

Learning to Interview People with a Learning Disability

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Abstract

When planning for a first project involving research amongst people with a learning disability, I found very little in the way of good practice guidance or practical tips on how to do it. In this article, I aim to share my learning experience and offer advice to other researchers who are new to the field.

Keywords

People with a learning disability, research methods, interviews, user views

Introduction

When I joined the Essex Social Care research team I had no prior experience of research amongst people with a learning disability, although I had over ten years experience of carrying out research. My first project was therefore a learning experience for me, as I explored what kinds of questions participants could and could not answer.

While planning for the project I read whatever I could find about interviewing people with a learning disability. However, there was very little in the way of good practice guidance or practical tips on how to do it. In this article, I aim to share my learning and offer advice to other researchers who are new to the field.

My first project was a qualitative study to evaluate the outcomes and process of self-reviews, where the person with a learning disability is supported by an advocate to carry out their own annual review. The research was commissioned by the Planning and Participation Manager from Essex Social Care's Learning Disabilities Service. He wanted to evaluate whether person-led reviews

(that is, self-reviews supported by an advocate) gave service users more control over the review process, with better outcomes, than the current person-centred but care management-led reviews. I developed a research proposal to meet his requirements, agreed it with him, and then submitted it to the Essex Social Care Research Governance Group for approval. This included an explanation of the reasons for the methodology and what the ethical issues might entail.

The project involved face-to-face interviews with 14 people with a learning disability, supported by their advocate. These interviews formed the main element of the research, but input from advocates, relatives and social workers were obtained. The interview took the form of a conversation with participants, asking questions about various aspects of their life. In addition, people in their 'circle' who could give a view about their life were sent a self-completion questionnaire to obtain extra information about their lives.

Interviewing

Format of interviews

The advocates worked with each person in advance to prepare him or her for their self-review. Most of the research interviews were carried out after the pre-planning stage and before the review. However, I learnt that it was necessary to be flexible about this and adapt to each individual's circumstances, so that four research interviews took place within the review meeting itself. This meant that others present, such as parents and support workers, could give their views about the person's life: this was essential for the two people who had no verbal communication.

This article deals mainly with my experience of interviewing the 12 people who did have a level of verbal communication ability. I collected information about the lives of the two people with no verbal skills from parents, advocates and support workers who knew them well. This was the most practical way of gaining data about their lives, as I did not have the time or resources to develop a way of communicating with them. There was some evidence to suggest that the two people followed at least some of the discussion during the interview, and they at least understood that it was about them.

Interview arrangements and consent

The advocates had explained about the research and asked the participants to sign a simple consent form before I met them. They also arranged the time and venue, which was mostly someone's home or day centre, depending on where the person would feel most at ease. The fact that the advocates set up my interview with each person was a great help and saved me a lot of time. It meant I did not have to identify and recruit a link person for each of the 14 participants

to explain about the research, gain consent, and arrange for me to meet with them. It also made it very easy for me to arrive and start asking questions, as the people were expecting me and were meeting me with their advocate, who knew them well. Each interview began with a cup of tea or coffee (often made by the participant) and some general chat, which helped to break the ice before the interview as such started.

Although the advocates had previously explained why I was coming to talk to them, it was clear that participants did not really understand what the research process is, and what I would be doing with their replies, but were merely happy to answer my questions and tell me about their lives. A developmental area for me, which is something that I have done in subsequent projects, has been to produce an information sheet for the service user using simple words and symbols. This explains who I am, why I am asking them questions and what I will do with what they tell me. It also covers the fact that what they say will be kept confidential (unless they say someone is hurting them) and that the services they receive will not be affected. It has my photo on it and gives details of how to contact me. I have found it useful to go through this sheet with the person at the beginning of each interview, as it helps to reinforce why I am there and that their input is valuable.

Going through the information sheet also helps me to be more certain that people are in fact consenting to the interview. While they may not necessarily understand what research is, they must be able to choose whether they wish to talk to me and answer my questions. However, during the interview it's important to consider verbal signals to make sure that the person is still happy to continue with the interview and does not wish to withdraw.

Interview content

The interviews were designed to be a conversation about people's lives, with question prompts to elicit key information. These were themed around quality of life elements, such as housing, daytime activities, education, employment, leisure activities, money, and transport. To keep the conversation flowing, I did not write down what people said but tape recorded the interview and recorded answers later. Only one person was unhappy about me recording their interview and refused consent.

In order to establish people's priorities I showed a picture card for each aspect of their life and asked them to say which were important to them and which were not. However, almost all the cards were put into the important pile and no one said that more than two aspects were not important to them. Even when a card was judged unimportant initially, many people later went on to talk about issues within that aspect, so had to move it to the important category. Almost all of the participants found it difficult to distinguish whether the aspects were very important to them or just important.

Responses to questions

I found that if I asked questions with a 'yes/no' answer, I had to probe the response given, for example, 'why do you say that?' or 'can you give me an example?' since many respondents did not elaborate spontaneously. With some people, I also felt that they perhaps wanted to agree with me or give an answer that would please someone else present (especially if a family carer or support worker was listening).

During the interview, participants often contradicted something that they had said earlier, which meant going back to the specific question to test which one was the correct answer. Also, some

participants appeared very suggestible, agreeing with whatever was asked, so that I needed to probe to try to ascertain their actual feelings. This was one area where I found it helpful to have the advocate present, as they could challenge a response based on what they knew of the person or the preparatory work done.

The advocates' role during the interviews was to introduce me and what I was doing and then support the person in answering questions but not answer the questions on the person's behalf. This worked well and advocates only contributed if they thought the person had not understood the question fully or they needed to explain an answer to me. Advocates were usually able to explain questions in terms participants could relate to (for example, talking about a specific person's name rather than a job title) due to their knowledge of the person and their life. This kind of non-overpowering contribution may be unique to advocates since it is their role to support a person to speak up. I have found in subsequent projects that sometimes family carers and support staff can overpower or speak on behalf of the person with a learning disability, which may be contrary to what the person would say if on his or her own.

I asked each person how happy he or she was with each aspect of their life, at the end of the questions relating to that area. I had brought along a card with four faces on it, representing replies ranging from 'very happy' to 'not at all happy'. The person could indicate which face best described how they felt, either by pointing to it or telling me. I found this worked well in helping the participants to give a reply: a few of them were able to use the word scale, but most seemed to respond best to the pictures' expressions.

Challenges to asking questions about choice and control

The people interviewed found it very difficult to answer questions about what they would like to see change in their lives. This seems to be because they relate mostly to personal experience and were unable to think of an activity that they had not previously tried. Only one person gave any meaningful answer to the question that came towards the end of the interview: 'What one thing about your life would you like to change?' Most respondents clearly could not think in this way or give an answer: when prompted about things they had mentioned earlier in the interview some agreed with the prompt. Wider picture data was also difficult to extract, as almost all the participants brought general questions back to their individual, small-scale concerns.

In general, people struggled to understand what was meant by having a choice in their lives, with most requiring an explanation with concrete examples, such as choosing what to wear or what to have for breakfast. The only two people who were able to answer a question about how much choice they have in their everyday lives said that they have a lot of choice. However, the people in participants' 'circles' were divided fairly equally between those who felt that they had a lot of choice, quite a lot of choice, some choice or not very much choice. Only one family carer felt that their relative had no choice at all.

Most participants seemed hesitant when asked about how much control they had over their lives, with less confidence in themselves than others who know them. When asked who they feel is in charge, seven people said that the staff/carer was in charge and just three felt that they were. Family carers when asked this question were more inclined to say that

decisions were made jointly between the person and staff.

Length of interviews

My experience was that the length of the interview (the average was just over an hour long) was hardest for the people with a lower level of understanding or communication skills. Several people clearly found it difficult to concentrate after about an hour or so: sometimes having a break in the middle was useful to restore concentration, although where this was the case I found that there was little point continuing for more than another half an hour. One person was worried about when her support worker was going to arrive to take her into town to get her holiday money so that this interview was interrupted several times when the advocate needed to reassure her that everything was alright. It was therefore difficult to get this person to concentrate fully on my questions for very long at a time.

Discussion

Hints and tips when planning research

Based upon my experiences, I have drawn up a checklist for researchers, practitioners and policymakers who are hoping to include people with a learning disability in planning or evaluating services or in undertaking research.

- Decide whether you are going to include people with either limited or no communication skills/ understanding in your sample. If so, can you collect views/ perceptions about them from someone who knows them well?
- Always try to gather information using the face-to-face approach. Many people with a learning disability will be unable to read a questionnaire, even if symbols are used, and will have difficulty in

understanding how to fill one in. They may also worry about having to fill in an 'official form'. Most would have to ask someone for help to complete a written questionnaire, in which case you would not know whose opinions are provided - the person him or herself or what the helper thinks they might say.

- Although the person with a learning disability has to consent to the interview, it is courtesy to inform others in their immediate circle about the research. This can help to gain the person's consent and smooth the way to arranging the interview.
- Identify someone who can introduce you and the research to the participant: you cannot 'cold call' people with a learning disability. Ask if the person will need a supporter in the interview and if so who? If a supporter is present, check that the person is happy to have them there and lay down some ground rules, for example, that they are there to help the person answer the questions and not provide answers for them.
- Produce a simple and accessible information sheet explaining what the research is about, how it involves the person and details of how to contact the researcher. Go through this at the start of each interview and check the person's understanding before they sign the (simply worded) consent form.
- Try and hold the interview in a place that the participant knows and where they are comfortable. Spend a little time at the start of the interview to chat to the person and break the ice. It can take a while for them to get used to your presence and open up to questions. Explain that their replies will be kept confidential and anonymous.
- Keep interviews short. Have a break if the participant seems to be losing concentration. End the interview if the participant seems to be getting distressed or says that they would like to stop.
- Keep your questions simple and be prepared to probe the responses given. Avoid questions with yes/no answers, but where you include one of these types of questions then ask the participant to explain why they say that. If a supporter is present who knows the person well, they may be able to help you to understand what the participant actually means.
- Be aware that many people with a learning disability relate best to things they have experienced in their own lives. It is therefore difficult to ask them how they feel about something that is new or different to what they know, or get them to think creatively.
- Many people with a learning disability are eager to please, so be careful not to prompt them with a suggestion or they may just agree with what you have said.
- If you are using scales, keep them very simple with no more than four points and prepare some symbols (for example, happy/sad faces) to represent each point on the scale. Some participants will respond better to pictures than words.
- Pictures or symbols can help to engage the participant's interest and help them visualise the

topics. This technique is also used when interviewing children.

a full member of the Market Research Society.

Notes on contributor

Vanessa Baxter worked for a major engineering company for ten years, carrying out a variety of qualitative and quantitative research projects. This included researching customer satisfaction, brand values, market size and share. She then worked in the communications team for Essex Social Care for over four years, before joining the Essex Social Care Research Team in August 2003. She passed the Market Research Society Diploma in 1996 and is

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