

**OFFICE FOR DISABILITY ISSUES
EXPERIENCES & EXPECTATIONS OF DISABLED PEOPLE
ETHNOGRAPHIC DEPTH INTERVIEWS**

Objectives

- Overall, to explore the experiences and expectations of disabled adults themselves, in all aspects of their lives
- In particular, to investigate their:
 - > Daily experiences
 - > Future aspirations and expectations
 - > Self-perception and self-image
 - > Attitudes towards and experience of discrimination
 - > Awareness of and attitudes to human and civil rights

1. INTRODUCTION

5 mins

(Aim: to explain purpose of research, introduce moderator)

- Thank interviewee for taking part in the research.
- Introduce self, GfK NOP, interview will last 2 hours
- Explain purpose of research
 - > *We would like to talk to you about your life in general, to get a feel for what it is like and the things of importance for you. We may discuss specific issues relating to disability and health, in order to get your views and opinions on these. This interview is an opportunity for you to have a say about how you feel about things at present.*
 - > *During the interview we would also like to take part in some of the tasks and activities you would normally do during the course of the day to help us understand what your life is like.*
 - > *If at any point, you would like to take a break, just let us know.*
- Reassure re: confidentiality- nothing you say will be linked to your name, recording and MRS Code of Conduct.
- Explain importance of interviewee saying what they think, there are no right or wrong answers, all opinions valid and helpful.
- Check interviewee is comfortable with interview format and subject matter. Any questions?
- Pre-task: ask if interviewee has completed this. If so, how did they find it? What did they enjoy about it, find difficult, etc. Explain that we will discuss the pre-task during the interview.

- *Moderator, explain that throughout the discussion you may wish to observe some of the things the interviewee is talking about (e.g. artefacts, objects, activities), if this is possible, in order to get a deeper insight into their lives (please see Section 7).*

2. **CURRENT CIRCUMSTANCES** **10 mins**

(Aim: to allow interviewee to introduce themselves, investigate their present situation)

- Spontaneous:
 - > First of all, tell me about yourself (for example, where you live, who you live with, what you like to do in your free time, hobbies etc)
 - > At present, what would you say are the things of most importance to you?
 - Why do you mention these things?
 - Why are they important?
 - *Moderator to note these*
- If not mentioned spontaneously, prompt on the following issues *(these represent those identified in the design matrix for this research – please refer to the design matrix for further areas of investigation)*:
 - > Home life - *family set-up, children, housing arrangements, background*
 - > Learning - *if in education or training, please describe / explore educational history*
 - > Employment & income - *explore current employment situation / employment history*
 - > Personal relationships & identity - *age, ethnicity, background, etc.*
 - > Participation - *role in community, involvement in organisations, etc*
 - > Environment & transport - *length of time living in local area, likes / dislikes*
 - > Leisure - *hobbies and leisure activities*
 - > Health & security - *explore nature of disability / impairment / illness*
 - > Independent living - *explore feelings of independence and dependence / any support*

received

3. **DAILY LIFE** **15 mins**

(Aim: to explore interviewee's daily life, routines and activities, with reference to the pre-task exercise.)

- Tell me about your daily life (reference may be made to pre-task diary, if this helps)
 - > **On a weekday**
 - Can you describe a normal day for me?
 - What do you do?
 - Where do you go?
 - Who do you meet?
 - What do you see / hear / feel?
 - How do you feel?
 - Explore individual activities described – prompt for any services used here
 - Likes and dislikes
 - Triggers / barriers to undertaking each activity
 - Causes of satisfaction / dissatisfaction
 - Are there any particular activities you would like to do but can't?
 - Why? (probe cost, availability, accessibility etc)
 - If it is helpful, divide day up into morning / afternoon / evening / night and tell me about them one at a time
 - > **On a weekend**
 - Repeat the line of questioning
- The following 'design matrix' areas can be used as prompts:

> Home life	> Environment & transport
> Learning	> Leisure
> Employment & income	> Health & security
> Personal relationships & identity	> Independent living
> Participation	
- What would you say are the things of most importance to you in your daily life?
 - > Please try to think of at least three things
 - Why do you mention these things?
 - Why are they important?

- *Moderator to note these*
- **Pre-task exercise**
 - > Please talk me through the entries in your pre-task diary
 - What events, experiences, etc. stand out from the week over which you completed it?
 - Please could you tell me about these events / experiences?
 - Explore events / experiences in detail
 - > Please can you take me through your diary from beginning to end?
 - Explore diary entries, drawing out references to 'design matrix' issues where possible
 - > Please can you show me the objects that you selected as important to you
 - Please tell me about this object
 - Why is this important to you?
 - What do you think it says about you?
 - Explore object's history, personal significance, meaning for interviewee
 - > Throughout, moderator to note events, experiences of importance, etc.

4. IDENTIFYING ISSUES OF IMPORTANCE **10**

mins

(Aim: to prioritise the things of importance to interviewees and assess the degree of control they feel they have over each.)

- Explore the issues of importance mentioned across Sections 2 & 3
- For each issues mentioned, use Sheet A to determine how much control the interviewee thinks he / she has over it
- Write the issues down on post-it notes
- Pretend Sheet A is a dartboard. Those issues over which the interviewee feels they have control should be placed near the centre. Those they do not feel they have control over should be placed near the edge. (Where necessary, explain the concept of the dartboard- for those who can't identify their control levels, ask them to consider comparing to other people e.g. other young people)
- Throughout, examine the reasons and thinking behind interviewee's decisions
- IF VISUALLY IMPAIRED OR OTHER RESPONDENTS CANNOT UNDERTAKE THE TASK, PLEASE DISCUSS VERBALLY INSTEAD

5. SELF-PERCEPTION & IMAGE**5 mins**

(Aim: to investigate and understand in more depth how interviewees see themselves)

- Overall, what words would you use to describe yourself?
 - > How would you describe yourself to:
 - A new neighbour
 - A new person at work
 - A future employer
 - A new person participating in other activities with you (sport, arts, etc.)
 - On your blog/ personal website (where applicable- for young people)
- What would you say makes you the person you are?
- Considering the 'issues of importance' we have already discussed:
 - > To what extent do these define you / make you the person you are?
 - > How do you feel about the impact of these things on your identity?

Moderator: select from the following projective questions: (nb people with autism may find it difficult to put themselves in other peoples shoes)

Using Sheet B: this figure represents the interviewee – get interviewee to write in statements describing themselves around the figure

Selecting from respondent's interests: If you were a car, actress, footballer, etc. who would you be and why?

If I asked one of your neighbours, friends, family members, colleagues, etc. to describe you, what three things would they tell me?

If a film was made of your life, who would play you in it?

Why this person?

In what ways are they like you?

6. Disability

10 mins

(Aim: to investigate and understand in more depth how interviewees see themselves with relation to disability specifically)

- What does 'disability' mean to you?
- What do you think 'disability' means to other disabled people or people with impairments?
- To what extent do you see yourself as someone who is disabled or someone with an impairment?
 - > Why is this?
 - > How does this make you feel?
- What do you think are the positive / negative ways in which the way you see yourself has affected your life (e.g. decision making, activities, friendships, etc.)
- How do you think **other disabled people or people with impairments** see themselves?
 - > Positive / negative
 - > Why is this?
 - > How does this make you feel?
 - > Probe for different disability types if necessary
- How do you think **non-disabled people** see disabled people or people with impairments?
 - > Positive / negative
 - > Why is this?
 - > How does this make you feel?
 - > Probe for different disability types if necessary
- How do you think **non-disabled people** see you personally?
 - > Positive / negative
 - > Why is this?
 - > How does this make you feel?
- How do you think the **media** represent people who have disabilities or impairments these days?
 - > Positive / negative
 - > Why is this?
 - > How does this make you feel?
- To what extent have each of these views changed over time?
 - > How?
 - > Why do you think this is?

- > To what extent do you feel changes to the law have effected the current situation?
 - Which ones?
 - Why?
- To what extent has each of these different perspectives affected your view of yourself?
 - > How do they make you feel?
 - > Positive / negative

7. **DISCRIMINATION** **15 mins**

(Aim: to explore awareness of, experience of and attitudes to discrimination)

- What do you understand by '*discrimination*'
 - > What causes it?
 - > In what situations does it occur?
 - > Who does it affect?
 - > How widespread is it?
 - > How frequently does it occur?
- Do you feel you have ever experienced discrimination?
 - > For those instances mentioned spontaneously:
 - When was this?
 - What was the situation?
 - What led you to believe it was an incident of discrimination?
 - To what extent was disability a factor in this incident?
 - Did you take any action as a result?
 - Why? What was this?
 - Why not?
 - How did the incident make you feel?
 - How did it affect you / what impact did it have on your life?
 - How would you deal with it if it occurred now / again?
 - > Then prompt for instances across different spheres of life: family, education, work, social life, access to services, etc.
 - > Do you feel you personally have any power to tackle discrimination?
 - Why / Why not?
 - How would you go about this?
- Do you feel there is a difference between *discrimination* and *prejudice*
 - > Why? How are they different?
 - > What are the different ways they impact on people?

- *Show Sheet C – Definition of Discrimination*
- How widespread do you think discrimination against disabled people or people with impairments is today?
 - > Why do you say this?
 - > In which areas of life is it most prevalent? Why?
 - > In which is it least prevalent? Why?
- What impact do you think it has on disabled people or people with impairments?
- Are there disabled people who suffer from discrimination more / less than others? Why do you think this is?
- How has discrimination against disabled people or people with impairments changed over the last 10 years?
 - > Are things better / worse?
 - Why?
 - What makes you say this?
 - > What has brought about this change (if any)?
 - > To what extent do you feel changes to the law have effected the current situation?
 - Which ones?
 - Why?
- What can be done to overcome the kinds of discrimination we have been talking about?
- Who should be responsible for preventing discrimination?
 - > Explore: discriminators themselves, self, others, government, etc.
- What could be done to promote inclusion, reduce discrimination and enable disabled people or people with impairments to realise their potential?
- As far as you're aware, what has the government done to this end in the last few years?
- In what ways are your rights protected at present, e.g. against discrimination?
 - > What legislation is in place to do this?
 - > How effective do you feel it is?
 - > How open and accessible do you feel justice is?
 - > What else could be done?
- What do you know about laws designed to protect disabled people or people with impairments?

- > Probe awareness of Disability Discrimination Act?
 - *Moderator, refer to Sheet D for explanation if necessary*
 - How do you feel about this law?
- To what extent have things improved for disabled people or people with impairments since 1995? Why is this?
- To what extent do you think attitudes to disabled people have changed in the last 10 years? Why is this?
- How do you feel attitudes to disabled people are changing at the present time?
 - > Getting better / getting worse? Why?
 - > What makes you feel this way?
 - > What could make this situation better
- In 5 or 10 years time do you think people's attitudes to disabled people will be more positive or less positive than they are today?
 - > Getting better / getting worse? Why?
 - > What makes you feel this way?
 - > What could make this situation better

8. **FUTURE ASPIRATIONS AND EXPECTATIONS** 15 mins

(Aim: to identify the critical drivers of positive change: what would help interviewees lead the kind of life they want to)

- Please imagine that we have jumped five years into the future. I want you to tell me what you want your life to be like in 5 years time?
 - > Where are you living?
 - Who with?
 - Have you moved away from the place where you live now? Why?
 - How do you feel about this? Positive / negative
 - What has enabled you to do this?
 - What barriers did you experience along the way?
- Please explore in this way for each of the 'issues of importance' identified earlier

- The 'design matrix' areas may also be used to encourage comment:
 - > Home life
 - > Learning
 - > Employment & income
 - > Personal relationships & identity
 - > Participation
 - > Environment & transport
 - > Leisure
 - > Health & security
 - > Independent living

9. **OBSERVATION** **30 mins**

(Aim: to observe first hand aspects of the interviewee's daily life)

- This exercise may be carried out at the end of the interview, but can be engaged in at any point, as it seems relevant
- Please accompany and observe the interviewee in a task or activity that they would normally perform in the course of their day or have discussed during the interview. This maybe anything from a household chore or telephone call to a service provider to a recreational activity or journey out of the home
- Where possible, try to ensure the task / activity engaged in is pertinent to the discussion and of importance / significance to the respondent
- Discussion to aid understanding should accompany observation at all stages, where possible

10. **SUMMARY & CONCLUSION** **5 mins**

(Aim: to review and close the discussion)

- Of everything we have spoken about today, what three issues / subjects are of most importance to you?
 - > Discuss each:
 - Why is this of concern?
 - How is it affecting you at present?
 - How do you feel about this?
 - How would you like it to develop in the future?
- This is the first stage of a large piece of research with disabled people. What are the three main things you think we should be asking future interviewees?

- Are there any other comments you would like to make / questions you would like to ask before we finish this discussion?

THANK & CLOSE