

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

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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:

- (a) 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;
- (b) to 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 WHO 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.

The full report of these research findings is published for the Department for Work and Pensions by Corporate Document Services (ISBN 1 84123 856 2. Research Report 267. August 2005).

It is available from Paul Noakes at the address below.

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