



Frontline workers' perceptions and practice around sexual expression in people with severe or profound and multiple learning disabilities (PMLD)

I am looking for people to take part in a research project. Before you decide whether you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully, and feel free to think about it or ask others for an opinion before responding to me. You can keep an electronic copy of this information sheet. If you decide to take part you will also be given a signed consent form to keep. Please contact me if you would like further information or clarification.

Purpose of the project

I am a student on the MA Disability Studies course at the University of Leeds. In the past I have worked as a support worker for children and adults with learning difficulties. This project is part of my dissertation and aims to explore how support workers respond to clients' sexual expressions, especially when the clients have limited formal communication.

Why have I been chosen? What will I do?

I have chosen you because you have experience of working with adults (aged 18+) with learning difficulties. I would like to ask a few basic questions about your work via a questionnaire which can be done online, then have a discussion with you about your experiences and opinions working with adults with learning difficulties. It will be an informal discussion and will be around the topics of:

- Your work history (briefly)
- Communication with clients (in-depth)
- Enabling clients' choices (in-depth)
- Clients' sexual expression (in as much or little detail as you are comfortable with).

I will not ask you a list of questions: you can decide what you want to talk about and can ask to stop at any time. You do not have to discuss anything you feel uncomfortable with.

These key areas are the focus for discussion so that I can understand your views around working with people with learning disabilities and how you support them in making choices, including around sexual expression.

The discussion will last around 1-2 hours, or longer if you wish. You will only need to do this once, but I might contact you later on to clarify something that you said – this would only be brief and probably by email.

What information will be recorded? Will it be confidential?

I will take notes during our discussion. I will use a pseudonym (false name) for you so the notes cannot be connected to you, and these notes will be held securely. They will only be used for this project and any related work, and will be destroyed after three years unless they are still needed for related research (such as future journal articles).

I will also record the audio of our discussion, which will be used only for analysis. No one outside the project will be allowed access to the original recordings. I will transcribe the interview (write it down word-for-word). I will anonymise any names or identifying information. I will keep this securely both electronically and in hard copy. It will be deleted after three years unless they are still needed.

Please note that it is not possible to promise complete confidentiality: for example, it is possible that other people may read quotes from you and recognise a situation that you are describing. Also, if you disclose to me potential harm to yourself or others (e.g. about abuse) I will discuss this with my supervisor to decide what steps to take. In this unlikely event I may need to pass on your details to a third party. I will tell you if this happens.

Why should I take part?

There are no immediate benefits for you personally, but I hope that my research can contribute to understanding and improving the support given to people with learning difficulties, and taking part means you can be a part of this.

Do I have to take part?

No; it is entirely your decision. If you do not wish to take part, there will be no penalty. (However, it is helpful for me if you send a quick e-mail to me to let me know that you are not interested, so I know that I don't need to follow it up with you).

If you do wish to take part, you will receive a copy of this information sheet by e-mail and be asked to sign a consent form. You will be able to withdraw at any time, without giving a reason, up to **5 days after the discussion** as it will not be possible to withdraw responses once analysis has begun.

What will happen to the results of the research project?

The results of my research will be submitted to the University of Leeds as part of my programme of study. I may also use the information collected to submit to a journal for publication. You will not be identified in any publication. Please let me know if you wish to be kept updated with this project.

Contact details

Katharine Terrell (student)
School of Sociology and Social Policy
University of Leeds
LS2 9JT
Tel: 07746 217478
Email: ss14ket@leeds.ac.uk

Dr Alison Sheldon (supervisor)
School of Sociology and Social Policy
University of Leeds
LS2 9JT
Tel: 0113 3434715
Email: a.sheldon@leeds.ac.uk

This study received ethical approval from the School of Sociology and Social Policy on 26 January 2015.

Thank you for taking the time to read this information!

Your help is appreciated.

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