BSA Attitudes towards the rights of disabled people

Findings from cognitive interviews

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Contents

Acknowledgments

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1 Background

For 2009 a suite of questions is being developed to assess public attitudes to disabled people and their rights. Data obtained from these questions will assist the Department to monitor implementation of the United Nations' Convention on the Rights of Persons with Disabilities. The UK is currently working towards ratification of the Convention.

Article 8 of the Convention commits States that are party to the Convention to:

- raise awareness throughout society, including at the family level, regarding persons with disabilities and foster respect for the rights and dignity of disabled people;
- combat stereotypes, prejudices and harmful practices relating to disabled people, including those based on sex and age, in all areas of life; and
- promote awareness of the capabilities and contributions of disabled people.

Monitoring implementation of this Article therefore requires, amongst other things, data on public awareness of, and attitudes towards, the human rights of disabled people.

The DWP and the Office of Disability Issues (ODI) - a cross-government unit within that Department which works across government to deliver the Government's commitment to equality for disabled people - asked NatCen's Questionnaire Development and Testing (QDT) Hub to investigate people's attitudes and prejudice towards disabled people in a range of social situations by cognitively testing the set of new questions. The questions, similar in nature to those from the Disability Rights Commission module in 2005, have been carefully designed to gauge public attitudes to disabled people who are actively exercising their rights and the extent to which people accept the consequences of human rights for disabled people. Each of the 'scenarios', as they are referred to in this report (shown below), is linked to a specific human right outlined in the convention.

1. Scenario 1: Right to choose a place of residence
2. Scenario 2: Right to marry and found a family
3. Scenario 3: Right to employment
4. Scenario 4: Right to access to general education system
5. Scenario 5: Right to participate in political and public life; and,
6. Scenario 6: Right to participate in cultural life, recreation, leisure and sport.

Rather than referring to 'disabled people' in the new question set, as similar scenario questions have done in the past, a decision was made to break this broad group down into five impairment types specified by the Equalities and Human Rights Commission 1) physical disability, 2) sensory impairment, 3) mental health condition, 4) learning disability and 5) longstanding illness or health condition It was considered desirable to break responses down by impairment type, as opposed to asking about 'disabled people' as a whole as previous work has shown that prejudice varies depending on impairment type (e.g. DRC BSA module 2005 showed this). ODI therefore felt it would be beneficial to have data on all five categories.

Each of the six scenarios was combined with each of the five impairment types, along with two or three examples representing the range of conditions within that impairment type. This meant there was a total of 30 questions to test. The scenario/impairment combinations were split over two test questionnaires: Version A and Version B. Each questionnaire contained 15 scenario/impairment combinations and was tested on half of the sample (12 respondents). This allowed for all of the combinations to be sufficiently 'tested'. The testing was designed to ensure that each respondent was asked questions involving all six scenarios and all five impairment types but not every combination.

At the end of both test questionnaires a set of questions about awareness of the UN Convention as well as two general questions about the human rights of disabled people were included. Table 1 below shows the structure of the test questionnaires.

Table 1: Structure of test questionnaire Version A and test questionnaire version B.

Test questionnaire A		Test questionnaire B	
Scenario 1:	▪ with physical impairment ▪ with sensory impairment ▪ with mental health condition	Scenario 1	▪ with learning disability ▪ with long-standing illness
Scenario 2:	▪ with physical impairment ▪ with sensory impairment ▪ with mental health condition	Scenario 2:	▪ with learning disability ▪ with long-standing illness
Scenario 3:	▪ with physical impairment ▪ with sensory impairment ▪ with mental health condition	Scenario 3:	▪ with learning disability ▪ with long-standing illness
Scenario 4:	▪ with learning disability ▪ with long-standing illness	Scenario 4:	▪ with physical impairment ▪ with sensory impairment ▪ with mental health condition
Scenario 5:	▪ with learning disability ▪ with long-standing illness	Scenario 5:	▪ with physical impairment ▪ with sensory impairment ▪ with mental health condition
Scenario 6:	▪ with learning disability ▪ with long-standing illness	Scenario 6:	▪ with physical impairment ▪ with sensory impairment ▪ with mental health condition
Awareness of the Convention Questions			
General human rights questions (in both questionnaires)			

1.1 Aims of the Cognitive Testing

The purpose of cognitive testing is to check that survey questions are understood in the way intended and therefore that they measure what they are meant to. The technique focuses on four main processes involved in answering survey questions:

1. understanding and interpretation of the question,
2. ability to recall information needed to answer the questions,
3. judgements involved in deciding on an answer, and
4. the use of response categories to answer the question.

In a cognitive interview, respondents are asked the survey questions and then asked a series of probe questions by the interviewer once they have answered one or a group of survey questions. Probing allows for problems with the survey questions to be identified and the reasons for these explained, which would not be revealed in a standard field pilot.

The aims of Cognitive testing for this project were to explore:

- the extent to which participants understood the questions (looking at particular key terms used) and therefore whether the questions were likely to produce valid and reliable data;
- acceptability of the questions;
- willingness to answer the questions;
- whether understanding/willingness to answer varied by respondent background (for example gender/age/ethnicity);
- potential sensitivity of the questions and whether this was more so for particular respondents; and,
- To assess whether the questions were potentially subject to social desirability bias.

1.2 Report Structure

Chapter One provides an overview of the background for this research and the aims of the study.

Chapter Two gives a brief overview of methodology used for cognitive testing, with particular emphasis on the characteristics of the respondents who were included in the sample. The methodology chapter includes a table showing the sample composition and also explains how the interviews were conducted. Full details of the recruitment processes and technical details of the cognitive testing are presented in Appendix A.

Chapter Three presents findings on the scenarios and further recommendations. Chapter Three is divided up into sections, whereby each scenario is examined on an individual basis. Each section shows:

a) The scenario that was cognitively tested;
b) An outline of the findings; and,
c) Final recommendations for improvement.

Chapter Four presents findings on the impairment types, and the examples used and further recommendations. Chapter Four is divided up into sections, whereby each impairment type is examined on an individual basis. Each section shows:

  a) The impairment type and the examples that were cognitively tested;
  b) An outline of the findings; and,
  c) Final recommendations for improvement.

In Chapter Four particular problematic scenario-impairment combinations are discussed.

Chapter Five presents findings from testing the questions on awareness of the UN Convention and disabled people's human rights and again shows the questions that were cognitively tested, an outline of the findings and final recommendations for improvement.

Finally, Chapter Six gives an overview of respondents' general feelings towards being asked all of the test questions, giving consideration to acceptability of the questions and also to social desirability. In this chapter, we also make recommendations around the order in which the scenario/impairment type combinations should be administered in the survey.

The findings from the cognitive testing provide evidence as to where problems existed and the possible reasons for them. However, it should be noted the data can not be used to quantify the size or extent of these problems. To do this would require a larger scale experimental pilot. Additionally where we make recommendations for change, we cannot guarantee that the 'new' is better than the 'old' and therefore strongly advise that any implemented recommendations should be re-tested before the pilot stage.

2   Methodology

2.1   Methodological Overview

Cognitive interviewing is a qualitative technique and as such samples are usually small and purposive and designed to represent the diversity of views relevant to the questions, rather than being statistically representative. To ensure a true representation of society a larger sample size and a different method would be required.

2.2   Sample composition

The sample for this study was designed to reflect the range and diversity of the survey population, covering characteristics which were anticipated to have a bearing on how respondents might go about answering the questions including:

- Gender
- Age
- Educational attainment; and
- Disability status.

Twenty four interviews were conducted in total with the sample composition agreed after discussion with the department. The table below provides details on the characteristics of respondents interviewed as part of this study. The sample included an equal number of men and women, with equal numbers of respondents with high and low levels of education. The age range of the sample was 18 – 81 years. Our sample was designed to have at least 6 people who are disabled or who live with and/or care for a disabled person. We also wanted to interview at least 4 non-white respondents.

Table 2 Characteristics of the sample

Characteristics of Respondent		No with characteristic
Gender	Men	12
	Women	12
Level of education	High: left school aged 17 or above	12
	Low: left school aged 16 or under	12
Age of respondent	18-34	8
	35-60	10
	61+	6
Disability status	Disabled	10
	Non-disabled	14
Ethnic group	White	20
	Non-White	4
Location	Kent	6
	Manchester	6
	Nottinghamshire	6
	Leeds and Yorkshire	6

Cognitive interviews took place in respondents' homes across the country and were conducted face-to-face, on a one-to-one basis (where possible), to ensure respondent confidentiality. The interviews lasted around an hour to an hour and a half and were digitally recorded with respondents' consent. Respondents were given a £20 High Street voucher as a thank you for taking part in the interview.

Full details of the study's methodology can be found in Appendix A.

3 SCENARIOS: Cognitive Findings

3.1 SCENARIO 1: Right to choose a place of residence

The Right to choose a place to live (this scenario) is linked to Article 19 of Convention which provides, amongst other things, that:

"Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement"

SCENARIO 1

How do you think you would feel if a person with a {IMPAIRMENT TYPE} such as {EXAMPLE} or {EXAMPLE} were to move in next door?

1 Very comfortable with this
2 Fairly comfortable with this
3 Fairly **un**comfortable with this
4 Very **un**comfortable with this

Findings

This scenario was combined and tested with each of the five impairment types. Respondents reported feeling *"fine"* about being asked this scenario and did not report finding it sensitive. Comprehension of the scenario itself was good – respondents experienced no difficulties in considering and thinking about the situation of someone with a disability or long-term illness moving in next door. Respondents were generally able to provide an answer easily with only slight difficulties arising when the mental health condition impairment type was introduced; these difficulties were more to do with the specific examples, however, rather than any fundamental problem with the scenario type or the scenario/impairment combination (discussed in chapter 4).

As this scenario came first, interviewers asked respondents what they thought the set of questions were about/why they were being asked them. Respondents had a tendency to speak in general terms about *"discrimination"* and whether people are *"prejudiced against the disabled"* or *"bothered by people who are not normal healthy people"*.

Answer strategies adopted

When deciding upon an answer, it was clear that when respondents were thinking about the situation of a disabled person moving in next door, they were focused on considering what the **impact** would be on their own lives. For example, they thought about:
- Whether they would be more/less happy with a disabled person moving in compared with anyone else;
- Whether someone with the particular impairment type would *"encroach"* or have an adverse impact upon the respondent and/or his/her family; and,
- How they could/may have to help out. For example, a disabled respondent said she would not feel 'very comfortable' as she would not be in a position to help a disabled neighbour.

Respondents who knew someone with a particular disability or illness would draw on the experiences they had had with this person and think about the impact that this had had on their lives.

Understanding and use of the answer scale

Respondents' understanding of the terms 'comfortable' and 'uncomfortable' was influenced by their interpretation of the scenario. For example, they spoke about how accepting, happy or at ease they felt, bothered, doubtful, embarrassed, worried or threatened they would be with/in the particular situation.

Difficult combinations

Any difficulties that respondents experienced while answering these questions were due to the impairments and the examples used alone rather than the actual combining of scenario and impairment. Impairment types and the examples used will be discussed later in this report.

Recommendations:

- Consider including a short introduction alerting respondents to the format that the questions will take; this may help them to focus on the scenario type from the first question, rather than on their feelings towards disabled people in general.

3.2 SCENARIO 2 – Right to marry and found a family

The Right to marry and found a family (this scenario) is linked to Article 23 of the Convention which amongst other things provides that:

"The right of all persons with disabilities who are of marriageable
age to marry and to found a family on the basis of free and full consent of the
intending spouses is recognised"

SCENARIO 2

How do you think you would feel if one of your close relatives were to marry a person with a [IMPAIRMENT TYPE] such as [EXAMPLE] or [EXAMPLE]?

1 Very comfortable with this
2 Fairly comfortable with this
3 Fairly uncomfortable with this
4 Very uncomfortable with this

Findings

Regardless of whether the respondent was disabled or not, the cognitive testing did not highlight any major problems regarding the question combinations which used Scenario 2 and respondents reported feeling fine about and having no problems being asked these questions. There was a tendency to compare this scenario with the previous one (right to choose a place of residence), with respondents describing questions including this scenario (right to marry) as "*closer to home*" and more personal where the situation would require more **contact** and **involvement** if the disabled person was to become part of the family as opposed to the stranger who lived next door.

Occasionally respondents found it difficult to choose a code but this tended to occur where the impairment type (e.g. mental health condition) or examples used (e.g. 'schizophrenia' or 'depression') were those that the respondents:

- did not have much knowledge of, to enable them to give an informed answer;
- considered to be either genetic (e.g. Downs Syndrome) or could be terminal (e.g. cancer) and therefore their answer would *depend* on the person and/or their circumstances; or,
- knew had a potential to be serious and therefore their answer would depend on the severity of the disabled person's condition or illness.

See Chapter 4 for a fuller discussion of impairment types and examples.

Answer strategies adopted

Respondents were consistent in their understanding of the term close relative and were thinking about a sibling, an aunt or uncle or even their own children. The close relative in mind would differ depending on the respondents own circumstances, for example, whether they had children who were old enough to marry.

Respondents answers could be shaped by personal experience of the impairment types and/or the examples given or the experience of people they knew. The following considerations were mentioned by respondents:

- The extra workload involved in looking after the disabled person;

- The emotional risk involved to the family member;
- Concerns for the relative in terms of whether they realised what they were taking on and how they would cope;
- Concerns for the relative if the disabled person's condition were to deteriorate or if they were to die;
- Concerns that the relative could end up being a long term carer for the disabled person; and,
- Concerns over the practicalities of having children and conditions being passed onto children.

Marriage (or long term partnership) Vs having children

Although the scenario specifies marriage, respondents could think about a range of different partnerships including long-term relationships and co-habitations as well as marriage. Since the scenario does not mention having children, some respondents automatically thought about or included this when answering while others answered without considering the possibility of the marriage providing children at all. Interviewers explored whether respondents answers might have changed had having children specifically been mentioned. There were mixed feelings amongst those in the sample and respondents' said their answers would either:

1. remain the same;
2. change; or
3. depend on the disabled person's condition (as certain conditions are hereditary and others might restrict the person from having children).

One respondent for example, who answered 'very comfortable' at all of these questions, suspected his answers would change if children were included as this would add burden to the family, especially if the child had the same disability as the disabled parent. Another respondent, who hadn't considered children when answering, said there would need to be another set of questions about children due to the genetic nature of some conditions. There were also respondents who questioned whether having children would even be feasible for some conditions so again their answer would depend on the disabled person's condition.

Understanding and use of the answer scale

It appears that 'comfortable' was thought about in a number of ways, including the respondents' own:

- comfort levels with the scenario
- levels of acceptance of these scenarios
- happiness or unhappiness with the close relative's decision
- concerns for those involved (both the relative and the disabled person)

Respondents talked about how *comfortable* I would be, how *accepting* I would be, how *happy* I would be and how *concerned* or *worried* I would be.

Difficult combinations

In Chapter 4 we discuss the issues the cognitive testing aired with regards to problems with the impairment types and examples when combined with this scenario.

Recommendations:

Scenario related:

- If the intention of this scenario is to measure attitudes towards the right to marry **and found a family**, we would recommend a reference to 'have a family' or 'have children with'. E.g.:

How do you think you would feel if one of your close relatives were to marry [and have a family with/and have children with] a person with a [IMPAIRMENT TYPE] such as [EXAMPLE] or [EXAMPLE]?

Impairment type related:

- Avoid combining this scenario with impairment type examples which could be considered to be genetic or terminal or those for whom having children is complicated or even impossible.

3.3 SCENARIO 3: Right to employment

The Right to employment (this scenario) is linked to Article 27 of the Convention which among other things requires states to:

"Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions"

SCENARIO 3

How do you think you would feel if a person with a {IMPAIRMENT TYPE} such as {EXAMPLE} or {EXAMPLE} was/had been appointed as your boss?

1 Very comfortable with this
2 Fairly comfortable with this
3 Fairly uncomfortable with this
4 Very uncomfortable with this

Findings

Respondents reported that this scenario was slightly more difficult than previous ones as they felt that the answers they gave were *"cruel"* or "*awful"* and made them feel *"guilty"*. Despite these reservations, however, they did not feel that the question was too sensitive and were willing to provide honest answers. Where respondents could not provide an answer it was not due to the combinations but rather the impairment types and examples used: for example, one respondent was unable to answer for the sensory impairment question as her answer would differ depending on whether the boss was blind or deaf (see 4.2 for further discussion).

The scenario itself was unproblematic for respondents to comprehend, regardless of whether they were currently in paid work or not: those who were not were easily able to imagine a hypothetical situation where someone may have been appointed as their boss. In terms of 'boss', there was a shared understanding that this referred to *"someone...in charge",* or *"someone above* (them) *on the ladder".* It was not clear whether respondents were thinking about their line managers or the overall boss of their place of employment.

Respondents thought the scenario was asking about:
- Whether they thought a person with a disability could do a job as well as a person without a disability;
- Whether they would be able to work with a person with a disability;
- Whether they could imagine a person with a disability being in a position of authority;
- Whether they would feel comfortable being in the workplace with a person with a disability.

Answer strategies adopted

When answering, respondents tended to be thinking about how **capable** someone with each of the impairment types would be in that position. They spoke about *"merit"* and

explained that if a person had been appointed to a position, they would have had to demonstrate that they were capable of doing *"what the job entails"*. Respondents also thought about the **practicalities** of someone with a disability working in certain positions. One respondent, for example, was a roofer and was thinking about whether someone with a mental health condition would be safe working on a roof.

Respondents also thought about how it would **affect** themselves (e.g. whether they would feel comfortable taking instructions from a disabled person), other staff or other people (e.g. how it would affect children in the school if the head teacher had a mental health condition).

Understanding and use of the answer scale

The answer scale worked well for this scenario though one respondent was unable to choose an answer as he wanted another answer option of 'it doesn't bother me' – his interpretation of 'comfortable/uncomfortable' was *"positive/negative"*.

Difficult combinations

Any difficulties that respondents experienced while answering these questions were due to the impairments and the examples used alone rather than the actual combining of scenario and impairment. Impairment types and the examples used shall be discussed later in this report.

Recommendations

- ▪ Consider how effective this scenario is at uncovering respondents attitudes towards 'rights to employment'. Respondents focussed on the issue of a disabled person being in a *position of authority* and the issues surrounding this. If the aim of the scenario is to tap into attitudes towards 'rights to employment' in general it may be more suitable to ask instead about a 'colleague'. However, if the aim is to collect attitudes towards disabled people being in positions of authority then the scenario works well and should be left as it is. The scenario as it stands covers both the authority aspect as well as how respondents feel about working with a disabled person.

3.4   SCENARIO 4 – Right to access the general education system

The Right to access the general education system (this scenario) is linked to Article 24 of the Convention which amongst other things provides that:

*"Persons with disabilities are not excluded from the general
education system on the basis of disability, and that children with disabilities
are not excluded from free and compulsory primary education, or from
secondary education, on the basis of disability"*

SCENARIO 4

How do you think you would you feel if your son/daughter or the son/daughter of a close family member or friend was in a class at school with a child with a [IMPAIRMENT TYPE] such as [EXAMPLE] or [EXAMPLE]?

1 Very comfortable with this
2 Fairly comfortable with this
3 Fairly uncomfortable with this
4 Very uncomfortable with this

Findings

On the whole respondents thought about the general education system and/or mainstream learning as opposed to Special Education or schools for children with special educational needs (SENs). Incidentally, respondents would often talk about the **conditions** that would need to be in place (when vocalising their comfort levels), such as:

- As long as it was safe (thinking both about health and safety measures and also precautionary measures for certain conditions, such as H.I.V.);
- As long as it didn't affect their child or their child's learning;
- As long as the teachers knew about and were able to manage it; and,
- Assuming there were the necessary aids available and facilities in place to help the disabled child.

One respondent for example said "*it doesn't bother me as long as the needs of my child are taken into account*" (Male, 27, Disabled).

Respondents did not report anything to suggest that this scenario was potentially sensitive and/or unacceptable. However on occasion it could feel irrelevant: notably if the respondent did not have any children of their own. This however did not affect ability to answer, as instead these respondents tended to think about the child of a family member or friend.

Answer strategies adopted

Respondents either thought about their own child or the child of someone they knew being in the same classroom as a disabled child. When answering questions which used this scenario, respondents could think about very young or primary school aged children, secondary school aged children or across the spectrum.

A number of different answer strategies were adopted by respondents when answering question combinations which used this scenario, including:

- Considering the effect the disabled child would have on the other children in the class;
- Considering how fair it would be on other children in the class due to the disruptive nature of certain conditions (such as Autism and ADHD);
- Thinking about the fact that certain conditions might 'hold back' or slow down learning for other children in the class and whether this would be fair on the class as a whole;
- Thinking about the welfare of the disabled child and worrying they might get bullied or teased by other children;
- Considering their own child's welfare and worrying that they might be at risk of harm from the disabled child or even start to mimic the behaviour associated with certain conditions; and,
- Worrying that their child might not understand the disabled child's condition or might assume that behaviours associated with certain conditions (such as ADHD) were acceptable.

'Comfortable', in the context of this scenario, tended to refer to either the respondent's own comfort levels with the scenario or the respondents concern or worries for the disabled child or their own child.

Difficult combinations

There were no seriously problematic combinations and difficulties respondents reported related to impairment types and/or the examples given, as opposed to the scenario itself. The particular impairment types which could cause difficulty when combined with this scenario will be highlighted and discussed throughout chapter 4.

Recommendations:

> - We would recommend the addition of the phrase:
> Assuming the necessary help and assistance was in place, how do you think you would you feel if your son/daughter or the son/daughter of a close family member or friend was in a class at school with a child with a [IMPAIRMENT TYPE] such as [EXAMPLE] or [EXAMPLE]?

3.5   SCENARIO 5: Right to participate in political and public life

The Right to participate in political and public life (this scenario) is linked to Article 27 of the Convention which provides amongst other things for States:

"To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected"

SCENARIO 5

How do you think you would feel if your local MP had a {IMPAIRMENT TYPE} such as {EXAMPLE} or {EXAMPLE}?

1   Very comfortable with this
2   Fairly comfortable with this
3   Fairly uncomfortable with this
4   Very uncomfortable with this

Findings

Respondents did not find this scenario sensitive at all and were happy to give their answers to all of the combinations. Respondents thought this scenario was similar to scenario 3 (right to employment) as they were being asked to think about, as one respondent put it, *"people in authority, in a position of importance, how* (they) *would feel about them having anything wrong with them"* (Female, 41, non-disabled). Respondents felt this scenario was asking about whether a disabled person would be able to carry out the job, make decisions and represent people effectively.

The term 'local MP' was well understood as *"someone in charge of a local ward or district"*, someone in *"power"* and *"someone in Parliament who is making decisions on my behalf and representing my views"*. One young respondent (aged 18) thought that MP stood for 'Military Police' whilst other respondents could be unsure as to who their local MP actually was (although this did not affect their ability to answer). Although the responent who confused MP with the Military Police did live closeby to an army baracks, hence possibly explaining why he had become easily confused, it should be noted that the survey will be carried out in areas where the Military Police operate and therefore this may well be a wider problem. The findings also show that respondents were thinking about any Member of Parliament, rather than their local one specifically, as well as the Prime Minister. David Blunkett was mentioned as an example of a disabled politician. This finding is not problematic, however, as respondents were still thinking of an elected politician.

Answer strategies adopted

As with scenario 3, respondents thought about the ability of the disabled person to carry out the job. When deciding upon an answer for each of the combinations, respondents took into consideration:

- How capable the disabled person might be;
- How they thought they might cope in such a stressful position;
- Whether the disability may be a hindrance to them performing the roles well; and,

- The unpredictability of certain conditions and how this could affect the person performing the role.

Respondents also spoke about **merit**, for example one respondent said:

"He's got there by merit so it wouldn't matter to me. He wouldn't be in that position if he did not have the ability…If they weren't good at their job; they would not have been elected". (Male, 63, disabled)

Understanding and use of the answer scale

Respondents generally found it easy to select a suitable answer option to reflect their views. Social desirability effects were evident where respondents reported choosing 'fairly uncomfortable' rather than 'very uncomfortable' so as to not be seen as discriminatory.

One respondent, who throughout the scenarios had struggled to make his preferred answer of 'neither comfortable nor uncomfortable' fit with the given answer scale, realised at this scenario that he should have been answering 'very comfortable' to reflect his views of *"it does not matter"* if the person was disabled or not.

Difficult combinations

Two of the combinations were found to be problematic for respondents – learning disability and mental health condition impairment types. Respondents struggled to imagine the situation where someone with one of these conditions would be in the position of MP and felt that it was *"unrealistic"*. These difficulties did not, however, prevent respondents from being able to provide answers; they simply chose an answer option at the lower end of the scale to reflect their doubts.

Other problems occurred with the learning disability scenario, for example, where the respondent was unsure what the example conditions were. This will be discussed in detail later on but does show the tendency for respondents to focus on the specific examples given rather than thinking about the impairment type in general.

Recommendations

- We recommend leaving this scenario as it is.
- It should be noted that there was tendency for respondents to distance themselves from the person in political authority and not necessarily be thinking about their local MP who might potentially interact with, or be represented by for local issues. The department should consider whether this matters and if it does, and the intention is in fact to gauge attitudes towards more of an involved role with the disabled person, consideration should be given to the use of MP. Either way caution needs to be taken when analysing the answers people give at this scenario because of this 'distancing'.
- To avoid this risk that respondents will confuse MP with the Military Police, we would advise that 'Member of Parliament' (MP) is inserted at this scenario.

3.6 SCENARIO 6 – Right to participate in cultural life, recreation, leisure and sport

The Right to participate cultural life, recreation, leisure and sport (this scenario) is linked to Article 30 of the Convention which amongst other things requires measures to be taken:

"With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities"

SCENARIO 6

Think about a club, group or team with a shared cultural or recreational interest that you could be involved with in your spare time. How do you think you would feel if a person with a [IMPAIRMENT TYPE] such as [EXAMPLE] or [EXAMPLE] also attended this club?

1 Very comfortable with this
2 Fairly comfortable with this
3 Fairly uncomfortable with this
4 Very uncomfortable with this

Findings

Cognitive testing of this scenario revealed that respondents had very similar and consistent understandings of its aims. Universally, when describing what they thought this scenario was about, respondents talked about:

- Whether they would be happy to socialise with people with these conditions;
- Whether they thought people with disabilities should be allowed to join in with other people, described by one particular respondent as "*normal people*"; and,
- Whether they would be comfortable accepting disabled people into their groups or clubs.

One respondent said:

   "*Would I socialise with these people in a social area*" (Female, 41, non-disabled).

Answer strategies used

Respondents who were able to answer this question without difficulty thought mostly about the clubs, groups or teams they were already, or had previously been, involved in. In the context of this question, a group or club was described by one respondent as:"*a collective social setting*" (Male, 39, Disabled), whilst other respondents talked about anything where a group of people with similar interests got together.

The kinds of clubs, groups or teams respondents thought about included swimming, a singing group, gymnastics, evening classes at college, the gym, a football team, a quiz team, a reading club and a darts team. When answering this question, it was common for respondents to visualise the disabled person being involved, for example one man said he had pictured himself on the river bank and thought about whether the disabled people would be **able** to take part in the fishing activity. Another man tried to visualise a disabled person playing snooker with him. Worryingly, respondents occasionally thought about groups which are especially for disabled people whilst occasionally respondents wondered what the club might be and expressed a need for an example as it was felt their answer might vary depending on the *type* of club and therefore made it impossible for them to answer.

Would they be capable of taking part?

The main problem experienced by respondents when trying to answer this question related to their own perceptions of whether the disabled person would be **able** to be involved in the club, group or team they had in mind and ability to answer this question was linked to:

- The type of club group or team; and/or,
- The type of disability.

For certain types of clubs, notably those involving physical or sporting activities, some respondents found it difficult or impossible to think about disabled people with certain impairments taking part. One respondent for example talked about how a paraplegic would not be able to join a football team but may be perfectly **capable** of being on a committee whilst another respondent was unable to give an answer as he couldn't imagine how someone who was blind or deaf could play football or box.

The implication of this problem is that respondents could be using the comfortable/uncomfortable scale in a different way to those who were able to answer the question without difficulty. Rather than interpreting comfortable in terms of how happy/at ease/ok/bothered they would feel or be about a disabled person attending the same group as themselves, answers could instead be measures of comfort levels with the abilities of disabled people taking part in certain sports or activities.

Recommendations:

> When left open for the respondent to imagine a club/group/team, there is a risk that they will think of activities which, by nature, would be difficult or impossible for certain disabled people to take part in. To avoid this risk, and also to provide an anchor for those who will find it difficult to imagine a club/group/team, we would recommend that the scenario refers to something specific. This specific club/group/team(s) would need to be an activity or some activities which:
>
> - Most people could imagine themselves taking part in; and,
> - People could imagine any disabled person taking part in.
>
> It is difficult however to think of a 'one size fits all' approach and therefore our recommendation is to give three examples, as follows:
>
> Imagine you were a member of a book club, quiz team or swimming group. How do you think you would feel if a person with a [IMPAIRMENT TYPE] such as [EXAMPLE] or [EXAMPLE] also attended (this club team or group)?

4   IMPAIRMENT TYPES: Cognitive Findings

This chapter is divided up into sub-sections for the findings which relate to the five separate impairment types and the examples that were used for each of them. It was necessary to alter the wording in the question stem to accommodate for the impairment types and examples so that they were appropriate for specific scenarios. Usually the words '**a person/someone who has**' or '**a person/someone with**' preceded the impairment type, however when combined with scenario 4, the wording was altered to refer to '**a child with**'. Similarly, for scenario 5, the question wording was adjusted to '**an MP had**'.

The five impairment types, and the examples used, are shown in the table below.

Impairment type	Examples used (in bold) and the wording used in the questions
1. Physical Disability	A person who has **difficulty using their arms** or someone who **uses a wheelchair**
2. Sensory Impairment	Someone who is partially or fully **blind** or **deaf**
3. Mental health condition	A person with a mental health condition such as **schizophrenia** or **depression.**
4. Learning disability	A person with a learning disability such as **Down's syndrome** or **autism**
5. Longstanding illness or health condition	A person with a longstanding illness or health condition such as **cancer, diabetes**, or **Multiple Sclerosis**

4.1   Physical Disability (1): A person who has difficulty using their arms or someone who uses a wheelchair

Understanding of Physical Disability

Respondents reported few difficulties with this impairment type and the examples given. 'Physical disability' was defined by one respondent as:

> *"some form of physical impairment that has an affect on a person's life...basically doing everyday things"* (Male, 39, disabled)

The need for special equipment or help doing day-to-day activities were also felt to be characteristics of physically disabled people.

Confusing other impairment types with physical disabilities

Despite there being apparently few difficulties with this impairment type, when interviewers asked respondents to give examples of other physical disabilities, it was clear that there was some overlap with other impairment types. Whilst some of the conditions

they referred to fell within the definition of physical disability e.g. paralysis and the loss of a limb, others did not. Question order effects (Sudman and Bradburn, 1974) go some way to explaining why respondents were thinking about the following when they were answering this question:

- Down's syndrome (learning disability);
- Blindness/deafness (sensory impairment); and,
- Multiple sclerosis and other degenerative diseases (long-term illness).

Where physical disability was asked first respondents tended to include those disabilities covered by the sensory impairment type. If respondents had been asked the sensory impairment type question first, for example, they may have concluded that, as blindness and deafness were being asked about in a separate context, the physical disability impairment type must be referring to other conditions. We found other evidence to support a change in order of the sensory and physical impairment types. See section 4.2. Confusion over the categorisation of conditions is not wholly explained by question order effects however: the findings also suggest that respondents' understanding of how certain conditions are grouped was not always consistent with the grouping of impairments set out by the EHRC and adopted for these questions by the ODI.

Use of Cerebral Palsy as an alternative example

This confusion when grouping impairment types was particularly evident when respondents were asked whether their answer would have changed had the condition 'cerebral palsy' been used as an example of physical disability within the question as there was a question amongst respondents about whether this was a mental health condition rather than a physical disability. The findings were mixed as to whether respondents would have answered differently had the example of cerebral palsy been used: where answers would have changed respondents explained that they would feel less comfortable with conditions that would affect a person's brain and/or judgement. Other reasons for a change of answer included:

- Concern for how the child would be treated by other children (right to access to general education system scenario); and,
- Experience of how *"difficult"* people with cerebral palsy can be.

Difficult combinations

There was only one combination that raised any difficulties for respondents when answering this set of questions.

Scenario which caused difficulty when combined with physical disability	Reported reasons for this difficulty
Scenario 4: Right to access general education	- It could be difficult for respondents to answer where they considered a child's disability to be so serious that it would be more beneficial for them to be in a special needs school anyway

4.2   Sensory Impairment (2): Someone who is partially or fully blind or deaf

Understanding of Sensory impairment

Respondents sometimes had difficulty answering for this impairment type and occasionally were unable to provide an answer. This difficulty stemmed from inability to give one answer for the two different examples. One respondent for example said he could not give an answer as it would depend on whether someone was blind or whether someone was deaf.

Respondents tended to think of the same types of impairments at each of the six scenarios and these were consistent across the sample. Someone with a sensory impairment was someone who:

- has trouble hearing;
- has problems with their sight;
- has difficulties with their hearing, sight or touch;
- has problems with their senses: *"hard of hearing or blind or deaf"*;
- is blind; or,
- is deaf.

On occasion respondents referred to David Blunkett when this impairment type was combined with Scenario 5 (with reference to 'your local MP'). Interviewers explored whether respondents could think of other examples of sensory impairments other than the ones the question mentions. Respondents mentioned problems tasting, loss of feeling in the hands, speech problems (although questioned whether this would in fact be a 'physical problem') and no sense of touch.

Confusing sensory and physical impairments

Occasionally respondents considered a 'sensory impairment' to be similar to or the same as a 'physical impairment' and responses could mirror those given at the physical impairment questions. Respondents could also confuse the two and/or describe sensory impairments as related to or linked with physical impairments. One respondent, for example, talked about a Paraplegic having no sense of touch whilst another considered nerve damage as a sensory impairment but linked this to the spinal damage of a wheelchair user.

It could be that the order the impairment types were asked about in the test questionnaires resulted in question order effects[1]: where answers to survey questions are affected by prior items (in this case those which used the physical impairment type), which may provide respondents with cognitive cues that are used to answer subsequent questions.

Partially/Fully blind or deaf

'Partially' blind meant being able to see certain things, having "*fuzzy*" eye sight and requiring Braille or other special reading materials whilst 'partially' deaf meant only being

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[1] See Sudman S and Bradbum N (1974) Response effects in Surveys. Chicago: Aldine.

able to hear certain things, requiring a hearing aid or having Tinnitus. There was one respondent in the sample who thought about prescriptive glasses (as partial blindness), and another who wondered whether "*just wearing glasses would class them as partially blind*" (Male, 18, Non-disabled). Interestingly, **both** of these respondents mentioned prescriptive glasses at scenario 4, which refers to a child being in a class at school with a child who is partially or fully blind or deaf. We are unable to say whether other respondents, at other scenarios, were always correctly excluding people with correctable visual impairments.

It was not felt necessary to change the wording of this impairment type for the following reason. It is suspected that prescription glasses may have come to mind at this particular scenario as a result of a perception that blind (and deaf) children would not be involved in mainstream schooling and might instead go to schools especially for blind/deaf children. To use the case where the respondent wondered whether wearing glasses would count as partial blindness as an example, this respondent did not think that a child with a serious sight or hearing problem would go to the same school as other children and therefore found scenario 4 difficult to imagine.

'Fully' blind meant full blindness, not being able to see at all and being in complete darkness whilst 'fully' deaf meant full deafness and not being able to hear at all. As the words 'partially or fully' come before blind but not deaf in the question stem, occasionally respondents could interpret these words to refer to someone who 'partially or fully' blind but not to someone who is 'partially or fully' deaf.

Difficult combinations:

There were some scenarios which, when combined with the sensory impairment type and the examples, were more difficult or impossible for respondents to answer. The table below summarises these difficult combinations and the reasons for this.

Scenario which caused difficulty when combined with sensory impairment	Reported reasons for this difficulty
Scenario 3: Right to employment	▪ It could be difficult to answer about one's boss .If their boss was blind some respondents felt they could still communicate using speech but this would be more difficult if they were fully deaf
Scenario 4: Right to access general education	▪ It could be difficult to answer if it was assumed that children with serious sight or hearing problems (i.e. was full blind or deaf) would go to a different school to other children, appropriate for their education, and therefore this scenario was difficult to imagine
Scenario 5: Right to participate in social and political life	▪ It could be difficult to answer as an MP who was fully deaf might not be able to fully function in that role
Scenario 6: Right to participate in culture life, recreation, leisure and sport	▪ It could be difficult for respondents to answer if they were thinking about a sport such as Hockey, Snooker, Cricket

Scenario which caused difficulty when combined with sensory impairment	Reported reasons for this difficulty
	or Boxing as it was difficult to imagine a blind and/or deaf person playing or being involved in such sports.

Recommendations:

- Retain the examples. We would recommend however that the words 'partially or fully' come before both blind and deaf.

4.3 Mental Health Condition (3): A person with a mental health condition such as schizophrenia or depression.

As late adolescence and early adulthood are peak years for the onset of schizophrenia, Attention Deficit Hyperactivity Disorder (ADHD) replaced schizophrenia when this impairment type was combined with scenario 4, which mentions children.

Understanding of Mental Health condition

Respondents' understanding of mental health conditions was fairly consistent: a mental health condition was something to do with or that affected the brain, which would have an adverse affect on your behaviour and/or how you think and make decisions. Other conditions respondents reported as mental health conditions, but were not necessarily thinking about when they answered, included:

- Bipolar or dual personality;
- Unstable or unbalanced conditions;
- Post-natal depression;
- Aspergers;
- Paranoia; and,
- Agoraphobia and claustrophobia.

Respondents also mentioned conditions associated with older people such as Dementia and Alzheimer's and could on occasion think of mental health conditions as exclusive to elderly people.

Changing/altering attitudes

It was common for respondents' answers, on the 4-point scale, to change from 'very/fairly comfortable' to 'fairly/very uncomfortable' when this impairment type was introduced and combined with any of the six scenarios. Reasons for this, as reported by respondents, included:

- The **unpredictable** nature of depression, schizophrenia and/or personality disorders;
- The **risk** involved with being around the disabled person (such as a relative marrying someone with depression or schizophrenia);
- The knock on **effect** of the disorder to other people (such as the family);
- The **dangerous or frightening** nature of schizophrenia as a condition; and,
- The **distracting** nature of ADHD for other children (in a class at school).

Two extreme examples

There were respondents who were able to think about the two examples and answer as a whole for scenarios which were combined with mental health conditions, for example one respondent said "*two extremes*" in the question was a good thing as depression varies in degrees whilst "*schizophrenia is a long-term problem which is difficult to battle with*" (Female, 34, not-disabled).

The two examples however were often described as "*extremes*" or at "*opposite ends of the spectrum*", and as a result respondents could either find it difficult to provide an overall answer or they wanted to give different answers for each example, which is essentially the same problem. One respondent for example wanted to code 3 ('fairly uncomfortable') for depression and 4 ('very uncomfortable') for schizophrenia at the local MP scenario. Another respondent wanted to answer 'fairly comfortable' for depression but 'very uncomfortable' for schizophrenia at the living next door scenario, due to the perceived unpredictability of schizophrenia as a condition.

Rather than aiding the response (as they are designed to do), the examples could hinder ability to answer. We found evidence of respondents:

- focussing on the example they had better knowledge of;
- focussing on the example they had experience of;
- focussing on the example they considered to be more serious; and,
- focussing on the example they considered to be more manageable and less obvious to others.

Even those who were able to think about the two examples, as a whole or together, had other problems when answering. Respondents could say their answer would depend on whether it was a child or an adult with the condition and also that their answer would depend on the severity of the condition. For example, if the depression was mild then they would "*be ok*" with this but if the schizophrenia was serious they might be less comfortable.

Eating disorder

To assess the appropriateness of the current examples, interviewers encouraged respondents to hypothetically evaluate whether their answers would change had 'an eating disorder' been given as the example. There were two types of respondents in the sample:

1. Those who said their answers would change had 'an eating disorder' been used as one of the examples for this impairment type; and,
2. Those whose answers would have remained the same.

The direction of change for respondents who fell into type 1 above was not the same for all respondents however. Respondents could either say their answers would edge from the uncomfortable end of the scale (when answering about depression/schizophrenia), up towards the comfortable end for an 'eating disorder' (direction A in the diagram below) or visa versa moving them from the comfortable end of the scale (for depression/schizophrenia) down towards the uncomfortable end for an eating disorder (direction B in the diagram below). The diagram below shows the reasons given for these shifts in response.

Diagram: Showing the answer scale and reasons for change in direction of response had an 'eating disorder' been given as the example instead of 'depression' or 'schizophrenia'.

Direction A		Direction B
▪ Less of a threat/not "*as bad*" ▪ Decreased fear ▪ More predictable ▪ Would be less worried about the strain/effect/impact on other people ▪ Would not impact on person's ability to do the job	1 Very comfortable 2 Fairly comfortable 3 Fairly uncomfortable 4 Very uncomfortable	▪ Would be more unsympathetic ▪ Would be upset for the person ▪ Would have concerns for own child and other children (copying behaviour)
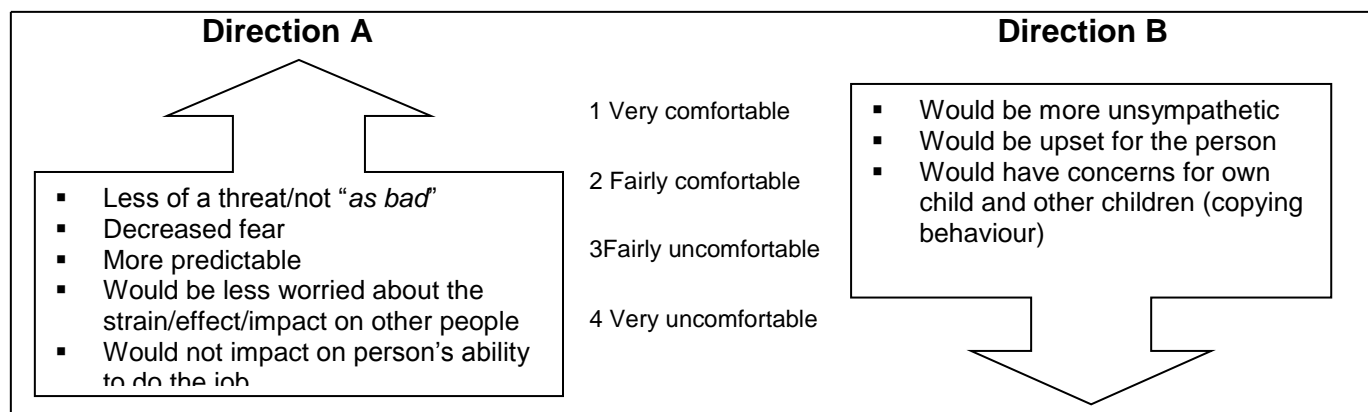
Difficult combinations

There were some scenarios which, when combined with the mental health condition impairment type and the examples, were more difficult or impossible for respondents to answer. The table below summarises these difficult combinations and the reasons for this.

Scenario which caused difficulty when combined with mental health condition	Reported reasons for this difficulty
Scenario 3: Right to employment	▪ It could be difficult to imagine ones boss being schizophrenic or having severe depression
Scenario 4: Right to access the general education system	▪ It could be seen as strange to use Depression as an example for children ▪ Some people could consider ADHD to be a result of bad parenting as opposed to a mental health condition
Scenario 5: Right to participate in social and political life	▪ It could be difficult to imagine an MP with schizophrenia
Scenario 6: Right to participate in cultural life, recreation, leisure and sport	▪ It could be difficult for respondents to answer if they were thinking about a sport or a club as it was difficult to imagine someone with schizophrenia playing the sport or attending the club.

Recommendations

- We would recommend the addition of a 'middle ground' example to avoid respondents fixating on one of the existing examples, which are seen as extreme examples. Suggest eating disorder is avoided due to reasons outlined above; however possibly consider 'Personality disorder' or 'Obsessive compulsive disorder'.
- An alternative solution to the problems associated with schizophrenia, described above, would be to remove it altogether and replace with another mental health condition.

4.4 Learning Disability (4): A person with a learning disability such as Down's syndrome or autism

Understanding of Learning disability

Respondents seemed to have a good grasp of what it meant to have a 'learning disability', explaining that it could be *"somebody who finds it difficult to learn and* (who) *is slightly behind the rest"* (Female, 41, non-disabled) and *"anybody that has some impairment which means that their development is lower than age related expectations"* (Male, 27, disabled). Other features of learning disability respondents mentioned were:

- Difficulty with learning, reading, writing and numeracy;
- Difficulty learning new things the same way as others; and,
- Needing extra help.

Before being prompted by the interviewers probing, respondents mentioned 'dyslexia' as another example of a learning disability; other conditions mentioned were speech impediments and Asperger's Syndrome.

Respondents were generally familiar with the examples used though one respondent commented that she considered Down's syndrome and autism to be mental health conditions rather than learning disabilities. There was a feeling amongst respondents that they would have liked to have been given more information about the degree of seriousness of the disability; the autism spectrum, for example, is wide and someone at one end of it may be very different to someone at the other.

Use of alternative examples

To establish whether the examples used in the scenario were the most suitable, respondents were asked about alternative learning disabilities to see how familiar they were with them.

Respondents were aware of the condition **dyslexia** and were clear about what it was. Whilst it could be recognised by respondents as a learning disability, others felt that it was not a disability at all and was something that could be *"overcome"*. It was certainly seen as something less 'severe' than conditions such as autism or Down's syndrome: respondents felt that it would have limited **impact** on others and was **predictable** in nature unlike other learning disabilities.

Respondents were also aware of the condition **ADHD**, mentioning that they had seen programmes about it on television or had personal experience of someone who had it. Again, respondents considered how someone with this condition would **affect** their own lives or the lives of others.

Different answers for different examples

When respondents were asked whether their answers would have changed had the examples instead been 'dyslexia' or 'Attention Deficit Hyperactivity Disorder (ADHD)' – they either said:

- Yes, the use of these examples would have altered their answer;
- Yes, the use of one of these examples would have altered their answer; or,
- No, their answer would have remained the same regardless of the examples used.

Respondents appeared to be MORE comfortable with dyslexia and they reported that their answers would have changed to reflect this. Respondents were LESS comfortable with ADHD and again would have chosen a different answer on the scale to convey this.

Even when considering the two examples given in the original scenario type (Down's syndrome and autism), however, the findings show that respondents wanted to give different answers for each one. One respondent, for example, explained that she did *"not have a problem"* with Down's syndrome so wanted to give an answer of 'very comfortable' but had to opt for 'fairly comfortable' because the question also referred to autism which she felt was a more unpredictable condition.

These findings show that respondents were focusing more on the examples given rather than on the impairment type in general.

Difficult combinations

Scenario which caused difficulty when combined with learning disability	Reported reasons for this difficulty
Scenario 2: Right to marry and found a family	▪ When respondents considered the issue of starting a family, genetic conditions caused concern; respondents felt that questions about marrying and children should be separated as they raised different issues to think about.
Scenario 3: Right to employment	▪ Respondents were not sure that this scenario was realistic and so found it difficult to think about someone with a learning disability being their boss
Scenario 4: Right to access the general education system	▪ Respondents wanted to know the *"degree of the disability"*. Answers would differ if they considered someone with a 'mild' learning disability compared to someone with a 'severe' learning disability.
Scenario 5: Right to participate in political and public life	▪ Respondents were not sure that this scenario was realistic and so found it difficult to think about someone with a learning disability being an MP

Recommendations

- We recommend removing 'Down's syndrome' as an example so as to alleviate problems associated with the 'right to marry and found a family' scenario and the use of a genetic condition.
- Dyslexia could be used as an alternative example as it was commonly understood and was recognised as a learning disability.
- In addition, it may be worth considering whether a third example should be included: this may help respondents focus more on the impairment type as a whole rather than on specific examples. However, this would need to be tested.

4.5 Longstanding illness or health condition (5): A person with a longstanding illness or health condition such as cancer, diabetes, or Multiple Sclerosis (MS).

Onset of MS usually occurs in adults therefore this example was omitted at scenario 5, which refers to children.

Understanding of Longstanding illness or health condition

Cognitive testing revealed a consistency in understandings of a longstanding illness or health condition. Respondents talked about conditions or illnesses which have lasted a long time or that are never likely to get better or go away. It was common for respondents to immediately consider the "*serious*" conditions such as cancer or those which were life threatening or terminal. Respondents also tended to describe these types of conditions as those which people live with and are often controlled by medication. One respondent for example said these were conditions which could be "*treated and controlled but unfortunately not cured"* (Female, 65, non-disabled). These conditions were also linked to taking time off work for hospital visits (particularly when answering about ones' boss in scenario 3).

When asked which other conditions they considered to be longstanding illnesses or health conditions during probing, respondents mentioned heart problems; angina; bowel conditions; ME; arthritis and muscular dystrophy.

Appropriateness of the current examples

It was felt that the current examples (cancer, diabetes and MS) work well as these were conditions which most people could "*relate*" to, according to one respondent in the sample. There was a feeling from the odd respondent in the sample that these conditions were generally more socially acceptable (in comparison to some of the other conditions that had been discussed during the interview), and that people do not tend to feel wary or threatened by people who have them.

As with some of the other impairment types, respondents could focus on one of the example conditions when answering. Notably this tended to be either 1) the one they thought was most serious 2) the one they had most experience of or 3) the one they felt they had the most knowledge about. It should be noted here that whilst cancer and diabetes were universally well know conditions, respondents sometimes said they did not know what MS was.

Had epilepsy been used

Interviewers explored whether answers might have changed had different examples been used: epilepsy and/or H.I.V. Those who said their answers would change (from comfortable towards uncomfortable), if epilepsy was used tended to be thinking about the **fear** of not knowing what they would do if the person was to have a fit. One respondent, for example, would have changed her answer from very to fairly comfortable at scenario 4 as she would be worried that a child having an epileptic fit in the classroom might frighten or upset the other children. Respondents who said their answer would probably remain

the same for epilepsy relied on the assumption that it would be under control, notably when answering scenario 5 about an MP).

Had H.I.V. been used

H.I.V. similarly elicited both answers changing and remaining the same. Those who said they would change their answer (from the comfortable end of the scale towards the uncomfortable end) tended to talk about the **transmittable nature** of and **health risk** associated with the condition. Respondents, for example, worried about their children being at school and the risk of other children catching it (scenario 4) and also about the concerns they would have for the health of their relatives (scenario 2). Occasionally respondents hesitated when they were asked whether their answer would change had H.I.V. been used, before proclaiming they would not, or they said their answer would change but they could not explain why. There were also cases where respondents said they didn't know enough about the condition so would not be able to answer. There were respondents in the sample who said their answers would remain the same if H.I.V. was an example, giving the following reasons for their unchanged responses:

- They (people with H.I.V.) are still human, it wouldn't bother me;
- It wouldn't affect me so it doesn't bother me;
- H.I.V. can only be caught through blood; and,
- The authorities (school) would not put the rest of the class in danger.

Difficult combination

There only seemed to be one scenario which, when combined with the longstanding illness or health condition impairment type and examples, could be more difficult or impossible for respondents to answer. The table below summarises this difficult combination and the reason for this.

Scenario which caused difficulty when combined with mental health condition	Reported reasons for this difficulty
Scenario 2: Right to marry and found a family	- It could be difficult to imagine why someone would want to marry someone with an illness that will lead to death

Recommendations

- We would recommend that the current examples (cancer and diabetes) are retained and that MS is dropped and/or replaced with another (well known) longstanding illness or health condition such as arthritis. As noted earlier, MS can be seen as falling into other categories such as possibly becoming a physical disability (in time, with degeneration).
- We would strongly advise that H.I.V. is avoided for reasons outlined above.

5 Awareness of the UN Convention / General questions on disabled people's human rights.

Three questions (referred to here as Q16, Q17 and Q18) about awareness of the 'United Nations (UN) Convention on the Rights of Persons with Disabilities' and a further two questions (referred to as Q19 and Q20) collecting data on general attitudes towards the human rights of disabled people were tested. The Convention has not yet been ratified and subsequently awareness was likely to be very low. The aim of testing questions 16-18 therefore was to establish whether the formats of the questions work and whether the answer categories are sensible, appropriate and inclusive as well as to gain a sense of whether people feel willing to give honest responses. The question numbering shown below was that which was used in the test questionnaire and has been retained here to show the routing instructions.

5.1 Awareness of international agreements regarding disabled people's human rights (Q16)

{ASK ALL}
Q16
SHOWCARD D
Do you know whether the British government has signed up to any international agreements which deal with protecting the human rights of disabled people? If you don't know, just say so.
1 Yes definitely
2 Yes probably
3 Probably not
4 Definitely not
5 I don't know / I am not sure

Findings

Respondents reported no problems when answering this question. The question seemed to make sense to people, the answer options seemed to have worked well for respondents, covering the range of responses people wanted to give and finally, and most importantly, there was no evidence to suggest that respondents were only opting for the yes options (codes 1 and 2) to appear knowledgeable (in the eyes of the interviewer). 'International agreements' tended to be understood as anything outside of the UK, and therefore within the European Union and/or the rest of the world but could occasionally make people think of charity organisations such as Oxfam, UNICEF and the Red Cross.

There were no respondents in the sample who chose code 3 or code 4. Responses were distributed amongst answer codes 1 (Yes definitely), 2 (yes probably) and 5 (I don't know/ I am not sure).

Yes definitely/ Yes probably

Those respondents who answered 'yes definitely' tended to mention the EU convention or were vague about what thought they knew, whilst those who answered 'yes probably' tended to be respondents who either:

- Thought this was the case;
- Believed the British government had signed up to something; or,
- Thought the British government must have done so / couldn't believe that they would not have done.

I don't know / I am not sure

This answer option worked well for respondents who lacked knowledge as they were comfortable admitting they didn't know. The following types of respondents opted for this code:

- Those who had a lack of knowledge but assumed the British Government would have taken these actions;
- Those who claimed they had something in mind but were not sure of the details; and,
- Those who knew about the human rights convention but not about this one.

The types of respondents who chose this code suggests that some of these could/should have answered yes, had they been more confident, and therefore the question does not really work as intended and might result in a risk that respondents will not be routed to Q17 when in fact they should be.

Recommendations

- Retain the current question wording and the existing answer codes
- Caution would need to be taken when interpreting code 5 at the analysis stage as respondents can choose this code if they lack the confidence to admit that they think they know something.
- We would therefore suggest that the answer codes, presented on a show card, should be changed to:
1. Yes definitely
2. Yes probably but I'm not absolutely sure
3. Probably not
4. Definitely not
5. I don't know

5.2 Awareness of the names of international agreements (Q17)

{ASK IF Q16 CODED 1 OR 2 (YES)}

Q17

Do you know the name of any such international agreements or the organisations which set them up?

INTERVIEWER: DO NOT READ OUT ANSWER OPTIONS. CODE RESPONDENTS UNPROMTED ANSWER

1 UN or United Nations [Convention/agreement] → GO TO Q19
2 EU or European Union [Convention/agreement]
3 Other (specify)
4 Don't know the name

Findings

There was no mention of the UN or United Nations, either in terms of a convention or any agreements. Respondents, who were routed to this question and therefore asked it, instead mentioned the EU (coded to 2), said they didn't know the name (coded to 4) or mentioned something else (coded to 3: Other). Answers that were coded to 'Other' included:

- The Human Rights Act;
- The Disability and Discrimination Act; and,
- Disabled rights.

Recommendation

- Retain the current question wording and the existing answer codes.

5.3   Awareness of the 'UN Convention on the Rights of Persons with Disabilities' (Q18)

{ASK IF Q16 CODED 3, 4 OR 5 AT OR IF Q17 CODED 2 OR 3 (ALL WHO DO NOT MENTION UN CONVENTION)

Q18

There is a UN Convention on the Rights of Persons with Disabilities, which the British Government has signed up to. Had you heard of this before I mentioned it? If you don't know, you can just tell me so.

1 Yes
2 No
3 Don't know

Findings

There was some suspicion that this question might make people feel as though they *should* have already been aware of this, feel stupid (for not being aware of the Convention) and/or bring about a heightened risk that people might answer 'yes' despite the fact that it is highly unlikely that they would have any awareness of a Convention which the British government has not yet ratified. A few interviewers commented that they found the phrase 'If you don't know, you can just tell me so' awkward to read out however there were no signs that respondents felt uncomfortable on hearing this.

The cognitive interviews did reveal however that people did not seem to have a problem with saying they did not know. One respondent for example said: "*If I don't know something, there is no point pretending that I do*" (Male, 27, Disabled). Occasionally respondents commented that they felt they probably should know this but even so they were still able to answer 'No' or 'Don't know' and one respondent said he did not know if the British Government had done this but if they hadn't, they should have done.

It should be noted that respondents may well answer 'I don't think so' to this question and in advance of the survey, there should be an agreed convention for how interviewers should code this response: should these answers be coded to 2 or 3?

The odd respondent in the sample said yes, or that they thought so (which was coded as a yes). For example one (non-disabled) respondent, whose answer to Q16 had been coded to code 5 'I am not sure', mentioned after she had been asked Q16 that she was pretty sure that the government had signed up to an agreement which gave disabled people the same rights as non-disabled in terms of job opportunities. It is difficult to tell whether this respondent was actually thinking about the UN Convention and not something else.

Recommendation

- Retain the current question wording and the existing answer codes.

5.4 Perceived importance of the protection of the human rights of disabled people (Q19)

{ASK ALL}
Q19
SHOWCARD E
How important or unimportant do you think it is that the human rights of disabled people are protected by the government in the same way as other people?

1 Very important
2 Fairly important
3 Fairly unimportant
4 Not at all important

Findings

On the whole, respondents found this question quick and easy to answer. One respondent commented that it was actually the hardest question he had had to answer but it is not clear why this was.

The answer scale caused few difficulties: all respondents were able to choose an answer with all but one respondent choosing 'very important'. It would appear that the one respondent who answered 'fairly unimportant' misunderstood the question and/or answer scale because he commented that the rights of disabled people are *"not protected…* (and that)…*they should be"* (Male, 71, disabled).

Understanding of 'the human rights of disabled people'

Respondents were asked what they had thought about when they heard the phrase 'the human rights of disabled people'; the following were all mentioned:
- *"the right to be treated as a member of the community"* (Female, 84, disabled);
- *"the right to not be abused, attacked…not to be discriminated against, not being treated in any way unfairly purely on the grounds of the condition you may have"* (Male, 39, disabled);
- The right to be treated *"the same as everyone else"* (Male, 71, disabled);
- The right to have equal opportunities in the work place and in the job market;

- The right to have a say in the community;
- The right to have equal access to education; and,
- The right to have access to public places, for example, leisure facilities and shops.

Understanding of 'other people'

The term 'other people' was understood in a number of ways - respondents thought it referred to:

- Able bodied people (i.e. those who are not disabled);
- Ethnic minorities;
- Other minorities; and,
- People from overseas.

Understanding of 'protected by the government'

When they heard the phrase 'protected by the government', respondents tended to be thinking about the **laws** (for example, the Disability Discrimination Act) that the government has in place to ensure that disabled people are not *"discriminated against"* and that facilities are in place to help them, for example, ramps in shops. One respondent explained that:

> *"Sometimes it needs legislation for people to implement things for disabled people…people won't do it without legislation. It is very important that the government makes them do it"* (Male, 53, non-disabled)

Others compared it to the protection the government gives to other groups, children, for example, and one respondent thought about monetary benefits the government may provide to disabled people.

Recommendations

- As there were no serious problems with this question we recommend leaving it as it is

5.5 Attitudes towards attempts to give disabled people equal rights (Q20)

{ASK ALL}
Q20
SHOWCARD F
Overall, do you think attempts to give equal rights to disabled people have gone too far or not gone far enough?
1 Gone much too far
2 Gone too far
3 About right
4 Not gone far enough
5 Not gone nearly far enough

Findings

Respondents did not find this question sensitive and were willing to provide an answer, though were not always able to. They understood the question to be asking:

- Whether the rights of all people, including disabled people, are equal OR
- Whether disabled people and other people are equal.

Use of and understanding of the answer scale

All answer codes were chosen with the exception of 'Gone much too far'. Though most respondents were able to choose an answer, some were not. This was because:

- They did not know enough about the issues in order to be able to make an informed decision; or,
- They had conflicting opinions and therefore could not find a suitable answer code to reflect their views. For example, one respondent felt that attempts have not got far enough for people who suffer from depression but attempts have gone too far in situations where people can claim 'sickness benefit' but can *"manage just fine"*.

Other respondents who felt they did not know enough about the rights of disabled people and were therefore not *"equipped"* to answer chose 'about right' whilst suggesting they would prefer to answer 'don't know'. There was a feeling that the answer codes 'gone much too far' and 'not gone nearly far enough' were redundant – respondents felt that 'gone too far' and 'not gone far enough' reflected their views adequately enough. Reasons for choosing each of the answer options are described now and shown in the table below.

Answer code	Reasons for choosing
Gone too far	- A disabled respondent thought about jobs and felt that it is not realistic to treat disabled people equally all the time as they cannot always do things that other people are capable of.
About right	- Did not know enough about the issues/what rights disabled people have so opted for the middle option - Wanted to answer 'don't know' - Thought that disabled people have the same rights as anyone else - Felt there is positive discrimination and that *"they* (disabled people) *are almost over protected"* (Female, 32, non disabled)
Not gone far enough	- The more help disabled people get the better - Thought about places that still do not have full access for wheelchairs/places that do not provide information in Braille - One respondent thought about the Disability Discrimination Act - *"how can something like 'rights or equal rights' go too far?"* (Male, 63, disabled)
Not gone nearly far enough	- Access to shops/buildings is not always available for people in wheelchairs

Thoughts about 'attempts to give equal rights to disabled people'

Respondents thought that 'attempts to give equal rights to disabled people' meant ensuring that that there is *"no negative discrimination"* towards disabled people and that they are not treated differently to anyone else; this could cover things such as rights to employment and rights to access public buildings, shops and buses.

Recommendations

- Remove answer codes 'gone much too far' and 'not gone nearly far enough' so as to simplify the scale
- Include a 'don't know' answer code so that those who do not know what has been done can say so, rather than being forced into choosing 'about right'.
- Consider whether an example of what 'attempts' have been made is needed – this would focus respondents on what the question is asking about and prevent them thinking that it is a question about 'whether disabled people are equal'

6 General feelings about the questions and recommendations for question ordering

This final chapter allows us to finish this report with a section detailing the general feelings respondents had about answering the test questions. Here, we also discuss social desirability and give recommendations for the order in which we feel these questions should be best asked.

At the end of the cognitive interview respondents were asked about their general views of the questions, and specifically:

- How they found the questions;
- What they thought the questions were asking and their perceived reasons for being asked them;
- How they felt answering the survey questions;
- Whether they were seen to be acceptable;
- Whether they had any difficulties answering any of the questions;
- Their thoughts on how others would perceive the questions and;
- Other suggestions for ways in which the questions could be improved.

6.1 Thoughts on acceptability of the survey questions

At the end of the cognitive interviews the issue of acceptability was explored with respondents. On the whole respondents' reactions and feelings towards the questions were **positive** and there was a universal consensus that it is acceptable to ask these questions.

Respondents tended to report feeling comfortable about being asked these questions. However occasionally respondents talked about how their answers to certain questions had made them feel uneasy about their own opinions on the issues being discussed. One respondent, for example, said some of the questions were difficult as she was not always sure how she felt and it really made her think. Another respondent (Female, 45, non-disabled), thought the questions were acceptable and felt comfortable answering them, however did not always feel comfortable with her honesty, wondering how others might judge her because of her views.

Generally speaking the questionnaire did not cause any major problems for respondents; it was described as "*quite interesting*" and *"thought provoking"* with *"good questions*". There was a little concern about the questions referring to a boss or a MP as this could be seen as "*far fetched and ridiculous".* Earlier in the report these scenarios are discussed in more detail.

There were respondents, in our very small sample, who were a little curious as to why these questions were being asked in the first place and how the data would be used. Nothing specific was reported by respondents about what they thought the data might be

used for. On the whole however there was a good understanding of the purpose of the questions (see 6.4 below).

6.2 Difficult questions

When respondents were asked about any difficulties that they faced, the universal response was that the difficult questions were asked towards the end of the survey where they felt they had to *"listen closely"* as it could be confusing and difficult to be sure they understood the questions well enough to be sure of the answers given.

Respondents felt that certain questions were more difficult to answer than others due to the question topic: notably question combinations which referred to relatives marrying disabled people (scenario 2) and those combinations which involved children (scenario 4). Respondents described these two particular scenarios as more personal or "*closer to home*" which could, occasionally, make them more sensitive and/or thought provoking to answer. There was no evidence found to suggest that respondents were unable to answer the closer to home scenarios however.

6.3 Perception of the questions

Respondents were told that the survey questions will be asked to all kinds of people, they were asked if there was anything that needed to be considered before the survey was distributed to a larger population. Universally respondents could not think of anything that needed to be altered. It was thought that the questions were acceptable and appropriate for the wider population as they are. However there was an overall slight concern about whether people would understand the term disability. Suggestions to overcome this problem were:

1. To ask people in the first question to define the word disability; and,
2. To have descriptions of or explanations of how an impairment type might affect a person as this might help people to understand how people are affected by disabilities.

6.4 Improvement of questions and why they are being asked:

Collectively no one had any suggestions on how to improve the questions; generally the questions were seen as necessary and appropriate to ask. All respondents were asked why they thought these questions were being asked and the generic response was that the survey was about what people think and feel about disability, other response's also included;

- To explore further around the topic of disability as there is not enough recognition of the topic;
- To overcome prejudice;
- Whether people felt differently about different disabilities or whether they all come under one category;
- To see if people discriminate towards people with disabilities and;
- To see how people react to the equal rights of disabled people.

6.5   Number of combinations and respondent burden

Although there was no evidence from the cognitive interviews that respondents felt over burdened from being asked a number of very similar questions, it should be noted that these questions will be administered in a completely different context: as part of a larger questionnaire which is asked in a survey interview which can last up to 60 minutes. The number of scenario-impairment combinations that any one respondent should receive should therefore be born in mind.

6.6   Question order

There was a feeling from interviewers at the cognitive de-brief, which was then supported through an interrogation of the data, that respondents found some scenarios more personal than others. The literature states that potentially sensitive questions should follow more neutral items where possible and therefore our advice would be to present the scenarios in this order on the BSA:

1. Scenario 5: Right to participate in political and public life;
2. Scenario 6: Right to participate in cultural life, recreation, leisure and sport
3. Scenario 1: Right to choose a place of residence
4. Scenario 3: Right to employment
5. Scenario 4: Right to access to general education system; and finally,
6. Scenario 2: Right to marry and found a family.

A further finding was that there could be question order effects associated with certain impairment types and therefore we would recommend that:
- Sensory impairment is always asked before physical disability.

Although there was a plan to randomise the scenario-impairment combinations on the survey, we feel that it is important to retain the order suggested above to avoid some of the problems the cognitive testing highlighted (discussed in previous chapters).

6.7   Social desirability

There are certain facts, behaviours and opinions or attitudes that respondents would rather not report accurately in a survey interview and respondents can instead lie or adjust their responses. The implication of this resistance to give an 'honest' response is underreporting (for events or behaviours) and skewed responses in the direction of the 'socially desirable' response for other questions (Fowler, 2002). Although there are limits to what people will report in a standard interview setting, there are some steps which can be considered for particularly sensitive questions such as using self-administered data collection methods and the addition of confidentiality and anonymity assurances.

This study however has highlighted that on the whole there was no evidence of social desirability bias and the spread of answers that respondents (so honestly) gave at each of the scenarios, when combined with the five different impairment types, supports this. We would not recommend, therefore, that the questions are instead administered in a self completion format as we are confident that, with the implementation of changes to the

scenarios and the impairment types/ examples we suggest in our recommendations, respondents will generally answer honestly in the survey.

6.8   Misconception and poor understanding of disability

It has become apparent to the research team, through writing this report, that some of the ways in which respondents in the sample described particular conditions suggests a great deal of misconception and poor understanding about them. Schizophrenia, for example, had negative connotations with danger and violence and respondents could report feelings of fear when hypothetically thinking about being in contact with people with this condition. In reality, there is little evidence to back this up but unfortunately acts of violence committed by people with schizophrenia get a great deal of high-profile media coverage which can give the impression that such acts happen frequently when they are in fact very rare.

We were not able to fully explore the way in which people group disabilities and therefore are unable to give clear recommendations to the ODI for a grouping system that would be any more meaningful to respondents. A further qualitative study might be useful for exploring this and the issues in more detail.

Appendix A   Details of cognitive question testing

This appendix describes in further detail the design and conduct of the cognitive testing.

Study Design

This project was designed to test a number of new scenario type questions which have been designed to measure attitudes towards the rights of disabled people. These questions will be asked on the British Social Attitudes (BSA) Survey.

All questions requiring cognitive testing formed two test questionnaires which were administered by interviewers, face to face. In addition, and prior to the questions that were cognitively tested, the questionnaire included five survey questions to establish whether the respondent was disabled and/or whether they lived with or cared for someone who was disabled. These questions were included in the test questionnaire to establish whether the respondent was disabled.

Respondents were asked each survey question. At various points in the questionnaire, and the majority of the time concurrently after each question, respondents were then asked some probes about how they went about answering the question. Probes also addressed how easy or difficult they found answering the question, how they comprehended particular terms as well as recall strategies and how they felt about being asked the question.

Interviews were conducted by field interviewers trained in cognitive methods and recorded using digital technology. Interviewers listened to the tapes and made detailed notes on each interview. Cognitive interview data were analysed using a content analysis approach described below.

Twenty four cognitive interviews were conducted in total. A purposive sample was designed to ensure that a range of respondent characteristics were included. As the questions will be asked on the British Social Attitudes (BSA) Survey, the sample needed to reflect the general population and adequately cover the main equality groups such as Gender, Age, Disability and Ethnicity.

Cognitive Methods

Cognitive interviewing methods, which are derived from cognitive psychology, enable researchers to examine (in greater detail) the question and answer process, helping to identify problems with questions and possible solutions. Cognitive interviewing techniques focus on four main processes:

- How respondents understand and interpret questions;
- How respondents recall the information required to answer questions;
- The judgements they make as to what information to use when formulating their answers; and,

- How to respond to the questions.

The two most frequently used cognitive interviewing techniques are 'think aloud' and probing. In this study mainly probing techniques were used but occasionally respondents would think-aloud and when this happened they were not discouraged from doing so. In the think aloud technique, respondents are asked to say out loud what they are thinking as they go about answering the survey questions. For example, respondents would be encouraged to articulate what they think a particular question means and what information they are drawing on to answer each question. During think-aloud respondents are also encouraged to articulate the internal decisions they are making about what they are being asked to provide or what information is required to answer and how they provide their (final) information for each item.

In the probing technique the interviewer asks specific, usually scripted, questions which provide similar information. These 'probes' are partly pre-scripted and provide a guide to the topics to be covered in the cognitive interview. Probing was carried out concurrently, once the respondent had answered one or a number of survey questions.

Recruitment

To identify people with particular characteristics to take part in cognitive interviews, interviewers were given a recruitment protocol and asked to go out and conduct a doorstep screening exercise. The interviewers were asked to target a mix of different areas (i.e. areas that they know have (relatively) high proportions of higher income households and also those which are more deprived) and asked to 'knock on doors'. On the doorstep interviewers used a short screening questionnaire to identify a range of different people to fill particular quotas, set by the research team. If the person was eligible to take part and agreed to do so, an appointment was arranged for the interview. Letters were left with respondents, confirming the date and time of the interview, a more detailed explanation of the study and what taking part involved and the contact details of the researcher in case people had any queries or concerns before the interview.

Fieldwork

Interviews were carried out by members of NatCen's core team of highly experienced cognitive interviewers. The areas in which interviewing took place were:
- Kent;
- Manchester;
- Nottinghamshire; and
- Leeds and West Yorkshire.

Conduct of Interviews

Cognitive interviews took place in respondents' homes and were conducted face-to-face, on a one-to-one basis, to ensure respondent confidentiality. Each interview lasted around an hour and a half. Interviews were recorded with respondents' consent. Respondents were given a £20 High Street voucher as a thank you for taking part in the interview.

Analysis

The core team field interviewers made detailed notes on their cognitive interviews, with reference to the recording of the interview. These notes, recordings of the interviews and the completed test questionnaires were reviewed as part of the analysis process.

Notes were analysed using a content analysis approach based on Framework, an analytic tool developed by the Qualitative Research Unit at NatCen. For this analysis framework a matrix was set up, which listed the test questions as column headings along the page and individual cases down the page. The matrix included a summary of the characteristics of respondents, such as their gender and age. Under each question a summary was made of each respondent's understanding of the question, recall strategies used, judgements made in formulating an answer and the answer provided. Any other problems were also recorded. Thus data could be read horizontally as a complete case record for an individual, or vertically by question, looking across all cases.

Once the matrix was completed the data were reviewed. In reviewing the matrix the full range of problems with the question were explored.