

# Nothing About Disabled People Without Disabled People

Working Together To Transform Public  
Services In Hammersmith & Fulham.

## Key Findings

Many say  
quality of life  
has  
gone  
down



Some feel they  
can't influence  
local decisions



Councillors &  
staff want to  
work  
better  
with  
disabled  
residents



## Recommendations

Take a  
human rights  
approach



Commit to  
coproduction  
(working together)



Skill up  
to  
work  
better  
together



Develop a  
communication  
strategy for  
Co-production

Strengthen  
Disabled  
Peoples  
Organisations (DPOs)



Make  
services  
deliver  
what disabled  
residents want



Develop a  
budget



Do  
independent  
monitoring

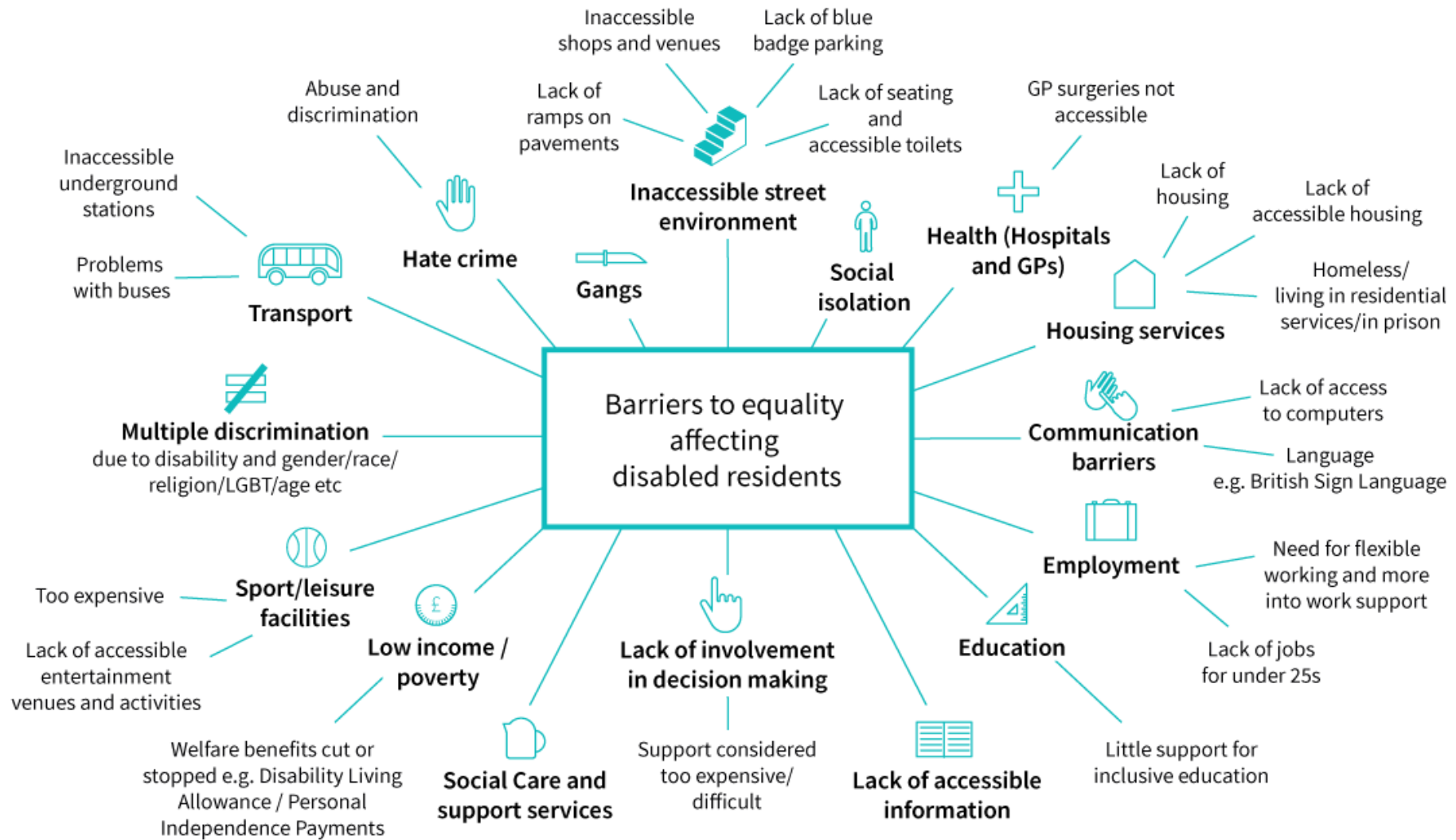


Report by the Disabled People's Commission  
Hammersmith and Fulham, November 2017.

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**A snapshot of the barriers reported by disabled residents in Hammersmith & Fulham to the Commission. Barriers were reported through a disabled residents survey and public events in 2017.**



## 2. Chair's summary

Tara Flood, Chair of the Disabled People's Commission

Discrimination and exclusion of Disabled people is not an inevitable fact. The barriers we experience are created by society.

We use the term Disabled people in this report to include ALL Disabled people with physical, cognitive, and sensory barriers, people with learning difficulties; Deaf people, deafened, hard of hearing people, mental health system users, and survivors, neuro-diverse people such as those with Dyspraxia, Attention Deficit Disorder (ADHD), Asperger Syndrome and Dyslexia, people with long term health conditions and people who self-identify. We mean Disabled people of all ages that experience barriers including Disabled children & young people with Special Educational Needs labels.

It is now unacceptable for other minority groups to be represented by others, for example a women's organisation run by men. However, we continue to be routinely represented by non-Disabled people and by organisations not led by disabled people.

We are also aware that as Disabled people we might be discriminated against for more than one reason. So, as a Disabled person, a black Disabled person might also be discriminated against because of the colour of their skin. Our approach to bringing about change recognises our common but also our different experiences of discrimination.

In many respects, this has been an easy report to write because it recommends what Disabled people have been calling for over many years – that we must be partners in the re-organisation of society and particularly decision making in everything that affects our lives. In the words of the international Disabled People's Movement – Nothing About Disabled People Without Disabled People!

For many Disabled people life remains, or is increasingly becoming, a complex experience of segregation from our non-Disabled peers. We experience limited life choices and opportunities, unmet personal and social care needs, isolation, unemployment, unsuitable housing, persistent poverty, abuse, and violence.

I agreed to chair the Disabled People's Commission on the understanding that removing our barriers locally was the priority. In the long term, we would hope to influence wider policy makers both regionally and nationally.

The Commission is made up of 10 Disabled residents of Hammersmith and Fulham. Disabled residents told us about the many different types of barriers that we still face. As a Commission, we decided the best approach would be to change the way we are involved in decision making.

We have taken a Social Model of Disability<sup>i</sup> approach to our work. We have also referred to the UN Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>ii</sup> and the Public Sector Equality Duty<sup>iii</sup> (PSED) (Equality Act 2010).

The Commission's recommendations are all about change to improve Disabled people's lives. We recognise that neither we, nor Hammersmith & Fulham Council can change everything that we would like, in particular, the central government policy decisions which currently affect us so drastically.

Therefore, our recommendations have focused on embedding 'co-production' (working together) as the vital ingredient required to deliver all the changes we suggest. Our intention is that all Disabled people are involved in decision making, including those furthest away from decision making, such as Disabled children, young people, and adults in institutions or those living in out of borough placements.

We recognise that Co-production can be a difficult word so this report sets out what we mean by co-production, how it will be designed by local Disabled people and the change that can be achieved when organisations, such as the Council, Health (Clinical Commissioning Group) co-produce ideas, policies, and services with Disabled people.

We have created a working definition of co-production:

*“Co-production (working together) means local Disabled residents are working together with decision makers to actively identify, design, and evaluate policy decisions and service delivery that affect our lives and remove the barriers we face”.*

The recommendations will all need to be implemented across all Council departments, as well as, community and other public-sector partners, to include all Disabled residents of all ages if we are to secure real and lasting change.

### 3. What needs to happen now - Recommendations

The Commission welcomes the clear commitment by the Leader of the Council to tackling inequality and discrimination. The Commission's recommendations build on the Council's good start in delivering on that commitment.

The Commission is aware that these recommendations focus on Disabled residents and Hammersmith & Fulham Council. However, if the recommendations are co-produced as we hope, they will affect how Disabled residents and many other organisations in the borough work together.

#### Creating a co-production culture

**Recommendation 1:** The Council to implement a human rights approach to its policy and service development, using the UN Convention on the Rights of Persons with Disabilities (UNCRPD) as the framework for change.

**Recommendation 2:** The Council adopts and implements a policy which commits the Council to working in co-production with Disabled residents.

**Recommendation 3:** The Council develops and implements an accessible communication strategy that promotes the development of Co-production across the Borough.

#### Training and development

**Recommendation 4:** The Council with the Co-production Hub develop a co-production support strategy and resource its implementation to skill up and build the capacity of Disabled residents, local Disabled people's organisations (DPOs), staff and Councillors to participate in the co-production of policy and service development.

## Service design and commissioning

**Recommendation 5:** The Council to co-produce a quality assurance and social and economic value framework, which will define the values, behaviours and characteristics of all service providers and organisations funded or commissioned by the Council.

## Resourcing Co-production

**Recommendation 6:** The Council analyses existing financial expenditure and resources on all co-production, engagement, and consultation activities with Disabled residents to identify current expenditure and then reconfigure to develop a co-production budget.

## Review support and funding of Disabled People's Organisations (DPOs)

**Recommendation 7:** Recognising the unique role, values, and authentic voice of Hammersmith & Fulham's Disabled peoples organisations (DPOs) and their network, the Council works with them to identify and agree a long-term funding strategy, which will ensure that local Disabled residents' rights are upheld, inclusion and equality advanced and that Disabled residents can lead on co-production.

## Independent Monitoring and evaluation

**Recommendation 8:** Carry out monitoring and evaluation of the implementation of the recommendations and associated co-production work to evidence the impact and share learning within and beyond Hammersmith and Fulham.

## 4. Message from Councillor Stephen Cowan

Leader of the Council for the London borough of Hammersmith and Fulham

Some years ago, when I was the borough's leader of the opposition, a resident kindly set out to educate me about the challenges she faces as a Disabled person and the difficulties Disabled people have in affecting change to national and local policies that have huge impacts on their lives.

I had understood disability to be an issue of discrimination and rights but those insights, and those of other Disabled people, gave me a more profound understanding of the need for Disabled people to take the lead in developing services and making us an inclusive society.

In 2014, after I became the Leader of Hammersmith & Fulham Council, we abolished home care charges, and were the only borough in the country to do so. We guaranteed funding for Independent Living Fund when it looked like the government might remove it and enjoyed a close working relationship with local Disabled people's organisations.

But we aspire to be the most inclusive borough and asked Tara Flood to chair a new independent Disabled Peoples' Commission to chart how we achieve our goals. I am therefore deeply grateful to Tara and all who worked so hard on the Disabled People's Commission. This work will make a major difference.



## 5. Disabled People's Commission – who we are and how we got started

On International Day of Disabled People in December 2015, representatives of Hammersmith & Fulham Council made a commitment to working closely with Disabled residents to make decisions about our support and services. As a result, we took the opportunity to have, we believe, the first local Disabled People's Commission in the country.

The purpose of the Commission was to "set in place a new way of doing things that sees Disabled residents, Councillors and officers and other organisations in the borough working together to build a culture that values and respects and advances the rights of Disabled people living in Hammersmith & Fulham where "Nothing About Disabled People Without Disabled People" is at the heart of this unique and diverse borough".<sup>iv</sup>

### 5.1 Who are the commissioners?

All ten DPC commissioners self-identify as Disabled people who experience a wide range of barriers in their daily lives and live in Hammersmith and Fulham. The Disabled People's Commission (the Commission) was set up to run from September 2016 with a plan to publish our findings and recommendations in the spring of 2018.

Below are photos of the ten commissioners and on the facing page are quotes from each commissioner about the barriers they experience.



**Tara Flood**



**Ali Buhdeima**



**Victoria Brignall**



**Jane Wilmot**



**Patrica Quigley**

**Hammersmith  
and  
Fulham  
Disabled  
People's  
Commission**

**The Commissioners**



**David Issac**



**Ramona Williams**



**Kate Betteridge**



**Martin Doyle**



**Mike Gannon**

## Barriers experienced by the Commissioners

"In the street non disabled people are not comfortable communicating with me".

"So difficult to get a sign language interpreter I often have to bring my brother".

" I am unable to use most public disabled toilets because they lack the space I need or do not have a hoist installed."

"People judge me because of the way I walk. They assume I am drunk because of my physical impairment."

"The Blue Badge bay outside my house isn't dedicated to me and I find I regularly have nowhere to park in our street due to the increase in cars, the pain and stress this incurs is hard to describe."

"I think one of the main barriers for me is, communication, and for me, that can come in all sorts of formats, lack of information, me being misinformed, basically people not listening or asking the correct questions."

"I tend to be patronised by people, I'm often talked down to because people make assumptions about my height and my ability to have an adult conversation."

"Small print, theatres, cinemas, TV or YouTube services without audio description or subtitles/captions."

"....the number of Underground stations that still do not have lifts, e.g. Parsons Green, Goldhawk Road, Putney Bridge, Ravenscourt Park etc. ... difficult to get information from Transport for London (TfL) on planned improvements in this area. ..."

"Council housing tried to place me in unknown areas, being blind means placing me in an unknown area will render me housebound".

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Hammersmith and Fulham.

## 5.2 Our approach to the work

The commission's work was in four stages:

Timing	Action
Stage 1: A review of relevant information	We looked at research and examples of co-production (working together)
Stage 2: Hearing from local Disabled residents and other people	The Commission ran three separate surveys to get a snapshot of what people thought: A Disabled resident's survey (see barriers p3) and surveys for elected Councillors and Council Staff.
Stage 3: public events and evidence sessions.	We held eleven meetings where we invited speakers to tell us about their experiences of decision making and co-production to understand what happens now in reality. We held three public events, including one for younger Disabled people.
Stage 4: The final report	The report sets out our findings and recommendations for change and it was accepted by the Council's Cabinet meeting in December 2017.

The Commission decided that the work would have a "Nothing About Disabled People Without Disabled People" approach to developing policy and services to try and ensure we are involved from the beginning at the ideas stage to bring about real change that will remove as many barriers as possible that prevent local Disabled residents in Hammersmith and Fulham from living as equal citizens.

The commission has taken a 'Social Model of Disability' approach to its work with a commitment to inclusivity and accessibility and has been guided in its work by the U.N. Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>v</sup>.

The United Nations Convention on the Rights of Persons with Disabilities, (UNCRPD) ratified by the UK Government in 2009, places a duty on the Government to promote the rights and equality of Disabled people. That duty

is also relevant to leaders of local authorities who have responsibility for governance and strategy at a local level, and should be using the UNCRPD as a framework for addressing the issues faced by Disabled people in their local area. The UNCRPD requires Governments (including local government) to:

*'(m) Recognize the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities...'*<sup>vi</sup>

The Convention enshrines in international law that Disabled people have human and civil rights and must be in the leadership of any activities that promote our equality as human beings and citizens.

Disabled people developed the Social Model of Disability to identify and act against Disabled people's oppression and exclusion. It was developed as a direct challenge to the models of disability that viewed disability as an individual, medical problem that needed to be prevented, cured, or contained; and/or as a charitable issue that viewed Disabled people as unfortunates who needed to be pitied and catered for by segregated, charitable services.

*"The Social Model frames disability as something that is socially constructed. Disability is created by physical, organisational, and attitudinal barriers and these can be changed and eliminated. This gives us a dynamic and positive model that tells us what the barrier is and how to fix it. It takes us away from the position of "blaming" the individual for their shortcoming. Therefore, the only logical position to take is to plan and organise society in a way that includes, rather than excludes, Disabled people."* Barbara Lisicki, 2013

We have also considered the Public Sector Equality Duty<sup>vii</sup> (PSED) (part of the Equality Act 2010) that flows through all decision-making. The PSED says that Councils and Health Authorities must when providing support and services aim to;

- Eliminate discrimination, harassment and victimisation and any other conduct that is prohibited by or under the Equality Act.
- Advance equality of opportunity between people who share a relevant protected characteristic i.e. Disabled person and people who do not share it.
- Foster good relations between people who share a relevant protected characteristic and those who do not share it.

## 6. Key findings

The findings mostly come from our surveys of residents, Council staff, local Councillors, and our public events, which give a snapshot of the current situation.

### **What Disabled residents told us about their lives now**

**Finding:** Local Disabled residents face numerous barriers on a day to day basis not faced by non-Disabled people and are often experiencing more than one form of discrimination. (Please see 'Barriers to equality affecting Disabled residents' map on page 3).

- 60% of respondents to our local Disabled residents' survey said that their quality of life has gone down/ or gone down a lot in the last 12 months

“...as a Disabled person, I am feeling less equal than I used to feel and certainly less valued by society generally.”  
(Disabled resident)

### **Experiences of being involved in decision making**

**Finding:** Disabled people are virtually invisible in positions in society where key decisions are made that impact on our lives

**Finding:** Local Disabled residents say there are low levels of shared decision making across the Borough.

- 46% thought that currently they cannot influence decisions in their local area' and a further 22% don't know

“I feel left out of all the decisions which have affected my life. I'm never informed about any changes and it makes my life much more difficult.”  
(Disabled resident).

“Any engagement is asked for at the last minute and is reliant on the goodwill of DPOs. Therefore, contributions are rarely of the highest quality as they are rushed and made by organisations that don't have time or funds to engage our members properly”.  
(Disabled People's Organisation).

**Finding:** Disabled residents would like to change our current ability to make decisions.

- 86% would like to be more involved in the decisions that affect them as a Disabled resident in their local area.

**Finding:** Council staff would like to work better with Disabled residents

- 94% of Council staff survey respondents wanted to involve local Disabled residents who get support and/or use council services in the council's work.

**Finding:** Over half of Councillors survey respondents said there was, 'room for improvement', in the way the Council develops policy in a way everyone understands.

### **What does this mean and what needs to happen next?**

**Finding:** Because of our lived experience local Disabled residents and Disabled people's organisations (DPOs) are the best people to identify how to remove the barriers that exclude us.

"Disabled people should be leading decision making not following"  
(Disabled resident).

- 100% of councillors who responded to survey agree that they would like to have specific objectives for improving how they work together with Disabled residents across the council's work.

**Finding:** To tackle removing Disabled people's barriers experienced in day to day living we need a resourced, systematic response which we don't currently have.

"Co-production needs to be done across the board and as scary as it sounds; it needs to be done in a big way." (Disabled resident).

## 7. Disabled people's lives now

### Disabled people's participation in decision making

“Nobody has ever asked me about who I am or what I need.” (Disabled resident)

In the U.K. twenty-one per cent (13.3 million) of people reported having an impairment in 2015/16, an increase from 19 per cent (11.9 million) in 2013/14. Most of the change over the two years came from an increase in working-age adults identifying a need. (16 to 18 per cent).<sup>viii</sup>

In the 2011 Census, 12.6%<sup>ix</sup> of Hammersmith & Fulham residents reported to have a long-term health issue or an impairment that limits their day to day activities (14.7% in 2001); this is lower compared to both London (14.1%) and England & Wales average (17.9%). 12.6% from the Census data = 22,998 from the total borough population at that time, which was recorded as 182,500.<sup>x</sup>

However, despite Disabled people being a significant part of the population, we are generally excluded when it comes to being in positions in society to initiate, lead and implement the policy decisions that affect our lives. We are often just 'consulted' 'involved' 'informed' about decisions and mostly not at all.

If, for example, the numbers of Disabled Members of Parliament (MPs) reflected the proportion of Disabled people in the UK's there would be about 136 Disabled MPs, but following the election in June 2017 there appears to be only six MPs who self-identify as Disabled people.<sup>xi</sup>

There is also strong evidence nationally that supports our local findings in relation to barriers that shows Disabled people are experiencing increasing levels of inequality, poverty, exclusion, prejudice, and discrimination. Life is getting a lot worse, not better, for the nearly 13 million Disabled people living in the UK<sup>xii</sup> including the 1.2 million Disabled people living in London.<sup>xiii</sup>

Nationally:

Though less than 20% of the population are Disabled people, or families with a Disabled member, Disabled people now make up half of all



people in poverty.

- 30% of households with at least one Disabled member were in “absolute poverty” in 2013-14, a rise from 27% in 2012-13.
- Disabled adults are twice as likely as non-Disabled adults to live in persistent poverty, defined as spending three or more years in any four-year period in poverty.
- Income, after housing costs, of Disabled Londoners fell by 29% between 2007/8 and 2013/13. This is double the drop for non-Disabled Londoners

## 8. Disabled people’s organisations (DPOs) as a response to the invisibility of Disabled people in decision making...

As the Commission has seen, despite the barriers and discrimination, there is not a lack of interest from Disabled residents and local Disabled People’s Organisations (DPOs) to inform us and to work on solutions.

Disabled People’s Organisations have led the way in shifting society’s understanding of disability (and Disabled people) from a medical or charitable model to a social model of disability and human rights understanding.

DPOs have also led the way in developing and delivering a range of practical support services that have improved the lives of generations of Disabled people such as self-directed support and personal budgets, the Independent Living Fund<sup>xiv</sup> as well helping to get key legislation passed including the Direct Payments Act 1996<sup>xv</sup>, the Disability Discrimination Act 1995<sup>xvi</sup> and the UN Convention (UNCRPD).<sup>xvii</sup>

If it is accepted that local Disabled residents are the best place to start to develop co-production then DPOs have an important role. The support for DPOs should mean a more co-ordinated approach to addressing the rising levels of exclusion, discrimination and inequality faced by Disabled people; strengthening and sustaining DPOs to deliver a range of work, most importantly to develop the capacity for co-production in decision making and policy development.

## 9. Co-production

### 9.1 Why is co-production (working together) the solution?

Our main priority as a Commission was to find a way to tackle the barriers experienced by local Disabled people in a strategic way that everyone could understand and be involved in.

The Commission has listened to many Disabled and non-Disabled people telling us about 'co-production' over the past year and we have looked at lots of information and examples of co-production. Also, we have heard a wide range of people who often say 'we don't understand what you are talking about. What do you mean co-production?'

*"Co-production is a difficult word for us. If it means doing and making things together it is right that we should be involved. We know what the best things to help us are"* (A group of people with learning difficulties participating in a co-produced project).

Our working definition of co-production is:

*"Co-production means local Disabled residents are working together with decision makers; to actively identify, design, and evaluate policy decisions and service delivery that affect our lives and remove the barriers we face".*

### 9.2 What co-production is not....

There is often a lack of understanding around the meaning of co-production and that different communities and organisations are at different stages of working together. Disabled people are rarely enabled to be involved at the beginning of important policy work that affects us, or as the initiators of ideas for policy change resulting in policy having limited impact on Disabled residents' lives.

Several people told the Commission that what was often described now as 'co-production' 'was the same old nonsense as before'.

A Disabled People's Organisation told the Commission:

*".... lots of people talk about co-production, some people think it is just about involving Disabled people at some point or just to launch the new policy or service".*

*“Quite often, we are asked to tick a box consultation, someone will come over to you and ask you what you need and how best they can help you, they will then go away and totally ignore all of that and do what they planned to do in the first place.” (Disabled resident)*

One Hammersmith & Fulham Council staff member told us:

*“I think for me in my department, you can talk about engagement, involvement and consultation, and then if any organisation goes and does what it wants to do anyway then that has been a wasted effort”.*

So, co-production is not just a tick box approach to involving people, taking a couple of people from each ‘relevant equalities strand’ or a “hard to reach” community<sup>xviii</sup> and bringing them all together in a room to talk about a policy or service and then feeling pleased that that part of the process has been completed. It is not enough.

### 9.3 What do other organisations say about co-production?

There are varying definitions of co-production and explanations of citizen participation, which have been produced by national organisations. Think Local Act Personal's (TLAP) Ladder of Participation,<sup>xix</sup> which is based on Arnstein's Ladder of Citizen Participation (1969), is used to show a ‘series of steps towards co-production’.<sup>xx</sup>

The ladder of participation shows co-production working as part of a continuum: as you go up the ladder, moving away from coercion at the bottom, power is shared more equally between citizens and decision makers as you get closer to co-production. (Please see the ladder on the next page).

**CO-PRODUCTION:**  
It's a long-term relationship!



**Co-production**

Co-production is an equal relationship between people who use services and the people responsible for services. They work together, from design to delivery, sharing strategic decision-making about policies as well as decisions about the best way to deliver services.



**Co-design**

People who use services are involved in designing services, based on their experiences and ideas. They have genuine influence but have not been involved in 'seeing it through'.



**Engagement**

Compared to the consultation step below, people who use services are given more opportunities to express their views and may be able to influence some decisions, but this depends on what the people responsible for services will allow.



**Consultation**

People who use services may be asked to fill in surveys or attend meetings; however this step may be considered tokenistic if they do not have the power to influence or affect change.



**Informing**

The people responsible for services inform people about the services and explain how they work. This may include telling people what decisions have been made and why.



**Educating**

The people who use services are helped to understand the service design and delivery so that they gain relevant knowledge about it. That is all that is done at this stage.

**Coercion**

This is the bottom rung of the ladder. People who use services attend an event about services as passive recipients. Their views are not considered important and are not taken into account.

Co-production is not our idea, the following definition of co-production was developed by NEF (New Economics Foundation) and Nesta (National Endowment for Science, Technology, and the Arts), which are organisations that have been working together to understand ideas about co-production and how it can work for public services:

*‘Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change.’<sup>xxi</sup>*

West London Collaborative is a community-led organisation, working across London ‘to co-produce better and braver solutions to local health and social care challenges’.<sup>xxii</sup> They also work in Hammersmith & Fulham. They bring people with lived experience of using the NHS and social care systems to work with professionals at all levels to remove barriers to people getting what they need from the current system.

They told the Commission what they had learnt from their experiences of co-production:

- How we get there with policy change and decision making is everything, because it is the how we get there that will change our community in the future.
- Most institutions, whether a local authority, or the NHS, are very hierarchical, to get anything done you must get up the chain and by its nature co-production is networked and non-hierarchical.
- We need to create reflective spaces and make time to reflect.
- If you don't evaluate what you have done you can't prove it so evaluation is important.
- Is about sharing power, it is about changing the role of citizens, all those important values are easy to lose.
- If we all know what we want – we must keep asking for it.

The Commission is not alone in promoting co-production (working together) with people who use services. The local NHS, Hammersmith and Fulham Clinical Commissioning Group (CCG) is moving in a similar direction. The CCG engagement and communication strategy 2017/2021 has an outcome of embedding co-production by April 2021.

## 9.4 Barriers to Disabled people taking part in co-production

Shaping our Lives, a national user controlled organisation and network outlined in its 2013 report 'Towards inclusive user involvement, Beyond the Usual Suspects'<sup>xxiii</sup> that often Disabled people are denied opportunities to get involved in policy development because of:

1. Equality issues
2. Where people live
3. Communication issues
4. The nature of impairments
5. Unwanted voices (from Disabled people that challenge how things are).<sup>xxiv</sup>

Their report highlighted two essential issues for Disabled people to enable co-production, both of which need to be in place. These are:

- Access – ensuring all Disabled residents have effective ways into organisations and decision-making structures.
- Support – for example, building confidence and skills, offering practical help and opportunities to get together so Disabled people are in a realistic position to get involved.<sup>xxv</sup>

## 9.5 Co-production – recognising residents for their time and experience

As the 'Towards inclusive user involvement' report says, 'It's important for Disabled people, many of whom are on low incomes with limited resources, that co-production is a zero-cost. This means that where Disabled residents have costs, these are recognised and either paid up front if necessary or paid quickly.' The report goes on to say, 'The principle of paying Disabled residents for their involvement has gained increasing official recognition in recent years. It represents recognition of our contribution and a valuing of our knowledge and expertise'.<sup>xxvi</sup>

Remember how poorly Disabled people are represented at all levels of decision making where non-Disabled people are rewarded financially in their paid roles developing policy and practice for Disabled people. A policy will need to be co-produced.

## 9.6 Making the economic case for co-production

For some organisations, the push to use co-production has been to create services that effectively meet Disabled people's needs; this is relevant to the economic case because services that do not meet needs are a waste of tax payer's money.<sup>xxvii</sup>

In 2013 the Social Care Institute for Excellence (SCIE) published its 'Co-production guide'.<sup>xxviii</sup> The Guide highlights that the issues around the costs of co-production are complicated because while there is evidence that it can reduce costs, it is inconclusive and varies between different organisations and projects. Some key points are:

- Co-production may lead to some costs being reduced and others increased.
- It may only be possible to know whether co-production is cost-effective by looking at things over a period. If it is cost-effective it will have reduced the number of inefficient, ineffective, and unwanted services.<sup>xxix</sup>

There are costs for training and costs for professionals in taking time to work more effectively with Disabled people. However, these activities can reduce cost if support and services are better and more effective.<sup>xxx</sup>

SCIE highlights that one of the key arguments on the economic benefits of co-production is from support/ services that also focus on prevention and early intervention, so people are less likely to need more expensive services, such as crisis and emergency services, later. SCIE says the clearest examples of this approach are in Nesta's 'People Powered Health' report.<sup>xxxi</sup>

Nesta's 'The Business Case for People Powered Health' report<sup>xxxii</sup> contains examples of co-production in six different NHS areas<sup>xxxiii</sup> as well evidence from a survey of the most reliable evidence of similar interventions in the UK and best practice globally'.<sup>xxxiv</sup>

According to Nesta's report the NHS in England could save over £21 million per average clinical commissioning group or £4.4 billion across England, if ways of working 'involve patients, their families and communities more directly'. The savings represent a 7% reduction in Accident & Emergency attendance, planned and unplanned hospital admissions and outpatient admissions; as a result, there is both a social and financial benefit.

Nesta highlights that investment is needed to achieve the reduction in costs.

According to the report the evidence is 'not yet unequivocal' and that in many areas the collection of evidence of the benefits has just begun. But Nesta believes:

*'There is enough evidence to support further scaling of those approaches which have been shown to make a qualitative and quantitative difference on the ground.'*<sup>xxxv</sup>

## 9.7 Co-production (working together) in Hammersmith and Fulham

The Commission's view is that the co-production we want to see in Hammersmith and Fulham will involve Disabled residents to a much higher degree throughout policy development and decision making. Not just one or two Disabled people isolated around the table. Supporting Disabled residents and Disabled People's Organisations is essential if we are to address our barriers and achieve real co-production.

This would also involve professionals/ elected officials, being honest with Disabled residents about barriers to achieving our aspirations and the challenge of making the best use of resources.

We think co-production is about real and lasting partnership working between the Council, other public and community organisations and Disabled residents. We are talking about working together, so that people really understand that we are trying to make change happen in terms of decision-making and policy setting at the council.

As mentioned previously the Commission is suggesting using the following description from what we have found out:

***Co-production (working together) means local Disabled residents are working together with decision makers to actively identify, design, and evaluate policy decisions and service delivery that affect our lives and remove the barriers we face.***

Our definition of co-production is based on the 'Nothing About Disabled People Without Disabled People' principle. It means that everything that



happens about Disabled people is involving Disabled people and led or co-led by Disabled people.

We believe the Council will need to co-produce a Co-production 'hub' to make our recommendations work. The hub would provide a physical space to coordinate work across the borough, support the practical development of co-production across Council departments, providing a source of support, problem solving and expertise.

## 9.8 Working together – real examples of change for Disabled residents in Hammersmith & Fulham...

In Hammersmith and Fulham, we have strong examples of local Disabled people initiating policy ideas, campaigning for their adoption, and working with local Councillors and others to make them happen:

- 'Homecare' - charging Disabled people for essential support to live in our own homes (Independent Living)

The campaign, by local Disabled people, to stop the Council from charging Disabled people for 'home care services' highlighted that the policy undermined Independent Living and was discriminatory i.e. charging a person for their support needs arising from an impairment or health condition.

After lobbying and a change in the Council's political leadership, the policy was abolished in April 2015. Ending homecare charging in the Borough sent a strong message to Disabled residents and demonstrated a policy change that was positive for all Disabled people, receiving that support, regardless of their background.

- Independent Living Fund

In June 2015, the government closed the Independent Living Fund (ILF) (a fund to assist people facing significant barriers to live in the community. local Disabled people, once again, had the idea that the Council should commit to protecting ILF support. The Council supported that idea and agreed to protect ILF support until the next local elections in May 2018.

- **Direct Payment Support Service**

Local Disabled people had been concerned for some time about the direct payment support service which has been run by the Council, since 2012.

Until 2012, the support service had been delivered by a local Disabled people's organisation (DPO) which was stopped without any consultation with people using the service. Since 2012 local Disabled people have been pushing for that decision to be changed. Last year the Council agreed to have a review of the support to people in the Borough who receive direct payments/ personal budgets. The review has been carried out by an independent Disabled people's organisation (DPO) based in Richmond and recommends returning the service to a DPO.

The Commission has been in discussion with the Council about working with residents to develop an Independent Living strategy, Independent Living is an important part of the UN Convention (Article:19) and includes disabled people of ALL ages.

These are three significant examples of local Disabled people successfully leading on policy ideas and it's the inspiration of such changes that the Commission believes we can now build on to achieve much more.

## 9.9 Co-production (working together) – first steps

Alongside developing an overarching co-produced approach to all council policy that affects Disabled people, we recommend that early consideration be given to co-production of specific policy areas and suggest three below.

### **Independent living**

As noted, the council has already commissioned a review of direct payment/personal budgets from a DPO. We would recommend that the current personalisation strategy be replaced by a co-produced independent living strategy for Disabled people in Hammersmith & Fulham. (to include disabled people of all ages).

### **Disabled people's housing**

Work in the Council on better housing for Disabled people is already underway. Moving forward, we recommend that this be formally co-produced.

### **Transition to adulthood**

The Council's Transition Taskforce has recommended the creation of a new, single Preparing for Adulthood team that brings together Children's Services and Adult Social Care to support young Disabled people from the age of 14 to 25. Implementation of the taskforce's report should be co-produced with young Disabled people themselves, as well as with their families and this work be incorporated into the Independent Living Strategy.

### **Plans to refurbish Hammersmith Town Hall and the surrounding area**

This work will be co-produced with disabled people to ensure that the plans are to the highest standard of inclusive design.

## **10. Conclusion**

Our work has highlighted how Disabled residents often feel no one is concerned about us or our lives, but that there is a desire amongst Disabled residents in the borough, to be more involved in decision making, supported by staff and Councillors, to make change together.

*"I think I am getting really excited about the whole notion of co-production, I think it covers everything. It is instrumental in changing culture" (Council staff member).*

Many Disabled residents are missing out compared to non-Disabled residents because of the cumulative effect of barriers that discriminate and exclude us, barriers, created by local, regional, and national government, either individually or collectively.

Overall from what people have told us we conclude that there are few examples of what we think of as Co-production. Most 'Co-production' activities do not consistently engage or attempt to engage Disabled residents.

Activities are often led by one or two professionals trying to involve residents some of the time, but Disabled residents are not being involved in a way that results in significant change to our daily lives. Professionals are often isolated, lacking in the support and resources to make working together a success. The lack of an engine for co-production change (Hub) results in an understandable drop in enthusiasm and co-ordination. No one organisation is to blame for that. The Commission also concludes that so far 'co-production' has gone nowhere near far enough to have any long-lasting impact on removing barriers for Disabled residents.

The Commission found evidence that some Council initiatives have adopted co-production approaches in some of their service redesign but this is not across all departments with many still using traditional resident/provider/service user engagement methods.

The co-production we are aiming for in Hammersmith & Fulham includes not just the co-design and delivery of services, but also ideas that start from Disabled residents and from campaigning and social action for what is often so obvious to us.

As co-production starts to develop, using the information the Commission has already collected and the collection of more specific data we will start to change our experiences of experiencing barrier after barrier.

Different public authorities have a legal and moral duty to address those barriers with Disabled people, given that we are not in the positions of power to make the necessary decisions and non-Disabled people are generally designing policies for us using our money and resources.

Diversity and inclusion are important values in co-production and citizenship. 'Disabled people', as we have already said share common experiences, but have their own identities, which may result in other experiences of discrimination. We believe that if we can implement our recommendations that the levels of inclusion and diversity of Disabled residents involved in decision making will increase.

The Commissioners value this unique opportunity, supported by Hammersmith & Fulham Council, to look at the way things are today for Disabled residents, not limiting what we could look or influence our conclusions. It has been a challenging year but a very important one for us and unique.

We are very excited by the prospect of turning the recommendations into action so that creative co-production can flourish. As a result of shared decision making Disabled residents will start to notice a more positive impact on our daily lives.

We hope going forward that we can create a momentum for change across the Borough. The Commission believes that without the full inclusion of Disabled residents the full inclusion of equality and equal citizenship are impossible to achieve - in other words... **NOTHING ABOUT DISABLED PEOPLE WITHOUT DISABLED PEOPLE**

# 11. Appendices

- Hammersmith & Fulham Disabled Peoples Commission recommendations with measures of success.

The next step will be to co-produce a short/medium/long-term work plan to achieve the Commission’s recommendations.

Recommendations	Measure of success
<p><u>Creating a co-production culture</u></p> <p><b>Recommendation 1:</b> The Council to implement a human rights approach to its policy and service development, using the UN Convention on the Rights of Persons with Disabilities (UNCRPD) as the framework for change.</p>	<p>(i) The articles of the UNCRPD and the social model of disability are being used as the foundation for the development of all policy with Disabled residents and are clearly reflected in council policies.</p>
	<p>(ii)The Council work plan includes work streams to embed a human rights and social model approach.</p>
	<p>(iii)Co-production principles and practice are included in all Council work for example departmental business plans, project review processes, e learning, changes to publicity, staff recruitment, training, professional development, and management.</p>
	<p>(iv) Co-produced review of all monitoring and evaluation mechanisms and internal reporting processes e.g. independent review by Internal Audit and review and challenge by Public Accountability Committees, supported by an external peer review to</p>

	maximise co-production learning and improving processes.
<p><b><u>Recommendation 2:</u></b> The Council adopts and implements a policy which commits the Council to working in co-production with Disabled residents.</p>	(i)The development of co-production with Disabled residents across all the Council’s work has been practically resourced and implemented.
	(ii) establish a co-production group of Disabled residents who work with the strategic director to turn the recommendations of this report into reality
	(iv) The hub has a strategic director who oversees the setting up and implementation of the co-production strategy and other recommendations in this report
<p><b><u>Recommendation 3:</u></b> The Council develops and implements an accessible communication strategy that promotes the development of co-production across the borough.</p>	Increased awareness of co-production demonstrating solutions to Disabled people’s barriers locally.
<p><b><u>Training and development</u></b> <b><u>Recommendation 4:</u></b></p>	(i)Changes in policy and services can be directly traced back to ideas initiated by Disabled residents through co-produced work.

<p>The Council with the Co-production Hub develop a strategy and resource its implementation to skill up and build the capacity of Disabled residents, local DPOs, staff and Councillors to participate in the co-production of policy and service development.</p>	<p>(ii) Disabled residents, local DPOs and the Council report and evidence increased levels of engagement in council activity and decision making.</p>
<p><b><u>Service design and commissioning</u></b></p> <p><b><u>Recommendation 5:</u></b> The Council to co-produce a quality assurance and social and economic value framework, which will define the values, behaviours and characteristics of all service providers and organisations funded or commissioned by the Council.</p>	<p>(i) Evidence that a co-produced quality assurance and social value framework is produced and being implemented by commissioning and procurement.</p>
	<p>(ii) Evidence the new quality assurance and social and economic value framework is changing the commissioning behaviour and/or outcomes from council contracts.</p>
	<p>(iii) Co-produced service specifications for key priority services for Disabled residents are developed and implemented through the council's grants, commissioning, and procurement processes.</p>
	<p>(iv) Contracts are developed and awarded that reflect co-produced specifications.</p>
	<p>(v) Review with Disabled residents existing contracts that are viewed by Disabled residents as creating</p>

	barriers.
<p><b><u>Resourcing Co-production</u></b></p> <p><b><u>Recommendation 6:</u></b> Council to analyse existing financial expenditure and resources on all co-production, engagement, with Disabled residents in order to identify current expenditure and then reconfigure to develop a borough wide co-production budget.</p>	<p>(i) A co-produced financial audit has been carried out on existing financial expenditure and other resources on all co-production, engagement, and consultation activities, including Resident Satisfaction Surveys with Disabled residents<sup>1</sup> across the council, health, and community sectors to ascertain levels of funding for consultation and engagement.</p> <p>Co-production budgets should be reflected in the Council's the medium term financial strategy (MTSF).</p>
	<p>(ii) The Co-production hub looks at the use of available resources to enable Disabled residents to lead on decision making.</p> <p>Resources will need to include staffing of sufficient seniority to co-lead the development and embedding of the Hub and its work across Council departments.</p>
<p><b><u>Review and funding of Disabled People's Organisations (DPOs)</u></b></p> <p><b><u>Recommendation 7:</u></b> Recognising the unique</p>	<p>(i) A long term DPO funding strategy is agreed with DPOs and implemented by the Council.</p>

<sup>1</sup> This includes services for people with impairments and long term conditions and special educational needs



<p>role, values, and authentic voice of Hammersmith &amp; Fulham Disabled People’s Organisations (DPOs) and their network, the Council works with them to identify and agree a long term funding strategy, which will ensure that local Disabled residents’ rights are upheld, inclusion and equality advanced and that Disabled residents can lead on co-production.</p>	<p>(ii) DPOs are an effective, independent, and authentic voice of local Disabled residents, as well as effective providers of essential peer run services</p> <p>(iii) The Council commissions DPOs to inform Disabled residents of their rights and assists Disabled residents to uphold and exercise their rights.</p> <p>(iv) Co-production activities will show that Disabled residents are leading on ideas and all elements of policy making and service development.</p>
<p><b><u>Independent Monitoring and evaluation</u></b></p> <p><b><u>Recommendation 8:</u></b> Carry out robust monitoring and evaluation of the implementation of the recommendations and associated co-production work to evidence the impact and share learning within and beyond Hammersmith and Fulham.</p>	<p>(i) Hammersmith and Fulham Council can evidence the impact of a co-produced approach to decision making and policy development with local Disabled residents; so the experience of resident led co-production can benefit other communities both locally and nationally.</p> <p>(ii) Learning is disseminated at a regional and national level with relevant policymakers and government to demonstrate what can be achieved.</p>

## Hammersmith & Fulham Disabled People's Commission (HFDPC)

What does success look like? Nothing About Disabled People Without Disabled People

<p>1. Co-production defined in an agreed accessible way that's easy for everyone to understand.</p>	
<p>2. A co-production strategy which prioritises local Disabled citizen's ownership of everything the Council delivers.</p>	
<p>3. Completing the agreed work plan and the content of Terms of Reference</p>	
<p>4. Active commitment to the DPC and adoption of agreed Co production strategy resulting in change of policies and implementation across the Council including from Cabinet and the Leader.</p> <ul style="list-style-type: none"> <li>4.1 Agreed commitments in the 2018 corporate plan.</li> <li>4.2 A commitment to work with Council staff on making sure implementation happens.</li> <li>4.3 Develop a commitment to partnership-working across different sectors within the Borough to promote co-production with Disabled people.</li> <li>4.4 Actively engaging local Disabled people / communities and partners, in developing the co design, development, commissioning of local support and services.</li> </ul>	
<p>5. Taking time to hear local Disabled people's voices, particularly those whose inclusion and views are not easily heard including through the surveys, public events and evidence provided.</p>	

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- <sup>ii</sup> <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>
- <sup>iii</sup> Section 149 of the Equality Act 2010  
<https://www.legislation.gov.uk/ukpga/2010/15/section/149>
- <sup>iv</sup> <https://www.lbhf.gov.uk/councillors-and-democracy/resident-led-commissions/Disabled-people-s-commission>
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- <sup>xii</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/600465/family-resources-survey-2015-16.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/600465/family-resources-survey-2015-16.pdf)
- <sup>xiii</sup> See 'Disability data tables' at: <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-201516>
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<sup>xxvii</sup> The Personal Social Services Research Unit<sup>xxvii</sup> summaries this approach as the *effectiveness* aim and the aim of *cost-effectiveness* in their report, *The Building community capacity: making an economic case* available at:

<http://www.pssru.ac.uk/pdf/dp2772.pdf>

The PSSRU defines Cost effectiveness re social care and support as: ‘... a system of care and support that has improved cost-effectiveness – from the available resources – is one that has secured better outcomes for people who use services or people who might otherwise have developed a need for such services’.

<sup>xxvii</sup> The evidence in the guide meets the requirements for NHS Evidence Accreditation.

<sup>xxviii</sup> [https://www.ndti.org.uk/uploads/files/Co-production\\_Guide51Fin.pdf](https://www.ndti.org.uk/uploads/files/Co-production_Guide51Fin.pdf)

The evidence in the guide meets the requirements for NHS Evidence Accreditation.

<sup>xxix</sup> [https://www.ndti.org.uk/uploads/files/Co-production\\_Guide51Fin.pdf](https://www.ndti.org.uk/uploads/files/Co-production_Guide51Fin.pdf)

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<sup>xxxi</sup> [https://www.ndti.org.uk/uploads/files/Co-production\\_Guide51Fin.pdf](https://www.ndti.org.uk/uploads/files/Co-production_Guide51Fin.pdf)

<sup>xxxii</sup> <http://www.nesta.org.uk/publications/business-case-people-powered-health>

<sup>xxxiii</sup> The 6 difference localities were: Leeds, Calderdale, Stockport, Earl’s Court, Lambeth and Newcastle).

<sup>xxxiv</sup> The survey evidence of similar interventions in the UK and best practice globally, included: the Co–creating Health Programme, Chronic Disease Self–Management Programme, Expert Patients Programme, Lambeth Living Well Collaborative, LinkAge Plus, Mental Health Care Improvement Initiative, National Refractory Angina Treatment Centre, Recovery Innovations, Service User Network, and Year of Care Programme.

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<sup>xxxv</sup> [https://www.nesta.org.uk/sites/default/files/the\\_business\\_case\\_for\\_people\\_powered\\_health.pdf](https://www.nesta.org.uk/sites/default/files/the_business_case_for_people_powered_health.pdf)

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## Thank you / acknowledgements

The Commission would like to express a huge thank you to:

The many Disabled residents and Disabled people's organisations of Hammersmith & Fulham that gave us their time and information about their lives.

Organisations and individuals that gave evidence at Commission meetings, from the voluntary and community sector, health, Hammersmith & Fulham Council, and national organisations.

Hammersmith & Fulham staff who provided the necessary support to make the Commission work and who shared their advice and knowledge, particularly the Policy & Strategy team. Also, the staff who participated, in our events and activities.

The Leader and Deputy Leader of Hammersmith & Fulham Council and other Councillors who supported our work.