



Ask, Listen, Act - working together to inform the provision of Special Educational Need and Disability support for children after the COVID-19 pandemic. Ethics committee reference number:

Priority setting workshop information sheet for parents and carers

Introduction

Thank you for reading this information, you are being asked to take part in a research study. Before you make your decision it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If you would like more information then please feel free to ask Emma (contact details are at the end of this sheet).

What is the purpose of this project?

This project has been looking at the impact of COVID-19 on children with special educational needs and disabilities and is now trying to work out the priorities for these children moving forward.

Why have I been chosen?

We are asking you to take part as you are a parent or carer for a child with special educational needs and disabilities and we hope you can help us decide what the priorities should be for these children as we move forward out of COVID-19. We will be holding workshops with children and young people with special educational needs and disabilities, other parents and also professionals.

Do I have to take part?

No, it is entirely up to you to decide whether or not you take part in this project.

Whatever you decide, no-one will mind. You can change your mind about taking part at any time before or during the workshop without giving a reason, but once the workshop has taken place we will not be able to remove the information you have shared as it will be all mixed up with the data from other people. We will ask you to sign a consent form and will give you a copy for you to keep.

You must not take part in a face-to-face workshops if you have symptoms of COVID-19 - <https://www.nhs.uk/conditions/coronavirus-covid-19/symptoms/>

What will happen to me if I decide to take part in the project?

If you are happy to take part, please contact the research team. Taking part involves attending one workshop with other parents. We are planning for these workshops to be face-to-face in a setting you will already be familiar with such as school or a parent group you are already part of. The workshops may run online depending on what parents tell us they prefer.

During the workshop, you will be presented with the key findings (anonymised) from the surveys and interviews that were conducted during the previous phase of the study. These findings relate to the provision of special educational needs and disability support during COVID-19. You will then be invited to share any initial thoughts about the key findings with the group, or with the person next to you. We may ask parents/carers to vote in order to facilitate this discussion and determine the number of votes for each priority. This workshop will last about an hour.

Will I be photographed or video/audio recorded and how will the recorded media be used?

We will audio-record the meeting, so we can remember the important things everyone says. You are free to decline to be audio-recorded. The audio recordings will be used only for analysis. No other use will be made of them without your written permission. We will not photograph or video record you.

What are the possible risks of taking part?

We do not think that there are any risks for you taking part in this project. We will take great care of the information that you tell us about. We do not think that anything sensitive will be discussed at the workshops and we will not ask any personal questions, but parents may share information during the discussion which could potentially be upsetting. If you feel worried or in low mood we would like to point out that there are several sources of advice or help which are free and readily available to you and which may provide useful. Specifically, these include: Samaritans, SOS!SEN and 'Contact'.

There are also possible risks of COVID-19 infection during travelling to the workshop, or contact with individuals who might possibly be infected during the workshop. If you would like to wear a mask or PPE during the workshop this is up to you.

What are the possible benefits of taking part?

We hope that you will enjoy taking part in this project. The information that you share with us will help us decide the priorities for children with special educational needs and disabilities.

Payments, reimbursements of expenses or any other benefit or incentive for taking part

There will be no payment or any benefit or incentive for taking part in this study. Unfortunately, we cannot reimburse any expenses you may incurred.

What will happen to information/data provided?

The information you provide as part of the study is the study data. Any study data from which you can be identified (e.g. from identifiers such as your name or an audio recording), is known as personal data. Your participation in this study will involve the collection/use of personal data. All the information that is collected during the online workshop will be kept strictly confidential and will not be shared and any identifying information will be removed in the final reports or publications so that you cannot be recognised. We will not tell anyone that you have taken part in the focus group, although there is of course a possibility that another member of the group might recognise you. All members of the focus group will be asked to respect the confidentiality of their fellow participants. If you tell us information which makes us think someone is being harmed then we may have to share this outside the research team. In some very exceptional circumstances where you, your child or others may be at serious risk of harm, we may need to report this to someone. If we felt we needed to do this we would usually discuss this with you first. Examples of those exceptional circumstances when confidential information may have to be disclosed are:

- o The investigator believes you are at serious risk of harm, either from yourself or others
- o The investigator suspects a child may be at risk of harm
- o You pose a serious risk of harm to, or threaten or abuse others
- o As a statutory requirement e.g. reporting certain infectious diseases
- o Under a court order requiring the University to divulge information
- o We are passed information relating to an act of terrorism

Who is organising and funding the study?_

This study is funded by the National Institute for Health Research and has been organised by Liverpool John Moores University in collaboration with Edge Hill University, The University of Liverpool and Liverpool Health Partners.

Who has reviewed this study?_

This study has been reviewed and given ethics clearance through the Liverpool John Moores University Research Ethics Committee.

What if something goes wrong or I have a concern?_

If you have a concern about any part of this study, please contact the lead researcher, Dr Emma Ashworth (E.L.Ashworth@ljmu.ac.uk) who will do their best to answer your query and will acknowledge your concern within 10 working days and give you an indication of how they intend to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at Liverpool John Moores University who will seek to resolve the matter as soon as possible: Chair, Liverpool John Moores University Research Ethics Committee; Email: FullReviewUREC@ljmu.ac.uk; Tel: 0151 231 2121; Research Innovation Services, Liverpool John Moores University, Exchange Station, Liverpool L2 2QP

Data Protection Notice

Liverpool John Moores University is the data controller with respect to your personal data. Information about your rights with respect to your personal data is available from: <https://www.ljmu.ac.uk/legal/privacy-and-cookies/external-stakeholders-privacy-policy/research-participants-privacy-notice>

Or you can ask one of the study team or contact us using the information below.

Contact for further information or to let us know you would like to join a workshop

Dr Emma Ashworth E.L.Ashworth@ljmu.ac.uk 0151 904 1052,
5.26a James Parsons Building, Liverpool John Moores University, Byrom Street,
Liverpool, L3 4AF

Thank you for reading this information sheet
and for considering taking part in this study.