

Information sheet for parents with learning disabilities and informal carers who support them

Understanding and improving support for people with learning disabilities who are pregnant or caring for a baby

Principal investigator: Dr Anna Cox

Introduction

We are a group of experienced researchers from the Faculty of Health and Medical Sciences at the University of Surrey. We would like to invite you to take part in a service evaluation. Before you decide whether you would like to take part it is important for you to understand why this evaluation is being conducted and what it is going to involve. Please take time to read through this information sheet carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you need further information.

The purpose of the study

This service evaluation seeks to improve the care given to parents with learning disabilities. We aim to do this by creating a resource to support the health and social care workforce to meet the needs of parents with learning disabilities.

Why have I been invited to take part?

We are inviting you to take part in this evaluation because you have a learning disability and are pregnant or raising a baby under 24 months old in England, or because you support someone with a learning disability who is pregnant or caring for a baby under 24 months old. We would like to hear about your views of the care received and what you think could be improved.

Do I have to take part?

No, you are under no obligation to take part at all. If you do decide to take part and later change your mind, you are free to leave the evaluation at any time. You can ask us any questions before you decide.

What will happen to me if I take part?

We would like to ask you some questions about the care given to parents with learning disabilities. We want to find out what good support they receive and what you think needs to be improved. You can use a computer to complete our online survey or we can ask you the

questions over the telephone. We expect either of these options to take 30 minutes of your time. Or if you would like to, you can do both.

If you decide to answer our questions over the phone, we will ask you to complete a consent form. With your consent, this phone call will be audio-recorded so that we don't forget any of the things you tell us.

What are the possible disadvantages or risks of taking part?

The research team do not anticipate any risks or disadvantages from answering our questions. If thinking about the care parents with learning disabilities receive makes you feel sad, you can stop answering at any time. If you would like to speak to someone about how you are feeling after you answer our questions, you can contact the learning disability helpline hosted by Mencap (https://www.mencap.org.uk/contact/contact_mencap_direct) or if you would like support with your role as a carer you can contact the Carers Trust which helps carers to cope with their caring role through specialised services across the UK (<https://carers.org/our-work-locally>).

What are the possible benefits of taking part?

It is hoped that you will find taking part in this study interesting and enjoyable. It is also hoped that the information you give will help us to improve the care parents with learning disabilities receive in the future.

How is the project being funded?

The project is being funded by Health Education England.

This service evaluation has been given a favourable ethical opinion by the University of Surrey's Ethics Committee.

What if there is a problem?

If you wish to make a complaint about the conduct of the evaluation you can contact Dr Anna Cox (Project Lead) or her Head of School, Professor Melaine Coward using the details below for further advice and information:

Dr Anna Cox, Faculty of Health and Medical Sciences, University of Surrey, Guildford, Surrey GU2 7XH

Email: a.cox@surrey.ac.uk Phone: 01483 684626

Professor Melaine Coward, Head of School, Health Sciences, Faculty of Health and Medical Sciences, University of Surrey, Guildford, Surrey GU2 7XH

Email: m.coward@surrey.ac.uk Phone: 01483 686693

The University has in force the relevant insurance policies which apply to this evaluation. If you wish to complain or have any concerns about any aspect of the way you have been treated during the course of this study, then you should follow the instructions given above.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

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Improving support for parents with learning disabilities

Dr Treena Parsons, Research Fellow, School of Health Sciences, University of Surrey, 30 Priestley Road, Surrey Research Park, Guildford, Surrey, GU2 7YH

Phone 01483 684563

Email: c.parsons@surrey.ac.uk

Who is handling my data?

The University of Surrey, as the sponsor, will act as the 'Data Controller' for this evaluation. We will process your personal data on behalf of the controller and are responsible for looking after your information and using it properly. This information may include your name, age and ethnicity which is regarded as 'personal data'.

What will happen to my data?

As a publicly-funded organisation, we have to ensure when we use identifiable personal information from people who have agreed to take part in research, this data is processed fairly and lawfully and is done so on the basis of public interest. This means that when you agree to take part in this study, we will use your data in the ways needed to conduct and analyse the study.

All project data related to the administration of the project, (e.g. consent form) will be held for at least 6 years and all research data for at least 10 years in accordance with University policy. Your personal data will be held and processed in the strictest confidence, and in accordance with current data protection regulations.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. You are free to withdraw your consent at any time during the study without giving any reason and without being disadvantaged in any way. Furthermore, you are able to withdraw your data up to 3 weeks after the date of the interview / completion of the questionnaire. You can find out more about how we use information at <https://www.surrey.ac.uk/information-management/data-protection> and/or by contacting dataprotection@surrey.ac.uk.

What will happen to the results of the study?

We will produce a final report summarising the main findings. You can request a summary of this report by emailing c.parsons@surrey.ac.uk

We also plan to disseminate the research findings through publication and conferences.

Will my data be used for future research?

When you agree to take part in a study, the information we collect may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in research in this country or abroad. Your information will only be used by organisations and researchers to conduct research and processed on the basis of public interest. This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of research, and cannot be used to contact you or effect you. It will not be used to make decisions about future services available to you, such as insurance.

What if I want to complain about the way data is handled?

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer Suzie Mereweather who will investigate the matter (dataprotection@surrey.ac.uk). If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) (<https://ico.org.uk/>).

Limits to confidentiality

Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. If this was the case, we would normally inform you first of any decisions that might limit confidentiality.

What do I do next if I am interested in taking part?

You can contact Dr Treena Parsons to ask any questions:

01483 684563 or c.parsons@surrey.ac.uk

If you are happy to take part:

- If you are reading this on line you can [click here](#) to go to our online survey and start answering questions. Or you can enter this address into your browser [give address].
- If you would rather speak to us over the telephone you can email Dr Treena Parsons at c.parsons@surrey.ac.uk or phone her on 01483 684563 to arrange a convenient time to answer some questions.
- Before we ask you questions over the telephone we would need you to complete a consent form, but we can give you more information about this once you hear from you.

Thank you for taking the time to read this Information Sheet