



PARTICIPANT INFORMATION SHEET

Study Title

Development of National Guidance to enable Social Workers to better identify and support parents who have a Learning Disability.

We would like to invite you to take part in a focus group or individual interview as part of a research study that aims to develop guidance for social workers on how to identify and better support parents with learning disabilities. Before you decide whether to take part you need to understand why the research is being undertaken and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or you would like more information. Take time to decide whether to take part.

What is the purpose of the study?

This research is part of a wider project, commissioned by the Welsh Government, that will lead to the development of guidance for social workers to assist them in identifying and better supporting parents with learning disabilities. We have already reviewed relevant literature, surveyed local authorities and interviewed parents with learning disabilities. The specific aim of this stage is to seek the views of a wide range of stakeholders regarding the information we have gathered to date, what they feel should be included in the guidance and what format it should take.

Why have I been invited?

You have been asked to participate in this research, as you may have relevant personal or practice experience/ knowledge that could inform development of these guidelines. As mentioned above we wish to consult with a wide range of stakeholders.

What will happen to me if I take part?

If you are happy to participate then you will be asked to take part in an on-line focus group along with up to about 10 other people. The group will last 1 – 1.5 hours and will be conducted using Microsoft Teams. It will be facilitated by Dr Wahida Kent and Professor Ruth Northway who will seek the views of the group regarding the issues that need to be covered in the guidance and the format it should take. Each focus group will be recorded using the Teams facility so that we can later transcribe and analyse what has been said.

We are planning to hold four focus groups, but you will only be required to attend one and we have attached a form with the covering email which asks you to identify your availability. Prior to the date of the focus group we will forward a meeting link to all participants so that you are able to join.

Should you be unable to join one of the scheduled focus groups we would still be interested in hearing your views. We would, therefore, seek to arrange a one-to-one interview (again using Teams). This would be conducted by either Dr Wahida Kent or Professor Ruth Northway.

The focus groups (and interviews) will all be video/audio taped. All participant details will be anonymised. All participants will sign a confidentiality agreement as part of the study consent form, meaning no information or personal details will be shared outside the group session.

What will I have to do?

We will ask you to discuss your experiences and offer ideas which you feel could improve the process of identifying and supporting parents with a learning disability. For reasons of confidentiality, we will not be asking you to discuss specific examples but would like you to share with us your views (based on your experience), those things which you feel present barriers to providing effective and timely support, and those that enable the provision of such support.

We will be putting questions to the group and it is up to you to decide whether you wish to comment or not. If you have an individual interview then you can decline to answer any questions.

Do I have to take part?

No - taking part in this research is entirely voluntary and it is up to you to decide whether you wish to participate. We would, however, value your contribution

If you decide that you do wish to participate then we would ask that you electronically sign the attached consent form and return it to Dr Wahida Kent (wahida.kent@southwales.ac.uk) along with the proforma indicating your availability to attend a focus group. Once this is received then we will arrange for you to attend an on-line focus group or an individual interview.

What are the possible disadvantages and risks of taking part?

We do not foresee any negative impact on those participating in interviews. However, topics may come up which may cause distress from recalling negative previous experiences. Should this occur during a focus group then please let one of the researchers know – one of them will then speak to you in a separate Teams 'room'. You have the option of whether to withdraw from the group or to continue. Should this occur during an interview then the researcher will pause the interview and give you the option of either ending it or continuing.

What are the possible benefits of taking part?

We cannot promise the study will help you directly. However, the information we get from the study may help to improve understanding of issues faced by parents with learning disabilities and how support can be more effectively provided. We hope that by seeking a wide range of views the guidance produced will meet the needs of practitioners and enable them to provide such support.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Our contact details are included at the end of this document.

If you remain unhappy and wish to complain formally you should contact Mr Jon Sinfield who is the University of Wales Research Governance Manager (contact details at end of document).

Please be aware that disclosure of information identifying a vulnerable child or adult at risk may need to be referred to safeguarding and/or police.

Data Protection Privacy Notice

The data controller for this project will be the University of South Wales. The University Compliance Manager provides oversight of university activities involving the processing of personal data. The University of South Wales Compliance Manager is Mr Rhys Davies (rhys.davies@southwales.ac.uk).

Your personal data will be processed for the purposes outlined in this information sheet. Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you. However, the legal basis on which this task is being performed is public interest, approved by the Faculty of Life Sciences and Education Research Ethics Committee.

If you are concerned about how your personal data is being processed, please contact Compliance Manager, Mr Rhys Davies (rhys.davies@southwales.ac.uk). Details of your individual rights are available on the ICO website at: <https://ico.org.uk/fororganisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

Will my taking part in the study be kept confidential?

At the beginning of each focus group we will remind all participants of the need to keep what is discussed in the group confidential. We will record the focus groups and interviews (audio and visual) using the Teams function and these will be stored on a password protected computer in a password protected file and accessed only by members of the research team.

Once the focus groups and interviews have been completed, we will transcribe the recordings. When doing this we will allocate each participant a participant number so that the transcripts will not include the names of individuals or services. Once transcription is completed, then the recording will be deleted.

Your name will be included on the study consent form that you have signed but it will not be possible to link your name to any specific comments. The electronic consent forms will also be stored on a password protected computer in a password protected file.

We will be using quotes from participants in the guidance document and also in any publications and presentations. However, as indicated above we will only label these with a participant number – no names will be included.

As you can see we therefore aim to keep what you say to us confidential. The only time we would need to disclose what you have said is if you were to disclose information that indicated either you or another person were at risk of harm. Should this occur then we would discuss this with you before contacting the relevant authority.

Once the study is complete then all data will be stored securely for a period of five years and then destroyed securely.

What will happen if I do not carry on with the study?

If you withdraw from the study all the information and data collected from you, to date, will be destroyed and your name removed from all the study files. However, once we have transcribed the focus groups and interviews then it will not be possible to link specific data to individuals. We would ask, therefore, that if you do not wish for what you have said to be included in the study, you inform us within 24 hours of participating in a focus group or interview. This can be via email (see below for addresses).

What will happen to the findings of the research study?

Once data has been collected and analysed guidance will be produced for social work practitioners. This will be published by Welsh Government and will be publicly available. In addition, we will be writing up our findings for publication in academic and professional journals and may make presentations at (for example) conferences. However, as indicated above no names of individuals or organisations will be included in any publications or presentations.

Who is organising or sponsoring the research?

This research has been funded by the Welsh Government. It is sponsored by the University of South Wales and it has received ethical approval from the Faculty of Life Sciences Research Ethics Committee.

Further information and contact details:

Should you require any further information please contact one of the research team:

Dr Wahida Kent

E mail: wahida.kent@southwales.ac.uk

Telephone (voicemail): 01633 432987

Professor Ruth Northway

E mail: ruth.northway@southwales.ac.uk

Telephone (voicemail): 01443 483177

Should the research team not be able to resolve a query and you wish to raise a concern regarding the project then please contact:

Mr Jon Sinfield

Research Governance Manager

Telephone (voicemail): 01443 484518.