Ask, Listen, Act - working together to inform the provision of Special Educational Need and Disability (SEND) support for children after the COVID-19 pandemic.

Information Sheet for Parents/carers

We are asking if you and your child would like to take part in a project. This sheet will tell you all about it.

You are being invited to take part in a research project. Before you decide if you are happy to take part, and if you would like your child to take part, it is important for you to understand why the study is being done and what taking part will involve. Please take time to read this information sheet and decide whether or not you would like to take part and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

Who is doing this study?

The study is being led by Dr Emma Ashworth from Liverpool John Moores University and the team includes researchers from Edge Hill University and the University of Liverpool.

What is the purpose of the study?

This study is trying to find out how children and young people with SEND aged 5-15 years have been impacted by the COVID-19 pandemic. We are keen to find out what worked well, what was challenging and what the priorities should be moving forward.

Why have we been invited to take part?

We would like to understand more about how the COVID-19 pandemic and lockdowns have impacted on you and your child with SEND and so we are asking children and young people aged 5-15 years with SEND and their parent/carers to tell us about it.

Do I or my child have to take part?

No. It is up to you to decide whether or not you or your child take part. You can take part separately from your child, if they are not able or do not want to join in. Your child’s part of the survey is linked to yours so they can only take part if you do. If you do not wish to take part there is nothing more that you need to do.
What will happen if I take part?
You will be asked to complete a short online survey. The survey will take about 20-25 minutes or longer to fill out, depending on how much you want to tell us. The survey asks questions about your experiences of how COVID-19, lockdown, and school closures have impacted on your child with SEND. You will not have to answer any questions you do not want to, and you can end the survey at any time. We will not be asking for any information which will identify who you are. There will be a separate link at the end of the survey where you can leave your contact details if you would like to volunteer to take part in an interview.

What will happen if my child takes part?
If you and your child decide they would also like to take part and share their views then please read the children’s information sheet about the study with them. There is a link to the children's survey at the end of the parent on. There is also a box at the beginning of their survey which we will ask you to tick to say you are happy for them to take part. Your child can fill in their part of the survey on their own, or you can help them by typing in what they say. The survey for children will take about 15-20 minutes for them to fill out. They can share their views by writing, drawing or labelling a picture or using emojis. We will not be asking for any information which will identify who they are. Your child will not be able to go back and see your answers.

Are there any possible disadvantages or risks from taking part?
We hope that taking part will not involve any risks for you or your child, but some of the questions may be upsetting as they ask about what things have been like for you and your child over the last year. You do not have to answer any questions that you do not want to and at the end of the survey and this sheet there are some links and numbers to support services. As we cannot identify who has filled out a survey, we will not be able to offer individual help or support.

What are the possible benefits of taking part?
We hope that what we find out from this study help policymakers and Local Authorities across the country to develop strategies to reduce the impact COVID-19 has had on children and young people with SEND.

What will happen to the results of the study?
The research team will share the results in articles, presentations and we will also work with parents and children to write a summary of the key findings which will be posted on our webpage. The report from the project will be shared with policymakers and Local Authorities across the country.
Who is organising and funding the study?
This study is funded by the National Institute for Health Research (NIHR) 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. UREC Reference: 21/PSY/016

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 wish to make a complaint, please contact the chair of the Liverpool John Moores University Research Ethics Committee (researchethics@ljmu.ac.uk) and your communication will be re-directed to an independent person as appropriate.

Data Protection Notice
Liverpool John Moores University is the organiser for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Liverpool John Moores University will process your personal data for the purpose of research. Research is a task that we perform in the public interest. 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 study to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting secretariat@ljmu.ac.uk.
If you are concerned about how your personal data is being processed, please contact LJMU in the first instance at secretariat@ljmu.ac.uk.
If you remain unsatisfied, you may wish to contact the Information Commissioner’s Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Contact for further information Principal Investigator: 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

If you are experiencing any worries or distress at any time before or after completing the survey you may want to get in touch with the relevant organisation below.

<table>
<thead>
<tr>
<th>I Feel Like…</th>
<th>Who to Contact</th>
<th>How to Contact Them</th>
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</thead>
<tbody>
<tr>
<td>I need information or advice around SPECIAL EDUCATIONAL NEEDS</td>
<td>SOSISEN</td>
<td>Call 0300 302 3731 or 0208 538 3731</td>
</tr>
<tr>
<td></td>
<td>A free, friendly, confidential telephone helpline and advice centres for those seeking information and advice on special educational needs.</td>
<td>(Term-time, Monday-Friday 9:30am-12:30pm, 1pm - 4pm)</td>
</tr>
<tr>
<td>I need someone to talk to about my child's DISABILITY</td>
<td>‘Contact’</td>
<td>Call 0808 808 3555</td>
</tr>
<tr>
<td></td>
<td>A free helpline for parent/carers with a disabled child who are looking for a listening ear, reassurance, and practical and emotional support.</td>
<td>(Monday – Friday 9:30am-5pm)</td>
</tr>
<tr>
<td>I might have symptoms of COVID-19</td>
<td>NHS</td>
<td>The NHS website</td>
</tr>
<tr>
<td>I am struggling with my MENTAL HEALTH</td>
<td>Talk to your GP</td>
<td>Phone your GP surgery</td>
</tr>
<tr>
<td>I am in an UNSAFE ENVIRONMENT</td>
<td>Samaritans</td>
<td>Call 116 123 Text &quot;SHOUT&quot; to 85258 (24/7)</td>
</tr>
<tr>
<td>I am experiencing a MENTAL HEALTH CRISIS or am having thoughts about harming myself</td>
<td>Samaritans</td>
<td>Call 116 123 Text &quot;SHOUT&quot; to 85258 (24/7)</td>
</tr>
<tr>
<td>I am close to ACTING ON THOUGHTS, or have attempted to harm myself or end my life</td>
<td>Hospital/999</td>
<td>Call 999 Visit your local Accident and Emergency department (you can find your nearest here)</td>
</tr>
</tbody>
</table>

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