



Including Disabled People

Breakthrough UK Ltd.

Policy Think Tank

Response to the Census Consultation

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1. Introduction:

Breakthrough UK Ltd is a successful independent company, managed mainly by disabled people. It brings together disabled people, local businesses, and other agencies to plan and deliver projects and services to promote independence. On average 60-70% of Breakthrough's staff are disabled people, with first hand knowledge and experience of the barriers to independence and employment. Based in the North West of England, Breakthrough UK Ltd provides training, employment and business opportunities to disabled people within the social model of disability.

The Social Model of Disability: traditionally disabled people have been seen as a problem, to be tackled by focusing interventions on the individual. Developed by disabled people themselves, the social model locates the problem with the structures and organisation of society, which take little or no account of what disabled people need to be autonomous and to live independently.

The Policy Think Tank: this initiative is a response to what we see as a 'policy vacuum' in relation to disability and the social model. Its membership brings together a small group of people known to subscribe to the social model, who are known for their analytical approach, and their tendency to stretch the boundaries in a variety of areas. This response to the Census consultation has been produced collaboratively, with input from many Think Tank members.

The Policy Think Tank has two major aims:

- To influence government, or other strategic bodies, on matters to do with disability, from a 'social model' perspective.
- To provide briefings on current matters to do with disability, for general dissemination.

We welcome the opportunity to respond to the current consultation, and hope that our input is welcomed and viewed constructively. We would be delighted to expand on any of the points.

In our discussions we have identified that it is difficult to simply give a response relative to the consultation document. This is because we feel that the consultation itself does not adequately reflect the realities of disabled people's lives, but that the opportunity exists to contribute most significantly to the twenty year vision of the Prime Minister's Strategy Unit. We have largely framed our response on this basis.

2. Context:

The Prime Minister's Strategy Unit reported in January 2005 on "Improving the Life Chances of Disabled People", outlining an ambitious 20 year vision that:

"By 2025 disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society."

This was a cross-government report and was endorsed by the Department for Work and Pensions (DWP), the Department of Health (DoH), the Department for Education and Skills (DfES) and the Office of the Deputy Prime Minister (ODPM). Its successful implementation and realisation of the vision will be severely compromised if the evidence base is lacking.

Recent extensions to the Disability Discrimination Act (DDA) have further widened the legislative cover for disabled people, whilst the newly established Equalities Review aims to set out an analysis of the long term and underlying barriers to opportunity that face many individuals and groups in society.

If such initiatives are to be successful – and indeed if they are to be able to *measure* their success – then there must be an improvement in ways of accounting for who disabled people are, where they are, and what the factors are that work to improve or damage their life chances.

The next Census will take place in 2011; it is a massive piece of research giving information on the population as a whole and is used in policy development, planning and action. The information gathered will therefore influence major decisions in all sectors in the UK and it is essential that it more accurately reflects information about the population of disabled people.

3. Summary Comments:

3.1. Process:

The Office of National Statistics (ONS) consults with advisory groups before compiling the questions: groups representing disabled people include the Royal National Institute for Blind People (RNIB), the National Federation of the Blind (NFB), the Royal National Institute for Deaf People (RNID), the Disability Rights Commission (DRC) and Scope. We feel that this is an inadequate representation of the views of disabled people and urge the ONS to review its advisory arrangements to take more account of the views of disabled people's own organisations, i.e. those controlled by disabled people, in the advisory arrangements.

3.2. Classifying disabled people:

Disability, long term illness and level of general health: we understand that it has been decided already that consideration will be given to distinctions between these matters and we welcome this important move.

Understanding the situation of disabled people is vital to government plans and the 2011 census must be asking the right questions about disabled people. Information concerning carers is to be included too, due to the recognition that the ageing population will result in a rise in the number of carers. However, the matter of collecting information about young carers, and of disabled people themselves as carers, should also be addressed.

3.3. Resource allocation:

The Government has a major policy commitment to employment as a route out of poverty and the agenda over the next 10 years is going to be about moving people into work. If funds are allocated mostly to people not working, when many disabled people do work, then resources are not going to be used most effectively. Also, this policy push means that the idea that disabled people cannot work needs to be changed – and the census questions should reflect this.

4. General comments:

Numbers of disabled people:

There is no authoritative figure on the number of disabled people, their status and the social factors which contribute to or inhibit their quality of life. We urge ONS to address this fact.

Service planning and delivery:

Local authorities (LAs) have a duty of care and each LA is supposed to know and understand the profile of age, gender and race of their population. No LA has a register of disabled people, other than possibly a register - sorted according to type and severity of impairment, but not social factors - of those receiving services through Social Services.

Wider planning matters:

Many bodies, including LAs and regeneration schemes use census information to inform and justify plans and provision of services. However, this information can be conflicting, may not match other data sets and can be less than useful.

Health and disability:

The Office of National Statistics (ONS) needs to recognise that sickness and ill health are not the same as disability, and that impairment is different again. The “Improving the Life Chances of Disabled People” report offers a useful distinction, and we would be pleased to contribute to further development of the thinking around this matter.

Definitions:

It is vital that a clear definition of disability be agreed which should then be used consistently across all legislation and policy.

Transport:

We are concerned that the census will ask about transport but not whether this is accessible for disabled people.

Housing:

Questions will be asked concerning housing, and deprivation levels in housing, but none about accessibility or usability. We feel this is a missed opportunity.

Employment:

There are many factors which contribute to the unemployment of disabled people; appropriate census questions must be asked in order to help plan and monitor actions.

5. Numbers of disabled people:

There is no authoritative figure on the number of disabled people, their age, status and the social factors which contribute to or inhibit their quality of life. We urge ONS to address this fact.

Perhaps the question "Do you identify yourself as a disabled person?" should be asked. The statistics extracted should then be able to identify

- where disabled people are,
- where they are working,

- what their incomes are,
- whether their homes are accessible
- whether the transport they need to use is accessible,

The questions should be structured to enable us to do this, and if the census is to reflect the diversity of our communities and provide the widest possible access, questions should be phrased in a simple format, e.g. "Are a disabled person? Are you in work – yes or no?"

6. Service planning and delivery:

Local authorities (LAs) have a duty of care and each LA is supposed to know and understand the profile of age, gender and race of their population but no LA has a register of disabled people, other than possibly a register - sorted according to type and severity of impairment, but not social factors - of those receiving services through Social Services.

The census should be able to show young carers, as questions regarding age and whether providing care are asked of each person. Equally the census should identify young disabled people or disabled children.

7. Wider planning matters:

Many bodies, including LAs and regeneration schemes use census information provided in LA profiles to inform and justify plans and provision of services. However, this information can be less than useful, or even confusing: for example below is the Manchester profile from the 2001 census which shows the following numbers (this is also used to rank LAs against each other).¹ There are people with a 'limiting long term illness', or 'not good' health, or 'permanently sick or disabled'. This clearly is an unhelpful and confusing situation.

HEALTH

Limiting long-term illness	84,507
General health 'not good'	49,115
People providing unpaid care	34,476
Providing unpaid care 50 or more hrs/wk	9,178

WORK

Employed	132,145
Unemployed	14,316

¹ REFERENCE? NOT SURE WHAT POINT IS BEING MADE (LG)

Long-term unemployed	5,006
Student (economically active)	12,666
Retired	29,185
Student (economically inactive)	35,063
Looking after home/family	19,952
Permanently sick or disabled	27,106
Other inactive	14,561

8. Health and Disability:

The Office of National Statistics (ONS) needs to recognise that sickness and ill health are not the same as disability, and that impairment is different again. The “Improving the Life Chances of Disabled People” report offers a useful distinction, and we would be pleased to contribute to further development of the thinking around this matter.

The definition used in Q13 of the 2001 census "Do you have a long-term illness, health problem or disability which limits your daily activities, or the work you can do?" is not useful for those trying to implement the DDA. If this ‘joining together’ of essentially different – though often related – factors is used for resource planning then it means that the vast majority of requirements will go unrecognised or even be excluded because people will not relate to it, and it is therefore neither useful nor equitable.

In the 2001 census no distinction was made between long-term illness, health problems, age related problems and disability, giving rise to the assumption that disabled people did not work and were economically inactive. It is expected that the 2011 census will do the same. This is regrettable, as it results in an inaccurate and unhelpful set of statistics.

9. Definitions:

Many definitions exist across the policy and legislative spectrum, and this is not helpful to either planners or analysts. It is vital that a clear definition of disability be agreed, as well as accurately defining impairment and ill health. These definitions should then be used consistently across all legislation and policy.

Joint planning is hindered by the use of a variety of definitions, as is analytical and review work. This group would welcome the opportunity to suggest

definitions that would be useful to planners and resources, and would be useful to disabled people in identifying their rights and securing their rights.

10. Transport:

The proposed questions relating to transport to work will miss the number of disabled people who do not have employment because they do not have access to transport. People who do not use transport will not respond to this so the resulting 'facts' will be misleading. There should be a question which identifies whether transport is an inhibitor in securing employment; this would apply to everybody, but would also give useful information in respect of disabled people.

11. Housing:

Inaccessible housing is known to be a major issue for disabled adults and children. For adults the impact of poor or inaccessible housing can be a major determinant on opportunity to work, or to move with your career. We understand that questions will be asked in the census concerning housing, and deprivation levels in housing, but none about accessibility or usability. This is a major omission which will impact negatively on initiatives which seek to improve the accessibility of available housing stock – for example in Greater London and Wales. There should be a specific question or questions about accessible housing. (Pam, can you suggest say 2 specific questions?)

12. Employment

There is currently no dependable information available on how many disabled people of working age in the country are in employment. No effective planning and monitoring can be carried out without this kind of basic statistic. Because the number of disabled people in work cannot be quantified this is contributing to the Government moving towards counting IB claimants as disabled people.

Factors which contribute to the unemployment of disabled people include inaccessible transport and there should be a question which identifies whether transport is a contributory factor to people's unemployment.

13. Conclusion:

The census information is tremendously important: it informs planning and service design and delivery, and other surveys use census data to validate their results.

Previously the census has counted disabled people and ill people as one group. This is clearly unhelpful to planning, design and delivery purposes and procedures, and the opportunity now arises to correct this anomaly.

The Prime Minister's Strategy Unit have published their 20 year vision, which includes a clear separation between disability, impairment and ill health and the census needs to recognise this distinction to pave the way for the vision.

We hope that this response/report proves useful, and look forward to feedback on our comments.

14. Further reading:

“Improving the Life Chances of Disabled People”: The Prime Minister's Strategy Unit, January 2005.