Office for Disability Issues
HM Government

Involving disabled people in social reseach

Guidance by the Office for Disability Issues

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Contents

Acknowledgements

This guide refers to work from a number of existing guidance papers and sources. They are drawn together here, and fully referenced, to help disseminate guidance for including disabled people in government social research. In particular chapter 6 is largely reproduced from a previously published DWP research report (Purdon, 2005).

The guide also draws upon the lessons learned from ODI’s involvement of disabled people in two research projects: the Experiences and Expectations of Disabled People project and the Life Opportunities Survey. We wish to thank all disabled people involved in these projects for their time and effort, the improvements made to the projects as a result, and for their patience and understanding as we strive to get the process right.

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Foreword

The Office for Disability Issues is committed to involving disabled people and their organisations at each stage of its work to achieve progress towards disability equality. This includes social research. This guide provides advice on how to involve disabled throughout the research process and how to make fieldwork accessible to people with different types of impairment. It aims to help those responsible for research in government find the support and examples necessary to take research with disabled people forward, including finding ways for disabled people to say how and when they want to be involved.

1 Introduction

This guidance provides advice on how to involve disabled people in government social research. Involving disabled people can improve the quality of research by ensuring it addresses the most pertinent issues faced by disabled people. Advice is also provided on ways to ensure data collection is as inclusive of disabled people as possible. Ensuring that disabled people can take part in your research will improve data quality by ensuring disabled people can contribute their views.

This guidance is mainly relevant to projects where disability issues or the views of disabled people are a specific focus. You may also find the advice helpful for projects where disabled people are likely to fall within the wider sampled population. Nevertheless, the appropriate level of involvement, and the extent to which you ensure data collection is accessible to disabled people, should remain in line with the objectives of the research and the likelihood of disabled people falling within the sample.

After further describing the benefits of involvement in this Introduction, and outlining different definitions of disability in Chapter 2, we provide advice on determining the appropriate level of involvement in Chapter 3. We explore some of the different approaches to involvement developed in the field of disability studies, and in Chapter 4 explain the practical steps you can take to meaningfully involve disabled people at each stage of the research process. Guidance on designing research that is accessible to and inclusive of disabled people is provided in Chapter 5. Chapter 6 provides practical advice on how to make survey based research accessible to people with different impairments.

1.1 Why involve disabled people?

Actively engaging with disabled people throughout your project can benefit your research in a number of ways. Drawing on the first-hand experience of disabled people can help you to develop research questions and identify issues for your research to explore. Disabled people can also provide valuable advice on how to make fieldwork, research reports and presentations accessible to people with different types of impairments.

Disability academics have also stressed that, in the past, government social research on disability issues has failed to focus on the issues of greatest relevance to disabled people (see for example, Barnes, 2003). Failing to involve disabled people in research that concerns their experiences or to communicate research results in an accessible way could mean that research alienates disabled research participants. It could be exploitative, if data is collected from disabled people, using pre-determined research questions that do not address the key issues they face and is then published in reports that disabled people cannot read or use.

Disability academics have therefore argued that if research is to fully reflect the experiences of disabled people, then disabled people should be involved from the outset in formulating research questions, developing methodology, interpreting results and drawing conclusions.

There are also legal considerations. The Equality Duty, provided by the Equality Act 2010, says that public bodies must ‘pay due regard’ to advance equality, eliminate discrimination, and foster good relations. ‘Paying due regard’ means consciously thinking about the potential impact of a policy or practice from the early stages of planning, considering any risk of negative impact and how this might be mitigated. Considering the available evidence and conducting an ‘equality analysis’ is crucial to assessing impact[1]. A key step in this process is engagement with groups

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[1] Guidance on ‘equality analysis’ is available from the Equalities and Human Rights Commission (EHRC): http://www.equalityhumanrights.com/advice-and-guidance/public-sector-equality-duty/guidance-on-the-equality-duty/

representing people with different protected characteristics[2]. This will help ensure the evidence developed to assess a policy is relevant to the issues faced by stakeholder groups.

1.2 Why should research be accessible to disabled people?

There are over 10 million disabled people in Britain, of whom 5 million are over state pension age and 800,000 are children[3]. This means it is likely that sample drawn for general population surveys, as well as for many smaller research projects, will include disabled people. Where this is the case, fieldwork should be accessible to all those invited to take part. If disabled people cannot participate, they will not be able to contribute their views to the overall picture. In such cases, the sample will be skewed to non-disabled people and fail to provide a representative, meaningful picture of the subject of investigation. Ensuring that all groups of interest can fully participate in the research helps to reduce any bias that may result from the non-response of certain groups.

To reduce this risk, we provide advice and examples of how you can choose research methods and adapt methods of data collection that can enhance the participation of people with different impairments in your research.

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[2] There are nine protected characteristics: disability, age, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation.

[3] These figures are from the Family Resources Survey 2008/09 and provided by the annually updated ODI disability prevalence factsheet, available at: http://odi.dwp.gov.uk/disability-statistics-and-research/disability-facts-and-figures.php#gd

1.3 Scope of this guidance

This guide is designed to be used by those involved in funding, conducting or managing social research in government. It is primarily intended for use by government social researchers. Broad advice rather than detailed technical guidance is provided.

It does not replace existing ethical guidelines in social research. The GSR Ethics Guidance[4], the DWP working paper “Doing the right thing”[5] and the Mental Capacity Act Guidance produced by Department for Health[6] cover the wider legal and ethical issues involved in commissioning, managing and undertaking social research. If you are interested in the benefits of involving the public more widely in your research, then you may find guidance produced by the National Institute for Health Research helpful[7].

1.4 Feedback

We would welcome feedback on this guide. If you found it useful, or feel that it could be improved, or if you have a case study that we could use in a future revision, please contact us at odi.losteam@dwp.gsi.gov.uk

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[4] GSR (2006) ‘Ethical Assurance for Social Research in Government http://www.civilservice.gov.uk/Assets/ethics_guidance_tcm6-5782.pdf

[5] Bacon, J and Olsen, K (2003) Doing the Right Thing: Outlining the DWP's approach to ethical and legal issues in social research http://statistics.dwp.gov.uk/asd/asd5/report_abstracts/wp_abstracts/wpa_011.asp

[6] The Mental Capacity Act – Fact Sheet for Social Scientists http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@pg/documents/digitalasset/dh_106217.pdf

[7] Available from: http://www.invo.org.uk/pdfs/6822_INVOLVE_SCCS_brochure_WEB.pdf

2 Understanding disability

A wealth of literature exists on sociological understandings of ‘disability’ and the extent to which it is caused by illness or impairment or by social barriers and oppression. Academics from the fields of medical sociology and disability studies have taken different standpoints, with the result that different models for understanding disability have been developed (Carol Thomas, 2004, gives an overview).

2.1 The social model of disability

The social model of disability was developed by the disability rights movement that emerged in the UK in the 1970s and 1980s. It provides a framework for characterising the barriers that disable people with impairments[8] from fully participating in society. These barriers generally fall into three categories:

- the environment — including inaccessible buildings and transport services
- people’s attitudes — stereotyping, discrimination and prejudice
- organisations — inaccessible information and inflexible policies, practices and procedures.

The social model can be used to encourage the removal of these barriers, or to reduce their effects.

The social model contrasts with the medical model of disability. According to the medical model, an individual’s health condition or impairment is viewed as the cause of disability. The medical model says that by fixing their body, disabled people will be able to participate in society like everyone else. This is an outdated model that is not supported by disabled people or their organisations.

The social model is preferred by disabled people. It empowers disabled people and encourages society to be more inclusive. The Office for Disability Issues encourages government departments to use this model when considering disability.

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[8] Impairments are the long-term physical or mental characteristics of an individual that affects their functioning and/or appearance e.g. a visual impairment or a hearing impairment.

2.2 Implications of the social model for research

Applying the social model to social research can help you to identify the barriers disabled people face. For example, if your research concerns understanding service delivery to disabled people, your questionnaire could focus on the social barriers to successful service delivery, such as the format in which information is provided or the attitudes of staff to disabled people. In this way, your research can help to identify policy solutions to any disabling barriers identified.

Aside from helping you to identify areas for your research to focus on, conducting social research from a social model perspective also means considering the following:

- Involving disabled people throughout the research process. Involvement from the start will lead to better outcomes and will help you to meet your objectives. Guidance on the appropriate level and method of involvement is provided in Chapter 3. Chapter 4 provides advice on how to involve disabled people in each stage of research.

- Designing research that is accessible to and inclusive of people with different impairments. Enabling disabled people to participate in your research will improve the quality of your data by reducing the risk of excluding groups of interest. Guidance on designing accessible and inclusive research is provided in Chapter 5, and Chapter 6 provides practical advice on how to make survey based research accessible to people with different types of impairments.

3 Involving disabled people

Understanding the perspective, needs and priorities of disabled people will help you to deliver better quality research and help you to meet your research objectives. Involving disabled people can help you to identify the choice of research topics, determine the relevant research questions, and improve the accessibility of fieldwork and dissemination of findings.

This chapter provides advice on how to determine the appropriate level of involvement. It describes different approaches for involving disabled people in research, including emancipatory research, collaboration and partnership research, in addition to steering and advisory groups and consultation. Each approach follows the social model but differs in the extent to which disabled people have an opportunity to influence decision making.

3.1 Determining the appropriate level of involvement in research

Before going on to discuss particular models and methods of involving disabled people in research, it is important to recognise that the level of involvement adopted should be meaningful, proportionate and appropriate to the particular research project. The level of involvement should reflect the extent to which your project is relevant to disability issues and whether the views or experiences of disabled people are likely to differ from those of the general population.

The two contrasting hypothetical examples in the box below help to explain what level of involvement might be appropriate.

Example 1: More limited involvement

A government social researcher is assessing customer satisfaction among callers to the DWP Pensions Service information line. The experience of a number of client groups with various characteristics have to be taken into account (including older people, young people, lone parents, employed people with different types of pensions and salaries). The research project has been funded to meet specific objectives on measuring progress against set targets on customer satisfaction.

In this project, customer satisfaction among disabled people with the Pensions Service would form one component. It would be good practice to involve disabled people to help make certain decisions, such as what questions would be relevant to understand disabled people's experience of the Pensions Service, or how the modes of interviewing can be made more accessible. In these circumstances, however, it may not be proportionate to involve disabled people in every stage of design as certain parameters have been set in advance and further involvement would not offer a fair and meaningful opportunity to change the aims of the project.

Example 2: A higher level of involvement

A Government researcher has been asked to explore whether their Department's website is accessible to disabled people and what content disabled people would find most useful on the website.

Given the focus of the research is on the views of disabled people, rather than the general population, it would be appropriate for involvement to take place throughout the research process. Disabled people could be involved in the development of the specification (e.g. by requesting research organisations tendering for the contract to involve disabled people in the production of their proposals) to the prioritisation of topics for interviews, to the structure of the subsequent report. You would need to be clear as to how much influence disabled people have over each decision point in the research process.

3.2 Methods of involvement

Having decided the appropriate level of involvement, the next step is to determine the approach you wish to take to involve disabled people in your project.

Among others, these approaches include emancipatory research, collaboration research, consultation, and, as is common to many research projects, convening steering, advisory and reference groups. These approaches provide differing levels of control over decision making. In emancipatory research, disabled people and the participants themselves decide on the aims and outcomes of the research, whereas in consultation or steering or advisory groups, decision making ultimately lies with the research managers or project commissioners.

3.2.1 Emancipatory research

Disability studies academics, conscious of the level of control that researchers traditionally have held over the research process, have written extensively about emancipatory research since Mike Oliver developed the approach in the early 1990s (Oliver, 1992). Emancipatory research aims to facilitate the empowerment of disabled people and their organisations through the research process. It requires researchers to put their knowledge and skills at the disposal of disabled people, for them to use in whatever way they choose (see for example Oliver, 1997). It also involves allowing disabled people and their organisations to have a high level of control over the research process, including both funding and the research agenda (see, for example, Barnes, 2001).

> ...disabled people and their organisations, rather than professional academics and researchers, should have control of the research process. Also, that this control should include both funding and the research agenda (Barnes 2001).

Emancipatory researchers adopt an openly partisan approach in order to facilitate the emancipation of disabled people i.e. it is understood from the outset that disabled people face barriers to participation and disadvantage, so the research is a tool to highlight and increase understanding of these barriers in order to bring about their removal.

Whilst it is important to acknowledge the power relations inherent to social research, and to recognise the value of evidence provided by emancipatory researchers, Government sponsored research involving disability people could not accurately meet the model of ‘emancipatory research’ as described here. First, Government Departments typically control their research budgets and commission research according to policy priorities, rather than give control of their budgets and research agenda to external organisations. Second, government social research must be rigorous and impartial. The GSR Code[9] states that:

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[9] GSR Code :
http://www.gsr.gov.uk/professional_guidance/gsr_code/index.asp

> It [research] must be designed, conducted and produced/published to high research standards, and be objectively judged as meeting these standards. It must be impartial and objective and based on the best design available, given constraints.
>
> Research must not be undertaken with a view to reaching particular conclusions or prescribing particular courses of action; it must strive to be objective, and any limitations to objectivity should be made transparent.

Much debate exists over the extent to which true objectivity is achievable (e.g. Barnes, C. 1996) but it is nonetheless a core principle for government social researchers to embrace.
That said, government social research on disability issues should share the ultimate aim of 'emancipatory research' to reduce barriers and improve the life chances of disabled people.

In addition, emancipatory research should not be considered as solely for use by external disability organisations and specialist disability studies academics or as projects that need to be solely carried out by disabled people. As Colin Barnes has written:

> Emancipatory research is about the systematic demystification of the structures and processes which create disability, and the establishment of a workable 'dialogue' between the research community and disabled people… . To do this researchers must put their knowledge and skills at the disposal of disabled people. They do not have to have impairments themselves to do this (Barnes, 1992a: 122).

In line with this perspective, departments can for example foster closer working relationships with disabled people, their organisations and disability studies academics, and make better use of the wealth of evidence that exists (e.g. see the Leeds Centre for Disability Studies Archive[10]).

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[10] The Disability Archive: http://www.leeds.ac.uk/disability-studies/archiveuk/index.html

3.2.2 Collaboration research

Collaboration research involves active, ongoing partnership with people and/or organisations who share or represent the issues that are the focus of the research. Disabled people and their organisations may work with or advise government social researchers on some or every stage of the research process. In this way, collaboration research requires an ongoing dialogue between researchers and the individuals or organisations who agree to be involved. Compared to emancipatory research, control over the production and direction of the research does not rest solely in the hands of those who are the subject of the research.

Researchers at the University of Manchester promote the collaborative approach, which they term ‘Partnership Research’. Useful online guidance is provided on co-operating with ‘research partners’[11]. In terms of government social research, these could be members of any of your Department’s customer groups or stakeholders or third sector organisations who represent them. According to the University of Manchester, a partnership approach is appropriate “where all participants (existing researchers and those new to research) agree at the beginning that they have much to learn from each other, and want to work together in order to learn more”[12]. Four broad principles shape the design of partnership research:

1. All partners are actively involved in the research process.
2. All partners can influence the design, planning and conduct of the research.
3. Different partners bring different things to the research, so that … [Government Social Researchers] … (for example) are not experts in all things.
4. The research outputs may be different from traditional research and more in line with the interests, needs and intentions of the research participants.

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[11] Further information can be found here: http://partnership.education.manchester.ac.uk/navigation/02.htm

[12] http://partnership.education.manchester.ac.uk/documents/what_is_pshiprsc_full.htm

Social researchers in government may want to consider how best to involve external parties in the research process. Adding the perspective of those who are the subject of the research could help to improve the quality of a study at specific stages, such as in defining questions for the research to address and choosing an appropriate methodology.

3.2.3 Steering and advisory groups

A steering or advisory group, established specifically for the purposes of a project, can act as a resource to provide ideas and direction in the planning of the research and feedback at subsequent intervals throughout the research process. A steering group has a relatively strong influence over the direction of research and may be involved in making key decisions. An advisory group can provide advice which the researcher can consider in light of their own expertise, the requirements of policy makers and other stakeholders, before making decisions about the research. In both cases, the researchers benefit from the knowledge that the group has of the research topic(s). Determining the membership of the group is therefore important for maximising the value it provides in delivering the desired breadth and depth of advice. Inviting disabled people with appropriate knowledge and experience to join the group will help to ensure its success.

A decision to establish an Advisory Group or a Steering Group will be informed by the level of input and additional expertise the researchers require, the willingness of researchers to accept the group's input and advice and whether there is an opportunity to change the objectives or scope of the project. Once a group is established, its Terms of Reference should be agreed by all participants at the outset.

More detailed advice on Steering and Advisory Groups is provided in guidelines published by Ireland's National Disability Authority (NDA):
http://www.nda.ie/cntmgmtnew.nsf/0/2B766F9C159E070680256C7B00640CFF?OpenDocument

3.2.4 Consultation

Consultation could involve the researcher organising a one off meeting, seminar, or conference with disabled people about a particular issue.

A benefit of consultation events is that they provide an opportunity for targeted engagement on a specific topic, and require a smaller time commitment than other methods of involvement (however, it is important not to underestimate the time and effort taken to organise any form of consultation event). They could be particularly useful if your timetable is constrained and the opportunity for ongoing involvement is limited as a result.

As there may be no opportunity to hold another consultation event later in the process, some disabled people may feel frustrated by any apparent lack of commitment among government researchers to take on board their views on an ongoing basis. In addition, there is a limit to the amount of advice and knowledge that can be expected to be shared in a one day event, something that is less of an issue in longer term, on-going forms of involvement where working relationships and trust can develop over time. This lack of influence, or perception of it, may result in disabled people feeling that participation in a consultation event will be a waste of time and, as a result, they may decline to get involved. This is sometimes referred to as ‘tokenism’, the feeling that disabled people are being used to ‘tick a box’ without being taken seriously. Nevertheless, if an event has clearly defined objectives, those invited to attend are well briefed in advance and feedback is provided after the event, consultation with disabled people is likely to benefit your research and is preferable to not involving disabled people at all.

The box below provides an example of where good practice in consultation has been applied.

Example: Using Consultation to Receive Feedback on the Measurement of Disability Equality

The Office for Disability Issues carried out consultation events across Britain in 2006/7 to gather views on how to measure progress towards equality for disabled people. This involved three large conferences, helping local organisations and groups of disabled people to run their own meetings and also publishing a request for written responses.

A report written by an independent research team at the University of Lancaster includes details of how the consultations were carried out, and their results. It detailed all the areas people said were important for making progress towards equality, covering the key areas in disabled people's lives such as education, employment, health, housing, social networks and transport. The report is available on the ODI website:
http://odi.dwp.gov.uk/docs/wor/new/ded-difference.pdf

3.3 Managing involvement

Once you have decided on your broad approach to involvement, there are a number of more practical issues that will help your involvement process to be a success. This section provides advice on who you may wish to involve in your project and the steps you can take to maintain good working relationships.

3.3.1 Who should I involve?

Understanding who the outcomes of your research will affect will help you to determine who the target groups for involvement in the research are. You may, for example, need to consider if it is appropriate to involve people with different impairment types. This is because disabled people with different impairments can experience fundamentally different barriers to participation. Where relevant, it is therefore important to involve people with different impairments, including mental health service users, people with learning difficulties, people with learning disabilities, people with sensory impairments, people with physical impairments, people who are neurodiverse (such as people with autism, dyslexia, or dyspraxia) and the Deaf community.

Depending on the objectives of your research, you may also want to consider taking steps to involve disabled people from black and minority ethnic communities, older disabled people, disabled children and young people, lesbian, gay, transsexual and transgendered disabled people, disabled people who live in rural and remote areas and disabled people currently excluded from using your services.

If you approach and involve disability organisations, it is good practice to include organisations that are run and controlled by disabled people. Non-disabled representatives of disabled people may not be best placed to represent the views of disabled people. The involvement of disabled peoples' family, friends and carers can also be considered, where relevant, but not as a substitute for the views and opinions of disabled people themselves.

3.3.2 When should I start involvement?

Deciding when to involve people will be informed by your chosen method of involvement. In general it is good practice to begin active engagement as early as possible, rather than just asking people to comment on work that is already planned. Starting involvement early also means that it is more likely that the quality of input will improve over time as relationships and trust develop. It will also help to secure the commitment of all parties involved.

3.3.3 Establishing the parameters for involvement

In determining the appropriate level of involvement, power and control clearly rest with the researcher. Academics such as Mike Oliver and Colin Barnes have argued that research can disempower disabled people by placing knowledge in the hands of the researcher who interprets evidence and make recommendations on their behalf (see for example, Barnes (2003)). Some sensitivity in defining and guiding the relationship between the researcher and disabled people involved in the research is therefore likely to be required. One way to manage this relationship is to develop a clear Memorandum of Understanding or Terms of Reference which sets out the agreed parameters of involvement. More detailed advice on developing a Terms of Reference is provided in the following chapter.

3.3.4 Keeping people updated and informed

Once you’ve established a way to involve people and brought the group together, it’s important to keep people informed on progress. For example, ODI produced a quarterly newsletter for the Reference Group of Disabled People who provide advice on the Life Opportunities Survey. This gave updates on fieldwork progress and survey developments. After consultation events with group members, we also produced a written report approved by members of a core group that would be available to everyone, including those who were unavailable to attend on the day of an event.

In addition, you can also help to ensure people feel sufficiently engaged by allowing plenty of time for people to provide input before key decisions are made, and then describing why particular ideas could be taken forward as well as the reasons why others could not be accommodated.

A successful involvement strategy will also depend in part on the accessibility of the meetings to which disabled people are invited to attend. The Office for Disability Issues has produced advice on how to run accessible meetings separately, and this is reproduced in Annex A.

4 Involving disabled people in each stage of the research process

This section gives a practical overview of how disabled people can add value to each stage of the research process. You will already have determined the appropriate extent and method of involvement, guidance on which is provided in the previous chapter.

Advice and examples are given in relation to the following:

1. Identification and prioritisation of topics for research
2. Commissioning and tendering
3. Determining the terms of involvement
4. Research design
5. Analysing results
6. Reporting results
7. Dissemination of findings
8. Reflexivity – learning from the process

You may also find guidance produced by the Department of Health in 2006 on how to involve people with learning difficulties in research helpful[13].

4.1 Identification and prioritisation of topics for research

In Government Social Research the priority topics for research are normally set in accordance with the policy agenda of the sponsoring Department. Typically, policy officials identify the need for research evidence to inform policy development. This research might aim to: monitor the effectiveness of existing policies, programmes and services; to develop an understanding of the disadvantage faced by different groups; or, to examine customer experience with services. Where a policy is being developed to provide better outcomes for disabled people, it follows that policy and research colleagues should work together and involve

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[13] Department of Health (2006) Let Me In – I'm a Researcher! Getting Involved in Research. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132916

disabled people to set the direction of policy and service delivery and to identify evidence needs.

Some government departments publish an overview of their proposed research programme for the coming year in advance of finalising it. This provides a useful opportunity to invite comment on relevant projects from external organisations, such as academic institutions, research bodies and organisations led by and/or representing different groups of disabled people.

In the box below an example is provided of how the identification of research priorities can be linked to policy development.

Example: Combining policy development with the identification of research needs

In 2006/07 ODI consulted on what equality means for disabled people and what changes were needed to reach equality. This informed the prioritisation of ODI's objectives, the choice of policy areas to focus on, and the improvements needed in service delivery. These consultations also informed subsequent analytical projects, such as: prioritising what data to collect for measuring progress towards disability equality and in providing the starting point for the development of questionnaire topics for the Life Opportunities Survey (LOS).

Involving disabled people in the identification of research needs was also recommended by the former Disability Rights Commission for public authorities when implementing the Disability Equality Duty[14]. The guidance stressed the importance of involving disabled people in determining evidence needs:

> Authorities will find that involving disabled people in prioritising evidence will reap rewards, as authorities will then be able to tackle the key problems identified by disabled people, and avoid the risk that they divert resources to gathering detailed

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[14] This guidance refers to the equality duties that existed until April 2011. On 5 April 2011 the Public sector Equality Duty came into force in England, Scotland and Wales with new top level guidance published: http://www.equalityhumanrights.com/advice-and-guidance/public-sector-equality-duty/guidance-on-the-equality-duty/

information about areas with little significant impact on disability equality (DRC, 2006).

4.2 Commissioning and tendering

The commissioning and tendering process offers an early opportunity to involve disabled people in prioritising research topics before the objectives and methods of research have been finalised. One option is to invite external organisations of disabled people or disability studies academics to provide advice. They could be asked to critically assess an early draft of your specification if budget has been built in to pay for their time. Comments could be sought on the objectives of the research, the proposed research design and on the specific research tools such as the sampling frame, the recruitment strategy, the choice of fieldwork method and the choice of topics for the questionnaire or discussion guide.

Some research organisations have particular experience or expertise in research with disabled people and so you may wish to consider this when appointing a contractor for your project. If you are unsure, it might be appropriate to request evidence of relevant experience in the project specification.

Example: Involving Disabled People in the Tendering Process

The invitation to tender for the Office for Disability Issues' Experiences and Expectations of Disabled People project set out a broad requirement for research to improve understanding of the extent of disadvantage faced by people with different impairments.

Each tendering organisation was required to involve disabled people in developing their proposals, so as to help define the scope, methods and objectives of the research. They were asked to set out their proposed mechanisms for involvement at each stage of research after commissioning.

This approach to tendering underlined the importance of involving disabled people to potential contractors. It meant that the winning proposal was informed by active engagement prior to award of the contract, and meant that proposals gave a clear outline for ongoing engagement throughout the life of the project.

4.3 Determining the terms of involvement

After the project has been commissioned, the contractor for the work should be expected to elaborate its approach to engaging disabled people. This will involve specifying how relevant stakeholders will be identified and invited to participate, and giving an overview of the proposed roles, responsibilities and means of managing working relationships.

The way the group will function should be discussed among the individuals invited to participate in order to inform the Terms of Reference for the group. All participants should be encouraged to sign up to this at the start of the project. This will help to avoid misunderstandings and to establish strong working relationships between the researchers and those invited to take part in the research process.

When developing a Terms of Reference, the objectives and scope of the research project should be discussed at the outset. You should set out the key areas that are necessary for the project to address and clarify what its limitations are. For example, the available budget will influence sample size and the coverage of different groups. It is important to be clear and honest about what you would like to achieve. If people don’t understand this they may feel that they have been ignored. For example, members may request that the report includes analysis of sub-groups that are of particular interest to them. If the sub-group analysis is not feasible within the given sample, then this should be clearly explained in advance in order to manage expectations.

Defining the intended frequency and timing of involvement is also important. You should allow sufficient time for group members to review documents and provide feedback before key decisions are made. By ensuring the group feels satisfactorily involved at critical stages, you will be able to maintain a good working relationship. You may wish to retain some flexibility over the extent and timing of involvement, as you or other members of your steering/advisory group may decide that input and advice on specific issues is best provided by certain members of the group or at certain critical stages.

One successful example of comprehensive engagement with disabled people throughout the research process is the Life Opportunities Survey, as described in the box below.

Example: The Involvement of Disabled People in the Development of the Life Opportunities Survey

The Life Opportunities Survey is a major piece of research on disability in Britain, informing the Government's work towards equality for disabled people. The Office for National Statistics was commissioned by the Office for Disability Issues to undertake the survey in June 2009.

How were disabled people involved?
A Reference Group of disabled people advised on development work for the survey for 18 months before fieldwork began. The Office for National Statistics contracted RADAR, a large disability campaigning organisation, to help recruit a group of 60 disabled people to join this Reference Group. Following the start of fieldwork, the Reference Group has been maintained in order to provide advice on survey developments and reporting needs.

Some members represent national or local disability organisations and are active lobbyists. Others are disabled people who do not represent any particular organisation and have not been involved in this type of advisory role before. The group has a range of experience, includes people with different types of impairments and goes beyond the large organisations Government usually consults with. This was important because the aims of the survey and the language it uses have to be clearly understood by members of the public who are not experienced in disability policy or research.

The Reference Group provided advice through a series of engagement events which were held every few months. In addition smaller group workshops on areas of interest to members, such as the experiences of young disabled people, and an on-line forum where members could comment on research documents or discuss any issues, were set up. For members who were not internet users, information was posted in hard copy, and RADAR staff were available to discuss matters over the telephone.

What was their role?
The purpose of the group was to provide advice on each stage of survey development including questionnaire development, accessibility of recruitment and interviewing, priorities for reporting and how to disseminate results to other organisations.

A draft terms of reference was circulated in advance of the first meeting of the Reference Group. It was revised following discussion with group members. It was agreed a ‘Core Group’ of 15 Reference Group members would work with RADAR on drafting minutes of meetings in order to provide assurance that the minutes accurately reflected what was discussed.

It was agreed that final decisions over survey were the responsibility of the ONS and ODI. ONS provided feedback on how the advice of the Reference Group had helped to shape the survey. When we could not take a recommendation forward, we explained why not. This feedback was provided in written reports after each meeting[15]. This helped to ensure that members of the group felt their contributions were relevant and meaningful.

Improving the process
After each event, members were asked to provide feedback. This helped us to make improvements for future events. For example, we learned to provide more time to fully explain issues to enable members to provide more relevant and helpful advice. We also developed techniques to explain as clearly as possible, avoiding non-technical language, why some ideas had been take taken forward and not others.

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[15] Reports from these meetings are available on the ONS website: http://www.ons.gov.uk/about/surveys/a-z-of-surveys/life-opportunities-survey/reference-group-zone/index.html

4.4 Payment for involvement

Much literature exists on the appropriateness and legality of making financial payments to participants involved in the research process (SCIE, 2007). Asking disabled people to give their time and effort to provide input to a project without proper reimbursement for their contribution can be seen as exploitative. This is a growing issue as disabled people and their organisations are regularly asked to input to public sector consultations and to become more involved in research projects.

Payment to cover travel, subsistence and support costs (such as for a Personal Assistant or BSL interpreter) for a one off consultation event is often acceptable, but active engagement in a long-term research project may warrant further payment to reflect the level of each participant’s contribution. Advisory Group members are, for example, usually entitled to claim a fee. It should be noted that if members are paid from public funds or working for an organisation which is directly or indirectly funded by Government they cannot be paid a fee for their participation.

Individuals will need to consider their own circumstances and possible tax liability concerning this reimbursement, if they wish to claim. Consideration should be given as to whether payment would affect benefit claims. Further advice on this issue is provided below.

There are potential risks that may affect the quality of the research process as a result of providing payment for involvement. To take the example of user controlled research, Turner and Beresford (2005) note that some participants may feel under pressure to provide a level of input to the project beyond their means, because of high expectations raised on provision of payment.

4.4.1 Benefit barriers to involvement

A crucial factor in considering level of payment for ongoing involvement in research projects is whether the financial contribution will exceed income allowance for benefit claimants and potentially jeopardise their benefit receipt. Through communication with experts within the DWP Benefit Reform Division and the Jobcentre Plus Transformation Team, the following advice has been obtained for the involvement of disabled people at one-off consultation events and for the reimbursement of Advisory or Steering Group members.

Disclaimer

This section should be considered as general guidelines on how payment for involvement may affect benefit receipt. For specific advice on individual circumstances we recommend participants obtain advice from their local Jobcentre when considering any participation.

One-off consultation events

Where people are participating in events and in receipt of expenses and remuneration they will, for employment purposes, be deemed as ‘not working’ and this will not affect their being available for work for benefit purposes.

- Any payments received however will be either taken into account as income or may be treated as capital (determined by the decision maker at the Jobcentre).
- Expenses paid for travel or provision of a carer will probably be ignored by Jobcentre Plus but they will need to declare this if they are receiving benefit as this is ultimately the decision of Jobcentre Plus.

Ad-hoc advisory or steering group members

Any fees paid in excess of expenses will be treated as ‘working’. This will impact on the person’s availability for work (for Jobcentre Plus purposes) and any remuneration received will be treated as earnings.

- Remunerations received will be subject to the Jobcentre Plus earnings rule; and
- All work and expenses must be declared. Expenses will probably be disregarded but again this will be the decision of Jobcentre Plus.

4.5 Research design

Research design, encapsulating the choice of research methods, interview modes, and other research tools, can also benefit from the involvement of disabled people. Disabled people can advise on the effectiveness of different methods for carrying out research with people with different impairments and so help to ensure that the research is as inclusive as possible.

For example, the Reference Group of Disabled People set up by the Office for Disability Issues for the Life Opportunities Survey helped to make the survey more accessible by:

- Advising that the accessibility of recruitment materials such as advance letters and information leaflets could be improved by printing them in size 14 font and by issuing Easy Read versions as standard.
- Providing feedback on how to make interviewing more accessible for people with a range of impairments. One way in which this was done was by providing Reference Group members with demonstrations of the Computer Assisted Personal Interviewing process. Reference Group members also participated in pilot testing to run through draft versions of the questionnaire.

A wider benefit of involvement was that the contractor applied this advice to their interviews generally, making their other surveys more accessible.

The advice of disabled people can also help to shape the choice and design of questions and response categories in survey questionnaires as well as the topic coverage of qualitative discussion guides. In this way, your research tools can be improved by drawing on the experiences and advice of people who have real life experience of the issues you want your research to investigate.

Two examples of effective engagement with disabled people to inform question choice are provided in the box below.

Examples: How Involving Disabled People can Improve Survey Questions

1. Ten members of the Reference Network set up for the ODI's 'Experiences and Expectations of Disabled People' project took part in telephone interviews to discuss the proposed survey questions. There was consensus among interviewees that the draft screening question was too heavily based on the medical model of disability. Including questions on impairments was felt to be unnecessarily long and clinical. In response this was replaced with a shorter version which would enable people to self-identify which broad category they felt best described their impairment.

2. The Office for Disability Issues started with a long list of topics to include in the Life Opportunities Survey questionnaire. The survey's Reference Group provided a good reality check on what issues are important to disabled people and helped to prioritise and reduce the list. The Group's first hand expertise on the social barriers experienced by disabled people helped to inform the range of response categories to questions on social barriers. For example, the Group commented that our draft transport questions were initially too focused on physical barriers to accessing different modes of transport. They emphasised the importance of other issues such as fear of crowds, attitudes of other passengers and the helpfulness of staff. The questionnaire was revised as a result.

4.6 Analysing results

The analytical stage of research is usually controlled by the researchers. Tasks which require greater technical expertise, such as statistical analysis using specialist software, may legitimately be retained within the research team. However, involving disabled people who are external to the research team can help to determine the themes of analysis, as demonstrated by the example provided in the box on the next page.

Example: How Engaging Disabled People can Improve the Relevance of Analysis

Two national workshops were set up to consider emerging findings from the ‘Experiences and Expectations of Disabled People’ project commissioned by the Office for Disability Issues. The workshops involved all members of the project’s Reference Network. The first workshop looked at the findings of the qualitative research and the second at the findings of the quantitative survey. Network members agreed that it would be helpful if the findings could be compared to the experiences of non-disabled people and if analysis could be undertaken to see whether there was any difference in experiences between different sub-groups of the disabled population. These suggestions helped to improve the focus of the analysis.

Disabled people can also assist with the interpretation of results. This helps to ensure that the researcher fully understands and appreciates the evidence provided by disabled research participants. Validation exercises, where emerging findings are reviewed with the research participant, provide one way of doing this, as shown by the example below.

Example: Using Validation in the Interpretation of Qualitative Research Findings

A number of filmed ethnographic in-depth interviews were commissioned by ODI to gather evidence of the social barriers encountered by disabled people. Rather than the research team analysing the film footage alone, the research contractor was asked to review the footage with each research participant to check that the emerging findings were in line with their experiences. This helped to ensure that the researchers drew conclusions that genuinely reflected the experiences and views of the research participants. It also brought greater balance to the power relationship between researcher and research participant, with participants happy to see how their evidence was being used in the analysis stage.

4.7 Reporting results

The advice of disabled people can help to ensure that results are presented in a way that is accessible to people with different types of impairments. This helps to ensure that those who are the subject of the research can access the findings, and that no one is excluded from making use of the results.

Making results accessible will help to ensure that published research outputs are in line with the GSR Code, which requires that government social research products are accessible. If the report includes official or national statistics, it will also help to meet Principle 8 of the Code of Practice for Official Statistics, which states that official statistics should be disseminated in forms that, as far as possible, are accessible to different audiences, including disabled people[16].

Disabled people are best placed to identify the range of report formats that may need to be provided and to advise on whether draft versions are accessible. For example, if the research examines the experiences of people with a learning disability it would be appropriate to provide an Easy Read version of the summary of the main project report[17]. Disabled people could be asked to comment on a draft version of the report to provide a check on accessibility.

Involving disabled people on reviewing draft documents can also help to ensure that the findings are clearly presented and that the language used and overall tone of the report is appropriate and in line with the social model of disability. For example, using the term ‘disabled people’ is preferable to using ‘people with disabilities’ since it follows the social model and implies that these people are disabled by society. Involving disabled people can also help you to avoid medical model terminology or emotive language which portrays disabled people as suffering tragedy or as objects of pity or admiration.

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[16] Available from: http://www.statisticsauthority.gov.uk/assessment/code-of-practice/index.html

[17] An example of an Easy Read research report is the one produced for the interim results of the Life Opportunities Survey, available from odi.gov.uk/los

Example: How involving disabled people can improve the presentation of research results

Draft chapters of the research report for the ODI's 'Experiences and Expectations of Disabled People' project were sent to ten members of the project's Reference Network for comment. The comments made related to instances where language did not fit the social model of disability and the most suitable way for presenting statistical information. This process also helped to identify some outstanding gaps in the analysis. The report was revised as a result of these comments.

4.8 Dissemination of findings

For research findings to reach the widest possible audience, you could ask the disabled people involved in the research process to distribute the results. It is possible that some of these people may be willing to use their networks to help disseminate the findings. An additional communications strategy could be to invite disabled people who have been involved throughout the research process to present the findings of the work to their own organisations. This helps to lend credibility to the research and to raise awareness of the findings beyond the stakeholders who traditionally engage with government.

4.9 Reflexivity – learning from the process

Throughout the research process, it is important for the research team to critically reflect on the success of the chosen model of engagement. Asking for, and acting on, ongoing feedback will help to improve working relationships. When a project is complete, a more thorough evaluation of the lessons learned should also be performed, and the conclusions taken forward to the next project that requires the involvement of disabled people.

Example: Learning Lessons from Involving Disabled People

When ODI completed its ‘Experiences and Expectations of Disabled People’ research project, a workshop was organised to reflect on the model of engagement and gather ideas for how involvement could be improved for its next project, the Life Opportunities Survey. The workshop drew on the recommendations of a report produced by the organisation who facilitated the project’s reference network. The key benefits of involvement were seen as: improving and providing a reality check on the research approach and tools, making the research more transparent and increasing stakeholder confidence in Government research. The key learning points included: the importance of establishing trust with network members early on and assuring confidentiality; giving feedback to the whole group after different involvement strands had taken place; and, communicating to the group when opportunities to influence decisions were very limited.

5 Accessible and inclusive research design

Ensuring that research is accessible to disabled people will help to achieve the collection of high quality data by reducing any bias that may occur if an important group were unable to take part. For example, if it is likely that deaf people who use British Sign Language (BSL) will fall within your sample you will need to consider booking sign language interpreters to assist during an interview. This chapter will help you understand if people with different types of impairments are likely to form part of your sample, and if so, provides advice on how you might adapt your methodology to enable participation from as wide a range of disabled people as possible.

5.1 Estimating impairment prevalence

Undertaking a preliminary analysis of the prevalence of different types of impairment will enable you to decide on the most appropriate method to enable disabled people to fully participate in the study. Depending on the focus of your research, you may also want to consider the prevalence of people with more severe impairments and people with multiple impairments, as these characteristics may affect decisions on using an appropriate mix of accessible formats in communication and modes of interview.

The following resources provide statistics on prevalence of different types of impairments:

- The Life Opportunities Survey provides detailed prevalence data on different impairment types and impairment severity. Reports and data are available from www.odi.gov.uk/los
- The Labour Force Survey, the General Household Survey and other data sources used by the NHS Information Centre and Department for Health provide information on prevalence of different types of long-term illness and physical or mental impairments.

The Family Resources Survey also provides data on the percentage of the population covered with rights under the Disability Discrimination Act. Further information is available from: http://research.dwp.gov.uk/asd/frs/

5.2 Choice of methods

5.2.1 Quantitative research methods

Common research methods such as household surveys are entirely appropriate for collecting data from people with different impairments so long as steps are taken to ensure the interview mode is accessible. The following chapter describes how conventional methods of survey data collection, including face to face interviews, telephone interviews and postal self-completion questionnaires, can be made accessible to a sample that includes people with a different types of impairments.

5.2.2 Qualitative research methods

As with research with other audiences, qualitative methods can allow you to explore the experiences of disabled people in greater depth than permitted by quantitative techniques. Qualitative methods have particular strengths in terms of improving accessibility, particularly for people with more profound learning disabilities or more severe communication or neuro-diversity impairments. People with these types of impairment may prefer the flexibility associated with in-depth interviews or ethnography, where they are able to discuss issues in their own words rather than answering according to pre-defined response categories in a questionnaire.

Asking participants with learning difficulties to construct collages using images and symbols may also enable their participation in in-depth interviews (an example of this approach is provided in the following section on mixed methods). For people who use specific tools to enable communication, such as Talking Mats, it would also be appropriate to develop a methodology that allows them to respond using their preferred method of communication, as shown in the example.

Example: Using Talking Mats to Enable Participation in Research

Mitchell and Sloper (2011) developed methods to use with young people who had learning and/or communication impairments for a study for the Department of Health. It was felt that traditional semi-structured interviews and research materials based on a written format were unsuitable for this study. Instead a symbol based approach was developed using Talking Mats, whereby participants were asked simply worded questions and invited to choose the symbols that matched their ideas and feelings. Mitchell and Sloper (2011) concluded that “in terms of participation, Talking Mats enabled young people with learning and/or communication impairments to participate in the project and provide real insights into the choices/decisions that they make and want to make, how they make them and how they fell about decision making processes”.

Ethnographic techniques, where research participants are observed going about their daily life and the researcher makes notes about their observations, may be particularly helpful for enhancing the participation of people with more severe communication impairments (see example below).

Example: Removing barriers to participation in research by using video ethnography

This example shows how the use of video ethnography helped to meet two needs. The first was to provide a rigorous way to observe the disabling barriers experienced by people with impairments, and the second was to ensure that the research was accessible to research participants with a range of impairments, including some who were non-verbal. Overall, the research aimed to provide a depth of evidence to complement the statistics provided by the Life Opportunities Survey.

A total of 14 participants were filmed for between 4 and 6 hours as they went about their daily tasks, answering questions posed by the interviewer as particular barriers were encountered or topics discussed. This approach allowed the researchers to develop a rapport with the participants, allowing them to explore issues in more detail than might be permitted in a shorter qualitative interview. Capturing experiences of social barriers on film, also meant that the researchers were able to capture and observe information that the participant may otherwise have found difficult to explain. The researchers also used the films as part of a validation exercise. The potential burden on research participants was seen as appropriate given the wealth of information that could be collected, and indeed for many participants taking part in the research was an empowering experience, as shown by the following quote.

"Overall the experience was extremely positive and I'm ecstatic to hear the findings. It's comforting to know that others are going through the same as you and that I am not alone because sometimes I feel that I am. I feel privileged to be involved in the research and pleased to voice my opinions… I feel important to be contributing on behalf of others."

Once the research was completed, edited films were produced which have been used by ODI to help communicate the lived experienced behind the statistics produced by the Life Opportunities Survey.

The final research report is available from ww.odi.gov.uk/los

Nind (2008) provides a useful review of qualitative studies with people with learning disabilities and communication impairments, and further demonstrates how interviews, focus groups, visual methods (such as photo elicitation), ethnography and observation and life story/narrative techniques can be used to enhance the accessibility of research.

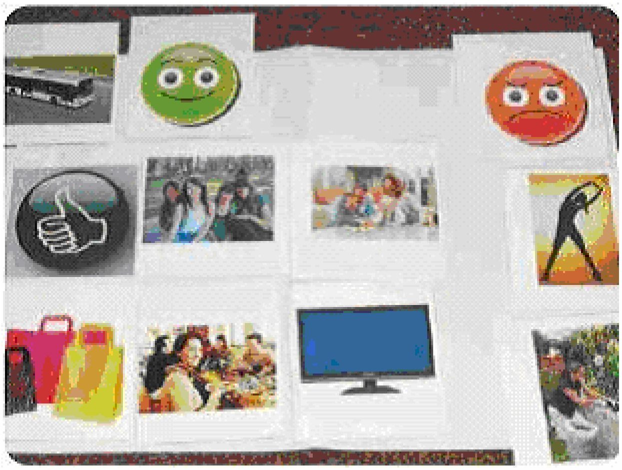
5.2.3 Mixed methods

If a survey is your intended mode of data collection, you may need to consider whether accessibility can be improved by adopting a mixed method approach. Whilst many people with impairments should be able to take part in a well-designed and accessible survey interview, there may be exceptions for people with certain, more severe impairment types, such as people with more profound learning disabilities or more severe speech impairments. In order to ensure these groups are not excluded from the research, it would be appropriate to consider the use of alternative methods. Qualitative methods, such as in-depth semi-structured interviews, may provide the flexibility required to allow people with more severe impairments to take part, as described in the example below.

Example: Making the Life Opportunities Survey accessible to people with more profound learning disabilities

A sample of people with learning disabilities who could not complete the full face to face survey interview were invited to take part in a face to face semi-structured qualitative interview. Some factual information on the research participant's situation was collected by proxy during the main survey interview to ensure the collection of some statistical data for comparison with other groups in the sample.

The topic guide for this interview was based on the themes covered by the survey, with a series of images and symbols developed to enable people to take part. Participants could select between these to show how they felt about certain issues, with the resulting collage photographed by the researcher to be used for analysis. The collage below shows the images used by one participant to describe her leisure activities.



To help ensure that the interview and interview materials would be accessible, the recruiter spoke to the research participant's carer or support worker in advance to develop an understanding of how the research participant preferred to communicate.

The findings from this study were analysed and written up in a report published alongside the findings of the main survey. It is available from www.odi.gov.uk/los

Whilst employing a mixed method approach can make fieldwork more inclusive, it can present a challenge for analysis in combining the reporting of quantitative survey data with verbatim qualitative data. Using a mixed method approach however can mean that a study becomes more inclusive and as a result provides a more comprehensive analysis of the experiences of all disabled people. Qualitative research findings can also add to the explanatory power of statistical reports, for example, by using verbatim quotes to illustrate the key statistical findings.

5.3 Informed consent and the Mental Capacity Act

When developing your methodology you are likely to need to consider whether your research might involve people who may not be able to make their own decisions. This might include people with more profound learning disabilities or certain severe cognitive or communication impairments who may not be able to provide informed consent to participate in your study. If this is the case, the requirements of the Mental Capacity Act (MCA) will apply to your research. The purpose of the MCA is to enable the involvement of such participants where it is appropriate to do so.

A set of guidelines provided by the Department of Health explains what you need to consider if you wish to include people who lack the capacity in your study. If their inclusion can be justified, you will need to ensure that they can be meaningfully involved. This is likely to mean making adaptations to your research methodology, perhaps taking on board the examples provided in this chapter. You may also wish to check that interviewers have received appropriate training to be able to identify people who lack capacity to consent and how to obtain consent from somebody close to the person concerned who can advise on whether he/she would want to be involved. You should also be aware that if you wish to undertake research with people who lack capacity, you will need to obtain approval from an appropriate body such as a Research Ethics Committee.

The Department of Health fact sheet is available at:
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@pg/documents/digitalasset/dh_106217.pdf

5.4 Collecting data by proxy

To address instances where individuals lack capacity to give their informed consent, or in circumstances where people have severe communication impairments and cannot take part regardless of how accessible the interview is, it may be best to collect some data from a proxy respondent. This will depend on the type of information being collected. Certain types of information, such as a respondent’s opinions, attitudes and experiences may not be appropriate for collection via proxy. However, it may be appropriate to collect some factual information on the respondent’s situation via a proxy, rather than to risk introducing some bias by excluding certain groups altogether.

5.5 Other accessibility considerations

Accessibility extends to all interactions with a research participant. This could mean, for example, ensuring that any screening exercise which takes place in advance of a main stage survey is accessible. Any opt-out letters, information leaflets and summary of findings documents can also be made accessible by making these documents available in a variety of formats, including as appropriate, in large font, Braille, Easy Read and audio.

6 Conducting accessible survey fieldwork

This chapter describes how methods of survey data collection, such as face to face interviews, telephone interviews and postal self-completion questionnaires can be made accessible to a sample that includes people with different impairment types. The advice in this chapter is largely reproduced from a feasibility study for the Life Opportunities Survey commissioned by DWP and completed by NatCen (Purdon, 2005).

This chapter provides advice on how to make different modes of interviewing accessible to people with hearing, visual, speech, dexterity and learning impairments. It also provides advice on how to make research accessible to people with lower levels of literacy and people with mental health conditions. Interviewing that is accessible to people with different impairments will likely necessitate the use of a range of interview modes. This may give rise to mode effects, which are discussed at the end of this chapter.

6.1 People with hearing impairments

Methods of communication

Depending on the severity of the hearing impairment, 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. 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 portable loop systems are now available.

Face-to-face interview

Among people who have a mild to moderate hearing impairment, a face-to-face interview is easily accessible for people without any hearing difficultly when using a hearing aid. A face-to-face interview that relies on speech may also be accessible to some people with a mild/moderate hearing impairment, depending on the severity of their hearing impairment and the complexity of the interview.

However, a large proportion of those with a mild/moderate hearing impairment would not be able to rely solely on speech but would have to use lip-reading and writing to communicate. Ample use of visual aids can also improve accessibility. Visual aids should not be limited to showcard response categories and may require interviewers to show the written questions to respondents.

Most people who are severely or 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 for long questionnaires may not be accessible, without appropriate provision of breaks.

For people who use BSL as a preferred means of communication, facilitation of the interview with a qualified BSL user can ensure accessibility. In order to translate the questionnaire accurately, the researchers and BSL translator will need to discuss all the words and concepts that have no direct equivalent in BSL.

Computer-Assisted Self-Interviewing

In Computer-Assisted Self-Interviewing (CASI) 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 people with a hearing impairment this should be an acceptable method of collecting survey data.

For people with a less severe hearing impairment, use of Audio-CASI may also be accessible 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 people who also have visual impairments.

It should not be presumed people who use BSL as their first language can use a CASI instrument because they may have limited knowledge of English.

Telephone interview

Many people who have a hearing impairment 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.

According to the RNID, almost two-thirds of people 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. People 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. If a research project’s preferred mode of interview is by telephone, it may be possible to interview hearing impaired people by using a textphone, RNID Typetalk or Computer Assisted Telephone Interviewing (CATI) to send text questions and receive text answers.

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

Postal questionnaire

The majority of people who have a hearing impairment can read, so a postal questionnaire would be an accessible option. Research using only postal methods would exclude deaf-blind people, depending on the severity of the visual impairment and the design of the postal questionnaire.

Most deaf people who use BSL as their first language may also be excluded because their knowledge of English may be limited. However, this amounts to a very small proportion of all hearing impaired people.

Advance letters

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 could also include a textphone number and/or a Typetalk number.

6.2 People with speech impairments

Methods of communication

People with a severe speech impairment may use unaided communication methods such as body language, sign language, verbal and gestural strategies. They may also use written words as an alternative to speech.

Some people with speech impairments 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. The term ‘augmentative communicator’ is often used to describe people who use speech devices to communicate.

Face-to-face interview

A person who has 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 assistance to understand the respondent and/or the respondent may require some form of assistance to answer the questions. Furthermore, this approach is likely to be tiring for the respondent and may increase the length of the interview considerably.

Respondents who use VOCAs can be interviewed face-to-face without help from others. It is possible that the use of VOCAs may also increase the length of the interview. Respondents with a severe speech impairment who do not use VOCAs can, to some extent, be interviewed on their own without help from others. It may place less burden on the respondent if they are asked questions that require short response answers without need for long explanation. Answers could be given using verbal or gestural strategies. Closed questions requiring responses other 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 may require written answers from the respondent. The interviewer would be able to read the respondent's answers and, if necessary, seek clarification and probe for complete responses. It should be noted that some people with speech impairments may also have difficulty with writing and recognising the written word.

If the cause of the speech impairment is cerebral palsy, a degenerative disease or brain damage, respondents may have reduced manual dexterity, making a requirement to write answers inaccessible for some people. Other aspects of language may also be affected, such as the ability to read and write words.

Self-completion methods

On the whole, self-completion methods (e.g. CASI, postal, web) are completely accessible for people who only have a speech impairment. However, some may also have other impairments, such as reduced manual dexterity or impairments that associated with a loss of ability to understand written words. These other impairments may reduce an individual's ability to use a self-completion questionnaire.

Telephone interview

A standard telephone interview would not be accessible to people with severe speech impairments. People with textphones can be interviewed by telephone, with the interviewer using speech to ask questions and the respondent using text to answer. If the questionnaire only included closed questions with relatively short response lists, it should be possibly to use Touchtone Data Entry (TDE) to receive responses from the respondent.

6.3 People with visual impairments

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.

Generally, the use of large and clear font (e.g. Ariel point 14) will improve readability for many people with visual impairments. It is also beneficial to keep communications short and to ensure that the layout of text is also clear.

There are various aids available to help blind and partially sighted people to 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.

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.

More detailed recommendations on clear print can be found on the RNIB website[18]. The RNIB also offer an accessible information consultancy service.

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[18] http://www.rnib.org.uk/professionals/accessibleinformation/Pages/see_it_right.aspx

Show cards can be produced in Braille. The number of respondents who can read Braille in the sample is likely to be small however. Only around 3 per cent of people registered blind or partially sighted use Braille. People who have had visual impairments since birth may have learned Braille. However, it is a lengthy process. People who lose their sight later in life often feel that other options, such as audio are more suitable.

For 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).

Telephone interview

A telephone interview is an accessible 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. 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. For example, RNIB’s ‘See It Right’ pack, AbilityNet’s ‘Web Accessibility Key Info’ pack, and the Disability Rights Commission’s report ‘Web Access and Inclusion for Disabled 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 so that questions and responses can be heard through headphones as well as being displayed on the screen.

Postal survey

All postal questionnaires should be printed using clear print so that the number of visually impaired people who can read them is maximised.

For people 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 or 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 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.

People with visual impairments with access to the internet can complete accessible email and web questionnaires. 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. For example, 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.

People with visual impairments could self-complete an interview telephone. All questions would be recorded and then the respondent could provide his/her answers using Touchtone Data Entry and/or speech (spoken answers could be recorded in audio or speech recognition software could be used).

6.4 People with manual dexterity impairments

Methods of communication

People with limited manual dexterity can communicate using verbal and written information, unless they have an additional impairment such as aphasia, dysarthria, or a visual impairment.

Manual dexterity impairments 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.

Face-to-face interview

A face-to-face interview is a suitable data collection mode for people with a more severe dexterity impairment. Consideration should be given to any section of the questionnaire that may require self-completion (due to sensitive topics).

Self-completion methods

Depending on the severity of the dexterity impairment, it might be possible to use a self-completion instrument in a face-to-face interview. For example, if the self-completion document is paper and pencil, respondents who can hold a pencil (with or without a writing aid) may 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 will be less accessible for people with this type of impairment.

Telephone interview

A telephone interview is a suitable data collection mode for people with a dexterity impairment who can operate a telephone. However, holding a handset might be difficult for some and keypad operation could be slow and inaccurate. Some people with a less severe dexterity impairment will have adapted telephones, e.g. enlarged keys, handsets that are light weight and easy grip, hands-free operation and/or 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.

For people who find typing easier than handwriting, a CASI instrument could be used. On the whole, laptops are increasingly used in social research fieldwork. 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.

Postal questionnaires

Some people with a dexterity impairment 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.

People with access to a computer and who 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.

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 and/or interviews allow sufficient time for breaks.

6.5 People with learning difficulties or disabilities

Having a learning difficulty or disability can affect the way someone learns, communicates or does other everyday things. Learning disability is a more general term for impairments that can affect learning and understanding. Some people may have more profound learning disabilities. This can mean they have great difficulty communicating, need high levels of support and may have additional sensory or physical impairments.

It is important to recognise the distinction with learning difficulties. Learning difficulties refer to specific difficulties that can be present from birth or can develop later in life, for example, due to a brain injury. There are many different types of learning difficulty affecting specific areas of learning, for example in relation to reading such as dyslexia. It can be mild, moderate or severe. Some people with a mild learning difficulty do not need a lot of support in their lives and therefore would not consider themselves to be disabled. Other people need support with getting dressed, going shopping, or filling out forms.

Information should be clearly presented and straightforward to understand e.g. plain English , large print, audio or the Easy Read format.

Some people prefer to get information graphically. This does not necessarily mean they cannot read text. Publications and websites with simple text and images can help people to understand information.

Speech is a suitable communication method for most people with Moderate learning difficulties or disabilities. However, some people may have problems grasping complicated concepts and may not be able to absorb a lot of information at one time. Repetition may be important to help people remember what is being said. Speech is unlikely to be an effective means of communication for most people with severe to profound learning difficulties.

Accessible research

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 Department of Health commissioned Feasibility Study on Learning Difficulties (DH, 2003) 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 difficulties or 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 difficulties include (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 or qualitative topic guide to interview most people with learning difficulties or disabilities.

Because many people with learning difficulties or disabilities have problems reading, the use of show cards with written response options should be avoided unless they are made accessible. Accessible show cards can aid understanding, with illustrations and symbols used alongside text to help people understand and remember the meaning of the words. The best known symbol systems in the UK are Makaton and Talking Mats[19].

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[19] Further information about Makaton can be found at http://www.makaton.org/ ; further information on Talking Mats can be found at http://www.talkingmats.com/

Telephone interview

Although many people with learning difficulties or disabilities are able to operate a telephone, it is unlikely to be a suitable survey data collection method. It is more difficult to establish rapport on the telephone, as 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 difficulties or disabilities will have difficulty reading and writing. Consequently, postal surveys are likely to have low response. It might be possible to send electronic versions of the questionnaire with audio or offer people 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 or difficulties.

6.6 People with low levels of literacy

Methods of communication

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

Some forms of written communication may be accessible, depending on the level of literacy and the complexity of the written document.

Face-to-face interview

A face-to-face interview is a suitable data collection mode for people with lower levels of literacy. 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 font. Illustrations can be used to keep written text to a minimum.

Telephone interview

A telephone interview is an accessible data collection mode for people with a lower level of literacy.

Self-completion methods

Depending on the level of literacy, some people 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.

Respondents may be unwilling to disclose they have low literacy, through fear of embarrassment. This may be difficult for the interviewer to detect but should be treated with caution and sensitivity. For example, the respondent may ask the interviewer to read out the questions for them. 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 a lower level of literacy. 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 questionnaires

Postal surveys are likely to have high levels of non-response among people with literacy problems. The cognitive burden of completing the questionnaire will discourage many people with lower levels of literacy problems from taking part. People with access to a computer could be sent an electronic questionnaire with audio. There are various guidelines for developing written documents for those with lower levels of literacy, including using plain language, being as concise as possible, and using clear type.

6.7 People with mental health conditions

People with mental health conditions such as anxiety, depression or schizophrenia may find the standard forms of research interview accessible, in terms of formats of communication. However, interviewers may need disability equality training in how to communicate with people with specific mental health conditions and be sensitive to their needs. Steps should be taken to ensure the topics of the questionnaire, their purpose and intended usage are clearly understood and do not cause undue stress.

6.8 People with multiple impairments

Many disabled people will have more than one impairment. Therefore a range of communication methods discussed above may have to be used together in order to make recruitment and interviewing accessible.

6.9 Mode effects

Where different interview modes are used, measurement differences by mode may be produced. This is because respondents might answer questions differently if asked in one mode rather than the other e.g. the presence versus absence of an interviewer. On the whole, sensitive questions and attitudinal questions tend to be more susceptible to mode effects than factual questions.

For example, 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. This may be an issue with certain people with learning disabilities as there can be a tendency towards acquiescence if they perceive the interviewer as someone of authority.

A second example relates to the ‘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 the ‘recency effect’ when the response options are presented orally (e.g. respondents are more likely to select options that are read out last). To take an example of people with different impairment types, the need to present response options visually to deaf people and orally to blind people is likely to introduce mode effects, particularly if the list of response options is long. If mode effects are a concern, they may be able to be addressed through methods such as rotating the response options on different versions of the questionnaire i.e. one half of the sample are asked one rotation of response options and the other half another rotation (i.e. where the ordering of the response options is reversed).

Overall, despite the possibility of mode effects, using different interview modes is likely to benefit the overall quality of the research by ensuring a wide a range of people with different impairments can participate in the research.

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8 Annex A: Tips for running accessible meetings

This advice is reproduced from the ODI publication ‘Involving disabled people: an introduction’, available from: http://odi.dwp.gov.uk/involving-disabled-people/index.php

1. Find out if delegates have particular access requirement before the event.

2. Check the venue is accessible. Ideally there will be step-free access throughout and the meeting will be on the ground floor.

3. Make sure the venue can be easily reached using public transport.

4. Make sure there is appropriate parking available and that spaces can be pre-booked. Check that it is easy for people to be dropped off at the entrance.

5. Timing is important. Start meetings as late as possible and finish as early as possible. Schedule plenty of breaks, with sessions lasting no longer than an hour. Make sure you finish on time since many people will have made specific travel arrangements

When delivering presentations, always read out slides in full and describe all diagrams or pictures. Treat slides as a way to support what is being said, not as the principle method for supplying information.

Use a public address system. Make sure all the presenters have microphones and that there are microphones available for questions from the floor.

Sign language interpreters need to be booked well in advance.

Make sure the venue is well-lit and there is no background noise. Arrange quiet areas and plenty of seating.

Make sure accessible toilets are available as close as possible to the meeting.

Make sure staff at the venue know how seriously you take accessibility and that it’s not an optional extra. Ideally, they should have had experience of running events with disabled people.

Smaller meetings

1. Ask everyone to introduce themselves at the start of a meeting and identify themselves whenever they start speaking.

2. Make sure that people speak one at a time.

3. Give everyone a chance to speak and the time to make their point.

4. Send papers at least two weeks before a meeting, including any alternative formats. Try to avoid changing the agenda and introducing new papers at short notice.

Printed material

1. Write in clear English. Keep your language as simple as possible and avoid initials and acronyms.

2. Use 14 point Arial font as standard in any printed material.

3. Producing alternative formats will help you to include more people. The most common formats to consider are:
   - large print (18 point minimum)
   - Easy Read (easy words and pictures)
   - Braille
   - audio (CD or computer file)
   - different colour contrasts (e.g. dark blue text on pale yellow paper).

Find out what individuals require and prepare appropriate alternative formats for them in advance. You don’t need to produce all formats for every document – make sure you promote their availability and monitor demand. Don’t be afraid to ask your audience what they would like. This will help you to meet their requirements and build trust in the relationship.

For more tips and information and about alternative formats, visit www.odi.gov.uk/communications