Removing barriers, raising disabled people’s living standards

May 2014
Acknowledgements

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Executive summary

Introduction

This report contains the findings from a research programme aimed at understanding disabled people’s priorities for change. The research was commissioned by the disability charity Scope, and conducted by OPM (focus groups and qualitative interviews) and Ipsos MORI (national survey).

This research contributes to the evidence base and to the case for action to work with disabled people to improve living standards.

The methods used in this research involved two key elements:

- In-depth qualitative research, conducted by OPM, including 10 focus groups and 30 one-to-one interviews with disabled people with a range of experiences.
- Quantitative survey research, conducted by Ipsos MORI, including an online survey of 1,674 disabled people and a face-to-face survey with 371 disabled people.

The survey findings show us the prevalence of different experiences and perceptions, both amongst the disabled population as a whole and amongst specific groups. The qualitative findings then allow us to explore in more depth why some of these patterns may be as they are, as well as giving us powerful insights into the experiences of individual disabled people.

The big picture

Satisfaction with life – findings from the survey

Our survey found that disabled people are less satisfied with life than the population as a whole. If we contrast the scores given in our research with results from The Annual Population Survey (although the two surveys are not directly comparable), we see that disabled people give a mean score of 5.9 out of 10 for life satisfaction, compared to 7.4 for the general public \(^1\). Life satisfaction is lower among some groups of disabled people than others, notably disabled people of working age (a mean score 5.54 vs. 6.57 for disabled people over 65) and disabled people with children (5.53 vs. 6.05 for disabled people without children). People with an intellectual, social or behavioural or learning difficulty give the lowest life satisfaction rates by impairment type (5.09).

\(^1\) First Annual ONS Experimental Subjective Well-being Results, Office for National Statistics, July 2011, [http://www.ons.gov.uk/ons/dcp171766_272294.pdf](http://www.ons.gov.uk/ons/dcp171766_272294.pdf). In this research, almost two in five (38.5 per cent) people who described themselves as having a ‘work-limiting disability’, ‘DDA disability’ or both, gave a rating of less than 7 out of 10 for the ‘life satisfaction’ question (indicating lower life satisfaction). This is almost twice the proportion of non-disabled people (19.4 per cent).
Overarching barriers and challenges faced by disabled people

The focus groups and in-depth interviews provide insights into a number of possible thematic explanations for disabled people feeling less satisfied than non-disabled people. In summary the qualitative research suggests disabled people face notable barriers in relation to:

- Having sufficient choice and control – for example limits to choice of employment, or choice and independence of young disabled people.
- Access and inclusivity – including around the accessibility of places and spaces and the inclusiveness of mainstream education and the workplace.
- Having their voice heard – despite being no less likely to want to get involved in improving society, disabled people consistently reported not being listened to.
- Stigma and discrimination – compounding the other challenges, many disabled people are treated unequally because of the stigma attached to their condition.
- Participation and connectedness – the research suggests that reduced funding and other pressures are limiting the ability of disabled people to maintain social connections.

We asked disabled people to tell us which areas of life they find most challenging. As the chart below illustrates, health and wellbeing is the area most people find challenging, with seven in ten (71%) identifying this. This is followed by money and benefits, a challenging area for two in five (41%) disabled people, and leisure at over a third (35%).

Fig. A In which of these areas, if any, do you find life challenging? Please select all that apply.

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Base: All disabled respondents (2,045)

Disabled people choosing more than one option were asked to identify what their most challenging area is, and later in the survey were asked what their second most challenging area is.
challenging area of life is. As the chart below shows, the key areas in life disabled people find most challenging are health and wellbeing, money and benefits, and work and employment.

**Fig. B Challenging areas of life**

<table>
<thead>
<tr>
<th>Area</th>
<th>Most Challenging</th>
<th>Second Most Challenging</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health and well-being</td>
<td>59%</td>
<td>16%</td>
</tr>
<tr>
<td>Money and benefits</td>
<td>27%</td>
<td>12%</td>
</tr>
<tr>
<td>Work and employment</td>
<td>15%</td>
<td>7%</td>
</tr>
<tr>
<td>Social &amp; Community life</td>
<td>8%</td>
<td>8%</td>
</tr>
<tr>
<td>Leisure</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>Family life</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>Transport</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Care and support</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Crime, safety and security</td>
<td>2%</td>
<td>2%</td>
</tr>
</tbody>
</table>

*Base: All disabled people (2,045)*

**What needs to change?**

**Attitudes in health and social care**

Research participants who took part in the qualitative research feel very strongly that there is an urgent need for a change in the attitudes and behaviour of health and social care professionals and staff, through training and education. More specifically, they feel that health and social care professionals need to make more time for disabled people:

“I find they are always in a rush if they are explaining something to you ….they are just doing tick boxes with you to get out of the door.”

Hammersmith focus group

They also feel that they need to have more empathy and sensitivity and a better understanding of the social impact of their conditions. Participants feel that disabled

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It is worth mentioning here that no one under 16 took part in the quantitative research and we did not design the sample to specifically include parents of disabled young people/children. It is reasonable to assume that education would feature more strongly in research among both groups.
people themselves are best placed to deliver such training and awareness-raising effectively. However any organisations seeking to tackle this problem with attitudes will need to be aware of the systemic and structural constraints acting on health and social care professionals in terms of many competing priorities for training and limited funding.

Financial wellbeing

Many participants who took part in the qualitative research feel that the government could do more to make disabled people a priority and ensure that they are not disproportionately affected by the reductions in public expenditure. They also feel that it needs to be recognised that good working arrangements are those that allow for flexibility, including part-time working and self-employment.

Participants also feel that there is an urgent need for a more sensitive benefits applications and assessment process that ‘treats people as people not just as figures.’

Employment and education

Research participants who took part in the qualitative research feel that key changes relate to greater awareness and training for employers and education providers delivered by disabled people. In particular, they feel there is a need for employers to have a better appreciation for the types of support that allows disabled people to stay in and perform highly in their jobs.

Research participants also feel that there is a need for more positive attitudes in relation to recruitment such as accessible job application and recruitment processes. This includes employers having a better understanding of reasonable adjustments and being more sensitive when asking questions about gaps in employment. Some participants also feel that there is a need for greater support with job applications and finding employment and, finally, the government playing a bigger role in enforcing employment practices.

Leisure, social connections and living independently in the community

A number of changes to leisure, social and community life were suggested by participants in the focus groups and interviews. These included the involvement of disabled people in the design of places and spaces, in order that the needs of different impairment groups are taken into consideration.

They also felt that there is a need for national and local government to play a ‘regulatory’ and ‘enforcement’ role to ensure that spaces, places and transport are accessible for disabled people. Some also felt that there is a need for more support for DPOs given that they play a valued role in enabling disabled people to establish and maintain a sense of social connectedness.
Public attitudes

Participants in the focus groups and interviews made a number of suggestions to improve attitudes towards disability. These included changing children and young people's attitudes to disability. Participants felt strongly that in order to tackle the discrimination and stigma associated with disability, attitudes needed to be shaped at an early age.

Participants also recommended delivering disability-specific awareness campaigns and greater positive representation of disabled people on the television and in mainstream media.

Working together to raise living standards

Survey respondents were asked what role they would like to play in improving society for themselves and other disabled people. The key ways in which disabled people would like to be involved are: educating non-disabled people (21%), supporting or mentoring other disabled people (14%) and taking part in campaigns to change something locally or nationally (12%).

Over half (57%) of disabled people want to be involved in improving society for themselves and other disabled people. This is a higher proportion than some of the figures for the public as a whole seen in other surveys. For example The Audit of Political Engagement shows that only a third (33%) of the general public want to be involved in decision making nationally and around two in five (38%) involved at a local level.

Survey findings suggest that a desire to get involved is related to age and how limited people feel in their day-to-day lives, with those of working age and those feeling very limited having a greater appetite for getting involved.

As well as their own involvement, those in the qualitative research identified charities and the government as having vital roles to play in helping to deliver this change. While they felt it was the role of charities to protect the interests of disabled people and use their contacts in government and media to influence change, they felt the government had to lead the way in changing attitudes to disabled people and reversing the damage done with the portrayal of disabled people by the media as ‘benefit scroungers’ and as ‘undeserving’ benefit claimants.

Participants also called for government to listen to the needs of disabled people, in order to make policy decisions which took into account diverse needs among disabled people.

Conclusion

It is clear from the research presented in this report that disabled people have wide ranging ideas about the positive changes that would make important differences to various domains of their lives and improve their living standards. There are a few key themes and common threads that underpin these ideas and suggestions:
• **Greater awareness and a better understanding of disability** has the potential to improve disabled people’s lives considerably. Participants advocate training to be delivered by disabled people themselves, aimed at building this awareness among health and social care professionals, employers, education providers and benefit application assessors. They also call for the delivery of disability specific campaigns which they feel play a role in challenging ignorance.

• Research participants also advocate strongly for more positive attitudes and for **being treated with greater sensitivity and empathy**. This related to a wide range of people including health and social care staff, employers and children and young people.

• Many disabled people feel that various aspects of their lives could be better if they had access to **more tailored information and personalised support**. Examples include better information about the accessibility of buildings and spaces, and support for interviews and during employment.

• Participants also believe that removing the barriers disabled people face, depends on the **government playing a greater regulatory and enforcement role**. This relates to ensuring that spaces, places and transport are accessible for disabled people and that employers have policies, strategies and processes in place that relate to ensuring equal consideration of disabled people for job opportunities.
1. Introduction

1.1 Background, context and objectives

This report contains the findings from a research programme aimed at understanding disabled people’s priorities for addressing the barriers they face in their everyday lives. The research was commissioned by the disability charity Scope, and conducted by OPM (focus groups and qualitative interviews) and Ipsos MORI (national survey).

Considerable data are available about the experiences and expectations of disabled people in the UK, including the structural and attitudinal barriers faced. The most recent large scale research evidence available, from the ONS Life Opportunities Survey, shows that these barriers are significant and profound. As well as barriers relating to education, employment, transport and housing, disabled people surveyed were more likely than non-disabled people to experience barriers in the way of frequent social contact.

Few studies, however, give a national picture of the perspective of disabled people on where priorities should be set in addressing the barriers they face. As such, this research and report constitutes a significant contribution to the evidence base and to the case for change to improve disabled people’s living standards.

This study builds on previous research such as the cross-sectional research in the Office for Disability Issues (ODI) report ‘Experiences and expectations’³, which included a major focus on civic participation and social networks.

The ODI study found, for example, that many disabled people – particularly younger disabled people and those with mental health conditions – reported attitudinal and other barriers to civic participation and engaging in social networks (a quarter of younger disabled people reported this). Most strikingly: the proportion of disabled people engaging in learning activities – a crucial indicator of social interaction – was much lower than the population as a whole (one in ten compared to one in four).

To a certain extent this research also shared with other studies a focus on the capacity of disabled people themselves to be part of communities, civic participation and social change (e.g. whether they had taken action to solve a local problem, whether they volunteered) rather than the systemic, behavioural and attitudinal constraints imposed by society itself. There is therefore very little evidence that has applied the social model of disability – a model that argues that disability is the product of society’s failure to deal with the needs of a disabled person, and that has become widely accepted due in part to the rapid growth of the disabled people’s movement since the 1960s⁴.

⁴ For more on this, see Hasler (1993), Davis (1993) or Campbell and Oliver (1996).
In order to build up a more sophisticated picture, the methods used in this research involved two key elements:

- In-depth qualitative research, conducted by OPM, including 10 focus groups and 30 one-to-one interviews with disabled people with a range of impairments and/or mental health conditions.
- Quantitative survey research, conducted by Ipsos MORI, including an online survey of 1,674 disabled people and a face-to-face survey with 371 disabled people.

Taken together, these two strands of research help to tell a coherent and rounded story about the barriers to living standards that disabled people face, and their aspirations for change. The survey findings show us the prevalence of different experiences and perceptions, both amongst the disabled population as a whole and amongst specific groups, and allow us to establish the different weightings attached to a range of issues and priorities. The qualitative findings then allow us to explore in more depth why some of these patterns may be as they are, as well as giving us a powerful insight into the experiences of individual disabled people.

1.2 Principles underpinning the research

Collaboration and co-design

We worked closely with a ‘coproduction group’ of disabled people. The group oversaw the design and development of the research, and helped with the analysis and interpretation of the findings. The coproduction group met four times over the life of the project and was also consulted with regularly via email.

Valuing disabled people’s contribution

Through this research, disabled people were asked to contribute their time, expertise and energy to help coproduce a research project which is grounded in their experiences. We offered a financial incentive for participation in the qualitative research as due recognition of the expertise and time that people committed to the project.

Ensuring accessible tools and venues

We were committed to designing research tools that were accessible and easy to use. This included careful planning relating to accessibility such as easy read topic guides for participants with learning disabilities and visual supporting tools such as drawing, symbols or photosymbols, and to the data collection methods employed. We also ensured that the location of any interview, group or event was easily accessible by public transport and accessible under the provisions of the Equality Act.
A commitment to the social model of disability

As noted earlier, many studies focus on the capacity of disabled people themselves to be part of communities and get involved in civic participation. This research, on the other hand, has taken into account the systemic, attitudinal and behavioural constraints imposed by society that restrict the ability of disabled people to address the barriers they face.

1.3 Qualitative research methods

Expert interviews and rapid review of evidence

To help inform the design of this research and build on the existing evidence base, OPM conducted ten interviews with disability experts, change experts and members of the coproduction group. The interviews explored participants’ understanding of the concept of social change, their reflections on significant past and future changes that have had an impact or will impact on disabled people and the factors that will be important in addressing the barriers that disabled people face.

To complement these perspectives we also completed a rapid review of selected research and evidence on disability inequality and the experiences and aspirations of disabled people in the UK.

Focus groups with disabled people

Following the expert interviews and rapid review of evidence, OPM designed the topic guide to be used in focus groups with disabled people, with input from colleagues at Scope and the coproduction group. Feedback from experts emphasised that discussions about change needed to be grounded in the everyday lived experience of disabled people. The guide was further refined after the first four groups were completed, in order to ensure that there was a better balance between ‘looking at change in the past’ and ‘aspirational and future changes’. It was designed to be used flexibly, depending on the support needs and group dynamics of the participants. An easy-read version of the guide was developed for use with groups attended by people with learning disabilities. Copies of the guides can be found in Appendix 1.

Recruitment for focus groups involved contacting a range of Disabled People’s Organisations (DPOs) and disability charities to introduce the research and identify the extent to which they were able and willing to help recruit for the qualitative fieldwork. The list of organisations to contact was largely drawn from OPM’s previous work in the area as well as recommendations from Scope. Organisations were offered a £150 donation as a thank you for helping with recruitment and to cover staff time. We also offered a £25 high-street voucher to focus group participants as a thank you for taking part.

A total of ten focus groups were completed with disabled people with good coverage across urban and rural areas, different impairment groups and age groups as well as with representation from Black and Minority Ethnic (BME) and Lesbian, Gay,
Bisexual and (LGB) groups. Further details about the sample can be found in Appendix 2.

**Interviews with disabled people**

OPM conducted 30 in-depth, semi-structured telephone interviews with disabled people with a range of physical and/or sensory impairments, mental health conditions and cerebral palsy. People with learning disabilities were not included in the interview sample because of their over-representation in the focus groups. Participants were recruited through DPOs, disability charities, the coproduction group and through snowballing – where interviewees were asked to suggest potential participants. The interview guide was adapted from the focus group guide and a copy of this can be found in Appendix 3. Additional details about the sample can be found in Appendix 4.

**1.4 Quantitative survey research methods**

A representative survey of 2,045 disabled adults aged 16+ in Great Britain was conducted between 14 June 2012 and 13 July 2012. Further details about the sample and the survey questions can be found in Appendix 5 and Appendix 6 respectively.

Interviews were conducted online using the Ipsos Panel and face-to-face over three waves of the Ipsos MORI weekly Capibus. The Capibus provided a representative quota sample of adults aged 16+ across 154 sampling points. From this sample, participants were screened for disability and use of the internet, with interviews conducted among those who did not regularly use the internet (defined as those who used it once a month or less). As a significant proportion of the disabled population do not use the internet, the intention behind the face-to-face element was to allow a wider pool of disabled people to take part, and therefore provide a more representative sample for the survey. Interviews were conducted in-home, using CAPI (Computer Assisted Personal Interviewing).

For the online survey, a representative sample was drawn from the existing Ipsos panel of disabled panellists with participants screened for disability. Data from the Family Resources Survey (FRS) were used to estimate demographics for the disabled population and hard quotas set on age, gender, and working status. In addition, balancing quotas were set on region. Following fieldwork, the combined data for the online and face-to-face fieldwork was compared to the FRS data to see if the data would need to be weighted for representativeness. As the demographic profile closely matched that drawn from the FRS, the decision was made not to weight the data.

**In total, 1,674 interviews were conducted online and 371 interviews face-to-face.**

<table>
<thead>
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<th>Count</th>
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<tr>
<td>Female</td>
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## Age group

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<tr>
<td>State pension age (65+)</td>
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## Employment

<table>
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</tr>
<tr>
<td>Not working</td>
<td>1616</td>
</tr>
</tbody>
</table>
2. The big picture

The chapters that follow look at specific areas of the lives of disabled people and explore what makes these areas challenging and the changes that would improve material and non-material living standards. However, in order to provide important context for that analysis, it's worth standing back to consider the bigger picture. The sections below highlight the background and context for this research, findings from the survey about overall satisfaction and disabled people’s highest priorities for change, and the overarching barriers and challenges facing disabled people that were highlighted in both the qualitative and quantitative research. These barriers describe the overall social pressures that disabled people face and thus define the parameters of the changes prioritised in specific areas of people's lives.

2.1 Background and context

More than eleven million people in Britain have a limiting long-term illness, impairment or disability. As the evidence summarised below demonstrates, disabled people are more likely to live in poverty, be unemployed, experience discrimination at work or be targets of crime than other members of society:

- Families with disabled members are more likely to live in poverty (20% of individuals in families with at least one disabled member live in relative income poverty compared to 16% of individuals in families with no disabled member).
- Disabled people are far less likely to be in employment. In 2012, the employment rate of disabled people was 48.9%, compared with 78.0% of non-disabled people.
- Disabled people are more likely to experience unfair treatment at work than non-disabled people (19% of current or recent disabled employees versus 13% of non-disabled employees).
- Disabled people are around twice as likely not to hold any qualifications compared to non-disabled people, and around half as likely to hold a degree-level qualification.
- Disabled people are more likely to be victims of crime than non-disabled people. This gap is largest amongst 16-34 year-olds, with 39% of disabled people reporting having been a victim of crime compared to 28% of non-disabled people.

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7 Labour Force Survey, Quarter 2, 2012
8 Fair Treatment at Work Survey 2008 (see Fevre et al. 2008)
9 Labour Force Survey, Quarter 2, 2012
10. Disabled people are also more likely to be victims of personal hate crimes than non-disabled people (0.2% vs. 0.4%)\(^{11}\).

The Welfare Reform Act 2012, and reform of Disability Living Allowance with the introduction of the Personal Independence Payment in April 2013 constitute significant changes to the financial support that many disabled people rely on. As Scope’s research shows, money and benefits represent a significant challenge for disabled people\(^ {12}\).

There are indications that the general public is becoming less sympathetic to those less well off. In 1987, 55% agreed that the Government should spend more money on welfare benefits for the poor, even if it leads to higher taxes. By 2009 this had fallen to 27%\(^ {13}\). This has implications for disabled people and indeed Ipsos MORI’s research for Mencap shows that a majority of the public believe that at least some of the claims made for disability benefits are bogus\(^ {14}\).

### 2.2 Satisfaction with life – findings from the survey

Our survey indicates that disabled people are less satisfied with life than the population as a whole. If we contrast the scores given in our research with results from The Annual Population Survey (although the two surveys are not directly comparable as they used different methodologies for the data collection) we see that disabled people give a mean score of 5.9 out of 10 for life satisfaction, compared to 7.4 for the general public\(^ {15}\).

**Fig.1** Overall, how satisfied are you with your life nowadays? Please use a scale of 0 to 10, where 0 is not at all satisfied and 10 is completely satisfied.

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\(^{10}\) British Crime Survey 2010/11


\(^{12}\) Ipsos MORI (2013) Disabled people and financial well-being.

\(^{13}\) Ipsos MORI analysis of British Social Attitudes survey dataset


\(^{15}\) First Annual ONS Experimental Subjective Well-being Results, Office for National Statistics, July 2011, [http://www.ons.gov.uk/ons/dcp171766_272294.pdf](http://www.ons.gov.uk/ons/dcp171766_272294.pdf). In this research, almost two-fifths (38.5 per cent) of people who described themselves as having a 'work-limiting disability', 'DDA disability' or both, gave a rating of less than 7 out of 10 for the 'life satisfaction' question (indicating lower life satisfaction). This is almost twice the proportion of non-disabled people (19.4 per cent).
Life satisfaction is lower among some groups of disabled people than others, notably disabled people of working age (a mean score 5.54 vs. 6.57 for disabled people over 65) and disabled people with children (5.53 vs. 6.05 for disabled people without children). People with an intellectual, social or behavioural or learning difficulty give the lowest life satisfaction rates by impairment type (5.09).

Key driver analysis was undertaken to identify which of the challenges experienced by people were the strongest drivers of satisfaction with life. The model constructed explains 23% of the variation in the satisfaction from person to person, which is reasonable given the extent and complexity of the potential factors that can influence life satisfaction. The model found seven drivers to be significant, with ‘money and benefits’ being the most important. The percentages in the chart show the relative strength of each driver in explaining the variance to the question of overall satisfaction with life.

Fig.2 Significant drivers of satisfaction

* Source for general public score: Office for National Statistics, Annual Population Survey April-September 2011, Base: UK adults aged 16+ (80,000).
Removing barriers, raising disabled people’s living standards

Our analysis also found that the total number of areas that disabled people find challenging in relation to living standards is a very significant driver of life satisfaction. The more areas of life someone finds challenging, the lower their level of satisfaction, with no ‘levelling off’ when a particular number of areas is reached. The number of challenges disabled people face therefore has a cumulative impact on their overall feelings about their lives.

2.3 Overarching barriers and challenges faced by disabled people

The focus groups and in-depth interviews provide insight into a number of possible thematic explanations for disabled people feeling less satisfied than non-disabled people. Each of these is picked up again in more detail in the chapters that follow, but in summary the qualitative research suggests disabled people face notable barriers in relation to the following factors.

**Having sufficient choice and control**

One of the key planks of government policy in the UK and elsewhere over the last ten years has been to ensure that disabled people (and indeed non-disabled people) can exercise a good degree of choice over the services they receive, and enjoy a strong feeling of autonomous control.  

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Overall satisfaction with life

- Money and benefits: 17.0%
- Social and community life: 14.5%
- Housing: 13.4%
- Health and wellbeing: 12.9%
- Care and support: 11.4%
- Work and employment: 11.1%

This model explains 23% of the variation in satisfaction

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16 DH (Department of Health) (2001) Valuing people: a new strategy for learning disability for the 21st century, London: The Stationery Office; HM Government (2007) Putting People First: a shared vision and commitment to the transformation of adult social care. This document is a concordat with the Local Government Association, the Association of Directors of Adult Social Services, the NHS, the Social Care Institute for Excellence and others. Much material on personalisation has been written since the concordat was published, including a range of Department
This research suggests that there is a long way to go to fulfil this aim: with examples of health and social care support options being tightly limited, a benefits application process that makes it very difficult for disabled people to exercise choice over the kind of work they do (i.e. by privileging full-time over part-time work), and the inadvertently limiting impact of family attitudes, which can mean that disabled young people have decisions made on their behalf rather than having a say.

**Barriers to access and inclusion**

Moving towards equality of outcome for disabled people’s living standards means, in many areas of life, making reasonable adjustments to increase the accessibility of everything from shops and services to employment and education.

In addition to the challenges and barriers centring on health and social care and negative attitudes, both of which can have a knock-on effect in terms of accessibility, this research suggests three areas where there’s a long way to go in terms of improving inclusive access:

1. **Accessibility in the workplace.** In common with other research and evidence, this report highlights a consistently exclusive labour market and workplace, with lack of adjustments made to the recruitment process, and evidence of lack of appropriate support for disabled people once in a job.

2. **Inclusivity in mainstream education.** Disabled people involved in the research with current or recent experience of mainstream education reported patchy awareness of different conditions amongst school staff and fellow students.

3. **Accessible leisure and cultural activities.** Over and above the challenges involved in accessing leisure and other activities caused by disabled people’s health conditions, lack of tailored support, accessible information, and basic inaccessibility of places and spaces are serious issues.

**Having my voice heard**

The survey findings suggest that, despite the significant challenges they face, disabled people are no less likely than the population as a whole to want to get involved in improving society and conditions for themselves and others. This matches the findings from OPM’s review of the UK’s progress in meeting its commitments as a signatory to the UN Convention on the Rights of People with Disabilities, which showed, for example, that disabled people participated in elections at the same rate as non-disabled people. Indeed, many of the participants in the focus groups and in-depth interviews demonstrated enthusiasm for getting involved in campaigns, awareness raising and training.

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Yet despite this, the research suggests a strong feeling of disabled people’s voices not being listened to, for example in national policy debates or budget settlements. The research suggests that meaningful involvement is a positive thing in and of itself, and is a fundamental, non-negotiable requirement for positive change. We also know from the UN Convention research mentioned above that particular groups of disabled people – for example those over 75, living in low income households, or in certain BME communities – are much less likely to be active participants in civil life.

**Negative attitudes, stigma and discrimination**

The qualitative research suggests that many disabled people face an additional challenge (over and above the others) caused by the stigma attached to their condition. This was felt particularly strongly by people with mental health conditions and learning disabilities and was felt most acutely in the case of ‘critical moments’ such as getting access to health and social care and getting a job.

The research findings suggest that systemic and structural pressures may be at least partly to blame and that pressures on time and resources are likely to mean that professionals and carers struggle to provide disabled people with the level of attention they are due. But more than this, the research suggests a broader problem of a society that may, in some cases, be awkward with disability. For example, the people we spoke to described widespread stigmatisation in the national media.

**Participation and connectedness**

Research participants spoke of the empowering impact of being able to establish and maintain a sense of connectedness, whether with other disabled people or people in general, and the important role of DPOs and other local community groups in fulfilling this aim. Yet the research also shows that in the current climate, funding to support these groups and organisations is under threat. And yet this kind of support is not a luxury. Findings from our research indicate, as laid out in the following chapters, feelings of isolation and segregation can quickly spiral to cause very real negative impact on disabled people’s mental health and sense of wellbeing.

**2.4 Challenging areas of life**

We asked disabled people to tell us which areas of life they find challenging. As the chart below illustrates, health and wellbeing is the area most people find challenging, with seven in ten (71%) identifying this. This is followed by money and benefits, a challenging area for two in five (41%) disabled people, and leisure at over a third (35%) of people.

**Fig.3 In which of these areas, if any, do you find life challenging? Please select all that apply.**
It’s notable that the challenges chosen by disabled people differ from the drivers of overall satisfaction identified in our analysis in the previous section. While health and wellbeing is an important factor, money and benefits, family life, community and social life and housing all have more weight. Given that some of the other factors, such as family life, are very personal and complex, they may be difficult to explain or even admit to. In contrast, health is relatively straightforward and disabled people will often be very used to discussing such issues on a regular basis – itself arguably a function of the dominance of the medical (impairment-focused) model amongst health and social care professions. Another possible explanation is that as health is an issue that affects most disabled people, so its ability to predict differences in life satisfaction is limited.

Disabled people choosing more than one option were asked to identify what their most challenging area is, and later in the survey were asked what their second most challenging area of life is. As the chart below shows, the key areas in life disabled people find most challenging are health and wellbeing, money and benefits, and work and employment ¹⁸.

Fig. 4 Challenging areas of life

¹⁸ It is worth mentioning here that no one under 16 took part in the quantitative research and we did not design the sample to specifically include parents of disabled young people/children. It is reasonable to assume that education would feature more strongly in research among both groups.
The social model emphasises the societal barriers (for example attitudes and institutions) that disable people, rather than people being disabled because of their impairments. However adhering to the social model does not mean ignoring these impairments. Condition and impairment management is an important resource and part of life for disabled people. The social model recognises this and the participants in the focus groups and in-depth interviews spoke powerfully and consistently about the significant challenges they faced in relation to managing their conditions or impairments. For example, many participants highlighted the negative impact of the disrespectful attitudes sometimes displayed by health and social care professionals.

We also asked disabled people to think about a time they faced the biggest challenge in these areas of life and what issues were involved in making it challenging. Where people chose more than one issue, we asked which one or two of these they would most like to see changed. As the following chart illustrates, most disabled people who have faced a challenge due to two or more issues would like to see their general health or condition changed for the better (59%).

Looking beyond health and conditions the most significant issues are around money, with a quarter (25%) of disabled people who have faced a challenge in two or more areas saying they would most like to see a change for the better in this area. This shows the clear importance of money in the lives of disabled people. As we have discussed, disabled people are economically disadvantaged, and are also facing significant changes to benefits entitlements.

The attitudes and behaviour of others, as well as disabled people’s own levels of confidence, are also of importance. Around a quarter (24%) of disabled people who have faced a challenge in two or more areas would like to see a change for the better in their own anxiety/lack of confidence. This echoes Ipsos MORI’s research for Leonard Cheshire which found that many disabled people are not aware of their rights or do not feel confident enough to engage in a legal battle when they are
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victims of discrimination. Around a fifth (19%) would like to see other people’s attitudes or behaviour change for the better.

**Fig 5.** Thinking of all the issues that have made [option] challenging for you, which one or two would you most like to see changed for the better?

In the following chapters we look in detail at what areas of lives are challenging and for whom. Chapters three, four, five and six address the challenges disabled people experience around four of the core areas of their lives – health and social care, money and benefits, employment and education, and leisure, social and community life – and, for each, identify the priorities to make things better. Chapters seven and eight address important cross-cutting themes: chapter seven focuses on the experiences and impact of negative attitudes (held by the general public, the media, local communities and even families), while chapter eight looks at who needs to be involved in delivering and achieving the change that will remove the barriers disabled people face.

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## 3. Attitudes in health and social care

### Summary of key findings:

- Health and wellbeing is the issue most likely to be found challenging by disabled people that participated in this research, with six out of ten (59%) people reporting this as a main or secondary challenge in life. Among those who identify this as a main or secondary challenge, women are more likely than men to say their own anxiety/lack of confidence is an issue (37% compared to 27%) and are also more likely to mention other people’s attitudes and behaviour (23% compared to 16%).

- The Marmot Review\textsuperscript{20} has made it clear that we cannot tackle health inequalities without tackling social inequalities and this message came through strongly in the qualitative research. Participants in focus groups and qualitative interviews, particularly those with mental health conditions, reported that their experiences of health and social care are often marred by stigma and discrimination, with professionals treating disabled people like children, not taking them seriously and confusing mental health conditions for learning disabilities.

- The qualitative research also revealed a number of other issues that contributed to participants experiencing health and social care as a significant challenge. Many participants reported receiving insufficient support, particularly from social care services, poor experiences of diagnosis/post-diagnosis support, and ineffective joining up between health and social care services. These experiences often mean that participants are unable to access personalised support or exercise sufficient choice and control.

- Research participants feel very strongly that there is an urgent need for a change in the attitudes and behaviour of health and social care staff, through training and education. They feel that health and social care professionals need to make more time for disabled people, have more empathy and sensitivity and have a better understanding of conditions. Participants feel that disabled people themselves are best placed to deliver such training and awareness-raising effectively. However any organisations seeking to tackle this problem will need to be aware of the systemic/structural constraints acting on health and social care professionals in terms of many competing priorities for training and limited funding.

### 3.1 The social determinants of health

Having the care and support you need to go about your everyday life, to get dressed, get washed, have a meal and leave the house, are prerequisites for many of the areas of life covered in this report. In its absence, the ability to learn, work and

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participate in community life or leisure and cultural activities, are all significantly hampered.

As such it is not surprising that challenges around health and wellbeing were barriers reported by many disabled people. Health and wellbeing is an area of life found challenging by seven in ten (71%) disabled people and is a main or secondary barrier for six in ten (59%). When those identifying health and wellbeing as a main or secondary challenge in life were asked about the issues involved when they faced their biggest challenge in this area, by far the most pertinent is general health or condition (83%), and this is also the area most of those who faced more than one issue would like to see changed for the better (70%). Moreover, anxiety/lack of confidence was considered to be a major challenge by a third (33%) of disabled people identifying health and wellbeing as a main or secondary challenge, as illustrated in the chart below.

Fig.6 Thinking of a time when you faced the biggest challenge relating to health and wellbeing which, if any, of the following issues were involved?

Thinking of all the issues you have said made health and wellbeing challenging, which one or two would you most like to see changed for the better?

Barriers faced
Barriers people most want changed for the better

Your general health or condition

Your anxiety/lack of confidence

Money issues

Other people's attitudes or behaviour

Difficulty getting into buildings or using facilities

Base: All respondents who faced a main or secondary challenge in health and well-being (1,192), All respondents who faced a challenge in health and well being due to two or more issues (627)

However, we also need to understand why disabled people find health such a challenging area of life. The qualitative research suggests that disabled people’s views on health and wellbeing are complex. In accordance with the findings of The Marmot Review 21, participants identified not only health issues but also social and

attitudinal barriers as part of the problems they face around their health and wellbeing.

When we look at the survey findings, a fifth (20%) of disabled people who see health and wellbeing as a main or secondary challenge in life identified other people’s attitudes or behaviour as an issue when they faced their biggest challenge in this area. This view also came out very strongly in the focus group and interview discussions. The possible relationship between this and perceived anxiety/lack of confidence is an interesting one to consider. For example, women identifying health and wellbeing as a main or secondary challenge are more likely than men to say their own anxiety/lack of confidence is an issue (37% compared to 27%) and are also more likely to mention other people’s attitudes or behaviour (23% compared to 16%). The reasons for this are not clear, but the gendered nature of these issues certainly merits further investigation.

When we look at disabled people who identify health and wellbeing as a main or secondary challenge in life, some pertinent differences emerge when they are asked about the issues involved when they faced their biggest challenge in this area. Those in households on the lowest incomes, earning less than £10,000, are more likely to say anxiety/lack of confidence is an issue (40%). This may not be surprising given that the relationship between low incomes and health inequalities is well documented, and it is worth reiterating here that money and benefits was the strongest predictor of life satisfaction in the regression analysis (see Chapter 2).

For those with children in the household, caring responsibilities are seen as a more important issue, with 18% identifying this as a problem area, compared to 7% of all disabled people who identify health and wellbeing as a main or secondary challenge in life. This serves as a reminder that disabled people are carers as well as cared for, and managing health while also caring for others can be very challenging.

As might be expected, there is considerable variation by type of impairment when those identifying health and wellbeing as a main or secondary challenge in life are asked to think about the issues involved when they faced their biggest challenge in this area. While 17% of disabled people as a whole identify ‘difficulty getting into buildings or using facilities’ as an issue, this rises to a quarter (25% and 24%) of those with mobility problems or sight problems and over a quarter (27%) of those with dexterity problems. Anxiety and lack of confidence is identified as an issue by seven in ten (71%) of those who say they have a mental health condition, and two thirds (65%) of those with social and/or learning difficulties.

### 3.2 Attitudes of health and social care professionals

As mentioned above, the qualitative research helps to explain why disabled people find their health such a significant challenge. While The Marmot Review makes

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surprisingly little mention of the importance of the attitudes of health and social care professionals, disabled people themselves stressed the importance of this issue in shaping their experiences of health and social care. The issue reported most frequently by a range of research participants in the focus groups and qualitative interviews was how the unhelpful and discriminatory attitudes that shape the behaviour of health and social care professionals have a sizeable negative impact on their lives.

The survey findings suggest that among disabled people who identify health and wellbeing as a main or secondary challenge in life other people’s attitudes or behaviour are more of a barrier for people with a mental health condition than for disabled people in general, with four in ten (42%) mentioning this. Half (51%) of learning disabled people also say this is an issue.

When looking at whose attitudes or behaviour caused problems, the general public are the most problematic. Among people who found other people’s behaviours or attitudes an issue when facing a challenge in health or wellbeing, 42% mentioned the general public. A third (33%) identify health, social care and support staff, and just under a third (31%) local authority or government staff. Family are a problem for a quarter (25%), demonstrating that the relationship between families and disabled people can be very complex.

As with the quantitative research, negative attitudes of other people were a particular issue for people with mental health conditions in the qualitative research. Participants reported that their impairments often mean that they have significant interaction with health and social care professionals and therefore are exposed to their negative attitudes on a regular basis. There is also evidence in the wider literature of the manner in which negative attitudes in the form of inappropriate stereotypes and inaccurate assumptions have had an impact on disabled people’s experiences of health and social care.

Many participants discussed the lack of respect displayed by health and social care professionals. They feel that these professionals, particularly general practitioners, are often dismissive of disabled people and do not listen to them or take them seriously. The following quotes are typical:

"Sometimes doctors see the chair and not the person, or speak to my carer and not to me, which makes me feel uncomfortable."

Chester focus group participant

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24 This omission was recognised by the Review team and was addressed to some extent in a later report. See UCL Institute of Health Equity (2013) Working for health equity: the role of health professionals. http://www.instituteofhealthequity.org/projects/working-for-health-equity-the-role-of-health-professionals

“People don’t listen anyway, don’t really listen because you’ve got a disability or illness. Healthcare professionals are like that, think you (patient) don’t know anything.”

Interviewee – Female, 26-50 years, White British, mental health condition

Participants feel that this is because these professionals have insufficient understanding of the nature of mental health conditions and often confuse them with learning disabilities. As well as the barriers associated with stigmatisation of people with certain conditions mentioned in the previous section, there appears to be a barrier experienced by disabled people which is linked to lack of access to appropriate information. The quote below is indicative of these issues:

“All with my mental condition people treat me like I’m a child – like benefit people and GPs, even at the day centre, they explain everything as if I’m not understanding what’s going on!”

Interviewee – Male, 51-70 years, White Irish, mental health condition

Additionally, LGB participants in the group in Norfolk talked about the ‘double whammy’ effect of being gay and disabled, pointing to examples of where they have been made to feel embarrassed by comments made by doctors and nurses.

“Doctors and nurses are totally insensitive and have little understanding of the needs of people like us.”

Norfolk LGB focus group

A number of research participants also drew on their personal experiences to relate how health and social care professionals are often rude and inconsiderate. For example:

“Healthcare staff are the worst! You get good and bad doctors…but tolerance levels are limited. Some healthcare staff have short tempers, and are quite easy to snap. They don’t always apologise! If they’ve had a bad day, they blame it on that.”

Interviewee – Female, 26-50 years, White British, mental health condition

Participants feel that this behaviour on the part of health and social care professionals is a direct result of them being pushed for time and under an increasing amount of pressure. To this end they recognised that this behaviour is not specific to disabled people but did impact on them more because of their greater exposure to and interaction with these professionals. This points to a challenge for organisations seeking to improve equality for disabled people in responding to this barrier. Structural/systemic constraints mean that health and social care professionals already face many competing priorities for their time, attention and training, at the same time as resources are under severe pressure.

“They are under strain and pressure, they bring their problems in to their patients’ lives. More and more people want treatment and need help, and there is more burden on services.”
3.2 Barriers in health and social care services

In addition to the impact of negative attitudes of health and social care professionals discussed above, we found in the qualitative research that three further issues generally shape negative experiences of health and social care.

Firstly, many participants reported receiving insufficient support, particularly from social care services. Lack of resources for appropriate support, and/or for the disabled person in question to be able to receive the kind of treatment they prefer, act as barriers that impinge on disabled people exercising as much choice and control as they would wish. For example, one participant related how difficult it had been for him to get access to a wheelchair after surgery:

“I had major surgery recently, and I wasn’t provided with a spare chair. I eventually got a new one now but that’s not the point: they don’t come out and check the wheelchairs enough, and they keep people with very, very old chairs, which I don’t agree with. Every couple of weeks or once a month they should come out and check. I was very angry.”

Chester focus group

Similarly, receiving insufficient support is also often closely related to not being able to access a personalised coproduced package of support. For example, one participant related how the NHS would not agree to fund a specialised allergy treatment because this treatment is not recognised as being effective:

“I have specialised allergy treatment for my Tourette’s. It has improved my condition a lot and has helped me rebuild my life. Every time I ask for a small amount of funding, it’s very difficult to get it. They are not prepared to see alternative treatment, it would have been ok to throw drugs at me, psychiatrist sessions – all the expensive stuff. Not prepared to see what the patient is telling them they want.”

Interviewee – Male, 26-50 years, White British, physical/sensory impairment

These findings reflect national level figures which highlight that in 2011 more than one quarter (26%) of disabled people did not believe that they frequently have choice and control over their lives – a figure that has gone up over the years. The importance of a health and social care system that fosters personalised support and

26 Office for Disability Issues,(ODI) Disability Equality Indicators, online
real choice and control was also echoed by a number of expert interviewees. They felt that positive change for disabled people means ensuring that they have real autonomy in commissioning services and directing their care.

Another issue that has shaped participants’ experiences of health and social care is **negative experiences of diagnosis** which relate to doctors not taking them seriously. This was particularly the case for participants who had eventually been diagnosed with Myalgic Encephalopathy (ME):

> “When I was diagnosed with ME I had to face the disbelief of the medical profession which treats people with ME as lazy, hypochondriac malingerers.”

Norfolk participant

Some participants also related how experiences of diagnosis are often accompanied by little tailored information or support to help deal with the diagnosis:

> “It was a case of ‘you’ve got MS, off you go’, and you have no idea how you will react.”

Surrey focus group

Just as in the case of disabled people seeking employment, and disabled children in mainstream education settings, these findings suggest that there is an issue around disabled people with particular conditions being treated negatively by health professionals because of the stigma associated with those conditions. This was also echoed by participants with mental health conditions who often feel that they are not taken seriously by doctors who tend to focus only on people’s mental health conditions whilst ignoring other symptoms they may be presenting with. This has had a significant negative impact on many participants – some described how accessing care can be very difficult whilst others reported delays in treatment due to long drawn out experiences of diagnosis:

> “If you have mental health problems you are not allowed to have physical health problems.”

Harrow focus group

> “I’ve been waiting for 6 months for a prostate operation and I’m still on antibiotics. But it’s not getting better.”

Harrow focus group

Other participants with mental health conditions talked about the difficulties they experienced in being diagnosed with mental health conditions. The slow process involved meant that many people feel they had hit ‘rock bottom’ by the time they were correctly diagnosed. Participants feel that this is a result of doctors, particularly general practitioners, having insufficient training about mental health conditions:

> “If doctors treated heart disease in the same way they treated mental health conditions, people would be flat lining before they got any help”.

Cardiff focus group
A number of participants also talked about the frustration caused by a lack of joining up between health and social care and other services. For example, a participant from the Surrey focus group voiced the feelings of the rest of the group when she said “it’s really frustrating to have to give the same information over and over again.” This view was also echoed by participants in the Norfolk LGB group who felt that this lack of joining up was particularly frustrating ‘when a person has multiple health needs.’

Most importantly, participants reported that it was not their impairment or condition that stopped them from doing things, but rather the attitudes of health and social care professionals and the lack of appropriate care and support. Those who had formal health or social care packages often suggested that these only covered the ‘basics’ and this tended to limit their independence and caused difficulty in going about their daily family, working and community lives.

### 3.4 What needs to change?

In 2010, the Marmot Review\(^{27}\) made it clear that we cannot hope to tackle systemic health inequalities without tackling social inequalities. These challenges are considered in more detail in the following chapters, but here we highlight the changes that disabled people taking part in the focus groups and depth interviews identified in relation to health and social care professionals.

**Health and social care systems should be resources in a way that allows professionals to find more time for disabled people**

Participants drew on their own experiences of feeling ‘rushed’ by health and social care professionals to suggest that these professionals need to provide disabled people with more time and attention than they currently do:

“I find they are always in a rush if they are explaining something to you ….they are just doing tick boxes with you to get out of the door.”

Hammersmith focus group

As discussed earlier, many participants recognise that health and social care staff are often in a rush because of the pressures imposed on them by their managers and the wider system. At the same time they reported how health and social care staff who had taken the time ‘to have a cup of tea and a chat’ had been really valued by them. This is important for disabled people because of the empowering impact of being able to establish a sense of connectedness with other people.

The pressures facing providers of health and social care services are well documented. An ageing population and rising costs of new technology coupled with the need to make efficiency savings whilst delivering high quality care has created a challenging environment for health and social care professionals. Additionally, the changing legislative and policy context, in the form of the Health and Social Care Act

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(2012) and the Care Bill (due to receive Royal Assent in summer 2014), is resulting in large scale structural and organisational changes in the way in which care is commissioned and delivered. All these factors combine to mean that health and social care professionals are having to do more, with less time and fewer resources. Reflecting these pressures on time, and the lack of resources for training, there may be sense in emphasising to health and social care professionals (and the bodies that represent them) that whilst the need for wider and more substantive change should not be ignored, these findings do suggest that in some cases ‘a little time can go a long way’. There’s also a case for demonstrating the ‘preventative value’ of investing a little more time in more ‘routine’ interactions with disabled people: many of the participants in the research indicated that they felt reluctant to ask questions to help them understand their condition or the treatment they were being prescribed.

**Negative attitudes need to be challenged so that health and social care professionals have greater sensitivity, empathy and dignity**

Closely related to having more time for disabled people was the sense that health and social care professionals need to display greater sensitivity and empathy towards disabled people. This need for greater empathy (not sympathy) for disabled people by all non-disabled people was also mentioned by the experts that we consulted with. Participants feel that care provided needs to transcend a focus simply on disabled people’s physical needs and instead foster real choice and control for disabled people.

> “Need more empathy from social workers. They’ve just been told that this is what you’ve got to do. They need to think beyond physical needs. It’s the dignity of it.”

Interviewee – Male, 26-50 years, White British, physical/sensory impairment

**Health and social care professionals need to have a better understanding of conditions**

Participants with mental health conditions feel very strongly that health and social care professionals, particularly general practitioners, need a better understanding of the nature of mental health conditions and how they impact on people’s lives. This reflects the wider feeling amongst participants that as disabled people they often struggle to have their voices heard:

> “People who know you suffer from mental illness, who may have seen you on your down days – they think that maybe you have learning disability. Again, need education about what the problem is.”

Interviewee – Male, 51-70 years, White Irish, mental health condition
4. Financial wellbeing

Summary of key findings

- Money and benefits is a main or secondary issue in its own right for over a quarter (27%) of disabled people as well as a recurrent theme among other areas of life that disabled people find challenging. More specifically, lack of money (76%), the cost of utility bills (62%) and benefits being cut or lost (38%) are the top three specific concerns amongst disabled people who identify money as an issue in its own right or in relation to other areas of life.

- Mortgage or rent payments and benefits being cut or lost are more likely to be an issue for those disabled people that are of working age compared to those over 65. Those not in work are more likely to mention costs related to their health problem or disability (22% compared to 15% of those in work).

- Participants in the focus groups and qualitative interviews described how changes to the welfare system have been stressful and have had a negative impact on the amount of choice and control they are able to exercise in their lives. They described the insensitivity of the benefits application and assessment process which makes them feel like they have to ‘prove’ they have an illness. They also described how the welfare system imposes unrealistic work expectations on disabled people and how returning to work doesn’t always ensure people will be better off financially.

- Reductions in spending on services, centres and support workers have also increased the exclusion and isolation of many participants. A small number of participants also described how they have insufficient financial resources to take up educational opportunities, self-employment or leisure activities.

- Achieving positive change to disabled people’s living standards therefore needs to focus on changes to the welfare system, the impact of reductions in public expenditure and improving the benefit application and assessment process, where participants feel the government has a big role to play.

4.1 Challenges associated with financial wellbeing

Money and benefits is a recurrent theme among all the areas of life disabled people say they find challenging, as well as being a main or secondary issue in their own right for over a quarter (27%). As we have seen, it is also a key driver of disabled people’s overall sense of satisfaction with life.

This is not surprising given that there is wide ranging evidence showing that the level of poverty experienced by disabled people is significantly greater than that experienced by non-disabled people. Not only are disabled people and families more likely to live in low income households, but they are also more likely to be...
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unemployed and earn less than non-disabled. Disability poverty is also enormously exacerbated by the fact that disabled people are likely to incur a higher cost of living, for example due to the need to pay for additional equipment, transport or support (IPPR 2005; Rigg 2005; OPM 2011). In fact Sen (2010) argues that when the extra costs associated with disability are included, the proportion of disabled individuals living in poverty rises from 23.1% to 47.4%. This compares with a figure of 17.9% for the population as a whole.

All disabled people who identified money as an issue either in its own right, or in relation to another area of life (e.g. housing) were asked what ‘best describes the money issues you mentioned’. As can be seen in the following chart, lack of money is the biggest problem for disabled people, with three quarters (76%) saying this best describes the money issues they face. Findings from the Life Opportunities Survey show that one in ten (10%) disabled people say they have great difficulty making ends meet, compared to 5% of non-disabled people.\(^{26}\) Taken together, this clearly demonstrates the significant problem lack of money is for disabled people.

The cost of day-to-day living is also a considerable issue for disabled people who identify money as a challenge, with more than three in five (62%) having a problem with the cost of utility bills, and over a quarter (27%) having difficulties with the cost of rent or mortgage payments. Additionally, almost four out of ten (38%) reported that their benefits being cut or lost is a specific money issue faced. This latter issue is explored in the next section where we highlight the impact of welfare changes on the disabled people that participated in the qualitative research.

Fig.7 Which, if any, of the following best describes the money issues you mentioned? Please select all that apply.

\(^{26}\) Office for National Statistics, Life Opportunity Survey – additional analysis conducted by Ipsos MORI.

© Ipsos MORI

Base: All respondents who find money issues main or secondary challenge (1,346)
As in other challenging areas, the attitudes or behaviour of others also emerges as an area people faced difficulty with in relation to financial wellbeing, with a fifth of people (21%) saying this is a problem. Again, respondents were asked whose attitude or behaviour had caused them a problem in relation to money and benefits. Three in five (60%) said local authority or government staff had been the problem. A third (33%) had problems with the attitudes or behaviour of other professionals or service providers (e.g. staff at banks, housing associations, utility companies), and a third (33%) with the general public.

Looking at how money issues affect different groups of disabled people, those of working age are more likely to say that mortgage or rent payments (29% compared to 20% of those aged over 65) and benefits being cut (42% vs. 27%) are an issue. Those not in work are more likely to mention costs related to their health problem or disability (22% compared to 15% of those in work). Additionally, those with a sight impairment face more problems around accessing suitable financial products, with 15% mentioning this. Nearly a fifth (18%) of those with a social and/or learning difficulty who have had money problems also identify access to suitable financial products as an issue. Where costs related to an individual’s health condition or disability is an issue, it is mentioned more by those with a sight impairment (37%) and those with dexterity problems (35%).

4.2 Experience of changes to welfare system

Money and personal finances were discussed much less in the focus groups and qualitative interviews than in the survey. There were, however, extensive discussions of benefits and the wider assessment and welfare system.

The majority of participants appreciate that changes to the welfare system are necessary. However, they also talked in depth about how the manner in which the changes are being implemented has been stressful and has had a very negative impact on their health and wellbeing. Additionally, concerns about how changes to welfare system are having an impact on disabled people were also voiced by many of the experts we interviewed as part of this research.

In particular, participants in the focus groups and interviews noted the difficulty of the benefits application and assessment process and reported feeling that the system, in particular DLA and Employment and Support Allowance (ESA) has become ‘obstructive’ and ‘difficult’. They described it as stressful and tiring and many reported that they often ‘feel like giving up’.

“Your life can become so stressed out trying to work through the system or with the system, I am a strong person, if I wasn’t I would have a mental breakdown.”

Surrey focus group

These findings highlight how the benefits application process can be alienating and disempowering for participants by making them feel like they have little choice and
control in making decisions about their lives. In particular, participants described how they constantly feel like they have to ‘prove’ that they have an illness and that the assessors are trying to ‘catch them out’. They feel like they have to ‘jump through hoops’ to get the support they need.

“The doctor asked me so many questions, it was like a cattle market, I was a number. It was awful. He was digging and digging, I was giving him an answer and he kept asking questions as if he thought I was lying”.

Interviewee – Female, 26-50 years, Black British, mental health condition

Participants also feel that the benefits application and assessment process is particularly insensitive to the fact that there are often no ‘yes/no’ answers to questions about needs because of the fluctuating and complex nature of many impairments and conditions. Similarly, participants with mental health conditions feel that the invisibility of their conditions also often means that the benefits application process does not recognise their needs:

“They might ask do you have problems getting out of bed. If you just put no, you won’t get anywhere, need to explain that you have good days and bad days.”

Interviewee – Female, 26-50 years, White Irish, physical/sensory impairment and mental health condition

There is also evidence that the welfare system imposes unrealistic work expectations on disabled people and places a premium on full-time rather than part-time work. Participants reported that, due to the nature of their conditions, flexibility in the work place allowing for part-time work rather than full-time work, and opportunities for self-employment are necessary. Others reported that their job prospects, particularly in a time of recession, are poor after having been unemployed for so many years. These findings are another example of how disabled people struggle to access personalised and coproduced packages of support.

“If I’m realistic, I’m a 58 year old man, with a history of mental illness and lung disease. No one is queuing up to give me a job.”

Interviewee – Male, 51-70 years, White Irish, mental health condition

One participant described how disheartened she had felt when she had failed to receive the Return to Work Credit when she took up self employment:

“I did try and do self employed work last year. The lack of support from government was disheartening. They didn’t give me return to work credit because they conveniently changed goal posts. The best case would definitely have been that I could go back to full time work outside home – but for a lot of people that’s just not possible. Even if they had paid the return to work credit they would have been paying me less than if I was on benefits.”

Interviewee – Female, 26-50 years, White British, physical/sensory impairment
Other participants reported how they were reluctant to apply for jobs or even to say they were feeling better, because *returning to work would mean less financial support*. This was because participants feared that they would no longer be eligible for certain benefits and that their salary in itself would not be enough to cover their costs of living:

> “I saw a job for 1 day a week for a coordinator, but the salary was 50p over allowed earnings, and they would have stopped all my benefits. So there’s glaring holes in the system.”

Interviewee – Male, 26-50 years, White British, mental health condition

Some participants also described how having *lost benefits* such as DLA or even simply the fear of losing benefits is causing them a great deal of stress and worry. The survey findings suggest that those of working age are more likely to say their benefits being cut or lost is an issue (41% compared to 35% of those aged 65+). Participants in the qualitative research that have seen their benefits taken away or reduced described how they are trying to cut back their expenditure and how this has had a severe impact on their living standards:

> “Financially it’s caused me a problem. I eat less, I don’t pay bills when I should do. The stress, leads to depression, I can isolate myself.”

Interviewee – Male, 51-70 years, White Irish, mental health condition

This loss or fear of loss of benefits is particularly concerning given that participants described how these benefits play a crucial role in providing them with the support they need:

> “I’m on DLA right now, it’ll hit me big if that’s taken away, I don’t know what I would do. DLA works for me because at least I know on my bad days that I still have that coming in. I am on the lower rate, so I could lose it.”

Interviewee – Male, 26-50 years, White British, physical/sensory impairment

### 4.3 Fewer services and resources

A number of participants in the focus groups and qualitative interviews described how reductions in public expenditure have resulted in a *reduction in the availability of services* and support for disabled people. At the focus group in Coventry, participants reported that in the current climate disabled people are only getting support to help meet their basic needs with little focus on wellbeing and independence. Many spoke very positively about Direct Payments[^29] which had afforded them choice in control in accessing care and support and which are no

[^29]: Direct payments are local council payments made to people who have been assessed as needing care and would like to arrange and pay for their own care and support services instead of receiving them directly from the local council. The duty to provide these payments was introduced in 2003.
Removing barriers, raising disabled people’s living standards

longer as readily available as they used to be. Public spending reductions are a source of great frustration for the participants because of the significant impact they have on their living standards, quality of life, choice and independence.

Some participants talked specifically about the cuts to mental health centres which have made people feel more isolated and excluded:

“It’s made it more difficult. For example, there was an art group that used to meet on Wednesday afternoon but it’s closed now. So there are less opportunities really, compared to a few years ago. Even when centres are open people aren’t going much because there is not much on offer.”

Interviewee – Female, 26-50 years, White British, physical/sensory impairment and mental health condition

Other participants talked specifically about a fall in the number of support workers which ‘means that more and more blind people will become more and more excluded.’ These findings indicate as resources become scarcer and funding for these types of services disappear, disabled people are finding it more and more difficult to establish and maintain a sense of connectedness with others.

A small number of participants also described how they have insufficient financial resources to take up educational opportunities, self-employment or leisure activities. For example, one interviewee described how she is keen to start up a jewellery making business but needs financial support in order to get some business and accounts training. Another interviewee reported being keen to attend gyms and health centres but found those in his local area are unaffordable. All participants described how being able to participate in activities such as these would give them a greater sense of confidence and independence.

4.4 What needs to change?

Welfare reform and reductions in public expenditure

Research participants in the focus groups and qualitative interviews feel very strongly that the government has a big role to play in improving the welfare system and changing the manner in which public spending cuts are being implemented. In particular they feel that the government needs to:

Make disabled people more of a priority: Many feel that the government could do more to make disabled people a priority and ensure that they are protected against spending cuts. As some interviewees commented:

“They need to stop and have a rethink about continuously making cuts in resources to people who really need them, people with ongoing registered conditions.”

Interviewee – Male, 51-70 years, White British, physical/sensory impairment and mental health condition
Be more flexible in their work expectations of disabled people: Some participants feel very strongly that the government needs to realise that good working arrangements are those that allow for flexibility, including part-time working and self-employment. A true commitment to inclusivity and personalisation means recognising the variability in people’s experiences of disability and their needs, Encouraging part time work or self-employment may also increase the numbers of disabled that are in work:

“Government needs to accept that work for disabled people isn’t as black and white as getting your CV and going to job centre. People with fluctuating chronic conditions can’t be reliable – it’s sad but true.”

Interviewee – Female, 26-50 years, White British, physical/sensory impairment

Moreover, they feel it is important for government to support and reward them for doing this type of work because of its potential positive impact.

“I felt I was supporting my family…I was contributing to my household. I felt like part of society.”

Interviewee - Female, 26-50 years, White British, physical/sensory impairment

These views were also echoed by expert interview participants who feel that a better welfare system is one of the key changes that could bring about better outcomes for disabled people. In particular expert interviewees emphasised the need for a welfare system that is flexible, allows people to move in and out of work, and covers the real costs of disability.

Listen to the concerns of disabled people: Participants generally feel that policy makers have a responsibility to listen to disabled people. For disabled people, having their voices heard is a key theme that runs throughout this report. In particular, there is a need for the government to get a better understanding of the impact of changes to the welfare system and reductions in public expenditure on disabled people. There is also a need for them to learn more about the extra costs disabled people face, so that they better understand their need for benefits. As one interviewee commented:

“They need to consult disabled people, come face to face with people who these things affect, how proposed changes would impact on them, how they currently use the money.”

Interviewee - Female, 26-50 years, White British, physical/sensory impairment

A better benefits applications and assessment process

Participants feel that there is an urgent need for a more sensitive benefits applications and assessment process that ‘treats people as people not just as figures.’ They feel that assessments should move away from being simply a tick box exercise and instead focus on affording disabled people real choice and control:
“People have feelings, people need to be treated as humans, their responses need to be accepted without being made to feel like they’re lying”.

Interviewee – Female, 26-50 years, Black British, mental health condition

Participants with mental health conditions also specifically feel that assessments are often focused on ‘physical needs’ and that the assessors need more training about the nature of mental health conditions:

“With mental health problems, when they’re assessing you, because you don’t have a visible problem, unless you’re talking to someone whose been trained in it, they will just wonder what’s wrong with you. So we need better training for them, to give them more insight into what they’re dealing with.”

Interviewee - Male, 51-70 years, White Irish, mental health condition

Some participants also feel that it would be very helpful to have advocates who can help them apply for benefits:

“What would be good is to have independent advocates…to help people claim what they’re entitled to”.

Interviewee – Female, 51-70 years, White Other, physical/sensory impairment and mental health condition

This was felt to be particularly important for those people for whom English is a second language. As one South Asian participant of the Harrow group commented: ‘You might have received a form and straight away it is a panic, oh, what is that letter, is it to deport me out of the country? It is scary, especially when it comes from the council, you just don’t know’.

Participants also described how a better benefits application and assessment process would have a positive impact on their health and wellbeing:

“It would make people feel less vulnerable, less scared, less ill as a result of the process. It’s about looking at more than just the numbers.”

Interviewee - Female, 26-50 years, White British, physical/sensory impairment
5. Employment and education

Summary of key findings

- Employment is seen as a challenging area of life by a quarter (26%) of disabled people and this number rises to more than four out of ten for those people who are in employment (47%) or of working age (44%). In addition to one’s general health or condition (59%) that might reasonably prevent someone from working, lack of confidence (42%), lack of suitable job opportunities (40%), and the attitudes or behaviour of other people (38%) are the most frequently reported specific barriers among those who find this the main or secondary challenge in life.

- Among those who reported the attitudes or behaviour of other people as a specific barrier, the main problem was identified as being with employers (76%), followed by colleagues (51%) and then the general public (26%).

- The qualitative research highlighted that Participants’ experiences of employment are often shaped by bullying and isolation in work which coupled with a lack of support from managers often meant that they were either ‘let go’ or left themselves as they found it increasingly difficult to cope.

- Participants in focus groups and qualitative interviews also report difficulties in finding employment because of stigma and discriminatory attitudes on the part of employers and by a lack of support by job centres. Some also described how their own fears of rejection results in a reluctance to seek employment.

- Young people also reported experiences where they received little support and stigma relating to their conditions in mainstream schools, which meant that educational professionals had low expectations of them.

- Research participants therefore feel that key changes relate to greater awareness and training for employers and education providers delivered by disabled people. They also feel that there is a need for more sensitive job application and recruitment processes, greater support with job applications and finding employment and, finally, the government playing a bigger role in enforcing employment practices.

5.1 Experiences of employment

Employment is seen as a challenging area of life by 26% of disabled people. However, this rises to 44% of those of working age, and 47% of those who are in employment. Amongst those of working age, work and employment is the third highest challenging area, after health and wellbeing and money and benefits. This is not surprising given that in the current economic climate, with high levels of unemployment, there is widespread evidence to indicate that disabled people are significantly worse off than the general population. Figures from the 2011 Labour
Force Survey indicate that the employment rate for disabled people was 48.8% which is far lower than the employment rate for non-disabled people which was 77.5%\(^{30}\).

As in other areas, the most commonly given reason behind their biggest challenge in work and employment is ‘general health or condition’, with three in five (59%) mentioning this. This echoes the findings from the Office for National Statistics’ Life Opportunities Survey (LOS)\(^{31}\) where a health condition, impairment or disability was the most common reason given for limits to employment. Similarly, in our survey 40% of disabled people who identify work and employment as the main or secondary challenge in life say lack of suitable job opportunities is a barrier, just as in the LOS 43% of unemployed adults with impairments said this was a barrier to work. This issue is explored in more depth in the next section where we highlight the difficulties faced by disabled people that participated in the qualitative research in finding suitable employment.

The chart below illustrates the key barriers for disabled people in work and employment and what those who have faced more than one issue would most like change.

**Fig. 8 Thinking of a time when you faced the biggest challenge relating to work and employment which, if any, of the following issues were involved?**

**Thinking of all the issues you have said made work and employment challenging for you, which one or two would you most like to see changed for the better?**

<table>
<thead>
<tr>
<th>Barriers faced</th>
<th>Barriers people most want changed for the better</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your general health or condition</td>
<td>59% 34%</td>
</tr>
<tr>
<td>Your anxiety/lack of confidence</td>
<td>42% 27%</td>
</tr>
<tr>
<td>Lack of suitable job opportunities</td>
<td>40% 22%</td>
</tr>
<tr>
<td>Other people’s attitudes or behaviour</td>
<td>38% 23%</td>
</tr>
<tr>
<td>Money issues</td>
<td>28% 11%</td>
</tr>
</tbody>
</table>

Base: All respondents who faced a main or secondary challenge in work and employment (298), All respondents who faced a challenge in work and employment due to two or more issues (196)

\(^{30}\) Labour Force Survey, Quarter 2, 2011

Other people’s attitudes or behaviours were an issue for 38% of disabled people who faced a main or secondary challenge in work and employment. Among those who had faced a challenge because of other people, the main problem was identified as being with employers (76%) followed by colleagues (51%). The general public was mentioned by a quarter (26%).

Many participants in the focus groups and qualitative interviews drew on their personal experiences to describe the bullying and isolation they experienced at the hands of colleagues and managers. This tallies with other available evidence: for example the Department of Business, Innovation and Skills’ Fair Treatment at Work survey has found that disabled people are more than twice as likely to report bullying and harassment than non-disabled people. Some participants feel that this is because their colleagues have little understanding of why disabled people might need additional support such as job coaches or support workers and are thus wary of them. This particularly seems to be the case where people’s impairments are less visible, for example when someone has a mental health condition. The following quotations are typical of experiences reported by a number of research participants:

“I used to work full time, my manager used to bully me, I had a job coach but [that was] taken away from me. My depression got worse. So they redeployed me. At the end of the year [they] didn’t renew my contract.”

Interviewee – Female, 26-50 years, White British, mental health condition

“I don’t look disabled….so people make assumptions of what I can and can’t do. Because of the problems with my eyes I need to be near natural lighting so I sit 30-40 feet away from the team and that meant we would have to adapt the way we communicate…but they didn’t adapt and left me alone all day. And I felt isolated. They would have conversations about work I was involved in, wouldn’t brief me on it, I had to play catch up all the time. They made me feel that ‘you’re the one with the problem, we’re too busy to adapt to you.”

Interviewee – Female, 26-50 years, White British, physical/sensory impairment

Other participants described how they often received insufficient support from their managers whilst in employment and were ‘left to get on with things’ themselves. There is wider literature to indicate that the concept of ‘reasonable adjustment’ is poorly understood by employers who often tend to wrongly assume that adjustments for disabled members of staff would require large-scale infrastructural changes to their workspaces that can be very costly, whereas in fact adjustments are often simple and low-cost (OPM, 2011).

Some participants also reported having been penalised for having taken too much time off work:

“Then when I went back to work, had a disciplinary hearing because I’d taken too much time off work. I didn’t realise I could take an advocate with me to

Removing barriers, raising disabled people’s living standards

*Speak on my behalf. They decided if I took a certain amount of days off again then I would be dismissed.***

Interviewee – Female, 26-50 years, Asian British, mental health condition

A number of participants described how they were ‘let go’ by employers because they were unable to do aspects of the job or because they had been signed off sick for a while. Others described how experiences of bullying, isolation and insufficient support had made it increasingly difficult for them to cope and that they had ended up leaving themselves:

“I aimed to go back to work. I was really trying to get in touch with my employer but they weren’t being honest, that I was due for redundancy, I was signed off sick. I was supposed to see HR after sick leave, and I was told I didn’t have a job and was made redundant.”

Interviewee - Female, 26-50 years, Asian British, mental health condition

“I just went home one day and took an overdose. I had a breakdown and I’m always depressed now so I find it hard to work and even be round people and socialise. I was good at my job and the managers appreciated it but they expected me to do too many shifts, I couldn’t work seven days and seven nights… It got on top of me.”

Hammersmith focus group

These findings highlight very clearly that, as in many other areas of life, experiences of employment for these participants are often shaped by stigma and discrimination at the hands of colleagues or managers. What is particularly concerning is that these experiences have often had severe detrimental impacts on disabled people’s health and wellbeing, as well as on other aspects of their living standards.

5.2 Difficulties finding employment

As mentioned earlier in the chapter, four in ten (40%) of disabled people who see work and employment as a main or secondary challenge say a lack of suitable job opportunities is a barrier they face in work and employment. There is also wider evidence to indicate that even though most disabled people would like to be able to work, a large number experience discrimination when applying for work which makes securing work very difficult (OPM, 2011; Rigg, 2005).

A large number of research participants in focus groups and qualitative interviews drew on their personal experiences to describe the difficulties they have experienced in finding a job.

Many feel that this is because of the stigma that employers attach to disability which makes them reluctant to hire disabled people. They tend to see them as unreliable and therefore a risky investment. This reflects wider research which indicates that employers often make assumptions about the productivity of disabled
Removing barriers, raising disabled people’s living standards

people in that they expect them to take more time off, to be less able to do the work effectively and need more supervision. They thus feel that employing a disabled person is risky (OPM 2011; Simm et al. 2007). Some participants believe that employers often conflate disability and ill-health and therefore presume that disabled people will take a lot of time off. Others feel that employers ‘pay lip service’ to equalities legislation and have little commitment to employing disabled people:

“Tourette’s is still a barrier, it puts employers off, I go to potential customers, they love my portfolio and then work doesn’t come, and I do believe that they are not prepared to take a risk on me and because they have other choices they won’t use me. It’s not direct discrimination. It’s just the way of the world.”

Interviewee - Male, 26-50 years, White British, physical/sensory impairment

Participants with mental health conditions in particular feel that the stigma attached to mental health conditions has made their job seeking particularly difficult:

“I applied for job at Post Office, with 8 other people, I was the only one who passed the English and Maths exams. But because of my mental health history, I didn’t get the job”.

Harrow focus group

“I remember 5 years ago Jobcentre told me to go for an interview and tell them I’m disabled, I told them at interview and as soon as I saw his face when I told him that I’m a mental patient and even when I said the Jobcentre would pay my salary, but I didn’t get the job.”

Interviewee – Female, 51-70 years, Mixed Race, mental health condition

Participants also described how their negative experiences have meant that they are often conflicted about whether or not to disclose their mental health conditions:

“I’m worried that they’ll think I’m dangerous, or have lots of problems…they’ll think that I’m a nutter…or maybe also that I’m incompetent, or stupid.”

Interviewee – Female, 26-50 years, White British, mental health condition

This reflects wider literature which indicates that the most negative assumptions are made about people with mental health conditions. For example, research suggests that only 37% of employers would even consider employing someone with a mental health condition even if they faced labour shortages (Perkins et al. 2009).

Some participants also feel that looking for employment is made all the harder because of more structural or systemic constraints such as insufficient support or help from job centres. Some described how staff at job centres are particularly unhelpful if people have little or no experience of paid work. Similarly, others described how job centres are unable to offer people much help if they are looking for part time work. Both these situations are quite common for disabled people and such
experiences mean that even when disabled people are keen to find employment, the lack of a support structure means they are unable to do so. This is another indication of how disabled people are struggling to find personalised support.

“If I had been wanting full time work then the job centre could have helped me, but because I want part time work there’s no support. Seems to be air of resignation… they all just held their arms up and said the system isn’t working for the likes of you. They all seem defeated. Don’t have willingness to help you like they have in the past.”

Interviewee – Male, 26-50 years, White British, physical/sensory impairment

A number of participants also feel that their difficulties in finding employment are exacerbated by negative recruitment experiences where employers often display little understanding of reasonable adjustments and ask people questions about disability in an insensitive and demeaning manner:

“The manager rang me up and asked me about reasonable adjustments and said well ‘how will you cope with this?’ and ‘how will you cope with the visits?’ rather than ‘how can we help or support you?’ And it destroyed me.”

Interviewee – Female, 26-50 years, White British, physical/sensory impairment

A small number of participants, particularly those with mental health conditions, also described how their own fears and worries result in a reluctance to seek employment. Some worry that the process itself will be too stressful and therefore have a negative impact on their health and wellbeing. Others described their ‘fear of rejection’ and the potential impact of this on their self-esteem:

“Quite a few people with depression have heightened fear of rejection. There is the worry, I have panic attacks. So if you do get a rejection, it fulfils your image of yourself. And the anxiety as well. It takes me 3 months to ring up a recruitment consultant because it’s daunting.”

Interviewee – Female, 26-50 years, Asian British, mental health condition

5.3 Young people’s experiences of education

Many of the barriers disabled people face in the workplace also occur in the classroom, and suboptimal educational outcomes – as well as the impact on confidence and self-esteem – have a knock-on effect in terms of employability.

Although only 5% of survey participants identified education and training as a challenging area of life, young people that participated in the focus groups drew on their personal experiences to highlight negative experiences in education, particularly in mainstream schools. For example, many described how their experiences of mainstream school included being bullied and intimidated by other non-disabled young people. Young people moved from mainstream schools to special schools which, because of their negative experiences, felt more inclusive:
“There was lots of fighting and people teasing each other so I moved to a Deaf school which I prefer because there’s less fighting ….. the hearing people would pick on Deaf people and that would cause a lot of issues … It’s a lot better now, there’s no fighting and it’s peaceful.”

Essex focus group

Participants in the Norfolk LGB group also described instances of bullying in schools although in this case whether this bulling was the result of being gay and/or disabled was unclear. A number of participants reported feeling very miserable and isolated whilst they were at school.

Young people also described how their experiences of mainstream schools have been shaped by a lack of personalised help and support for disabled students:

“You don’t get much help in mainstream…there’s no help, there’s just the teacher.”

“In lessons I couldn’t keep up with the work so I was just sitting there doing colouring and no TA (teaching assistant) or teacher helped me.”

Essex focus group

Low expectations of disabled people, as a result of stigma in the form of inaccurate assumptions, amongst education professionals were also reported frequently by young people that took part in this research. This was incredibly frustrating for participants, particularly those that had a desire to achieve. One participant described how he had been dissuaded to take up construction by a career advisor:

“I want to get into construction and I was told I wasn’t allowed because I was Deaf.”

Essex focus group

Similarly, a number of young people reported how they haven’t been able to do the courses they want at college because the tutors thought the courses were too advanced for them.

“It’s like they judge you from the outside, not the inside and you’ve got that name (i.e. of having a learning disability) and that’s it really, it’s not fair”.

Leeds focus group

These findings also tally with other evidence showing that disabled people often do not achieve the educational outcomes and qualifications that they could at school. This is caused by factors including negative experiences of schooling (including bullying), low expectations from teachers, special schools lacking an academic orientation, and a lack of education provision during hospital and other absences (Mencap 2007; Disability Rights Commission 2003; OPM 2010b). This is particularly concerning given the established link between skills and employability (Evans 2007) such that fewer than one in two people with no qualifications are currently in work. This has implications for the longer-term employability of disabled people given that
Removing barriers, raising disabled people’s living standards

disabled people are around twice as likely not to hold any qualifications compared to non-disabled people, and around half as likely to hold a degree-level qualification.\textsuperscript{33}

5.4 What needs to change?

Research participants in the focus groups and qualitative interviews identified a number of priorities for change.

**Awareness and training for employers delivered by disabled people:** Participants feel that there is an urgent need to educate employers about the nature of different impairments, how they shape disabled people’s lives and the barriers that disabled people face. This is regarded as key in addressing the stigma and discrimination that disabled people experience in the workplace. In particular, they feel there is a need for employers to have a better appreciation for the types of support that disabled people may need in order to perform their jobs. One interviewee highlighted the need for employers to be ‘more facilitative and supportive’ when it comes to disabled people. Participants also described how ‘life would be easier’ if employers were more aware of the needs of disabled people:

“I spend far too much time to fending them off, dealing with their lack of understanding. I find it mentally and physically exhausting and already have complex medical conditions. I get more and run down and don't take care of myself spend most of my weekends in bed. I don't sleep very well because am always thinking about it.”

Interviewee - Female, 26-50 years, White British, physical/sensory impairment

**Better job application and recruitment processes:** Participants feel that employers need a better understanding of reasonable adjustments and that this should relate to providing more personalised support for interviews. For example, some participants spoke positively about instances in which they have been able to take support workers with them to interviews: ‘Managers think it’s about giving people unfair advantage when it’s just about bringing us back up to level playing field.’

Interviewee - Female, 41 years, White British, physical/sensory impairment

Other participants feel that people shouldn’t always have to disclose their mental health conditions in job applications:

“If people have had a mental health problem in the past, people seem to have to disclose it, and sometimes it’s not relevant to whatever they’re going to do. They should be given a choice if they want to disclose.”

Interviewee – Female, 26-50 years, White British, mental health condition

\textsuperscript{33} Labour Force Survey, Quarter 2, 2011
Similarly, other participants feel that employers need to be more sensitive when it comes to asking questions about gaps in employment:

“Maybe change the way they formulate the job application forms – like for example, if there’s a gap between employment…they should be more educated about what the possible answers could be.”

Interviewee - Female, 26-50 years, White British, physical/sensory impairment and mental health condition

**More support with job applications and finding employment:** Some participants also feel that it is very important for those disabled people that are keen to find employment to be able to access help with completing job applications, identifying employment opportunities and advice about interviews. Participants at the Hammersmith focus group feel that having Disability Employment Officers at job centres is one way that disabled people can access the support they need. This was also echoed by expert interviewees who feel that better and more equal access to employment is an important improvement that would impact positively on disabled people. In particular, they feel that providing disabled people with the support they need to get into work was very important and therefore there was real concern about access to Access to Work.34

**Government has a role in enforcing equality in employment practices:** A number of participants also feel that the government has a regulatory role to play in ensuring that employers have policies, strategies and processes in place that relate to ensuring equal consideration of people with disabilities for job opportunities. They also feel that the government should ensure that employers are fully committed to providing disabled people with the support and adjustments they need to perform their jobs.

“They should expect employers to have a strategy, to have provided training, to be gathering data. So you can pull a lot of levers by shifting emphasis on what the employer is doing. At the moment the narrative is all about what the individual is doing.”

Interviewee – Female, 26-50 years, White British, physical/sensory impairment

**Educating young people in schools about disability:** Participants feel that this is important as it will help tackle bullying in schools and ensure that young people develop a sense of empathy with disabled people from a young age.

“People need to learn that they have a disability and not call them anything just because their life is different to someone else.”

Essex focus group

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34 Access to Work (AtW) is a programme that provides financial support to disabled people and their employers for both one-off and ongoing costs associated with employing a disabled person.
Greater awareness amongst education providers about disabled people's potential: This is felt to be important because of low expectations of teachers caused by stigma attached to disabled people’s conditions. Participants want to feel like they have the chance to try things without educators assuming that they will not succeed.

“Not everybody is the same, not everybody has the same abilities, it needs to be so they have more training in what is going to come. So they can support us and let us have a chance…instead of doing life skills.”

Leeds focus group
6. Leisure, social connections and living independently in the community

Summary of key findings

- Social and community life is seen as a challenging area by around three in ten (28%) of disabled people, and this is a particularly pertinent issue for people on low incomes (with over a third – 36% – of those earning under £9,999 mentioning this) and for those with children in the household (with 40% mentioning this). One’s general health or condition (58%), anxiety/lack of confidence (56%) and other people’s attitudes or behaviour (34%) are the most frequently cited barriers among those who identify this as a main or secondary challenge in life.

- The qualitative research also identified a number of reasons why disabled people find social and community life challenging. Research participants who were physically and/or sense impaired reported that the places and spaces they wished to visit were often inaccessible to them and this created a barrier to independence and their enjoyment of leisure activities. Participants felt that issues of accessibility contributed to feeling isolated, as it often seemed easier to stay at home rather than attempt a trip out.

- Over a third (35%) of disabled people say they find leisure a challenging area of life, with general health or condition (74%) cited as the main barrier among those who identify this as a main or secondary challenge. The qualitative research identified a number of further barriers to accessing appropriate and specialist leisure activities including a lack of specialist activities and not having the support required to participate in leisure facilities.

- The ability to get out and about was consistently reported by the disabled people we spoke to as being essential to mental health, a sense of independence and happiness. Lack of access to appropriate transport can also have a knock-on effect, particularly in terms of a person’s ability to get and retain employment. Participants reported receiving little help from members of the public when they were trying to access and navigate public transport - experiences which they found frustrating and stressful.

- Participants in focus groups and interviews were very enthusiastic about the role played by DPOs in supporting their wellbeing and independence. Through participation in local groups, research participants gained access to leisure activities; information about services, rights, opportunities and emotional support.

- A number of changes to leisure, social and community life were suggested by participants in the focus groups and interviews. These included the involvement of disabled people in the design of places and spaces, in order that the needs of different impairment groups be taken into consideration and for national and local government to play a ‘regulatory’ and ‘enforcement’ role to ensure that spaces, places and transport are accessible for disabled people.
6.1 Challenges in social and community life

Around three in ten (28%) disabled people have faced a challenge in social and community life. These challenges were particularly pertinent for people on low incomes, with over a third (36%) of those earning under £9,999 mentioning this. Disabled people with children in the household were also more likely to find this challenging, with two in five (40%) agreeing this was the case.

When prioritising areas of life they find challenging, one in seven (15%) disabled people say social and community life is either their main or second most challenging area. For these people, the main barriers involved are their own general health or condition (58%), anxiety/lack of confidence (56%) and other people’s attitudes or behaviour (34%). Smaller numbers of disabled people (18%) say that difficulty getting into buildings or using facilities was a key barrier faced in social and community life. The issue of other people’s attitudes and behaviours is explored in depth in chapter 7.

Fig 9. Thinking of a time when you faced the biggest challenge relating to social and community life which, if any, of the following issues were involved?

6.2 Inaccessibility of spaces and places

Expert interviewees felt that improvements in the accessibility of goods and services, through the introduction of ramps and wider spaces to manoeuvre, mean that more disabled people have been able to participate and live in the community. Despite this, the current research suggests that more needs to be done. Inaccessibility of places and spaces was identified as a barrier to participation in community and social life in
the quantitative research and was mentioned repeatedly by participants in the qualitative focus groups and interviews.

As we have seen above, around a fifth (18%) of survey respondents who rated social and community life as the main or secondary challenging area in their life identified difficulties getting into buildings or using facilities as a key issue when they faced the biggest challenge in this area.

This finding was explored in more depth in the interviews and focus groups. Participants with physical and/or sensory impairments described how their freedom to exercise choice and control in their lives was constrained due to the shops, cinemas, restaurants, council buildings, historical buildings and churches they wished to visit being inaccessible. Buildings were difficult to access if they are up a flight of steps, a very steep slope, if they have a narrow entrance or if there is limited room within them to accommodate a wheelchair. As an example of this, one participant was denied the choice to shop where she wanted to because of inaccessibility - she was limited to shopping at the only local supermarket which had aisles large enough to accommodate her wheelchair. Below she speaks about the difficulties of getting in to, and out of, shops:

“Either the shops are up steps or the passageways are too narrow and the chair won’t get through…sometimes the shops don’t open double doors, they leave them locked. They open it to let me in and then they closed it again and so I can’t get out”.

Interviewee – Female, 51-70 years, White British, physical/sensory impairment

Inaccessibility of places and spaces also emerged from the research as a key barrier to being able to establish and maintain a sense of connectedness to the wider world. For example, inaccessibility meant that some physically or sensory impaired interviewees were unable to participate in social, community and civil activities and events - one woman with physical impairments was prevented from attending a wedding because she was unable to get into the church or the hotel where the wedding was being held.

A lack of reliable information about accessibility created uncertainty when visiting somewhere new and acted as a barrier to maintaining social connectedness. Interviewees felt that Disability Awareness signs were not reliable indicators of how accessible a building was. Interviewees also felt that staff often didn’t have enough knowledge and awareness of accessibility to tell visitors whether they would be able to access a building when they were planning a visit. The quote below, from one interviewee with physical impairments who had to use hotels when she wanted to visit her grown up children, demonstrates how a lack of reliable information can act as a barrier to maintaining connectedness to friends and family:

“Most places have to display the disability awareness sign but it doesn’t always mean anything. When you phone to book a room in a hotel, the receptionists don’t know if their rooms are accessible or not and often the rooms are not accessible. We end up staying in places like a Travelodge or Premier Inn because they are
the same wherever you go, or we tend to avoid seeing our daughters because of the hassle.”

Interviewee – Female, 51-70 years, White British, physical/sensory impairment

A lack of clean and adequate disabled toilet and changing facilities created a further barrier to participating in social and community life for many of the interviewees with physical and sensory impairments. This meant those with physical impairments either had to wear pads for a long period of time, which they found undignified, or they avoided going out. One interviewee with a physical impairment wanted to attend council meetings but was unable to because the disabled toilet in the building was located far from the meeting room and she had to find the key holder every time she wanted to use it.

Experiences of inaccessibility led many of the interviewees with physical and sensory impairments to feel that their needs were not considered when places were designed – for some, this was a sign that disabled people were not expected to go out.

As described above, the uncertainty, stress and hassle involved in going out acted as a barrier to participation in social and community life and maintaining connectedness. It led some interviewees to feel it was easier to stay at home than to attempt a visit out and as a result of this, become isolated. The quote below, on the impact of the inaccessibility of places and spaces, illustrates this:

“[the impact of the inaccessibility of places and spaces is] frustrating and annoying and limiting. Before I got involved in the charity work, I was very socially isolated, easy to slip into a place of feeling sorry for yourself and feeling as though you cannot change things”

Interviewee - Female, 51-70 years, White British, physical/sensory impairment

6.3 Lack of access to appropriate leisure activities

Participants in the focus groups and interviews told us about the profound impact engaging in leisure activities has on physical and mental wellbeing. Leisure activities help participants across all impairment groups to maintain their physical health, manage weight, ‘blow off steam’ when they are feeling stressed and boost their emotional wellbeing. In addition, leisure activities were seen as a means of maintaining a sense of connectedness as well as a way in which interviewees could participate in social life. Interviewees, particularly those with mental health conditions felt that isolation, a lack of purpose in daily living and limited social connections severely worsened their condition. The importance of leisure activities was particularly strongly felt amongst research participants with mental health conditions, for example one person said:

“[Leisure activities are important for]….getting together with other people, diverting your mind and for a little while you forget your problems…. Every morning we are lost and this is a hard feeling”

Harrow focus group
Removing barriers, raising disabled people’s living standards

This reflects one of the key findings from OPM’s research for the RNIB, for example, was that apparently simple provisions – such as accessible information and modest support to enjoy accessible leisure activities – could nevertheless be the crucial difference between a blind or partially sighted person living independently and them becoming isolated and unwell (RNIB/OPM, 2012). And yet there is considerable evidence that disabled people are much less able to benefit from this kind of community participation, as a result of several barriers. ODI disability equality indicators, for example, show that disabled people are significantly less likely to participate in cultural, leisure and sporting activities (such as visiting a museum or going to the cinema) than non-disabled people.

Over a third (35%) of disabled people say they find leisure a challenging area of life, although it is only seen as the main or secondary challenging area by 12% of people. Once again, general health or condition (74%) is the main barrier for disabled people identifying leisure as an area of life which is a main or secondary challenge. A fifth (20%) mention difficulty getting into buildings or using facilities, rising to a quarter (25%) of people aged 65 and over.

**Fig. 10 Thinking of a time when you faced the biggest challenge relating to leisure which, if any, of the following issues were involved?**

![Bar chart showing challenges related to leisure](image)

The focus groups and interviews explored these barriers in more depth. A strong barrier to emerge from the qualitative research was the lack of appropriate and specialist leisure activities. Participants with physical impairments reported difficulties in accessing activities such as swimming - many felt they were unable to take part in sessions open to the public or that they needed help and support to participate in this activity which was not available. For some participants with mobility impairments and learning disabled participants, swimming was felt to be a crucial for keeping weight down and maintaining wellbeing and the only option accessible to them.
Some younger participants felt that existing specialist provision generally catered for older people with physical impairments and so acted as a barrier to participation in social life. One participant reported being very disappointed that a scheme that had provided disabled people help to use gym equipment had recently been abolished.

For other participants, a barrier to accessing appropriate leisure activities was the time of day these were held. This applied to participants with mental health problems who wanted activities to be held at times of the day that were considered particularly difficult to ‘get through’ (such as long evenings in the winter) or participants who were in full or part time employment:

“Having somewhere to go (is important) – clubs etc around here are all on only until lunch time, like day centres are from 10-2 and I’m working in the morning. So if there were things at a more suitability time in my area, I would have a try”.

Interviewee – Male, 26 - 50 years, White British, physical/sensory impairment

6.4 Inaccessibility of transport

Another major barrier to participation and maintaining a sense of connectedness that emerged from the research was the inaccessibility of transport.

A quarter (26%) of disabled people say they find transport a challenging area of life, while 8% choose it as their most or second most challenging area. Disabled women are more likely to say they have faced a challenge in transport (28% compared to 22% of men). This may be linked to the fact that when we look at figures for the general public, a higher proportion of men than women have a driving licence\(^3\)\(^5\), leaving women more reliant on public transport or on other drivers. Those not in work are also more likely to find transport challenging (mentioned by 27% compared to 20% of those in work).

The main reason for finding transport challenging is lack of accessible transport, with nearly three in five (58%) of those who identify it as a main or secondary challenge in life mentioning this. Accessing transport is also a barrier, with a quarter (25%) saying that difficulty getting into buildings or using facilities is an issue.

Fig. 11 Thinking of a time when you faced the biggest challenge relating to transport which, if any, of the following issues were involved?

\(^3\)\(^5\) Department for Transport, National Travel Survey 2010
The ability to get out and about was consistently reported by focus group and interview participants as being essential to mental health, a sense of connectedness and the ability to participate in community and social life. In line with the survey findings, access to appropriately adapted and affordable transport was cited as a key issue, repeatedly identified (in almost every focus group). For many research participants, particularly those with mobility issues, travel by taxi was too expensive and other forms of public transport were often not accessible.

Research participants also reported receiving little help from members of the public when they were trying to access and navigate public transport, these experiences were frustrating and not being able to rely on help from others increased the stress involved in travelling by public transport.

### 6.5 Local groups and support networks

The research suggests that Disabled People’s Organisations (DPOs) and other local groups and support networks play a vital role in enabling disabled people to maintain a sense of connectedness to other disabled people as well as people in general. Such groups can also provide very practical support to enable opportunities to participate in social and community life and leisure/cultural activities.

Many of the participants in the focus groups and interviews, across all impairment groups, spoke very enthusiastically about their involvement in local groups, which offered them access to broader social networks of disabled people. For example, participants in one focus group for people with mental health conditions described how the local DPO group they attended provided an opportunity to be socially connected to other people with mental health conditions. Being socially connected to similar others enabled those we spoke to feel as though they could ‘be themselves’, without fear of being laughed at by the outside world:
“We have the space to talk to each other and we can make plans to see each other again”

Harrow focus group

Similarly, the young people participating in the focus group in Essex talked about being able to participate in residential activities, trips and events put on in half terms and holidays by local disability organisations. These were often creative or activity-based and participants said how much they enjoyed them.

Disabled people reported that benefits of involvement in DPOs also included the opportunity to meet and share experiences with other disabled people and the opportunity to develop a sense of independence and purpose. Developing a sense of independence was particularly important for younger participants in one focus group we conducted – the experience of volunteering for the local disabled people’s organisation (DPO) was described as ‘life-changing’ by one participant:

“At the time I started volunteering my parents wouldn’t let me open the front door and they wouldn’t speak about money in front of me. When I started volunteering I was in a situation for the first time in my life when I was treated like an adult.”

Surrey focus group

Participants with learning disabilities expressed similar views: participants in one focus group for young people with learning disabilities felt strongly that coming to the group gave them the chance to be around other young disabled people. One young man said that not being able to attend the group – when he was unable to afford the taxi fare – made him ‘very upset’.

DPOs provided research participants with advice and information which could be otherwise difficult to access. This view was strongly felt in two of the focus groups with participants with physical/sensory impairments. In one of these groups, having access to this information was described by one participant as making her feel ‘empowered’.

On the one hand the importance attached to local disability groups is, perhaps unsurprising. The focus groups were arranged with the direct help of DPOs, and often held at their premises, and in some cases participants were active volunteers or members of the organisation in question. (This approach to recruitment was an explicit choice: to provide a familiar and supportive environment in which disabled people could feel comfortable discussing sensitive issues.)

6.6 What needs to change?

Research participants in the focus groups and qualitative interviews identified a number of areas where they would like to see change.

More consideration of disabled people’s needs when spaces and places are designed: Participants with physical impairments and mobility issues wanted to see more understanding and consideration of their needs when spaces and places are designed.
Removing barriers, raising disabled people’s living standards

designed. This includes making it mandatory that all buildings have disabled access, having more ramps for wheelchairs and building more disabled toilets in central areas. Those who wanted this change felt the impact would be greater choice and control as to where and when they could go out as well as greater participation in social and community life. Participants felt strongly that disabled people should be closely involved in making alterations to places and spaces, in order to ensure that needs are met:

“Everyone should learn what it is like to be in a wheelchair. If a place is making an alteration to become accessible, disabled people should be involved. Generally it is clear that disabled people are not involved”

Interviewee – Female, 51-70 years, White British, physical/sensory impairment

Clearer and more reliable information about accessibility of buildings or spaces: Several participants called for clearer and more reliable information available about how accessible a building or space was and felt this would minimise the amount of anxiety and uncertainty involved in trying to access a place or space. For example one participant suggested that a gold, silver or bronze rating system could be developed and widely used to indicate different levels of accessibility. This information could be displayed on a website so people with mobility issues could check accessibility before they left home.

“Places could be graded according to levels of accessibility, you could go on to the website ahead of time and see that it is level three of a level four and then you would know what to expect when you got there. At the moment you think, ‘I will just stay at home’, because it is worrying not knowing whether somewhere is accessible”.

Interviewee - Female, 51-70 years, White British, physical/sensory impairment

Role for government: Participants identified a big role for local and national government to play a ‘regulatory’ and ‘enforcement’ role to ensure that spaces, places and transport are accessible for disabled people. There was a view amongst participants that while the Disability Discrimination Act (superseded by the Equality Act 2010) was supposed to introduce a standard of accessibility which buildings had to conform to, because this Act stated ‘wherever possible’, this meant that buildings were often not accessible.

Appropriate leisure activities: In light of the positive impact of leisure activities on the mental and physical wellbeing of disabled people, participants wanted leisure facilities to cater for a range of disabilities and ages and to be held at a suitable time for disabled people in employment to access:

“I would like for example to be able to get some exercise and I know that there are exercise classes for disabled people, e.g. chair-based, but when I’ve tried them, it’s been me in a group of people 20-30 years older.’
Support for DPOs: In a climate of spending reductions on services, support groups and DPOs were seen as playing a major and much valued role in enabling disabled people to establish and maintain a sense of social connectedness. Focus group participants argued strongly for organisations like Scope to offer support for DPOs where it can, and putting pressure on local authorities and the government to protect sources of funding.

There was consistent feedback from focus group participants that recent spending reductions had already had a negative effect, in particular causing the local support they had previously received to be sufficient only for ‘the basics’: unable to cover the activities and opportunities that were felt to be absolutely vital for independence, health and wellbeing. Many focus group participants hoped that Scope would be a strong voice in national debates about financial support to disabled people.
7. Public attitudes

Summary of key findings

- The behaviour and attitudes of other people contribute to the challenges a significant proportion of disabled people have faced in life. In the survey, disabled people were asked to identify the groups where positive changes in awareness and attitudes would make most difference to them personally. The general public (29%) as a whole was most likely to be chosen followed by local authority/government staff (23%) and health/care/support staff (23%).

- Participants in the qualitative research described the insensitivity and rudeness of members of the public and how they have been avoided and rejected by strangers, friends and family. The stigma attached to having a disability was felt to be particularly strong for participants with mental health conditions. Participants reported other people thinking they were ‘unstable’ or ‘unsafe’.

- Participants felt that the media played a vital role in reinforcing negative attitudes towards disabled people – a number of examples of this were given, such as the recent focus of disabled people as ‘benefit scroungers’ and of those with mental health conditions as ‘psychotic’ and ‘violent’.

- A number of participants described the negative impact of attitudes held by family members and parents. Participants with mental health conditions in the Asian community reported that the stigma attached to mental health problems led them to feel isolated from family and other in the community. Many younger participants described the excessively cautious attitudes of their parents which limited them from having new experiences.

- Participants in the focus groups and interviews made a number of suggestions to improve attitudes towards disability. These included: changing children and young people’s attitudes to disability; delivering disability-specific awareness campaigns; and greater positive representation of disabled people on the television and in mainstream media.

7.1 Public and community attitudes

There is a wide range of evidence to indicate that disabled people are more likely than non-disabled people to experience the attitudes of others as a major barrier to an area in their life such as education, leisure, transport, access to public services, social contact and accessibility outside the home (Life Opportunities Survey, 2009/2010). Whilst the number of people expressing negative views towards disabled people has decreased since 2005 (from 9% in 2005 to 7% in 2009) and the

Removing barriers, raising disabled people’s living standards

number of people expressing positive views has increased over the same period (from 77% in 2005 to 85% in 2009), negative views towards disabled people persist. Nearly four in ten (36%) of people think of disabled people as less productive than non-disabled people and over three quarters (76%) think of disabled people as needing to be cared for. This evidence supports other studies into attitudes that have shown that the key attitudes towards disabled people are that they are: less capable than non-disabled people; in need of care; and dependent on others (DWP, 2002; DRC, 2007).

In this survey, disabled people were asked to identify the groups where positive changes in awareness and attitudes would make most difference to them personally. The general public as a whole was most likely to be chosen (29%), particularly by disabled people with mental health issues (38%), who are more likely than average to identify all the groups asked about.

Around a quarter (23%) mention local authority/government staff and health/care/support staff. Disabled people with certain impairments are more likely to choose local authority/government staff – people with conditions relating to mental health (35%), dexterity (34%) memory (33%) and intellectual, social or behavioural or learning difficulties (34%). Among disabled people who work, 32% would like to see attitudes change among employers and 15% among colleagues.

Fig. 12 Among which groups, if any, do you think a positive change in awareness and attitudes towards disabled people or people with health condition would make most difference to you personally?

38 Opinium (2013) Understanding of and attitudes towards disability, Report for Scope. The research consisted of an online survey of a representative sample of 2,000 UK adults aged 16 and over.
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A lack of understanding of their individual needs is the attitude or behaviour most commonly experienced – and which disabled people who have experienced more than one type of attitude or behaviour most want to change. Indeed as the chart below illustrates, the proportions experiencing and wanting to change specific attitudes or behaviours are very similar.

Fig. 13 Have you experienced any of the following behaviour or attitudes from other people because of your health condition or disability? Please select all that apply.

Which, if any, of these behaviours would you most like to see changed?

<table>
<thead>
<tr>
<th>Behaviour/attitude experienced</th>
<th>Behaviour/attitude most want changed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not understanding my needs</td>
<td>41</td>
</tr>
<tr>
<td>Expecting less of me because of my health condition or disability</td>
<td>24</td>
</tr>
<tr>
<td>Treating me like I am a nuisance</td>
<td>23</td>
</tr>
<tr>
<td>Thinking I can't make my own decisions</td>
<td>16</td>
</tr>
<tr>
<td>Being awkward around me</td>
<td>15</td>
</tr>
<tr>
<td>Ignoring me or pretending not to see me</td>
<td>16</td>
</tr>
</tbody>
</table>

Base: All disabled respondents (2,045), All respondents who experienced more than one behaviour/attitude from other people (894)

Certain groups of disabled people are more likely to have experienced a lack of understanding of their needs – people with conditions relating to mental health (67%) intellectual, social or behavioural or learning difficulties (67%), memory (62%), dexterity (54%) and stamina/breathing difficulties (51%).

These groups are also generally more likely to have experienced the other behaviours or attitudes asked about. For instance two-fifths of people with mental health (42%) or intellectual, social or behavioural or learning difficulties (41%) have felt treated like a nuisance. Disabled people of working age are more likely to have experienced most of these behaviours or attitudes compared to the over 65s, with the biggest gap seen in relation to ‘not understanding my needs’ (52% vs. 27%). Disabled people from social grade E are also more likely than average to have experienced most of the attitudes or behaviours asked about.

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39 Those on lowest levels of subsistence including pensioners, casual workers, and others with minimum levels of income.
In line with survey findings presented above, participants in the focus groups and interviews experienced a great deal of stigma and discrimination from members of the public which had a severe negative impact on the lives. Research participants felt that the stigma attached to their disability led to some members of the public to be rude and insensitive. Participants had been stared at, pushed or bumped whilst in their wheelchairs or mobility scooters and had received offensive comments from strangers about their appearance, lifestyle or disability. Whilst experiences of insensitivity and rudeness were prevalent across all impairment groups, they seemed to be greater amongst participants with the more ‘visible’ conditions. The quotes below illustrate some of these experiences:

“Have had a rough time – people have walked up for me saying ‘why’ve you’ve had a child, you shouldn’t have had a child’”.

Interviewee – Female, 26-50 years, White British, physical/sensory impairment

“Sometimes people bump into me and don’t say sorry and some people are really not very friendly. Once I was in Tesco’s and this lady said ‘you should have had an operation on your eye when you were baby’ and I said ‘excuse me I’ve got cerebral palsy’”.

Chester focus group

For research participants who had come to be disabled later in life or had an existing condition worsen, a common experience of discrimination was avoidance and rejection by peers and friends. Several participants were of the view that the stigma of disability was so great that non-disabled people didn’t want to be associated with disabled people:

“After it became known why I’d lost my job, the people I trained with didn’t speak to me, they ignored me. One woman wouldn’t acknowledge me or say a word to me – even though I went to her wedding.”

Interviewee – Female, 26-50 years, White British, physical/sensory impairment and mental health condition

The stigma attached to having a disability was felt to be particularly strong for participants with mental health conditions. Some of these participants felt that knowledge of their condition greatly impacted on how other people perceived them. This was exacerbated by the ‘invisibility’ of a mental health condition and a general lack of understanding about mental health conditions. Participants reported other people thinking they were ‘unstable’ or ‘unsafe’, ‘lazy’ if they slept a lot as a result of medication or ‘aggressive’ if they were undergoing an episodic fluctuation in their condition.

Several participants also felt that other people didn’t believe they could have a mental health problem if they were an educated, professional person and had a tidy appearance. For several participants, the experience of discrimination was being perceived as less credible once they had been diagnosed with a mental health
condition, which led to others questioning their judgement even when they were not experiencing a mental health episode:

“The moment I disagree with someone, they say “Are you all right? Have you taken your meds” or “Are you having an episode” instead of listening to my viewpoint. This makes me more paranoid. I can’t even discipline my children without being questioned”

Cardiff focus group

In some cases, concern about being treated differently or discriminated against because of a disability led to participants keeping their conditions a secret:

“I've felt that when I've met people in mainstream society I've had to hide myself, have been worried about how they might think about me – worried that they'll think that I'm dangerous, or have lots of problems, or I don't know. They'll think that I'm a nutter”.

Interviewee - Female, 26-50 years, White British, mental health condition

7.2 The influence of the media on attitudes

Expert interviewees were of the view that greater visibility of disabled people, both in the community and in prominent roles, has had a very positive impact on attitudes towards disability. They pointed to, for example, more disabled people in television shows and documentaries, Paralympians in the London 2012 Olympics and people with disabilities in leadership roles. Similarly, a strong theme to emerge from the interviews and focus groups was the portrayal of disability in the media and the amount of influence these portrayals had on the public attitudes toward disability.

Participants gave several examples of the media playing a positive role in promoting awareness of disability, for example, with characters with disabilities in soaps such as Coronation Street or Eastenders or public figures, such as Stephen Fry:

“I think it’s a good thing that there’s a disabled character in Coronation Street because it makes people more aware of a disability”

Chester focus group

On the whole, however, participants in the qualitative research felt that the media portrayals of disability were currently more negative than positive. Participants were of the view that these portrayals greatly impacted on the stigma and discrimination which they experienced from the wider community. The programme ‘The Undateables’ was mentioned as an example of this. Whilst participants acknowledged that the actual content of the programme didn’t promote negative attitudes, they felt the provocative and overwhelmingly negative connotations associated with the title ‘The Undateables’ outweighed any positive content:

“I think television goes a bit too far. I think they are very critical of disabled people and can promote the wrong messages. The media must be careful; I don’t see
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why we should be targets, it shouldn’t just be disabled people being portrayed badly”.

Surrey focus group

A strong message from participants was how tightening eligibility for benefits and the focus of the media on ‘undeserving’ benefit applicants and ‘scroungers’ was having a profound and unhelpful impact on the attitudes of members of the public. This reflects the wider finding that disability groups say they have been increasingly contacted by people who have been taunted on the street accused of faking their disability. The cause of this is seen as inflammatory media coverage as well as ministers and civil servants repeatedly highlighting the supposed mass abuse of the disability benefits system, which disability groups see as unfounded.

Messages such as these have made research participants feel stigmatised and vulnerable.

“I think the public are very influenced by what they read and see on television. There are some very negative stories…like committing fraud around disability benefits. The media focuses on it and then people think we’re all at it and that’s horrible for disabled people.”

Interviewee – Female, 26-50 years, White British, physical/sensory impairment

Participants with mental health conditions felt strongly that the media was influential in portraying people with these conditions as ‘violent’ or ‘aggressive’, particularly for those who had schizophrenia or had experienced episodes of psychosis. Participants feel there is a lack of positive messages about mental health in the press and pointed to how the press often report that a person, who is suspected of committing a violent crime, also has a mental health condition - which serves to strengthen the association between mental health and violent behaviour. Research participants felt that these associations contribute to the stigma and discrimination they experience as a result of having a mental health condition.

Several participants referred to how the media will either portray disabled people as ‘heroes’ or as ‘villains’ - so disabled people are either being vilified as being violent or a ‘benefit scrounger’ or celebrated as ‘heroic’ or ‘deserving’. One participant with mobility issues who took part in a focus group with people with physical and sensory impairments told us how people were very keen to talk to her about benefit fraud and their attitude was that she was ‘deserving’, compared to those who were ‘undeserving’ - an attitude which she found to be very patronising.

7.3 Impact of family and parental attitudes

Expert interviewees felt that increasing globalisation, shifts in transport and the fact that people have become highly mobile has all had an impact on the notion of

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40 As reported in the Guardian newspaper in February 2012
http://www.guardian.co.uk/society/2012/feb/05/benefit-cuts-fuelling-abuse-disabled-people
community. They felt there was been a degradation of community which has led to increased pressure on the nuclear family. This shift provides an important backdrop to the experiences of disabled people and, importantly the extent to which they feel included and supported if this doesn’t come from their immediate family.

Family and parental attitudes had the impact of limiting some research participants and led to others feeling ‘cut off’ and unsupported. Amongst survey respondents, women (12%) are more likely than men (8%) to mention family members as a group where a positive change in awareness or attitudes would make the most difference to them personally.

Qualitative research participants with mental health conditions in the Asian community described the stigma attached to having a mental health problem and the lack of understanding about these conditions, which led some participants to be isolated from family members and other members in the community:

“You cannot be honest about it – if I tell family members or friends that ‘oh I had a bad weekend, I was very depressed’ they don’t respond. Would be nice if people I had approached and told would ask me how I am...Would be nice once a week to be asked ‘how is your depression?’, ‘how is your bulimia?’”

Interviewee – Female, 26-50 years, Asian British, mental health condition

In several of the focus groups, a particularly strong theme to emerge from discussions centred on the limiting and excessively cautious attitudes of participants’ parents and other family members.

Young people participating in one focus group talked about feeling held back by parents being very cautious, with one person saying ‘sometimes when I go out my mum texts me and asks where I am and I say I’m at a friend’s house and she says it’s too far and she gets worried.’ A learning disabled participant in the Leeds focus group said of her foster mother: ‘When she was in a bad mood, she doesn’t let me go out, like go out for a walk’ when walking around the local area would, she felt, give her ‘a bit of confidence and a bit of freedom’.

Expanding on this theme, a participant in a focus group for people with physical and sensory impairments described the difference it had made when she started receiving support from a personal assistant. With support from the personal assistant, this participant had taken a trip to London, which was something her parents would never have allowed because of their concerns about her safety (which the woman in question felt to be excessive): ‘they wrap you up in cotton wool, because they are worried about you’.

Another participant in the same group said that the view her parents had imparted was ‘the world was really scary and bad things would happen, which is why it was so liberating when I got out and did things for myself’ and that there was still stigma attached to disability by some parents.
7.4 What needs to change?

Participants in the focus groups and qualitative interviews were clear that a number of changes were required to improve attitudes. Participants felt these changes would reduce the discrimination and stigma they experienced from friends, family and the wider community and have an overwhelmingly positive impact on their lives:

“If you knew people weren’t going to look at you and laugh, or point at you, you would know it’s okay to be free to be yourself. You wouldn’t hear about lots of disabled people suffering, you could be less fearful when going out, you wouldn’t be afraid that something bad might happen”

Interviewee – Female, 26-50 years, White British, physical/sensory impairment and mental health condition

Changing children and young people’s attitudes towards disability: Participants felt strongly that in order to tackle the discrimination and stigma associated with disability, attitudes needed to be shaped at an early age. Some participants suggested this could happen through more interaction between disabled and non-disabled children. Others felt there should be more education for non-disabled children about different types of disability and what it was like living with these. There was a strong message that schools and in particular, teachers, had an important role to play in shaping and modelling attitudes.

“In an ideal world children of 2 or 3 would be well aware that not everyone is able bodied”.

Norfolk focus group

Delivering disability-specific awareness campaigns: Participants talked positively about awareness campaigns focused on motor neurone disease, dementia and mental health and those which were fronted by well-known personalities, such as Ruby Wax. Participants were clear there should be more of these types of campaigns. Such campaigns were important for challenging the lack of understanding, ignorance and negative assumptions about disabled people in wider society. Campaigns such as these need to highlight that ‘disabled people have feelings, intelligence and deserve respect’. As one participant explained:

“I would like to see better awareness of conditions particularly mental health campaigns – Ruby wax fronted one which was good. Making people aware of how common it is, showing people it is ok to talk about it. Disabled people don’t want to be treated too differently, just want to be accepted”.

Interviewee – Female, 26-50 years, White British, physical and sensory impairment

More emotional and psychological support for parents and carers of children with disabilities. Participants who had experienced what they believed to be delimiting attitudes from their parents said that there should be more emotional and psychological support for parents, with workshops and other opportunities to talk
through what it was like to have a disabled child, in order to help cope with a feeling that it was ‘them against the world’.

**Greater visibility of disabled people.** A strong message from expert interviewees and from focus group and interview participants was the positive impact greater visibility of disabled people on reducing the stigma and discrimination towards disability. Participants were very keen to see more positive portrayals of disabled people on the television and in mainstream media. Whilst participants' views about the best way to portray disabled people and disability issues on television varied, there was consensus that seeing more disabled people as ‘normal characters’ (rather than obviously ‘good’ or obviously ‘bad’ characters) would help to raise awareness of disability amongst the wider public and reduce stigma and discriminatory attitudes:

> “We need a more realistic view of disabled people – we’re not all heroes or villains, even though I love stories about disabled people becoming heroes, overcoming adversity. But we all have the right not to climb a mountain!”

Interviewee - Female, 26-50 years, White British, physical and sensory impairment

Expert interviewees were particularly keen to see more disabled people as role models and in the leadership positions which were responsible for championing change. They felt that this would be powerful in changing wider society’s attitudes towards disabled people.
8. Working together to raise living standards

Summary of key messages

- The key ways in which disabled people would like to be involved in improving society for themselves and other disabled people are: educating non-disabled people (21%), supporting or mentoring other disabled people (14%) and taking part in campaigns to change something locally or nationally (12%).

- Just over a third of disabled people (36 per cent) would not want to be involved at all. Nevertheless the proportion of disabled people who would like to participate in some way is higher than some of the figures for the public as a whole seen in other surveys. For example The Audit of Political Engagement shows that only a third (33%) of the general public want to be involved in decision making nationally and around two in five (38%) involved at a local level.

- Survey findings suggest that a desire to get involved is related to age and how limited people feel in their day-to-day lives, with those of working age and those feeling very limited having a greater appetite for getting involved.

- As well as their own involvement, those in the qualitative research identified charities and the government as having vital roles to play in helping to deliver this change. Whilst they felt it was the role of charities to protect the interests of disabled people and use their contacts in government and media to influence change, they felt the government had to lead the way in changing attitudes to disabled people and reversing the damage done with the portrayal of disabled people by the media as ‘benefit scroungers’ and as ‘undeserving’ benefit claimants.

- Participants also called for government to listen to the needs of disabled people, in order to make policy decisions which took into account the needs and implications of different types of disability.

8.1 The role of disabled people

Survey respondents were asked what role they would like to play in improving society for themselves and other disabled people. As the graph below indicates - the key ways disabled people want to be involved are in educating non-disabled people about disability, with a fifth (21%) showing interest in this. Supporting or mentoring other disabled people is mentioned by 14% of disabled people. As with the general population, being involved in local decision making is also appealing, with 16% saying they would like to ‘work with local authorities to help them make decisions about local services’.

Fig. 14 If you were offered some support to do so, how, if at all, would you like to be involved in improving society for yourself and other disabled people and people with health conditions?
Expert interviewees were clear that disabled people had a big role to play in facilitating social change, pointing to the success of past social movements where oppressed people have led campaigns and protest.

Participation by disabled people in civic activity has been shown to be important for reducing social exclusion, building skills for employment, establishing community cohesion and breaking down negative perceptions of disability (SEU, 2004). Overall the evidence reviewed finds that disabled people are significantly more likely to participate in public life than non-disabled people. Participation in public life, often referred to in studies as ‘civic life’, is defined as undertaking at least one of the following activities in the previous 12 months: contact a councillor, local official, government official or MP, attending public meeting or rally, taking part in demonstration or signing petition. There are important differences between groups of disabled people however, white disabled people, disabled people aged between 35 and 74 and disabled people with households with annual incomes of £28,800 or more per year (OPM, 2010) are more likely to participate.

Participants in the focus groups were enthusiastic to have their voice heard, get involved in national debates and awareness-raising campaigns. Some participants had past experience of this. For example participants in the Leeds focus group talked about going and telling other schools, families and colleges about what it was like to be a learning disabled young person.

When asked why they would like to be involved in this way, research participants reported that they believed the involvement of disabled people in these debates and campaigns was key to increasing their effectiveness. Participants felt that the involvement of disabled people in campaigns would increase the visibility of disabled people, challenge preconceptions and stigma about disabilities and would be an
opportunity to educate non-disabled people about what it is like to be a disabled person. The quotes below illustrate these points:

“I absolutely love it when you see people in wheelchairs protesting against changes. Nothing works better. People who are prepared to put their bodies on the line, they are heroes to me. Direct action has an influence on the media. It’s a good way to target the opinion changers”

Interviewee – Male, 26-50 years, White British, physical/sensory impairment

“Disabled people need to speak up. I’m looking at what’s happening in the country and I’m worried. To come out and say yes there are people who take advantage but are also people who’ve lost everything to illness, and for every person whose taking advantage there are so many others who are victims, have made contribution to society before that”

Interviewee – Female, 26-50 years, White British, physical/sensory impairment

Expert interviewees were of the view that non-disabled people also needed to be involved in removing the barriers disabled people face. They felt that, in the same way that wider society was involved in campaigning against racism or other forms of discrimination, non-disabled people need to be involved in campaigning for change for disabled people. They called for more empathy (not sympathy) on the part of non-disabled people about what it is like to be disabled.

At the same time as these expressions of enthusiasm, a sense of perspective is needed: just as the general population as a whole, many disabled people do not, currently, want to be involved in making a difference to society. More than a third of disabled people (36 per cent) did not wish to be involved at all. Nevertheless the proportion of disabled people who would like to participate in some way is higher than some of the figures for the public as a whole seen in other surveys. For example The Audit of Political Engagement shows that only a third (33%) of the general public want to be involved in decision making nationally and around two in five (38%) involved at a local level. However it is worth bearing in mind that there will be a gap between the people who say they would like to and would actually participate.

Disabled people taking part in focus groups and qualitative interviews suggested that some of their peers would need encouragement to get involved in campaigning as well as particular types of support to make it accessible for them - for example, mentoring to increase self-confidence, advocacy support or public transport assistance:

“Sometimes confidence is low, need support to know that you have the right to demand things, or people who need someone to speak for them. Depending on the person, they could need a lot of support – training, encouragement, access to internet”

Interviewee – Female, 26-50 years, White Irish, physical/sensory impairment and mental health condition
There was a strong feeling amongst participants in the qualitative research of disabled people’s voices not being listened to, for example, in national policy debates and in budget settlements. In some cases, this can create a barrier to wanting to get involved:

“In important to put your point of view across but get tired of it. You should write to your councillor but frankly feel like you’re bashing your head against the wall”

Interviewee – Male, 26-50 years, White British, physical/sensory impairment

The survey results suggest a relationship between wanting to be involved in improving society and feeling limited in life. Those who say their health condition or disability limits them “a lot” in day-to-day life are more likely to say they would like to get involved in a number of areas, for instance educating non-disabled people about disability issues (24% vs. 18% of those who only feel “a little” limited), working with local authorities to help them make decisions about services (20% vs. 13%) and mentoring or supporting other disabled people (17% vs. 12%).

Another factor influencing a desire to get involved was age. The survey found a greater appetite for being involved in improving society among those of working age, they are more likely than over 65s to want to be involved in every way, with the exception of working with local authorities, where there is no difference. As an example, a quarter (25%) of those of working age would be interested in educating non-disabled people about disability issues, compared to 15% of those aged 65 and over.

8.2 The role of charities

Participants and expert interviewees felt that the role of disability charities in protecting the interests of disabled people was of utmost importance, particularly for those disabled people who were unable to campaign or ‘fight’ for themselves. There was a strong view across participants that charities had a role in mobilising people to come together to campaign for change and could use their influence to lobby the government on the issues faced by disabled people, for example, such as tightening eligibility for benefits, issues of inaccessibility and the suitability of ESA assessments. Participants suggested that charities should form a coalition and work together to lobby the government on specific issues, to increase their weight and influence.

Several participants felt that national charities should work closely with the media and with educational institutions to promote positive messages about disability and to raise awareness of the issues faced by people with disabilities, for example, by releasing press releases, going on the television or going into schools to deliver training to teachers and students.

As the quote below illustrates this was seen as particularly important in the current climate of welfare reform which many participants felt was creating negative associations with disability:
“Crucial thing is effective campaigns to change public opinion, e.g. in schools, working with the media, to counter the poison coming out at the moment”

Interviewee – Female, 51-70 years, White Other, physical/sensory impairment and mental health condition

Expert interviewees were particularly keen that charities get the media and opinion formers on board because of the role they play in shaping public attitudes. They felt that it is important for the media to engage with and get to know disabled people so that they able to portray them more accurately.

There was a strong view amongst research participants that disabled charities need to continue with the work they are already doing and many participants were very positive about the impact of the work of disabled charities. Participants felt that disabled charities should continue to deliver campaigns and services which supported and empowered disabled people:

“They do campaigns … they represent us and stand up for what we are and show people that we can be just as equal as they can and we are entitled to a chance.”

Hammersmith focus group

8.3 The role of government

There was a strong feeling amongst participants that the government needed to lead the way in changing attitudes towards disabled people. In particular there was consensus that it was the government’s role to reverse some of the damage perceived to have been done by the media portraying disabled people as ‘benefit scroungers’ and as ‘undeserving’ benefit claimants.

Many participants felt that the government needed to listen more to the needs of disabled people in order to have a greater understanding of different types of disability and the implications of living with a specific disability. Participants suggested that MPs should support local disability initiatives; work closely with disabled charities, visit disability groups and to continue funding disabled charities to indicate that this is an area of priority for them.

Specific changes which participants felt government could make included slowing down the reductions in public expenditure and making disabled people more of a priority – reflecting the fact that in many constituencies disabled people make up a fifth or a quarter of voters, and yet disabled people seem to be such a low priority on the political agenda. One interviewee gave voice to the views of many when he said: “The government’s attitude has to change first, it goes from the top down … we need disabled people in wheelchairs in the government”.

Other ways in which disabled people felt the government had to take the lead included on:

- Ensuring that public bodies and employers take disability equality more seriously, by investing in more thorough regulation and inspection of workplaces, public facilities and other public places.
• Working with employers to make it easier for disabled people to be in employment, for example using regulations to ensure that employers have policies, strategies and processes in place that relate to ensuring equal consideration of people with disabilities for job opportunities

• Developing a more sensitive benefits application and assessment process and ensure that assessors have more training about the nature of mental health conditions

• Taking stock and targeting money more effectively.
9. Conclusion

It is clear from the research presented in this report that disabled people have wide ranging ideas about the positive changes that would make the most difference to their living standards across various areas of their lives. At the same time, there appear to be a few key themes and common threads that underpin these ideas and suggestions:

- **Greater awareness and a better understanding of impairments** and how they impact on disabled people has the potential to improve disabled people’s lives considerably. Participants advocate training to be delivered by disabled people themselves, aimed at building this awareness among health and social care professionals, employers, education providers and benefit application assessors. They also call for the delivery of disability specific campaigns which they feel play a role in challenging ignorance.

- Research participants also advocate strongly for **being treated with greater sensitivity and empathy**. This related to a wide range of people including health and social care staff, employers and children and young people.

- Many disabled people feel that various aspects of their lives could be better if they had access to **more tailored information and personalised support**. Examples include better information about the accessibility of buildings and spaces, and support for interviews and during employment.

- Participants also believe that removing the barriers disabled people face, depends on the **government playing a greater regulatory and enforcement role**. This relates to ensuring that spaces, places and transport are accessible for disabled people and that employers have policies, strategies and processes in place that relate to ensuring equal consideration of disabled people for job opportunities.
Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>BME</td>
<td>Black and Minority Ethnic</td>
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<tr>
<td>Direct payment</td>
<td>Money given to social care service users by their local authority to enable them to buy care services themselves</td>
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<tr>
<td>DLA</td>
<td>Disability Living Allowance</td>
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<tr>
<td>DPO</td>
<td>Disabled People’s Organisation</td>
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<tr>
<td>LGB</td>
<td>Lesbian, Gay and Bisexual</td>
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<td>LOS</td>
<td>Life Opportunities Survey</td>
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<tr>
<td>ME</td>
<td>Myalgic Encephalopathy</td>
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<td>MS</td>
<td>Multiple Sclerosis</td>
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<tr>
<td>Personal Budgets</td>
<td>An allocation of funding given to care users to meet their assessed care needs. Users can choose care services and providers themselves, but also have the option of giving local authorities responsibility for commissioning the service</td>
</tr>
<tr>
<td>PIP</td>
<td>Personal Independence Payment</td>
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<tr>
<td>PSI</td>
<td>Physical or Sensory Impairments</td>
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<tr>
<td>TA</td>
<td>Teaching Assistant</td>
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Definition of social grades

A Professionals such as doctors, surgeons, solicitors or dentists; chartered people like architects; fully qualified people with a large degree of responsibility such as senior editors, senior civil servants, town clerks, senior business executives and managers, and high ranking grades of the Services.

B People with very responsible jobs such as university lecturers, hospital matrons, heads of local government departments, middle management in business, qualified scientists, bank managers, police inspectors, and upper grades of the Services.
Removing barriers, raising disabled people’s living standards

C1  All others doing non-manual jobs; nurses, technicians, pharmacists, salesmen, publicans, people in clerical positions, police sergeants/constables, and middle ranks of the Services.

C2  Skilled manual workers/craftsmen who have served apprenticeships; foremen, manual workers with special qualifications such as long distance lorry drivers, security officers, and lower grades of Services.

D  Semi-skilled and unskilled manual workers, including labourers and mates of occupations in the C2 grade and people serving apprenticeships; machine minders, farm labourers, bus and railway conductors, laboratory assistants, postmen, door-to-door and van salesmen.

E  Those on lowest levels of subsistence including pensioners, casual workers, and others with minimum levels of income.
References


ONS (2012) *Life Opportunities Survey: Wave two Interim Results*.


OPM (2011) *All in This Together? The Impact of Spending Cuts on Deaf and Disabled People in London. An Evidence Base on Deaf and Disabled Londoners and the Impact of Past and Future Policies*, Inclusion London.


RNIB and OPM (2012) *Quick Wins… and Missed Opportunities: How Local Authorities can Work with Blind and Partially Sighted People to Build a Better Future*, RNIB.


Appendix 1: Focus group topic guides

3.1 Topic guide for qualitative research – Focus groups 1-4

TOTAL TIME: 2 hours plus comfort break halfway through

*NB. Our key guiding principle will be to tailor the timings and specific approach to meet the needs and expressed preferences of disabled people participating*

*With this said, we will aim for each session to be split into two halves: one focused on ‘looking backward’ (section A) and the other focused on ‘looking forward’ (sections B and C).*

Because of the focus of the research on future change the balance of time should be weighted towards sections B and C.

**Introduction, background and warm up (20 minutes)**

- Introduce OPM / Scope / Background to research – We are an independent research organisation that have been commissioned by Scope to conduct some research. Scope works with disabled people of all ages and their families to help change their lives. The aim of the research is to get a better understanding of what positive social change looks like from the point of view of disabled people. We want to know what types of changes would make sure that disabled people have the same opportunities to fulfil their life ambitions as everyone else. As part of this research, we are conducting interviews and focus groups, including this one you have been invited to take part in.

- Confidentiality / Anonymity - The report will not have your name in it and the information you tell us will be kept safe and secure. The only time we might tell someone what you have said is if you tell us something that makes us concerned about your safety or the safety of someone else. If this happens we would try and discuss this with you at the time.

- **Information sheet, consent forms and demographics forms**

- About the discussion / ground rules / planned breaks (acoustics and ensuring that only one person is speaking at any one time are important)

- Permission to record the session

- Introductions and warm up: Participants to go around the room and introduce themselves, saying how long they’ve lived in the area and what they like doing in their free time.

**A. Looking backward: Identifying key moments in our lives (25 minutes)**

*When introducing this first exercise, it’s important to make clear that in this first exercise we want to think about people’s lives as a whole, with as much or as little focus on disability specifically as people would like.*
Participants will be asked to take some time to themselves to think about, and then record, the ups and downs in their lives – the good moments and hard times - using an illustrated life path provided by the facilitator - early childhood, school age, adolescence/early adulthood, adulthood, middle age, older age, end of life.

Participants will then be asked to feed back what they have recorded to the full group. FACILITATOR TO REASSURE PARTICIPANTS THAT THEY SHOULD ONLY FEED BACK AS MUCH OR AS LITTLE AS THEY FEEL COMFORTABLE DOING.

1. Can you tell me about the most important ups and downs – the good moments and hard times – that have happened at different stages in your life?

These can be about times when you’ve felt really proud of yourself or where you feel you’ve been able to reach your potential, or they can be about times when you’ve felt held back or judged. They can relate to any area of your life - work, school, relationships, home and family life, leisure.

ONLY IF NECESSARY: If you prefer think of someone you know (who is disabled), it could be a friend, family member or someone you know from school or work, and tell me about the good or hard times in their life.

- These could be really big or really small moments, the key thing is that they’re important for you.

Facilitator to ask group to feed back on good moments first:
- What happened and who was involved?
- Why was this good time important to you, what difference did it make to you?
- What was your role in making this happen?

Facilitator to ask for feedback on hard times?
- What happened and who was involved?
- What impact did these difficult times or moments have (personally, economically etc)?
- What got in the way to make things difficult? What were the barriers you faced?

[COMFORT BREAK – approx. 15 minutes but flexible]

FACILITATOR chooses a 3 or 4 specific challenges/barriers/hard times identified in part A of the discussion that are likely to be relevant to many disabled people. For example, accessing education, finding accessible leisure activities, experiences of discrimination when looking for work.

B. Looking forward: Identifying key changes (35 minutes)

Facilitator to tell the group that we will be focusing on the 3-4 specific challenges/barriers/hard times, for the next discussion.
For question 2, the facilitator will ask the participants to work in groups (where appropriate), with each group focusing on 2 challenges/barriers/hard times. Participants will be asked to discuss in groups and record on a template provided the different national, local and individual changes that would make the specific challenging/hard times better. Each group will feed back to the wider group after their discussion. [Template to include concentric circles indicating individual/local/national levels]

To help you get started, here are some examples of what other people have said about the types of changes they think have been important. USE STIMULUS MATERIALS – anonymised quotes from the OPM film, scoping interviews.

2. What are the main changes that would need to happen to make this challenging/hard time better?

- At the national or society level? So, for example, public attitudes, legislation
  
  Note to facilitator: If participants mention change in attitudes, please probe:
  - Whose attitudes need to change? e.g. teachers, employers?
  - What are the specific attitudes that need to change? e.g. disabled people as benefit scroungers, disabled people as ‘stupid’.

- At the local level? So for example, services or support.
  
  Note to facilitator: If participants mention the need for support groups, please ask:
  - What type of support groups? Do these need to be made up of disabled people only?

- At the individual level? So, for example, disabled people themselves

FACILITATOR TO USE OWN JUDGEMENT ABOUT WHETHER PEOPLE WILL BE COMFORTABLE THINKING ASPIRATIONALLY:

3. Thinking now more widely about your own experiences – imagine a better society, where disabled people are more equal:

- What would be different in your day to day life?
- What types of changes would help to make this happen?
- Who would be behaving differently?

C. Looking forward: Making change happen and prioritising changes (35 minutes)

4. Thinking about the different types of changes we have just discussed, who do you think needs to be involved to make this happen?

Facilitator to refer to specific changes identified by group in previous session, to ask:
Removing barriers, raising disabled people’s living standards

- What do you think disabled people themselves need to be doing? What kind of support may they need to do this? Note to facilitator: very important to explore what disabled people think their role is in bringing about change. e.g., disabled people campaigning, disabled people in leadership positions?
- What do you think disability charities such as Scope need to do?
- What about the Government (local/national)?
- Any other organisations or bodies?

5. Of all the changes we’ve talked about today that we think would make things better, which are the most important, and why?

Thanks
Close
Incentive arrangements

3.2 Topic guide for qualitative research - Focus groups 5-10

TOTAL TIME: 2 hours plus comfort break halfway through

NB. Our key guiding principle will be to tailor the timings and specific approach to meet the needs and expressed preferences of disabled people participating

Introduction, background and warm up (20 minutes)

- Introduce OPM / Scope / Background to research – We are an independent research organisation that have been commissioned by Scope to conduct some research. Scope works with disabled people of all ages and their families to help change their lives. The aim of the research is to get a better understanding of what positive change looks like from the point of view of disabled people. We want to know what types of change would make sure that disabled people have the same opportunities to fulfil their life ambitions as everyone else. As part of this research, we are conducting interviews and focus groups, including this one you have been invited to take part in.
- Confidentiality / Anonymity - The report will not have your name in it and the information you tell us will be kept safe and secure. The only time we might tell someone what you have said is if you tell us something that makes us concerned about your safety or the safety of someone else. If this happens we would try and discuss this with you at the time.
- Information sheet, consent forms and demographics forms
- About the discussion / ground rules / planned breaks (acoustics and ensuring that only one person is speaking at any one time are important)
• Permission to record the session

A. Warm-up and talking about ‘the here and now’ (15 minutes)

1. Can you tell me about some of the key things that might happen to you in a typical week?

2. What would you say were the key barriers you face to doing what you want to do?

To help you get started, here are some examples of what other people have said about the barriers they face. USE STIMULUS MATERIALS RELATING TO BARRIERS – anonymised quotes from the OPM film, scoping interviews.

FACILITATOR chooses a 3 or 4 specific challenges/barriers identified by the group that are likely to be relevant to many disabled people. For example, accessing education, finding accessible leisure activities, experiences of discrimination when looking for work.

B. Looking forward: Identifying key changes (45 minutes)

Facilitator to tell the group that we will be focusing on the 3-4 specific challenges/barriers, for the next discussion.

For question 3, the facilitator will ask the participants to work in groups (where appropriate), with each group focusing on 2 challenges/barriers. Participants will be asked to discuss in groups and record on a template provided the different national, local and individual changes that would make the specific challenging/hard times better. Each group will feed back to the wider group after their discussion. [Template to include concentric circles indicating individual/local/national levels]

[FOR EACH BARRIER]: 3. What are the main changes that would need to happen to overcome this barrier and make things better for you personally?

To help you get started, here are some examples of what other people have said about the types of social changes they think have been important. USE STIMULUS MATERIALS RELATING TO CHANGES SPECIFICALLY – anonymised quotes from the OPM film, scoping interviews.

[FACILITATOR TO PROMPT, AS APPROPRIATE:]
Removing barriers, raising disabled people’s living standards

- Would any of the changes identified (in the quotes) make a difference for you, personally?
- Are there any of the changes identified (in the quotes) that would make no difference at all, or actually make things worse?
- Are there other changes you can think of, and if so what are they?

[PROMPTS FOR ALL CHANGES IDENTIFIED (whether in quotes or not):]
- Can you remind us what things are like at the moment? Why do you think that is?
- What would be different in your day to day life if this change happened?
- What would you be doing more of, what would you be doing less of?
- What would other people be doing more of, and what would other people be doing less of?
- What else might have changed, for you personally?
- Have you seen something like this change before, in your own life? If so what happened?
- How likely do you think it is that this change will happen... in the short term? In the longer term?
- What do you think would need to happen to make this change more likely in the short term?

4. Thinking now more widely– imagine a better society, where disabled people are more equal and do not face any barriers:

- What would be different in your day to day life?
- What types of changes would help to make this happen?
- Who would be behaving differently?

[COMFORT BREAK – approx. 15 minutes but flexible]

C. Looking forward: Making change happen and prioritising changes (45 minutes)

5. Thinking about the different types of social changes we have just discussed, who do you think needs to be involved to make this happen?

Facilitator to refer to specific social changes identified by group in previous session, to ask:

- What do you think disabled people themselves need to be doing? What kind of support may they need to do this?
- What do you think disability charities such as Scope need to do?
• What about the Government (local/national)?
• Any other organisations or bodies?

6. Of all the changes we’ve talked about today that we think would make things better, which are the most important, and why?

Thanks
Close
Incentive arrangements
Appendix 2: Focus group samples

Ten focus groups were completed with disabled people, the details of which are included below. It is important to note that the impairment types noted below are only indicative as there were some participants that have multiple of impairments.

- 12 participants with a range of Physical or Sensory Impairments (PSI) in Coventry
- 8 LGB participants with a range of PSI’s in Norfolk
- 14 BME participants with a range of mental health conditions in Harrow
- 7 participants with a range of PSIs in Surrey
- 5 participants with learning disabilities in Leeds
- 5 children and young people with a range of PSIs in Essex
- 6 participants with a range of PSIs and learning disabilities in a Scope skills centre in Chester
- 8 participants with a range of mental health conditions in Cardiff
- 7 participants with learning disabilities in Hammersmith and Fulham, London
- 13 participants with learning disabilities in Scope residential service in Essex
Appendix 3: Interview guide

Introduction and background

We are an independent research organisation that have been commissioned by Scope to conduct some research. Scope works with disabled people of all ages and their families to help change their lives. The aim of the research is to get a better understanding of what positive change looks like from the point of view of disabled people. We want to know what types of changes would make sure that disabled people have the same opportunities to fulfil their life ambitions as everyone else. As part of this research, we are conducting interviews and focus groups, including this interview that you have been invited to take part in.

Confidentiality / Anonymity - The report will not have your name in it and the information you tell us will be kept safe and secure. The only time we might tell someone what you have said is if you tell us something that makes us concerned about your safety or the safety of someone else. If this happens we would try and discuss this with you at the time.

The interview should last about 45 minutes – do you have any questions before I start?

NOTE TO INTERVIEWER: YOU CAN CHECK BASIC DEMOGRAPHICS HERE BEFORE THE INTERVIEW. PLEASE CONFIRM DEMOGRAPHICS AND FILL IN ANY BLANKS.

NOTE TO INTERVIEWER: THERE ARE THREE SPECIFIC ISSUES WE ARE INTERESTED IN KNOWING MORE ABOUT SO PLEASE PROBE ABOUT THEM:

1. MONEY AND BENEFITS
2. EXPERIENCES OF SOCIAL CARE SUPPORT
3. FRIENDS AND RELATIONSHIPS

About you

1. Just to start, can you tell me a little bit about yourself? (Where you’re from? How old you are? What you do? Whether you live with friends, family or on your own?)

Prompt, if necessary (i.e. if not covered as a natural part of question 1):

2. And now can you tell me a little bit about what you did last week?
   • What did you get up to?
   • Who did you see or talk to?
   • Where do you go?
• Was this a pretty typical week (and if not, why not)?

3. Is there anything that you would **like to do** that you aren’t able to do right now?
• Or anything that you would like to do **more of**?

4. What do you think stops you from being able to do these things? What are the barriers you face? What is it that gets in the way?

**Identifying key social changes**

INTERVIEWER TAKES EACH MAIN BARRIER IDENTIFIED IN ANSWER TO Q.4 IN TURN AND ASKS:

5. What would need to change to overcome this barrier, and make things better for you personally?

*About each change identified:*

6. What would be different in your day to day life if this change happened?
7. What would you be doing more of, what would you be doing less of?
8. What would other people be doing more of, and what would other people be doing less of?
9. How likely do you think it is that this change will happen… in the short term? In the longer term? Why?

10. What do you think would need to happen to make this change more likely in the short term?

11. Thinking more widely, imagine a **better society, where disabled people are more equal and do not face any barriers:**
• What would be different in your day to day life?
• What types of social changes would help to make this happen?

**Making change happen**

12. Thinking about the different types of changes that we have just talked about, who do you think needs to be involved to make these changes happen?
• What do you think disabled people themselves need to be doing? What kind of support may they need to do this?
What do you think disability charities such as Scope need to do?
What about the Government (local/national)?
Any other organisations or bodies?

Prioritising change

13. Of all the changes we’ve talked about today that we think would make things better, which in your opinion are the most important? Why?

14. Would you be happy to be contacted again by Scope, when it comes to raising awareness about the report?

15. Do you know any other people that you think would be interested in taking part in this research?

16. Could you tell me your address so that I can send you a £20 high street voucher?

Thanks and close
Appendix 4: Interview sample

A total of 30 interviews were conducted and the interview sample is highlighted in the table below:

<table>
<thead>
<tr>
<th>Gender</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>13</td>
</tr>
<tr>
<td>Female</td>
<td>17</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Impairment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical or sensory impairment</td>
<td>13</td>
</tr>
<tr>
<td>Mental health condition</td>
<td>4</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>16</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age group</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>16 to 25 years</td>
<td>1</td>
</tr>
<tr>
<td>26 to 50 years</td>
<td>17</td>
</tr>
<tr>
<td>51 to 70 years</td>
<td>10</td>
</tr>
<tr>
<td>71 years and over</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White British / White other</td>
<td>23</td>
</tr>
<tr>
<td>Black/Black British</td>
<td>2</td>
</tr>
<tr>
<td>Asian/Asian British</td>
<td>4</td>
</tr>
<tr>
<td>Mixed/Other</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Full time work</td>
<td>4</td>
</tr>
<tr>
<td>Part time work</td>
<td>6</td>
</tr>
<tr>
<td>Not working</td>
<td>10</td>
</tr>
<tr>
<td>Voluntary work</td>
<td>10</td>
</tr>
</tbody>
</table>

41 Impairment numbers will add up to more than 30 as many people have more than one type of impairment
Appendix 5: Survey sample

Final results are based on a survey of 2,045 respondents, conducted using a face-to-face approach (using Capibus) and online approach (using the Ipsos Panel).

Fieldwork was conducted between 14 June 2012 – 13 July 2012.

The table below provides further details about the sample of disabled people included in the survey.

Where results do not sum to 100%, this may be due to multiple responses, computer rounding or the exclusion of 'don't know/not stated' response categories.

An asterisk (*) indicates a value of less than 0.5% but not zero.

<table>
<thead>
<tr>
<th>Illness/condition</th>
<th>Percentage</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility (e.g. walking short distances or climbing stairs)</td>
<td>57</td>
<td>1159</td>
</tr>
<tr>
<td>Long-term pain or discomfort</td>
<td>55</td>
<td>1116</td>
</tr>
<tr>
<td>Stamina, breathing or fatigue</td>
<td>37</td>
<td>759</td>
</tr>
<tr>
<td>Chronic health (e.g. heart condition or cancer)</td>
<td>21</td>
<td>423</td>
</tr>
<tr>
<td>Dexterity (e.g. lifting and carrying objects, using a keyboard)</td>
<td>19</td>
<td>392</td>
</tr>
<tr>
<td>Mental health</td>
<td>15</td>
<td>306</td>
</tr>
<tr>
<td>Hearing (e.g. deafness or partial hearing)</td>
<td>15</td>
<td>299</td>
</tr>
<tr>
<td>Memory</td>
<td>14</td>
<td>294</td>
</tr>
<tr>
<td>Sight (e.g. partial blindness or partial sight)</td>
<td>8</td>
<td>161</td>
</tr>
<tr>
<td>Learning, understanding or concentrating</td>
<td>6</td>
<td>122</td>
</tr>
<tr>
<td>Social or behavioural (e.g. difficulty making friends or aggressive outbursts)</td>
<td>5</td>
<td>95</td>
</tr>
<tr>
<td>Speaking (e.g. difficulty making yourself understood, or using special aids to help)</td>
<td>2</td>
<td>47</td>
</tr>
<tr>
<td>Condition</td>
<td>Count</td>
<td>Total</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td>Arthritis/rheumatism</td>
<td>*</td>
<td>6</td>
</tr>
<tr>
<td>Vertigo/balance</td>
<td>*</td>
<td>6</td>
</tr>
<tr>
<td>Intellectual difficulty or developmental delay (e.g. Down’s syndrome)</td>
<td>*</td>
<td>5</td>
</tr>
<tr>
<td>Crohn’s</td>
<td>*</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>62</td>
</tr>
</tbody>
</table>
Appendix 6: Questionnaire

SCREENER QUESTIONS

ASK ALL

Q1 Do you have any long-standing physical or mental impairment, condition, illness, or disability? By ‘long-standing’ I mean anything that has affected you over a period of at least 12 months or that is likely to affect you over a period of at least 12 months. SINGLE CODE

Yes
No – THANK AND CLOSE

ASK IF Q1 = 1

Q2 And does your health problem, illness or disability limit your day-to-day activities in any way?

1. Yes, a lot
2. Yes, a little
3. No – THANK AND CLOSE
4. Prefer not to answer – THANK AND CLOSE
OVERALL SATISFACTION WITH LIFE

ASK ALL

Q3 Overall, how satisfied are you with YOUR LIFE nowadays? Please use a scale of 0 to 10, where 0 is not at all satisfied and 10 is completely satisfied. SINGLE CODE

0 = not at all satisfied
1
2
3
4
5
6
7
8
9
10 = completely satisfied
Don’t know

ASK ALL

Q4 To what extent, if at all, do you feel limited from doing all the things in life that you would like to do? SINGLE CODE

1. A lot
2. A little
3. Not at all
4. Don’t know

CHALLENGING AREAS

We are now going to ask you some questions about challenges you may face in your day to day life.
ASK ALL

Q5 In which of these areas, if any, do you find life challenging? Please select all that apply. MULTICODE OK

RANDOMISE ORDER

1. Education & training
2. Work & employment
3. Housing
4. Health and wellbeing
5. Leisure
6. Care and support
7. Money & benefits
8. Transport
9. Social & community life
10. Family life
11. Crime, safety & security

DO NOT RANDOMISE ORDER
12. Other (PLEASE SPECIFY)
None of these (SINGLE CODE)- ROUTE TO Q16
Don’t know (SINGLE CODE)- ROUTE TO Q16

ASK IF Q5 = 2 OR MORE ANSWERS AT CODES 1-12

Q6 And in which ONE of these areas do you find life the MOST challenging? Please pick just one area. SINGLE CODE

DISPLAY ONLY THOSE OPTIONS CHOSEN AT Q5, PLEASE SHOW IN SAME ORDER

1. Education & training
2. Work & employment
3. Housing
4. Health and wellbeing
5. Leisure
6. Care and support
7. Money & benefits
8. Transport
9. Social & community life
10. Family life
11. Crime, safety & security
12. Other (PLEASE PIPE IN ANSWER FROM Q5)
Don’t know – ROUTE TO Q16
OPTION TO BE PIPED IN AT Q7, Q9, Q10, Q11:
– IF Q5 = 1 ANSWER, PIPE IN OPTION SELECTED AT Q5
– IF Q5 > 1 ANSWER, PIPE IN OPTION SELECTED AT Q6

ASK IF Q5 = 1 OR MORE ANSWER AT CODES 1-12 AND NOT Q6=13

Q7 Thinking of a time when you faced the biggest challenge relating to [OPTION] which, if any, of the following issues were involved? Please select all that apply.
MULTICODE OK

RANDOMISE ORDER.

1. Other people’s attitudes or behaviour
2. Difficulty getting into buildings or using facilities
3. Lack of accessible transport
4. Lack of special aids or equipment
5. Lack of qualifications, skills or experience
6. Lack of accessible information or advice
7. Lack of personal or social care
8. Your caring responsibilities
9. Your anxiety / lack of confidence
10. Fear of harassment or being harmed
11. Money issues
12. Problems with your benefits
13. Lack of suitable job opportunities
14. Your general health or condition

DO NOT RANDOMISE ORDER

15. Other (PLEASE SPECIFY)

None of these
Don’t know
ASK IF Q6 = 7
OR IF
Q5 = 1 ANSWER AT CODES 1-12 AND CODE 7 SELECTED
OR IF
Q7 = 11 OR 12

Q8. Which, if any, of the following best describes the money issues you mentioned? Please select all that apply. MULTICODE

RANDOMISE ORDER

1. Cost of rent or mortgage payments
2. Lack of money
3. Your benefits being cut or lost
4. Lack of confidence in managing your money
5. Having to trust supporters or carers with your money
6. Difficulty accessing suitable financial products (eg. credit, bank accounts)
7. Cost of utility bills (eg. gas, electricity, water)
8. Costs related to your health problem or disability (eg. specialist equipment, adaptations, transport)
9. Difficulty using financial systems (eg. cash points, internet banking)
10. Difficulty getting into banks or other financial institutions

DO NOT RANDOMISE ORDER

11. Other (PLEASE SPECIFY)

None of these
Don't know

ASK IF Q7 = 1

Q9 Which, if any, of these groups of people made your situation relating to [OPTION] challenging because of their behaviour or attitudes? Please select all that apply. MULTICODE OK

RANDOMISE

1. Teachers and education staff
2. Health, social care and support staff
3. Public transport staff
4. Retail and leisure services staff
5. Other professionals or service providers (eg. staff at banks, housing associations, utility companies)
6. Family
7. Colleagues
8. Local authority or government staff
9. Employers
10. Friends
11. General public

DO NOT RANDOMISE

12. Other (PLEASE SPECIFY)

None of these

Don't know
ASK IF Q7 = 2 OR MORE ANSWERS AT CODES 1-15

Q10 Thinking all of the issues you have said have made [OPTION] challenging for you, which one or two would you MOST like to see changed for the better? PLEASE SELECT UP TO TWO.

SUPPRESS OPTIONS NOT CHOSEN AT Q7, SHOW IN SAME ORDER
RANDOMISE

1. Other people’s attitudes or behaviour
2. Difficulty getting into buildings or using facilities
3. Lack of accessible transport
4. Lack of special aids or equipment
5. Lack of qualifications, skills or experience
6. Lack of accessible information or advice
7. Lack of personal or social care
8. Your caring responsibilities
9. Your anxiety / lack of confidence
10. Fear of harassment or being harmed
11. Money issues
12. Problems with your benefits
13. Lack of suitable job opportunities
14. Your general health or condition
15. Other (PLEASE PIPE IN ANSWER FROM Q7)

None of these
Don’t know

NOTE TO SCRIPTER: THE CODEFRAMES FOR Q12-15 ARE EXACTLY THE SAME AS Q7-10

ASK IF Q5 = 3 OR MORE ANSWERS AT CODES 1-12 AND NOT Q6=13

Q11 After [OPTION], which of the areas you mentioned do you find the MOST challenging? Please pick one area.

SINGLE CODE SUPRESS OPTIONS NOT CHOSEN AT Q5 AND OPTION CHOSEN AT Q6
Removing barriers, raising disabled people’s living standards

1. Education & training
2. Work & employment
3. Housing
4. Health and wellbeing
5. Leisure
6. Care and support
7. Money & benefits
8. Transport
9. Social & community life
10. Family life
11. Crime, safety & security
12. Other (PLEASE PIPE IN ANSWER FROM Q5)

None of these – DELETE THIS CODE

Don’t know – ROUTE TO Q16
SHOW ONLY IF Q5 = 2 ANSWERS AT CODES 1-12 AND NOT Q6= 13

You said you also found [option identified at Q5 and not chosen at Q6] a challenging area in your life, we’d now like to ask you about this.

OPTION TO BE PIPED IN AT Q12, Q14, Q15:
- IF Q5 = 2 ANSWERS PIPE IN ANSWER NOT INCLUDED IN Q6
- IF Q5 > 2 ANSWERS PIPE IN Q11 ANSWER

ASK IF Q5 = 2 OR MORE ANSWERS AT CODES 1-12 AND NOT Q11 CODE 13

Q12 Thinking of a time when you faced the biggest challenge relating to [OPTION] which, if any, of the following issues were involved? Please select all that apply. MULTICODE OK

RANDOMISE ORDER

1. Other people’s attitudes or behaviour
2. Difficulty getting into buildings or using facilities
3. Lack of accessible transport
4. Lack of special aids or equipment
5. Lack of qualifications, skills or experience
6. Lack of accessible information or advice
7. Lack of personal or social care
8. Your caring responsibilities
9. Your anxiety / lack of confidence
10. Fear of harassment or being harmed
11. Money issues
12. Problems with your benefits
13. Lack of suitable job opportunities
14. Your general health or condition

DO NOT RANDOMISE

15. Other (PLEASE SPECIFY)

None of these
Don’t know

ASK IF Q5 = 2 or more answers and (code 7 from Q5 selected and NOT INCLUDED in Q6)
OR IF
Q11 = 7
OR IF
Q12 = code 11 or 12

Q13 Which, if any, of the following best describes the money issues you mentioned? Please select all that apply. MULTICODE

RANDOMISE ORDER
1. Cost of rent or mortgage payments
2. Lack of money
3. Your benefits being cut or lost
4. Lack of confidence in managing your money
5. Having to trust supporters or carers with your money
6. Difficulty accessing suitable financial products (eg. credit, bank accounts)
7. Cost of utility bills (eg. gas, electricity, water)
8. Costs related to your health problem or disability (eg. specialist equipment, adaptations, transport)
9. Difficulty using financial systems (eg. cash points, internet banking)
10. Difficulty getting into banks or other financial institutions

DO NOT RANDOMISE
11. Other (PLEASE SPECIFY)

None of these
Don’t know

ASK IF Q12 = 1

Q14 Which, if any, of these groups of people made your situation relating to [OPTION] challenging because of their behaviour or attitudes? Please select all that apply. MULTICODE OK

RANDOMISE
1. Teachers and education staff
2. Health, social care and support staff
3. Public transport staff
4. Retail and leisure services staff
5. Other professionals or service providers (eg. staff at banks, housing associations, utility companies)
6. Family
Removing barriers, raising disabled people’s living standards

7. Colleagues
8. Local authority or government staff
9. Employers
10. Friends
11. General public

DO NOT RANDOMISE
12. Other (PLEASE SPECIFY)

None of these
Don’t know

ASK IF Q12 = 3 OR MORE ANSWERS AT CODES 1-15

Q15 Thinking all of the issues you have said have made [OPTION] challenging for you, which one or two would you MOST like to see changed for the better? PLEASE SELECT UP TO TWO

SUPPRESS OPTIONS NOT CHOSEN AT Q12, SHOW IN SAME ORDER

RANDOMISE
1. Other people’s attitudes or behaviour
2. Difficulty getting into buildings or using facilities
3. Lack of accessible transport
4. Lack of special aids or equipment
5. Lack of qualifications, skills or experience
6. Lack of accessible information or advice
7. Lack of personal or social care
8. Your caring responsibilities
9. Your anxiety / lack of confidence
10. Fear of harassment or being harmed
11. Money issues
12. Problems with your benefits
13. Lack of suitable job opportunities
14. Your general health or condition
15. Other (PLEASE PIPE IN ANSWER FROM Q12)

None of these
Don’t know

ASK ALL
Q16 Among which groups, if any, do you think a positive change in awareness and attitudes towards disabled people or people with health conditions would make most difference to you personally? Please select up to three options.

MAXIMUM OF THREE CHOICES

RANDOMISE

1. Teachers and education staff
2. Health, social care and support staff
3. Public transport staff
4. Retail and leisure services staff
5. Other professionals or service providers (eg. staff at banks, housing associations, utility companies)
6. Family
7. Colleagues
8. Local authority or government staff
9. Employers
10. Friends
11. General public

DO NOT RANDOMISE

12. Other (PLEASE SPECIFY)

None of these
Don’t know

ASK ALL

Q17 Have you experienced any of the following behaviour or attitudes from other people because of your health condition or disability? Please select all that apply. MULTICODE OK

RANDOMISE

1. Being awkward around me
2. Being too protective
3. Expecting less of me because of my health condition or disability
4. Treating me like I am a nuisance
5. Being pitying
6. Not understanding my needs
7. Being aggressive towards me because of my health condition or disability
8. Ignoring me or pretending not to see me
9. Thinking I can’t make my own decisions
DO NOT RANDOMISE

10. Other (PLEASE SPECIFY)

None of these
Don't know
Removing barriers, raising disabled people’s living standards

ASK IF Q17 = 1 OR MORE ANSWER AT CODES 1-10

Q18 Which, if any, of these behaviour or attitudes would you most like to see changed? [IF Q17 = 4 or more ANSWERS AT CODES 1-10]: Please pick two or three options. NO MORE THAN THREE OPTIONS CAN BE CODED

RANDOMISE

SAME ORDER AS Q17 - SUPPRESS OPTIONS NOT CHOSEN AT Q17

1. Being awkward around me
2. Being too protective
3. Expecting less of me because of my health condition or disability
4. Treating me like I am a nuisance
5. Being pitying
6. Not understanding my needs
7. Being aggressive towards me because of my health condition or disability
8. Ignoring me or pretending not to see me
9. Thinking I can’t make my own decisions
10. Other (PLEASE PIPE IN ANSWER FROM Q17)

None of these
Don't know

ASK ALL

Q19 If you were offered some support to do so, how, if at all, would you like to be involved in improving society for yourself and other disabled people and people with health conditions? MULTICODE OK UNLESS CODE 12 OR DON’T KNOW SELECTED - MULTICODE, CODE 12 and 13 EXCLUSIVE

RANDOMISE ORDER

1. Taking part in campaigns to change something locally or nationally
2. Leading campaigns to change something locally or nationally
3. Standing for elected office (eg. as an MP or Local Councillor)
4. Holding a senior or management position in an organisation
5. Educating non-disabled people about disability issues
6. Supporting or mentoring other disabled people
7. Being a media spokesperson or presenter
8. Having a role on a public body
9. Becoming a Trade Union representative
10. Work with Local Authorities to help them make decisions about local services

DO NOT RANDOMISE

11. Other (PLEASE SPECIFY)
12. I would not want to be involved (SINGLE CODE)

Don’t know (SINGLE CODE)
ASK ALL

Q20 Do you have any conditions or illnesses that affect you in any of the following areas? Please select all that apply. MULTICODE OK

1. Sight (for example blindness or partial sight)
2. Hearing (for example deafness or partial hearing)
3. Speaking (for example difficulty making yourself understood, or using special aids to help you communicate)
4. Mobility (for example walking short distances or climbing stairs)
5. Dexterity (for example lifting and carrying objects, using a keyboard)
6. Long-term pain or discomfort
7. Chronic health (for example a heart condition or cancer)
8. Intellectual difficulty or developmental delay (for example Down’s Syndrome)
9. Learning, understanding or concentrating
10. Memory
11. Mental health
12. Stamina, breathing or fatigue
13. Social or behavioural (for example difficulty making friends or aggressive outbursts)
14. Other (SPECIFY)

None of these (SINGLE CODE)
Don’t know (SINGLE CODE)

DEMOGRAPHICS

ASK ALL

QD1 Which of these applies to you? SINGLE CODE

- Have paid job - Full time (30+ hours per week)
- Have paid job - Part time (8-29 hours per week)
- Have paid job - Part time (Under 8 hours per week)
- Not working - Housewife
- Self-employed
- Full time student
- Still at school
- Unemployed and seeking work
- Retired
- Not in paid work for other reason
- Not in paid work because of long term illness or disability
- Rather not say

<PLEASE INSERT THE SOCIAL GRADE MODULE>

ASK ALL
QD2 Which, if any of the following apply to you? I am the parent or legal guardian of...
SINGLE CODE

- a child/ children under the age of 16 who does/do live with me
- a child/ children aged under 16 who does not/do not live with me and to whose upbringing I contribute financially
- a child/ children aged under 16 who does not/do not live with me and to whose upbringing I do not contribute financially
- a child/ children aged 16 to 19 who is/are currently in full time education
- None of these

ASK ALL
QD3 How many children aged fifteen or under are there in your household?
SINGLE CODE

- NONE
- 1
- 2
- 3
- 4
- 5+

ASK ALL
QD4 Which group do you consider you belong to?
SINGLE CODE

- White - English / Welsh / Scottish / Northern Irish / British
- White - Irish
- White - Gypsy or Irish Traveller
- White - Any other White background
- Mixed - White and Black Caribbean
- Mixed - White and Black African
- Mixed - White and Asian
- Mixed - Any other Mixed / multiple ethnic background
• Asian - Indian
• Asian - Pakistani
• Asian - Bangladeshi
• Asian - Chinese
• Asian - Any other Asian background
• Black - African
• Black - Caribbean
• Black - Any other Black / African / Caribbean background
• Arab
• Any other ethnic group
• Rather not say

QD4_bis In which area of Great Britain do you live? Please select one option only SINGLE CODE

1. East of England
2. East Midlands
3. London
4. North East
5. North West
6. South East
7. South West
8. West Midlands
9. Yorkshire and the Humber
10. Wales
11. Scotland

ASK ALL

QD5
Can you tell me which of these applies to you?

• Heterosexual/straight
• Bisexual
• Gay man/homosexual
• Gay woman/lesbian
• None of these
• Prefer not to say

THANK AND CLOSE