.

Disability is not a standalone issue: disabled people come from all sorts of different backgrounds, ethnicities, genders and sexualities. Where these characteristics intersect, it can have an impact on access to services and make being heard even more of a challenge.

If you can get non-disabled people to see the intersectional nature of disabled people's experience, I think we will get further faster. But that's tricky because getting people to understand intersectionality is tricky.
DPO chief executive

In our project we heard from a Black woman who has a hearing impairment. She attended a local co-production event run by commissioners. As she explained, no one had asked about her access needs and her request for a hearing loop had been ignored, so she struggled to hear what others were saying. Because she could lip-read, she noticed that the white person running the event was making comments to colleagues about her being rude and interrupting, and that he was ‘trying to get rid of her’. Not only had this event not considered the needs of people with hearing impairments, but as she pointed out, the comments the organiser made also played into negative stereotypes of people from minority ethnic groups.

Statutory organisations and DPOs need to understand the importance of these intersections. One of our stakeholders represented a DPO that supports people from a particular ethnic background. They provide culturally sensitive support, but described how local commissioners often don’t recognise this specialist expertise and community insight, meaning they prioritise generalist organisations.

We heard about a lack of understanding or consideration of people’s multiple identities and experiences, leading to narrow engagement such as a focus on a single condition or treatment pathway.

[NHS organisations]struggle with the concept that someone might have cancer and also be Deaf.
Lead, Healthwatch England

We also heard about DPOs that wanted to improve their diversity of representation. This is something the wider [DPO sector has already identified](https://www.inclusionlondon.org.uk/uncategorised/understanding-the-needs-of-ddpos-in-england/) it needs to improve on.

## What does working together in solidarity involve?

The need for an intersectional approach to including disabled people was clear during this project. We heard from some a feeling that at a national level disability equality had been neglected in recent years, contrasting this with the way the NHS in particular has – rightly – focused on race equality. But equality issues can’t be addressed in isolation.

Heath and care systems and DPOs need to embrace diversity of voices, opinions and challenges as an opportunity to think differently, and embrace any discomfort as part of progress, rather than seeing this as a threat to the status quo.

## When it works: taking an intersectional approach

Some DPOs working with other user-led organisations (led by people from other minoritised groups) took an intersectional approach to strengthen disabled people’s voices. A DPO chief executive told us about a local campaign working alongside other user-led groups with different protected characteristics to ensure disabled people’s voices, and those of other excluded groups, were represented on a key health decision making board:

We will be speaking as one voice. We're not competing with each other. We're saying we don't care who it is, what we care about is having a balance on that board […] I don’t think we should push for a [disability] seat, I think we should push for an equalities seat and whether that's the user-led [organisation] that represents [ethnic minority communities] and I work with them or whether it's [the DPO] and I work with them – it doesn't probably matter.

The most important factor here was recognition for the work and expertise of user-led organisations, and working in solidarity with other user-led groups to achieve this.

**What is an intersectional approach?**

We heard throughout this project that it’s important not to look at disability in isolation. It’s vital to ensure other aspects of people’s identities – their race, gender or sexual orientation, for example – are not forgotten. An intersectional approach acknowledges that other issues – such as racism or sexism – may have an impact on disabled people’s lives and may compound the experience of disablism.

An intersectional approach can also help to identify parallels with other marginalised groups who face other inequalities. Our multiple identities change and complicate our experience of disabling barriers. For example, a focus on race equality or disability equality needs to consider the experiences of disabled people from ethnic minority backgrounds, as well as different genders and sexualities. Taking into account both the specific issues affecting disabled people, and making links across other groups facing inequalities, gives opportunities to build solidarity, get a greater number of people involved, and ultimately have a greater influence.

# 5 Towards a new partnership

The engagement landscape working properly, in an integrated way, offers lots of opportunities… It's everybody's responsibility to do engagement and to use the views of users appropriately, to make sure that we're improving the quality of care that's being delivered.
Lead, Healthwatch England

When we started this project, we identified the establishment of ICSs as statutory bodies under the Health and Care Act as a key opportunity for organisations and services to review their approaches to engagement. [Integration](https://www.kingsfund.org.uk/audio-video/integrated-care-systems-health-and-care-act) and partnership working provide the opportunity for joined-up listening, not just joint services. Only by listening together can services work with the whole person and not define people by individual conditions, because people’s stories and experiences move beyond their experience of individual services. This means recognising that starting with people will make services more effective.

Statutory services and DPOs can draw on learning from how wider voluntary sector and health and care organisations are learning to collaborate – for example [on how to ‘partner’](https://www.kingsfund.org.uk/blog/2021/11/partnering-verb-voluntary-community-social-enterprise), build relationships, learn about each other’s roles and pay attention to power dynamics embedded in things like different access to resources, organisational security, etc. Leaders also need to show humility, recognising they do not hold all the answers.

There needs to be a tool kit or a formula for both local authorities and CCGs [clinical commissioning groups] and user-led organisations, which basically enables all of us to understand the value – because they're missing out so much. And that's what they're starting to realise with us, the value of the data and the intelligence we gather actually helps them build better services.
DPO chief executive

Another important aspect of getting disabled people’s voices heard is ensuring work on lived experience is influenced by people with lived experience. But we heard about statutory organisations hiring engagement professionals who didn’t have lived experience, and who don’t understand the importance of paying people for their time, hiring processes that didn’t involve DPOs those organisations usually worked with, or expecting DPOs to work for free. While small, grassroots DPOs might not expect to be directly involved in every conversation, having a trusted representative or route into discussions is important. There is a crucial role for a link between grassroots organisations and the statutory sector, but this needs to be held by people or organisations that have existing strong networks, and understand the unique contribution of grassroots organisations.

While this work is often best conducted at local levels there is a clear need for national bodies to set expectations, determine how they will get assurance from systems on what they are doing and lead by example. As NHS England and the Care Quality Commission develop their frameworks and regulatory models for ICSs, it’s important to think about how they will monitor these systems – both on how they have involved people and, more importantly, what steps they have taken as a result of that involvement. Disabled people should be involved in ensuring this accountability.

A final aspect of this is taking a flexible and solution-focused approach. As one discussion group participant described her experience of involvement:

They just basically looked at everything and rather than seeing the problem, they said OK, how can we work around this?

This flexible approach speaks to the change of mindset, not just of practice, that ran through everything we heard during this project. Disabled people need to be at the heart of health and care service design, and this requires health and care organisations and disabled people’s organisations to work better together. None of the issues raised in this work are new – and in fact in many ways things have got worse for disabled people in the past decade. Ensuring disabled people’s voices are heard requires constant attention, until it is thoroughly embedded in business as usual.

# Acknowledgments

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* the representatives from disabled people’s organisations, NHS and voluntary and community sector organisations that took part in our advisory group and provided crucial support and challenge throughout the project
* the people who took part in our group discussions and interviews, and everyone who attended our project workshop and generously shared their experiences and insights.

# Further reading

* [Understanding integration](https://www.kingsfund.org.uk/publications/understanding-integration-listen-people-communities?utm_source=in_text&utm_medium=website&utm_term=thekingsfund)
* [Lessons from the Wigan Deal](https://www.kingsfund.org.uk/projects/lessons-wigan-deal)
* [Developing place-based partnerships](https://www.kingsfund.org.uk/publications/place-based-partnerships-integrated-care-systems)

# Methodology

Our project explored what partnership working between disabled people and health and care systems looks like, and we tried to model partnership working as part of how we ran the project.

We convened an advisory group of DPO representatives, disabled people working in health and care, and representatives from NHS leadership to provide support and challenge to the work. The project team and the advisory group included a mix of people with and without lived experience of disability, health and care sector expertise. People also brought their lived experiences across a range of different backgrounds.

As a project team, we conducted a rapid literature review examining existing reports and research about disabled people’s involvement in health and care design and planning. We also engaged with disabled people, disabled people’s organisations, and NHS and local authority representatives through two focus groups and 12 individual or small group interviews. We also invited all participants, and several more DPO and NHS representatives, to an online workshop towards the end of the project to share and test our initial findings.

Additionally, at key stages – the start of the project, the end of the literature review, and after the online workshop – we asked our advisory group for advice and comment on what we had found and on our plans for the next stages. Our advisory group also acted as external reviewers for a draft version of this final output.

More than 50 people, including representatives from 15 disabled people’s organisations, took part in this project and contributed their insights and experience.

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