Meeting DWP’s long-term information needs on disability: A feasibility report

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Acronyms/Abbreviations

AA  Attendance Allowance
BHPS  British Household Panel Survey
BSA  British Social Attitudes
BSL  British Sign Language
CAI  Computer Assisted Interviewing
CASI  Computer Assisted Self-Interviewing
CATI  Computer Assisted Telephone Interviewing
CIS  Clinical Interview Schedule
CLS  Centre for Longitudinal Studies
CMD  Common Mental Disorder
CPS  Continuous Population Survey
DDA  Disability Discrimination Act
DfES  Department for Education and Skills
DLA  Disability Living Allowance
DWP  Department for Work and Pensions
ELSA  English Longitudinal Study of Ageing
FACS  Families and Children Survey
FRS  Family Resources Survey
GHS  General Household Survey
HDD  Handicaps, Disability and Dependency
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>HSE</td>
<td>Health Survey for England</td>
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<tr>
<td>IB</td>
<td>Incapacity Benefit</td>
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<tr>
<td>ICD</td>
<td>International Classification of Disease</td>
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<tr>
<td>ICIDH</td>
<td>International Classification of Impairments Disabilities and Handicaps</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<td>LFS</td>
<td>Labour Force Survey</td>
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<tr>
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<td>Millennium Cohort Study</td>
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<td>MRC</td>
<td>Medical Research Council</td>
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<td>National Centre for Social Research</td>
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<td>NHS</td>
<td>National Health Service</td>
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<td>NHIS</td>
<td>National Health Interview Survey</td>
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<td>ONS</td>
<td>Office for National Statistics</td>
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<td>OPCS</td>
<td>Office of Population Censuses and Surveys (now ONS)</td>
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<tr>
<td>PAF</td>
<td>Postcode Address File</td>
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<td>PALS</td>
<td>Participation and Activity Limitation Survey</td>
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<td>Royal National Institute for the Blind</td>
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<td>RNID</td>
<td>Royal National Institute for the Deaf</td>
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<tr>
<td>SDAC</td>
<td>Survey of Disability, Ageing and Carers</td>
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<tr>
<td>SEN</td>
<td>Special Educational Needs</td>
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<tr>
<td>TDE</td>
<td>Touchtone Data Entry</td>
</tr>
<tr>
<td>VOCA</td>
<td>Voice Output Communication Aids</td>
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<tr>
<td>WHODASII</td>
<td>World Health Organisation Disability Assessment Schedule</td>
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Summary

The Department for Work and Pensions has a broad range of information needs on disability. Some of these might be met through secondary analysis of existing datasets, and some by adding questions on disability to existing surveys. However other information needs will require fresh data collection, with some needs potentially being met through a cross-sectional survey with a focus on disability, but with others requiring a longitudinal survey. In particular DWP have identified a growing need for information about the dynamics of disability over time and the factors associated with transitions and onsets of disability. These questions can only adequately be addressed with a longitudinal study.

The National Centre for Social Research (NatCen) were commissioned in 2004 to look at the range of data needs identified by DWP and to provide advice on research design options for addressing these needs.

The information needs and how to meet them

The identified information needs of DWP fall under the following broad headings:

- Disability dynamics and transitions
- Experiences of disability by sub-group
- Up-to-date disability prevalence rates
- The relationship between disability and work and incapacity
- The relationship between disability and education
- Income, and the direct and indirect costs of disability
- Benefit receipt and take-up
- Social participation and access
- Attitudes towards disability
- Issues around independent living, support and care.
Addressed separately, many of these needs could be met through a new large cross-sectional survey. However, the information needs around transitions and dynamics can only be met with longitudinal data. Plus, some of the other information needs, such as the relationship between disability and work, would be addressed considerably more fully with longitudinal data.

Although a minority of the information needs considered in isolation could be addressed through adding new questions on disability to existing surveys, if the entirety of the information needs are to be met there is very clearly a need for:

- a new cross-sectional survey of disability;
- a longitudinal survey of disability that will map onsets and transitions.

The design of a survey

The design recommended is for DWP to:

- commission a new large-scale baseline survey of the general GB population that will provide data from which prevalence estimates for disability can be derived alongside a range of other associated cross-sectional factors;
- then use this cross-sectional sample as the baseline for a longitudinal study of disability.

The baseline survey could either be designed as an entirely new survey, or as a follow-up to another large-scale GB survey. Under the latter model, for cross-sectional estimates it would be sufficient to commission new data collection only on those from the ‘source’ survey who are, or may be, disabled. The new data collection exercise would fill in the details on disability not captured in the source survey.

Of these two design options, the follow-up model is the least expensive. However it has a serious drawback in that none of the possible source surveys have disability as a focus and only moderate efforts will have been made to include disabled people who find traditional survey interviews difficult. For this reason, although more expensive, the ‘entirely new survey’ approach is recommended.

The sample size for the baseline survey will have to be at least 40,000 adults if it is to generate sufficient numbers of disabled people for analysis and for longitudinal follow-up. A sample of this size should cover approximately 8,000 disabled people. If children are included this would boost the overall sample size to 50,000.

Under either model for a baseline survey, the recommendation is that the longitudinal survey uses respondents to this baseline as the longitudinal survey sample source. The approach recommended is to follow-up all baseline respondents irrespective of disability status, but to divide the respondents into three groups and use different follow-up strategies per group.
The three groups are:

1. Those disabled at baseline. This group would be followed-up annually using face-to-face interview surveys and would provide information on life courses of disabled people. The starting sample size would be about 8,000 for a total baseline survey sample size of 50,000 adults and children.

2. A comparison sample of about 4,000 non-disabled at baseline. This group would also be followed annually using face-to-face interview surveys. The questionnaire content would be comparable to the content for the ‘disabled at baseline’ group.

3. The remainder of the baseline survey respondents. This group (of whom there would be about 38,000 from a baseline survey of 50,000) would be used to identify future disability ‘onset’ cases. People in this group would be followed-up annually by telephone and asked a series of questions to establish whether they are now to be classed (for survey purposes) as disabled. Those that are would be asked to take part in a longer face-to-face interview during which information on the experience of disability onset would be captured. All future interviews for this group would be face-to-face.

The population coverage of the baseline and longitudinal surveys

Since the baseline survey will generate prevalence estimates for disability there is a very clear case for adults of all ages to be included. There is also a strong case for including children, although the questionnaire content will need to be different for children so it may prove practical to carry out a child baseline survey as a separate survey operation to that for adults (even if the sample of children is generated through the sample of adults). The sample of disabled children generated through a general population survey of about 50,000 will inevitably be small, and a boost sample of children is probably appropriate.

Most ‘general population’ surveys in GB exclude adults who live in communal establishments. Given that the exclusion of these adults from a prevalence study of disability would underestimate the true prevalences, it is recommended that communal establishments be included in the baseline survey at least. The sampling for this group will be different to the sampling for the general household population, so this component of the baseline survey could be treated as a separate exercise.

Although coverage of communal establishments is recommended for the baseline survey so that ‘all population’ prevalence estimates can be generated, no clear case has been identified for including communal establishment residents in a longitudinal survey. In fact, given that the English Longitudinal Study of Ageing (ELSA) will, as it matures, generate considerable data on the life courses of older people, the option of excluding those not of working age from the longitudinal study needs consideration.
Outstanding areas for development

Before either the baseline or the longitudinal study can be launched, additional research is needed in two key areas.

Firstly, extra research is needed on how disability should be defined and asked about in a survey context. The two previous large scale surveys of disability in GB both used the same survey instruments. These were based on the original World Health Organisation (WHO) International Classification of Impairments, Disabilities and Handicaps (ICIDH) model of disability which has now been replaced. The instruments need to be re-written to reflect this change. It is very likely that different instruments will be needed for adults and children.

Secondly, there appears to be no consensus on how a disability transition or onset should be defined. Additional research is needed to help conceptualise what counts as a transition or onset. These concepts will then need to be translated into survey instruments.

In addition, if either the baseline or the longitudinal surveys are to be used to estimate eligibility rates for DLA and AA, additional research is needed to test the feasibility of developing sensitive and specific survey questions.
1 Introduction and background

The Department for Work and Pensions (DWP) have identified a number of long-term information needs on disability, some of which might be addressed by commissioning a new cross-sectional survey on disability or by adding questions to existing surveys, but others that will require a longitudinal study with a particular focus on disability if they are to be met. The National Centre for Social Research (NatCen) were commissioned in 2004 to look at these data needs and to provide advice on research design options for addressing these needs. Inevitably, because of the difficulties and costs involved and because nothing similar has been attempted in GB before, we have paid particular attention to the potential design of a longitudinal survey.

The report is structured as follows:

- Chapter 2 gives a summary of the information needs identified by DWP and sketches out the survey design implications for each;
- Chapter 3 describes what we have called the ‘basic’ longitudinal survey design;
- Chapter 4 addresses a number of design issues, such as how to define disability, and what members of the population to include in any new survey;
- Chapter 5 considers alternatives to the ‘basic’ design;
- Chapter 6 focuses in more detail on the survey design implications of the DWP information needs;
- Chapter 7 looks at issues amongst three sub-groups (children, those with mental health problems, and minority ethnic groups);
- Chapter 8 looks at how to conduct survey interviews across a wide range of disability types;
- Chapter 9 gives our conclusions.
2 The information needs of the DWP

The Department for Work and Pensions (DWP) have identified a series of long-term information needs on and around disability issues. These can be condensed into a small number of ‘headings’:

- Experiences of health and disability over time/disability dynamics and transitions.
- Different experiences of disability by sub-group.
- Disability prevalence rates.
- The relationship between disability and work and incapacity.
- The relationship between disability and education.
- Income, and the direct and indirect costs of disability.
- Benefit receipt and take-up (with a particular emphasis on the take-up rates for Disability Living Allowance (DLA) and Attendance Allowance (AA)).
- Social participation and access.
- Attitudes towards disability.
- Issues around independent living, support and care.

The three main objectives of this report are:

- an assessment of what type of data is needed to support these information needs;
- suggestions on a study design (or designs) that will provide data of the type required; and
- recommendations on the development work that will be needed before any large-scale study can begin.
In this section we take each of the headings above, outline what the information needs under that heading are, and then draw conclusions on what type of data is required to meet those needs.

2.1 Experience of disability over time/disability dynamics and transitions

DWP have identified a growing need for information about the dynamics of disability over time, which includes having data on variations in the levels or severity of impairments, how lifestyle affects the onset of disability (and vice versa) and how experiences of disability affect people over the course of their lives. In addition there is a need for information on, for example, what happens on the onset of disability and whether some people experience cycles of disability.

All of the large UK disability studies to date have collected data cross-sectionally (that is, at one point in time) rather than longitudinally. Studies of this type allow for ‘prevalence’ estimates (however defined) to be derived and for the associations between disability status and other aspects of life to be explored and quantified. But what they do not tend to allow for is analysis of change over time, such as the factors that accompany changes in disability or around onset of disability. In other words cross-sectional studies give little opportunity for understanding disability transitions. Nor do cross-sectional studies provide much understanding of how other transitions (such as the move from childhood to adulthood) are impacted by disability.

To meet information needs around transitions requires data with a longitudinal element where individuals are tracked over time. We could consider whether a retrospective study, rather than a prospective study, would meet the information needs (wherein people are asked to look back over their life course retrospectively) but because of the difficulties in getting data of good quality through this route, together with the fact that it would give historical trajectories rather than current (or short-term future) trajectories, makes this an impractical option. Instead, to understand the factors associated with disability transitions what we believe is needed is a prospective study. Such a study will need to include samples of individuals tracked over time who:

- move from being non-disabled to disabled (that is, ‘onset’ cases), or vice versa;
- or
- are disabled people who experience some change in the nature of their disability.

In addition, to understand how other life transitions are impacted by disability, what is needed are samples of disabled people who are tracked over time. And, to put their experience into context, a similar (comparison) sample of non-disabled people who are tracked over the same time period would be highly desirable.
The obvious study design to meet these needs is a classic longitudinal survey that follows a sample (or samples) of the general population over time and includes, over time, identifiable sub-groups of:

- disabled people who experience a change in the nature of their disability (whether for better or worse) during the course of the study;
- non-disabled people who become disabled during the course of the study; and, for comparison purposes:
- disabled people who experience no change in their disability during the study;
- non-disabled people who remain non-disabled for the duration of the study.

The natural mode of data collection for this exercise would be a specially designed questionnaire with data collected by a trained interviewer. However, some of the data might be generated from administrative records. This is discussed further in Section 5.4.

Note that in the above we have not been precise about what a ‘change’ in disability or an ‘onset’ might entail. This is an extremely complex area, raising issues around what component of disability should be focused on (that is, following the International Classification of Functioning, Disability and Health (ICF) components for example, should ‘change’ be identified as a change in bodily functions or structures, a change in activity, a change in participation, or a change in barriers to participation?). There are also issues around the degree of change that should be identified as a ‘real change’, given that change for many will be a gradual process. Plus there are issues around duration (for instance, should a change that lasts for no more than a few weeks be counted as a ‘real change’). These issues are discussed further, although they are certainly not resolved, in Section 4.2.

2.2 Different experiences of disability by sub-group

In any new study of disability (whether it be cross-sectional or longitudinal), a thorough understanding of the experiences of different groups means that the sample size of the study should ideally be large enough for sensitive sub-group analysis.

A disabled persons sample could be divided into sub-groups along a large number of dimensions, but a natural split would be by type of impairment (such as mental health impairments, learning impairments, communication impairments, mobility impairments, multiple impairments, and so on). Other obvious splits would be in terms of socio-demographic characteristics, such as gender, age, socio-economic status, ethnic group and so on.
None of this has particular implications for study design: sub-group analysis is as possible with cross-sectional data as it is with longitudinal data. However, what it is true to say is that sub-group analysis that aims to identify reasonably small differences between different groups of disabled people will only be possible if the overall study has a large sample size.

2.3 Disability prevalence rates

The most recent large scale cross-sectional survey of disability in GB was the 1996/7 Family Resources Survey (FRS) follow-up study (Grundy et al, 1999). Given that the estimates from this survey are now almost eight years old there is a good case to be made for a new prevalence survey. Such a survey would add depth to the prevalence estimates generated from other surveys, such as the Labour Force Survey (LFS), which use a very short series of questions to identify numbers that are ‘Disability Discrimination Act (DDA) disabled’.

Estimating disability prevalence rates does not require a longitudinal study. In fact, reliable prevalence estimates, are almost always better collected through a cross-sectional survey than through a longitudinal survey because response rates tend to be higher.

To marry the two requirements for both accurate prevalence estimates and transition data suggests a design that starts with a cross-sectional sample which then provides the sampling frame for a longitudinal study.

Prevalence estimates will clearly differ depending upon the definition of disability adopted. This issue seems particularly thorny, and is discussed in some detail in Section 4.1.

2.4 The relationship between disability and work and incapacity

DWP have identified an information gap around the interaction between disability and employment and how the two evolve over a person’s working life. Information is needed on transitions in, out and between jobs, and how these transitions compare with the non-disabled population.

Cross-sectional surveys that cover both employment and disability (such as, arguably, the LFS) allow for the relationship between current disability and current and (if collected) previous employment to be explored. However, since disability transitions are not easy to identify retrospectively, cross-sectional surveys could not easily address the question of how changes in disability cause, and are caused by, changes in employment. A longitudinal survey that mapped employment change alongside disability change would be a far more powerful analytic tool.
A comparison sample of the non-disabled would offer a source from which counterfactual questions about employment could be addressed.

2.5 The relationship between disability and education

The same arguments can be made for education as for employment, although given that there is likely to be a less direct or immediate causal relationship between disability and education than there is between disability and employment, the added benefit of longitudinal data is less clear-cut\(^1\). A reasonably clear understanding of the relationship between disability and education can probably be derived from cross-sectional studies.

2.6 Income, direct and indirect costs

Employment and income are very closely linked, and the arguments for having longitudinal data on disability and employment extend very naturally to income. The more problematic issue here is estimating the costs of disability. This is discussed in some detail in Section 6.5. It is perhaps sufficient to say here that we have not identified any particular requirement for longitudinal data to support cost calculations – most of the available methodologies only require cross-sectional data. Having said that, we think there may be potential to create a more sensitive ‘before-after’ version of the standard of living approach if longitudinal data was available.

2.7 Take-up of DLA and AA

DWP would ideally like to be able to estimate eligibility and take-up rates for DLA and AA. The primary difficulty here is that there are no validated methods for assessing eligibility in a survey context, so if this information need is to be met, research to generate a survey instrument will be needed. Alternatively a research project that assesses eligibility rates using non-survey methods might be adopted. Possible approaches are discussed in Appendix A.

As with direct costs of disability, we have not identified any particular requirement for longitudinal data to support eligibility and take-up estimates – a cross-sectional approach should be sufficient.

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\(^1\) The impact of discriminatory attitudes and reduced educational activities may only be noted many years later and even a longitudinal study might struggle to detect a link.
2.8 Social participation and access

Assuming that social participation is a component of any definition of disability adopted for a major new study with a focus on disability, the need to collect some data on social participation is clear-cut. However, DWP have identified a need to understand, in some detail, how accessible society and the built environment is to disabled people, and how this is changing over time.

Other surveys of disability (notably the 1996/7 FRS follow-up survey) have covered social participation and access cross-sectionally. A repeating series of cross-sectional surveys would add in the ‘change over time’ element. Adding a longitudinal element, whereby change in social participation of individuals is monitored is, arguably, tantamount to studying disability transitions longitudinally, so the case for having a longitudinal study that looks at transitions in social participation need not be made separately. One particular data gap for social participation may be a suitable non-disabled comparison group so that the social participation of disabled people can be compared with social participation for their non-disabled counterparts.

The case for looking at access issues longitudinally is less clear-cut, and repeated cross-sectional surveys may be more than adequate here. There is possibly no role here for a comparison sample (assuming that access issues are minor for the non-disabled2).

2.9 Attitudes towards disability

To understand attitudes towards disability, and how they differ between non-disabled and disabled people, suggests the need for cross-sectional, general population, samples. A longitudinal survey could, in addition, help to understand change over time, but repeated cross-sectional samples could probably do the job equally well (or perhaps better).

2.10 Independent living, support and care

For disabled people living independently (which we take to mean, living in the general household population) the key information needs are around care and support (that is, who provides the support, how is it funded?). Much of this data could be collected cross-sectionally, although longitudinal data would allow tracking of the relationship between change in disability and the cost, and socio-economic implications, of care.

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2 One obvious exception being adults with children in pushchairs.
The design issues for those living in communal establishments are rather different. Although some surveys (the 1985 Office of Population Censuses and Surveys (OPCS) disability survey, and the 2000 Health Survey for England) have included disabled people living in nursing/care homes, much of the data was collected by proxy. Whether, with different interviewer procedures and different questionnaire design, more direct interviews could take place is not clear.

Although we think there is a very strong case for including communal establishments in any new survey designed to estimate the prevalence of disability, we would question the added benefit of including communal establishment residents in a longitudinal survey.

The table below summarises the minimum design requirements raised by the different information needs:

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<tr>
<th>Minimum data requirements</th>
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<tr>
<td>Disability dynamics</td>
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<tr>
<td>Experiences of disability</td>
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<td>Disability prevalence rates</td>
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<td>Disability and work</td>
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<tr>
<td>Disability and education</td>
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<tr>
<td>Income, direct and indirect costs</td>
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<td>Take up of DLA/AA</td>
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<td>Social participation and access</td>
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<td>Attitudes towards disability</td>
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<td>Independent living, support and care</td>
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3 A possible longitudinal design

As noted in the previous section, the data needs identified by the Department for Work and Pensions (DWP) can be divided into two broad groups: needs that can be met using cross-sectional data, and needs that require longitudinal data.

To meet the cross-sectional needs clearly requires a cross-sectional survey, although not necessarily a new survey. In principle at least, extra questions (on disability and associated areas) could be added to an existing survey or surveys. But assuming that meeting all the information needs through existing surveys is impractical (which we believe is the case) then a new cross-sectional survey is desirable. One obvious additional benefit of undertaking a new cross-sectional survey is that it could create a ‘sampling frame’ for a longitudinal study.

In Section 2.1 we concluded that the ‘simplest’ study design to meet the information needs around transitions would be a classic longitudinal survey that follows a sample (or samples) of the general population over time and includes, over time, identifiable sub-groups of:

- disabled people who experience a change in the nature of their disability during the course of the study;
- non-disabled people who become disabled during the course of the study;

and, for comparison purposes:

- disabled people who experience no change in their disability during the study;
- non-disabled people who remain non-disabled for the duration of the study.
This could be achieved as follows:

(1) **Conduct a baseline prevalence survey**

Start by, at Time 1 (baseline), taking a large sample of the general population. For all members of this sample:

- collect data on all sample members that will allow for disability status to be assessed;
- for those who are categorised as ‘disabled’, collect data on the cross-sectional factors of interest (nature of disability, aids and adaptations, social participation, income, employment etc);
- for those who are categorised as ‘non-disabled’, collect data on the factors that will be useful for comparison purposes, plus any additional factors that we would want before-after data on should a person subsequently become disabled. At a minimum this will include income and employment.

(2) **Conduct longitudinal follow-up surveys**

This baseline sample would then be divided into three groups:

- Group A – those disabled at baseline;
- Group B – a sub-sample of those not disabled who, over time, will act as a comparison sample for the first group;
- Group C – the remainder of the non-disabled.

The idea is then that all three of these groups are tracked over time, but that the three groups fulfil rather different purposes.

Group A (those disabled at baseline) would provide information on the life courses of disabled people, the changes associated with any change in the nature of their disability, and the impact of disability on other life events or transitions (such as transitions into, and out of, employment).

Group B (the non-disabled comparison sample) would be tracked in parallel to the first group with, as far as possible, the same questions being asked. This would allow for questions about how the disabled population compare with the non-disabled population to be addressed. The comparison sample would probably be selected so as to have the same sex and age profile as the disabled persons sample.

Group C (the remainder of the non-disabled in the baseline survey) would serve a very particular purpose, namely that by following them up they will, over time, generate a sample of ‘disability onset cases’. In the remainder of this report this group is referred to as the ‘onset screening sample’. People in the onset screening sample would need to be contacted on a regular basis to check for onset, probably using a very short telephone questionnaire. Those that experience an onset would be filtered off into an ‘onset case’ sample and this would mark a change to a longer, more detailed, series of interviews.
So, to summarise, the baseline sample would be divided into three longitudinal samples:

- A – the baseline disabled sample;
- B – the non-disabled comparison sample;
- C – the onset screening sample.

There would be some complications as to how to deal with a comparison sample member who subsequently became disabled. This is touched on again in Section 9.

As hinted at above, the three groups would be handled rather differently in interview terms. Groups A and B would get fairly lengthy interviews throughout, probably face-to-face. Group C interviews would, in contrast, be much shorter, and, we think, might be short and simple enough to merit a telephone rather than face-to-face interview mode. However, for Group C members who experience an ‘onset’, the interviews would immediately become more complex (because we would need to understand that onset) and would become face-to-face.

In terms of size, we anticipate that, of all baseline survey respondents, about 20 per cent would fall into Group A, a further ten per cent (at least) might be allocated to Group B, and the remaining 70 per cent would become members of the onset screening sample.

In what follows we will refer to this design as the ‘basic’ design, although in this instance ‘basic’ does not equate to cheap – many of the less basic alternatives would be less expensive. Variations on this model are discussed in Section 5.

Note that the baseline survey is sometimes referred to later as ‘the prevalence survey’ or ‘baseline prevalence survey’.

A flow-chart for the design is shown overleaf. The source of the sample numbers shown per stage are discussed later in this chapter of the report.
Figure 3.1  Baseline survey design

Baseline

Baseline survey
N=50,000
Mode=f2f

Disabled at baseline
N=c.8000

Non-disabled at baseline
N=c.42,000

First follow-up

Disabled at baseline
N=c.8000
Mode=f2f

Comparison sample
N=c.4000
Mode=f2f

Onset screening sample
N=c.32000
Mode=Telephone

Second follow-up

Disabled at baseline
N=c.8000
Mode=f2f

Comparison sample
N=c.4000
Mode=f2f

Onset cases
N=c.2000
Mode=f2f

Onset screening sample
N=c.30000
Mode=Telephone

Third follow-up

Disabled at baseline
N=c.8000
Mode=f2f

Comparison sample
N=c.4000
Mode=f2f

Onset cases
N=c.4000
Mode=f2f

Onset screening sample
N=c.28000
Mode=Telephone
3.1 Repeating the exercise

In principle, since under the basic design all baseline survey respondents are followed over time, it should be possible to generate fresh cross-sectional estimates of prevalence at any point during the life of the panel (with the exception of anybody new to the population, such as new-borns and immigrants). However, losses to the samples over time because of non-response are likely to make the cross-sectional estimates rather unconvincing. So there is a good statistical case for repeating the exercise after a number of years with a fresh baseline sample. However, this could be left as an option to be considered at a later date rather than as a commitment made from the start. Certainly the feasibility of a longitudinal study does not seem contingent on decisions being made at the start about fresh samples.

3.2 Sample size considerations

If the basic design were to be adopted then it would require a very large sample size, although the exact size depends upon how much sub-group analysis is needed.

The key figures that determine sample size are:

- likely prevalence rates for disability (overall, by ‘severity’ if this is a concept that is adopted, and by type of disability), by both age and sex;
- onset rates by age and sex.

(We assume in this that age and sex are the key sub-groups for which any survey will need to be able to generate estimates, age because of the strong correlation between age and disability, and sex because there is likely to be a need to examine whether the experience of disability differs for men and women. Certainly other surveys of disability use age and sex as the main sub-groups for prevalence estimates.)

The source of figures we have used for prevalence estimates are those from the 1996/97 FRS follow-up survey (Grundy et al, 1999) for adults and the 1985 OPCS survey for children (Bone and Meltzer, 1989). This is based on the rationale that these surveys allow for prevalence estimates by severity of disability (other surveys, such as the LFS only giving a binary DDA disabled/non-disabled split). In using these figures it has to be assumed that any new disability definition and severity scoring system developed for a new survey would match reasonably well with the 1996/7 estimates (although the observed, and largely unexplained, increase in prevalence between 1985 and 1996/7 slightly undermines this assumption.) Had the 1996/7 survey covered children it is plausible the estimates of prevalence for children would have been higher than in the 1985 survey. However, in the absence of any good sources for updating the figures for children we have used the 1985 figures instead. Based on this, Table 1 gives the expected prevalence of disability by age and sex.
Table 3.1 Prevalence of disability by age and sex

<table>
<thead>
<tr>
<th>Private households</th>
<th>Population (per 1,000 persons)</th>
<th>Prevalence of disability</th>
<th>Mild 1-2</th>
<th>Moderate 3-6</th>
<th>Severe 7-10</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Men</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-15</td>
<td>104</td>
<td>3.6</td>
<td>0.5</td>
<td>1.7</td>
<td>1.4</td>
</tr>
<tr>
<td>16-19</td>
<td>27</td>
<td>4.5</td>
<td>2.1</td>
<td>1.4</td>
<td>1.0</td>
</tr>
<tr>
<td>20-29</td>
<td>80</td>
<td>4.8</td>
<td>1.8</td>
<td>1.6</td>
<td>1.4</td>
</tr>
<tr>
<td>30-39</td>
<td>69</td>
<td>8.6</td>
<td>3.0</td>
<td>3.8</td>
<td>1.8</td>
</tr>
<tr>
<td>40-49</td>
<td>67</td>
<td>12.6</td>
<td>4.7</td>
<td>5.2</td>
<td>2.7</td>
</tr>
<tr>
<td>50-59</td>
<td>52</td>
<td>24.0</td>
<td>8.7</td>
<td>10.1</td>
<td>5.2</td>
</tr>
<tr>
<td>60-69</td>
<td>47</td>
<td>32.1</td>
<td>13.2</td>
<td>13.9</td>
<td>5.0</td>
</tr>
<tr>
<td>70-79</td>
<td>30</td>
<td>46.6</td>
<td>20.4</td>
<td>18.0</td>
<td>8.2</td>
</tr>
<tr>
<td>80+</td>
<td>11</td>
<td>73.7</td>
<td>27.4</td>
<td>34.3</td>
<td>12.0</td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-15</td>
<td>99</td>
<td>2.4</td>
<td>0.4</td>
<td>1.1</td>
<td>0.9</td>
</tr>
<tr>
<td>16-19</td>
<td>26</td>
<td>6.9</td>
<td>2.1</td>
<td>3.5</td>
<td>1.3</td>
</tr>
<tr>
<td>20-29</td>
<td>79</td>
<td>5.7</td>
<td>1.8</td>
<td>2.9</td>
<td>1.0</td>
</tr>
<tr>
<td>30-39</td>
<td>70</td>
<td>8.5</td>
<td>2.6</td>
<td>4.1</td>
<td>1.8</td>
</tr>
<tr>
<td>40-49</td>
<td>67</td>
<td>13.1</td>
<td>3.8</td>
<td>5.5</td>
<td>3.8</td>
</tr>
<tr>
<td>50-59</td>
<td>52</td>
<td>23.5</td>
<td>6.7</td>
<td>11.1</td>
<td>5.7</td>
</tr>
<tr>
<td>60-69</td>
<td>52</td>
<td>23.7</td>
<td>6.5</td>
<td>11.7</td>
<td>5.5</td>
</tr>
<tr>
<td>70-79</td>
<td>42</td>
<td>47.3</td>
<td>15.8</td>
<td>22.3</td>
<td>9.2</td>
</tr>
<tr>
<td>80+</td>
<td>26</td>
<td>76.7</td>
<td>19.6</td>
<td>36.4</td>
<td>20.7</td>
</tr>
</tbody>
</table>

What the figures of Table 3.1 suggest is that if a sample of, say, 50,000 members of the private household population are included in a new baseline survey then this will generate approximately the following numbers.
Table 3.2 Disability by severity

<table>
<thead>
<tr>
<th></th>
<th>All persons</th>
<th>Any disability</th>
<th>Mild disability</th>
<th>Moderate disability</th>
<th>Severe disability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Men</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-15</td>
<td>5,202</td>
<td>187</td>
<td>24</td>
<td>90</td>
<td>73</td>
</tr>
<tr>
<td>16-19</td>
<td>1,356</td>
<td>61</td>
<td>28</td>
<td>19</td>
<td>14</td>
</tr>
<tr>
<td>20-29</td>
<td>3,985</td>
<td>191</td>
<td>72</td>
<td>64</td>
<td>56</td>
</tr>
<tr>
<td>30-39</td>
<td>3,464</td>
<td>298</td>
<td>104</td>
<td>132</td>
<td>62</td>
</tr>
<tr>
<td>40-49</td>
<td>3,327</td>
<td>419</td>
<td>156</td>
<td>173</td>
<td>90</td>
</tr>
<tr>
<td>50-59</td>
<td>2,590</td>
<td>622</td>
<td>225</td>
<td>262</td>
<td>135</td>
</tr>
<tr>
<td>60-69</td>
<td>2,333</td>
<td>749</td>
<td>308</td>
<td>324</td>
<td>117</td>
</tr>
<tr>
<td>70-79</td>
<td>1,489</td>
<td>694</td>
<td>304</td>
<td>268</td>
<td>122</td>
</tr>
<tr>
<td>80+</td>
<td>549</td>
<td>405</td>
<td>151</td>
<td>188</td>
<td>66</td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-15</td>
<td>4,970</td>
<td>119</td>
<td>19</td>
<td>56</td>
<td>44</td>
</tr>
<tr>
<td>16-19</td>
<td>1,292</td>
<td>89</td>
<td>27</td>
<td>45</td>
<td>17</td>
</tr>
<tr>
<td>20-29</td>
<td>3,970</td>
<td>226</td>
<td>71</td>
<td>115</td>
<td>40</td>
</tr>
<tr>
<td>30-39</td>
<td>3,487</td>
<td>296</td>
<td>91</td>
<td>143</td>
<td>63</td>
</tr>
<tr>
<td>40-49</td>
<td>3,334</td>
<td>437</td>
<td>127</td>
<td>183</td>
<td>127</td>
</tr>
<tr>
<td>50-59</td>
<td>2,621</td>
<td>616</td>
<td>176</td>
<td>291</td>
<td>149</td>
</tr>
<tr>
<td>60-69</td>
<td>2,608</td>
<td>618</td>
<td>170</td>
<td>305</td>
<td>143</td>
</tr>
<tr>
<td>70-79</td>
<td>2,120</td>
<td>1,003</td>
<td>335</td>
<td>473</td>
<td>195</td>
</tr>
<tr>
<td>80+</td>
<td>1,301</td>
<td>998</td>
<td>255</td>
<td>474</td>
<td>269</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>50,000</td>
<td>7,841</td>
<td>2,618</td>
<td>3,515</td>
<td>1,708</td>
</tr>
</tbody>
</table>

Certainly for those in younger age groups these sample numbers give very little scope for analysis of the factors associated with disability, especially if there is any desire for analysis of those with moderate to severe disabilities. This suggests that a sample size of about 50,000 is probably the minimum tolerable sample size for a baseline prevalence survey. Note that the figure of 50,000 is in line with the size of the Family Resources Survey (FRS) follow-up survey which included close to 40,000 adults, but is much smaller than the 1985 Office of Population Censuses and Survets (OPCS) survey sample size, which was about four times larger. The sample of 50,000 gives a rather too small sample for children – ways to handle this are discussed later in the report.

In terms of the type of disability, based on the 1996/7 report, the disabilities for adults would distribute largely as follows in a sample of 50,000 (although the categories might be different in a new survey). The classification is the one used in the 1985 OPCS survey (and repeated in the 1996/7 survey), respondents being asked in those surveys whether their activities were limited by impairments in any of these areas.
Table 3.3 Disability by impairment type

<table>
<thead>
<tr>
<th>Impairment Type</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Locomotion</td>
<td>72</td>
<td>5,424</td>
</tr>
<tr>
<td>Dexterity</td>
<td>35</td>
<td>2,637</td>
</tr>
<tr>
<td>Personal care</td>
<td>35</td>
<td>2,637</td>
</tr>
<tr>
<td>Hearing</td>
<td>34</td>
<td>2,562</td>
</tr>
<tr>
<td>Behaviour</td>
<td>32</td>
<td>2,411</td>
</tr>
<tr>
<td>Intellectual</td>
<td>29</td>
<td>2,185</td>
</tr>
<tr>
<td>Seeing</td>
<td>23</td>
<td>1,733</td>
</tr>
<tr>
<td>Reaching and stretching</td>
<td>20</td>
<td>1,507</td>
</tr>
<tr>
<td>Continence</td>
<td>16</td>
<td>1,205</td>
</tr>
<tr>
<td>Digestion</td>
<td>12</td>
<td>904</td>
</tr>
<tr>
<td>Communication</td>
<td>6</td>
<td>452</td>
</tr>
<tr>
<td>Disfigurement</td>
<td>6</td>
<td>452</td>
</tr>
<tr>
<td>Consciousness</td>
<td>3</td>
<td>226</td>
</tr>
</tbody>
</table>

For most categories this gives reasonable numbers for sub-group analysis.

The above figures should not be interpreted as a *recommendation* that the sample size be 50,000. The 50,000 should instead be interpreted as a minimum.

### 3.2.1 The sample size of transition cases

Assuming for now that the sample size of 50,000 is appropriate, this means, based on these figures that the sample size for the first of the three longitudinal samples (i.e. those disabled at baseline) would be about 8,000. This would leave a pool of 42,000 from which the comparison sample could be drawn. And, assuming the comparison sample was about 4,000 people, this would mean that about 38,000 people would be allocated to the onset screening sample. The question is, would the comparison sample, plus the onset screening sample, generate sufficient numbers of onset cases to allow for separate analysis either each year, or by cumulating the sample of onsets over a small number of years.

The two sources of data on onset that researchers (Burchardt (2003), Jenkins and Rigg (2003)) have used are the British Household Panel Survey (BHPS) and the Labour Force Survey (LFS). The BHPS is somewhat problematic because it has only a small number of disability questions, most of which focus on health rather than disability. Based on responses to the question ‘Does your health in any way limit your daily activities compared to most people of your age?’ Burchardt found that 4.7 per cent of the ‘at risk’ working-age population (i.e. those not already disabled) become disabled each year. Restricting ‘disabled’ only to those who report limited activities for two consecutive years, which is one way of removing short-term disability, reduces this percentage to two per cent.
Jenkins and Rigg used a second BHPS question ‘Does your health limit the amount or type of work you can do?’ to explore a similar question. They defined an onset of disability as ‘two interviews without disability followed by two interviews with disability’ and found that of those ‘at risk’ 1.3 per cent become disabled each year. Again this definition excluded short-term disabilities. They also found that the rate differed somewhat by age (one per cent for those aged 16-34; 1.4 per cent for those aged 35-49; and 2.5 per cent for those aged 50+).

The LFS ought, in principle, to be a very good source of data on disability onset rates, partly because it includes questions about Disability Discrimination Act (DDA) disability, but also because the sample size is so large. However its design does restrict the definition of onset that can be used: individuals are interviewed over the period of just one year, so it is difficult to distinguish between long and short term disability spells, although the wording of the question may eliminate some short-term disabilities.

As part of this study we requested tables from ONS on the DDA disability rates for Spring 2003 cross-tabulated with the rates for Spring 2004 (based on those recruited to the LFS in Spring 2003). These figures give considerably higher ‘onset rates’ than either of the studies discussed above, at 7.4 per cent for those of working age. There is some gradient by age in these figures, ranging from about four per cent to those aged 16-34, to about 13 per cent for those aged 50+.

The explanation for the large difference in the estimates must, at least in part, be due to the fact that the LFS onset estimates will include many more shorter-term disabilities than the estimates of Burchardt and Jenkins/Rigg. However, the LFS is still 50 per cent higher than the estimate of 4.7 per cent that Burchardt found for ‘all onsets’.

Our belief is that the LFS data tends to exaggerate onset rates. Burchardt (2003a) has observed that the LFS disability rates increase implausibly with each wave of the panel, and the data we obtained certainly shows some very unlikely increases (for instance between Spring 2003 and Spring 2004 the DDA disability rate for those aged 30-34 rose from ten per cent to 11.8 per cent, yet the DDA rate for those aged 35-39 was just 11.0 per cent in 2003). The most likely explanation appears to be a mode effect, since after the first wave the LFS moves from face-to-face interviewing to, predominantly, telephone. Based on a second request for data, the onset rate over the period Summer 2003 to Spring 2004 (which holds the mode of interview constant, but reduces the period to nine months) reduces the onset rate to a more plausible 5.4 per cent for men of working age, and five per cent for women.

Faced with all these different estimates of onset rates it is unclear which to use in sample size estimates. For reasons discussed later in this report, we believe that it would be preferable to use a broad definition of ‘onset’ for a longitudinal study so that at least some medium-term disabilities are not excluded. This means that sample sizes used for the study should either be based on the nine-month LFS rates, or we can assume the 4.7 per cent from Burchardt is the best estimate. Given that we
have the LFS data by age and sex we have chosen to use the former. We have no data on onset rates for those not of working age so for children and older people we have had to guess the rate\(^3\).

### Table 3.4  Estimated onset cases per year

<table>
<thead>
<tr>
<th>Private households</th>
<th>All persons</th>
<th>Non-disabled</th>
<th>Onset rate (over 1 year) %</th>
<th>Number of onset cases</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Men</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-15</td>
<td>5,202</td>
<td>5,015</td>
<td>1.5</td>
<td>75</td>
</tr>
<tr>
<td>16-19</td>
<td>1,356</td>
<td>1,295</td>
<td>1.8</td>
<td>23</td>
</tr>
<tr>
<td>20-29</td>
<td>3,985</td>
<td>3,794</td>
<td>3.0</td>
<td>114</td>
</tr>
<tr>
<td>30-39</td>
<td>3,464</td>
<td>3,166</td>
<td>4.9</td>
<td>155</td>
</tr>
<tr>
<td>40-49</td>
<td>3,327</td>
<td>2,908</td>
<td>6.7</td>
<td>195</td>
</tr>
<tr>
<td>50-59</td>
<td>2,590</td>
<td>1,968</td>
<td>8.5</td>
<td>167</td>
</tr>
<tr>
<td>60-69</td>
<td>2,333</td>
<td>1,584</td>
<td>10.5</td>
<td>166</td>
</tr>
<tr>
<td>70-79</td>
<td>1,489</td>
<td>795</td>
<td>15.0</td>
<td>119</td>
</tr>
<tr>
<td>80+</td>
<td>549</td>
<td>144</td>
<td>20.0</td>
<td>29</td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-15</td>
<td>4,970</td>
<td>4,851</td>
<td>1.5</td>
<td>73</td>
</tr>
<tr>
<td>16-19</td>
<td>1,292</td>
<td>1,203</td>
<td>1.8</td>
<td>22</td>
</tr>
<tr>
<td>20-29</td>
<td>3,970</td>
<td>3,743</td>
<td>3.0</td>
<td>112</td>
</tr>
<tr>
<td>30-39</td>
<td>3,487</td>
<td>3,191</td>
<td>4.9</td>
<td>156</td>
</tr>
<tr>
<td>40-49</td>
<td>3,334</td>
<td>2,897</td>
<td>6.7</td>
<td>194</td>
</tr>
<tr>
<td>50-59</td>
<td>2,621</td>
<td>2,005</td>
<td>8.5</td>
<td>170</td>
</tr>
<tr>
<td>60-69</td>
<td>2,608</td>
<td>1,990</td>
<td>10.5</td>
<td>209</td>
</tr>
<tr>
<td>70-79</td>
<td>2,120</td>
<td>1,117</td>
<td>15.0</td>
<td>168</td>
</tr>
<tr>
<td>80+</td>
<td>1,301</td>
<td>303</td>
<td>20.0</td>
<td>61</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>50,000</td>
<td>41,971</td>
<td></td>
<td>2,209</td>
</tr>
</tbody>
</table>

If these onset rates are reasonably accurate, then after one year the 42,000 cases in the onset screening sample and comparison sample will generate a sample of about 2,200 onset cases a year (even less with non-response), with, after the age of 20 there being between 100 and 200 onsets per ten year age group (within sex). This is on the low side for separate analysis, especially by age-group, so the sample may need to accumulate for two years before a full analysis is possible.

The key question this raises however, is whether the costs of running onset screening sample interviews for two years (which involves about 76,000 interviews, albeit relatively short interviews) is merited as a means of identifying about 4,400 onset cases (a strike rate of six per cent).

\(^3\) The ONS tables provided to us only cover those of working age
This ‘high cost for relatively low return’ problem is, in our minds, the main reason why a longitudinal study may ultimately be judged infeasible. That is, it can be done, but it may simply be too expensive.

Note however, that the onset rates are based on onset rates primarily for physical disabilities or longer-term mental disabilities. If common mental disorders are included then this could increase the numbers quite considerably. Whether this changes the conclusions about sample size however is debatable, assuming that analysts would want some breakdown by type of disability.

For children we have only been able to guess at the onset rates, so the sample size per year of 150 onset cases in total may be very inaccurate. However, unless our guess is far too low, a sample of this size will only allow for very ‘top-line’ conclusions each year, and only the broadest patterns by age and sex will be identifiable. Furthermore, as is discussed in Section 7.1, many of the ‘onsets’ may simply be late identifications. We discuss in Section 4.3 whether a better way of looking at ‘transitions’ in children, is to focus on the effect of disability on life-stage transitions rather than to focus on disability transitions per se.

In Section 5 we consider whether there are ways of reducing the cost of the survey by using other surveys to generate the samples.

### 3.2.2 The impact of non-response on sample size

The figures of this section do not take into account the fact that surveys never achieve 100 per cent response rates. In practice, a starting sample of 50,000 would need to be generated from a rather larger (say, 40 per cent larger) issued sample to allow for a baseline response rate of, say, 70 per cent. After baseline the sample will still reduce wave-on-wave, so that, say, a baseline sample of 8,000 disabled people might reduce to around 6,000 by wave 3.
4 The key design issues

4.1 Identifying disabled people

In designing a survey of disability one of the most controversial issues will inevitably be the questions used to identify disabled persons. The issues are slightly more complicated with a longitudinal rather than a cross-sectional survey, but the main issues are common to both.

It is likely that most commentators would agree on the following points at least:

- That the questions used should be as inclusive as possible, so that less severe disabilities are picked up as well as severe ones, and all types of disability should be covered. In other words, the number of false negatives should be minimised. But the survey questions should allow for analysts to make distinctions so that some individuals can be left out of some analyses where appropriate.

- That some means of graded scoring is needed (that is, some coding that specifies the extent or magnitude of the functioning or impairment in a particular category of disability). We choose, in what follows, to refer to this as ‘severity scoring’ but other types of grading might be considered more appropriate in some circumstances.

These two points suggest that a series of questions comparable (in intent at least) to those developed for the 1985 Office of Population Censuses and Surveys (OPCS) survey are needed. Certainly, the short questions used in many surveys, such as the Labour Force Survey (LFS) Disability Discrimination Act (DDA) questions, and the census long-standing illness question would not meet the criteria, in the sense that they would not on their own allow a ‘severity’ score to be developed.

However, although the approach taken for the 1985 OPCS survey is clearly the appropriate one, the questions developed for that survey were based on what is now considered an out-dated understanding of disability, and to simply replicate those questions (and use the same scoring system) would be, at best, very controversial. The issue is particularly acute given that we are considering a longitudinal survey, so any definition used at the start of the survey needs to have a fairly long shelf-life.
The ideal would appear to be to adopt the International Classification of Functioning, Disability and Health (ICF) definition of disability and design survey questions, and a severity scoring system, that reflects this model. The ICF model replaced the original World Health Organisation (WHO) International Classification of Impairments, Disabilities and Handicaps (ICIDH) model of disability. The ICIDH model implied causation between impairments, disabilities and handicaps and, it is argued, led to the misconception that impairment was simply a consequence of disease conditions. Plus it ignored the fact that handicap could lead to disability rather than the causal pathway always being the other way around. The ICF model is an attempt to avoid these difficulties by removing the one-way causation and viewing disability as an interaction between health, personal factors, and social and environmental factors. The ICF model has two components: body functions and structures, and activity and participation.

It is worth noting that the Canadian Participation and Activity Limitation Survey (PALS 2001) uses a set of screening questions that, the survey researchers claim, follow the ICF model. The PALS questions begin with four filter questions:

1. Do you have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?
2. Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do at home?
3. Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do at work or school?
4. Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do in other activities, for example transportation or leisure?

The questionnaire then goes through a series of questions on hearing, sight, speech, mobility, agility, pain, learning difficulties, confusion/memory limitations, and emotional/psychological limitations. The questions cover aids used as well as degree of difficulty experienced. These questions are followed by questions on perceived disadvantages created by the limitations, and then by questions on the causes of the limitations.

As a separate exercise the PALS researchers have developed a severity scoring system based on their questionnaire.

Another possibility would be to use the WHO Disability Assessment Schedule (WHODASII) questions which gives a profile of functioning across six activity domains as well as a general disability score. The domains are: Understanding and Communicating, Getting Around, Self Care, Getting Along with People, Life Activities, and Participation in Society. However this questionnaire does not cover impairments or the use of aids and adaptations, so it should probably be viewed as a screening questionnaire rather than a complete set of questions.
One way forward would be to use one or both of these questionnaires as a starting point and then examine whether the questions appear to identify disability adequately in a Great Britain (GB) context. The ideal process from there would be a research project that at least covers the following:

- develop a set of questions (which might come directly from one or both of the questionnaires considered, and might include all or some of the original OPCS85 questions) and then consult with disability experts, potential users and, probably, groups of disabled people on their face validity;
- test these questions for sensitivity and specificity;
- if possible, test the questions against the old OPCS questions and other ‘short’ disability questions so that change over time since the 1985 and 1996/7 surveys is understood.

Having developed the questions there may then need to be a separate research programme devoted to developing a severity scale (however severity is defined). Again, although the Canadians have developed a severity scoring system for PALS, it is not clear to us how this system was developed, and it would be inappropriate to adopt it without at least considering other approaches. The OPCS survey developed a severity scale using an expert panel approach, and a similar methodology may prove more appropriate.

An added complication for a longitudinal survey is that the questions designed will have to be capable (either automatically or with suitable modification) to identify transitions from non-disabled to disabled and vice versa, plus, ideally, to identify changes within disability. This might just be a question of repeating the same module of questions and then checking whether a person has moved from one state to another (which essentially is how onsets have been identified in the British Household Panel Survey (BHPS) secondary analysis). But to avoid this generating a large number of false transitions (because of measurement error) it is preferable to ask specifically about change since the last survey. This should, ideally, also allow for the identification of disablement periods that occur between interviews, so that short to medium-term disability is measured.

There are further issues around the relationship between developing a module of questions suitable for identifying disabled persons in a disability survey, which will, we assume, involve several ‘pages’ of questions, and developing a short series of questions that could be used to identify disabled people in other surveys. Almost inevitably any short series of questions will not identify exactly the same population members as the longer instrument, but it would be highly desirable to have a set of questions that minimised the false positive and false negative rates. If such a set of questions could be developed then, by including these questions on other GB surveys, at least some of the information needs of the Department for Work and Pensions (DWP) could be met through secondary analysis, even if it is highly unlikely that any short set of questions would allow for accurate severity scoring.
We have not identified much literature on the relationship between short disability questions and longer sets of questions. The 1996/7 survey of disability, which screened people in from the Family Resources Survey (FRS) based on a series of ‘short’ questions, was able to demonstrate that the false positive rate can be kept reasonably low as long as the short questions are broad enough. (This check was possible because those screened-in were subsequently asked to complete the 1985 longer screening questionnaire.) However, the false negative rate was not checked. Other evidence comes from the Canadian PALS survey which is essentially a census follow-up survey, those screened in being those who answered positively on a short series of questions about activity limitation. In developing these questions the Canadians found that the short questions were good at identifying the moderately to severely disabled, but relatively poor on the least severe categories.

4.1.1 Observed measures of physical functioning

The approaches to identifying disabilities and functional limitations described above all depend on self-report. Some surveys, most notably, the Health Survey for England (HSE) and the English Longitudinal Study of Ageing (ELSA) have recently introduced a range of physical tests that are interviewer-administered during the course of a standard survey interview. These add to, rather than replace, self-report. They by no means cover all aspects of physical functioning, and if a survey with a disability focus were to include these types of tests, extra tests may need to be developed to give a more comprehensive range covering more impairments, and including impairments that vary over the course of a day. The tests included in the HSE (those aged 65 and over only) or ELSA (those aged 55 plus) are:

- **Timed walk** – The time taken to walk eight feet.
- **Grip strength** – Gives a measure of upper body strength and, combined with the walking speed, balance tests, and chair rises, is an indicator of frailty. Measured with a gripometer.
- **Balance measures**: side by side; semi-tandem; and full tandem – These are three balance and co-ordination measures that become progressively more difficult. Each position is held for ten seconds.
- **Leg raises** – These involve lifting one leg at a time and holding the position for 30 seconds. Those who manage this are asked to repeat the exercise with their eyes closed.
- **Chair rises** – These are a measure of lower body strength. There are two parts: a single rise without the use of the arms and repeated rises with the use of arms. For the repeated rises a target of 10 is set for those aged 65 to 70 and a target of five for those aged 70 and over. The time taken is recorded.
4.2 Defining a ‘transition’

As we noted in Section 2.1, a longitudinal study that is designed to examine transitions in disability will clearly need a working definition of a transition. We are not aware of any literature that suggests an appropriate definition, so it seems almost certain than a separate research project will be needed to look at this.

The main issues are:

- There are two types of transition that need definitions: onset of disability, and a change within disability. Under the ‘basic’ longitudinal design of Section 3, the definition of a change within disability can, to a degree, be left to the survey analysts as long as the survey covers the right questions. For onsets, which will be identified through the onset screening sample, the issue has to be resolved upfront because an onset will result in a change from a short telephone interview to a longer face-to-face interview.

- The definitional difficulties appear to be around issues such as: what aspect of disability should determine change (bodily function change, activity change, or participation change, assuming the International Classification of Functioning, Disability and Health (ICF) model is adopted)?; what degree of change should count as a transition?; and for how long should the change be experienced before counting as a transition?

It is worth noting in this context that recent surveys (such as PALS 2001) capture information on functioning on an ordinal rather than binary scale (i.e. ‘yes, sometimes’, ‘yes, often or always’, or ‘no’). If this approach is replicated in a GB survey this complicates the definitional issues around transitions yet further because of the need to decide on how much of a move along the ordinal scale counts as a change. This isn’t a reason for avoiding ordinal scales: it simply means that the survey definitions need to reflect the complexity of real life.

In terms of duration, secondary analysts of data on transitions on the BHPS (Burchardt and Jenkins and Rigg) have tended to define a transition from non-disabled to disabled as having occurred if the respondent is ‘disabled’ for two follow-up interviews. This is partially a means of excluding those with only short-term disabilities, but also a means of reducing false positives because of measurement error. This seems like a reasonably pragmatic approach, but it is not one that needs to be replicated in a longitudinal survey with a focus on disability.

Our starting position on this is that, in designing the longitudinal survey, any transition from non-disabled to disabled, irrespective of duration, should trigger a move to the ‘disabled’ sub-group as long as the disability could, under normal circumstances, have a long-term impact. Under this model many common mental disorders (for instance) would probably be ‘in’, but broken limbs would be out.

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4 Including interviewer mis-recording errors.
Assuming that data is collected on the duration of the disabled state, it would then be a decision for the secondary analysts as to whether or not to narrow the definition of ‘onset’. Note however that this would increase the sample size of onset cases estimated in Section 3.2.1 and would have obvious cost implications.

To resolve all of these issues, what is needed is a programme of work, which will include consultation with disability experts and disabled people themselves, on what should count as a transition and what should not. This research should also cover, if possible, a profile of the types of trajectories that are likely to be observed in practice.

4.3 Population coverage

At a reasonably early stage in the development of any new longitudinal study issues around population coverage of the study need to be decided on, in particular:

- What population coverage should be aimed for for cross-sectional estimates?
- Should any sub-groups of the population be excluded from the longitudinal element of the study?

The ‘population’ can clearly be sub-divided in very many ways, but three obvious divisions to consider here are:

- divisions by disability type;
- divisions by age;
- a division based on living arrangements (essentially the private household population versus those living in communal establishments).

These three divisions are discussed in turn below.

4.3.1 Divisions by type of disability

We believe that the most appropriate starting position for a survey about disability should be that all types of disability and impairment are covered and all are treated with equal status. Thus, any cross-sectional element should include all groups, and all groups should be followed up longitudinally.

In practice however, it is clear that this is an aspiration rather than a statement of what will happen. The biggest threat is non-response – it is inevitable that some disabled people will be hard to recruit to a survey, those with cognitive functioning difficulties (for example, those with senile dementia) and those with some types of psychoses, being likely examples.

Nevertheless, the survey will have to be designed with considerable sensitivity to these issues, and with the approach taken that all efforts are made to make the survey as inclusive as possible, even if this means being flexible about how and under what circumstances interviews are carried out.

This is discussed further in Section 8.
4.3.2 Divisions by age

In terms of age the groups that may need special consideration are children and older people. For both of these groups we can see no good theoretical reasons for exclusions in any baseline prevalence survey, although for children at least there are practical issues, given that their inclusion will inevitably mean developing a very different disability questionnaire (see Section 7.1).

Assuming for now that both children and older people are included in the baseline prevalence survey, separate decisions will be needed as to whether these two groups are followed up longitudinally.

Taking children first. Disability prevalence rates for children are low, at about three per cent (depending on the definition used) and onset rates must inevitably also be low, although we have not found any figures on this. (In Section 3.2 we took the rate to be 1.5 per cent per year.)

This implies that using the onset screening sample to identify a reasonably large sample of children who become disabled during the lifetime of the study is unrealistic – under our estimates following up 10,000 children will yield just 150 child disability onsets per year. So one option would be to exclude children from the onset screening sample, and to restrict the longitudinal study for children to a sample of disabled children (as identified at baseline) and a comparison sample of non-disabled children.

To take this approach would mean that the longitudinal analysis for children would take a different focus, with perhaps a focus on how disability affects life-transitions (e.g reaching school age) of disabled children compared to their non-disabled counterparts.

For older people the issues are almost the mirror-image of those for children. For those above working age disability rates are likely to be fairly high under any definition of disability and for those non-disabled at baseline onset rates are also likely to be high. So, in terms of sample size, there is no real problem in identifying both an adequate ‘baseline disabled’ and an adequate ‘onset’ sample. However, arguably, of these two groups the latter group are of more interest than the former in terms of providing an understanding of how disability affects other aspects of life. Certainly, for those aged 80 and over at least, under many definitions of disability almost all would be ‘disabled’, in which case trying to identify how disability impacts on other areas of life is almost impossible to answer. So there may be a case for considering that the very oldest groups are only included in the longitudinal element of the study if they are non-disabled at baseline screening. The counter-argument would be that by following the disabled older population we would gain an understanding of the impact of changes in disability or impairment.

Other options for both children and older people are considered in Section 5, including the option of excluding those over working age from the longitudinal follow-ups entirely, on the grounds that ELSA is already covering the area.
4.3.3 The general population versus the household population

Most national surveys are only of the population living in private households and exclude those living in communal establishments. This means, in particular, that older people living in care homes/nursing homes are excluded. In addition, but probably less crucially, students living in halls of residence are under-represented (only being picked up during vacation periods) as are some members of the armed forces. At any one time, the prison population is also excluded.

The 1985 OPCS study aimed for reasonably complete population coverage by including communal establishments where it might be expected that disability rates are higher than average, namely hospitals, homes and hostels. The sampling and interviewing of the permanent residents took place after the private household survey and used a shorter simpler questionnaire, primarily because much of the information was collected by proxy. In contrast the 1996/7 survey only covered the private household population.

We can see a strong case for including those living in communal establishments in the baseline prevalence survey of a new longitudinal study, although inevitably this will significantly add to survey costs. (The sample does not need to be large if the private household and establishments surveys are to be combined, but the costs of managing and conducting the establishment survey would be large.) The main argument in favour is, of course, that it is the only means of generating total population prevalence estimates for disability.

The issue that is less clear is the relative merits of including those sampled via establishments in any longitudinal component of the survey especially given that many of the interviews may have to be done by proxy. In our view most (perhaps all) the research questions around disability transitions could be phrased in terms of the private household population without too much loss of generality. So, unless a strong case for including the establishment population in the longitudinal element of the sample is identified during the consultation stage, we suggest that it is excluded.

This is not to say that establishments will always be excluded from the longitudinal study. For panel members who move permanently from a private household to an establishment during the life of the study, we would argue for one or two post-move interviews to establish the reasons for the move and to collect data on associated issues (such as the financial implications of the move). After this interview or interviews the affected individuals might then be dropped from the panel.

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5 Temporary residents were excluded on the grounds that they were covered by the private household sample.
4.4 Frequency of follow-up/panel duration/fresh samples

After sample size and mode of interview, the main cost drivers for panel studies are frequency of follow-up and number of follow-ups. There is also the issue of when the whole exercise should be repeated, but as we noted in Section 3.1, this is probably not a decision that has to be taken at the launch of a new panel.

4.4.1 Frequency of follow-up

The frequency of follow-up for the baseline disabled survey ought, in principle, to be based on answers to three questions:

- over what time-span would we expect to observe change?
- over what time period can retrospective data be provided?
- what is the optimal follow-up period for (a) maximising response rates and, a related issue (b) minimising the rate at which people move and cannot be traced?

Our feeling is that, for a study of this nature, the optimal follow-up period for the ‘disabled at baseline’ sample is either one or two years (anything shorter than a year would be too frequent; anything longer than two years would make any between-wave retrospective questioning too burdensome). Our suggestion is to start with a one year follow-up but re-assess the decision after, say, two follow-up waves.

Following the same arguments, the follow-up intervals for the non-disabled comparison sample should be identical to those for the disabled persons sample.

For the onset screening sample we tentatively suggest a one year follow-up, assuming, after consultation, that there is found to be a need to pick up disabilities, especially mental health disabilities, that are episodic. A longer interval between interviews would risk these short-term disabilities being missed, simply because people ‘put it behind them’. A shorter interval would increase the risk of survey overload. However, a decision on the appropriate intervals for all the groups will depend upon the conclusions reached on how to define onsets and transitions. Under some definitions a short follow-up might be appropriate; under others a longer follow-up might suffice.

4.4.2 Number of follow-ups

It may be possible to recruit people to the study for life (although we suspect that the intervals between interviews would have to increase if that was to happen). However, assuming that non-response starts to become a major problem after a few waves of interview, the better starting assumption may be to ask that people stay with the study for, say, ten years at most.
4.5 Improving the strike rate for the transition sample

A considerable proportion of the total cost of a longitudinal survey will be the costs associated with following up the onset screening sample to identify the onset cases. As we noted earlier, based on the sample sizes presented in Section 3, around 38,000 people would need to be interviewed each year to identify just 2,200 onset cases. To minimise costs it is worth considering whether it is possible to develop a likelihood score for onset and then to exclude a proportion of those with low likelihood. In this way it might prove possible to, say, identify 80 per cent of the new onset cases by interviewing maybe 60 per cent of the 38,000. (The figures are illustrative only – we have no hard evidence that this is possible.)

Although we raise this as a possibility, our instinct is that it is actually a bad idea. The problem with the approach is that, by definition, it will exclude a high proportion of the onset group who had, on the face of it, a low probability of becoming disabled. So, we are likely to disproportionately exclude the young and those in socio-economic groups where onset rates are lowest. Although the data can be weighted so that there will be no selection bias in the survey estimates, the potential for subgroup analysis of the low risk groups will be significantly reduced. To focus this on just one research question: a reasonable hypothesis would be that the impact of becoming disabled is more acute for those who had no reason to expect they would become disabled (i.e. their likelihood score was low). If we under-sample the low likelihood onsets, we will probably not be able to test this hypothesis.

4.6 A household or an individual panel?

Most of the GB research on disability transitions to date have concentrated on the BHPS so a natural question is whether, in designing a new panel study, that should be a panel of households (to the degree that this is possible\(^6\)) or a panel of individuals.

The issues to be considered here are:

- disabled people are individuals, but their disability has implications for the people around them, in particular their immediate household;

- the sampling frame for most of the baseline survey will probably be Postcode Address File (PAF), so it will be individuals within households that are selected. It would not be cost-effective to establish disability status for just one randomly selected person per household, so we envisage that all household members will be included in the baseline survey. In other words, for the ‘basic’ design all household members would be recruited to one of the three longitudinal samples: the baseline disabled sample, the comparison sample, or the onset screening sample.

\(^6\) The BHPS researchers argue that there is no such thing as a longitudinal household.
So, based on the second point above, it could be argued that the design can be treated as *both* an individual *and* a household panel.

Nevertheless, we do not see a case for conducting the panel as a strict household panel, if only because anybody new to the household after baseline would not be added to the sample. Nor would there be the need to monitor household changes as vigorously as is needed for a household panel.

Some analysis questions will, of course, need to be household based rather than individual based. For instance, any discussion of the impact of disability on income or poverty would probably be based on household rather than individual income. And some of the impacts of disability on, say, employment may be experienced by partners or other family members rather than by the disabled person themselves. So, even if individuals rather than households are selected for interview, some interview questions will need to be about the household or about other household members.

A final point. Given that households will be the focus of at least some of the longitudinal analysis, it is essential that basic data on the composition of the household be collected at each wave of the panel so that analysts can de-compose household structure change from other change.
5 Alternative designs

In Section 3 we set out what a ‘basic’ design for a longitudinal study might look like, the main elements being a large baseline survey of, at least 50,000 members of the general population (including children) after which individuals are divided into three samples: a disabled at baseline sample, a comparison sample, and an onset screening sample. This would involve a very large sample of around 38,000 ‘onset screening’ cases per year. Even with a telephone follow-up this would be a considerable undertaking every year.

In this section we consider the options for using other surveys as a sampling frame for either the baseline prevalence survey or for generating a sample of onset cases.

5.1 Alternatives to the baseline prevalence survey (piggy-backing on another survey)

As has already been said, we believe there is a strong case for starting any new longitudinal survey with a large baseline survey from which, at the very least, prevalence estimates can be derived. In addition, this baseline survey should be capable of generating a sample for a longitudinal sample of the ‘disabled at baseline’ and a comparison sample of the non-disabled at baseline.

Rather than doing a large-scale general population survey to generate prevalence estimates, the alternative model would be to adopt a design similar to that used for the 1996/7 Family Resources Survey (FRS) follow-up survey. In that survey, FRS respondents were identified as ‘possibly disabled’ if they met one or more of a number of criteria (such as reporting having a long-standing illness or disability). Any that passed these criteria were then approached for a follow-up interview where the 1985 Office of Population Censuses and Surveys (OPCS) disability questions were asked. Based on the responses to this follow-up questionnaire, prevalence estimates (overall and by severity) were derived.
About 25 per cent of those passing the FRS criteria were subsequently found not to satisfy the OPCS definition of disability so in that sense the approach looks to be reasonably satisfactory (in the sense that the ineligible rate is not excessively high). What was not tested (although in principle it could have been) was whether the FRS criteria led to the exclusion of some people who would have passed the OPCS criteria, a natural hypothesis being that the FRS criteria could have led to those with mild disabilities and perhaps those with mental health disabilities being excluded. This is however, speculation only – the checks done by the FRS analysts did not unearth any evidence of likely exclusions. Certainly the increase in prevalence between 1985 and 1996/7 is at least suggestive of the FRS approach being better at minimising false negatives than the OPCS postal screen.

To make a similar piggy-back approach work as the baseline for a new longitudinal study, several criteria would need to be met:

- the survey used would have to be large (at least 50,000 either in one year or over a small number of years);
- the survey would need to include one or a small number of questions that would identify a very high percentage of those with a relevant disability. This assumes that it would be very hard to persuade the sponsors of major surveys to add a large disability screening questionnaire to their survey. To design and test a short questionnaire may not be a simple exercise (see Section 4.1);
- the survey should, ideally, cover all members of the population including children and those above working age. Few large-scale national surveys cover children, so this might rule out children from the longitudinal study. (One possibility might, however, be to piggy-back on one survey for adults and another for children, although this would inevitably give a final sample that is very unclustered and subsequently expensive);
- to reduce non-response bias the piggy-backed survey should have a high response rate;
- if the survey was to be used as a sampling frame for a comparison sample and ‘onset screening sample’ then the survey sponsors would need to give permission for all their respondents to be followed-up, not just those thought to be disabled.

In our view, the biggest issue of those raised above is that of the non-response bias. For cost reasons, most general population surveys do not make special efforts to make their surveys inclusive of all people, and would simply accept that those with particular types of disability would either have to be excluded, or answers given by proxy. This means, we suspect, that people with severe communication or learning disabilities are effectively excluded. Whilst this may not be particularly biasing in a survey that is not about disability, it would obviously be far more biasing for a survey about disability.
Another, non-trivial consideration, is the subject matter of the piggy-backed survey. For the onset screening sample at least, the pre-onset data generated by the piggy-backed survey would be an obvious source of some ‘before-onset’ data from which change could be measured. For instance, if the piggy-backed survey was the FRS again, then the FRS would give pre-onset data on household income and resources, but it would not give pre-onset data on social participation. So, any pre-onset data not included in the piggy-backed survey would need to be collected during the subsequent interviews. This suggests that, given a choice, using a ‘relevant’ survey that generates lots of pre-onset data would be preferable.

The Great Britain (GB) surveys that are the most likely candidates for piggy-backing are the FRS, the Labour Force Survey (LFS) or, after 2008, Office for National Statistics (ONS’s) new Continuous Population Survey (CPS) (which in terms of sample size wins hands down). However all of these surveys have problems:

- the FRS has only a moderate response rate at about 65 per cent;
- the LFS includes a longitudinal element and survey respondents will have been asked to complete five interviews before being recruited to the disability study. The response rate to a subsequent survey on disability may be compromised;
- the CPS is proposed as a combination of six surveys: the LFS, local LFS boosts; annual population survey boost; expenditure and food survey; general household survey; and the omnibus survey. This gives a total sample size of about 270,000. However, the vast majority of this sample are being asked to take part in surveys with a longitudinal element (174,000 LFS or LFS boosts, 9,000 General Household Survey (GHS)) and the EFS has too low a response rate to make a good piggy-back source. So this really only leaves the annual population survey boost and the omnibus survey (at 80,000 in total). In terms of sample size this is still large enough, but the two surveys have the disadvantage of including relatively little relevant baseline data.

Were the piggy-back approach to be used then the design of the longitudinal study would look broadly as follows:

- all respondents to the ‘piggy-backed’ survey who give responses suggesting disability would be approached for re-interview; at that interview fuller questions on disability status would be asked. Anybody identified as disabled would be included in the ‘baseline disabled sample’; all others would be added back to the ‘non-disabled’ sample.
- the ‘non-disabled’ sample would be divided into two groups: a non-disabled comparison sample; and an onset screening sample. These two groups would not be interviewed straightway – their first interview would be at the equivalent of Wave 2 for the basic design.

So, piggy-backing effectively removes the need for a baseline (or Wave 1) survey for all those non-disabled at baseline.
Note, finally, that a piggy-backed survey would probably be less clustered than a survey that is designed from scratch, so the samples to be followed up face-to-face would be fairly unclustered. This will add to the costs of the longitudinal elements of the survey.

Returning briefly to the issue of using a short series of questions to use on a piggy-backed survey as a means of identifying those likely to be disabled. In Canada, where a similar approach was used (although the piggy-backed survey was in fact the census), the false negative rate was assessed by selecting a small sample of those who did not meet the criteria and then testing them using the full disability questionnaire. However, they concluded that although this did generate a ‘missed’ group of disabled people, the cost of the exercise, plus the fact that the sampling fractions for the two samples were so different, so that the extra sample cases had to have very large weights, made repeating the exercise unfeasible. Instead they spent time and money developing a more sensitive and specific set of short questions.

In our view, the piggy-back approach is very much a second-best option to the ‘basic’ design option of starting with a fresh sample. Only if the fresh sample option proves too expensive should the piggy-back option be adopted.

5.2 Alternatives to the onset screening sample

A major cost component of the basic design introduced in Section 3 is repeatedly interviewing the onset screening sample, and here we give some consideration as to whether there are any alternative sources of onset cases.

The number of alternatives seem be fairly limited here. The main obstacle is that cases are identified as individuals who experience a change. This means that we either use a:

- survey that does repeat interviews over a period with a large sample of individuals. The LFS is the most obvious example here. Other surveys, such as the British Household Panel Survey (BHPS), would simply not be large enough, nor would the BHPS researchers be willing to pass ‘onset cases’ to another study. The same would apply to other cohort studies;

- cross-sectional survey, but for those identified as disabled ask whether they would consider their disability to be new. Those saying ‘yes’ would become onset cases. This approach seems to be fraught with self-report difficulties, although it might be worth some researching. This research might, for instance, involve identifying a sample of people who we believe to be recent onset cases (perhaps from the LFS) and see if they self-identify as such. However, the approach also suffers from the fact that no pre-onset data would be available, except for any that can also be asked retrospectively.

Of the two possibilities the LFS route looks to be most promising, although it also gives very limited pre-onset data.
There are a number of reasons why using the LFS as a source of onset cases may not prove possible. Firstly, and foremostly, ONS may simply refuse. Secondly, the definitions of disability used on the LFS may not match those we would wish to use and may exclude some onset cases of interest. As an example, without adding extra questions it would not be possible to identify people who had a transitory common mental disorder in the last year. In fact, because the current Disability Discrimination Act (DDA) question asks about conditions that are expected to last for at least a year, even current Common Mental Disorders (CMDs) would largely be missed.

Other issues include the fact that, as already noted, the LFS may over-estimate onset rates. Some means of reducing misclassifications would be needed, which may mean adding extra questions to validate the responses. There is also the fact that many LFS interviews are done by proxy and it is not clear to us whether proxies can give permission for contact of the main respondent, especially if the names are to be passed to another survey contractor.

Yet another issue is that children are not included in the LFS, so it could not be a source of onset cases for children. Having said that, onset cases for children are so relatively rare that, as we have argued elsewhere (Section 4.3) we may simply have to accept that generating a reasonable sample size of onset cases for children by any means is simply not feasible.

Assuming most of the major problems can be overcome, the LFS does not have to be considered as an alternative to the onset screening sample. Instead, we could think about it as a supplementary source of onset cases. That is, we could carry out the large screening exercise with all, or a sub-sample, of the onset screening sample each year, but boost the sample numbers via the LFS, accepting that the boost may be a somewhat biased sample of the total.

Another potential source of a boost sample might be new Incapacity Benefit (IB) cases. This sample however would be very seriously biased towards those with a particular employment outcome, so, although a relatively inexpensive option, it would only be useful if there were particular research questions to be asked of this group.

A third route that might be worth exploring is using General Practitioner (GP) records to identify those who, according to National Health Service (NHS) records, move from non-disabled to disabled. This would however probably generate criticisms along the lines that it adopts a purely medical approach to disability. Plus there would be a large number of practical, administrative, and data protection issues to overcome that would, we believe, probably make the option unfeasible.

One final point. The LFS option may not be as cost-effective as appears at first sight. The onset cases identified will be an unclustered sample spread across the whole of GB. Assuming that follow-up interviews will be face-to-face this will increase the unit interview cost (relative to the costs for those identified through the onset screening sample).
5.3 Other possibilities

We have identified four other possible variations or alternatives to the basic design that merit discussion. Three of them are based around making more use of existing cohort studies, namely the BHPS, English Longitudinal Study of Ageing (ELSA), and Millennium Cohort Study (MCS).

Taking each in turn:

The British Household Panel Survey

The BHPS has already been used as a source of data on the factors associated with transitions into disability, so we should at least ask whether this undermines the case for a new longitudinal study. Especially since what we are proposing is much larger.

The two relevant facts appear to be:

- that although the BHPS has question(s) on long-standing illness, it does not have a specific disability question or questions;

- the sample size of onset cases is very small each year, so analysis has only been possible by aggregating up to eight years worth of data. Even with such aggregation the number of onsets is low (700) so there is relatively little potential for sub-group analysis.

The English Longitudinal Study of Ageing

We are firmly of the view that those over working age should be included in any baseline prevalence survey of disability, if only to give a source of prevalence estimates that are based on a standardised instrument used across all age-groups. However, there is at least a case to be made for excluding those not of working age (say, those 65 and over) from the longitudinal follow-ups because this is territory already covered by ELSA.

The arguments against relying on ELSA would probably boil down to issues around questionnaire coverage. Although ELSA probably already covers a great deal of the issues of interest to the Department for Work and Pensions (DWP), there must be some gaps, or some areas where a different set of survey instruments would suit DWP better. But ELSA already has an extremely long interview per wave (up to 2.5 hours) so the potential for adding new questions must be very limited.

Using the Health Survey for England to boost the sample size for children

We have already noted the problem of small sample sizes of disabled children that even a very large starting sample would achieve. One way to boost these numbers might be to include one or more years of the Health Survey for England (HSE) children’s samples in the baseline survey. In other words, select a sample of 50,000 persons in the main sample, and boost this with children from the HSE. Access would, of course, have to be negotiated with the Department for Health. The cost of
doing this would depend upon whether agreement to include some disability screening questions into the HSE questionnaire could be reached. If it could, then only those children likely to be disabled need adding to the next stage sample; if not then the next stage sample would need to include all children and check for disability status7.

One potential objection is that boosting one survey with another would give a sample that was too unclustered. In practice this can be overcome by selecting the disability study sample in the same sampling points as the HSE.

**The Millenium Cohort Study**

Another option for children is to rely on the MCS as the source of longitudinal data on children. The MCS is based on a random sample of 15,000 children born in 2000. It has not to date included any standardised questions about disability, but these could be added (and possibly there are already plans to do so) in future waves.

The main disadvantage is, of course, that the MCS only includes children born on one year. It will not provide any data on older disabled children for many years. The best way to consider the MCS may be as a source of extra data but not as an absolute alternative.

**5.4 Using administrative data to supplement a longitudinal study**

It is becoming increasingly common for social surveys to link to administrative data systems, the idea being that:

- using administrative data as the source of some survey information avoids the survey having to cover those data items (for instance, if a survey individual can be matched to their benefit records there should be no need to ask about their current benefit receipt or benefit history);

- linking surveys to administrative data should help to minimise discrepancies between estimates derived from the two sources.

In addition, there is the extra benefit that if administrative data is available for both survey respondents and non-respondents, comparing administrative outcomes gives a very valuable insight into the extent and direction of non-response biases.

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7 Arguably, if the HSE sample does not provide basic data on disability then a fresh sample of children, perhaps selected from child benefit records, would be a simpler alternative.
For all these arguments, we believe there is a very strong case to be made for asking consent of any new longitudinal survey respondents for their data to be linked to administrative records. We do not believe however that the use of administrative data removes the need for a survey – the data from administrative sources will always be rather ‘thin’ and will never cover areas such as attitudes, experiences, and motivations. Nor can follow-up interviews wholly be replaced with administrative follow-ups. It seems better to consider administrative data as a supplement rather than a replacement.

The main sources of administrative data that are likely to prove particularly useful in the context of a disability study are:

- DWP and Inland Revenue data (on benefits and income);
- NHS data on use of health services;
- ONS data on deaths (event, date and cause); and
- for children, school attainment data.

One of the obstacles to linking administrative data with survey data is that respondent consent has to be sought. There has been a lot of discussion recently about how informed consent should be gained, and there is a risk that consent gained at the start of a longitudinal study may prove inadequate if the law, or the interpretation of the law, changes in the future. So it could happen that consent to match data is gained, but that subsequently the administrative data cannot be matched because the consent is deemed inadequate. Given this risk it makes good sense to design studies that will benefit from administrative data linking but are not dependent on it.
6 Meeting the particular information needs of DWP

This section of the report expands on the areas of information need discussed in Section 2 (with the exception of prevalence estimates and disability transitions which have been covered in other sections of this report). For each area we have taken a broadly similar approach:

- what we understand the needs to be;
- whether some (or all) of the needs could be met using other datasets;
- how meeting those needs impacts on the design of a longitudinal survey.

6.1 Disability, work, and income

There has, historically at least, been a very strong association between disability and employment (or non-employment) and between disability and income. So, inevitably, tracking changes in employment and household income alongside changes in disability would be a key theme of any new longitudinal study. The implications are:

- questions in employment and income should be included at all waves of the study and for all samples, including the onset screening sample (assuming that is the design adopted)
- at baseline, a short employment history should be collected.

To relate changes in disability to changes in employment needs, in principle, good data on dates of change. However, although dates for changes in employment can be collected, for most people putting a date on a change in disability will be impossible (probably the only exception being those who become disabled following an accident). This means that, if causal relationships are to be explored, then respondents should be asked their views on how their disability has affected their employment, and vice versa.
Questions on employment would, of course, have to be more detailed than simply collecting whether in employment or not. Details of hours worked (and any changes to those), change in job tasks, time off work sick etc. would all be needed. Plus questions might be added on self-report on the degree to which employers were perceived to be aware of issues, and any steps they took to address those issues.

A complication that arises for employment and income is that the impacts of disability on both can be thought of as a household level impact rather than an individual level impact. In particular, in some cases if one family member becomes disabled, then his/her partner may have to change their employment. However collecting data for the whole household will create some survey design and administration difficulties that will need some careful thought. In particular:

- the disabled person may not be the person most able to give reliable data about the whole household;
- under the ‘basic’ design model members of the same household could be either in the ‘disabled’ sample, the comparison sample, or the onset screening sample, so will already be included in the survey under some guise or another. We would have to avoid asking the same questions multiple times.

We have argued that a comparison sample of non-disabled would be analytically valuable. One of the key arguments for having this sample would be to compare employment patterns for disabled persons with their non-disabled counterparts. It is possible, however, that comparisons could be made, instead, with the non-disabled in other surveys such as the Labour Force Survey (LFS), or if change over time is needed, the British Household Panel Survey (BHPS). There would, inevitably, be some issues around whether the two survey sources could strictly be compared, but the cost savings might outweigh the disadvantages. Note, however, that dropping the comparison sample would mean that other areas of interest, such as social participation, would need different sources of comparison data.

Finally there is the question of mode of interview. As noted above, we believe that questions on employment and income should be included at all waves of the study and for all samples, including the onset screening sample. For the baseline disabled persons longitudinal sample, and the comparison sample, we envisage that all interviewing will be face-to-face, so this raises no particular problems. The onset screening sample, in contrast, would be more cost-effectively handled by telephone. This would mean that at each contact, respondents in this sample would be asked about any disability onsets, plus a few questions on their employment. Plus, one person per household would be asked about income. This level of coverage ought to be possible by telephone, but the need to keep the interview short and relatively simple could put constraints on the level of detail that is collected.

Estimating the direct and indirect costs of disability raises very different issues, and is discussed in Section 6.5.
6.2 Social participation and access

The social participation of disabled people (or the lack of it) was a major topic for the 1996/7 Family Resources Survey (FRS) follow-up survey, and with the move to a more social model of disability, this is likely to stay high on the agenda. In fact, following the International Classification of Functioning, Disability and Health (ICF) model, questions on participation would be essential for any survey purporting to cover disability issues.

We have not looked in detail at whether other current UK surveys could provide data on the relationship between social participation, access and disability if they were to add a few disability questions—our assumption is that some aspects of participation could be monitored this way, but it would be hard to put together a complete picture.

The main benefits of including questions on social participation in the longitudinal survey (rather than rely on other surveys) would be that:

- questions could be added on both participation and barriers to participation;
- assuming there will be a comparison group, the social participation of disabled persons can be compared to the social participation of non-disabled persons. (This is something that neither the Office of Population Censuses and Surveys (OPCS) nor the FRS follow-up surveys were able to do.)

There is possibly not a strong case to be made for repeating all questions on access at every wave of interview. A five-year cycle might be adequate for, say, questions on the accessibility of the built environment. Plus, although adding questions on social participation to every wave of the onset screening questionnaire (including before-onset waves) would allow for before-after onset comparisons, it could possibly over-burden what ought to be a short questionnaire.

Finally, having ruled out collecting social participation data entirely through other surveys, there is probably still a case for collecting some more detailed information on particular aspects of participation by adding short disability questions to some continuous or repeating surveys. The obvious survey is the National Travel Survey, but the England and Wales Day Visits Survey is another possibility. In addition we understand that the DCMS are considering undertaking a very large survey (c.35,000 respondents) of participation, attendance and attitudes across its sectors.
6.3 Attitudes towards disability

Attitudes towards disability are, arguably, one area where other surveys could provide information as well, if not better, than a longitudinal survey. The two obvious vehicles would be the British Social Attitudes (BSA) survey and the Office for National Statistics (ONS) Omnibus survey, both of which have included questions in the past around disability. The advantages of these two alternatives are that:

- they are cross-sectional so provide good population-based estimates each year (that is, they don’t suffer from panel attrition);
- in the case of the BSA, attitudes towards disability can be compared to attitudes in other areas.

The main disadvantages however, are that:

- the sample sizes of these surveys are fairly small so the number of disabled people included will also be small;
- as well as including attitudinal questions, questions allowing disability status to be measured would also be needed; and
- for cost reasons these surveys do not make special attempts to include those with severe disabilities who find standard interviewing techniques difficult. Thus, they are likely to under-represent those with communication disabilities, severe hearing difficulties, or learning disabilities.

If questions on attitudes were to be included in a longitudinal study, there does not seem to be a strong case for including them at every interview wave. Including questions, say every five years might be adequate. Or we could consider linking the questions to legislative or political change that we anticipate might impact on attitudes. Alternatively there could be a short module of the questionnaire devoted to attitudes at each wave, but with the questions changing each wave.

6.4 The role of carers

Carers could be dealt with in a number of ways in a longitudinal study of disability. The ‘simplest’ approach is to allow the disabled persons in the survey to identify their main carer (although that is not necessarily a straightforward process, because, anecdotally, the caring role of partners is frequently overlooked). We would then ask questions about the role of their carer directly of the disabled person.

The more complex approach would be to identify the main carer and then to carry out a separate interview with that carer. The assumption here is that the carer would be in a better position to report on the type and level of support they provide than would the person they care for.
So, on the face of it, the more complex approach is preferable. However, we have some reservations about recommending it in the context of a longitudinal study for two reasons:

- asking disabled people to nominate an extra person for interview would make, for many households, an already burdensome survey even more of a burden;
- the carers may already be in the study either as a comparison sample member or as an onset screening sample member (since for many households the carer will be in the same household) and having interviews covering dual purposes would be technically and administratively complex (although far from impossible).

The research brief for the study does not identify any very pressing information needs for carers so the simpler approach would probably meet those needs. It is possible however that, after consultation, a bigger role for carers might be identified – in which case the more complex design would need to be considered.

6.5 Measuring the extra costs of disability

In this section we consider the survey implications of collecting data to support calculations of the extra costs of disability.

There are currently four alternative approaches to estimating the extra costs of disability:

- the subjective approach;
- the comparative approach;
- the standard of living approach;
- the budget standards approach.

6.5.1 Different approaches to measuring extra costs of disability

Studies using the subjective approach ask disabled people (or experts) to estimate what their additional expenditure is (or would be if their needs were to be met) and on what items. Estimates of extra costs are then derived from respondents’ answers. Estimates based on what people actually spend are likely to be under-estimates of what people would spend if all their needs were met, simply because they are constrained by their budgets. So, unless the hypothetical (what would you spend?) approach is taken the approach under-estimates extra costs.
The comparative approach

The comparative approach compares the spending patterns of disabled people with those of ‘similar’ non-disabled people. Studies ask both populations about how much they spend on individual items and the differences show where disabled and non-disabled people’s priorities differ. Like the subjective approach, the comparative approach is hampered by the budgetary constraints of respondents, and there is no obvious means of measuring how much respondents would spend if income were no object. This means the approach cannot measure what the potential costs of disability are.

The standard of living approach

The standard of living approach is based on the assumption that disabled people experience a lower standard of living than non-disabled people with the same income because of diversion of scarce money resources to goods and services required because of their disability. A range of indicators of standard of living can be used (there is no consensus on what is most appropriate). The approach needs a non-disabled comparison sample: for a given standard of living the incomes of disabled and non disabled people are compared and the difference between the two means represents the extra costs incurred by disability.

The budget standards approach

In the budget standards approach a panel of experts determines the extra costs of disability under a range of scenarios. The approach involves (a) itemising what extra services and goods are needed if a disabled person is to achieve the same standard of living as a non-disabled person; and (b) attaching costs to these extra items.

All of the approaches have their critics, the main objection to the subjective and comparative approaches being that they are budget constrained. And the main objection to the standard of living approach being that it is a model-based approach and the answer achieved is dependent upon the assumptions underlying the model. We have not included a critique of the various approaches here. Instead we have concentrated on the issue of which, if any, of the approaches could be implemented through either a new cross-sectional or new longitudinal study. And, if one or more approach was adopted, what impact including the relevant questions might have on survey burden and subsequent non-response.

The subjective approach

The subjective approach (whereby respondents estimate how much they spend under various headings of expenditure as a direct result of their disability) has a number of attractions, probably the two key ones being:

- it gives an estimate of extra costs directly (in contrast to the comparative approach which involves comparing spending patterns of households with disabled members against households with all members non-disabled);
a precise (i.e. low standard error) estimate of extra costs should be achievable
with a smaller sample size of disabled households than is needed for the
comparative approach. (Note, that although more precise, we are not claiming
it will be accurate – that is, bias-free.)

The main survey objection to the subjective approach is that, in the context of an
interview (and perhaps in all research contexts) asking people to decompose their
spending in broad categories into ‘spending because of their disability’ and
‘spending that would have occurred anyhow’, is clearly an impossible task. Which
isn’t to say that people will reply with a ‘don’t know’ – most survey respondents will
provide answers to any questions you put to them. If they aren’t sure they will give
their best estimate.

Conceivably, if a lot of interview time was devoted to asking these questions, so that
individuals would be able to think through exactly how they spend money, and how
much of it could be saved in the absence of the disability, then the approach might
be harder to criticise. But this would be closer to an in-depth qualitative or semi-
structured interview than a quantitative survey, and could probably only be achieved
with small sample sizes. Certainly trying to conduct an ‘enhanced’ subjective
approach in the context of a large-scale longitudinal survey does not look feasible.
The interviews would become very long, and respondents would probably leave the
study to avoid such difficult questioning in the future.

What might be possible is to take a sub-sample of disabled people (and their
households) out of the longitudinal study and ask them to take part in the ‘extra
costs’ exercise. Having done so they would not re-enter the panel. The fact that we
would have good data on the nature of their disability, plus their household income
(from the baseline survey) means we could select a highly stratified sample (with
reasonable numbers across income groups and by type and nature of disability).

As will be clear from the discussion above, we are not absolutely clear what the
interview for those selected will look like. One approach might be to ask respondents
to complete an expenditure diary (like the EFS diary) for two weeks. Interviewers
could then use these diaries as the starting point for discussions on how to divide
that spending into ‘extra’ and ‘counterfactual’ costs.

6.5.2 The comparative approach

The comparative approach needs detailed expenditure data for a sample of disabled
persons plus a comparison sample of non-disabled. The only practical approach to
collecting this data is to carry out an EFS style interview plus diary. (The alternative of
simply asking people how much they spend in different areas (food, clothing etc.)
would be too imprecise.)

The EFS interviews are very burdensome and, for the same reasons we gave above
for rejecting a long ‘subjective’ interview with all members of a longitudinal study,
we would not recommend asking all respondents in a longitudinal study to go
through an EFS style interview. The alternative, discussed above, of filtering off a sub-sample from the longitudinal study, looks to be far more practical. Clearly, for the comparative approach, a similar sub-sample would need to be filtered off the comparison sample.

The sample sizes used in the comparative study of Matthews and Truscott (1990) were fairly large (1,382 households with one or more disabled members). Filtering off this many households from a longitudinal survey would leave a pretty large hole. However, the 1,382 was simply the number that came from one year of FES interviews, and it is possible that a smaller sample size would have been adequate. Furthermore, as we noted above, as filtering from a longitudinal study would allow for stratified sampling from a fairly information-rich sampling frame, it should be possible to reach equivalent precision with a smaller sample size.

### 6.5.3 The standard of living approach

The standard of living approach is far less data-hungry than either the subjective or comparison approaches and hence is far more compatible with a ‘large sample size/limited interviewing time’ survey. In principle all that is needed is household income plus data on indicators of standard of living (which might be white-goods, or savings, or other items so far not tested.)

The use of this approach by Burchardt and Zaida (2003) involved comparing households with one or more disabled persons (‘disabled households’) with a comparison group of households with no disabled members. In essence the approach works by estimating the standard of living of the disabled households, matching them to non-disabled households with the same standard of living and then comparing incomes. Assuming the average income for the disabled households is higher, the difference in the means reflects the ‘extra costs’.

A natural extension in the context of a longitudinal study would be to take a sample of households who have made a transition (either from non-disabled to disabled, or from, say, moderate to severe disability) and, contingent on there having been no change in income, compare standard of living before and after. (If there has been a change in income the two changes can probably be modelled in parallel.) If disability change has an impact then, the change in disability should trigger a lowering in the standard of living (either immediately or over time).

The question of how ‘standard of living’ is measured probably needs additional research. The Zaida and Burchardt study used data that just happened to have been collected on the surveys they were looking at, and had they been looking at other surveys they would no doubt have constructed a different index based on different items. If a decision was taken to collect data specifically to measure standard of living in a new longitudinal study, then identifying the best possible index in advance would obviously be a help. Note that ‘the indicator should consist of goods and services preferences which are not systematically related to disability status’ so some natural indicators (holidays abroad might be an example) would not be appropriate.
Conceivably, different indices are needed for different types of disability. The main constraint is, of course, that the indices have to be based on questions that can be asked quickly and easily in a longitudinal survey. If this condition is met then there should be no impact on subsequent response rates.

One problem that relying solely on the standard of living approach might create is accusations of non-transparency. The approach is harder to understand than either the subjective or comparative approaches (since, essentially, the extra costs are modelled rather than observed) and so explaining how the estimates are derived may prove tricky. One approach might be to combine the standard of living approach (based on the whole of the longitudinal sample) with the comparative approach (based on a sub-sample).

### 6.5.4 The budget standards approach

The budget standards approach to measuring extra costs does not, by definition, require survey data – the extra costs are established by panels of experts. So, the main contribution of survey data here would be expenditure data on a random sample of disabled households that monitors how much of the extra costs are being met (and how). The EFS sub-sample we have suggested for either the subjective or comparative approaches would be the most obvious source of such data. In other words, a study that allowed for either the subjective or comparative approach could be used to compare reality against the budget standards.
7 Issues around sub-groups

This section looks at issues around three particular sub-groups: children, those with mental health problems, and minority ethnic groups. The sub-groups have been chosen because they throw up particular issues of survey design.

7.1 Children and the parents of disabled children

There are a large number of issues around including children in any new survey of disability (longitudinal or otherwise) some of which have already been touched on. As has already been noted, the greatest obstacle to overcome is sample size: as indicated in Section 3, in a starting sample of 50,000 persons, only around 300 disabled children would be identified. The Office of Population Censuses and Surveys (OPCS) 1985 survey identified a sample of close to four times this, but it was achieved, quite simply, by screening close to four times as many persons. In Section 5.3 we identified a potential solution to this, so ultimately, whether or not the new survey includes children, is probably just a cost issue.

7.1.1 Defining and identifying disability amongst children

We have already discussed the fact that there are currently no up-to-date survey instruments for identifying and scoring disability for adults. This is also the case for children, so we do not discuss how it might be done here. However, we have identified a number of issues that would need to be taken into account in developing any such instrument.

Taking into account development or ‘growing up’

There are examples of studies of disabled children that tried to use a standard definition and measurement of disability for children and adults. The key Great Britain (GB) study to do this was the OPCS surveys of disability (1985-1988), in which they interviewed disabled adults and parents or carers of disabled children. With a few minor revisions, largely for under 5s, OPCS used a standard list of disabilities and severity rating for adults and children to model and define disabilities. In taking this
standardised approach, the study has been criticised for compromising the measurement of disability amongst children for the sake of adult-child comparability (Gordon et al, 2000).

In developing a child specific instrument account would need to be taken of what is ‘usual’ for a child of that age. Lewis and Kellet (2004) point out the dangers of relying too much on a scoring system for children which can hide underlying differences between children with different conditions. For instance, they give the example of a Down’s Syndrome child who may score higher than average for a child of their age on some social aspects but lower on others. The net result may be to underplay the severity of key elements of their disability.

The survey may need to include some of the standard developmental tests as a measure of children’s cognitive development, potentially for inclusion into a model to measure disability and severity.

**Frequent lack of early identification/non-diagnosis**

There are issues around the fact that disabilities in children – at least in the early years – may be undetected and become apparent or be diagnosed only later. This has particular implications for any longitudinal study that attempts to identify transitions: a decision would be needed as to whether to treat some newly diagnosed disabilities as onset cases or as previous mis-classifications. Plus, being able to make sense of these later ‘onsets’ may have implications for what information is collected on younger children at least. Such information might include issues around the pregnancy, birth and early stages of development.

The importance of, and interest in, early identification and how this is handled is a key issue for policy makers, medics and child development experts (Cabinet Office, 2004). For instance, the need to identify deafness before the age of six months is important to avoid delays in cognitive development; there is evidence that early intervention for young children with speech and language difficulties is more effective than at a later stage; there is evidence that failure to provide early targeted support to disabled children in their own home can increase the likelihood of residential care.

**Educational development or ‘special needs’**

Whilst any survey of disability amongst children will need to develop and use a definition of disability, as defined in medical and social terms, its focus and content would suggest the need to include questions on children’s special educational needs (SEN), either as part of the ‘disability definition’ questions or as contextual information. Most school-aged (and some pre-school) children with disabilities are likely to be identified as having SEN. They will be going through the action stages towards being statemented or will have reached the stage of being statemented.
There are standard Department for Education and Skills (DfES) definitions of SEN and suggested ways of measuring and recording SEN. However, these are not particularly usable in a survey of parents or children, and several studies (e.g. Families and Children Survey (FACS) and Parents’ Demand for Childcare) use a similar — largely comparable — set of questions which would be more appropriate.

**Need for proxy information from parents for younger children at least**

Survey interviews about children have traditionally been conducted with their parents, although there is an increasing recognition of our ability and the importance of interviewing children themselves when possible. The age at which children can be expected to answer questions about themselves is one about which there is much debate, with the perceived lower age limit falling in recent years. Most surveys that include interviews or questionnaires amongst children still tend to take eight as the lowest age limit. There is then a very grey area about the type of questions that can be asked of children and assessing their cognitive abilities. By middle teens, children are commonly treated as adults in the ways that questions are worded; below that questions are often adapted or limited as thought appropriate for the age group. This is discussed more below.

This means we will be reliant on the information provided by parents on their children’s disabilities and the effect of the disability certainly for children under eight and probably partially for children under the age of around 13. In addition, we need to consider the mental or cognitive age of some disabled children. The point here is that the adult and child surveys differ in as much as we will often be asking the parent to describe and define the disability, rather than the disabled person themselves. This has implications for the quality of the information (discussed more below) and consent issues (discussed below).

### 7.1.2 Collecting data on or about children

**Selecting the survey respondent**

There are three possible ways to collect information about disabled children (and a comparison group of non-disabled) children. Two involve interview data from:

- parents;
- the children.

The other involves the use of administrative sources, such as health and education records.
In all likelihood a combination of all three approaches would be optimal approaches, dependent on the age (or cognitive ability) of the child and the subject matter of the survey:

- **under eights**: Parents (although some cognitive tests might be conducted with the child), combined with admin sources.

- **eights to 13s**: Parents and children, plus admin sources. We might envisage collecting basic information from parents about the child’s disability, the impact that has on the household, education issues, and so on. We would then expect to get the child’s perspective on their disabilities (it would be a useful methodological exercise to calibrate the assessments of the parents and children, plus the admin sources) and on the social aspects of their disability.

- **over 13s**: Children and parents, plus admin sources. The child would become the main respondent at this time, with the parent being interviewed about issues about the family and parenting.

Of course, these age bands would need to be used as guidelines, rather than rigid rules. Amongst all children, we find a broad range of cognitive abilities across the age groups. For disabled children the range will be even more diverse, particularly amongst children with mental disabilities. Developmental work would probably be needed on how best to brief interviewers on assessing the capabilities of children to take part in the interview at the various possible levels. In particular, we would need to ensure that the decision is not made by the parent or carer who (anecdotally from previous research) can sometimes be over zealous in their role as gatekeeper.

The usefulness of administrative data would also need careful piloting. Certainly, linking survey data on children with administrative information on their educational attainment from the National Pupils Database is increasingly common.

**Mode of data collection**

For a survey of disability, the level of detail and sensitivity would imply that face-to-face interviews with the parents and children over 14 would be required at least at the first interview. Given that very different – and often complex or sensitive – issues will arise at different life stages, several – if not all – of the panel waves would be best face-to-face. Issues around the potential for using other modes for follow-up interviews are discussed below.

Thinking now about the children, most quantitative surveys of children rely on self-completion. This is often to do with cost efficiency (with children being a ‘tag on’ to a face-to-face interview with parents, where a paper self-completion is used for children). However, it also has the practical advantage of allowing children more privacy with which to give their answers. Certainly, it can be difficult to ensure privacy from parents when conducting a face-to-face interview with children (and there are obvious security and ethical issues around this (discussed a bit more below)), and the content of the questionnaire may be quite sensitive/private for the
children. However, the disadvantages to the self-completion approach are the limitations of a child’s reading ability (particularly amongst some disabled children) and on levels of filtering, complexity of questions, etc. Audio-Computer Assisted Self-Interviewing (CASI) would be worth considering in that it would get over potential literacy or sight problems and would enable a greater degree of privacy for particularly sensitive questions when the respondent can listen to the question and code the answer without having either on the screen.

For follow-up interviews, telephone or postal self-completion could be considered, but both present problems. Certainly we could find no examples of interviews undertaken with children over the telephone (apart from 16 plus). The reasons for this may be several:

- most studies of children have chosen self-completion for practicality (combining with face-to-face adult interviews) and cost;
- parents may be less happy with children being interviewed over the phone, where they have less control over what is being asked, less ability to assess how comfortable they are with the interviewer, etc.;
- privacy with phone interviews can be difficult to achieve;
- inability to use visual aids, which are particularly important for children;
- inability to build up rapport, again particularly important for children and vulnerable groups.

This is not to say that the telephone might not be an option – particularly for older children (14 and over) – but it would require testing and be far from ideal. With mobile phone usage amongst children increasing, privacy may become less of an issue. However, parental consent issues would need to be considered before going down the route of contacting children for interview on their mobiles.

There are more precedents for self-completion amongst children. However, these are usually in the presence of interviewers (or at least handed out and returned to interviewers), rather than sent through the post. The opportunity for interviewers to help children who need help with the completion would be lost in a postal self-completion. There may also be concerns over who completes the children’s questionnaires (or influences responses).

7.1.3 Consent issues

Including children in research raises a number of ethical and consent issues.

It is necessary to obtain the consent of parents to approach children to ask them to be interviewed. We would suggest obtaining this for children under 16, although some studies use a younger age break. Whilst many studies are content with obtaining the verbal consent of parents, the vulnerability of this group would suggest that we should gain written consent from parents. There are issues around
what is perceived as giving ‘informed’ consent – i.e. making sure parents are entirely sure to what they are agreeing. Other studies have provided parents with written information about what the children’s interview would contain.

It will also be necessary to obtain the consent of children to take part in the study. Here, it is important to ensure that children are aware that this is their choice and it should not be taken as read that parental consent implies the child’s consent. Issues around informed consent are even more important amongst children and there is much written about how to ensure that children are fully aware of what they are agreeing to. There are examples (e.g. FACS) of written materials that are given to children to explain what participation means (confidentiality, the content, their rights, their ability to break the interview at any time, etc.). With children (and other vulnerable groups) it is also important to reiterate these issues during the interview, to ensure that they are happy to continue through the interview, rather than rely on the consent before they start. For children with different communication disabilities, deciding on and explaining how they should communicate an unwillingness to take part or to continue part way through the interview will include non-verbal signs, like body language.

In the view of National Centre for Social Research (NatCen) colleagues working on studies of disability and children the approval of the ethics committee would need to be sought for a longitudinal study of disabled children (or about disabled children). Whilst not all studies including children require ethics committee approval (e.g. FACS does not), the highly vulnerable nature of the group of interest (children with a wide range of disabilities) would imply its requirement.

7.1.4 Issues around parenting

If the survey is to include children, and assuming that, for younger children at least, we will be interviewing the parents of those children, it would be appropriate to collect some information from parents on how having a disabled child impacts on various aspects of their lives. For most aspects, the impact on parents will have a knock-on impact for the children themselves. The questions might cover:

- parents’ (particularly mothers’) preferences and ability to take paid work;
- availability/suitability of childcare;
- need for/availability of/use of formal and informal support services;
- the wider impacts on household;
- schooling;
- helping disabled teenagers’ transitions in to adulthood;
- dealing with children living away from home.
7.2 Mental health issues

Most, if not all, survey questions on disability attempt to include those who are disabled with a mental health condition. What is not clear is how successful such questions are, nor under what circumstances individuals include or exclude themselves. We have not attempted to solve the problem as part of this study (it would need to be considered when developing a new disability screening instrument) but we have identified a number of issues that we think would be important to consider.

Firstly, mental health problems fall into two categories:

- severe and enduring mental problems (psychoses); and
- common mental disorders (CMD) which covers anxiety, depression and phobias.

About 0.5 per cent of the population fall into category (a) and, at any one time, 16 per cent of adults have a CMD.

Those with a psychosis should almost certainly be covered by any definition of disability, even if the disabling aspects are managed. However, we might expect those with severe conditions to be less likely to agree to take part in a survey than others, and the drop-out rates from a longitudinal survey may be higher than average. This is not to say that no attempt should be made to cover them – in contrast, efforts should be made to include them whenever possible. But some bias due to under-coverage of these groups should be anticipated. Furthermore, the accurate classification of psychoses needs semi-structured, clinical follow-up by a mental health professional (likely cases being identified using a screening instrument).

It is less clear if, and when, common mental disorders should be counted as disabilities, although one approach would be to concentrate on functioning. Certainly if CMDs are included they will be a very significant component of the total (for instance, 900,000 adults in England claim sickness and disability benefits for mental health conditions according to Incapacity Benefit (IB) administrative data). Secondary analysis of the 1993 Office for National Statistics (ONS) Psychiatric Morbidity Survey (Meltzer et al, 2004) has suggested that about one-third of people with a CMD are limited by their condition, and 20 per cent are disabled by it (where ‘disabled’ was defined as having a limiting disorder and at least one difficulty with an activity of daily living). Certainly mental health problems have a large impact on activities: only 24 per cent of adults with long-term mental health problems are in work – the lowest for any of the main groups of disabled people (Social Exclusion Unit, 2004) – and people with mental health problems have more than double the risk of losing their job than those without (Burchardt, 2003). Whether this is because of discrimination rather than because mental health problems are limiting is difficult to judge.
The real issue around CMDs for a longitudinal study is that they are frequently transitory. About half of people with a CMD at one point in time are no longer affected after 18 months (Singleton and Lewis, 2003). Most severe episodes of depression usually last between three and nine months, but with a high risk of recurrence. Even those with severe mental health conditions will show transitions in disability – about 25 per cent of those with schizophrenia will make a good recovery with treatment within five years (DoH, 2001), but two-thirds will experience multiple episodes with some degree of disability (Bird, 1999). Nevertheless, even transitory CMDs can create discrimination and barriers that may be long-lasting.

Assuming that we would be interested in identifying CMDs that are at least of ‘medium’ term duration (although it is not clear how medium-term should be defined) there are issues around how they would be identified. Most survey questions around CMDs are designed to identify ‘current’ conditions, and so ask about the week before interview. If a longitudinal survey took this approach it would miss any CMDs that began and ended between interviews which, assuming follow-up interviews are one year apart, would mean that a proportion of conditions lasting for less than a year are missed. What may be needed are new questions that ask retrospectively about the last year, with perhaps a focus on mental health conditions during that year that had a significant impact on daily activities.

There is a related issue as to whether we drop people from the longitudinal study if they are included because of a CMD that they recover from and, for subsequent interview waves, there is no recurrence. One option would be drop them from the main study but keep in touch (perhaps with a short telephone interview along the lines of the one envisaged for the onset screening sample) to check for future recurrences. (Note that this is also an issue for people with physical disabilities, but we would anticipate there being smaller numbers of ‘exits’ and ‘recurrences’ for these.)

7.3 Minority ethnic groups

Minority ethnic groups now make up a significant proportion of the GB population (about eight per cent) with about half being Asian or Asian British and a quarter being Black or Black British. In practice, most general population surveys handle interviews with minority ethnic groups in identical ways to other groups: only in surveys with a special minority ethnic focus have serious attempts been made to be inclusive of all groups, irrespective of language issues, and to design culturally sensitive questions. However if the decision was taken to launch a new longitudinal survey of disability we anticipate there being pressure to ensure:

- that sufficient sample numbers of minority ethnic groups are included for separate analyses;
- that translations are offered to those for whom interviewing in English is not possible;
- that questions are designed that identify real differences between groups.
Taking each of these in turn:

**Sample size issues**

Although the overall size of the non-white population is now fairly large, most analysts interested in minority ethnic group issues need to be able to analyse sub-groups within the overall ‘non-white’ population. For instance, in years when the Health Survey for England (HSE) has had a focus on minority ethnic groups, the sample sizes have been set so as to allow for separate analysis by Indian, Bangladeshi, Pakistani, Black Caribbean, Black African and Chinese. The problem is that this can only be achieved by large and expensive boost samples, which involve doorstep screening to identify cases. There may be a case for doing this for a disability study, but it would be very expensive.

**Translations**

Translations are used as a means of ensuring that surveys are as inclusive as possible. They are, however, very costly: firstly, the translations have to be done (which is no small task – there is a good deal of guidance on how to ensure that translations are ‘equivalent’ yet practice tends to fall rather short for practical, timing, and cost reasons.); and secondly, interviewers with the relevant second language have to be employed. These interviewers are more expensive than English speaking interviewers because they have to deal with considerably less clustered samples. Nevertheless, it is useful to note that translations were used fairly frequently when offered: the table below comes from the 1999 HSE.

**Table 7.1** HSE99 Language of interview by ethnic minority group 16+

<table>
<thead>
<tr>
<th>Language of interview</th>
<th>Indian</th>
<th>Minority ethnic group</th>
<th>Chinese</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td><strong>Men</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wholly in English</td>
<td>89</td>
<td>75</td>
<td>39</td>
</tr>
<tr>
<td>Partly in English, partly in another language</td>
<td>3</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Wholly in another language</td>
<td>8</td>
<td>19</td>
<td>40</td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wholly in English</td>
<td>82</td>
<td>66</td>
<td>29</td>
</tr>
<tr>
<td>Partly in English, partly in another language</td>
<td>3</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Wholly in another language</td>
<td>15</td>
<td>29</td>
<td>54</td>
</tr>
</tbody>
</table>
Cultural differences in reporting behaviour

There is some evidence that different ethnic groups interpret questions on health and disability differently. The key issues are outlined below:

Somatization

Prevalence of generalised musculoskeletal pain is higher among adults of South Asian origin than those in the general population (Allison et al, 2002). While this may reflect ‘real’ differences in the prevalence of such pain, cultural differences may also be relevant. There is strong evidence that ‘South Asians and other immigrants from non-Western cultures tend to express psychological distress through somatization or somatic metaphors more frequently than native Britons’ (Njobru et al (1999), Williams and Hunt (1997)). Psychological distress expressed as physical pain may be misdiagnosed as a physical, and possibly longstanding, illness by doctors. There is evidence that somatization may be influenced more by recent migration than ethnicity per se, as it appears to decrease with increasing acculturation (Westermeyer et al, 1984).

Berthoud and Nazroo (1997) examined the proportion of adults who had symptoms of depression at follow-up after screening positive for depression, using the Clinical Interview Schedule (CIS-R). At the follow-up interview, the Present State Examination (a ‘semi-structured interview and coding frame’) was administered by trained psychiatric researchers. At follow-up, 64 per cent of South Asian adults had symptoms of depression at follow-up; this was significantly lower than the proportion of White (80 per cent) and Caribbean (77 per cent) adults who had symptoms of depression at follow-up after screening positive on the CIS-R. The different rates of depression at screening and follow-up suggests that standard screening instruments may be less effective in identifying illness among South Asian adults.

Acculturation

Berthoud and Nazroo also examined the impact of acculturation. They compared prevalence of depression and psychosis among those who had migrated (after the age of 11) and those who were born in the UK (non-migrants). Rates of depression were marginally lower and rates of psychosis marginally higher among Caribbean migrants than non-migrants. Among South Asians, rates of mental illness were significantly higher among migrants than non-migrants. Although language was considered to be an issue, as migrants were more likely to require translated interviews, further analysis indicated that migration, rather than language per se, was the salient factor. Among non-migrants rates of depression and psychosis were similar to those of the white population. It was suggested that acculturation among non-migrants minimised sources of bias, such as somatization.
Disclosure

Cultural differences in disclosure have been reported. Differences in disclosure may be related to a number of factors, including what are perceived to be appropriate levels of disclosure, trust and cultural context (respondents may be less likely to report symptoms that are prevalent within a cultural group) and the context of the interview. Respondents may be less willing to report symptoms or illnesses if a family member is acting as an interpreter in an interview or meeting with a health professional (Bywaters et al, 2003).

There are particular issues around disability. Katbamna and colleagues examined attitudes to disability among carers from South Asian communities using focus groups and in depth interviews (Katbamna et al, 2000). The study revealed negative attitudes of other family members towards disability and stigma that could influence carers, and in particular parent’s, willingness to talk about disability. With congenital illnesses, disability in children was often linked to one or both parent’s kinship network (or khootum) and carers were less willing to discuss congenital illnesses, e.g., muscular dystrophy, because of the potential effect on other family members, e.g., difficulty of arranging a marriage if disability is perceived to be associated with a khootum.

Of particular relevance for this study, there is some evidence that the concept and definition of a ‘limiting longstanding illness’ appears to differ between ethnic groups. Among respondents who reported a diagnosed illness, such as diabetes or hypertension, prevalence of self-reported longstanding illness was found to be lower among South Asians than White respondents (Pilgrim et al, 1993). Kelehar and colleagues examined the relationship between ethnicity and health. Health was based on self-reported health status (longstanding illness and general health), doctor-diagnosed illness and functional limitations (difficulty in walking 400 yards, difficulty with balance). They found that less than two-thirds of respondents with a functional limitation reported that they had a limiting longstanding illness, but that there were no ethnic differences in this underreporting. However, there were some ethnic differences in overall health status and these appeared to be related to functional limitations rather than reported longstanding illness. Kelehar et al. suggest that specific questions about specific functional limitations relating to mobility, balance, etc. are more appropriate than general questions about longstanding illness. This is salient, although we would not advocate dropping questions on longstanding illness from surveys.

Questionnaire adaptation

In designing questions for different ethnic groups it is important to consider their cultural equivalence. For example, Ainsworth (2000) suggested that questions about physical activity among women were less appropriate for lower income Hispanic women than women in other groups as they focused on leisure activity. Cultural context is important even in monolingual countries as monolingual groups are not homogenous and there are key differences by age, education, etc.
Willis (2004) suggests three techniques for improving cross-cultural equivalence of survey questionnaires:

1. Expert review methods in which experts or groups with linguistic and/or cultural expertise review the translated questionnaires.

2. Cognitive testing. Testing with monolingual respondents (as mentioned above) and multilingual respondents. This may be particularly useful to develop translations around complex terms and core questions.

3. Behaviour coding in which respondent and interviewer behaviour is observed during the interview to identify sources of difficulty, e.g., interviewer misreading translation, respondent asking for clarification, or respondent qualifying responses to express uncertainty.

An alternative approach, is the use of vignettes to ‘anchor’ responses. Vignettes are brief (one or two line) descriptions of people or situations that are presented to a respondent. Respondents must rate their own response on a scale, e.g., general health, and then assess people or situations described in the vignettes on the same scale. Ratings for standard vignettes may be used to anchor or adjust the respondents ‘self-rating’ and to minimise variation in responses due to cultural factors, e.g., different health expectations (King et al, 2004). Vignettes have been used in various contexts, including health. Examples of vignettes used to anchor responses on mobility questions, used on the World Health Pilot Survey are shown below (Salomon et al, 2004):

**Questions:**

Q1. Overall in the past 30 days, how much difficulty did you have with moving around?

(a) none, (b) mild, (c) moderate, (d) severe, (e) extreme.

Q2. In the past 30 days, how much difficulty did you have in vigorous activities, such as running 3km or cycling?

(a) none, (b) mild, (c) moderate, (d) severe, (e) extreme.

**Mobility vignettes, examples:**

- Paul is an active athlete who runs long distances of 20km twice a week and plays soccer with no problems.

- Anton does not exercise. He cannot climb stairs or do other physical activities because he is obese. He is able to carry the groceries and do some light housework.

- Vincent has a lot of swelling in his legs due to a health condition. He has to make an effort to walk round his home as his legs feel heavy.
8 Conducting surveys amongst disabled persons

In this section of the report we turn to the issues likely to arise in conducting survey interviews with people with a wide range of disabilities, and consider how these issues might be addressed.

We have focused on categories of disability and impairment that are relevant to the collection of survey data from disabled people. Classifications such as International Classification of Disease (ICD-10) (focus on diagnosis and health condition) are less relevant for this purpose than a classification that relates to functions that affect communication (spoken and written). With this in mind we have constructed the following classification which divides communication problems along lines that are survey mode-sensitive:

- hearing;
- speech;
- vision;
- manual dexterity;
- literacy;
- cognition.

It is important to consider all levels of severity, as even minor impairments may affect the ability to use certain survey instruments and data quality.

For each of the above categories, we have presented prevalence figures (if available) and discuss the appropriateness of various methods of collecting survey data. To put the prevalence figures into context, a baseline survey of 50,000 persons would represent a sampling fraction of about 1 in 1,000. So dividing the prevalence figures by 1,000 gives some indication of how many people we can expect in a survey of the size we are discussing.
8.1 Hearing

8.1.1 Prevalence figures

According to the Department of Health’s Triennial Return SSDA 910, there were 50,282 registered hard of hearing people and 144,558 registered deaf people in England in 2001. They classify people as being deaf if they have little or no useful hearing (even with a hearing aid), and hard of hearing if they have some useful hearing (with or without a hearing aid) and their normal method of communication is by speech, listening and lip-reading.

However, it is generally accepted that these registers severely under-estimate the true number of people who are deaf or hard of hearing. The Royal National Institute for the Deaf (RNID) quote much higher estimates on their web site: almost 7.5 million people in England are either deaf or hard of hearing of which 577,000 are severely or profoundly deaf (rely on lip-reading and British Sign Language (BSL) to communicate, even with hearing aid). Equivalent figures for Great Britain (GB) are 8.7 million and 670,000 respectively. These figures equate to about 15 per cent of the GB population being deaf or hard of hearing, including one per cent who are severely or profoundly deaf.8

The RNID figures correspond closely with estimates obtained from the General Household Survey (GHS); 16 per cent of those aged 16 and over living in private households in GB reported hearing difficulties in 2002.

It should be noted that sixty per cent of people who are deaf or hard of hearing are over 70 years old and are therefore likely to have other disabilities. For example, there are about 23,000 deaf-blind people in the UK.

8.1.2 Methods of communication

Depending on the severity of hearing loss, people who are hard of hearing or deaf use one or more of the following methods of communication: speech with or without a hearing aid, lip-reading, BSL and written communication.

According to the 2002 GHS, among those who reported having hearing difficulties, about one in four wore a hearing aid. However, 62 per cent of those who have a hearing aid continue to have hearing problems. In other words, there are about eight million people in GB with hearing problems, even with a hearing aid. A loop or infrared system helps people who use a hearing aid to hear sounds more clearly by reducing background noise. Loop and infrared systems are usually installed in public buildings such as banks but they can be installed in the home and a portable loop system is also now available.

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8 Most of the estimates on the RNID web site were derived from research carried out by the Medical Research Council (MRC) Institute of Hearing Research
A User Survey among RNID members showed that 39 per cent of respondents reported that they used lip-reading to communicate. However, there was no information available to assess the representativeness of this survey among RNID members, let alone among the population of deaf and hard of hearing people. Deafened people, i.e. those who became profoundly deaf after developing speech, tend to rely heavily on lip-reading and written communication. There are an estimated 123,000 deafened people in the UK aged 16 and over.

BSL is a separate language with its own grammar and it cannot be written down. It is unclear how many people use BSL as their first or preferred language. The RNID web site suggests that current estimates vary between 50,000 and 70,000 in the United Kingdom (UK). Many people who are born deaf or are deafened early in life use BSL to communicate and tend to have limited understanding of English; the average reading age of severely/profoundly deaf school-leavers is nine years old. Consequently it may not be possible to collect survey data from them in writing.

In summary, there are about eight million people in GB who are deaf or hard of hearing, even when using a hearing aid. The majority of these people communicate using various combinations of speech, lip-reading and writing. A small proportion (less than one per cent) use BSL, but they are a distinct group which differs significantly from other groups of deaf or hard of hearing people.

Table 8.1 Estimated number of deaf and hard of hearing people by degree of deafness and main method of communication

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mild/moderate deafness</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can hear with hearing aid</td>
<td>762,850</td>
<td>9</td>
</tr>
<tr>
<td>Hearing problems with/without hearing aid; rely on speech, lipreading and writing</td>
<td>7,267,150</td>
<td>84</td>
</tr>
<tr>
<td>Total</td>
<td>8,030,000</td>
<td>93</td>
</tr>
<tr>
<td><strong>Severe/profound deafness</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rely on lip-reading and writing</td>
<td>610,000</td>
<td>7</td>
</tr>
<tr>
<td>BSL as first or preferred language</td>
<td>60,000</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>670,000</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>8,700,000</td>
<td>100</td>
</tr>
</tbody>
</table>

Source: Figures derived from RNID web site

8.1.3 Data collection modes

**Face-to-face interview**

Among those people who have mild to moderate hearing problems, a face-to-face interview is definitely possible with those who do not have any hearing problems when using a hearing aid (about nine per cent of all people who are deaf or hard of hearing). A face-to-face interview may also be possible with some of the other
people with mild/moderate hearing problems, depending on the severity of their hearing problem and the complexity of the interview. However, a large proportion of those with mild/moderate hearing problems would not be able to rely solely on speech but would have to use lip-reading and writing to communicate. Ample use would have to be made of visual aids. It is highly likely that interviewers would have to show the written questions to a large number of these respondents.

Most people who are severely/profoundly deaf rely on lip-reading and writing to communicate. Interviewers would have to be trained to enunciate well and to keep their lips visible throughout the interview. However, it is very tiring to lip-read for a long time and therefore a face-to-face interview with this group is unlikely to be feasible, even with ample visual aids.

About ten per cent of those who are severely/profoundly deaf (and less than one per cent of all people with hearing problems) have BSL as their first or preferred language. It is possible to interview these people face-to-face with a qualified BSL translator. In order to translate the questionnaire accurately, the researchers and BSL translator need to discuss all the words and concepts that have no direct equivalent in BSL.

Computer-Assisted Self-Interviewing

Increasing use has been made of Computer-Assisted Self-Interviewing (CASI) in face-to-face interviews whereby the interviewer hands a laptop to the respondent with the questions displayed on the screen and the respondent enters their answers directly into the computer. For most deaf and hard of hearing people this should be an acceptable method of collecting survey data.

For those people with some hearing, use could also be made of Audio-CASI whereby questions are not only displayed on the screen but also read out through headphones, with or without amplification. The combined use of text and audio could be particularly helpful to those with eyesight problems.

Most deaf people who use BSL as their first language would not be able to use a CASI instrument because most of these people have limited knowledge of English. However, this amounts to less than one per cent of all deaf and hard of hearing people.9

Telephone interview

Many people who are hard of hearing can use the voice telephone with a telephone amplifier. Telephone amplifiers make incoming speech about two to four times louder. Some telephone amplifiers also have an inductive coupler for people who use hearing aids. There are no data available on the number of hard of hearing people who use a voice telephone, with or without an amplifier. Consequently it is unknown how many of them could be interviewed by voice telephone.

9 Although the proportion of BSL users among all people who are deaf or hard of hearing is small, it should be noted that they are likely to have very different needs from those who are included in the survey.
According to the RNID, almost two-thirds (64 per cent) of those who are severely or profoundly deaf cannot hear well enough to use a voice telephone, even with amplifiers.

People who cannot use voice telephones might use textphones or videophones. It is unknown how many people with hearing problems have textphones. Those with textphones can communicate directly to other people with textphones, or indirectly via an operator who acts as an intermediary (e.g. RNID Typetalk). Text messages can also be sent from computers to textphones and vice versa. So if we wanted to interview this group by telephone, we could use a textphone, use RNID Typetalk or use Computer Assisted Telephone Interviewing (CATI) to send text questions and receive text answers. How the latter would actually work requires further investigation. It is unknown how many hard of hearing people we could interview using any of these methods.

Videophones are still relatively new and few people have them. However, this is likely to become a valuable communication tool for those whose first or preferred language is BSL.

A new telephone invention that is likely to be marketed within the next four to five years is Synface, short for ‘Synthetic talking face’. Synface takes the incoming telephone voice and converts it into realistic lip movements on a face that is displayed on a screen. Trials with hard of hearing people showed that it helped 84 per cent of the testers to make phone calls.

Postal questionnaire

Almost all people who are deaf or hard of hearing can read, so a postal questionnaire would be a feasible option. A postal survey would exclude deaf-blind people, depending on the severity of the vision disability and the design of the postal questionnaire. Most deaf people who use BSL as their first language would also be excluded because most of these people have limited knowledge of English. However, overall this amounts to less than 1% of deaf and hard of hearing people being excluded from a postal survey.

Web survey

Same conclusions as for postal surveys. Those without access to internet would also be excluded.

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10 Telephone numbers for textphone users have access codes ranging from 018000 to 018009. So it would be possible to identify textphone users from the telephone numbers they provide.

11 Although the proportion excluded from a postal survey is very small, it should be noted that the people being excluded are distinct groups who are likely to have very different needs from those who are included in the survey.
8.1.4 **Advance letters**

It is generally accepted that advance letters should be sent to sample members before they are approached to take part in a survey. Advance letters tend to include a telephone number for those people who require further information. In addition to a standard telephone number, the advance letter should also include a textphone number and/or a Typetalk number.

8.2 **Speech**

8.2.1 **Prevalence figures**

According to the Royal College of Speech and Language Therapists approximately 2.5 million people in the UK have a communication disorder of some kind, including relatively minor disorders such as stuttering. This equates to about four-five per cent of the UK population. Of those 2.5 million people, about 800,000 have a difficulty so severe that it is hard for anyone outside their immediate families to understand them; about 1.5 per cent of the UK population. The source for these figures is not referenced.

8.2.2 **Methods of communication**

Those with severe speech difficulties use unaided communication methods such as body language, sign language, verbal and gestural strategies. They may also use the written word as an alternative to speech.

An unknown proportion of people with speech difficulties use communication aids such as objects, photos or symbols organised in charts or books and Voice Output Communication Aids (VOCAs). VOCAs are hardware units or laptops installed with communication software, using symbols and/or text, that produce speech with either digitised voice recordings or a synthesised voice.

In the disabled community, a person who uses speech devices to communicate is called an augmentative communicator.

8.2.3 **Data collection modes**

*Face-to-face interview*

A person who is only affected by a speech impairment should have no difficulty understanding well-designed questions administered by an interviewer. However, depending on the severity of the speech impairment, the interviewer may require help from others who can understand the respondent and/or the respondent may require some form of assistance to answer the questions.

If there is someone available who understands the respondent, then this person could repeat the respondent’s answers to the interviewer. However, this would be undesirable for sensitive questions. Furthermore, this approach is likely to be tiring for the respondent and will increase the length of the interview considerably.
Those respondents who use VOCAs can be interviewed face-to-face without help from others. It is possible that the use of VOCAs will increase the length of the interview. This needs further investigation.

Those respondents with severe speech impairment who do not use VOCAs can, to some extent, be interviewed on their own without help from others. On the whole, they should be able to answer questions that require a ‘yes’ or a ‘no’ answer. These answers could be given using verbal or gestural strategies. Closed questions requiring other responses than a simple Yes/No, could be answered by pointing at the appropriate response category on showcards and/or on the laptop screen. Open-ended questions would require written answers from the respondent. The interviewer would be able to read the respondent’s answers and, if necessary, provide clarification and probe for complete responses.

It should be noted that an unknown proportion of those with speech impairments have problems with writing and recognising the written word. If the cause of their speech impairment is cerebral palsy or a degenerative disease, they may have reduced manual dexterity making it difficult or even impossible to write. If they have damage to the left side of the brain (e.g. caused by stroke or head injury), other aspects of language may be affected such as the ability to understand and the ability to read and write words.

**Self-completion methods**

On the whole, self-completion methods (e.g. CASI, postal, web) are acceptable for those people who only have a speech impairment. However, as noted above, an unknown proportion of those affected will have other impairments, such as loss of ability to understand and reduced manual dexterity. These other impairments may reduce their ability to use a self-completion questionnaire.

**Telephone interview**

A standard telephone interview would not be possible with this group. Those with textphones can be interviewed by telephone, with the interviewer using speech to ask questions and the respondent using text to answer (see section 8.1.3 for further details). If the questionnaire only included closed questions with relatively short response lists, it should be possible to use Touchtone Data Entry (TDE) to receive responses from the respondent.
8.3 Vision

8.3.1 Prevalence figures
According to the Department of Health’s Triennial Return SSDA 902, there were 156,675 registered blind people and 155,230 registered partially sighted people in England in 2003. About five per cent of those registered blind or partially sighted are either deaf or have some other hearing impairment. The statutory definition of blindness is that a person should be ‘so blind as to be unable to perform any work for which eyesight is essential’. There is no official definition of partial sight, but in practice this category refers to people who are substantially and permanently disabled by defective vision.

However, it is generally accepted that these registers severely under-estimate the true number of people who have sight disability. According to the 1995 Health Survey for England, three per cent of adults aged 16 and over had sight disabilities. This proportion equates to about 1,065,000 adults which is 3.5 times more than the number of registered and partially blind people combined.

8.3.2 Methods of communication
Most blind and partially sighted people rely heavily on speech communication. Communication based on the written word is problematic to varying degrees, depending on the severity of the impairment.

The Royal National Institute for the Blind (RNIB) carried out a survey in 1986/87 among 595 blind and partially sighted adults in Great Britain (GB). They found that 48 per cent of their sample were able to read standard print (e.g. 12pt Century Book with 3pt leading) but not necessarily with ease. Thirty six per cent of blind respondents and 75 per cent of partially sighted respondents could read large print (e.g. 14pt and above). However, Gregory (1996) warns not to over-estimate the effectiveness of large print; it might be possible to decipher words in large print but it could be difficult to read a whole leaflet or a book in large print. In addition to the size of print, the font and layout may also affect readability for some blind and partially sighted people. However, there is no single design that would suit all. For example, text designed for someone with glaucoma (which affects peripheral vision) will not be suitable for someone with macular disease (which affects central vision).

There are various aids available to help blind and partially sighted people read standard print. Scanners (or Optical Character Readers) can be used to display standard print in an enlarged form on the computer screen. Speech synthesisers can be used to read text aloud from scanned text or from a computer file. Soft/renewable braille read-outs (movable pins on a special display linked to a computer) allow Braille readers to read text from a computer text. Text on disc or from the Internet can be converted into Braille using Braille embossers. Printed text and graphic images can be scanned and converted into a tactile image which can be ‘read’ with a fingertip. There are no data available on the number of blind and partially sighted people who use these aids.
It is standard practice for most service providers and Government Departments to offer information to blind and partially sighted people on audio-tape, as well as in large print and Braille.

Based on the 1986/87 survey results, the RNIB estimated that there were 19,000 Braille readers in GB of which 13,000 were active readers. It is very likely that the number of Braille users has increased since this survey was carried out. The RNIB now claim on their web site that there are 20,000 Braille users in the UK (data source not mentioned). For many deafblind people, Braille is an essential means of communication. Although Braille readers comprise a small proportion of all blind and partially sighted people (just under two per cent), they are a distinct group. Most of them have been blind since birth or lost their sight at an early age. They tend to be the most influential or most active members of the blind community. Twenty per cent of working age people who could be registered as blind (even if they are not actually registered) are able to read Braille. Active Braille readers have a strong preference to receive and store information in Braille (Gregory, 1996).

8.3.3 Data collection modes

*Face-to-face interview*

A face-to-face interview is a suitable data collection method for blind and partially sighted respondents.

If possible, visual aids such as showcards should be avoided. If visual aids are required, these should be printed in clear print to maximise the number of partially sighted respondents who can read them: e.g. black text on white background, non-ornate typefaces such as Arial, type size of 14pt, ample spacing, avoid capitalised and italicised text. More detailed recommendations on clear print can be found in the RNIB’s ‘See it right Pack’ 12. The RNIB also offer an accessible information consultancy service.

Show cards can be produced in Braille. Although the number of respondents who can read Braille in the sample may be small, the production of show cards in Braille should be seen as a reasonable adjustment to allow the respondent to read the show card using their preferred method.

For those respondents who cannot read clear print and cannot use Braille, interviewers can read out the response lists on show cards. Response lists should be kept as short as possible. In some cases, long response lists could be converted into ‘unfolding’ lists. If so, then ‘unfolding’ lists should be used for all respondents to minimise mode effects. Nevertheless, some mode effects may remain due to differences in response to visual stimuli and aural stimuli (i.e. recency versus primacy effects).

12 http://www.rnib.org.uk/xpedio/groups/public/documents/PublicWebsite/public_seeitright.hcsp#P70_4636
Telephone interview

A telephone interview is a suitable data collection method for blind and partially sighted respondents.

Self-completion methods

All self-completion instruments used in a face-to-face survey should be printed in clear print (see Section 8.3.2). Most large-scale surveys now use CAI (computer-assisted interviewing) in which self-completion documents are also computerised (CASI = computer-assisted self-interviewing). There are ample guidelines on how to make text on screens accessible to blind and partially sighted people. Ideally the CASI instrument should be designed to be flexible so that respondents are able to adjust text and colour settings to suit their individual needs. CASI instruments can be designed with audio; questions and responses can be heard through headphones as well as being displayed on the screen.

All postal questionnaires should be printed using clear print so that the number of blind and partially sighted people that can read them is maximised (see Section 8.3.2). For those who have a computer, it is also possible to send an electronic version of the questionnaire which could easily be adjusted by the respondent to suit their needs; e.g. text can be magnified, text-to-speech software can be used. The option of a questionnaire on audio-tape and Braille could be offered, but there is no practical way of recording the respondent’s answers in a standardised format. Consequently those blind and partially sighted people who cannot read clear print and do not use text to speech software would be excluded from a postal survey.

Blind and partially sighted people with access to the internet can complete accessible email and web questionnaires. Internet questionnaires must be designed to be flexible. Respondents should be able to adjust text and colour settings to suit their individual needs. The design should also take into account that some respondents may use ‘text to speech’ software; e.g. inappropriate use of HTML can make a web site unreadable. Respondents’ answers could be typed in or spoken answers could be sent in audio files. The technology that is required to store and send recorded answers in audio files needs further investigation.

Blind and partially sighted people could self-complete a questionnaire by telephone. All questions would be recorded and then the respondent could provide his/her answers using TDE and/or speech (spoken answers could be recorded in audio or speech recognition software could be used).

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13 For example, RNIB’s ‘See It Right’ pack, AbilityNet’s ‘Web Accessibility Key Info’ pack, Disability Rights Commission’s report ‘Web Access and Inclusion for Disabled People’.
8.4 Manual dexterity

8.4.1 Prevalence figures
Analysis of data from an Omnibus Survey showed that about 2.3 million adults in the UK had a manual dexterity disability; that was about four per cent of the adult population (In-house report 30, Grahame Whitfield, DSS, 1997). To qualify as a disability, the manual dexterity difficulty must be long-term (i.e. likely to last at least 12 months) and must also limit the adult’s ability to carry out normal day-to-day activities. Figures on the number of adults that cannot write or use a keyboard due to a manual dexterity disability are not available.

8.4.2 Methods of communication
People with limited manual dexterity can communicate using speech and can read, unless they have an additional disability such as aphasia, dysarthria, or a visual impairment.

Manual dexterity disabilities result in the loss of fine control of movement, which can affect writing speed and legibility. Some people may use writing aids such as pencil grips and wrist supports. Many people with limited manual dexterity may find typing easier than writing. Keyboards can be altered to make typing with the fingers easier, or they can be adapted to be used by another part of the body, e.g. a head pointer.

8.4.3 Data collection modes

*Face-to-face interview*
A face-to-face interview is a suitable data collection mode for people with limited manual dexterity.

*Telephone interview*
A telephone interview is a suitable data collection mode for those people who can operate a telephone. Holding a handset might be difficult and keypad operation could be slow and inaccurate. An unknown number of people with limited manual dexterity will have adapted telephones, e.g. enlarged keys, handsets that are lightweight and easy grip, hands-free operation, speech input. Even with adapted telephones, the task of operating a telephone might be painful for some people. This will have consequences for the maximum feasible length of the interview.

*Self-completion methods*
Depending on the severity of their dexterity limitations, it might be possible to use a self-completion instrument in a face-to-face interview. If the self-completion document is paper and pencil, respondents who can hold a pencil (with or without a writing aid) can indicate their choice of response to a closed question by making a mark in the relevant box. The boxes should be sufficiently large with ample spacing between the boxes. Open questions should be avoided.
For those who find typing easier than handwriting, a CASI instrument could be used. On the whole, laptops are used in the field. The relatively small keyboard with built-in mouse could be ideal for respondents with limited hand movement. Other respondents with limited dexterity may prefer sturdier keyboards with chunky keys. Interviewers could be given such a keyboard that could be plugged into the laptop when required. Some respondents may require a head pointer. It is essential to position the laptop and keyboard so that the respondent can use it comfortably.

Some people with limited dexterity may be able to complete a well-designed postal questionnaire, possibly using writing aids. As for the self-completion document used in a face-to-face interview, open questions should be avoided and response boxes should be large with ample spacing between them.

Those who have access to a computer and prefer to type than handwrite could be sent an electronic version of the questionnaire. If they also have access to the internet, they could be offered the option of completing a web questionnaire.

Respondents who can operate a telephone, can complete a questionnaire by phone using TDE and speech recognition.

For all of these self-completion methods, it should be noted that the task of completing the questionnaire could be painful and tiring for some people. Consequently, the questionnaire should be short.

8.5 Literacy

8.5.1 Prevalence figures

The most widely accepted rate of adult illiteracy, is that quoted by the Basic Skills Agency; roughly 20 per cent of adults in England (that is perhaps as many as 7 million people) have more or less severe problems with basic skills, in particular with what is generally called ‘functional literacy’ and ‘functional numeracy’: ‘the ability to read, write and speak in English, and to use mathematics at a level necessary to function at work and in society in general’.

However, relatively few adults are completely illiterate and therefore cannot read at all.

Research by the Centre for Longitudinal Studies (CLS) for the Basic Skills Agency has divided the overall 19 per cent with weak literacy skills into two categories. About six per cent of the adult working population are judged to have ‘very low’ literacy skills and a further 13 per cent to have ‘low’ literacy skills:

1. Those with ‘very low’ skills (six per cent) are likely to have great difficulty with any reading, struggling to read the simplest and shortest texts. However, they may be able to cope with simple signs and advertisements, especially when these are illustrated.
2. Those with ‘low’ literacy skills (13 per cent) may be able to read a short article from a tabloid newspaper and pick out favourite programmes from a TV guide, but may read slowly with little understanding.

Many people who have literacy problems will not admit to this because of the stigma attached to it. These people may have found ways of disguising their problems with literacy in day-to-day life. Gregory (1996) claims that ‘hidden’ illiteracy could include as many as one in six of the adult population.

Many people are unaware of their poor skills, and many, even if aware, don’t regard it as a problem. Less than five per cent of adults say they have a problem with reading.

Some people who have low levels of literacy will have specific learning difficulties such as dyslexia and dyspraxia. Some may have a general cognitive learning difficulty which affects their ability to learn how to read and write. Others may have missed out on education, resulting in low levels of literacy. However, not all those with these characteristics will have low levels of literacy.

8.5.2 Methods of communication

Communication through speech is not necessarily a problem for those with low levels of literacy. However, some people with low levels of literacy may find communication hard, particularly if their illiteracy is related to some other problem, such as damage to the left part of the brain affecting various aspects of language.

Written communication could be a problem, depending on the level of illiteracy and the complexity of the written document. However, relatively few people are completely illiterate and therefore cannot read at all.

8.5.3 Data collection modes

*Face-to-face interview*

A face-to-face interview is a suitable data collection mode for people with literacy problems. If possible, the use of show cards should be avoided. When show cards are used, they should be in plain language, as concise as possible and printed in a clear sans serif font. Illustrations can be used to keep written text to a minimum.

*Telephone interview*

A telephone interview is a suitable data collection mode for people with literacy problems.

*Self-completion methods*

Depending on the level of literacy, some people with literacy problems may not be able to use self-completion documents.
In a face-to-face interview which includes a self-completion document, it may not always be clear to the interviewer that there is a problem with literacy. The respondent may ask the interviewer to read out the questions for them (e.g. I left my reading glasses on the bus). Others may ask the interviewer to leave the questionnaire behind, so that they can then ask other household members to help them. Some may refuse to use the self-completion document or refuse to take part all together.

Audio-CASI is a useful self-completion instrument for people with literacy problems. The respondent can hear the questions and answers being read out through headphones, as well as being displayed on the screen. The combination of visual and auditory presentation will help people of various literacy levels. Use of Audio-CASI will increase the amount of time it will take to fill in the self-completion questionnaire.

Postal surveys are likely to have high levels of non-response among those with literacy problems. The cognitive burden of completing the questionnaire will discourage many people with literacy problems to take part.

Those with access to a computer could be sent an electronic questionnaire with audio.

There are various guidelines for developing written documents for those with literacy problems: in plain language, as concise as possible, in clear type. Columns and lines should not be positioned too closely to each other. Illustrations and diagrams can help keep text to a minimum (e.g. instructions in a questionnaire, routing). However, the text type should not be too large or the language too simplistic because this will give the impression that it has been designed for children or for people with learning difficulties.

In addition to these general guidelines for people with literacy problems, there are also guidelines for developing written material for people with dyslexia: black text on yellow paper, sans serif typefaces (Sassoon is generally recommended for dyslexia but Arial, Comic Sans MS, Tahoma and Trebuchet fonts are also acceptable), numbered lists rather than bulleted ones.

Preferred fonts and background colour may vary by person; electronic media can be changed to display the font and background preferred by the respondent.

Self-completions by telephone can be carried out using TDE and speech recognition.

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14 The British Dyslexia Association estimates that four per cent of the population is severely affected by dyslexia, and ten per cent of the population ‘show some signs’ of the condition.
8.6 Learning disabilities

8.6.1 Prevalence figures

A learning disability is a lifelong condition that affects people’s ability to learn, communicate or do everyday things. The severity of the learning disability varies greatly, with most people being able to live independently, albeit with some level of support in everyday activities. Others with a more severe or profound learning disability may require 24-hour care. According to Mencap there are nearly 1.5 million people with learning disabilities in the UK (about two-three per cent).

The Foundation for People with Learning Disabilities (2000) take the view that there are no reliable statistics concerning the number of people with learning disabilities in the UK. Nevertheless, they estimate that between 230,000 and 350,000 people have severe learning disabilities, and a further 580,000 to 1,750,000 have mild learning disabilities. This suggests that about 20 per cent of all people with learning disabilities have severe disabilities.

8.6.2 Methods of communication

The nature of people’s learning disabilities varies widely and will affect the kind of communication that they can use. According to the Foundation for People with Learning Disabilities (2000):

- Between 50 per cent and 90 per cent of people with learning disabilities have some communication difficulties.

- About 60 per cent of people with learning disabilities overall have some skills in symbolic communication, such as speech, signs or picture symbols.

- About 20 per cent have no verbal communication skills but do demonstrate intentional communication (i.e. communication where there is clear evidence of an intent to communicate and an expectation of a response).

- About 20 per cent have no intentional communication skills.

- About 80 per cent of people with severe learning disabilities have no effective speech, although they will demonstrate that they want to communicate by other means.

Speech is a suitable communication method for about three out of five people with learning disabilities. However, they may have problems grasping complicated concepts and may not be able to absorb a lot of information at one go. Repetition is important if people with learning disabilities have to remember what is being said.

Speech is unlikely to be an effective means of communication for most people with severe to profound learning disabilities. Mencap and Bild have jointly produced a brochure, ‘See what I mean’, which provides guidelines to aid understanding of communication by people with severe and profound learning disabilities (ISBN 01902519418, £10).
Many people with learning disabilities will have difficulty reading and writing. Section 8.5 provided guidelines on producing written documents for those with literacy problems. These guidelines also apply to people with learning difficulties who can read to some extent but have literacy problems. More detailed guidelines for accessible writing can be found on Mencap’s website, including a brochure ‘Am I making myself clear?’.

Mencap also provides other services such as giving advice on making documents accessible to people with learning disabilities, editing/writing accessible documents, and training in how to write and design accessible documents.

8.6.3 Data collection modes

The Foundation for People with Learning Disabilities claim that the effectiveness of communication with people who have learning disabilities depends to a large extent on the relationship between the people involved, the non-disabled person’s knowledge of the other person, and the opportunities people have to use their communication skills. Any initiative to develop communication must: be individualised; be developed at the individual’s pace; allow people to choose whether to communicate; and be sensitive to ethnic and cultural issues.

A BMRB Feasibility Study on Learning Difficulties (2002) concluded that the best way to collect survey data from people with learning difficulties is to:

- use multiple methods – written, verbal and visual;
- adopt a flexible and informal approach – like a friendly chat rather than an interview;
- carry out some preliminary research in order to uncover respondents’ needs and build rapport;
- provide both respondents and carers with comprehensive and accessible information prior to taking part;
- be realistic about who will be able to take part and what can be achieved;
- tailor the survey to the respondents’ needs as far as possible;
- include a full range of topics;
- ground the survey questions in experience as far as possible to aid understanding; and
- thoroughly brief the researchers.

Face-to-face interview

A face-to-face interview is a suitable method for collecting data from people with learning disabilities. It is the most effective data collection mode for developing rapport with the respondent. It also provides the opportunity to somewhat tailor the communication method to suit the respondent. However, the latter will require thorough training of the interviewers.
General rules when communicating with people who have learning disabilities are (Gregory, 1996):

- Don’t use long sentences.
- Include one main point, and only one or two clauses in a sentence.
- Communicate in the active voice, rather than the passive.
- Avoid abstract concepts.
- Use simple words, without being patronising.
- Repeat difficult or unfamiliar words.
- Don’t use jargon.
- Avoid abbreviations and acronyms.
- Avoid using the third person.

If the above guidelines are followed, it may be possible to use a standardised questionnaire to interview about three out of five people with learning disabilities (i.e. those with intentional verbal communication skills). If the questionnaire is relatively straightforward and only requires Yes/No answers, it may also be possible to include some people with no verbal communication skills but who can demonstrate intentional communication using other means such as gestures, signs, symbols.

Because many people with learning disabilities have problems reading, the use of show cards with written response options should be avoided. If show cards are necessary to aid understanding, illustrations and symbols can be used alongside text to help people understand and remember the meaning of the words. The best known symbol system in the UK is Makaton. Further information about Makaton can be found at http://www.makaton.org/.

**Telephone interview**

Although many people with learning disabilities are able to operate a telephone, it is unlikely that this would be a suitable data collection method. It is more difficult to establish rapport on the telephone, there are no visual cues to alert the interviewer of misunderstandings, and the length of a telephone interview would have to be relatively short, thus limiting the ability to conduct the interview at the respondent’s pace.

**Self-completion methods**

As noted before, many people with learning disabilities will have difficulty reading and writing. Consequently, postal surveys are likely to have low response.

Gregory (1996) claims that many people with learning difficulties are proficient at using computers. Access to computers is provided at many day centres and adult education places for people with learning disabilities. Also computers can be set up
to suit their particular needs. So it might be possible to either send electronic versions of the questionnaire with audio or offer them the opportunity to complete a web questionnaire. Similarly, the use of Audio-CASI in a face-to-face interview may be feasible for many people with learning disabilities.

Gregory (1996) provides guidelines on the design of written documents for people with learning disabilities:

- Keep line length short.
- Range text with a ragged right hand margin.
- Use short, clearly separated chunks of text.
- Allow enough space between columns of text.
- Avoid design features which impede legibility such as excessive use of capital letters; stretching or condensing text to fit a particular space or ornate type faces.

Illustrations and symbols can be used alongside text to help people with learning disabilities to understand and remember the meaning of the written word (e.g. Makaton).

More detailed guidelines for accessible writing can be found on Mencap’s web site (‘Am I making myself clear?’) as well as guidelines for making web sites accessible to people with learning difficulties.

8.7 Multiple disabilities

Many people with disabilities have more than one disability. According to the results of the 2001 Health Survey for England, just over half (55 per cent) of men and women with any disability had one disability, a third had two disabilities and about a tenth had three or more disabilities (private households only). The prevalence of multiple disabilities increased steadily with age. There is also a clear stepped relationship between severity and the number of co-morbidities.

According to Sense (UK Deafblind Charity), there are an estimated 23,000 people in the UK who are deafblind. Some of these people will have been born with impaired vision and hearing while others will have acquired their dual sensory impairment later in life. People who are deafblind have a significant impairment of both their hearing and vision. Some are totally blind and deaf, but others have some remaining use of one or both senses. The use of more than one communication method is required, such as the use of speech, writing words down, finger spelling, different types of sign language, body language, facial expression and gesture, pictures, significant objects of reference, models, symbols, line drawings, tape, Braille, Moon.

According to Mencap, there are an estimated 40,000 people in the UK who have profound and multiple learning disabilities. People with profound and multiple
learning disabilities have a profound intellectual impairment and additional disabilities. These may include sensory disabilities (visual impairment or hearing loss), physical disabilities, autism and mental illness. The majority of children and adults with profound and multiple learning disabilities have communication difficulties. They are often reliant on others to interpret facial expression, vocal sounds and body language to express their needs and preferences.

It is important to be flexible when helping people with multiple disabilities to communicate. It is likely that a range of communication methods will have to be used together. This is often called the ‘total communication approach’.

### 8.8 Mode effects

Based on the discussion above, it appears essential that to ensure good coverage of the population of disabled people the survey design needs to be flexible enough to allow different data collection modes to be used with different respondents. However, the use of different data collection modes may produce measurement differences by mode.

There are different reasons why respondents might answer questions differently if asked in one mode rather than the other; e.g. the presence versus absence of an interviewer, visual versus oral communication, whether interviewer or respondent controls delivery of stimulus.

The presence of an interviewer can improve data quality because the interviewer can motivate the respondent to answer the questions, help the respondent with queries and probe for complete answers. On the other hand, the presence of an interviewer may produce a social desirability effect; i.e. the respondent provides answers that they think are socially acceptable and desirable. People with learning disabilities may be more susceptible to this because of their tendency towards acquiescence and the possibility that they perceive the interviewer as someone of authority.

A well established principle in survey methodology is that there is a ‘primacy effect’ when response options are presented visually (e.g. respondents are more likely to select options that are at the top of a printed list) and a ‘recency effect’ when the response options are presented orally (e.g. respondents are more likely to select options that are read out last). The need to present response options visually to those who are deaf and orally to those who are blind, is likely to introduce mode effects – particularly if the list of response options is long.

In a postal survey, the respondent controls the delivery of stimulus; i.e. the respondent controls the order in which questions are answered and this does not necessarily comply with the order of questions in the questionnaire. This could be problematic if knowledge of subsequent questions can influence the answers to previous questions (context effects).
Measurement differences in mixed mode surveys can be minimised by adopting a unimode questionnaire construction, i.e. ‘...the writing and presenting of questions to respondents in a way that assures receipt by respondents of a common mental stimulus, regardless of survey mode.’ (Dillman, 2000). However, it is unlikely that mode effects could be eliminated completely.

On the whole, sensitive questions and attitudinal questions tend to be more susceptible to mode effects than factual questions.

8.9 Questionnaire development

The following bulleted list gives some thoughts on the implications of the discussion above on questionnaire design, especially for those with either specific or severe disabilities.

- **Questionnaire complexity:** Questionnaires should be kept as simple as possible; some respondents will be completing the questionnaire themselves in PAPI format; some respondents will be relying on lip-reading to understand the interviewer; some respondents will require help from others in the household to answer their questions (e.g. using gestures, symbols, etc); some interviews will have to be translated into BSL.

- **Increasing the complexity of the questionnaire will increase respondent burden.** Consequently, the respondent may resort to ‘satisficing behaviour’, i.e. the respondent shortcuts the cognitive processes involved in answering the questions. Such shortcuts include not answering the question at all (e.g. ‘don’t know’, refusal to answer), truncating answers to open-ended questions, a tendency to agree with attitude questions (acquiescence), a tendency to select extreme response categories with attitude questions, a tendency to select the same response category to a number of successive questions (non-differentiation), and a tendency to select a response category at random (mental coin flipping).

- **Questionnaire length:** Some interviews will take longer than others because of the method of communication. Some respondents will tire more easily than others. Some may be in pain. Questionnaire length should be kept as short as possible.

- **Due to the extreme diversity of the disabled population, it may be desirable to design the questionnaire in such a way that any individual can answer the maximum number of questions that they can cope with.**
The BMRB Feasibility Report ‘Learning Difficulties’ recommended that the questions be divided into three different levels:

- simple Yes/No questions for all to answer; should be answered by individuals in many cases;
- slightly more complex questions; e.g. scale questions, three or more pre-codes; may be answered by the individual or support person depending on circumstances;
- more complex questions; for some groups (e.g. those with learning disabilities), only a carer/support worker is likely to be able to answer.

An assessment procedure may be required at the beginning of the questionnaire to determine which data collection method is appropriate, whether a support person will be required, whether the respondent wants the support person to answer on their behalf, etc.

Development of the questionnaire can be done with help from The Informability Unit (government) and various charities such as RNIB, Mencap, Bild, Sense, People First, Speakability which provide consultancy on information accessibility.

Qualitative research may be needed with people who have hearing, speech, visual, dexterity, learning disabilities to determine the topics to be covered.

Questionnaires should be piloted, and possibly cognitively tested, with people who have hearing, speech, visual, dexterity, or learning disabilities.

8.10 Implications for survey administration

Clearly, dealing with the full range of disability in a single survey will generate a large number of design and administrative issues for which practical, and as far as possible cost-effective, solutions will be needed. Some of the key issues are listed below:

- Although it would be desirable to collect standardised data from all survey respondents the need for shorter interviews with some groups will require a compromise.
- The need to develop different questionnaires for different groups will mean the development time for any survey will be considerably longer than for more mainstream surveys.
- It will not be practical to train all interviewers to cover all interviews. Where special interviews are needed the first interviewer will need to arrange for a specialist interviewer to call back. This will add to interviewing costs and will lengthen the fieldwork period.
Designing a new longitudinal survey

Pulling together all of the discussion above we conclude the following (large) number of points:

- There is a need for a new prevalence survey of disability. For those living in private households this can either be done by carrying out a new large-scale population survey (with, we suggest, an achieved sample of at least 50,000) or by piggy-backing on some other large scale survey, although the latter option potentially leads to the exclusion of those with severe communication or learning disabilities. Of the two options we favour the former.

- If, of the two options, the new survey approach is adopted, the baseline surveys should be done face-to-face. Efforts should be made to make the survey as inclusive as possible for those with different disabilities. Dealing with different disabilities will mean employing flexibility in the survey mode and in the exact questions asked.

- A new set of questions that identify disabilities and allow severity to be scored are needed. Ideally, a short set of questions that cover the former should also be developed for use on other surveys. A different set of questions will be needed for children.

- The prevalence survey (or the piggy-backed survey) would become the sampling frame from which three follow-up samples are generated: a sample of currently disabled persons; a comparison sample; and an onset screening sample.

- The sample of ‘currently disabled persons’ would be followed up face-to-face for a number of years (we suggest about ten) with interviews either annually or biannually.

- The comparison sample would be followed up in the same way.
• The onset screening sample would be followed up once a year (for the full duration of the study) and by telephone with the aim of identifying those who have experienced an onset. Further research is needed on how to define and identify an onset (this will be based on the new screening questions).

• If screening a sample as large as the onset screening sample (approx 38,000 per year) proves too expensive it may be possible to replace some of the onset screening sample with onsets identified through the LFS. Or LFS onset cases could be used to boost the sample. Either way, there would be a number of obstacles to overcome first.

For children:
• The same approach could be used but it will generate rather small samples.
• The children’s sample could possibly be boosted using the Health Survey for England.
• The questions asked of children will inevitably be different to those of adults. This may be an argument for delaying a child survey until after the launch of an adult survey, but this may have opportunity costs if the delay is too great, if only because the adult sample is the natural source of a child sample (i.e. they would come from the same households).
• Consideration should be given to adding some questions on disability to the Millennium Cohort Study (MCS).

For the elderly:
• Older people should be included in any new prevalence survey, but rather than enter older people into the longitudinal study, the option of simply using ELSA data for this age-group should be considered.

For communal establishments:
• Communal establishments should ideally be included in any new prevalence survey. However, unless there are particular research questions to be addressed that we have overlooked, those living in communal establishments could be excluded from the longitudinal study.

There are a few outstanding design issues that we have not so far touched on, all of which need further thought but none of which are fundamental enough to affect the decision as to whether or not a longitudinal study is feasible. They are:
• the clustering and stratification of any new prevalence study;
• design of the comparison sample;
• fieldwork complications that are likely to arise.
Taking these in turn:

**The clustering and stratification of any new prevalence study**

If a new baseline sample was to be selected (rather than piggy-backing on another survey) then one way to reduce costs at subsequent waves is to take a sample with a large cluster size\(^{15}\). Although this means that interviewers will have a large assignment at baseline (which may in practice have to be split across several interviewers) it means that follow-up interviews will still be fairly clustered (even after tracing movers). This will help to keep costs down.

Other longitudinal studies (most notably the MCS) have over-sampled areas with higher than average deprivation scores or with high percentages of minority ethnic groups. In principle, a similar approach could be taken here, with over-sampling of areas where higher than average rates of disability are expected. However, having raised this as a possibility, if asked to make a recommendation we would probably recommend not over-sampling in this way. The reasoning is that an equal probability sample would be easier for analysts to handle. Plus the gains in sample size made (for those disabled) would largely be lost because of design effects due to weighting.

The other, more political, decision is whether there should be over-sampling by country to allow for separate analyses for England, Scotland and Wales. This is probably a question for the next stage, but it is probably worth noting here that if there was a demand for boost sampling in Scotland and Wales then that may create complications if the piggy-back design was to be adopted (that is, large enough surveys to piggy-back would be needed per country).

**The design of the comparison sample**

Although we have concluded that there are good arguments for including a longitudinal comparison sample to the study, the analysis demands made of this sample will not be as high as the demands made on the disabled person samples. So, although in statistical terms there is an argument for making the comparison sample as large as the baseline disabled sample, in economic terms there is an argument for making it rather smaller. Probably a sample of about half the size of the baseline disabled sample would be appropriate (about 3-4,000).

There is a discussion to be had about exactly how this sample should be designed, but a stratified random sample selected so as to match the baseline disabled sample in terms of age, sex, and geography would probably meet the needs of most analysts. For particular analyses this would allow for matching more closely on whatever are considered the relevant variables for that analysis.

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\(^{15}\) Almost all general population samples are selected in two stages: a sample of geographical ‘clusters’ followed by a sample of addresses within these clusters. The clustering of the sample helps to control interviewing costs.
A decision is needed as to whether comparison sample members should be restricted to households where there is no disabled person. Arguments can be made either way. For instance, one argument **against** is that excluding the non-disabled who live with a disabled person would bias the non-disabled sample, and would, in particular, mean that carers are under-represented. But an argument **for**, is that many of the comparisons will be at a household level, in which case we would want to compare households with a disabled person with households without. This issue probably needs to go to consultation.

Of course, some comparison group members will, during the life of the study, become disabled. This cross-over, and how it is handled in both fieldwork and analysis terms, needs consideration.

**Fieldwork complications**

The design we have proposed inevitably means that all members of households are included in the longitudinal study, different household members being allocated to either the baseline disabled, the comparison, or the onset screening samples. This will place a large burden on households, although for most we will only be following up by telephone. Nevertheless it may prove essential to use incentives to maintain high response rates.

(Note that the alternative would be to sub-sample within households, but this would add considerably to the survey costs if the same sample sizes are to be achieved.)

This design raises issues of how we would deal with households where one member is due a face-to-face interview and another is due a telephone interview. Should the interviewer be briefed to do both face-to-face, or does this simply introduce too many administrative problems?

In addition we know of no other surveys where more than one telephone interview is attempted per household (with the exception of the LFS where proxies are accepted). The problem doesn’t seem insurmountable, but will need some careful handling.
Appendix A
Measuring eligibility for DLA/AA

One of the information needs that the Department for Work and Pensions (DWP) has identified is the eligibility rate for Disability Living Allowance/Attendance Allowance (DLA/AA). There are a number of reasons why this is very difficult to do, and certainly it will not be possible to address this question without further research. We have limited ourselves here to a discussion of what we think are the possible options. For each of these we give a short description of the likely research and development programme that will be needed.

A.1 The problem

Assessing eligibility for DLA/AA is far from easy, entitlement being based on the overall assessment of the impact of someone’s impairments on their mobility or their capacity to care for themselves. Applicants complete a long series of open-ended questions about the problems they have, the help they require, the equipment they use to help, and the length of time per day help is needed for. Applicants are also asked to give consent for their General Practitioner (GP) (or other health professional) to be contacted so that the information given can be validated.

Somehow all this information is filtered and a conclusion reached as to whether or not the applicant is eligible.
A.2 The unknowns

There are several unknowns in this process:

- How often are claims checked with the nominated health professional? And when they are checked, how much weight is given to their view?

- How are the statements made by claimants assessed/scored, and how is an overall assessment, based on these assessments, made?

- To what extent do claimants exaggerate problems so as to maximise their probability of being declared eligible? (The answer to this may, of course, be ‘not at all’, but if there is any tendency for all, or sub-groups, of applicants to exaggerate, this affects what can be done. In particular problems arise if applicants tend to exaggerate when making a claim but don’t exaggerate in the context of a research project.)

A.3 What we need to be able to assess eligibility rates

To establish eligibility rates we need:

- to identify a random sample of people who might be eligible (we can exclude those who definitely aren’t eligible);

- each sample member should complete a questionnaire (or perhaps the application form itself) which covers all the areas of functioning that impact on eligibility;

- each person should then be given an eligibility score (which might be a simple ‘yes/no’ binary outcome, but in practice is more likely to be a score that includes a degree of uncertainty, such as an estimated probability of being eligible);

- estimates of eligibility rates (overall and for sub-groups) can then be made by counting the number of people with a score above some threshold. Or, if the score represents the probability of being eligible, then the eligibility rate can be estimated by taking the average of the estimated probabilities.

A.4 Two possible approaches to assessing eligibility

**Approach 1: Replicate the application process**

One possible approach is as follows:

- Take a random sample of disabled people who might be eligible. The ‘might’ could be based on a set of screening questions (which will need their own development or could perhaps be based on the ‘five minute tests’ developed by the Barton Hill Advice Service ‘www.bhas.org.uk’). Or, if it proves impossible to construct a convincing screening test, simply include all disabled people in the sample.
• Set aside those already claiming DLA. For the rest ask each person to complete the application form for DLA on their own behalf.

• Submit completed forms for assessment. Those deemed eligible would then, it is recommended, receive the benefit.

The advantage of this approach is that it directly replicates the application process. There are, however, several potential problems/issues that need some thought:

• Who should approach the sample: interviewers or professionals already expert in DLA rules? It would certainly make sense to use professionals if applicants tend to receive advice and help with completing the forms in ‘real life’. But using professionals is a more expensive option than using interviewers.

• To be able to estimate eligibility rates for sub-groups may require a fairly large sample size.

• One potential problem is that the sample going through the exercise may not approach the task in the same way as they would if making an application in more realistic settings. This could have all sorts of effects, but one plausible one is that the applicants may be more likely to understate their problems than they would be if they were applying because they genuinely wanted to receive the benefit. Having said that, the carrot of having the application genuinely assessed may reduce this problem.

• In the context of a longitudinal study there are problems associated with taking a large percentage of the sample through this process since the outcome of the exercise will impact on the future findings of the study. Put another way, after the exercise the sample members will no longer be a representative sample of disabled people because they will all have applied for DLA. So, either the design would need a sample of disabled people who are not part of a longitudinal sample, or the DLA sample would have to be a random sub-sample of the longitudinal sample who are subsequently removed from the study (or at least kept separate).

**Approach 2: Develop and test a survey version of the application form/develop and test a scoring system**

A more ‘survey-friendly’ model might be the following approach (which is divided into four stages):

Stage 1: Develop a set of survey questions that ‘replicate’ the application form

Stage 2: From a set of real claims develop a ‘prediction model’

Stage 3: Test the survey questions on a sample of claimants and refine the prediction model based on their responses

Stage 4: Ask the survey questions of a large sample of disabled persons to estimate eligibility rates.
Spelling out the four stages in more detail:

**Stage 1: Develop a set of survey questions that ‘replicate’ the application form:**
- take a sample of real claims that have been made for which the outcome has been decided;
- review the text that applicants provided and develop an appropriate coding frame per question;
- based on the application form and the coded responses, develop a set of survey questions that ‘translate’ the application form questions and their coded categories.

**Stage 2: From a set of real claims develop a ‘prediction model’:**
- on the same set of claims use statistical methods to develop a preliminary prediction model, where the dependent variable is eligibility (yes/no) and the predictors are the coded variables.

**Stage 3: Test the survey questions on a sample of claimants and refine the prediction model based on their responses**

There are two options under Stage 3:

**Option A**
Take a separate sample of real claims (this time restricting the sample to recent claims) and approach the individual applicants. The sample should include approximately equal numbers of eligible and non-eligible applicants. Every applicant approached would be asked to complete the newly developed survey questions. The answers to these questions would:
- be compared to the coded categories from the application form to see how well they correspond (This tests how well the survey questions mirror the application form process);
- be scored. Based on these scores, a new prediction model would be developed where the dependent variable is eligibility (yes/no) and the predictors are the survey coded variables.

The difficulty with Option A is that the survey responses could be influenced by the fact that the people in the sample have already made a claim, so it is not a true test of how the survey questions work ‘cold’. Another possibility is:

**Option B**
Take a sample of disabled people who have not made a claim and ask them the survey questions. Then wait to see if they make a claim (over a relatively short time-frame, so that there is only a small chance their mobility and self-care problems have
changed). Those that do can then be separated out into an ‘analysis dataset’. Whether or not they are deemed eligible would then be recorded. The survey responses, together with the binary eligibility outcome, would then be used to refine the prediction model for eligibility.

To implement Option B approach needs a large starting sample so that there are adequate numbers of new applications within the time frame we allow for. A baseline prevalence study, along the lines of the study proposed in this report, might just be large enough.

Assuming these development stages do not suggest that the whole approach is fatally flawed the next, and final stage, would be:

**Stage 4: Ask the survey questions of a large sample of disabled persons to estimate eligibility rates.**

Take a random sample of disabled people and ask them the survey questions. Code their answers and construct their prediction score. Base the estimates of eligibility on these prediction scores.

Whether this approach can be made to work hinges on several things:

1. **That, based on the application forms, a good prediction model of eligibility can be developed.**

Central to the approach is the idea that the application form contains all the information needed to assess eligibility. But this leaves out one very key piece of the jigsaw which is the assessment made by the nominated medical professional. If a large percentage of applications are ultimately based on their assessment then any prediction model is likely to be weak. It would be helpful to know what percentage of applications include an approach to the medical professional, what they are asked, and what weight is given to their responses.

2. **That the application form coded responses can be reasonably well replicated using a survey questionnaire (administered by survey interviewers).**

This ought to be possible, but needs testing.

**Incorporating an estimate of non-entitled recipients of DLA/AA**

As well as giving estimates of the eligibility rates of non-claimants, Approach 2 should also allow some estimates to be made of the number of DLA/AA recipients who, at any point in time, would not be eligible if they were to make a fresh claim. This would be achieved by asking the survey questions of a random sample of DLA/AA recipients and calculating their current ‘prediction score’. Those with a prediction score below the critical threshold might be judged as ‘non-entitled recipients’. Note that this is a statistical exercise designed to provide approximate prevalence estimates that are correct ‘on average’ rather than being correct for individuals – to make judgements about eligibility in individual cases would need individual assessments.
Summary

Approach 2 takes a survey approach to estimating eligibility, with no actual DLA application forms being completed and no genuine assessments of eligibility being made. The attraction of this is that:

- there are fewer ethical issues;
- it should be possible to assess eligibility for large samples of people;
- the approach (if it works according to plan) shouldn’t require data collection by trained professionals.

However, the approaches depend on the ability to develop a reasonably good prediction model for eligibility with survey responses as the predictors. The uncertainty around whether or not this is possible means we are not really in a position to propose that Approach 2 is adopted. Perhaps the best first step is to test whether a model-based approach might work and then decide on the next best steps from there. The simplest check is also the crudest, namely the first two stages of Approach 2. At the risk of repeating what we have said earlier this involves:

- take a sample of real claims that have been made for which the outcome has been decided;
- review the text that applicants provided and develop an appropriate coding frame per question.
- use statistical methods to develop a preliminary prediction model, where the dependent variable is eligibility (yes/no) and the predictors are the coded variables.

The size of the study needs to be determined, but we think that a sample of, say, 100 eligible applications and 100 non-eligible might be sufficient for this exercise.
Appendix B
Examples of approaches to collecting disability data in other countries

Most of the developed countries conduct specialist disability surveys using two basic approaches to identifying a large enough sample of the target population of disabled people – large-scale population screening or follow-up samples from an existing survey or census source. Most such surveys are cross-sectional and either form part of a continuous health survey (e.g. NHIS-D), or a separate survey (ad-hoc or regularly repeated). We have identified only one survey (INSEE in France) that includes a longitudinal element.

Below are examples of approaches taken by countries attempting to provide a comprehensive set of data on disabled people.

France:

The key survey in France is the INSEE Survey of Handicaps, Disability and Dependency (HDD). This is the only survey we have identified that has a panel element with the explicit aim of estimating flows into and out of disability. From the documentation available, there are currently only two waves planned with a gap of two years between waves.

The first main element of the HDD was carried out in late 1998. It covered a sample of about 15,000 people living in institutions even temporarily. The institutions included homes for the elderly, homes for disabled young persons and adults, and psychiatric institutions. The same persons were surveyed again in late 2000.
The second main element was a survey of the household population. This was done in two stages: firstly a brief questionnaire was added to the March 1999 component of the French rolling census, which in one month covers somewhere between 300,000 and 400,000 people. Those ‘screened in’ as disabled were followed up by interview in 1999 and then the same people were interviewed again in 2001. Our understanding is that this longitudinal element allowed for estimation of remissions and ‘aggravations’. It was not designed to allow for the estimation of new onset cases.

Most of our information on the survey is derived from a planning document from the INSEE web-site. We have not been able to identify any information on the success of the survey in practice – in particular we have not identified any information on response rates.

Canada:

Statistics Canada has developed a cross-survey approach to collecting data on disabled people. After a decade of testing in the 1990s, a unified definition of disability was developed and three sorts of question modules developed:

a filter questions (activity limitation and long-term disabilities) for use in the census;

b screening questions (to be used as a disability module in surveys whose main focus is not disability), based on ‘difficulty’ in physical, sensory, communication, learning activity or ‘restriction’ in social participation (work, school, leisure, transportation);

c full disability questionnaire (based on the new International Classification of Functioning, Disability and Health).

The main Canadian disability survey (called the Participation and Activity Limitation Survey, (PALS) and last carried out in 2001) uses the census as the sampling frame to select a target population who answer Yes to the disability filter questions in the census. This group is then interviewed and those who answer Yes to the filter questions and Yes to the PALS screening questions are included in the disability survey.

In 2001 both adults and children were included in the survey, but those in institutions were excluded. The survey was conducted by telephone, with a small number of face-to-face interviews being carried out where telephone wasn’t possible. The sample size was 43,000 (35,000 adults and 8,000 children) and the response rate was 82.5 per cent.

The questionnaire development for the PALS survey was very comprehensive and involved cognitive testing of the questions included in a, b and c above plus experiments of different formulations of the census filter question to minimise the number of false negatives. The research team judged, at the end of this exercise, that the census screening question was inclusive enough to eliminate any need to include any ‘census Nos’ in the follow-up survey. This was a change from the 1991
forerunner to PALs where a sample of ‘Nos’ had to be included because the filter question at that time excluded about half of the disabled population.

Nevertheless, it is still the case that the new filter question excludes 77 per cent of ‘mildly disabled’ persons, 39 per cent of ‘moderately disabled’ persons and 16 per cent of ‘severely disabled persons’.

Australia:

In Australia there are three sources of data on disability:

1. Survey of Disability, Ageing and Carers (SDAC) – this provides official prevalence estimates and is based on a large scale screening survey, repeated every six years the most recent of which was 2003.

2. Disability module in non-disability surveys – this is a harmonised series of questions used across surveys.

3. Global question in Census – to obtain small-area estimates of disabled population.

The SDAC is the main source of Australian disability prevalence estimates, by impairment, activity restriction, severity and underlying cause. The 2003 survey used International Classification of Functioning, Disability and Health (ICF) categories of body function (impairments), activity restrictions (self-care, mobility, communications, school/work for 5-60); environmental factors (personal need for assistance in performing IADLs, ADLs) and technical (aids and adaptations, treatment) to identify overarching ‘disability’ and severity (although we haven’t looked in any detail at how severity is measured).

The 2003 survey covered both the private household population (including children) and institutions, although a different data collection approach was used for the two.

For the private household population a single ‘responsible adult’ was asked (during a face-to-face interview) to identify any household members in the population groups of interest, namely: disabled individuals, those aged 60 or more, and carers of these two groups. Those satisfying any of these criteria were interviewed personally, with the exception of children aged under 15 (and those aged 16-17 whose parents did not give consent) who were interviewed by proxy. Proxy interviews were also used for disabled persons who were not able to give a personal interview. (We have not found any information on how interviewers made this decision.)

The institution survey was carried out via administrators of selected establishments and using a postal survey approach. Individuals were selected for the survey, but the information about those individuals was completed by the administrator rather than by the selected individual.

We have not found any figures on response rates for the survey. The achieved sample numbers in 2003 were 36,241 persons (disabled and non-disabled) from the household survey and 5,145 from the institution survey.
United States:

In the US, the major source of survey data on disability appears to be the National Health Interview Survey (NHIS) which included a special disability supplement (NHIS-D) in 1994/5. This was the first comprehensive survey of disabled people of all ages in the US. We are not aware of any plans to repeat it.

Interestingly, it is the only survey we looked at where a specified aim was to use several definitions of disability so that social, administrative and medical perspectives were covered and analysts were able to combine data items in different ways to meet their agency or program needs.

The survey covered the household population only (adults and children). Institutions were not included. All interviews were done face-to-face.

As with the Australian survey, the survey was administered in two phases. Phase I was administered at the same time as the NHIS core interview and collected information on disability for all members of the household. This interview was carried out with any available adult who was knowledgeable about the health of other household members. This interview acted as a screening device for Phase II.

Individuals were selected for Phase II either because they were screened-in based on the Phase I disability questions or on questions related to activity limitation of disability benefit receipt. Four questionnaires were used at Phase II: one for children, one for disabled adults, one for non-disabled adults aged 69 and over, and one for persons with a past history of polio.

Adults responded on their own behalf wherever possible. The questions on children were asked of the adult in the household who knew the most about the child’s health.

The numbers included were very large. The NHIS covered approximately 218,000 individuals in 85,000 households. Of these 8,800 adults were s per cent.
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