Local Voices

Hearing the voice of disabled people in

Tower Hamlets

Full report

June 2013

Contents

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Other reports and formats available

This full report is aimed at a policy audience. There is also:

- A summary report for a policy audience

- a less formal summary report for a general audience.

- a statistical report that has over 100 pages of quantitative data.

Real can also provide accessible formats. Please contact us for more information.

Part One – Summary

1 Introduction

Since 2010 there have been a number of very significant financial and policy changes affecting disabled people in Britain. Under the coalition government, welfare benefits are being reformed with major implications for disabled people including tightening of eligibility thresholds. Pressure on the budgets of many public sector organisations has affected provision of social care and other services used by disabled people.

Understanding the implications of these changes on disabled residents will be key to assuring that Tower Hamlets Council doesn't lose ground on improvements made to equality for disabled people.

For this reason, Real was commissioned to support the council to better understand the concerns, views and aspirations of local disabled people:

- to inform their review of the previous Disability Equality Scheme

- to better understand disabled people's priorities for a forthcoming Single Equality Scheme; and

- to develop an ongoing model for consulting with disabled people

We called the project Local Voices. It builds on previous consultation and engagement work in the borough by Real and other organisations, including the council's previous Disability Equality Schemes reviews

We've conducted research over a five-month period. We've had over 300 participants at workshops and other activities, and nearly 1,000 pieces of information to help generate this report. Participants reflected the diversity of the borough, with people from a wide range of ethnicities, age groups and impairment types having their say.

This report describes disabled people's worries and concerns and how we can work together in the future to improve equality in the borough, particularly given the difficult economic environment.

2 Key findings

2.1 Life's not fair for disabled people

In the survey we did as part of the research there was a question about whether respondents thought life was fair for disabled people. Worryingly, more than half (55%) of survey respondents think life's not fair for disabled people, and only 20% agree or strongly agree that it is.

Unfortunately, this sets the scene for the rest of this report, with many people sharing negative experiences and concerns in many parts of life.

If so many people feel that life's not fair for them it's not surprising that they also think there is a long way to go before they can achieve equality with non-disabled people.

2.2 Overarching themes

We found the following overarching themes emerging time and again across the workstreams:

- Negative attitudes towards disabled people

- Inaccessible, poor information

- Lack of participation and voice

Disabled people felt very strongly about how these themes impacted their sense of self, their well-being and their ability to participate in society as equal citizens.

These issues mattered regardless of what services or subjects disabled people connected with Local Voices about and mirrored findings from earlier research. This suggests a worrying lack of progress in the borough or may highlight the difficulty of changing people's perceptions.

2.3 Topics of most concern to disabled people

Where disabled people spoke about specific services or subjects, their concerns covered:

- Welfare and benefits

- Social care

- Getting out and about

- Crime, anti-social behaviour and safety

- Health and healthcare

- Housing

- Jobs, volunteering and training

We've separated these topics into chapters within the report to make it easier for people responsible for different sectors/policy areas to understand areas of concern to them.

Within each chapter we summarise the main issues and give the relative priorities, set out an analysis of the points that were raised and the differences for different sub-groups, produce statistics and quotations from our research activities to reinforce the messages we heard, and outline the solutions that were proposed by local disabled people.

2.4 Prioritising people's concerns

Local Voices has gathered data on a wide range of concerns, with participants holding strong opinions on what the council and others can do to better support disabled people in the borough.

However, to deliver tangible improvements, we need some sense of what issues matter the most, so that resources (people, money and time) can be targeted in the most cost-effective and efficient way. This helps not only Local Voices, but the council and other partners who we'll be working with to address disabled people's concerns.

We also know that the depth of information in this report (and in the project) may not be needed by everyone. Some people are only interested in the research 'highlights', or the biggest concerns. It's important that we can offer an easy way for people to find these out.

Therefore, we developed a scoring system to state the relative priority level of disabled people's concerns. Priority scores can range from 1 – 9, although levels in this report range from 3 - 9. A level from 7 - 9 is considered very high. More information about how this was done is in '26 How the priority scores are calculated'.

A collated table of the concerns and their priority levels is shown on the next page. High priority scores are marked in red.

Each priority score is repeated in a grid diagram at the start of the chapter or section about that issue or concern.

Issues of concern

	Proportion	Volume	Impact	Priority
Welfare and benefits	2	3	3	8
Not having enough money	2	3	3	8
Worries about further benefit cuts	3	3	3	9
The impact of the 'bedroom tax'	1	3	3	7
Impact on mental health - overall	2	1	3	6
Impact on mental health - people with mental health conditions	3	3	3	9
Not enough information	3	3	2	8
Universal credit	2	1	2	5
Accessibility issues	2	1	3	6
Affect on people's self-worth	1	1	3	5
New assessment process	2	1	2	5
Not trusting the council to get it right	1	1	2	4

	Proportion	Volume	Impact	Priority
Social care	2	3	3	8
Valuing day and community centres	1	1	2	4
Fear of cuts – overall	2	3	3	8

Fear of cuts – people with mental health conditions	2	2	3	7
Fear of cuts – people with learning disabilities	2	3	2	7
Not getting enough support	2	2	3	7
Poor experience of agencies	1	1	3	5
Poor experiences of council social services	1	2	2	5

Getting out and about	3	2	3	8
Value of travel support - overall	1	1	1	3
Value of travel support - people with learning disabilities	2	2	2	6
Poor pavements and roads	3	2	2	7
Buses	2	2	2	6
Hospital transport	1	1	3	5

Crime, anti-social behaviour and safety	2	1	3	6

Health and healthcare - overall	2	1	2	5
Health and healthcare - older people	3	2	2	7

Housing	2	1	2	5

Jobs, volunteering and training	1	1	2	4

Overarching themes

	Proportion	Volume	Impact	Priority
Negative attitudes towards disabled people	3	3	3	9
Attitudes about disabled people	3	3	3	9
Perceptions of benefit claimants	2	1	2	5
Negative attitudes from public agencies	3	2	2	7
Attitudes of council staff	2	2	3	7
Hate crime and harassment	1	1	3	5

Inaccessible, poor information	3	3	2	8

Lack of participation and voice	3	2	2	7

2.5 The big picture

Disabled people are worried. There is a wide range of issues that are of concern. Some of them are unique to disabled people, and some of them are universal issues that are exacerbated by one's disability.

Many of the issues have been around for a long time and were identified in previous Disability Equality Schemes. It is therefore of some concern that more progress has not been made in some areas.

Added to this are concerns drawn from the current political and social climate. The current environment is relatively unique. There is national commentary indicating that wider austerity measures can impact disabled people disproportionately.

Certainly local disabled people felt they were bearing the brunt of the cuts. This has been made harder by a worsening of negative attitudes towards disabled people. Added to a narrative in some of the national media around "the deserving and undeserving poor", this made for an environment where most people felt that progress on equality is going backwards not forwards.

There was also a sense that different issues interplay with one another. For example:

- poor street environments made getting out and about so much harder, which added to social isolation and made the prospect of getting to and from activities (including shopping and work) more difficult

- social isolation and not being able to do basic "getting out and about" increased dependency on social services, and also had negative impacts on people's physical and mental health

- but because people felt social care was being provided at mere subsistence levels, there were really basic barriers to participating equally in society - things as simple as not wanting to meet people when you knew you smell, or not wanting other people to come and visit your dirty house

- people are very worried about the benefit changes, and in particular the impact of the bedroom tax, especially as many don't feel they have enough money to live on now

- yet they also said there was inadequate good quality, accessible housing to move to and address these challenges.

The unique environment, the interplay between issues and the sense that equality is reducing instead of increasing means serious, 'whole person' solutions are needed.

3 Key recommendations

3.1 Addressing disabled people's concerns

Local Voices is committed to showing participants that their views count and that the council is listening to what people have said. We'd like to work with the council to help them understand disabled people's priorities, and make changes that reflect our concerns.

We'd like the council continue to work with Local Voices to:

- Co-develop an action plan

- Report back to disabled people on progress

- Develop a new model for consultation with disabled people

More information about how this should be done is in '19 Supporting the council to address disabled people's concerns'.

3.2 Suggesting some actions

Throughout the project, disabled people have been forthcoming with ideas on how issues and concerns can be resolved. The Local Voices steering group has also offered options for what can be done.

These suggestions are not an agreed action plan. There is work to be done to understand what's possible and to explore other solutions for those issues not yet addressed. But, we've listed some possible solutions for each issue to give a flavour of disabled people's ideas.

Some of the actions are ready-to-go, others will need some discussion about resources and timeframes. Many involve disabled people coming together for support; others depend on organisations taking the lead. We recommend you read the full report to understand what is involved.

Following the reporting event, we'll bring these solutions together in an action plan, working in partnership with the council to create something realistic, relevant and flexible. This co-designed and co-produced approach will also be used to help build a strong, sustainable model for the ongoing consultation of disabled people in the borough.

The action plan will contribute to effective and sustainable change to making the borough better for disabled people, and empower disabled people to play more active roles in private and public life.

3.2.1 Welfare and benefits

- More and better information from the council

- Financial training and self-advocacy support

- Council initiatives to protect people from the impact of cuts

- Changes to government policy

- Campaigning

- Building peer support for information and empowerment

- Changes to the benefit assessment processes

3.2.2 Social care

- Services helping social care users find innovative and cost-effective ways to meet their support needs

- Commitment to adequately funded social care

- Involving service users in delivering improvements

- Evaluating current service quality monitoring systems

3.2.3 Getting out and about

- Repairing pavements

- Improving driver and passenger awareness

- Exploring council processes for travel support

- Linking with the Accessible Transport Forum

- Linking with HealthWatch to explore the options for hospital transport.

- Maintaining links with Transport For All

- Linking with TfL's Disability Advisory Committee

3.2.4 Crime, anti-social behaviour and safety

- More CCTV on estates

- Tougher action against anti-social behaviour

- Training for disabled people on how to stay safe

- Local Voices joins Community Safety Partnership Board

- Local Voices members train as hate crime reporting supporters

3.2.5 Health and healthcare

- More staff training about disability issues

- More cooperation between council and NHS on co-funded support

- Local Voices signposts people to advocacy or complaints processes

- Local Voices link with HealthWatch and other groups

3.2.6 Housing

- More research into dissatisfaction among residents

- Local Voices link with Tower Hamlets Homes' Future Leaders Project

- Link with housing services to develop user-led solutions

- Supporting information sharing and co-operation

3.2.7 Jobs, volunteering and training

- Research support to help disabled people find out about vacancies

- Help with job applications, interviews and testing

- Ensuring disabled people have enough support to keep their job

- More research to identify employment barriers and design solutions

3.2.8 Negative attitudes towards disabled people

- Better treatment of disabled people

- Promoting role models and positive stories

- Customer service and disability awareness training for council staff

3.2.9 Inaccessible information

- Using accessible communication channels

- Improving content and distribution to disabled people

- Local Voices partners with the council and other organisations to improve communication to disabled people

3.2.10   Lack of participation and voice

- Council working with disabled people better

- Disabled people being part of decision-making mechanisms

- Using democracy to make changes

- Increasing advocacy and campaigning

3.3 Integrating our findings into the Single Equality Scheme

The council is moving to a Single Equality Scheme, analysing people's experiences, autonomy and outcomes across the protected characteristics.

So that disabled people's concerns are taken forward into the new scheme, we've mapped disabled people's priorities onto the Equality Measurement Framework. The priorities are summarised below.

More information on the Framework and why and how we've used it, is in '21 Developing a universal analysis for the Single Equality Scheme'

3.3.1 High priority domains

- Standard of living

- Individual, family and social life

- Participation, influence and voice

3.3.2 Medium priority domains

- Physical security

- Productivity

- Self-expression and self-respect

- Health

3.3.3 Lower priority domains

- Knowledge and skills

- Legal security

- Life

3.4 Developing a new model for consultation with disabled people

Part of the scope for the project was "developing a model to increase the representation and involvement of disabled people in decision making, service design and scrutiny".

More detail about what's influenced our recommendations and why our solution is and will be effective is in '20.3 Recommendations for an ongoing model of consultation'.

3.4.1 Factors that have influenced the recommendations

There are a number of factors that have influenced our proposals for the model, as follows:

- Enthusiasm for Local Voices and being heard

- Consultation fatigue/fear/cynicism

- The importance of understanding the impact of cuts and isolation

- The practicalities of accommodating people's impairment and health conditions

- Recognising the support disabled people need

- Recognising diversity within disabled people

- Recognising other networks

- Independence from the council

- Demonstrating empathy and legitimacy

3.5 Recommendations for a new model of consultation

Our experience during Local Voices and when speaking with people about previous experiences, shows that no single approach can effectively involve disabled people in consultation and decision-making.

Instead we need to build a multi-faceted solution that:

- recognises the additional support many disabled people need

- develops confidence in the participants that their involvement and action is worthwhile, is listened to and makes a difference

- recognises the "whole person" of the disabled people involved

- acknowledges that different people will be willing and/or able to contribute in different ways, at different times, and to facilitate this.

- provides avenues to go further than just consultation, and be involved in co-design, co-production and co-delivery of solutions.

With this in mind, we make the following recommendations:

- Keeping the name "Local Voices"

- Ensure an evolving, supported steering group

- Connecting a wider network

- Collaborating with other fora and organisations

- Combining with activities other than just consultation

3.6 In summary

People are wary of the council not meaning what they say when it comes to consultation. There are also some unique considerations when consulting with disabled people if you want to properly involve them and reach all parts of this diverse constituency.

But if things are done differently, there is a unique opportunity to involve people more effectively, deliver more effective outcomes (thus saving money in times of austerity), and better serve a significant subgroup of the Tower Hamlets population.

4 How to read this report

This report discusses complex issues and ideas, but it's important to us that it's as easy to follow as possible.

The report is split into six separate parts, which group related chapters together. The detailed explanation of the research findings are in Parts Three and Four. In those parts, each chapter has:

- an overall summary of that topic

- an analysis of the information that we've come across, including if there are differences between datasets and/or sub-populations

- priority scoring for whole topics and, where appropriate, sub-topics

- an explanation of the issues people talked about - in almost all sections we give you detailed comments disabled people made at activities and in the survey; hear their comments in their words

- key statistics from the survey; and

- possible solutions to each issue.

Even then, there's quite lot of detail to understand. So, we've used three other tools to help.

4.1 Numbered headings

We've used a numbered heading style to clarify the hierarchy of the content. Because the structure is quite complex, we've included a full table of contents at the back of this report.

The most complex content in this document are the chapters discussing 'Issues of concern' or 'Overarching themes'. Here's a summary of the typical structure in those chapters:

Part X – Part title

X. Chapter title

X.X – Section title

X.X.X – Issue title

Sub-title

For example:

Part Three – Issues of concern

10. Getting out and about

10.3 The issues people talked about

10.3.1. Value of travel support

Travel training

Not every chapter goes into enough detail to use every heading level.

4.2 Displaying the quotes and quote sources

Many of the chapters have quotes from the project in them. We want to show what source the quote came from and the demographic information about that source. So, we show the quote as:

'Content of quote.' (Source – demographics of source)

For example:

'My carer can be late and making me late.' (LDPB – people with LD)

More detail about the sources is in '6 About the five workstreams'.

4.3 Priority grids

As explained in '2.4 Prioritising people's concerns', the research data has been analysed to produce a set of priority scores. As well as being summarised in the introductory section, we've put a diagram called a 'priority grid' at the start of each relevant section to show the score:

Proportion	Volume	Impact	Priority
1	1	1	3

You can read through the report, using the priority grids to work out how important each issue or theme is within the context of the whole project.

More information is in '26 How the priority scores are calculated'.

Part Two – The research activities

5 Introduction

We set up five research workstreams to gather original data from as wide an audience as possible:

- workshops

- discussion groups at community activities

- Your Say, Your Day event

- surveys

- social media activity

These workstreams were designed based on the best practice review from previous research. More information about this review is in '22 Local Voices phase 1 – research review and proposal'

Some workstreams were delivered in groups and at venues throughout the borough; others were with people one-on-one in their homes. People could be involved once in a single workstream or take part on an ongoing basis.

All the workstreams were designed to provide qualitative data. The surveys were also used to gather quantitative data.

6 About the five workstreams

6.1 Workshops

We ran 5 workshops at our offices in Jack Dash House, including a pilot. Each workshop was around 3 hours long.

To make the workshops accessible, we offered travel support, childcare, parking, alternative information formats and on-site personal assistance.

The workshops were attended by 48 people altogether, with a mixture of age, gender, ethnicities and impairment types. Of those who attended, 33 filled in the demographic monitoring forms, although not every question on the forms was answered. At least 25 people answered each question, so we have complete data on almost 50% of attendees.

With this in mind, the data shows that most of the workshop attendees were 35 or older with a fairly even split of men and women. 50% of attendees were white, whilst 18% of attendees were Black Caribbean and another 18% were Bangladeshi.

The majority of attendees (80%) were heterosexual, with 3% (1 person) identifying as gay and another 17% not wanting to answer the question.

Over half the attendees were Christians, with another 19% identifying as Muslim.

Most people were unemployed (60%) and most were also social housing tenants (69%)

People were asked about their impairment, and many indicated more than one condition. The most frequently reported impairments were physical disability, mobility issues, mental health issues and/or a long-term health condition. Many attendees also reported other invisible disabilities or a learning disability.

A more detailed breakdown of these demographics is in '24.1 Workshops'.

6.2 Community activities

Local Voices team members visited 11 existing community activities (eg forum meetings or coffee mornings) that involved disabled people or

people with long-term health conditions. At each activity, we ran a discussion group lasting about 1.5 hours.

Altogether, around 120 people took part in the community activities. The groups focused on people with particular impairments, as well as groups with particular communication needs, such as Bengali or Easy Read.

The demographics of community activities were recorded at the group level, rather than asking people to fill out forms. This was because the relatively small amount of time at each activity made it crucial to prioritise the group discussion over gathering statistical data.

As a result, we only know about the 'common denominator' of each activity's target audience. So, an activity may be focused on people with mental health conditions (for example), but participants may have other impairments.

Many of the groups were mixed – with a range of ages, genders, ethnicities and impairments. However, the project team took care to involve groups specifically for:

- Bengali and Somali people

- People with learning disabilities

- People with a mental health condition

More information about the demographics of the activities is in '24.2 Community activities'.

6.3 Your Say, Your Day

Real and Community Options co-delivered a day-long event as part of the ongoing programme led by and for mental health service users in Tower Hamlets.

This session of Your Say, Your Day (YSYD) focused on changes to benefits and housing. The event included information, advice and peer support. There was also an hour-long session when attendees split into four facilitated groups to discuss their concerns and work together to find solutions. Two discussion groups were in English, another had BSL interpreters available and the last was in Bengali.

Approximately 150 people came to the event, with a mixture of ages, ethnicities and impairment types. We collected demographic monitoring forms from 101 people. At least 70 people answered each question, so we have complete data on about half of the attendees.

There was an even spread of ages at the event, with a slight majority for people aged 41-50. There were slightly more women than men at the event and there were more Asian (41%) people than white (33%) or other ethnic groups.

The event was run by and for mental health services users. Many attendees also said they had a long-standing illness (27%) or physical disability (25%).

Altogether, 78% of people lived, worked or studied in the borough.

A more detailed breakdown of these demographics is in '24.3 Your Say, Your Day'.

6.4 Social media activity

We set up discussions on our Facebook and Twitter pages. People responded positively to posts linking to the Local Voices workshops, activities or surveys, but no-one got involved in debates or interactions. However, people used social media to tell others about our events.

Although we had high hopes of reaching lots of people electronically, in reality less people participated than we had hoped. We need to establish whether this is because of the way that we promoted Local Voices, or whether in fact it is because significantly larger numbers of disabled people don't have a computer or easy access to the Internet.

We didn't gather demographic data on social media users.

6.5 Survey

Alongside the other activities, we conducted a survey to give us quantitative and qualitative information. The survey was promoted to other organisations (asking them to distribute it to their clients and membership), and also promoted on Real's website and social media channels.

In addition to an online survey, we knew that many disabled people, particularly older people, do not have access to a computer or the internet. So, we conducted survey interviews over the phone too.

Local Voices partnered with Tower Hamlets Friends and Neighbours to connect with members of the 'housebound forum' and encourage them to complete the survey.

We tried to engage local employers and universities, but many felt that it wasn't relevant to them/their members. A useful learning point in exercises like this going forward will be to engage these other stakeholders at the design stage to get their earlier buy-in.

A total of 99 people took the survey. 61 or more of the respondents answered each demographic question within the survey.

Of the people who completed demographic information, over 60% of survey respondents were aged 60 or over, with 25% over 80. Two thirds of respondents were women. Two thirds were white people, with Bangaldeshi (23%) comprising the other main ethnic group.

One third of respondents rented from the council and a third rented from other social landlords.

For those who indicated their employment status, half said they were retired, which is logical given the age range of respondents. Over 19% of people were in full-time or part-time paid employment, but another 20% said their disability or impairment prevented them being employed.

The survey included people from all impairment groups, with the majority having a physical disability (67%). Many reported a long-standing illness or health condition (38%) and a quarter had a hearing impairment (which again is likely to correlate with the higher average age of the respondents).

An example of the survey questions is in 'Appendix 1: Survey questions'

A more detailed breakdown of these demographics is in '24.5 Survey'.

Part Three – Issues of concern

7 Introduction

In the following chapters, we tell you what disabled people said about the topics that concerned them most.

Because our project was user-led, participants set the agenda and chose the majority of the topics, although they were supported by us when we thought there might be gaps. Many of the issues people wanted to talk about were common to the majority of the activities. Some of them were specific to just some groups.

In the survey we asked people to choose priority issues of concern from a pre-populated list (see Appendix 1). The list covered in the survey was much wider than the topics covered in this part of the report, as not all of the issues/services were currently of concern to disabled people.

The topics covered in this part are:

- Welfare and benefits

- Social care

- Getting out and about

- Crime, anti-social behaviour and safety

- Health and healthcare

- Housing

- Jobs, volunteering and training

We've separated the topics into chapters to make it easier for people interested in different sectors/policy areas to navigate the report.

However, it's important to read all of the information contained in this Part 3 in conjunction with the overarching themes discussed in Part 4, as these themes are threaded through the comments. The themes are:

- Negative attitudes towards disabled people

- Inaccessible, poor information

- Lack of participation and voice

8 Welfare and benefits

8.1 Summary

The overwhelming majority of Local Voices participants were concerned about welfare reform, including changes to unemployment, disability and housing benefits.

Proportion	Volume	Impact	Priority
2	3	3	8

8.2 Analysis

Disabled people were worried about all aspects of welfare. Many were already struggling and, even though they felt they needed more information about the changes, they were predicting some significant consequences.

The 'bedroom tax' was a particular issue; people who understand the changes were panicked and even those who were still 'in the dark' about how the changes might affect them knew enough to worry.

For those who may have to give up their homes, the stress of moving and losing support networks could trigger mental health crises. There was also a sense that the tax ignored whether people might need space for medical equipment. For those who wanted to move or share housing, they felt there were barriers stopping them from doing this.

It's not just changes to levels of benefits that worried people, but changes to processes for payment. Although some people did mention the empowerment the direct payment of universal credit could bring, most were really stressed about being responsible for paying the bills.

These concerns were shared almost universally across the project and were especially strong for people with mental health conditions, who also predicted the gravest impacts. This is significant because the survey also showed that people with a mental health condition think benefits and housing services don't serve disabled people well. Given they have the highest levels of concern, the poorest opinion of relevant services and the most serious predicted outcomes, people with a mental health condition must be given proper support to cope with the changes.

People with a learning disability didn't routinely mention welfare and benefits during the project. This may be because many of this group have parents, carers or support workers managing their money for them, and it would be useful to explore these issues with those groups.

Older people tended not to focus on welfare reform much either, which is most likely the combination of having their pension-level incomes protected but also having more immediate concerns about their health and social care – both of which are likely to be publicly funded.

For those who are affected by welfare reform and for those who want to show solidarity, it's crucial that people find ways to resist as many changes as possible and/or cushion the impacts.

People were forthcoming with ideas for building resilience. Disabled people not only recognised the problem; they want to be part of the solution. Next steps range from council-led improvements to policies, information and support provision to user-led, grass roots campaigning and peer support.

8.3 The issues people talked about

8.3.1 Not having enough money

Many participants expressed concerns about not having enough money for essentials like food and energy bills. There was a sense that people were already struggling, and that further cuts may have dire consequences:

Proportion	Volume	Impact	Priority
2	3	3	8

'My income is £99 a fortnight. I have to pay for water, gas, electricity - where's my dinner out of that? I don't know where my dinner's coming from next. I don't know where to ask for help.' (Pritchard's – people with MH needs)

'I find it hard to live on £118 a fortnight. I can't live on it. My mum still helps me. Other people are getting into debt and losing their homes.' (BbBC – people with MH needs)

'It's hard to manage a healthy life with the money I get as benefit.' (Survey)

'When my body is cold I get severe pain, and I need to keep warm to ease the pain. I find it hard to pay for the heating and I have to take more medication to manage the pain.' (Survey)

8.3.2 Worries about further benefit cuts

Given people were already struggling, there were concerns that further reductions will affect people badly:

Proportion	Volume	Impact	Priority
3	3	3	9

'Without benefits, I can't go out, I can't buy food, I can't make friends.' (LDPB – people with LD)

'When I get money cut, my diet suffers and I put on weight - nutrition, health, socialising is going to suffer.' (Upbeat – people with MH needs)

'My benefits will be cut, but I'm already struggling to get by' (YSYD – people with MH needs)

'I'm worried that the benefit cuts will affect my living and make it harder as I'm disabled, I get extra help with normal everyday tasks because I can't do them myself.' (Survey)

'People are going to get so stressed out about money they're going to go on the rob.' (Workshop – mixed group)

'Some people, instead of dying of starvation, will go ahead and nick something' (Upbeat – people with MH needs)

8.3.3 The impact of the 'bedroom tax'

The bedroom tax was a consistent issue for almost everyone under 60 and for all impairment types except for people with learning disabilities.

Proportion	Volume	Impact	Priority
1	3	3	7

'The bedroom tax is social engineering that will move people further out of the borough.' (YSYD – people with MH needs)

'With rooms being taken away - where are they going to shove us?.' (Workshop – mixed group)

'We should keep families together, not split them up with the bedroom tax. It's very stressful.' (Workshop – mixed group)

'I'm worried about being split up through changes to housing benefits. It's a very tight knit community, family group. It's culturally insensitive.'(Sonali – Older BME people)

'I am concerned with being moved to a different location like the Midlands, where we have no ties to our family, friends or heritage.' (BWHFS – BME women with MH needs)

'The relocations between houses in the UK is similar to the trauma we have experienced in Somalia during the civil war, with the family breakdown.' (BWHFS – BME women with MH needs)

'I'm concerned about the bedroom tax and the need for disabled people to have extra space in their homes for a carer or to store equipment.' (Workshop – mixed group)

'I've got a health condition called haemophilia. I need to store my blood product in a separate fridge but there's no room.' (BbBC – people with MH needs)

'It's very stressful, the council asked me to take in a lodger to help with costs and I got very stressed at the thought of having a stranger in my house.' (Pritchard's – people with MH needs)

'I'm not happy with my choices for adapting to the bedroom tax. Renting out the room would not be okay with my family.' (Workshop – mixed group)

'Where are the one bedroom flats to move people?' (Pritchard's – people with MH needs)

'Why do housing officers offer options that aren't available? They said I should take a smaller home, and then when I agreed to start the process they told me there weren't any smaller flats in my area anyway.' (Workshop – mixed group)

8.3.4 Impact on mental health

There were particular concerns about how benefit cuts might impact on people's mental health generally, and particularly for people already with mental health conditions:

Overall score

Proportion	Volume	Impact	Priority
2	1	3	6

Impact on mental health – for people with mental health conditions

Proportion	Volume	Impact	Priority
3	3	3	9

'I'm getting so stressed about it all; my blood pressure is going whenever I talk about it. I can't switch off, I can't forget about it. I'm worried people are going to top themselves over this.' (Workshop – mixed group)

'These changes are described as a revolution, but that's not how it seems at the grassroots. It's not an improvement; it's a wholesale change that's scaring people.' (Workshop – mixed group)

'I still panic when I see a brown envelope coming through the door. It caused my last breakdown.' (BbBC – people with MH needs)

'The changes are causing problems for people, it's stressful to deal with and is affecting our mental health.' (YSYD – people with MH needs)

'I'm already in trouble with my landlord, now with less money they could come and knock at my door any minute and take me to jail for all of the arrears and money I owe. It's very frightening' (Pritchard's – people with MH needs)

'The changes in benefits is causing people to be stressed and make them feel they cannot express themselves the way they want to as they feel intimidated and worried they will lose money.' (Survey)

8.3.5 Not enough information

Many people were confused and didn't know where to go for information.

Proportion	Volume	Impact	Priority
3	3	2	8

'I don't understand why these life-changing decisions and changes are happening.' (Create – people with LD)

'How will the local authority pay the benefits? How will people on higher rate disability be affected?' (YSYD – people with MH needs)

'I'm worried about the confusion of benefits and housing. Everyone tells you something else.' (Workshop – mixed group)

'I'm not getting much information yet. I'm hearing bits from the news. I'll wait until it's closer to my changeover date, because the policies are always changing and something I am told today may not be true by the time I am assessed, which means I will get in trouble I didn't make.' (Workshop – mixed group)

'The majority of people don't know where to go for support or changes to benefits. There's not enough information on where to go for help, some people can't find these places on their own.' (Sonali – Older BME people)

'Law centres and advice centres have shut down. There's not enough help available and the ones open are very far away.' (Sonali – Older BME people)

'Social workers don't understand benefits, so they signpost clients to other places, which makes clients give up.' (Workshop – mixed group)

'I first found out about changes when I was at the bank.' (Workshop – mixed group)

I'm worried about the bedroom tax. What's happening? Will I have enough space? Will it stop my family visiting and staying with me? (Workshop – mixed group)

'I've heard about [the bedroom tax] it on TV and don't know why they're doing it?' (Pritchard's – people with MH needs)

'Who does [the bedroom tax] affect? Is it clear what it means?' (Workshop – mixed group)

'Bedroom tax' – what is that? I have no information.' (Sonali – Older BME people)

'We don't have any information on handover of crisis loans to the council. Lack of information about the changes. The only time we find out about them is when we come to this service.' (BbBC – people with MH needs)

'I don't get the correct information from the council. What is the universal benefit and when is it changing? Keep us up to date with any changes. Better information needs to be provided.' (Survey)

8.3.6 Universal credit

Some people thought universal credit's use of a single, monthly payment can help disabled people fit in with the way the economy works for non-beneficiaries and that this might help to remove stigma. For example:

'I think it's better that [the council] give [rent money directly] to the tenant so the landlord doesn't know and can't stigmatise against people on benefits.' (BbBC – people with MH needs)

However, most Local Voices participants and especially those with mental health needs were worried or confused by the changes.

Proportion	Volume	Impact	Priority
2	1	2	5

'My rent is paid in advance but universal credit is paid in arrears - how do they do this?' (YSYD – people with MH needs)

'I'm worried about universal credit - how will it operate, how will it affect us, who is accountable for the changes?' (Workshop – mixed group)

'Getting money every week was what saved me when I came out of rehab - could put £20 on the meter etc, I knew how much to spend. I don't know what will happen when it's once a month.' (Upbeat – people with MH needs)

'My payments might change to universal payments and this could make things complicated and I will struggle to manage my money.' (Survey)

'I'm worried about the benefit money (rent) being paid direct to individuals and not the landlord. Paying rent yourself is complicated and if I won't be able to pay rent, eviction will follow.' (YSYD – people with MH needs)

'People are worried about being given their own rent to pay - it's scary - everything's happening too quick all at once.' (Workshop – mixed group)

8.3.7 Accessibility issues

People mentioned problems connecting with essential welfare services due to accessibility:

Proportion	Volume	Impact	Priority
2	1	3	6

'Benefits letters are unclear and inaccessible - not Easy Read - so I ignored a letter, then my benefits got cut off.' (Workshop – mixed group)

'I'm worried that all the information is now on computers and older people are saying "what do I want with a computer at this time of life?" - they're worried sick they're going to have to rely on computers for their money.' (Workshop – mixed group)

'You need to access a phone to call people like DWP etc. These calls cost money on 0845 numbers.' (Upbeat – people with MH needs)

'If you want a crisis loan you have to get all the way to Hoxton and wait for so long and they only give you £14' (Pritchard's – people with MH needs)

8.3.8 Affect on people's self-worth

As well as being inaccessible, some people felt the processes left them humiliated:

Proportion	Volume	Impact	Priority
1	1	3	5

'To have to beg for the support I feel I need makes me feel even more useless than I already feel.' (Survey)

'The government's saying there are no jobs, then when you go to claim money they make you feel like shit and you end up feeling even worse.' (Upbeat – people with MH needs)

8.3.9 New assessment process

One of the biggest concerns was the medical assessments for claiming disability benefits. People were concerned about being manipulated and having their disability misunderstood. Many found the process stressful, and were critical of Atos (the company running the assessments).

Proportion	Volume	Impact	Priority
2	1	2	5

'I'm really worried about assessment, having to re-apply, I'm concerned about the possible outcome. I know too many people who are ill and have been told they are fit to work.' (Survey)

'If we make an effort to move about and try to do our best with our disability we get penalised. Do they want us to lie in bed all day?' (Sonali – Older BME people)

'Illnesses fluctuate, it's not a flat thing. But they take you at face value on that day.' (Pritchard's – people with MH needs)

'It's really unfair to have an office worker to assess us. It should be medical staff who understand disability' (Sonali – Older BME people)

'I always have to show my hands - show my disability - and I hate it. It's like a real inspection, like they've never seen anything like it. I'm conscious of it' (Workshop – mixed group)

'I'm worried about filling out disability allowance forms. I really fear that I won't get anything because of the cuts. So many people have handed in forms that have not been approved.' (Survey)

'Forms are really repetitive and so stressful to fill out' (Pritchard's – people with MH needs)

'Atos use tactics to trick people. They nearly lost me my flat. I could be dead. I hate Atos.' (Pritchard's – people with MH needs)

'Atos have no awareness of learning disability, or the difference between good and bad days.' (Create – people with LD)

'Atos work assessments are awful.There's no support to get [to the venue] and the people who do them don't understand disability.' (YSYD – people with MH needs)

8.3.10   Not trusting the council to get it right

Alongside the general fears of the changes, there was a specific desire to hold the council to account for its policy choices and to be able to complain if things went wrong.

Proportion	Volume	Impact	Priority
1	1	2	4

'I'm worried about accountability and complicity with the benefit and service changes. What is the council's complaints procedure and how can I complain to the mayor, cabinet or ombudsman?' (Workshop – mixed group)

8.4 Statistics from the survey

Money and benefits was the number 1 concern for 14% of respondents.

Men (19%) were more concerned than women (11%), under 60s cared more (22%) than over 60s (3%) and Asian respondents (12%) were more concerned than white people (8%).

10% of respondents thought council tax and benefit services weren't serving disabled people well, but this rises to 30% for people with a mental health condition

8.5 Some suggested actions

The initial suggested actions from the project are:

- More and better information from the council
- Financial training and self-advocacy support
- Council initiatives to protect people from the impact of cuts
- Changes to government policy
- Campaigning
- Building peer support for information and empowerment

- Changes to the benefit assessment processes

The wide range of suggested actions reflects the wide range of organisations that participants felt could help - national government, the council, support organisations and individuals themselves.

The Local Voices steering group also made suggestions where possible actions weren't identified during the activities.

The following sections show some of the ideas people put forward for each of the suggested actions.

8.5.1 More and better information from the council

'Council needs to send out more information on changes to benefits because there is a lot of gossip.' (Sonali – Older BME people)

'There needs to be training so staff are more knowledgeable about benefit changes. Why can't social workers learn more so they can tell us? We trust our good social workers and need their help.' (Workshop – mixed group)

'We could go to social workers for information about benefits, and the CAB.' (LDPB – people with LD)

'We need to be told about benefit changes before they are put into place so that we are not shocked when we do not receive what we need.' (Survey)

8.5.2 Financial training and self-advocacy support

'I need more support to cope with monthly allowance.' (YSYD – people with MH needs)

'The council should train us to live on our own, to handle bills /benefits /travelling /jobs /money.' (Workshop – mixed group)

'I need an advocate when my benefit gets cut. I'd like help to sort out the benefits.' (Workshop – mixed group)

8.5.3 Council initiatives to protect people from the impact of cuts

Local Voices is keen for the council to explore strategic options to address some of these concerns. The changes are government driven and we think that the council has some leeway over how to apply them.

For example, the council could choose to continue crisis grants or re-allocate funding from other areas.

The project has highlighted the significant effect these changes will have on people with a mental health condition, so policy work must prioritise this user group.

Care must also be taken to consider the experiences of people previously displaced by war and other trauma – for example many members of the borough's Somali and Bangaldeshi communities.

'People should be exempt from bedroom tax if you are willing to move to smaller place but council can't offer you one.' (YSYD – people with MH needs)

'The council should put money aside to protect bedroom tax.' (Workshop – mixed group)

8.5.4 Changes to government policy

'The rich should pay more tax – the poor are targeted – it all comes down to social engineering.' (YSYD – people with MH needs)

'The benefit amount should go up in line with the higher cost of living.' (Workshop – mixed group)

8.5.5 Campaigning

'What we really need to do is get a nationwide campaign going. These people are just going to walk all over us otherwise.' (Workshop – mixed group)

'Disabled people need to demand more support, to lobby and campaign together. Charities and service providers can help us get our message across (Workshop – mixed group)

8.5.6 Building peer support for information and empowerment

The steering group felt very strongly that peer-led support could be a crucial solution for the lack of information and for the disempowerment of disabled people. They think the Local Voices network could support a group of disabled people to run some workshops. This could start with an 'Atos workshop' so people who have been through the process help

others understand what's involved and perhaps the group can continue to meet as people make their way through the process.

8.5.7 Changes to the benefit assessment processes

'I want a doctor to examine me, not an office worker.' (Workshop – mixed group)

'Instead of having to go through it twice, make it all one application and one assessment. DLA should have stayed indefinite for those on it, rather than re-apply for PIP.' (Survey)

9 Social care

9.1 Summary

Social care was a key issue for Local Voices participants. It was the number one concern for survey respondents and was mentioned in almost all of the community activities.

Proportion	Volume	Impact	Priority
2	3	3	8

9.2 Analysis

The research presents a mixed picture for social care, with some services valued highly. However, social care was the worst performing service for survey respondents, and this flowed through to the activities, where many people reported poor agency care, issues with social services and inadequate levels of support.

Day or community services were valued highly. Many felt these services were crucial and worried that future cuts would jeopardise their well-being. This was particularly true for people with a mental health condition and for people with a learning disability.

Besides gathering people's opinions about centre-based services, the project discovered strong feelings about agency carers and to a lesser degree, LBTH social services. Service users described very poor experiences and many felt they didn't get enough support.

Most of the solutions for concerns about social care aim to maintain the good bits and improve the bad bits. Compared to some of the solutions found for concerns in other areas, these could be considered 'business as usual' approaches, rather than innovative. However, that may be all that is needed and innovation may come from how the council involves disabled people in making those changes.

9.3 The issues people talked about

9.3.1 Valuing day and community centres

People in day or community centres were particularly positive about the services they got and the benefits for their well-being:

Proportion	Volume	Impact	Priority
1	1	2	4

'I like chatting to people here - they are very nice to each other. They understand each other and understand our disabilities.' (Workshop – mixed group)

'Spending time with friends here stops me being bored.' (Workshop – mixed group)

'I was so depressed and isolated at home, cutting the centre would cost the council more money in the long run. It's very good to talk to people here.'(Sonali – Older BME people)

'We feel very happy to come here, it is our only escape.' (Sonali – Older BME people)

'My social worker suggested places for me to go because they were good enough to find out and apply for me. Before coming here, I was at home all day; it is so isolating and depressing.' (BbBC – people with MH needs)

'The centre gives people one-to-one sessions, takes us on holiday. We like the people and they do a good job. We have a long history there.' (Workshop – mixed group)

'I think the council is doing lots of good things like exercise classes. You might not be friends with everyone here, but you can talk. They think of everything.' (Workshop – mixed group)

People were keen for more funding to improve services and outcomes:

'Some more funding would be nice so we could fund more activities like exercise classes, improve our quality of life.' (Sonali – Older BME people)

'More funding to the day centre would make a huge difference to the lives of people here. The centre is already such an important place and focus for people' (Pritchard's – people with MH needs)

'We should have more funding maybe for a trip to the seaside.' (Sundial – older people)

'It would be good if the day centre had money for its own bus. We can't do as many outings as we like because the school kids use the bus too and get priority.' (Riverside – older people)

9.3.2 Fear of cuts

People were worried about how current levels of funding for individual's packages and other support services might be cut and what the impact would be:

Overall score

Proportion	Volume	Impact	Priority
2	3	3	8

Fear of cuts – for people with mental health conditions

Proportion	Volume	Impact	Priority
2	2	3	7

Fear of cuts – for people with learning disabilities

Proportion	Volume	Impact	Priority
2	3	2	7

It's not explicit in the quotes or survey answers, but people with learning disabilities and/or with a mental health condition were significantly concerned about the future of community centres. Again and again, the research team noted how crucial these centres are for supporting independence, creating peer networks, maintaining resilience and preventing crises amongst these two impairment groups.

'I'm worried about changes to personalisation, people are getting judged unfairly and losing support.' (Pritchard's – people with MH needs)

'With all the cuts, I worry that they'll pull the plug here.' (Riverside – older people)

'We feel very happy to come here, it is our only escape. Don't cut funds to the centre it's making big steps in our community to address disability.' (Sonali – Older BME people)

'I'm worried about the centre keeping the same services and staff.' (LDPB – people with LD)

'I was so depressed and isolated at home, cutting the centre would cost the council more money in the long run, it's very good to talk to people here.' (Sonali – Older BME people)

'I'm happy with the current support received but am concerned this may reduce due to austerity measures.' (Survey)

'I'm worried about cuts in social care budget. I'd like the council to take a better look into the needs of disabled people. They should make social care easily accessible for disabled people.' (Survey)

9.3.3 Not getting enough support

People were quite concerned that they were not getting enough social care support. Interestingly there was good insight on the knock-on effect this would have on other aspects of their lives, recognising the value of good social care not just as "meeting the essentials" but also being the building blocks for other outcomes such as good physical and mental health and personal safety.

Proportion	Volume	Impact	Priority
2	2	3	7

'I'm not getting enough support for my mental health.' (YSYD – people with MH needs)

'They won't even give me a support worker because they say I'm coping, but getting better is a process. You can't just have crisis management. There needs to be preventative care. They put me in a big state when they told me that.' (BbBC – people with MH needs)

'It's important that I get help to be independent - with food, holidays, travel and communication.' (LDPB – people with LD)

'I'm worried about going out in the evenings. There aren't enough staff at my home.' (LDPB – people with LD)

'We need more trips with services, cos boredom makes people want to kill themselves.' (Upbeat – people with MH needs)

'I'm not getting any help from social services. As I can go out they said I am not eligible for social care. I need home help and want to go to the day centre.' (Survey)

'My carers are always changing. They have less time to do everything in. I don't know what could be done.' (Survey)

'My support hours have been cut back. I'm finding it difficult to manage and my carer feels rushed.' (Survey)

'I find it hard to do my own cleaning and can't do it myself. I don't get support with it. It affects my mood to see my flat dirty and it makes me depressed to be in my house. I get offered anti-depressants but I'd prefer to actually have the support I need and a clean house to live in. Even an hour a week would help. But I am told I have everything that I am entitled too – why can the money that the antidepressants would cost not be used for paying for someone to clean my house?' (Survey)

9.3.4 Poor experience of agencies

People had low opinions of care staff/support workers provided through agencies, and little faith that something could or would be done about them.

Proportion	Volume	Impact	Priority
1	1	3	5

'My support worker finished with me and didn't even tell me. It broke my heart. They see you for the wages. It's pot luck.' (BbBC – people with MH needs)

'There are issues around escorts not helping patients to their doors. Escorts means door to door, and anything could happen if I'm not escorted to my door.' (Riverside – older people)

'Incompetent carers don't do their jobs'. (Riverside – older people)

'Agency carers have a difficult attitude, not sympathetic, don't listen.' (YSYD – people with MH needs)

'I don't complain for the fear of being victimised. When I spoke on the phone about my condition, [the staff member] turned really nasty.' (BbBC – people with MH needs)

'My carer can be late and making me late.' (LDPB – people with LD)

'Some carers are lazy – it's not a lack of training. The council doesn't seem to do anything about it. I'm also fed up of the high turnover of care staff.' (Survey)

9.3.5 Poor experiences of council social services

Some people reported poor working practices by social workers, or felt unsupported by the processes social services follow.

Proportion	Volume	Impact	Priority
1	2	2	5

'Staff change too often and this means less rapport. This affects our relationship and means there is less trust.' (Workshop – mixed group)

'Getting a good social worker is a lottery.' (BbBC – people with MH needs)

'When I called social services the line cut off and they didn't call me back.' (BbBC – people with MH needs)

'Social workers don't listen. They have too much to do and are overloaded.' (LDPB – people with LD)

'The social service should inform us when they're doing a review. They call it a 'visit' and so people are unprepared and don't have relatives present and so it's not done properly or fairly and they don't get to voice their concerns.' (Sonali – Older BME people)

9.4 Statistics from the survey

Social care was the top area of concern for survey respondents, with 25% of respondents saying they were concerned about it. This was particularly true for younger people with 60% of respondents (who identified their age) aged 60 or under saying social care was their

number one concern. It was also the issue of most concern to people with a physical disability (30%) and the first equal issue for Asian respondents (24%), alongside health and healthcare. Although social care wasn't named as the primary issue by any of the respondents who identified as having a mental health condition, 18.2% of this group identified it as their second area of concern.

In addition, 35% of respondents said social care fails to serve disabled people well, making it the second worst performing service. Men had a particularly poor opinion, with 60% including it in their list.

Social care was also the worst serving service for people with a physical impairment (49%), people over 60 (31%) and white people (30%).

9.5 Some suggested actions

The initial suggested actions from the project are:

- Services helping social care users find innovative and cost-effective ways to meet their support needs

- Commitment to adequately funded social care

- Involving service users in delivering improvements

- Evaluating current service quality monitoring systems

These suggestions were implicitly rather than explicitly suggested. People had strong feelings about the problems they were experiencing, and this combined with a sense of disempowerment to prevent constructive focus on the solutions.

Real's experience with personalisation means we know how important it is that social care users find innovative, cost-effective ways to meet their support needs. But, a commitment to adequately fund social care might be the best way to maintain and protect the services that people think work well.

Where issues are around the quality of care services, we think it would be good if services users could be involved in delivering improvements. We know from some of the client contact during the council's recent survey to all social care users that people are reluctant to complain

about services they rely on. This was borne out in this project with people saying things like:

'There has to be more faith in reporting home helps and better information on who to speak to when you're not happy with your care. You shouldn't be afraid of reprisals.' (Riverside – older people)

The Local Voices network can work with the council to evaluate current service quality monitoring systems to see if anything can be done to make people more aware of them and more confident of using them. There may also be a place for anonymous processes such as third-party reporting and mystery shopping.

10 Getting out and about

10.1 Summary

Getting out and about easily and safely was important to many Local Voices participants.

Proportion	Volume	Impact	Priority
3	2	3	8

10.2 Analysis

Being able to move from place to place is a fundamental element of independence and inclusion. Many disabled people rely on publicly-funded services to make this happen.

Although some services (such as TaxiCards) are appreciated, project participants feel badly served by poor transport services and poor quality local pavements.

Survey respondents (who tended to have mobility impairments) said that pavements were the worst performing service. Mobilty-related services like parking, Blue Badge, Freedom Pass, TaxiCard and community transport were also in the top 25% of services that respondents didn't think served them well.

Roads and pavements were the number 1 concern for survey respondents, with transport coming third. However, people with visual impairments rated transport as their number 1 issue - with many struggling to recognise the buses they need.

Issues with buses were also reported by a wide range of people at the activities and workshops, and the link between good travel and independence was particularly clear for people with a learning disability.

Feelings about these issues ran strongly throughout the project and one of the very first observations made during the project suggest this has been the case for some time:

'I'm frustrated that the same access issues have been around for years and nothing has been done to improve access and attitudes despite countless consultations.' (Workshop pilot)

With this in mind, we think it's important that some progress is made soon. Some solutions are within the council's power and Local Voices can help them to act quickly. Others solutions require longer-term work with TfL and other fora.

10.3 The issues people talked about

10.3.1   Value of travel support

People valued the travel support they already get, whether in the form of travel training or assistance with the financial costs of travel.

Overall score

Proportion	Volume	Impact	Priority
1	1	1	3

Value of travel support for people with learning disabilities

Proportion	Volume	Impact	Priority
2	2	2	6

Travel training

Travel training is a crucial way of helping disabled people get out and about. Although not obvious from the transcripts, it was a very popular service for people with learning disabilities. Many others mentioned how it helped them stay independent:

'I'd like training so I can go out more and be more independent. I need travel training and a mobile phone to stay safe. Otherwise my parents will be concerned about my safety while I'm out.' (LDPB – people with LD)

'I'm worried when travelling on my own about getting mugged and using transport. So I'd like help to travel by myself to visit friends all over the place.' (Workshop – mixed group)

'I want help to travel to friends on the bus. It would be good to have help to stay over for a friend's birthday, but I would need support.' (Workshop – mixed group)

Travel passes

'A lot of us get Freedom Passes, which is really good' (Pritchard's – people with MH needs)

'I like TaxiCard, Freedom Pass etc.' (Workshop – mixed group)

'I'm worried about losing my Freedom Pass and being isolated' (YSYD – people with MH needs)

10.3.2   Poor pavements and roads

More survey respondents said this service failed to serve disabled people than said so about any other service.

Proportion	Volume	Impact	Priority
3	2	2	7

'Kerbs are a problem because you can't see them. Some have been painted white at the edge, but they are rubbing off.' (Neighbours – older people)

'I walk with my pusher and I've had falls because the pavement is uneven. It would save the council money because we could go ourselves. I could go to the shops on my own. The one and only time it was good around here was for the Olympics, as soon as that finished the council couldn't care less.' (Riverside – older people)

'The only time we can go out is to the day centre. If there were better pavements we could go out more ourselves.' (Riverside – older people)

'Bumps in the road make it impossible to use a scooter.' (Workshop – mixed group)

'The council should put decent pavements in. The cracks make it hard to use a wheelchair.' (Survey)

'The pavements are not wheelchair-friendly. Sometimes I have to be in the middle of the road because of rough or narrow pavements.' (Survey)

'I'm worried about tripping over as my sight is poor and I can't see the uneven bits of pavement.' (Survey)

'Pavements and roads are cracking up. I have tripped up.' (Survey)

'Pavements are not well maintained on back roads when I'm using the scooter.' (Survey)

'Roads and pavements need to be improved - too many pot holes and uneven pavements that make people trip up.' (Survey)

'The pavements are not mostly wheelchair-friendly. Sometimes I have to be in the middle of the road because of rough or narrow pavements.' (Survey)

'I'm worried about tripping over as my sight is poor now and I can't see the uneven bits of pavement.' (Survey)

'You have to avoid the holes, you have to be careful.' (Survey)

'Pavements have holes, pavements not ready for wheelchair people; this needs to be fixed.' (Survey)

10.3.3   Buses

Although not accessible to everyone, buses were a vital source of transport for many. However, all too often small things or actions which could be avoided made bus journeys much harder than they needed to be.

Proportion	Volume	Impact	Priority
2	2	2	6

'The buses are very dangerous; I'm sliding all over the place.' (Riverside – older people)

'I hate the braking on the buses - drivers aren't taking care of people with disabilities.' (Workshop – mixed group)

'Buses don't stop. It's not feasible to get rid of request stops, but if there is someone there then buses should stop. They should also slow down when they get to the stop so people can see which number bus it is. (Workshop – mixed group)

'Because of my poor eyesight. I can't always read the bus numbers, which means I miss my transport and sometimes wait for a long time until the next bus comes along.' (Survey)

'Spaces are limited for wheelchair users, as buggies occupy the space. Should be wheelchairs first.' (Workshop – mixed group)

'My nearest station is a bus ride away and buses are often too full to allow for my wheelchair.' (Survey)

'Buggies and prams are in the way and I get upset when there isn't a seat I can sit on.' (Create – people with LD)

'I worry when there aren't any seats on buses.' (LDPB – people with LD)

10.3.4   Hospital transport
For those that needed arranged transport for hospital or medical visits, there was a low opinion of the effectiveness or efficiency of the service.

Proportion	Volume	Impact	Priority
1	1	3	5

'I take taxis to the hospital because hospital transport takes ages.' (Neighbours – older people)

'There are issues around ambulances not being available for appointments at hospitals. They don't care about us.' (Riverside – older people)

'I don't like the waiting time for hospital transport.' (Survey)

'There's a long waiting time for ambulances.' (Survey)

'I always have to wait ages for transport when I go to Moorfields for my eye appointment.' (Survey)

10.4 Statistics from the survey
17% of respondents said transport or roads and pavements was their number 1 issue of concern.

Most survey respondents chose roads and pavement services as the worst performing for disabled people – with 37% including it on their list.

This was higher for people under 60 (38% compared with 25% for people over 60) and for men (50% compared with 23% for women).

12% of people chose parking, 18% chose Blue Badge, Freedom Pass and TaxiCard and 20% chose community transport as services they believed did not serve disabled people well.

10.5 Some suggested actions

The initial suggested actions from the project are:

- Repairing pavements

- Improving driver and passenger awareness

- Exploring council processes for travel support

- Linking with the Accessible Transport Forum

- Linking with HealthWatch to explore the options for hospital transport.

- Maintaining links with Transport For All

- Linking with TfL's Disability Advisory Committee

We think improvements to pavements would be an effective and quick win for the council. Whilst there will be some resource issues to consider, changes would show Local Voices participants that their opinions have been heard.

It was felt that improved driver and passenger awareness would help. We know that TfL put a lot of resources into this area (eg the recent buggy user campaign partnered with Trailblazers), but perhaps more work is needed to find out why problems are still occurring.

Some council processes around mobility and travel passes might also need improving. Local Voices and Real will explore this further via the Accessible Transport Forum.

It's slightly more complicated to implement solutions for poor hospital transport, not least because this is one of the most expensive lines in the NHS budget as well as mostly outside the council's remit. However, as with other health-related concerns, Local Voices can work with HealthWatch to explore the options.

Real already liaises with Transport For All about TfL bus issues (including driver awareness). However, we could link with TfL's Disability Advisory Committee too.

The following sections show some of the ideas people put forward as part of the first two suggestions.

10.5.1 Repairing pavements

There was strong criticism of the state of pavements, and not just by people in wheelchairs:

'The council needs to repaint the kerbs so partially sighted people can see where they are going.' (Neighbours – older people)

'If the council want older people to have independence, then fix the pavements and roads. There also needs to be better lighting.' (Riverside – older people)

'The council should make the pavements better by dropping kerbs, repairing exposed tree roots and putting more bins out. The council needs to fix the potholes and make sure there are accessible routes around road works.' (LDPB – people with LD)

10.5.2 Improving driver and passenger awareness

Many felt that some of the problems could easily be dealt with by better training and/or attitudes from bus drivers:

'Bus drivers should be trained in disability. Perhaps we could get people with disabilities into the training sessions to talk to them, or do a video where we show them different scenarios. (Workshop – mixed group)

'If bus drivers were aware about disabilities like mine and spent time at the bus stop to make sure everyone got on then it would help.' (Survey)

'People need to know that spaces should be wheelchair first and buggies should be folded up.' (Workshop – mixed group)

There were also suggestions that request stops should be abolished. But even if that wasn't possible, it was suggested that it should be a requirement for the bus to stop at any stop where someone was waiting. In that way, people with slow mobility, or low vision, would have enough time to identify the bus number and/or get the driver's attention.

11 Crime, anti-social behaviour and safety

11.1 Summary

Crime was a relatively low priority compared to other issues. But in some areas, people reported that things were getting worse not better.

Proportion	Volume	Impact	Priority
2	1	3	6

11.2 Analysis

Crime limits people's feelings of security and their ability to participate safely and equally in society.

Issues relating to crime and antisocial behaviour were raised much more by survey respondents than they were by people at the activities. This may be because a higher proportion of survey respondents were older and/or potentially more housebound.

The surveys showed that older people, Asian people and people with mental health issues are particularly concerned about crime. People with learning difficulties also mentioned their concerns during the activities and workshops.

Throughout the project, people discussed anti-social behaviour, hate crime and harassment. Many were also concerned about theft or robbery. Some people had experienced these crimes, others were worried about being affected by these crimes in the future.

To avoid becoming victims of crime, disabled people suggested solutions they could implement themselves - including learning safety skills and using technology. There were also opportunities for Local Voices to make strategic connections to reduce hate crime and harassment.

Two facets of concern about crime have been explored elsewhere in this report. Some people felt that upcoming benefit cuts may actually lead disabled people to commit crimes – see '8.3.2 Worries about further benefit cuts'. The effect of worsening social attitudes about disability are

influencing hate crime and harassment and what can be done about it are explored in '16 Negative attitudes towards disabled people'.

None of the research participants commented on police or community safety officer's awareness of disability issues or suggested changes to specific services. Although crime was mentioned by a fairly small number of participants, this was still unusual given the pattern in other areas of concern. It would be good to know if the council (or Police) would like this gap to be explored.

11.3 The issues people talked about

Although crime, anti-social behaviour and safety were discussed by a few participants at the activities, they aren't high priority issues overall. The issue gained higher prominence in the survey responses. However, people with an interest in safety and in older or Asian people or people with a mental health condition or learning disability may wish to explore the issues raised by these quotes.

11.3.1   Anti-social neighbours

'I've had a very noisy neighbour for the past 14 years and it affects my health badly. I called the council and the environmental officers came out and said that they couldn't do anything without more evidence. It's an impossible situation.' (Pritchard's – people with MH needs)

'The council and community safety people should look into complaints about noisy neighbours. I'm taking heavy medication and have epilepsy. I feel like I'm targeted because I'm ill. The council say I don't have enough evidence. I've had to install my own CCTV.' (BbBC – people with MH needs)

'I'm worried about anti-social behaviour in my area and about anti-social behaviour and attitudes in the community.' (Workshop – mixed group)

11.3.2   Fear of crime

'I worry about my safety when I'm outside. My head hurts, my eyes are bad and I feel completely horrible.' (YSYD – people with MH needs)

'I don't feel safe. I'm worried about being mugged and being asked for money.' (LDPB – people with LD)

'I don't feel safe going out alone and feel vulnerable. I got attacked before.' (Survey)

'I am worried for the security of my bed-ridden husband and myself. This area has lots of crime.' (Survey)

11.3.3   Hate crime and harassment
'Hate crime is getting worse.' (YSYD – people with MH needs)

'I'm getting abused in my neighbourhood because of my mental health issues.' (YSYD – people with MH needs)

'I'm worried about harassment from my neighbour – they're not being a proper neighbour and treat me badly.' (LDPB – people with LD)

11.3.4   Benefit cuts will cause disabled people to commit crime
'People are going to get so stressed out about money they're going to go on the rob.' (Workshop – mixed group)

'Some people, instead of dying of starvation, will go ahead and nick something' (Upbeat – people with MH needs)

11.3.5   Not being taken seriously by services
There was one participant at a workshop who had reported to housing officers that not only were they regularly targeted for antisocial behaviour, but they thought it was because of their disability. They were told that they must just be imagining this, and no action was taken.

11.4 Statistics from the survey
Crime and safety was identified as the number 1 issue for 12% of survey respondents, and as the number 2 issue of concern for 9.1%. Although this makes crime and safety a relatively low area of concern, it's worth noting that older people, Asian people and those with a mental health condition had slightly higher levels of concern and a greater sense that crime and safety services were failing disabled people than others.

Nearly half of survey respondents disagreed/ strongly disagreed that disabled people were safe from harassment and hate crime and only 30% agreed they were safe.

Within each gender, age and ethnicity groups, it was men, people under 60 and Asian people who most tended not to agree that disabled people were safe.

Amongst different impairment groups, disagreement was particularly high for people with visual impairment (55%), people with learning disability or cognitive impairment (80%) and people with a mental health condition (87%).

Overall 28% of survey respondents believed crime and safety services did not serve disabled people well, making it the fourth worst-performing service. People with a visual impairment were particularly critical, with 25% saying it fails disabled people.

11.5 Some suggested actions

The initial suggested actions from the project are:

- More CCTV on estates

- Tougher action against anti-social behaviour

- Training for disabled people on how to stay safe

- Local Voices joins Community Safety Partnership Board

- Local Voices members train as hate crime reporting supporters

One participant summed up the solutions nicely:

'We need bigger awareness about crime prevention, more CCTV in estates and tougher actions against anti-social behaviour.' (Survey)

Other participants echoed these ideas:

'We need CCTV cameras.' (Survey)

'I think there should be training for disabled people on how to stay safe. As a disabled person, I feel more of an easy target.' (Survey)

Also, it's important that any "culture of disbelief" in relation to disability hate crime is tackled through appropriate training, including all staff who interact with the public.

Real was recently invited to join the Community Safety Partnership Board, particularly to help reduce hate crime and harassment. Someone from the Local Voices network could be delegated as Real's representative, and connect with network members to identify solutions.

Real also provides a third party hate crime and harassment reporting service, although our capacity has been limited by staff resources. Some Local Voices network members could be trained as volunteer supporters and the service could be expanded.

12 Health and healthcare

12.1 Summary

Overall, health and health care was a significant priority for survey respondents (who tended to be older). However, it was a lower priority issue for most other groups.

Overall score

Proportion	Volume	Impact	Priority
2	1	2	5

Health and healthcare – for older people

Proportion	Volume	Impact	Priority
3	2	2	7

12.2 Analysis

People's comments about health and healthcare tended to be informed by personal experiences and described at the individual level. This was unlike welfare, housing and social care, where participants described not only the impact on them, but the implications for the wider community. However, the value of Local Voices is that it can pull individual comments together and explore patterns.

People didn't raise many positive comments in general, but some people did report positive experiences about healthcare:

'I am treated well at the doctor.' (Create – people with LD)

'I have no worries with GP/dentists etc' (LDPB – people with LD)

However, most people who commented about health and health care were reporting a bad experience or negative issue.

It was interesting to note the wide range of complaints people were making – there's a sense that dissatisfaction is widespread and touches many areas.

Local Voices can help with signposting for individual solutions. Where patterns emerge or problems are more systemic, we can work strategically and with partners to achieve larger scale change.

12.3 The issues people talked about

Because concerns about health and healthcare were mostly only reported by older people in the survey, they aren't a high priority issue overall. However, people with an interest in health or older people, may wish to explore the issues raised by these quotes.

The issues were quite broad ranging, but the following sections show that they can be grouped. They are fairly self-explanatory.

12.3.1 Poor experience of health services

'I was in hospital and I was left in soiled sheets and absolute fear for an hour and they put in a shoddy hip replacement. Now where do I go? (Sundial – older people)

'I had a bad experience of the hospital. There's a shortage of staff, the staff are poorly trained and the wards are dirty. Different teams don't talk to each other.' (Survey)

12.3.2 Poor service due to age

'Once you pass a certain age, they don't really want to spend money on you.' (Survey)

'I feel like I'm being denied an operation because of my old age.' (Survey)

'Older people get a poorer service than younger people.' (Survey)

12.3.3 Concerns about staff attitudes, awareness and skills

'Doctors should talk to us not around us; we can understand.' (LDPB – people with LD)

'Medical staff should have an understanding of Makaton.' (ELCE – people with LD)

'NHS staff need to learn about disability, so they will be less rude.' (Create – people with LD)

'Medical professionals don't seem to understand how debilitating mental health issues can be.' (Pritchard's – people with MH needs)

'I want to see a better understanding by the authorities of the sick people that they are helping.' (Survey)

'Doctors do not listen to patients or take them seriously, which results in further complications in health.' (Survey)

'I've found staff at outpatients, at the London Court and Mile End terrible and suggest better training.'

'I am concerned about the state of hospital services – they have poorly trained staff.' (survey)

12.3.4   Cuts to services
'Hospitals are closing and emergency wards are shutting.' (Workshop – mixed group)

'The NHS needs to keep this gym open. If they cut this off it's like cutting off their right hand. It's important to have the trained staff because they give good advice around disability access at the gym, which has a great impact on my overall performance. If you make cuts then people's health could deteriorate.' (Survey)

'I want the NHS to ensure the GP surgery and dentist remain open.' (Survey)

12.3.5   Waiting times for medical attention
'I am concerned that it takes long time to see a doctor. Less waiting times would be very good.' (Survey)

'I want to see doctors when I require one, but I don't get an appointment in time.' (Survey)

'The length of time it takes to get to see your own doctor bothers me.' (Survey)

'Waiting times have increased, this means I stay sick and have difficulty getting around.' (Survey)

'I've experienced big delays in getting physio at home.' (Survey)

12.4 Statistics from the survey

Health was the main concern for 21% of survey respondents – making it the second largest issue of concern.

Health was the main concern for men (31%), for people over 60 (40%) and for white people (30%), and was the first-equal issue for Asian people, with 24% saying it is their main concern (alongside social care).

It was also the biggest concern for respondents with a mental health condition (4.7%), with a hearing impairment (42%) and with a long-standing illness (38%). As healthcare isn't run by Tower Hamlets Council, we didn't include it in our list asking people which services didn't serve disabled people well.

12.5 Some suggested actions

The initial suggested actions from the project are:

- More staff training about disability issues

- More cooperation between council and NHS on co-funded support

- Local Voices signposts people to advocacy or complaints processes

- Local Voices link with HealthWatch and other groups

These suggestions were implicitly rather than explicitly suggested. People had strong feelings about the problems, yet this combined with a sense of disempowerment to prevent constructive ideas for solutions.

However, Real and the Local Voices steering group have experience with these issues and can provide some direction for the next steps. We think suggested actions could be more service-led solutions such as increased staff training and improved processes for delivering jointly-funded care - rather than disabled people making change themselves. Local Voices can work with the council and the NHS to find sustainable and effective actions.

Where issues are individual and need immediate resolution, the Local Voices network will signpost people to advocacy or complaints processes. Where there are opportunities for more strategic solutions (eg training) Local Voices will link with user groups like HealthWatch.

13 Housing

13.1 Summary

There were serious concerns about changes to housing benefit, and this element is dealt with in '8 Welfare and benefits'.

Outside of those highly topical benefit changes, other housing concerns had a fairly moderate priority for participants.

Proportion	Volume	Impact	Priority
2	1	2	5

13.2 Analysis

Most of the non-benefit-related housing concerns were raised by older people and related to accessibility, poor housing's effects on their disability and issues with overcrowding. Many of this group were unhappy about housing services - older Asian people in particular felt that disabled people's needs are not being served.

Many of the solutions would involve policy or process changes and it's likely more research is needed. The Local Voices network can bring agencies and users together to explore issues and ideas.

13.3 The issues people talked about

Many of the issues reported are universal. But there was an extra dimension for many disabled people, with poor quality or inaccessible housing exacerbating people's impairments, or their impairment making the underlying issue worse.

13.3.1   Accessible housing

'We need more, more accessible housing because people are getting older and need ground floor flats etc. There's not enough accommodation that has wheelchair access.' (Workshop – mixed group)

'We need more social housing to be built for disabled people.' (Survey)

'I'm not getting appropriate housing for my disability needs.' (Survey)

'It's been a long waiting time to be rehoused. There's not enough support for disabled people. The bidding website is hard to navigate and does not inform people if there is a house available.' (Survey)

13.3.2   Housing conditions and disability

'When they choose housing for disabled people they give out housing that is sub-standard. They offer downgrade properties. When I first got my property there was a lot of damp and there was something on my floor which came onto my leg and was very itchy.' (Pritchard's – people with MH needs)

'I have an issue with my housing, I have lived in this house for 13 years it's very cold and damp. The council is not doing a lot to relocate me.' (Survey)

'There is a lack of understanding of disability especially when it comes to needing repairs to be completed around a disability and especially mental health.' (Survey)

'Housing repairs are hard to get and the work is not done promptly.' (Survey)

'I am upset by the length of time it took to get work done on my house after my accident. The accident left me wheelchair-bound.' (Survey)

13.3.3   Overcrowding

'I have 6 children and I'm disabled. We live in a 2 bedroom flat. The children sleep in one room and my elderly mother sleeps downstairs.' (Sonali – Older BME people)

'Small apartments mean detrimental effects on the family. My 1-year old and 9-year old cannot share a room, as it results in fights.' (BWHFS – BME women with MH needs)

'My elderly mother has moved into the living room. She has severe sight issues. The house is really crowded. It's affecting my life and health. I had to split up from my girlfriend.' (BbBC – people with MH needs)

'I'm annoyed about overcrowding – I need a bigger property.' (Survey)

'Houses aren't offered to [disabled] people who need more space.' (Survey)

13.4 Statistics from the survey

Housing was a main concern for around 10% of survey respondents, however 15% of people with a visual impairment said it was their biggest concern, along with 20% each of people with mental health needs or who had a learning disability.

According to the survey, housing was the third worst performing service. Asian respondents were particularly critical, with a staggering 71% saying it fails to serve the needs of disabled people.

Among respondents with a mental health condition, housing was the most identified service for not serving disabled people well, with 50% of respondents with a mental health condition including it in their list.

13.5 Some suggested actions

The initial suggested actions from the project are:

- More research into dissatisfaction among residents

- Local Voices link with Tower Hamlets Homes' Future Leaders Project

- Link with housing services to develop user-led solutions

- Supporting information sharing and co-operation

It's clear that disabled people feel poorly served by housing services, with some groups in the borough holding particularly critical views. However, more work needs to be done to explore these issues, as clear pathways for improvement weren't evident during the project. So, these suggestions were implicitly rather than explicitly suggested

The Local Voices network can link with agencies to develop strategies and improve processes to better support disabled people. For example, we could work with the Tower Hamlets Homes' Future Leaders Project trying to engage with hard-to-reach and dissatisfied groups.

It's possible that housing services could be clearer about whether disabled people can resolve some of these issues themselves. So the network can also support information sharing and co-operation.

14 Jobs, volunteering and training

14.1 Summary

Jobs, volunteering and training were not identified as priorities for Local Voices participants.

Proportion	Volume	Impact	Priority
1	1	2	4

14.2 Analysis

Only one survey respondent indicated any concerns about employment, and hardly any workshop or activity participants had comments on the issue.

Those who did comment reflected on the lack of available jobs. Several unemployed survey respondents said that their disability or impairment prevented them from getting a job. People didn't comment on study or training.

The people commenting on this topic were unemployed or had unpaid roles. There were disabled people who had paid jobs and students participating in many of the project workstreams, so it was a shame not to have more comments from them on this issue.

However, we did ask people what was of concern to them. It's possible that other issues were more pressing (eg benefit changes) and so more long-term issues such as barriers to gaining skills and employment were not at the forefront of people's minds.

People tended to focus on issues rather than solutions.

Local Voices network hopes to increase our reach amongst people who work and/or study in the borough and this will give us a better understanding of the topic. Even just knowing more about what solutions are already working for these groups will be a useful start. We think there should be some more targeted, follow-up work on this topic.

14.3 The issues people talked about

Jobs and training wasn't a high priority issue in this project. However, data from the project is described here for those readers who are interested in this area.

14.3.1   Lack of jobs

'We can't get jobs. There aren't any out there!' (Upbeat – people with MH needs)

'I don't go to work because there's no jobs.' (Workshop – mixed group)

'Where are all the jobs?' (Workshop – mixed group)

14.3.2   Jobs support independence

'If I lose my job, I lose my independence.' (LDPB – people with LD)

14.3.3   Need for support

'My mental health has good days and bad, so how can I get accessibility into appropriate employment?' (YSYD – people with MH needs)

'Advisors in the JobCentre can help us get jobs. But, we need advisors who understand disability. (LDPB – people with LD)

'A disability employment advisor could help me back into work.' (YSYD – people with MH needs)

'We can need connections and networking support. We need help to get that first job to show that we're reliable.' (Upbeat – people with MH needs)

'The council should train people on speaking up, having confidence' (LDPB – people with LD)

14.3.4   Volunteering affecting benefits

'I'm worried that volunteering will go against my benefits.' (Workshop – mixed group)

14.4 Statistics from the survey

This issue had a low profile in the survey, with only one person indicated any concern about jobs and training.

Of unemployed respondents, 20% said their disability or impairment prevented them being employed.

14.5 Some suggested actions

The initial suggested actions from the project are:

- Research support to help disabled people find out about vacancies

- Help with job applications, interviews and testing

- Ensuring disabled people have enough support to keep their job

- More research to identify employment barriers and design solutions

These suggestions were implicitly rather than explicitly suggested. Jobs, volunteering and training were raised only occasionally, and any debate on solutions in this area was often overtaken by other areas of concern before anything firm could be agreed. Given that jobs, volunteering and training can be a pathway out of benefits, the council may wish to conduct further research on this topic.

Part Four – Overarching themes

15 Introduction

Although our initial analysis was framed by the topics covered in Part 3, we found the following overarching themes emerging time and again across the workstreams:

- Negative attitudes towards disabled people

- Inaccessible, poor information

- Lack of participation and voice

These were further tested and reinforced by the responses to the survey.

In the following three chapters we've brought together key quotes from all of the other topics to demonstrate how these overarching themes are, in many ways, the most important things that disabled people are concerned about.

As this part of the report shows, disabled people felt very strongly about how these themes impacted their sense of self, their well-being and their ability to participate in society as equal citizens.

16 Negative attitudes towards disabled people

16.1 Summary

Local Voices participants commented over and over again how badly they think disabled people are being treated by society at the moment.

Proportion	Volume	Impact	Priority
3	3	3	9

16.2 Analysis

People often felt very marginalised, and there was a sense that things are getting worse not better. Throughout the project, disabled people made the most of opportunities to share their anger and fear and to build solidarity with others facing the same challenges.

Disabled people expressed significant worries about cuts to the income, services and support that many of them rely on. Many felt that the negative attitudes of service providers, the media and members of the public was rubbing salt in the wound. Not only did this cause stress and affect self-esteem, but there was a worrying link drawn between worsening attitudes and increasing hate crime.

For the council, there is some reassurance to be had from many survey respondents reporting staff had positive attitudes to disabled people (although still a significant minority that thought the opposite). However, this is diminished by the wide range of negative experiences reported in other contexts. Negative perceptions were universal across the groups in the project and were discussed in every workstream.

Inevitably, the key solution for disabled people was needing to feel better treated. The things that could help make this happen include broad actions such as media campaigns as well as organisational solutions like staff training and to improve everybody's understanding of disability.

16.2.1   Life's not fair for disabled people

In the survey there was a question about whether respondents thought life was fair for disabled people. Worryingly, more than half (55%) of survey respondents think life's not fair for disabled people, and only 20% agree or strongly agree that it is.

Amongst white respondents, more (59%) feel this way than for other ethnic groups and 64% of people under 60 agree with them. Most Asian respondents (39%) weren't sure either way.

A huge 73% of people with a visual impairment said life was not fair for disabled people. Many respondents with a mental health condition agreed, as did respondents with a long standing illness – the figures being 68% and 61%.

16.3 The issues people talked about

16.3.1 Attitudes about disabled people

In general people thought society generally had a negative attitude towards disabled people.

Proportion	Volume	Impact	Priority
3	3	3	9

'Historically, disabled people are hidden away - seems like the same thing is happening.' (Workshop – mixed group)

'Disabled people are worried about their lives; people think we're a burden, will dispose of us.' (Workshop – mixed group)

'I've been a social worker and now I'm treated like nothing - like an old rag tossed onto the ground.' (Sundial – older people)

'People talk down, ignore you.' (Workshop – mixed group)

'We haven't done anything wrong. We are not criminals, mental health is not a crime' (Pritchard's – people with MH needs)

16.3.2 Perceptions of benefit claimants

There is increasing national research and evidence showing that there was negative reporting against disabled people in some parts of the media, and unfortunate associations of disabled people as "benefit scroungers", with a distinction between the deserving and undeserving poor. This was mirrored in some of the comments made to us locally.

Proportion	Volume	Impact	Priority
2	1	2	5

'People are treated worse and seen as benefit scroungers (YSYD – people with MH needs)

'Media influence is encouraging negative attitudes towards disabled people.' (Workshop – mixed group)

'People think we are a drain on the system.' (Pritchard's – people with MH needs)

16.3.3   Negative attitudes from public agencies

People also reported negative attitudes and ways of working from public agencies. This is potentially more concerning, and may indicate that more needs to be done by public agencies when delivering their responsibilities under the Public Sector Equality Duty.

Proportion	Volume	Impact	Priority
3	2	2	7

'I'm feeling hassled from benefit agencies and the DWP.' (YSYD – people with MH needs)

'The DWP has a threatening approach and long forms.' (YSYD – people with MH needs)

'People responsible for you in agencies have a difficult attitude; not sympathetic, they don't listen.' (YSYD – people with MH needs)

'Requesting so many documents to prove my disability is intimidating.' (Workshop – mixed group)

'I feel patronised about having mental health when I talk to officials. They have absolutely no understanding. They think you're stupid.' (BbBC – people with MH needs)

'They're chasing everyone like they're a benefit cheat. They take things out on people who are actually ill.' (Pritchard's – people with MH needs)

'It's very hard to survive. The government's punishing the wrong people.' (Pritchard's – people with MH needs)

'The government don't care about community, and think people with disabilities are faking.' (YSYD – people with MH needs)

'The government throws labels around like shirker and scrounger.' (Pritchard's – people with MH needs)

16.3.4   Attitudes of council staff

There were mixed responses to attitudes from council staff.

Proportion	Volume	Impact	Priority
2	2	3	7

In the survey, 51% of people felt council staff had a positive attitude towards disabled people. Typically, just a third of people in each group disagreed that staff had a positive attitude, however 53% of people with a mental health condition felt this way.

There were also some negative perceptions reflected in the feedback at workshops and events. For example:

'I get the feeling that [the council] don't like old people.' (Riverside – older people)

'The council don't care about us. And, why complain, it's not going to get better.' (Riverside – older people)

'Council workers can be patronising.' (BbBC – people with MH needs)

'Services think that disabled people won't be 'with it' because we are in a wheelchair.' (Survey)

'The council talk about us like we're not here - they don't have doctors to tell them how to work with us.' (Pritchard's – people with MH needs)

'Staff at the council are not helpful.' (Workshop – mixed group)

'The council are only nice when they're doing a survey.' (Workshop – mixed group)

'Council staff can't wait to get rid of you' (Workshop – mixed group)

16.3.5   Hate crime and harassment

There were a number of people that were linking hate crime and harassment to attitudes towards disability generally.

Proportion	Volume	Impact	Priority
1	1	3	5

'Hate crime is getting worse.' (YSYD – people with MH needs)

'I'm getting abused in my neighbourhood because of my mental health issues.' (YSYD – people with MH needs)

'I'm worried about harassment from my neighbour – they're not being a proper neighbour and treat me badly.' (LDPB – people with LD)

16.4 Some suggested actions

The initial suggested actions from the project are:

- Better treatment of disabled people

- Promoting role models and positive stories

- Customer service and disability awareness training for council staff

There was a strong feeling that simply being treated with respect would go a long way. Throughout the project, people identified different reasons for a perceived lack of respect, and there are some relatively inexpensive 'quick wins' here that would address those reasons.

The following sections show some of the ways people expressed their support for these solutions.

16.4.1   Better treatment of disabled people

'I wanted to be treated fairly.' (Riverside – older people)

'It would be nice to be treated with respect.' (Pritchard's – people with MH needs)

'I want some respect.' (Workshop – mixed group)

'Work with us, not against us.' (Workshop – mixed group)

'I want more care and understanding from the authorities. A little bit more respect and a more communicative approach.' (Survey)

'We need a better understanding by the authorities of the sick people that they are helping.' (Survey)

16.4.2   Promoting role models and positive stories

'People with experience of disability should be in the media and talking about stigma against disabled people in the workplace.' (Workshop – mixed group)

'People should read good stories and news about disability in the media, local and national.' (Workshop – mixed group)

'Disabled people respond to seeing other disabled people doing well and in a positive light.' (YSYD – people with MH needs)

'Get good news stories in the media.' (YSYD – people with MH needs)

'We need to be raising awareness about disability to make people nicer – a big campaign to make people more aware and understand.' (LDPB – people with LD)

16.4.3   Customer service and disability awareness training for council staff

'We want council workers to understand how a person without capacity CAN say what they need or want. We want them to listen instead of deciding for themselves what a person with disabilities needs without knowing them or even meeting the person.' (Workshop – mixed group)

'Council staff need training about manners, customer service and disability awareness. They could get basic training in Makaton.' (Workshop – mixed group)

'Staff should know how to talk to someone with a disability (eg autism: eye contact and calm voice).' (Workshop – mixed group)

'Staff should take the time to help - understand it can take time to communicate.' (Workshop – mixed group)

'Do council staff have a general knowledge person who knows about lots of council services and who people in the council can call if they don't know the answer?' (Workshop – mixed group)

'Let's tell the people of the council about being aware of disabilities and what it is like living with one.' (Survey)

'There should be medical staff in the council to advise workers about illness. Decisions have a big impact so they should be thoroughly advised.' (Sonali – Older BME people)

'I want council staff to treat us as equal.' (LDPB – people with LD)

'We want the council is to know the whole person. This is a priority for us.' (Workshop – mixed group)

17 Inaccessible information

17.1 Summary

In general people felt that they didn't have enough good, understandable, accessible information to make important decisions. This was particularly true for people worried about the welfare and housing benefit changes, as was explored in '8.3.5 Not enough information'.

Proportion	Volume	Impact	Priority
3	3	2	8

17.2 Analysis

Regardless of the topic they're interested in, participants at the activities often didn't know where to get information. This was true for people across the demographic groups.

Some of the information people did know about tended to be available via inaccessible channels such as phones or computers. Participants also mentioned the need for communications that were sensitive to privacy and language needs. Again, concerns were expressed by many different types of people.

The survey respondents were more even-handed, with equal numbers thinking the council did and didn't provide accessible information. However, there was a markedly negative perception amongst people with a learning disability and markedly more positive perceptions amongst older people. Perhaps the higher costs of Easy Read and interpersonal communications compared to the large print or audio formats favoured by older people leads to less of the former and more of the latter being produced.

Solutions highlighted in this section focus on the accessibility of different channels rather than the content within them. However, issues explored in other parts of the project (eg benefit changes) show that there's work needed on both content and distribution to improve disabled people's access to communications. The Local Voices network (itself a

communication channel!) is an ideal tool for this, and can partner with the council and other organisations to make progress.

17.3 The issues people talked about

17.3.1   Needing information about/from council services
Many people said they just did not have enough information. They also did not know where to go to find it.

'What support is available for people? Not everyone is able to access information or know where to go for help.' (Workshop – mixed group)

'I want more information from the council about the services they can provide. I may be missing out on opportunities like courses etc.' (Survey)

'I don't know where to go to for help.' (Workshop – mixed group)

'Why don't we know about things?' (YSYD – people with MH needs)

'Nobody is giving me information, nobody's helping me, nobody is on my side. I need help and I don't know where to get it.' (Workshop – mixed group)

'We don't get told what we need to know.' (Workshop – mixed group)

'I feel frightened. The council don't bother to explain service changes.' (Riverside – older people)

'Our involvement is down to the language barrier, if someone can help us in our language, we'll take part.' (BWHFS – BME women with MH needs)

'There's a lack of clarity around making complaints.' (LDPB – people with LD)

'East End Life isn't delivered regularly enough. Sometimes issues aren't delivered to my house.' (Workshop – mixed group)

17.3.2   Inaccessible communication channels
Even when people knew information was available they often complained that the channels to access the information were not accessible to them.

17.3.3   Phone lines

'The phone lines at the council and social services aren't free. Once I was on hold for 15 minutes, it cost a fortune' (Pritchard's – people with MH needs)

'Being able to get information by phone can be exhausting because of long wait time on hold.' (Workshop – mixed group)

'When you're on the phone to hospitals now they want you to give a password which they've printed on the back of the letter, but elderly people don't know about these passwords, so they end up missing appointments because of it.' (Riverside – older people)

'I have a hearing impairment, it's hard to use the phone when home alone.' (Survey)

17.3.4   Computers

'A lot of forms are on the computer and I don't have a computer.' (Pritchard's – people with MH needs)

'The council's website only works on Internet Explorer and the address it gave for a service was the library next door. Phone numbers don't work and links are broken.' (BbBC – people with MH needs)

'I'm worried that all the information is now on computers and older people are saying "what do I want with a computer at this time of life?" - they're worried sick they're going to have to rely on computers for their money.' (Workshop – mixed group)

17.3.5   Language

'The council neglects us because of the language barrier; you're the first person to speak to us about our concerns [about benefits].' (Sonali – Older BME people)

'We'll take part [in information events], as long as there is someone to translate. It's down to the language barrier; if someone can help to explain we will join in.' (BWHFS – BME women with MH needs)

17.3.6   Visits in public spaces

'Changes to One Stop Shops means clients have to go to and talk about private things in front of other people – this stops people asking for help.' (Upbeat – people with MH needs)

17.4 Statistics from the survey

Survey respondents were fairly evenly divided on whether disabled people get enough accessible information from the council. Just over a third (36%) thought this happens, but marginally more (43%) felt it didn't.

However, bigger gaps in opinion existed depending on the age group to which people belonged. Of respondents under 60, only 25% felt disabled people get enough accessible information, whilst 50% felt this wasn't the case – twice the size of the positive group. This was reversed for older people, with close to half (46%) thinking disabled people get enough information, with a much lower 31% thinking that they don't.

On the other hand, amongst the (relatively small sample of) survey respondents with a learning disability, 80% thought disabled people don't get enough accessible information.

17.5 Some suggested actions

The initial suggested actions from the project are:

- Using accessible communication channels

- Improving content and distribution to disabled people

- Local Voices partners with the council and other organisations to improve communication to disabled people

Suggested improvements tended to involve increased face-to-face communication. This is more expensive, but it's clearly important that the council don't marginalise some people further by providing only online or print access to information. Real and other organisations can also help.

The following section shows some of the ideas people put forward for the first suggested area of improvement.

17.5.1 Using accessible communication channels

'Make the path [to information and support] more clear for people to get help with their problems.' (Workshop – mixed group)

'The council should use screens in Idea Stores to advertise services/organisation - not just the library's best sellers.' (Workshop – mixed group)

'Go to school leavers' assemblies and tell them about council services (life skills).' (Workshop – mixed group)

'I'm worried about finding the right information. Face-to-face help is good, but where can I get it from? (Workshop – mixed group)

'I want help from people I know.' (LDPB – people with LD)

'Some people would prefer to seek help via face to face rather than on leaflets, computer etc.' (Workshop – mixed group)

'Council officers should make more home visits so we can discuss things privately.' (Upbeat – people with MH needs)

18 Lack of participation and voice

18.1 Summary

Overall disabled people did not feel that they were heard, or whether as individuals or collectively they had any meaningful influence.

Proportion	Volume	Impact	Priority
3	2	2	7

18.2 Analysis

The research team picked up a strong current of cynicism throughout the project. People were reluctant to get involved in activities either for their own sake or to influence changes in their community.

This was also true for some members of the steering committee. Ironically, involving people who had less faith in engagement made Local Voices more likely to succeed, as members were more determined that this project would be different. They also helped the project team understand the barriers to persuading local people to get involved. '

There were fairly high levels of disempowerment, with the survey showing that twice as many people thought disabled people don't have any influence over the council compared to those who thought they do. This opinion was stronger for white rather than Asian people and for younger rather than older respondents. A clear majority of people with a mental health condition also felt disabled people have little say.

Participants had lots of suggestions for ways disabled people can increase their participation and voice. For the council, this means connecting, sharing, supporting and listening more.

This project is a good start – and the immediate need for Local Voices is to work constructively and energetically with the council to implement suggestions from this report. Where the project has shown clear priorities, but no obvious solutions, the network can explore avenues and find user-led ways to make change happen. We also need a clear strategy for communicating and maintaining that change.

18.3 The issues people talked about

Throughout the activities, fairly high levels of cynicism were displayed as a group mood or implied in the greater work some facilitators had to do to bring people's opinions out. There were also specific comments around lack of influence:

18.3.1   Lack of influence

Many disabled people felt they had little power over the decisions that affect them:

'Why complain, it's not going to get better.' (Workshop – mixed group)

'We don't know how solutions are made, we are invisible and completely in the dark.' (BWHFS – BME women with MH needs)

'As Bangladeshi disabled people, we don't feel as though we get our say on council issues.' (Sonali – Older BME people)

18.4 Statistics from the survey

Around 10% of survey respondents indicated they were concerned about an issue that had an implied link to participation or inclusion, such as 'equality and discrimination' or 'making services accessible'. 3% of survey respondents felt that electoral services failed to serve disabled people well.

More significantly, when explicitly asked if they thought disabled people have influence and are involved in council decisions, only 20% of respondents felt this was the case. Almost half of respondents (47%) clearly feel that disabled have little influence and 31% were unsure.

Proportionally more people under 60 felt disabled people didn't have influence, with 58% stating they disagreed / strongly disagreed (and only 21% who agreed) compared to 33% of respondents over 60.

Very few (17%) white respondents feel disabled people have influence, whilst for Asian respondents, slightly more (39%) feel disabled people have influence than feel they don't (33%).

Amongst people with a mental health condition, over half feel disabled people don't have a say, whereas only a quarter feel they do.

18.5 Some suggested actions

The initial suggested actions from the project are:

- Council working with disabled people better

- Disabled people being part of decision-making mechanisms

- Using democracy to make changes

- Increasing advocacy and campaigning

These solutions cover a range of options, ranging from individual and group action from disabled people through to things the council and others can do differently.

The following sections show some of the thoughts people had on each of the suggested actions.

18.5.1   Council working with disabled people better

Participants had ideas for how the council can give disabled people a stronger voice and make them feel more in control of decisions:

'Council staff should meet the people that are affected so they can see what their decisions do.' (Pritchard's – people with MH needs)

'The social services should tell us when they're doing a review. They call it a 'visit' and so people are unprepared and don't have relatives present and so it's not done properly or fairly and you don't get to voice your concerns.' (BWHFS – BME women with MH needs)

'Social workers make decision about our needs. I think they should listen more to us.' (Survey)

'We want council/social workers to understand how a person without 'capacity' CAN say what they need or want. We want them to listen to us instead of saying themselves what a person with disabilities needs without knowing them or even meeting the individual person.' (Workshop – mixed group)

'The council should train people on speaking up, having confidence, getting a say and having influence.' (BWHFS – BME women with MH needs)

18.5.2 Disabled people being part of decision-making mechanisms

'We should allocate one person from the borough and community to the council to make sure they do everything they promised.' (Riverside – older people)

'The council should get service users involved in decisions every 3 months.' (Workshop – mixed group)

'Get disabled people on council panels, so people on the ground can have their say.' (YSYD – people with MH needs)

'We need forums and committees with representation from all different groups, ensuring each group's wants and wishes are heard.' (YSYD – people with MH needs)

18.5.3 Using democracy to make changes

'We need more petitions to force the council to listen.' (Workshop – mixed group)

'Use the elections to voice our concerns.' (Workshop – mixed group)

'Speak to councillors about issues.' (Workshop – mixed group)

'Councillors should come to public events so we can ask questions and listen to concerns.' (YSYD – people with MH needs)

18.5.4 Increasing advocacy and campaigning

'We need access to a good advocate and a good case worker to make sure we are heard.' (Workshop – mixed group)

'Disabled people need to demand more support, to lobby and campaign together.' (YSYD – people with MH needs)

'Charities and service providers can help us get our message across.' (Pritchard's – people with MH needs)

'Let's get people from disability rights/political groups invited to day centres etc to get people more involved.' (YSYD – people with MH needs)

Part Five – Next steps

19 Supporting the council to address disabled people's concerns

Local Voices has already started developing a network of disabled people ready to work together to help make change happen. We're committed to showing participants that their views count and that the council is listening to what people have said.

We'd like to work with the council to help them understand disabled people's priorities and make changes that reflect our concerns.

19.1 Developing an action plan

Previous Disability Equality Scheme reviews have included an action plan in their final report. We think that specifying detailed actions at this stage asks too much of disabled people and has been one of the weaknesses in previous projects.

Writing an effective action plan requires a detailed knowledge of council resources, relevant political considerations and strategic priorities. This is beyond the scope of a five month project and inadvisable in a constantly changing economic and service environment.

Although our report includes possible solutions and desired outcomes to address people's concerns, we've not taken this next step. Without the essential internal knowledge, our action plan would be speculative.

Instead, Local Voices will partner with council staff to combine our internal and external perspectives to create something realistic, relevant and flexible. The model for ongoing consultation that we propose in the next section builds on this approach of co-design and co-production.

19.2 Reporting back on progress

Local Voices and the council's equalities team have committed to showing participants the difference their input has made.

Alongside the action planning and ongoing scrutiny mechanisms discussed later in the report, we have publically agreed to co-host a reporting event in the summer. We'll also roll out a communications campaign in local media and with partner organisations to ensure information about the impact of the report is widely shared.

20 An ongoing model for consultation with disabled people

20.1 Introduction

Part of the scope for the project was "developing a model to increase the representation and involvement of disabled people in decision making, service design and scrutiny".

This section of the report explains the factors that have influenced the recommendations and why our solution is and will be effective. It then sets out our recommendations for consultation with disabled people going forward.

20.2 Factors that have influenced the recommendations

There are a number of factors that have influenced our proposals for the model, as follows:

20.2.1   Enthusiasm for Local Voices and being heard

The general thrust was that people felt Local Voices was a good idea, and people welcomed the different ways in which they could contribute. Several people said they had really enjoyed the workshops, and thought they had been worthwhile.

There was also a sense that the council needed to listen more. In the survey we asked "What is the most important thing the Council can do in 2013?". Responses included:

'Consider disabled people in the decisions they make.'

'Listen a bit better. Get involved with people and learn what they're about. Put council staff in the position (how would they pay their bills with the benefits?, try a wheelchair).'

'Listen to disabled about their concerns.'

'Remember people with disabilities in the decisions you make, it will certainly help.'

20.2.2 Consultation fatigue/fear/cynicism

Many people expressed concern at the workshops and events that Local Voices would be a tokenistic exercise. It took a lot of reassurance from Real staff to encourage people to contribute. People said things like:

'[I've] concerns that surveys are used sometimes to justify further cuts'.

When we were running the telephone interviews many people declined to take part. Reasons included they didn't have the energy because of their disability, but many others make comments along the lines of "what's the point, it won't change anything'.

In one of the workshops it was said 'The council are only nice when they're doing a survey.'

In the survey we asked if people agreed with the statement 'Disabled people have influence and are involved in council decisions'. Only 21.4% of people answering this question agreed or strongly agreed. 31% weren't sure, and 46.3% disagreed or strongly disagreed.

20.2.3 The importance of understanding the impact of cuts and isolation

Many people felt that they didn't have enough information to comment on some of the areas. One person was reported as saying "Can't really say as has been housebound for a long time and has lost touch with what is going on".

As mentioned above, the "daily grind" for many disabled people's lives means they just don't have the space in their day or mind to contribute in a more conventional way. So if we want to hear these people's views we need to reach out to them on their terms.

20.2.4 The practicalities of accommodating people's impairment and health conditions

People often felt that conventional consultations were not accessible to disabled people. This was said in one workshop:

'We need more notice in papers about events around the borough, so we can organise to get to them'.

This was also implicit in the high level of comments about poor accessibility of the council's information channels and communications.

We found even in our own steering group that sometimes people weren't always able to attend, and this could happen at short notice. This was often due to fluctuating health conditions and impairments. So it's important to build a model that can accommodate this.

20.2.5   Recognising the support people need

There was a general sense that disabled people did not necessarily have the same opportunities to contribute to consultations and/or be involved in decision-making as non-disabled people.

Comments that came back from the workshops included:

'Disabled people need to demand more support, to lobby and campaign together.'

'Charities and service providers can help us get our message across.'

In many of the workshops it was initially hard to get people to think about how they could hold the council to account. In many cases it appeared that this was simply because they didn't have experience of knowing how to do it. This could be because the indirect impact of their disability means that they haven't acquired the same life skills as others.

Finally, many people just couldn't make it to workshops because they didn't have access to accessible transport and/or the money to pay for alternatives and/or adequate support from social services/others to get out of the house. In fact we had offered to provide some of this support, but people had discounted the possibility just because they weren't used to getting access needs met. Providing adequate funding for meeting access needs is going to be an important part of any consultation model going forward.

20.2.6   Recognising diversity within disabled people

In the survey we analysed information (where people provided it) on gender (and gender identity), age, ethnicity, impairment type, religion and belief, sexual orientation, as well as whether people lived, worked and/or study in Tower Hamlets. In some cases the differences in the responses between the populations was not material, but in other cases

there were interesting differences. These have been highlighted in our analysis where applicable. In addition, the different workshops often had different predominant characteristics amongst the participants.

It is therefore important to understand the different dimensions of people's lives. People didn't appear to identify as "disabled" in priority to other characteristics or parts of their lives. For example someone might identify as Bangladeshi, Muslim and with a mental health condition rather than just generically disabled.

20.2.7 Recognising other networks

Perhaps because of the diversity of disabled people referred to above, people often had different avenues for connecting with others to communicate on disability-related topics. This might be a day centre, the "Your Say, Your Day" events, local general support centres such as the Bromley by Bow Centre, or may not have disability-related networking but instead rely on other informal networks.

It's clear that we will need to build alliances with and tap into many other existing and developing networks if we are to truly reach a wide group of people.

20.2.8 Independence from the council

Although difficult to prove, we strongly suspect that people told us more because we are independent from the council. Indeed, we often had to reinforce that independence at the beginning of sessions in order to get people to open up. We think it's because people were mistrustful of how the information would be used - potentially against them - without that reassurance. It is therefore important that any ongoing model can demonstrate that it is independent from the council.

20.2.9 Demonstrating empathy and legitimacy

Again, although difficult to prove, we think there was real value in all of the staff and volunteers working on the project being disabled themselves. It meant that the participants didn't have to explain themselves so much, because we "got it". In addition, as a Disabled People's Organisation already run and controlled by disabled people and supporting disabled people in a number of aspects of their lives, we

were able to evidence that we were already on their side. This reinforced the "independence from the council" point above.

20.3 Recommendations for an ongoing model of consultation

Our experience during Local Voices, and when speaking to disabled people about previous experiences in other projects, has shown that no single approach is going to work if we are to effectively involve disabled people in ongoing consultation and council decision-making.

Instead we need to build a multi-faceted solution that:

- recognises the additional support many disabled people need to have their voice heard

- develops confidence in the participants that their involvement and action is worthwhile, is listened to and makes a difference

- recognises the "whole person" of the disabled people involved

- acknowledges that different people will be willing and/or able to contribute in different ways, and at different times, and to facilitate this.

- provides avenues and channels to go further than just consultation, and be actively involved in co-design, co-production and co-delivery of solutions.

 With this in mind, we make the following recommendations:

20.3.1   Keeping the name "Local Voices"

There was clear benefit in getting other organisations/networks to collaborate in the exercise, in having a brand-neutral name such as "Local Voices". We see no reason why this shouldn't continue.

20.3.2   Ensure an evolving, supported steering group

The steering group has been invaluable in setting the tone of our work, and ensuring that this project has been user-led at many levels. There's been great ideas that have affected the way we conducted the survey, the facilitation of the workshops and the grouping and analysis of issues that arose.

There's also been real ownership of the project and what it's trying to achieve. At the end of the project, we asked the group what went well and what worked less well about the project; we were impressed at the level of insight demonstrated.

But it's also fair to say that the group needed a bit of support. Some of this was practical, and reflected that the steering group contained people with physical disabilities, visual impairments, hearing impairments, learning disabilities and autistic spectrum disorders, mental health conditions, and long-term health conditions. This meant that information had to be presented in very accessible formats.

In addition, the group needed coaching and supporting through the process. This does not in any way invalidate the contribution that the steering group made to the project - as we say above they made a really positive impact - but it does mean we need to recognise that any future steering group will need active support.

We should also plan for the fact that some people move away, get jobs, become too ill to continue, etc. We therefore need to have a rolling programme of new admissions to any steering group, pulled from a wider group of people (see below). They should have appropriate induction and support, to help them understand what their role will be and how they can best contribute. This is based on the similar model implemented in Islington, and which has been highly effective.

20.3.3   Connecting a wider network

As part of the research for our method statement we visited the successful consultation model used and adopted in Islington. The model focuses on a single, supported steering group. Individuals are trained and supported to understand how council procedures work and so on, to better enable them to do their work.

However, in our work we recognised that there were relatively few people who wanted to make such a strong commitment, and had a good level of understanding across all of the issues that we were consulting on and/or affected disabled people.

We also realised that lots of people were predominantly interested in one or two issues, rather than the full range of issues that will be

affecting all disabled people. Some people will be really interested in accessible transport, but have no interest in social care if they are not currently receiving these services.

Finally, due to fluctuating impairments or conditions, some people may only feel able to contribute when they are able to.

So we recommend having a much wider group of people that we can call on to be involved on different topics when it suits them. We would aim to build over a three-year period a group of at least 500 people who are interested in different topics, and have them decide which topics they would like to be consulted on. In this way we can deliver targeted consultations, which are more likely to get positive/active responses, and this should also mitigate against the risk of consultation fatigue/overload.

20.3.4 Collaborating with other fora and organisations

Really reaching out to all disabled people in all parts of our community will require active involvement in and collaboration with other fora and organisations. This has been demonstrated by the richness of and differences in responses from different workshops and events.

So we would actively want to work with these fora and organisations to:

- host joint events with them at their premises; and

- encourage their clients/membership to become directly involved in the wider sounding board.

In addition, we would want to spend time supporting Local Voices network members to have the skills and confidence to participate directly in other existing consultation fora and mechanisms (eg HealthWatch) so that Local Voices is not the only channel through which disabled people's views are heard.

20.3.5 Combining with activities other than just consultation

It was clear, particularly in the workshops, that what was enthusing people was the thought that they could make a difference, and make change happen. People started talking about writing letters, or lobbying councillors or the Mayor. There was a strong message in many areas that people realise that by coming together they have more influence than as individuals.

Whilst the focus of Local Voices should be a channel for consulting with disabled people, the model should allow and facilitate groups of people to come together to seek to influence on the issues or thoughts that come up, even if some are only indirectly disability-related.

People often had great ideas or solutions to problems. Many of them were quite practical, and not necessarily expensive to implement. But implementing them well and effectively would be so much easier if advantage was taken of the knowledge and insight behind the solutions.

So we'd like to use Local Voices to also be a platform for helping service providers and others co-design and co-produce the solutions. In that way the solutions are much more likely to work. And in some situations solutions can also be co-delivered with participants in Local Voices. For example people could be mystery shoppers, they could road test solutions before they are rolled out, or they could be part of disability awareness training for council or other providers' staff training.

20.4 In summary

People are wary of the council not meaning what they say when it comes to consultation. There are also some unique considerations when consulting with disabled people if you want to properly involve them and reach all parts of this diverse constituency.

But if things are done differently, there is a unique opportunity to involve people more effectively, deliver more effective outcomes (thus saving money in times of austerity), and better serve a significant subgroup of the Tower Hamlets population.

21 A universal analysis for the Single Equality Scheme

The council is moving to a Single Equality Scheme, analysing people's experiences, autonomy and outcomes across the protected characteristics.

This new approach recognises that people are often members of more than one marginalised group, creating intersections of inequality. It's unrealistic to expect people to unpack their overlapping perspectives to comment on one identity.

The Equality Measurement Framework (EMF) addresses 'the central and valuable things in life that people actually achieve"[1], across 10 domains that matter to people of any identity or protected group.

We've mapped the data from Local Voices into the domains to identify the high, medium and low priority domains for local disabled people. The prioritisation below is based on the number of times people made points that could be attributed to each domain.

21.1 High priority domains

- Standard of living (eg enough food, clothing, warmth, shelter etc)

- Individual, family and social life (eg developing as a person and forming relationships)

- Participation, influence and voice (eg making decisions affecting one's own life)

These domains related to disabled people's concerns about benefit and housing changes, pressures on family life and control over their support.

21.2 Medium priority domains

- Physical security (eg being free from violence)

- Productivity (eg participating in productive paid or unpaid activities)

- Self-expression and self-respect (eg living without fear of humiliation)

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[1] EHRC, 'Equality Measurement Framework' at www.equalityhumanrights.com/key-projects/equality-measurement-framework. Accessed 20 March 2013.

- Health (eg having the highest possible standard of physical and mental health)

Most of the issues in these domains were related to crime and safety, health care, jobs and volunteering and community attitudes.

21.3 Lower priority domains

- Knowledge and skills (eg accessing education, training and learning)

- Legal security (eg being protected and treated fairly by the law)

- Life (eg avoiding premature mortality through disease)

Participants indicated a slightly lower priority for these domains, linked to concerns about education/training, fear of benefit fraud accusations and discrimination. There were no explicit concerns about neglect or risk of death.

Part Six – How we delivered the project

22 Local Voices phase 1 – research review and proposal

The first phase of Local Voices was to explore recent prior research or consultation and engagement on disability issues to identify the most effective approach for our project. This review was done in two workstreams – one covering equality schemes and another exploring existing council consultations and strategies.

By knowing what questions had been asked, which methods were used, what disabled people's responses had been and the lessons to be learned from previous efforts, the Local Voices team could more effectively design the project - including framing the research focus, defining the audience and choosing the methodology.

22.1 Review stream 1 – Equality schemes

The first workstream was a study of 7 equality scheme reviews developed by key public services in Tower Hamlets and neighbouring boroughs:

- Tower Hamlets NHS

- Barts and The London NHS Trust

- Metropolitan Police (2 reviews)

- Hackney Council

- Newham Council

- Transport for London

Although focusing on disability equality, the reviews also explored issues relevant to gender, ethnicity and faith groups. A summary of the methods, audience and issues explored is in '22.7 Equality Scheme reviews in public services – summary table'.

22.2 Review stream 2 – LBTH consultations and strategies

The second review was of Tower Hamlets Council consultations or strategic documents published in the last 3 years that linked with disability issues in some way. There were 37 documents in this review;

they're listed in '22.8 LBTH consultations and research that links with disability - list'

It was possible to compare the varying priority levels different groups of disabled people gave for 6 service areas and the over-arching theme of 'information'. This comparison is shown in '22.9 Priorities for various groups of disabled people – summary table'.

22.3 Results

The equality scheme reviews and consultations used a wide range of activities, eg one-on-one and group methods, interpersonal, telephone and online tools, plus carefully structured and targeted approaches for key groups. The best examples combined several of these approaches.

The overall sense from reviewing the council's engagement and consultation was that it is uncoordinated, with gaps and some repetition.

Some of the gaps are around audience groups. For example, none of the reviews or consultations explored disabled people's experiences as workers or students, except as members of their organisation. There are also a number of sub-groups within the disabled community whose views are limited or absent.

Further, none of the consultations effectively addressed issues around identifying as a disabled person. We know from our work with the local community that stigma or personal politics can stop people from identifying as disabled, and so they don't participate in consultations. Sometimes this can be overcome by talking about 'long-term health conditions' or 'difficulties getting out and about'.

There were also some council departments consulting on the same topic or with the same audience as an existing consultation. As far as we could tell, consultations weren't logged centrally and findings aren't shared across departments. Also, council consultations use varying methodologies and terminologies (eg definition of impairment types) so although data might be gathered on similar topics, it can still be difficult to compare it.

Also, it seemed that opportunities for close exploration of disability issues were missed. In the council's consultations, questions about

identity and protected characteristics are used to establish the diversity of participants (eg '12% of Somali households in the consultation have at least one disabled person in them'[2]), but aren't consistently used to explore how being disabled might have influenced someone's input.

The council has done some deeper research into the experiences of disabled people, but it has done so by relying on consulting its own fora, supplemented by engagement activities with a small group of voluntary sector organisations. This approach has led to a focus on disabled people who use social care services.

Although it's important that health and social care services think about the interaction between a person's circumstances and their experiences, it would be helpful if understanding disabled people's lived experience could move beyond these areas. The lack of meaningful consultation in other areas maintains the stereotype of disabled people as mostly consumers of support, rather than stakeholders in universal services like recycling, education or citizenship.

Lastly, where protected characteristics are explored, this tends to happen via a 'single identity' approach, consulting with people because of their age, disability or ethnicity etc alone. Yet, like all other identity-based groups in the borough, the population of disabled people is diverse. Disability is just one part of our lives and many of us have other protected characteristics. A single identity approach denies the interaction between these identities in each of our lives as well as hiding patterns that might create solidarity between identity groups.

22.4 Designing our proposal

Based on our analysis, we wanted our project to:

- use a range of data gathering methods

- target previously missed groups of disabled people

- understand not just what disabled people's concerns are, but the influence disability has on the formation of those concerns

- highlight potential similarities with other marginalised groups

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[2] 'Meeting the needs of Somali residents Somali Tenants Engagement' Project Final Report, April 2012, p7.

Our project would pull together the previous research, summarising themes and concerns and identifying what disabled people had already told us mattered to them.

We'd then roll out original, targeted research to fill in the gaps around audience groups, topics and suggested actions. We particularly wanted to include people who don't self-identify as disabled and to move beyond focusing on disabled people as social care users

Although targeted research with previously un-reached groups requires greater time and money, we felt that delivering a more complete understanding of disabled people's concerns without replicating previous efforts would be an efficient use of resources.

22.5 Evolution of our proposal

Although they agreed with our rationale for focusing on unreached audiences and unexplored topics, the council asked us to expand the project with a wider approach. This was so they had as much information about disabled people's priorities as possible before the move to a Single Equality Scheme (SES).

It was also felt that the enormous political and economic changes since the last Disability Equality Scheme review would have had a significant impact on people's priorities. The council needed up-to-date information about people's concerns around welfare reform and service changes as well as potential for community resilience in the face of change.

We agreed to continue with the principles of our original proposal, but to expand the topics and audience more widely.

22.6 The impact and benefits of our evolved proposal

The expansion put a lot of pressure on our resources, giving us two months to deliver a much larger programme to a much larger audience.

This was both challenging and fruitful.

22.6.1   Some additional research needed

The broader approach gave us a very rich set of data, with more than 1,000 comments or concerns raised in the project. But, expanding our project reach meant a re-allocation of resources and we had to remove detailed case studies from our activity work streams. We think Local

Voices would benefit from some additional, focussed one-on-one research work, particularly to explore the cumulative effect the changes in benefits and services are having on disabled people.

22.6.2   Benchmarking

By more closely matching previous review methodologies, we also have the potential to benchmark our findings against previous results. It's outside the scope of this project, but it would be useful to explore:

- What actions have been taken since the previous review?

- What do disabled people think has improved, and why?

- What do disabled people think has got worse, and why?

If action has been taken since the last Disability Equality Scheme review, but this hasn't yet reduced disabled people's concerns or improved their perceptions of equality in the borough, the council may wish to explore why. Identifying barriers to implementation or improvement would be very useful for helping Local Voices support and scrutinise the action plan born out of this review.

22.7 Equality Scheme reviews in public services – summary table

	Date	Methods	Audience	Key Issues
Tower Hamlets NHS	2010-13	Monitoring information, customer feedback/ complaints, consultation results and surveys, analysing demographic data, monitoring data on service users and employees, gathering workforce information to analyse proportionality.	Disabled people: learning difficulties, cognitive impairment, metal health need, sensory impairment, physical disability, other.	Access to public buildings, negative attitudes towards people with hidden impairments, access to coordinated, multi-agency support for all disabled children, delivering services in more accessible settings within community, number of adults with learning disability receiving annual health checks - still below London and England average.
Barts and The London NHS Trust	2009-12	Public meetings, staff meetings/ road shows, service users consultation groups, focus groups, questionnaires, intranet voting buttons, 'walkabouts', partnerships and networking, events, mainstreaming throughout workplace, disability forum, access audit.	Patients, carers, relatives, service users, staff.	Ensuring easy access to toilet facilities, public meetings held in accessible venue, maintaining and extending partnerships.
Metropolitan Police (1)	2010	HR Forum, corporate policy database, enquiries, consultation through email.	Disabled Staff Association.	Concerns over complaints progressing, only being allowed one 'friend' and desiring a supporter from one of the Staff Associations, requiring consent for building adaptations.

Metropolitan Police (2)	2009-13	MPS Diversity Board, publication of equality data, Equality Standard measuring and monitoring performance tool, oversight and coordination of action plans (diversity forums), consultation and engagement. Senior officer responsible for each strategic theme	People across all protected characteristics.	Focus: homicides/ hate crime/ community engagement/ local accountability/ workforce. Fair and Responsive Services, Community Engagement, Workforce and Culture, Governance.
Hackney Council	2006-9	Partnerships, involvement, consultation, events, focus groups, staff diversity forums, evidence gathering exercise, mystery customer exercise.	Disabled people, carers, staff.	Genuine, ongoing involvement and engagement, customer care and choice/ empowerment.
Newham Council	2011	Performance data, consultation and engagement results (surveys), involving local people and organisations, focus groups, events, formal consultation, revision and agreement.	Local people, organisations, staff.	Eliminating discrimination, harassment and victimisation, advancing equality of opportunity, fostering good relations between disabled people and non-disabled people.
Transport For London	2012	Online questionnaires, independent advisory group, citizen's jury, partnerships, engagement forums.	Disabled groups, public, staff.	Availability of information (awareness, accessibility), physical accessibility.

22.8 LBTH consultations and research that links with disability - list

1. 2011-12 User Experience Survey

2. Adults Health and Wellbeing. Corporate Complaints and Member Enquiries report October 2011 – March 2012

3. An Open Spaces Strategy for the London Borough of Tower Hamlets 2006 – 2016

4. Factsheets on People's Views, Adult Social Care in Tower Hamlets 2012.
   a. Crime, Safeguarding and Safety
   b. Economic Wellbeing and Employment
   c. Housing
   d. Information, Advice and Advocacy
   e. Physical disabilities, frailty & sensory impairments:
   f. Personal Budgets
   g. Perceptions of Adult Social Care and the Council
   h. Neighbourhoods and Getting Around
   i. Mental health
   j. Locality-based views on social care

5. Involvement and Engagement: Overview of People's Views. Tower Hamlets Adult Social Care 2012

6. Tower Hamlets Council Complaints and Information Annual Report 2011-2012

7. LBTH Supporting people commissioning strategy 2011-2016

8. LBTH, 2012, Private Sector Housing Stock Condition Survey

9. Local Account consultation report, Adults Health and Wellbeing, November 2011

10. Tower Hamlets Housing Strategy Summary 2009 to 2012

11. Modernising Learning Disability Day Opportunities in the London Borough of Tower Hamlets: BME Communities – March 2012

12. Team Tower Hamlets Homes, Meeting the needs of Somali residents Somali Tenants Engagement Project Final Report April 2012.

13. THINk, 2011, A report on the barriers to self-management for people in Tower Hamlets with a long-term condition(s)

14. Tower Hamlets 2008-13 Homelessness Strategy

15. Tower Hamlets Residents' Survey, 2011-12

16. Tower Hamlets Community Plan: 2020 Vision

17. Tower Hamlets Council DES 2007 – 2010

18. Tower Hamlets Final Local Implementation Plan for Approval London borough of Tower Hamlets 2005/06 to 2010/11

19. Tower Hamlets Health and Wellbeing Board, Tower Hamlets Health and Wellbeing Strategy: An outline (Revised) September 2012

20. Tower Hamlets Homes: Equalities Analysis of housing needs and preferences July 2012

21. Tower Hamlets Involvement Network, Annual Report April 2010-March 2011

22. Tower Hamlets Local Development Framework, Development Management Development Plan Document (DPD) Engagement Document. 2011

23. Tower Hamlets Local Involvement Network (THINk) Annual General Meeting – June 2012

24. Tower Hamlets Local Involvement Network (THINk) Mile End and Bromley By Bow report and Report on the barriers to self-management for people in Tower Hamlets with a long-term conditions.

25. Tower Hamlets Overcrowding Reduction Strategy 2009 – 2012

26. Tower Hamlets Partnership, Older People's Mental Health Needs Assessment For Depression, Dementia and Severe Mental Illness October 2009

27. Tower Hamlets Voluntary and Community Sector Strategy Consultation Document September 2012

22.9 Priorities for various groups of disabled people – summary table

	Crime	Safety	Health care	Housing	Social care	Transport	Information
Employed physically disabled people	Medium	High	High	Medium	Low	High	High
Disabled people with visible impairments	Medium	High	Medium	Low	Low	Low	High
People with autism	High	High	Low	Low	Low	High	High
People with learning difficulties	High	High	High	High	High	High	High
Disabled students	Medium	High	High	Low	High	High	Low
BME physically disabled people	High	High	High	High	Medium	High	High
People with mental health issues	High	High	High	Medium	High	Low	High
BME people with learning difficulties	High	High	High	Low	High	High	High
Older people who use social care	High	High	High	High	High	High	High
Older people who don't use social care	High	High	High	Medium	Medium	High	High
People with hearing impairments	Low	High	High	Low	Low	High	High
People with visual impairments	Low	High	High	Low	Low	High	High

High priority	(purple)
Medium priority	(green)
Low priority	(orange)

23 Local Voices phase 2 – original research

After agreeing our proposal with the council, we were keen to start our original research.

23.1 Methodology

23.1.1 Research questions

Our research questions were developed from the best practice identified in the literature review. The questions were varied for interpersonal, electronic and hardcopy contexts. Questions from one of the hardcopy surveys are in 'Appendix 1: Survey questions'.

23.1.2 Population

Having agreed with the council to expand our initial proposal, we were keen to reach as wide a range of disabled people as possible.

The population for the study was all disabled people or people with long-term health conditions who live, work or study in Tower Hamlets.

A demographic breakdown of Local Voices participants is in '24 Participant demographics'.

23.1.3 Research tools

Our choice of tools was strongly influenced by what the literature review showed was effective in previous reviews and consultations.

We set up five workstreams to gather original data from as wide an audience as possible:

- workshops

- discussion groups at community activities

- Your Say, Your Day event

- surveys

- social media activity

Some workstreams were delivered in groups and at venues throughout the borough; others were with people one-on-one in their homes. People

could be involved once in a single workstream or take part on an ongoing basis.

All the workstreams were designed to provide qualitative data. The surveys were also used to gather quantitative data.

More information about the activities is in '6.2 Community activities'.

23.2 Recruiting participants

Participants were self-selecting. Many had connections to partner organisations or previous projects by Real.

We recruited participants via council channels (eg East End Life, Pan-Providers' Forum), our channels (eg mailing list, client contact, our digital media) and other organisations' channels (eg older people's forum, service user network). Of these, the council channels seemed the most effective.

Word-of-mouth was also an effective recruitment tool, albeit one that Local Voices didn't control or moderate. Many people attending an event had heard about it from someone else.

We experienced relatively high visitor stats on our website and social media, with 40 page downloads and 140 social media connections on our farthest-reaching days. On most days, we had at least double the usual digital connections. Our survey page was the most popular web content.

23.3 Data analysis

The qualitative data was classified by two researchers, then moderated by a supervisor. Quantitative data was analysed via Excel and SurveyMonkey.

The Local Voices steering group was kept up to date on emerging results and provided guidance on interesting avenues for analysis.

24 Participant demographics

Local Voices was designed to reach a wide range of disabled people. We've recorded demographic information about as many people as possible throughout the project to check if diversity has been achieved.

This section contains the detailed statistical data about the people who took part in Local Voices. It has some limitations.

To increase the chances of people participating in the research, we had to make participation easy. As people can be reluctant to answer too many questions and we knew there would be barriers to capturing some information, we prioritised gaining consent and recording interest in ongoing engagement work above collecting personal information.

In some cases (ie social media and community activities) it wasn't possible to gather individual data.

Where we thought we could collect data without annoying participants, we emphasised a co-operative approach and decided that some data was better than none. So, none of the questions in any forms were compulsory and people were encouraged to answer what they were comfortable with.

In some of the inter-personal situations (eg surveying over the phone) it was decided cultural sensitivities should be considered when asking about sexuality and faith.

Throughout the activities and even within each activity, different numbers of people have completed each question.

Some of our demographic classifications are also inconsistent. This is because our design evolved to reflect participant feedback and also that some forms (eg Your Say, Your Day) had to be agreed by partner organisations who wanted different approaches. We tried to maintain as much consistency as we could, but this wasn't always possible.

Bearing in mind the varying levels of compliance or completeness, we've taken care to consider or caveat the robustness of the findings when necessary. We stand by our analysis.

For transparency, the figures given below include 'N', the number of people within each activity answering demographic questions.

24.1 Workshops

As mentioned, we had 33 of 48 participants complete demographic monitoring forms for the workshops. Here is the detailed breakdown:

Age (N = 33)

	Percent	Number
18-35	9%	3
36-50	24%	8
51-65	36%	12
over 65	27%	9
no answer	3%	1

Gender (N = 31)

Male	52%	16
Female	48%	15

Ethnic group (N = 26)

Asian – Bangladeshi	18%	5
Asian – Pakistani	4%	1
Asian - Other Asian	4%	1
Black – Caribbean	18%	5
White – British	25%	7
White – Irish	11%	3
White - Other White	14%	4
Mixed - White and Black Caribbean	4%	1
Mixed – Other	4%	1
No Answer	0%	0

Sexual orientation (N = 30)

Lesbian / homosexual	0%	0
Bisexual	0%	0

Gay/homosexual	3%	1
Heterosexual	80%	24
No answer	17%	5

Religion or belief (N = 27)

Atheism	4%	1
Buddhist	4%	1
Christianity	52%	14
Islam	19%	5
Jainism	0%	0
Sikhism	0%	0
Other	4%	1
Hinduism	7%	2
Judaism	0%	0
No answer	11%	3

Nature of disability or long-term health condition (N = 56)

(People could choose more than one impairment type for this question.)

Mobility difficulties / wheelchair user	30%	8
Upper limb or back problems	7%	2
Long-term condition	30%	8
Blind / partially-sighted	11%	3
Deaf/hard of hearing	11%	3
physical disability	30%	8
mental health issues	33%	9
other unseen disabilities	22%	6
chronic progressive disorder	0%	0
chronic recurrent condition	4%	1
Autism Spectrum Disorder	0%	0
Dyspraxia	4%	1
Dyslexia/learning disability	22%	6
Other	4%	1
No answer	0%	0

Employment status (N = 25)

Full-time, paid work	4%	1
Part-time paid work	0%	0
Unpaid carer	8%	2
Unemployed	60%	15
Volunteer	16%	4
No answer	12%	3

Housing (N = 29)

Live in my own home	17%	5
Live in social housing	69%	20
Renting from a landlord	7%	2
Homeless	0%	0
No answer	7%	2

24.2 Community activities

As mentioned, we recorded activity demographic at groups level rather than for individuals. The groups were:

Group	Key audience
Riverside Centre	Older people with a range of impairments. Mixed ethnicities and genders.
Neighbours in Poplar	Older people with a range of impairments. Mixed ethnicities and genders.
Sundial Centre	Older people with a range of impairments. Mixed ethnicities and genders.
Black Women's Health and Family Support	Somali women with MH condition
Sonali Gardens	Older Bengali men and women, with a range of impairments
UPBEAT	People with MH condition. Mixed ages, ethnicities and genders.
Bromley by Bow Centre	People with MH condition. Mixed ages, ethnicities and genders.
Pritchard's Road Day Centre	People with MH condition. Mixed ages, ethnicities and genders.
Learning Disability	People with learning disabilities. Mixed ages,

Partnership Board	ethnicities and genders.
Create (formerly Coburn)	People with learning disabilities. Mixed ages, ethnicities and genders.
East London Communication Enterprise	People with learning disabilities. Mixed ages, ethnicities and genders.

24.3 Your Say, Your Day

We had completed monitoring forms from 101 of about 150 people at this event.

Age (N = 101)

	Percent	Number
17 or under	3%	3
18-20	1%	1
21-30	18%	18
31-40	21%	21
41-50	29%	29
51-60	20%	20
61-70	6%	6
71-80	3%	3

Gender (N = 101)

Male	44%	44
Female	56%	57

Ethnic group (N = 90)

Asian – Bangladeshi	28%	25
Asian – pakistani	4%	4
Asian – Vietnamese	1%	1
Asian – Indian	2%	2
Asian – Chinese	2%	2
Asian – Other Asian	4%	4
Black – British	4%	4
Black – Caribbean	8%	7

Black – Somali	1%	1
Black – Other African	4%	4
White – British	19%	17
White – English	2%	2
White – Scottish	2%	2
White – Welsh	0%	0
White – Irish	4%	4
White – Gypsy/Traveller	0%	0
White – Other White	6%	5
Mixed race/dual heritage	0%	0
Other	3%	3
Prefer not to say	3%	3

Nature of disability or long-term health condition (N = 134)

(People could choose more than one impairment type for this question.)

Physical impairment	25%	21
Visual impairment	17%	14
Hearing impairment	8%	7
Mental health condition	37%	31
Learning disability / learning difficulty	12%	10
Long-standing illness or health condition	27%	23
Other disability or health condition	7%	6
I don't have a disability or long-term health condition	26%	22

Working in Tower Hamlets (N = 78)

I work in Tower Hamlets	55%	43
I work outside Tower Hamlets	6%	5
I don't work	39%	30

Living in Tower Hamlets (N = 86)

I live in Tower Hamlets	67%	58
I do not live in Tower Hamlets	33%	28

Studying in Tower Hamlets (N = 71)

Yes, I study in Tower Hamlets	17%	12
No, but I study outside Tower Hamlets	9%	6
No, I don't study	75%	53

24.4 Social media

It wasn't possible to gather demographic data on social media users.

24.5 Survey

Of the 99 people who completed the survey, around two thirds or more answered the demographic questions.

We used software to collect the survey data, so have access to a sophisticated analysis of survey answers and respondents' demographics. We've produced an annex to this report that includes over 100 charts and diagrams. It offers a richness of data that people with an enthusiasm for detail will find fascinating. Please contact us if you'd like a copy.

Age (N = 61)

Which category below includes your age?
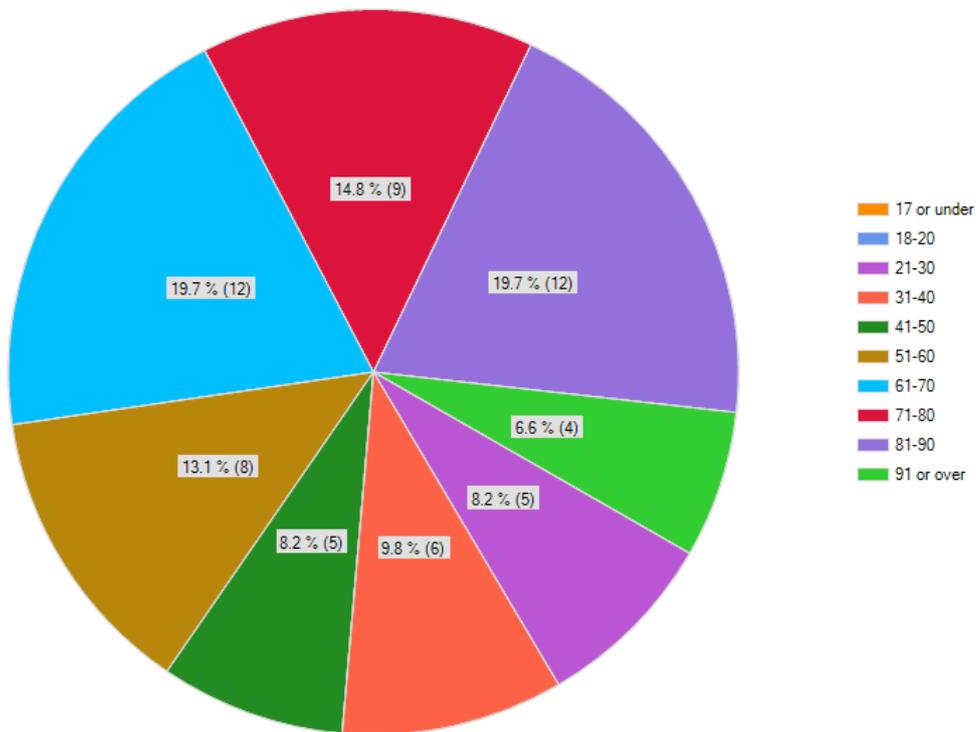
	Percent	Number
under 18	0.0%	0
18-20	0.0%	0
21-30	8.2%	5
31-40	9.8%	6
41-50	8.2%	5
51-60	13.1%	8
61-70	19.7%	12
71-80	14.8%	9
81-90	19.7%	12
91+	6.6%	4

Gender (N = 66)

What is your gender?
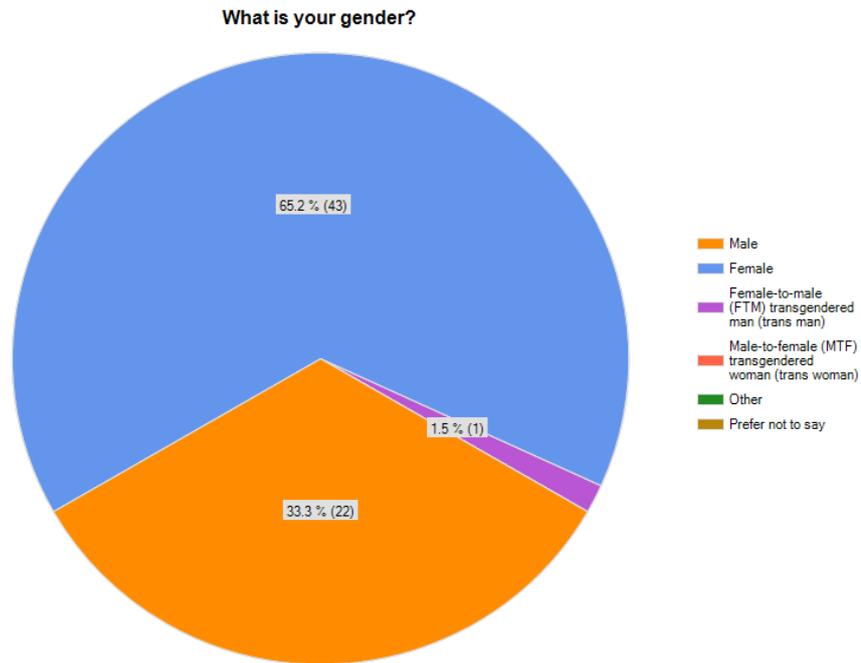
Male	33.3%	22
Female	65.2%	43
Female to Male Transgender (Trans Man)	1.5%	1
Male to Female Transgender (Trans Woman)	0.0%	0
Other	0.0%	0
Prefer not to say	0.0%	0

Ethnic group (N = 75)

Please describe your ethnic group
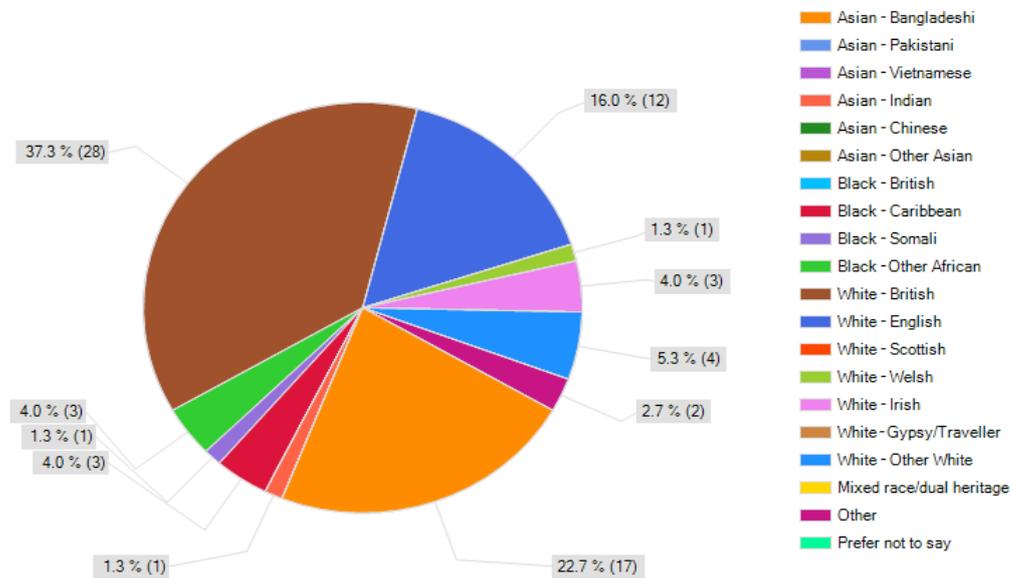
Asian - Bangladeshi	22.7%	17
Asian - Pakistani	0.0%	0
Asian - Vietnamese	0.0%	0
Asian - Indian	1.3%	1
Asian - Chinese	0.0%	0
Asian - Other Asian	0.0%	0
Black - British	0.0%	0
Black - Caribbean	4.0%	3
Black - Somali	1.3%	1
Black - Other African	4.0%	3
White - British	37.3%	28
White - English	16.0%	12
White - Scottish	0.0%	0
White - Welsh	1.3%	1
White - Irish	4.0%	3
White - Gypsy/ Traveller	0.0%	0
White - Other White	5.3%	4
Mixed Race/ Dual Heritage	0.0%	0
Other	2.7%	2
Prefer not to say	0.0%	0

Nature of disability or long-term health condition (N = 91)

(People could choose more than one impairmant type for this question.)

Please indicate the nature of your disability or long-term health condition (Tick as many as apply)
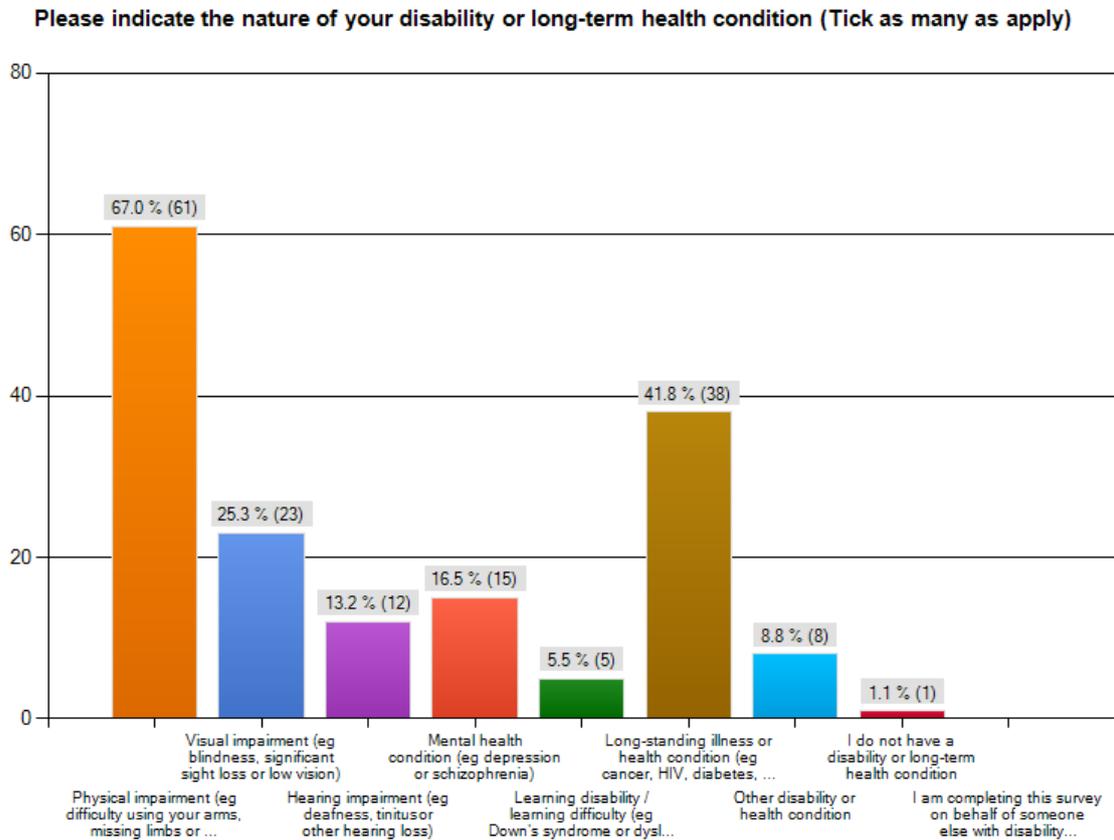
Physical impairment	67.0%	61
Visual impairment	25.3%	23
Hearing impairment	13.2%	12
Mental health condition	16.5%	15
Learning disability/ learning difficulty	5.5%	5
Longstanding illness or health condition	41.8%	38
Other	8.8%	8
None	1.1%	1

Type of housing (N = 92)

What kind of housing do you live in?
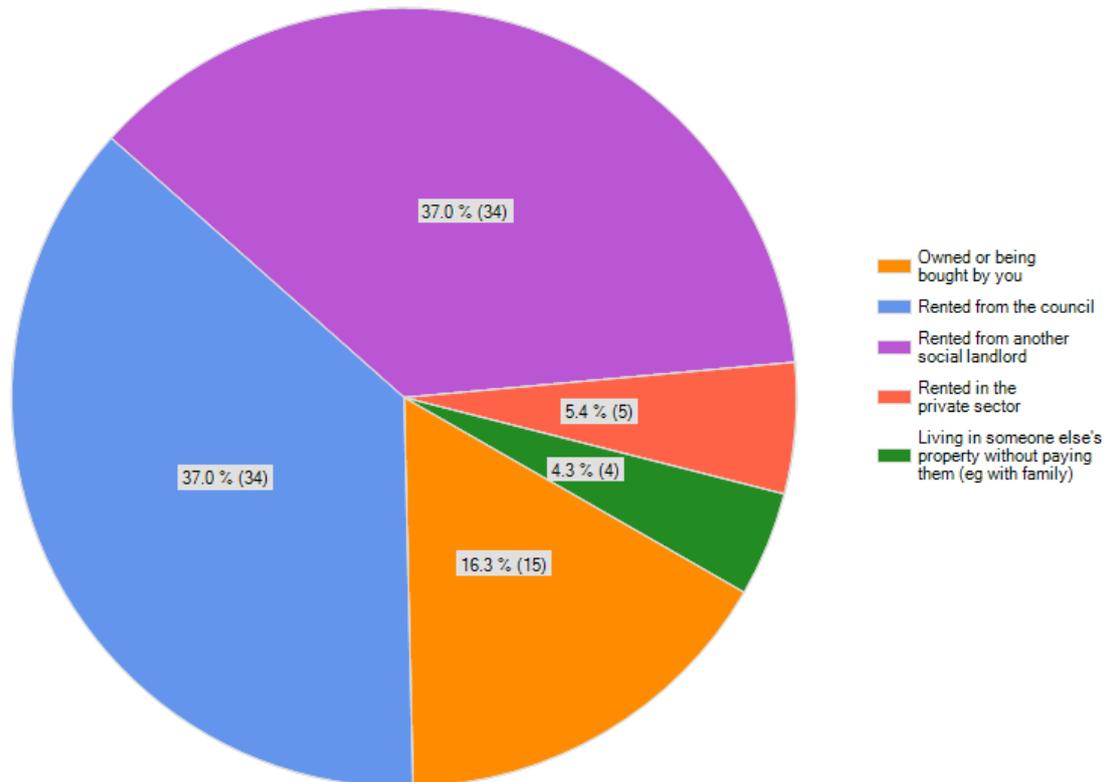
Home owner	16.3%	15
Rented- council	37.0%	34
Rented - other social landlord	37.0%	34
Private rented	5.4%	5
With friends or family	4.3%	4

Employment status   (N = 83)

What is your employment status? (Pick best match)
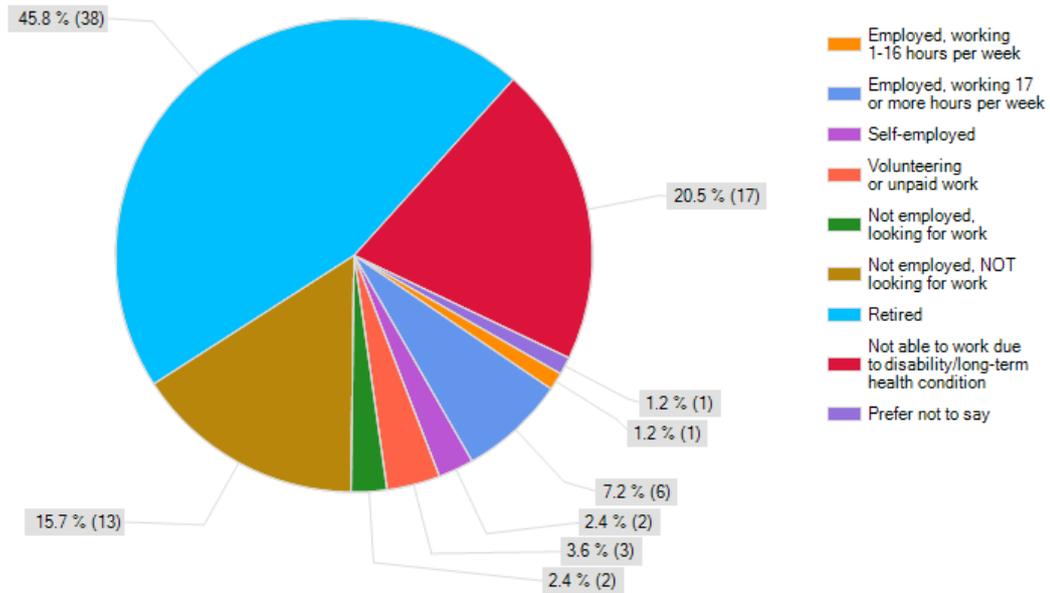
Employed - working less than 17 hours a week	1.2%	1
Employed - working 17 hours or more	7.2%	6
Self employed	2.4%	2
Volunteering or unpaid work	3.6%	3
Not employed, looking for work	2.4%	2
Not employed, not looking for work	15.7%	13
Retired	45.8%	38
Unable to work due to disability/ long term health condition	20.5%	17
Prefer not to say	1.2%	1

25 The Local Voices steering group

In accordance with Real's user-led principles, Local Voices was led by a steering group of 8 disabled people who met fortnightly to:

• provide suggestions to shape delivery (eg agree survey questions)

• help solve problems (eg response rates, unclear terminology)

• check data, assess key themes and explore any contradictions

• support development of the final report

The group included disabled people with a range of impairments and from a range of backgrounds. Members were recruited from events during the projects. Some members had previous experience in Real's steering group, which meant they were able to provide peer support to the newer members.

In the next stage, the steering group will work with the council to:

• explore the recommendations in the report

• support and scrutinise the council's actions following the report

• co-host an event to show how the report has influenced changes

• create a model for ongoing engagement

Real will continue to support the group as its responsibilities shift from project delivery to scrutiny and ongoing consultation.

26 How the priority scores are calculated

In the introduction we explain how we used a priority grid to indicate the relative priorities for the issues raised.

We used three elements to calculate the priority score:

Proportion
The proportion of disabled people in the borough likely to be affected.

Volume
How often or with what strength of feeling the concern was mentioned.

Impact
The degree to which this concern impacts on one of the Equality Measurement Framework domains. (You can find out more about these in '21 Developing a universal analysis for the Single Equality Scheme'.)

Concerns were given scores for each element as shown:

Proportion	Volume	Impact
3 = almost all	3 = almost always/ highly strongly felt	3 = substantial
2 = majority	2 = often/strongly felt	2 = significant
1 = many	1 = occasionally	1 = medium
0 = a few	0 = not often	0 = low

The scores were then added up to work out the priority level. Levels can range from 0 - 9, although the actual range in this report is from 4 - 9.

The scores for the proportion, volume and impact of the concern are based on evidence from three sources.

Survey data
The surveys asked people to indicate their number 1 and number 2 issues of concern from a range of options. More information about the answers to these questions is in '27 Overview of the survey results'.

Activity reports
As well as the data captured in transcripts from the community activities, researchers wrote a report for each event that describes the level of engagement, mood of the group and the overall priorities.

Our knowledge

Real is a disabled people's user-led organisation. We're constantly in conversation with other disabled people and this gives us an up-to-date awareness of what's going on in the borough. From the very beginning of the project, we've drawn on clients, volunteers and allies to inform and strengthen our analysis.

For example:

'Valuing day and community centres' has a relatively low score of 4. This was because day and community centres are relevant to only a few disabled people in the borough (Score = 1) and it wasn't mentioned very often during the project (Score 1), but the people who for whom day and community centres ARE relevant, do depend on the centres for some of their EMF domains (eg 'productive and valued activities'). (Score = 2)

	Proportion	Volume	Impact	Priority
Valuing day and community centres	1	1	2	4

In contrast, 'Worries about further benefit cuts' has a high score of 9 because this issue is relevant to almost all disabled people (Score = 3), this topic was mentioned at every activity in the project (Score = 3) and people depend on benefits to ensure wellbeing in lots of the EMF domains (eg 'Life', 'Human rights', 'Physical security'). (Score = 3)

	Proportion	Volume	Impact	Priority
Worries about further benefit cuts	3	3	3	9

It's inevitable that a model such as this includes some level of subjectivity when calculating the score for each element. We recognise that this process could be validated further through extra research and/or consultation with the Local Voices network.

27 Overview of the survey results

This chapter gives an overview of the main results that came from the survey. It addresses the main responses to each question. Where we feel sub-analysis is reasonably robust, we've identified differences in particular sub-populations.

27.1 Number 1 issue

We asked people to identify their first and second biggest areas of concern from a list in the survey; 85 people answered this question.

For the areas of biggest concern, social care scored highest with 24.7% of respondents saying this was the number 1 issue. This was followed by health with 21.2%. Money and benefits concerned 14.1% of respondents, crime and safety and with transport each concerned 11.8% of respondents, followed by housing with 9.4%.

This is shown in the chart below:

What is the number 1 issue you are concerned about? (Select one from the list in the box below)
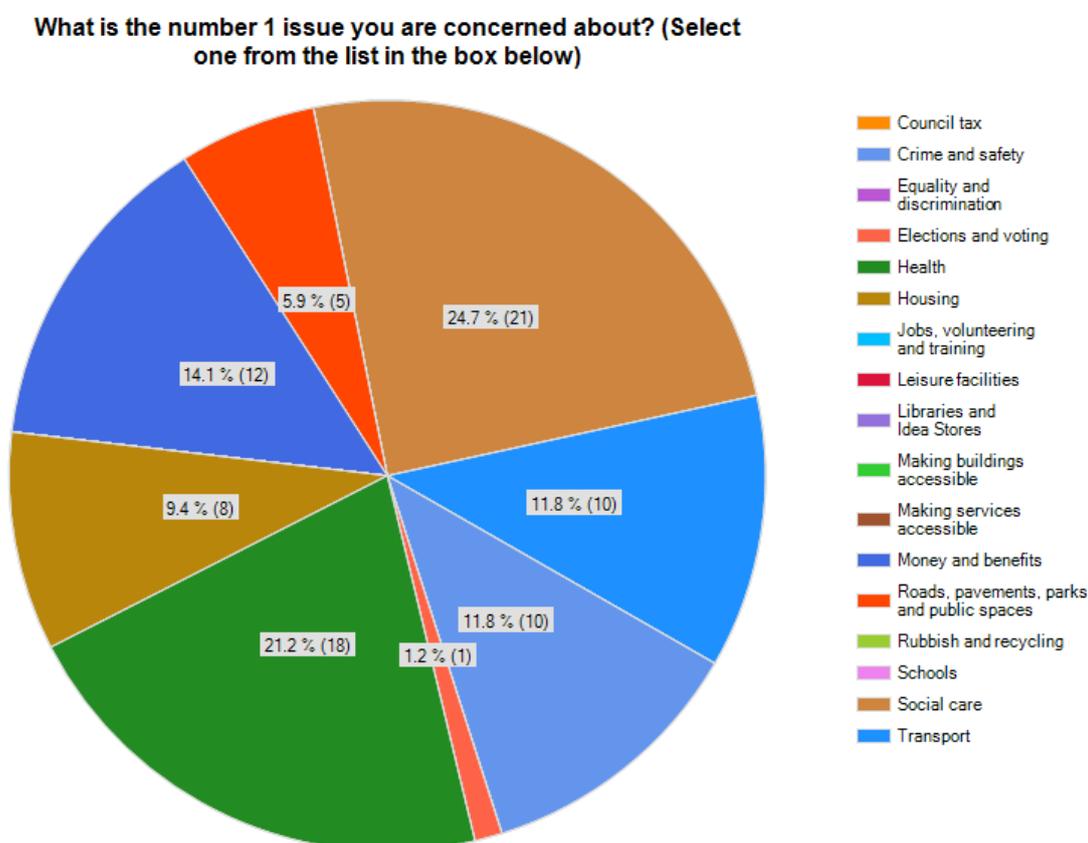
Council tax	0	0.0%
Crime & safety	10	11.8%
Equality and discrimination	0	0.0%
Elections and voting	1	1.2%
Health	18	21.2%
Housing	8	9.4%
Jobs, volunteering and training	0	0.0%
Leisure facilities	0	0.0%
Libraries and Idea Stores	0	0.0%
Making buildings accessible	0	0.0%
Making services accessible	0	0.0%
Money and benefits	12	14.1%
Roads, pavements, parks and public spaces	5	5.9%
Rubbish and recycling	0	0.0%
Schools	0	0.0%
Social Care	21	24.7%
Transport	10	11.8%
Total who responded	**85**	**100.0%**

27.2 Number 2 issue

Slightly less people (66 compared to 85) identified a number 2 issue of concern from the same list.

The range of people's choices was broader in this case. People's number 1 issue focussed on just 8 issues, whereas the number 2 issues reached across 15 topics.

Money and benefits now became the most chosen number 2 issue with 18.2%, followed by social care and transport each with 13.6% and then by health and housing, each with 10.6%. Lastly, crime and safety was the number 2 issue for 9.1% or respondents.

The chart showing the survey results for this question is shown below:

What is the number 2 issue you are concerned about?(Select one from the list in the box below)
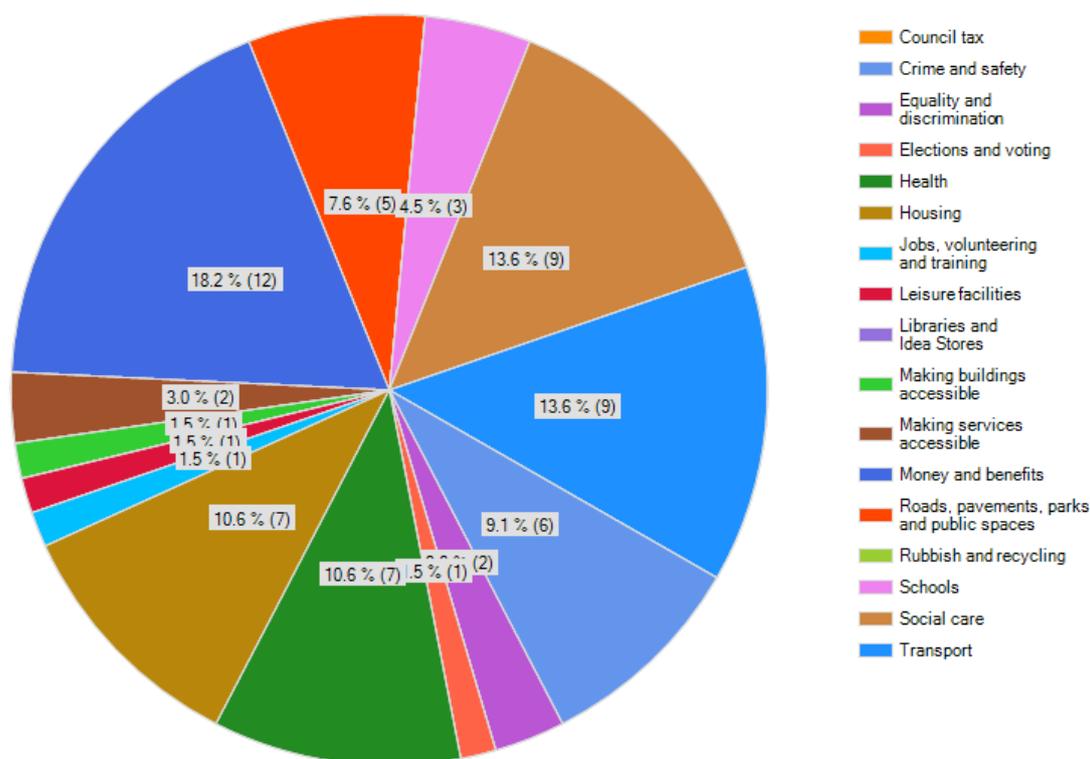
Council tax	0	0.0%
Crime & safety	6	9.1%
Equality and discrimination	2	3.0%
Elections and voting	1	1.5%
Health	7	10.6%
Housing	7	10.6%
Jobs, volunteering and training	1	1.5%
Leisure facilities	1	1.5%
Libraries and Idea Stores	0	0.0%
Making buildings accessible	1	1.5%
Making services accessible	2	3.0%
Money and benefits	12	18.2%
Roads, pavements, parks and public spaces	5	7.6%
Rubbish and recycling	0	0.0%
Schools	3	4.5%
Social Care	9	13.6%
Transport	9	13.6%
Total who responded	**66**	**100.0%**

27.3 All issues

When we combined people's number 1 and number 2 issues of concern, then social care is the biggest with 19.9%, followed closely by health (16.6%), money and benefits(15.9%), transport (12.6%) and crime and safety (10.6%).

A table grouping together first and second choices is shown below with percentage figures in this case representing percentage of responses (rather than percentage of respondents):

Identified as number 1 or 2 issue

Council tax	0	0.0%
Crime & safety	16	10.6%
Equality and discrimination	2	1.3%
Elections and voting	2	1.3%
Health	25	16.6%
Housing	15	9.9%
Jobs, volunteering and training	1	0.7%
Leisure facilities	1	0.7%
Libraries and Idea Stores	0	0.0%
Making buildings accessible	1	0.7%
Making services accessible	2	1.3%
Money and benefits	24	15.9%
Roads, pavements, parks and public spaces	10	6.6%
Rubbish and recycling	0	0.0%
Schools	3	1.9%
Social Care	30	19.9%
Transport	19	12.6%
Total who responded	**151**	**100.0**

27.3.1   Key issues for particular groups

We looked at what issues mattered more or what about each issue mattered for people from particular demographic groups (eg age, gender, ethnicity) or for those who shared any social characteristics (eg housing situation, employment status).

The survey results showed that:

- Social care was the main issue of concern for both male and female respondents, respondents under 60 (where the proportion rose to 27.8%), and respondents who identified as Asian.

- For people over 60, health became the main issue (40%), followed by social care and crime and safety both (both 16.7%). In contrast, only 5.6% of people under 60 identified crime and safety as their main issue.

- For respondents who identified as white, health was the main issue (29.7%), although social care was a close second (27%). These were also the main 2 issues for respondents who identified as Asian, but in this case followed by crime and safety (17.6%).

- For respondents with visual impairment the biggest single issue was transport (25%)

- For respondents with a mental health condition the single biggest issue was health (46.7%).

- Transport was the biggest issue for people with a visual impairment

27.4 Do council services serve disabled people well?

We then asked people which of a range of council services did not serve disabled people well. 60 people responded to this part of the survey.

People were able to choose as many services as they wanted when answering this question and they were 173 responses. So, each person thought an average of 3 services that didn't service disabled people well.

The steering group were very keen to ensure that this question was broad enough to cover accessibility and also whether it met their needs more generally.

Services that featured more prominently as not serving disabled people well were roads and pavement (37% of respondents) followed by social care (35%) and housing (33%).

Do you think there are particular services that do NOT serve disabled people well? (Please tick all that apply)

Service	Percentage (count)
Blue badge, freedom pass and taxicard	18.3 % (11)
Community transport	20.0 % (12)
Council tax and council tax benefit	10.0 % (6)
Crime and safety	28.3 % (17)
East End Life and Tower Hamlets Council website	10.0 % (6)
Elections and voting	3.3 % (2)
Leisure facilities	20.0 % (12)
Libraries and Idea Stores	8.3 % (5)
Housing applications, allocations and repairs	33.3 % (20)
Housing benefit	10.0 % (6)
One stop shops	10.0 % (6)
Parking	11.7 % (7)
Parks and open spaces	10.0 % (6)
Planning	5.0 % (3)
Public toilets	11.7 % (7)
Road and pavements	36.7 % (22)
Rubbish and recycling	3.3 % (2)
Schools	3.3 % (2)
Social care	35.0 % (21)

We also did some further analysis to establish whether different sub-groups of disabled people thought differently about these services.

- For female respondents the worst performer was housing (34%).

- For male respondents, social care was the worst performer (60%) with only 10% identifying housing.

- For people over 60, social care was the worst performer.

- For people under 60, housing was the worst performer.

- For respondents who identified as Asian the worst performer was housing (71%).

- For people identifying as white social care was the worst performer (31%).

- For people with a visual impairment, the worst performer was housing.

- For people with a mental health condition, the key issue is also housing.

27.5 Equality and discrimination

We also asked respondents a series of 5 questions around council attitudes, involvement, safety, accessibility and fairness. The results were as follows:

How strongly do you agree with these statements for people in Tower Hamlets
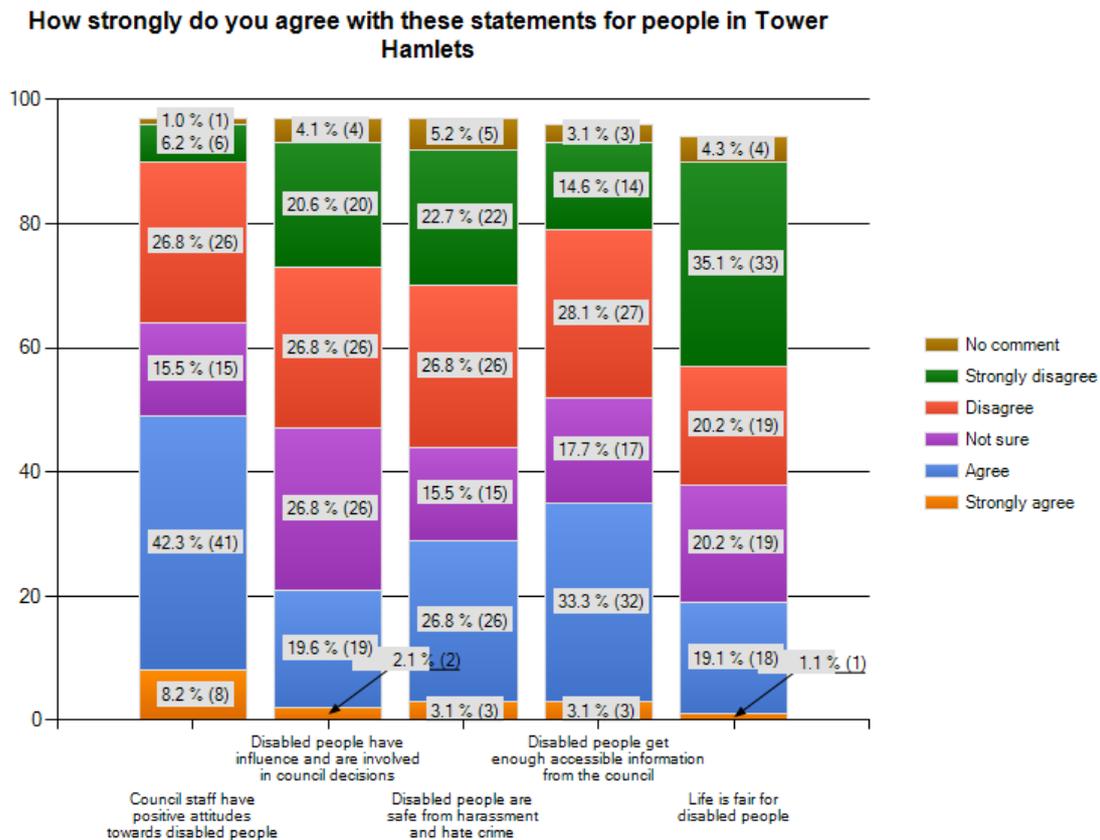
Although just over half of respondents felt council staff had a positive attitude towards disabled people, a third of respondents disagreed.

Only one fifth felt disabled people were involved in council decisions (and 47% felt they were not).

Nearly half of the respondents believed disabled people were not safe from harassment and hate crime (this rises to 65% for people with visual impairment and 87% for people with a mental health condition).

Just 36% of respondents believed disabled people get enough accessible information from the council, while 43% of people felt they did not.

20% felt life was fair for disabled people while 55% felt it was not.

Appendix 1: Survey questions

1. What is the number 1 issue you are concerned about?
(Select one from the list)

- Council tax
- Crime and safety
  Equality and discrimination
  Elections and voting
- Health
- Housing
- Jobs, volunteering and training
- Leisure facilities
- Libraries and Idea Stores
- Making buildings accessible

- Making services accessible
- Money and benefits
  Roads, pavements, parks and public spaces
  Rubbish and recycling
- Schools
  Social care
- Transport

2. For your number 1 issue, what are your concerns? What could be done about this?

3. What is the number 2 issue you are concerned about?
(Select one from the list)

- Council tax
  Crime and safety
- Equality and discrimination
- Elections and voting
  Health
  Housing
- Jobs, volunteering and training
- Leisure facilities
- Libraries and Idea Stores

- Making buildings accessible
  Making services accessible
- Money and benefits
- Roads, pavements, parks and public spaces
- Rubbish and recycling
- Schools
  Social care
- Transport

4. For your number 2 issue, what are your concerns? What could be done about this?

5. Are there any other issues that you want to tell us about?

6. How strongly do you agree with these statements for people in Tower Hamlets?
(Choose from Strongly agree /Agree / Not sure / Disagree/ Strongly disagree/ No comment)

- Council staff have positive attitudes towards disabled people
- Disabled people have influence and are involved in council decisions
- Disabled people are safe from harassment and hate crime
- Disabled people get enough accessible information from the council
- Life is fair for disabled people

7. Do you think there are particular services that do NOT serve disabled people well? (Please tick all that apply)

- Blue badge, freedom pass and TaxiCard
- Community transport
- Council tax and council tax benefit
- Crime and safety
- East End Life and Tower Hamlets Council website
- Elections and voting
- Leisure facilities
- Libraries and Idea Stores
- Housing applications, allocations and repairs
- Housing benefit
- One stop shops
- Parking
- Parks and open spaces
- Planning
- Public toilets
- Road and pavements
- Rubbish and recycling
- Schools
- Social care
- Other (please specify)

8. Do you have any further comments on these 2 questions?

9. What is the most important thing Tower Hamlets Council can do in 2013?

10. Please indicate the nature of your disability or long-term health condition (Tick as many options as apply to you.)

- Physical impairment (eg difficulty using your arms, missing limbs or mobility issues which mean you use a wheelchair or crutches)
- Visual impairment (eg blindness, significant sight loss or low vision)
- Hearing impairment (eg deafness, tinnitus or other hearing loss)
- Mental health condition (eg depression or schizophrenia)
- Learning disability / learning difficulty (eg Down's syndrome or dyslexia, or a cognitive impairment such as autistic spectrum disorder)
- Long-standing illness or health condition (eg cancer, HIV, diabetes, chronic heart disease, or epilepsy)
- Other disability or health condition

- I do not have a disability or long-term health condition

11. Do you live in Tower Hamlets? If you live in more than one place, do you mostly live in Tower Hamlets?
- I live in Tower Hamlets
- I do not live in Tower Hamlets

12. What kind of housing do you live in?
- Owned or being bought by you
- Rented from the council
  Rented from another social landlord
- Rented in the private sector
- Living in someone else's property without paying them (eg with family)

13. Do you study in Tower Hamlets?
- Yes, I study in Tower Hamlets
- No, but I study outside Tower Hamlets
- No, I don't study

14. What is your employment status?
(If more than one applies, pick the best match.)
- Employed, working 1-16 hours per week
- Employed, working 17 or more hours per week
- Self-employed
- Volunteering or unpaid work
- Not employed, looking for work
- Not employed, NOT looking for work
- Retired
- Not able to work due to disability/long-term health condition
- Prefer not to say

15. Do you work in Tower Hamlets?
(This could be paid work, or unpaid volunteering)
- I work in Tower Hamlets
- I work outside Tower Hamlets

16. Which category below includes your age?

17 or under	41-50	71-80
18-20		81-90
21-30	51-60	91 or over
31-40	61-70	

17. What is your gender?

- Male
- Female
- Female-to-male (FTM) transgendered man (trans man)
- Male-to-female (MTF) transgendered woman (trans woman)
- Other
- Prefer not to say

18. Please describe your ethnic group

- Asian – Bangladeshi
- Asian – Pakistani
- Asian – Vietnamese
- Asian – Indian
- Asian – Chinese
- Asian – Other Asian
- Black – British
- Black – Caribbean
- Black – Somali
- Black – Other African
- White – British
- White – English
- White – Scottish
- White – Welsh
- White – Irish
- White – Gypsy/Traveller
- White – Other White
- Mixed race/dual heritage
- Other
- Prefer not to say

19. Please indicate your religion or belief

- Buddhist
- Catholic
- Christian
- Hindu
- Jewish
- Muslim
- Sikh
- A follower of another religion
- Not religious
- Prefer not to say

20. What is your sexual orientation?

Bisexual
Gay man / homosexual
Gay woman / lesbian
Straight / heterosexual
Other
Prefer not to say
If you have another sexual orientation, please say which

Appendix 2: Full list of contents

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