Experiences and Expectations of Disabled People – Executive Summary

A research report for the Office for Disability Issues

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Office for Disability Issues
HM Government

DWP Department for Work and Pensions

The Government's vision is that by 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life, and will be respected and included as equal members of society.

The Office for Disability Issues is here to help deliver that vision. We work to make equality a reality for disabled people by:

- promoting joined-up government to improve the way policy is made and services are delivered
- involving disabled people and their expertise in what we do and encouraging others to do the same
- being a source of evidence and expertise on disability for the rest of government
- promoting human rights and ensuring effective disability equality legislation
- communicating what is happening across government on disability.

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1 Introduction

In 2006, the Office for Disability Issues commissioned a research project to explore the lives of disabled people in Britain today. The study aimed to develop a generalised picture to better understand disabled people's experiences and opinions. It also works to provide information to aid the monitoring of progress towards the Government's vision of achieving substantive equality for disabled people by 2025.

Over the course of this research project, 1,860 disabled people[1] in Britain were interviewed during July and August 2007. This was unusual because it actively involved disabled people at all stages of the study. For a more detailed description of the programme of work, please see page 33 of this report.

This is the first comprehensive look at the lives of disabled people in Britain since the 2001 'Disabled for Life?' survey[2]. It provides an important snapshot and, where possible, an indication of how disabled people's lives have changed recently.

The scope of the study, including the issues to be included in the research, were guided by disabled people. The study covered a wide range of issues including home life, social activities, transport, education, employment and finances. The study also looked at experiences of discrimination.

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[1] All respondents were likely to have rights under the Disability Discrimination Act including the 2005 Amendment.

[2] 'Disabled for Life? Attitudes to, and experiences of, disability in Britain', Grewal et al., 2002

2 Key findings

Disabled people are more likely than non-disabled people to experience disadvantage: compared with the population as a whole, disabled people tend to live in households on lower incomes, are less likely to be in paid work, and less likely to hold academic qualifications.

There is only limited evidence from this survey that these gaps between disabled and non-disabled people have closed between 2001 and 2007. However, disabled people were less likely to experience problems accessing goods and services in 2007 compared with 2001.

Disabled people's expectations were explored by asking about barriers encountered to participation in employment, learning, social activities and their local community. The main barrier to participation was not feeling well enough to participate, or to participate more. Other barriers included lack of time, lack of money, lack of confidence and the attitudes of others. Access barriers (such as difficulties getting to and from venues) were also noted.

The research also underlined the importance of choice and control in disabled people's lives. The majority of disabled people were satisfied with the level of choice they had in their life (for example, choice in relation to formal support and health services), and those who felt they had a choice were more likely to be satisfied with such services. These findings appear to support the government's policies on independent living, which aim to give disabled people more choice and control.

Older disabled people were the most likely to be satisfied with their lives, with their homes and with the services they receive. Younger disabled people, particularly those aged 16 to 34, were least likely to be satisfied. Young people's lower satisfaction levels are likely to reflect higher expectations, rather than different experiences.

These findings are consistent with research across a wide range of services which has found that older people are generally more likely than younger people to express satisfaction with services, particularly in relation to health services[3]. Many of the older disabled people interviewed appeared to view their disability as a reflection of their older age.

People with mental health conditions reported the least positive experiences and outcomes: they tend to live in households on lower incomes, were less likely than other disabled people to be in paid work, tend to live in households on lower incomes and more likely to feel they have experienced discrimination. Many of the barriers that people with mental health conditions encountered related to a lack of confidence and the attitudes of others.

Disabled people on the lowest incomes and those in workless households tended to report less positive experiences and outcomes.

Relatively few disabled people consciously articulated the social model of disability by saying that attitudes and barriers in society prevented them from leading a full life. However, many of the barriers described in the research are consistent with the social model, and this, along with other evidence of inequality, indicates that there may still be some way to go until disabled people achieve substantive equality in Britain.

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[3] Judge & Soloman, 2003

2.1 The profile of disabled people in Britain

There are clear differences in disabled people's experiences based on their age and the nature of their impairment, and this section provides a context for the interpretation of later findings.

Key findings

- The disabled population tends to be older than the general population. Forty-seven per cent are over State Pension Age (SPA) compared with 20 per cent of the general population.
- The types of impairment experienced varied by age, with the likelihood of having a physical, visual or hearing impairment increasing with age. For example, 53 per cent of 16-34 year olds had a physical, visual or hearing impairment, compared with 75 per cent of those aged 35 or older. Younger people were more likely to have a mental health condition: 23 per cent of 16-34, compared with nine per cent of those aged 35 or older.
- Nearly two in three disabled people (62 per cent) reported having one impairment. In comparison, (23 per cent) of the survey respondents had two impairments and one in ten (nine per cent) had three or more impairments. Likelihood of reporting multiple impairments increased with age: 15 per cent of those aged 16-34 had more than one impairment, compared with 34 per cent of those aged 35 or older.
- Just over half of disabled people (51 per cent) said they had acquired their impairment, condition or disability before the age of 50 (including three per cent who had had it since birth). A third (32 per cent) had done so between the ages of 50 and 69, and 16 per cent at age 70 or over.
- Around one in six (15 per cent) of people interviewed indicated that they had at some time been diagnosed with cancer, multiple sclerosis or HIV, and therefore have rights under the amendment in the 2005 Disability Discrimination Act.
- The most common area of substantial difficulty was mobility (57 per cent), followed by lifting, carrying or moving objects (53 per cent). Over one in five (22 per cent) reported that they did not have substantial difficulty with any of the areas asked about. This finding reflects the fact that some respondents had had an illness, disability or impairment in the past but did not have one at the time of the interview, while others were within the scope of the survey for ever having been diagnosed with cancer, multiple sclerosis or HIV.

2.2 Civic participation and social networks

Engagement with the wider community is seen as a key element of 'social capital'[4], which is important because other research has shown that high levels of social capital are associated with positive outcomes. The study explored aspects of disabled people's lives related to social capital, including involvement in social activities, volunteering activity and civic participation. Reference Network members and respondents to the qualitative research indicated the importance of the internet in their social lives, and this was also included in the study.

Key findings

- Over nine in ten (92 per cent) of disabled people had taken part in some social activities in the past month, and 90 per cent had taken part in activities outside their home.
- Older disabled people were less likely than younger ones to have taken part in activities outside their home (85 per cent of those aged 75+ have taken part in activities outside their home compared with 97 per cent of those aged 16-34).
- Three in ten (29 per cent) disabled people said that they did not face any barriers to further participation in social activities. The main barrier mentioned by those who did experience barriers was not feeling well enough (48 per cent), and this was particularly common for disabled people who had three or more impairments (75 per cent).
- Attitudinal barriers to further participation in social activities were seen as equally important as barriers related to access. Attitudinal barriers, for example lack of confidence, were mentioned by 15 per cent of disabled people, while barriers relating to access such as difficulties with transport or difficulties accessing facilities were mentioned by 19 per cent. Disabled people aged 16 to 34 (25 per cent) and those with mental health conditions (44 per cent) were particularly likely to mention attitudinal barriers as stopping them from doing more of the activities they would like to do.

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[4] Social capital describes the pattern and intensity of networks among people and the shared values which arise from those networks (ONS, 2003)

- Attitudinal barriers were also mentioned in the qualitative research:

> “What I don’t like is the patronising way people speak to me…are you alright sweetie, alright love, let me give you a hand…I don’t like that, they’re meaning well but especially when they’re older people it just makes you feel conspicuous.”
>
> **(Female, 60+, Wales)**

- Disabled people were equally as likely as the general population to engage in formal volunteering activities[5] (13 per cent volunteered at least monthly). However, disabled people (55 per cent) were less likely than the general population (66 per cent) to engage in informal volunteering[6].

> “Volunteering to me is part of my life, helping others... I am involved with a community centre and an academy... Because so many people have helped me since my accidents, and that’s why I feel I should give something back to the community.”
>
> **(Male, 50+, Scotland)**

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[5] Formal volunteering included helping in the past 12 months at an organisation such as a school, hospital, charity, voluntary or community organisation. General population data taken from British Crime Survey (Home Office, 2006).

[6] Informal volunteering activities included, for example, doing shopping, collecting pension, routine household jobs or home or car repairs for someone else, keeping in touch with, sitting with or providing personal care for someone who is sick or frail.

- A measure of disabled people's engagement in civic participation activities was obtained by asking respondents whether they had taken any of a list of actions, in an attempt to solve a problem they felt strongly about. The proportion of disabled people who had taken action (27 per cent) was significantly lower than among the population generally (38 per cent). The youngest (20 per cent of 16-34s), oldest (18 per cent of those aged 75 or older), poorest (18 per cent) and disabled people from ethnic minorities (11 per cent) were least likely to have engaged in civic participation.
- The benefits of participation were broadly acknowledged. Seven in ten of those involved in clubs, groups or the local community agreed that their involvement helped them to meet people they wouldn't otherwise have met. Half (53 per cent) agreed that their involvement helped them to feel more independent.
- For many participants in the qualitative research, belonging to a group or club provided them with a social network which offered them support and friendship. The importance of social contact through groups was discussed in the qualitative research:

> “Well I'm a widower so I don't see a lot of my kids, so my life now is the British Legion…I'm on the committee there.”
>
> **(Male, 50+, London)**

- Five per cent of disabled people seldom had contact with people from outside their household, but most (56 per cent) had daily contact.
- Learning activities were seen positively by those who were engaged in such activities at the time of the interview: over three quarters (78 per cent) of those engaged in learning agreed that they enjoyed it, and 63 per cent agreed that learning helped them stay active. Those who were not engaged in learning were less likely to perceive these benefits (40 per cent agreed they would enjoy a course or class and 44 per cent agreed that it would keep them active).

- Only two in five disabled people (42 per cent) had used the internet, either currently or in the past. These levels of use are substantially lower than those in the general population[7] (67 per cent of adults in the general public had used the internet).
- Lack of confidence (mentioned by 14 per cent), cost (13 per cent) and access (five per cent) were the main barriers preventing infrequent and non-users from using the internet more often. Younger respondents (80 per cent), those who were working (76 per cent) and those on higher incomes (70 per cent of those with household incomes of £20,800 and above) were most likely to have used the internet.
- Among those who used the internet at least every two or three months, the activities it was most commonly used for were email (72 per cent), finding out about goods and services (67 per cent) and general browsing (61 per cent). These are broadly similar to the activities for which non-disabled people use the internet[8].
- A quarter (26 per cent) of disabled people who had ever used the internet had done so to find out more about their impairment, although three fifths (62 per cent) thought the internet would help them to find out more.
- Many respondents in the qualitative research indicated that the internet was key to their feelings of social inclusion and participation.

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[7] ONS, 2007, http://www.statistics.gov.uk/pdfdir/inta0807.pdf

[8] Ibid.

2.3 Experiences and perceptions of discrimination

The study was wholly designed around the principles of the social model of disability, and these were borne in mind at every stage. The study also explored how disabled people view themselves in relation to the social model, and their awareness of the Disability Discrimination Act and how it may apply to them.

Further, the research aimed to see whether disabled people's experiences of discrimination and problems accessing goods and services had changed since 2001.

Key findings

- Over half of disabled people (55 per cent) said they could not lead a full life because of their impairment. Five per cent said they could not lead a full life due to their health problem/disability and because attitudes and barriers in society prevented them from doing so. Only one per cent of disabled people said they could not lead a full life purely because attitudes and barriers in society prevented them from doing so (that is, they did not mention their disability as having a role in preventing them from leading a full life).

> “I hate the word disabled because it's patronising and we don't ever use it.”
> **(Female, 24-55, North)**

- Disabled people from ethnic minorities (68 per cent), those who were not in paid employment (62 per cent), those aged 35 and over (57 per cent) and those with three or more impairments (77 per cent) were the most likely to see their disability as the barrier to leading a full life.
- In the qualitative interviews, some participants said that they saw themselves as disabled only in certain situations.

> I've got a condition that stops me from doing all the things other people can. I don't usually think of myself that way, but I've got a Blue Badge so I suppose I am!
>
> **(Female, 39-50, South-East)**

- Over half of disabled people (56 per cent) were aware of the Disability Discrimination Act (DDA), after prompting. Younger respondents aged under 55 were most likely to have heard of it (66 per cent).
- Two-thirds (65 per cent) of disabled people were aware that there were any rules, laws or regulations to stop people from being treated unfairly.
- Just over two-fifths of disabled people (44 per cent) said they thought they had rights under the DDA. Of those who did not think the DDA applied to them, 35 per cent said this was because they were not disabled and 21 per cent because they were not 'disabled enough'[9].
- One in eight disabled people (12 per cent) felt that they had been treated unfairly or discriminated against as a result of their disability, health problem or impairment. Younger disabled people (26 per cent), those with mental health conditions (35 per cent) and those with multiple health impairments (18 per cent) were the most likely to say that they had experienced disability-related discrimination.
- Discrimination due to disability was most frequently experienced in people's working lives. Nearly half (47 per cent) of all those who felt they had experienced disability-related discrimination had done so in relation to employment. This equates to six per cent of all disabled people or ten per cent of those of working age feeling they had experienced such discrimination. This discrimination manifested itself in a number of ways including not being given a job in the first place (nine per cent), not being given suitable hours due to their disability (nine per cent) or being asked to leave or made redundant (eight per cent).

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[9] All respondents participating in the research were likely to be classified as disabled under the DDA.

- The majority of disabled people (92 per cent) had not experienced problems accessing goods or services. People over 75 (96 per cent) were more likely than average to say that they had not experienced any difficulties. However, just under a fifth of people with mental health conditions (17 per cent) said that they had experienced such difficulties.
- The major difficulties experienced were getting into and around buildings (49 and 41 per cent of those experiencing difficulties respectively) and lack of facilities such as parking spaces, adapted shopping trolleys or an accessible toilet (29 per cent). Understanding or making themselves understood (24 per cent) and actually getting somewhere (23 per cent) were also mentioned by around a quarter of those who experienced difficulties accessing goods or services.
- Only a third (33 per cent) of those who experienced difficulties officially complained. Among those in our survey who did make a complaint, less than half found that their action was dealt with to positive effect (16 out of 41 said it was settled or dealt with).

2.4 Employment

The study explored the employment of disabled people, in terms of what types of work they do, whether their impairment impacts on, or is perceived to impact on, their ability to work and what support, adaptations and adjustments would help to support them in their employment. It also describes the barriers to getting back into work which were experienced by disabled people not in work.

Key findings

- Just under half (48 per cent) of all disabled people interviewed were retired, and a quarter (23 per cent) were in paid employment.
- Amongst disabled people of working age (16 to 64), 43 per cent were in paid work. This proportion is slightly higher than that observed in the 2001 'Disabled for Life?' survey (39 per cent)[10]. Disabled people remained significantly less likely than working age adults in the general population to be in paid work, as 74 per cent of working age adults in the general population were in paid work[11].
- Working age respondents with mental health conditions were significantly less likely than other disabled people of working age to be in paid work at the time they were interviewed (16 per cent, compared with 43 per cent of all disabled people of working age).
- Working disabled people were less likely than the working population as a whole to be employed in managerial or professional occupations (21 per cent of working disabled people compared with 28 per cent of the working population as a whole)[12]. Disabled people were instead more likely to be employed in elementary occupations[13] (18 per cent of working disabled people compared with 11 per cent of the working population as a whole)[14].
- When asked why they were not currently working, over half of those of working age who were not in paid work said that they were either unable to cope with work at the moment (42 per cent) or did not feel well enough (nine per cent). However, one in ten said that they did not have the skills required to get a job, and this was highest amongst those aged 16 to 34 (17 per cent).

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[10] Grewal et al., 2002

[11] 2007 Annual Population Survey

[12] Ibid.

[13] Examples of elementary occupations include postal worker, bar staff, warehouse assistant, hotel porter, waiter, etc.

[14] 2007 Annual Population Survey

> “I used to be quite a hands-on person, which has gone out the window. Changing a plug is out the window, I have to get somebody in to do that, which I find really frustrating... I can’t go to work anymore.”
>
> **(Male, 39-50, Midlands)**

- Over a third (37 per cent) of those who were disabled while in paid work said that they had to leave work for reasons connected to their impairment. Just under three in ten (27 per cent) of those who had ever left a job for reasons connected with their impairment felt that they could have remained in that job if some support, adjustments or adaptations had been made. Most of the adjustments that respondents would have wanted related to support and understanding from managers (14 per cent) and colleagues (eight per cent), but few (eight per cent) of these respondents were offered any support or adjustments/ adaptations.
- Fifteen per cent of respondents who had been disabled while of working age felt that they had not got a job they applied for because of their impairment.
- Respondents with mental health conditions were more likely than other disabled people to feel that they faced barriers to employment. They were:
  - more likely to feel that they were unable to cope with work (59 per cent of non-working people with mental health conditions, compared with 42 per cent on average)
  - more likely to feel that they had not got a job they had applied for because of their condition (27 per cent of people who had a mental health condition while they were of working age, compared with 15 per cent on average)

> “When I started getting depressed, I filled a form out for a job in a factory and I said I got depressed. I didn’t get the job anyway. But that’s what you think, when you filled the form out and you put down depression, you think that’s why you haven’t got it.”
>
> **(Female, 50+, Midlands)**

- Disabled people's expectations in relation to employment were explored by asking those of working age who were not working (and not retired) what would help them to take up paid work. Flexibility of working location and hours were most commonly mentioned (21 per cent mentioned the opportunity to work from home, and 17 per cent mentioned flexible working hours). Amongst disabled people in work, three in ten (30 per cent) felt that a better salary would enable them to have more choice of the work they do, and 21 per cent said flexible hours would help.
- Working disabled people expressed very positive views about how work contributed to their lives, with over nine in ten agreeing that work keeps them active (96 per cent), gives them financial independence (95 per cent), enables them to meet new people (92 per cent) and makes them feel they are contributing to society (90 per cent).
- Non-working disabled people also recognised these benefits of work, although levels of agreement were lower than those expressed by working disabled people. Of non-working disabled people, 74 per cent agreed that work would enable them to meet other people, 70 per cent agreed that work would keep them active, 69 per cent agreed that work would give them financial independence and 65 per cent agreed work would make them feel they were contributing to society.

2.5 Education

The research findings on the education experiences and qualification levels of disabled people to some extent reflect the older age profile of the sample, as, for example, older respondents were more likely to have left school before age 16 than younger respondents, and this has reduced levels of participation in post-compulsory education amongst the sample as a whole. Some of the survey findings reported here should be treated with caution, as respondents may be recalling experiences that happened many years ago.

It should also be noted that only ten per cent of the disabled people interviewed were disabled while at school (191 respondents), and very few attended a special school or a school with special provision. We are therefore limited in our ability to look in detail at the experiences or outcomes of disabled children and young people at school (for example, qualifications, working status).

Key findings

- Half (51 per cent) of disabled people aged 16 to 74 had any educational qualifications compared with seven in ten (71 per cent) of the general population of the same age[15]. The likelihood of holding formal qualifications declined with age (71 per cent of disabled people aged 16 to 34 had any formal qualifications, compared with 24 per cent of those aged 75 or older), reflecting patterns in the general population[16]. However within each age band, disabled people were still significantly less likely than the population as a whole[17] to hold formal qualifications.

> “I didn’t really want to go to Uni and I didn’t want to go because of health, because I’d been in and out of hospital quite a lot and I didn’t think they’d allow me so much time off at Uni.”
>
> **(Female, 18-24, London)**

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[15] ONS Census 2001 16-74 year olds

[16] LFS data reported in DRC Disability Briefings, March 2006

[17] Ibid.

- Respondents who were disabled at school were more likely than those whose impairment started to impact on their activities at age 16 or later to describe their experience of school as bad (27 per cent and 14 per cent respectively).
- Those who were disabled at school were also less likely than those who were not disabled at school to think that their experience of school had prepared them well for the future (53 per cent of those disabled at school, compared with 64 per cent of those who were not).
- At the time of the interview one in ten (11 per cent) of all disabled people were taking part in some form of course, class or tuition.
- Working disabled people (23 per cent) and those in households with higher annual income (20 per cent of those with an annual income of £20,800 or more) were more likely to have been taking part in learning at the time they were interviewed.
- Across the qualitative research respondents talked about enjoying the courses that they were undertaking:

> “If I can be doing writing, doing courses, something to use my brain just to cheer me up…so getting my mind off from thinking too much about my health.”
>
> **(Male, 40-50, South-East)**

- More than a fifth (22 per cent) of disabled people not taking part in any learning at the time of the interview said they would like to do so. A third (32 per cent) of those who wanted to participate in learning said that they did not feel well enough to do so, and cost and lack of time were each mentioned as barriers to participation by 30 per cent.

- A majority of respondents who were involved in learning activities at the time of the interview agreed that their course or class kept them active (63 per cent) and they did it because they enjoyed it (78 per cent). Those who were not current learners were less positive about these aspects of participation in learning, although 40 per cent of non-learners thought they would enjoy it.

2.6 Economic well-being

Economic well-being is central to overall feelings of well-being, and some survey respondents noted that their financial situation had presented a barrier to their participation in a range of activities. Furthermore, disabled people in households with lower income levels tended to report fewer positive outcomes.

The research explored disabled people's feelings about their financial situation, including their perceptions of the additional costs of disability. Please note that data shown (for example, household income, which benefits received, etc.) are reported by respondents and have not been validated or checked for accuracy against official records.

Key findings

- Just over half (52 per cent) were living in a household with an estimated total income of less than £20,800 per year, which is below the national median income of £24,700[18]. The median estimated household income amongst the disabled respondents in the survey was in the range £15,600-£20,800.
- People of State Pension Age, those who were not working or in households where the household reference person was not working and those with mental health conditions had the lowest median income.
- One in six (17 per cent) disabled people had some level of financial difficulty and many of those experiencing financial difficulties said that these caused stress/anxiety (79 per cent) or impacted on their mental health (28 per cent). Two fifths (38 per cent) said that their financial situation meant that they could not afford to pay for essentials.
- Half (49 per cent) of all disabled people interviewed were concerned about their financial situation over the next few years.
- This is supported by the qualitative research. People with a mental health condition were often concerned about their financial situation.

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[18] HBAI, 2006/07

> “That’s half the problem that causes some people’s depression – your income. Especially when you’ve got to live on the money they give you.”
>
> **(Male, 50+, Birmingham)**

- Although the proportion of disabled people who had ever had their benefits stopped or reduced was relatively small (12 per cent), the impact of that change in income for those people was considerable. A quarter (24 per cent) of those experiencing a change in their benefits said the change resulted in a drop in their income of more than half, and six per cent said they had no income at all at this time. Around half (53 per cent) said the change in their income had led to financial difficulties, and three fifths (61 per cent) had experienced stress or anxiety as a result.
- Over half (55 per cent) of disabled people felt they incurred additional costs as a result of their impairment. The main areas of extra costs were additional fuel/heating (28 per cent), transport (16 per cent) and the need to pay for medical treatment/prescriptions (13 per cent).

2.7 Housing and home life

The research aimed to explore disabled people's views of their housing and home life, including the support they received both within and outside the household.

The findings support the emphasis of government policy and disability advocacy groups on Independent Living, such as Direct Payments and extending choice and control over services that are provided.

Key findings

- Just under nine in ten (89 per cent) said that their property was suitable for their needs, but eight per cent thought that their property was not suitable. Younger disabled people (81 per cent) and those with visual impairments (61 per cent) were less likely than other disabled people to feel that their property was suitable for their needs.
- Amongst those who did not feel that their property was suitable for their needs, 29 per cent said that this was because of problems with stairs, and 27 per cent said it was because of structural limitations of the property.

> “A downstairs loo would be very nice, but I don't know if you can get grants or anything like that to rebuild outside. I don't know if the DWP would be able to tell me? I could ask.”
>
> **(Female, 60+, Wales)**

- The household composition and tenure patterns of disabled people reflect the fact that they are older, on average, than the general population[19].
- Disabled people were less likely than the population as a whole to be living in households containing children (13 per cent of disabled people, compared with 24 per cent in the population as a whole[20]).

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[19] ONS, Census 2001.
[20] Ibid.

- Compared with the general population of Britain, disabled people were more likely to own their home outright (41 per cent, compared with 30 per cent of the population as a whole[21]), or to rent from a social landlord (31 per cent of disabled people compared with 20 per cent of the population as a whole[22]).
- Just over half of disabled people (54 per cent) did not have any aids, adaptations or equipment to help them with day-to-day life. Most common were aids to mobility or dexterity (43 per cent). A quarter (26 per cent) would like to have aids they did not currently have.

> “I was wondering can they do adjustments in the house, like look at the toilet, look at providing a [stairlift] chair?”
>
> **(Female, 40-50, London)**

- Amongst those who had any aids, adaptations or equipment, just under half (47 per cent) always had a choice of what to get, but 26 per cent said they never had a choice.
- Two-fifths (41 per cent) of disabled people received some regular support with day-to-day activities, and 47 per cent got support with other activities, such as DIY or dealing with finances. Most (86 per cent) felt that they did not have any unmet needs for help or support, although 20 per cent of those in single person households said they had unmet support needs.

> “There’s so many jobs that I need doing that I can’t do, but I can’t ask my husband ‘cos he’s so busy and I don’t want to put any more on him.”
>
> **(Female, 50+, Cardiff)**

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[21] ONS, 2006
[22] Ibid.

- Most of those receiving support got it from their spouse/partner (46 per cent) or children (43 per cent). One in seven (15 per cent) received support from formal sources (for example, social services, home help).
- Of those receiving support from formal sources, around a quarter said that they had no choice in aspects of that service. For example, 26 per cent of disabled people felt that they have no choice over which person provides the support, and a similar proportion (25 per cent) felt they have no choice over what time the person comes to their home. Respondents who felt they had the least amount of choice over the help and support they received were most likely to express dissatisfaction with that support. For example, of the 49 per cent who said they had little or no choice over which person provides support, 13 per cent were dissatisfied with the quality of help and support given. In comparison, none of those who felt they had a great deal or a lot of choice over which person provides the support expressed dissatisfaction.

2.8 Transport

The report 'Improving the Life Chances of Disabled People'[23] emphasised the need to improve the provision of transport to enable disabled people to live more independent lives. The report states that, as a result of economic disadvantage, disabled people are more likely than the general population to be reliant on public transport.

The study explored disabled people's views about transport and getting around, and describes experiences of discrimination in relation to transport, and the barriers that disabled people face when travelling.

Key findings

- Almost all (97 per cent) of disabled people had made at least one trip out of home in the past month, although six per cent of those aged 75 or older had not taken any trips in the past month.
- The majority of disabled people (84 per cent) had travelled by private car in the past month, and nearly half (46 per cent) had travelled by public transport. Those in London were more likely than those in the rest of Britain to have used public transport in the past month (55 per cent), and younger people were also more likely to have used public transport in this time period (63 per cent of those aged 16-34 had used public transport in the past month compared with 44 per cent of those aged 35 or older).
- A quarter (26 per cent) of disabled people found travelling about very easy, and three in ten (30 per cent) of disabled people found travel difficult or very difficult.

> “Having to rely on other people all the time. It would be so nice to get out of bed one day and think, right, I'm going to London and to have the confidence to do it. I would love the achievement of just doing it.”
>
> **(Female, 24-35, London)**

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[23] PMSU, 2005

- Disabled people aged 75 or older were more likely than younger disabled people to say that they found travelling difficult (13 per cent of those aged 75 or older said they found travelling very difficult compared with five per cent of those aged 16 to 34).
- The main barriers to using transport identified by those who find travel difficult included not feeling well enough (65 per cent). Three in ten (30 per cent) said that attitudinal barriers such as lack of confidence or previous bad experiences made it difficult for them to travel about day-to-day. Attitudinal barriers were equally likely as access barriers (mentioned by 28 per cent) to make it difficult for disabled people to travel. Access barriers include difficulties getting to the stop/station or difficulties getting on to transport.

> “I have people shouting at me because they can’t see I’m deaf.”
>
> **(Female, 39-50, Midlands)**

- Half (50 per cent) of disabled people agreed that they accepted difficulties with transport as part of having their impairment. Younger disabled people were significantly less likely to feel this way (35 per cent of 16 to 34 year olds agreed with this statement, compared with 53 per cent of those aged 35 or over).
- Half (50 per cent) of all disabled people held some kind of transport concession A third had a Local Authority bus/rail pass (34 per cent), and a quarter had (25 per cent) a Blue Badge. The likelihood of holding any of these concessions increased with age (80 per cent of those aged 75 or older held any concessions, compared with nine per cent of 16 to 34 year olds).
- One in seven (14 per cent) of respondents had ever used a transport service for disabled people. The likelihood of using these services again increased with age (two per cent of 16 to 34 year olds had used any, compared with 17 per cent of those aged 75 or older).
- Two-fifths (42 per cent) of disabled people thought that improvements to public transport would make their life better. Respondents in London were more likely to agree with this (59 per cent), reflecting their greater use of public transport.

- Difficulties with transport were themselves seen as barriers to wider participation. Around one in ten mentioned transport difficulties as barriers to participation in social activities (ten per cent), community participation (seven per cent), and education and learning (ten per cent). Five per cent of those who had to leave work for reasons related to their impairment said that they could have remained in paid work if it was easier to get to their place of work.

2.9 Health and well-being

The report 'Improving the Life Chances of Disabled People'[24] acknowledged the role of health care services in enabling disabled people to live independent lives, and to participate in their local community. The study explored disabled people's use of and views on health services, as well as perceptions of their own health and general well-being.

Key findings

- Three fifths (59 per cent) of disabled people described their life as a whole as good, three in ten (30 per cent) said it was just "all right" and one in ten (ten per cent) described it as bad.
- Disabled people were less happy with their lives than other people[25]. The dissatisfaction was highest among the following groups:
  - younger people (13 per cent of 16-34s, compared with five per cent of those aged 75 or older)
  - people living alone (26 per cent of those in single person non-pensioner households)
  - people with mental health conditions (27 per cent)
  - people from black and ethnic minority communities (28 per cent)
  - people in urban areas (11 per cent of those in urban areas described their lives as bad compared with five per cent of those living in rural areas)
  - people in households on lower incomes (25 per cent of those households earning less than £5,200 a year)

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[24] PMSU, 2005

[25] Bowling, 2005

- Disabled people were more likely to say that they had enough privacy (85 per cent said they always or usually had enough privacy) and were treated with dignity and respect (86 per cent) than to say that they had enough control over what happens in their life (64 per cent), or that they had done the things they wanted to do (49 per cent).
- Fewer than one in five (18 per cent) of disabled people described their health as good, compared with two in three (68 per cent) of the general population[26]. A third (33 per cent) of disabled people felt their health had worsened in the last 12 months.
- For seven out of ten (70 per cent) disabled people, the substantial effects of their disability were with them all of the time.
- More than nine out of ten (92 per cent) disabled people had used a health service in the past three months, which is significantly higher than the general population[27].
- Disabled people were particularly satisfied with the staff in the health services they used, not only in terms of friendliness, helpfulness and understanding (90 per cent of disabled people were satisfied), but also in terms of being treated with dignity and respect (94 per cent) and their knowledge (88 per cent). Dissatisfaction was highest with the location of services (12 per cent) and choice over appointment times (18 per cent), whom they saw (12 per cent) and over treatment/therapy (ten per cent). Control over appointments was an issue particularly likely to be identified by working (21 per cent) and 35 –54 year old disabled people (23 per cent).
- Nearly half of the sample (48 per cent) felt there were barriers to using health services. The main barriers to health services were related to the journey itself, particularly in terms of transport difficulties (15 per cent), distance (14 per cent) and needing someone to accompany them (12 per cent).
- Four out of five disabled people (80 per cent) were satisfied with the information and advice they have received from health professionals about their impairment.

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[26] Census, 2001

[27] MORI, 2003

> “I’ve got an excellent GP and it is so important to me that I am even resisting moving house because I don’t want to lose this GP. I’m delaying it because I’ve got this good rapport with her, and I know I can trust her.”
>
> **(Female, 50+, Wales)**

- Doctors and nurses were preferred sources of information about their impairment/disability for disabled people generally (80 per cent), but younger people (72 per cent) and black and ethnic minority respondents (62 per cent) were less likely to say this. Family and friends were more favoured by younger people (21 per cent) and people with mental health conditions (20 per cent). The internet was not generally favoured as a source of information.

> “My specialist prescribed me medicine which was costing my doctor £350 a month and he [the specialist] said this medicine will open the veins and capillaries and I will be able to go back to work. My doctor said I cannot afford it.”
>
> **(Male, 25-64, North West)**


SODOR

3 Context of the research

3.1 Background and objectives

In September 2006, the Office for Disability Issues commissioned a research project which aimed to explore the lives of disabled people in Britain today. This research updates and develops previous research conducted by the National Centre for Social Research in 2001 and by NOP in 1996, and addresses information gaps on how disabled people's lives have changed and providing detail on their current experiences.

A consortium led by the research organisation GfK NOP was commissioned to carry out this research.[28]

The specific aims of the research were as follows:

- to help develop an evidence base and generalised picture to understand disabled people's lives
- to provide baseline information to aid the monitoring of progress towards the Government's 2025 Vision of achieving substantive equality for disabled people and trackable measures by which to monitor progress
- to produce a piece of research that involves and consults disabled people at all stages of the project
- to provide evidence on the effect of discrimination on disabled people's lives – particularly experiences of and reactions to discrimination
- to inform future policy development and feed into the formulation of further research, including the ODI longitudinal survey of disabled people.

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[28] The other organisations in the consortium were the Office for Public Management (OPM), ppre, Icarus Collective and the University of Nottingham.

3.2 Defining disability

Central to the research reported here is the definition of disability in the Disability Discrimination Act[29]. The Act[30] generally defines as disabled a person who has:

‘a physical or mental impairment which has a substantial and ‘long-term’ adverse effect on their ability to carry out normal day-to-day activities.’

This definition takes as its starting point the individual having an impairment. However, having an impairment is not a sufficient condition to be classed as a ‘disabled person’ for the purposes of the Act. Rather, the impairment must impart a significant disadvantage on the person compared with a non-disabled person. In this research, all respondents were screened to ensure that they met the Act’s definition before any interviews took place.

The Act’s definition of a ‘disabled person’ has been influenced by the ‘social model’ of disability. This is a perspective which sees disability as arising from how society is organised, emphasizing the ‘disabling barriers’ that arise from the ‘attitudinal, economic, and/or environmental factors that prevent disabled people from experiencing equality of opportunity with non-disabled people’[31]. The ‘social model’ acknowledges that different impairments impact upon people’s lives in different ways and that people with similar impairments might be disabled in different ways. This model has been influential in the UK, for instance, in supporting notions of Independent Living, direct payments, mainstreaming and the requirement to make ‘reasonable adjustments’ under the Disability Discrimination Act (DDA). More information about models of disability is given in the full report.

3.3 Related research

The experiences and views of disabled people have been the subject of other research. Research on disabled people has used a variety of quantitative and qualitative research designs, and some studies have, for comparative purposes, included non-disabled people as well as disabled people. There have been a few ‘subject’ reviews of research of people’s experiences of disability. There have also been various monitoring and evaluation studies of the DDA and of government programmes. Examples of these subject reviews, monitoring and evaluation studies are given in the full report, together with references.

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[29] DWP, 2006

[30] Disability Discrimination Act 1995, (Amendment) Regulations 2003

[31] Joint Committee of the House of Lords and House of Commons, 2004

One specific study worth highlighting is 'Disabled for Life?[32] Attitudes to, and experiences of, disability in Britain'. This earlier mixed method study included a survey of 2,064 respondents of whom nearly half (47 per cent) were disabled people according to the then DDA definition of disability and the remainder were non-disabled respondents. The fieldwork was conducted between January and April 2001. The study found that there was strong support for action to combat disability discrimination and that further action was required by government to address the attitudinal and structural barriers that disabled people at that time confronted. In part, the present study is a follow-up to the 'Disabled for Life?' research.

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[32] 'Disabled for Life? Attitudes to, and experiences of, disability in Britain', Grewal et al., 2002

4 How the research was carried out

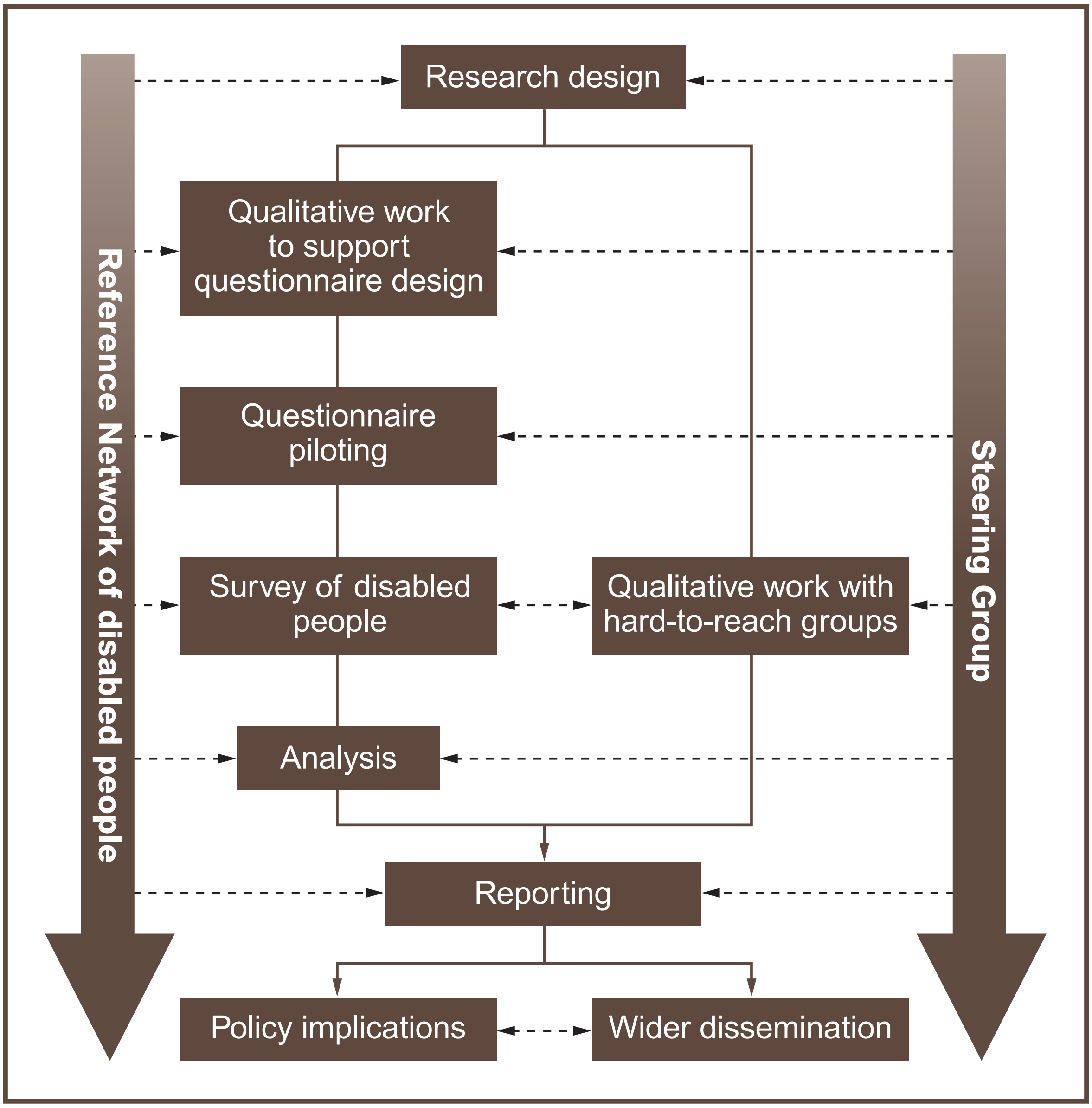
4.1 Overall research approach

The main strands of the approach to the research were:

- the involvement of disabled people and disability-focused organisations, through active engagement with a Reference Network and Steering Group
- three stages of qualitative research, which aimed to inform the scope and content of the survey questionnaire, and to enable the inclusion of some groups who would otherwise have not been included in the study
- a large-scale quantitative survey of disabled people in Britain.

Chart 1 summarises the overall model for the research, and shows how we integrated the different strands to the benefit of the study as a whole. Later in this section we give an outline of how each was carried out, with further detail available in the technical annexes.

Chart 1 Overall model for the research



4.2 The Experiences and Expectations of Disabled People (EEDP) Reference Network

A reference network is a group of people with shared expertise in relation to a particular issue who are brought together to inform and guide the development of a defined piece of work. Key to the success of the research was Reference Network which was made up of over 50 disabled people from a range of backgrounds and with very different experiences. The EEDP Reference Network had a number of objectives, including adding transparency and credibility to the process and ‘reality checking’ the research, but its principal purpose was to ensure that disabled people were substantively involved in the design, delivery and analysis of the research.

The EEDP Reference Network was facilitated by the Office for Public Management (OPM), an independent not-for-profit community engagement consultancy. To reflect different disabled people's experiences and expectations, and in particular different levels of experience of being involved in this kind of research, the Reference Network included people of three broad types:

- disabled people actively involved in disability equality issues on a national level, identified by the consortium
- disabled people actively involved in disability equality issues at a local level, recruited from a list of affiliated groups
- disabled people not aligned to any disability-related organisation

Network members were involved throughout the project – from the development of the research to the analysis and reporting stages.

The Reference Network had an impact on the research in four different ways:

- **Democratising the research process** – By involving disabled people in decision-making and ensuring that 'seldom-heard' disabled people participated and by challenging the traditional approaches to conducting government-funded research into the lives of disabled people and co-producing the research tools and outputs.
- **Making research more transparent and accountable to stakeholders** – Feedback from Network members suggests that this was particularly important given that they were stakeholders in the research (as disabled people) as well as part of the research's Reference Network.
- **Improving and 'reality checking' research approach and tools** – Feedback from the Reference Network led to improvements being made, with particularly useful suggestions around clarifying the language and advice on how best to embed the social model of disability in the approaches and research tools used.
- **Increasing credibility and stakeholder confidence** – When Reference Network members were asked to give feedback on their experiences of being part of the Network, many of the members said that being listened to was the most positive experience of their involvement. The Network itself attracted considerable attention from senior stakeholders in ODI and other government departments.

4.3 Involvement of the EEDP Steering Group

In addition to the Reference Network, researchers also engaged with a Steering Group comprised of representatives from national and international disability organisations, academics, ODI analysts and other Government officials. They were specifically recruited because of their expertise in research amongst disabled people in Britain.

4.4 Qualitative research methods and sample

The qualitative research design consisted of three stages:

- Stage 1 Ethnographic depth interviews (16), to explore participants' lives in some detail
- Stage 2 Focus groups (14) and depth interviews (eight), to explore emerging themes in more depth
- Stage 3 Depth interviews (16) with 'seldom heard' groups

Stages 1 and 2 took place before the quantitative survey and informed development of the quantitative questionnaire. Stage 3 was conducted after the quantitative survey and targeted groups whose views had not been fully captured by the survey. This included people who had experienced discrimination, people from ethnic minority communities, lesbian and gay people and people living in communal establishments.

In total, 134 people participated in the qualitative research (40 in the depth interviews and 94 in the group discussions). Given the smaller samples researched using qualitative methods, none of the three qualitative stages attempted to be statistically representative of disabled people as a whole. Nevertheless, we did attempt to reflect the population as broadly as possible, including all impairment groups covered by the Disability Discrimination Act (DDA), as well as a range of ages and locations.

A fuller description of the way the qualitative research was carried out is included in the annexes to the main report www.officefordisability.gov.uk/research/eedp.asp.

4.5 Quantitative approach

4.5.1 The quantitative survey

The quantitative stage of this research involved a large-scale survey of disabled people. The sample of addresses was randomly drawn across Great Britain from the Postcode Address File (PAF). A doorstep screening exercise was undertaken at each selected address, to establish whether there were any residents within the household who were eligible for interview. In total, just under 7,600 addresses across Great Britain were screened.

All of the people eligible to complete the full interview were likely to be classified as disabled under the DDA. This means that all respondents described in this report had a disability which had lasted for more than a year and which substantially limited their ability to carry out day-to-day activities, even if the effects of their disability were mitigated or controlled by medication or other therapies. The definition also included people who had had disabilities in the past which lasted for more than a year and substantially adversely affected their ability to carry out day-to-day tasks. Recent amendments to the DDA mean that people who have been diagnosed with cancer, multiple sclerosis (MS) or HIV are also covered by the Act from the time of diagnosis, and people covered under this amendment were also eligible for interview.

Fieldwork was conducted in July and August 2007. A total of 1,860 people were interviewed. Fieldwork was designed to be as inclusive as possible, and all interviewers received disability confidence training to enable interviewers and respondents to feel comfortable throughout the interview experience. In addition, three versions of the questionnaire were available:

- a full version which was completed by 94 per cent of all respondents
- a short version, which was used where the respondent's needs indicated that they would not be able to complete the full version. 110 interviews were completed using this version of the questionnaire (six per cent of all interviews)
- an easy read version, for use by people with learning disabilities. Seven respondents completed an easy read interview.

A fuller description of quantitative research methods is included in the annexes to the main report www.officefordisability.gov.uk/research/eedp.asp.

4.5.2 Analysis of the quantitative data

The survey data were weighted to compensate for the various design effects introduced by the sample design. The data were weighted so that the number of interviews per region was proportionate to the distribution of the general population. Corrective weights were also applied for age, gender, working status and housing tenure, and these were based on the 2001 Census data for people with a long-term limiting illness (LTLI).[33]

The Technical Annex to the full report contains full technical details of the survey, including the full breakdown of response and the weighting strategy.

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[33] The DDA definition differs from the LTLI definition as used in the 2001 Census. However, Census data provided the most robust and accessible dataset available for weighting purposes.

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