

PARTICIPANT INFORMATION SHEET

V2.0 28 April 2026

Title: A randomised controlled trial of a digital parent support programme for parents of children with intellectual disabilities: The Digital Family Support study ([DAISY](#))

Chief Investigator: Professor Kylie Gray

You are invited to take part in a research study called DAISY. Before you decide, it is important to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully.

This information sheet explains why the study is being done, what taking part involves and how it will be carried out.

You can talk to others (e.g. family and friends) about the study before you decide whether to take part. We will contact you in about 2 to 3 days to talk to you about the study and find out if you would like to take part. Please ask us if there is anything that is not clear, or if you would like more information.

Summary

- This is a research study for parents and carers who have a child between 2 and 11 years of age, and have a learning disability or developmental delay, as well as emotional and behavioural difficulties.
- This study is about an online programme called Stepping Stones Online.
- We would like to find out if Stepping Stones Online can support and empower parent carers.

What is the study about?

This is a research study to see if an online digital family support programme called Stepping Stones Online, improves the behaviour and emotional difficulties in children (between the ages of 2 and 11 years) with a learning disability or developmental delay. We also want to find out if parent carers might benefit directly from Stepping Stones Online, by boosting their wellbeing.

We would like to invite 432 parent carers to take part in the study. Half of the parent carers will be randomly selected (like flipping a coin) to take part in the 'Stepping Stones group' and the other half will take part in the 'comparison group'. This is called randomisation. The comparison group will not have access to Stepping Stones Online straightaway - they will have this opportunity at the end of the DAISY study. All parent carers will continue to access any other supports that are already available to them.

Why is the study being done?

Support for parents and carers can vary across the UK and it may even be difficult for some families to access support. You yourself as a parent carer may have had problems getting the support that you needed or currently need for you, your family and your child.

Providing support online is one way to support you and your family whilst caring for your child.

We would like to find out if Stepping Stones Online can support and empower you as a parent carer by giving you the confidence and the skills to manage behavioural and emotional problems your child may have. By supporting you to help your child, we hope to improve your wellbeing, reduce stress and help create happier family relationships.

What will happen if I take part?

1. Screening step 1 – online form

For the first screening, you have already answered some basic questions on an initial form to help the research team decide if you are eligible to take part in this study. This participant information sheet was sent to you because you have passed the initial screening for the study. Please read the information sheet carefully and take time to consider the study.

As a re-cap, you'll be able to take part if:

- You are a parent carer (biological, step, adoptive, foster) of a child aged 2 -11 years who has a diagnosis of a learning disability or is in the process of exploring a diagnosis, or your child may have a developmental delay (Global Developmental Delay), AND there are concerns about the behaviour and/or emotional problems of your child.
- You as the parent carer are over 18 years of age.

- If you live in England.
- If you have sufficient English language ability to participate with Stepping Stones Online.
- You are able to provide informed consent.

You won't be able to take part in the DAISY study:

- If your child is in 24-hour residential placement, a foster placement due to end before the 12 month follow up or if there are current child protection concerns relating to your child.
- If another parent carer of the same child has been recruited to the study, then you won't be able to be recruited as well.
- If you or another parent carer in the family is currently taking part in another programme with similar content to Stepping Stones Online.
- If you or another parent carer has taken part in another programme with similar content to Stepping Stones Online, in the last 12 months.
- If your primary residence is outside of England.

2. Screening step 2 –telephone or online call

A researcher will contact you (at a time you may have said is convenient, by telephone or online) two to three days after you have received this participant information sheet. If we are unable to reach you initially, we will attempt to contact you on further occasions. We may send text messages, leave voice mails and send emails to help get in touch.

During the call, the researcher will describe the study and go through the information sheet with you. The researcher will ask some further questions about you and your child to check if you are eligible to take part. The questions are commonly used in other research projects and will be about your child's practical, everyday skills. This call will be recorded.

Once all the eligibility questions have been completed, the researcher will look at all the information you have given us and will let you know whether you are eligible or not.

What if I am not eligible to take part?

If you are not eligible to take part in the study, we will discuss the reasons for this. Sometimes, there might be reasons why you are not eligible to take part now, but where you might be eligible to take part at a later point. If this is the case, with your permission we will keep your personal information (name and contact details) so that we can contact you at a later date and repeat the eligibility questions.

What if I am eligible to take part?

If you are eligible to take part in the study, and you have had the opportunity to discuss the study and ask questions, and have had your questions answered satisfactorily, and you are happy to take part in the study, you will then be asked to complete a consent form.

You have some options for completing the consent form:

- You can be provided with a link to complete the consent online, or
- You can provide verbal consent over the telephone or an online call (Zoom/MS Teams) with the researcher. If you provide verbal consent, we will need to record you agreeing to take part in the study. The researcher will complete the consent form on your behalf and send you a copy.
- You can also receive the consent form in the post for you to complete and return to the study team.
- We can also arrange for you to see a researcher in-person if you would prefer to meet face to face and complete a consent form this way.

3. Before the study begins (this is called the Baseline)

All parent carers will be asked to complete set of baseline questionnaires online (via email link). These may also be completed over the telephone with the researcher, or the questionnaires can be posted to you if you prefer. This will include questions about your well-being, parenting views, your relationship with your child, your quality of life and your child's quality of life. You might get upset while completing the questionnaires. If this does happen, you can talk to your GP or reach out to another organisation:

Mencap – 0808 808 111, www.mencap.org.uk

Samaritans by calling 116 123

These questionnaires may take up to about 40 minutes to complete. The questionnaires ask about parent carers' well-being and quality of life, their family, their views about parenting, the behaviour and development of their child, and of the different services your family accesses.

4. Randomisation

We will email or phone you about the group (Stepping Stones or comparison group) you will be in after the groups are picked by random.

Do I have to take part?

No, taking part in DAISY is entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part you will be asked to complete a consent form, but you will be free to stop taking part at any time and without giving a reason.

If you decide that you would prefer not be in the study, we may ask you why you have decided not to take part (as this could be useful for us to know for the study), but you don't have to answer this question if you don't want to.

What will happen if I am randomised to the Stepping Stones group and can take part in Stepping Stones Online now?

1. You will receive an email with a link, and an **individual unique code**. **You use the code to register on the Stepping Stones Online programme on the Triple P website.** You will have **two weeks** from when you first receive the email and code to be able to register onto Stepping Stones Online. On the Triple P website, there will be a privacy notice that you will need to read. It will tell you what personal data will be collected from you as part of the programme. You will need to agree to the privacy notice if you take part in Stepping Stones Online.
2. You will be asked to **complete ten modules** for the DAISY study and be **encouraged to complete it within 4 months**. You can complete the modules anywhere, but you will need to have access to the internet or mobile data to complete each module. You will have online access to the modules for 12 months. Your progress will be checked by the study team. It is important to complete the ten Stepping Stones Online modules.
3. Each module will take between 30 to 60 minutes to complete. The modules can be paused so you can take a break and come back to complete the module. Each module does need to be completed before moving onto the next module.
4. You will also be allocated a **Parent Supporter**.
 - This is a parent with lived experience of a child with a learning disability.
 - They will have received training for the role as parent supporter.
 - They will have completed the Stepping Stones Online themselves.
 - It is important that you meet with your parent supporter – they will offer motivation, support and encouragement.
 - Within 2-4 weeks of you being randomised to the Stepping Stones group, your parent carer will contact you for the first session.
 - You will have three sessions with your parent supporter, and each session will last up to 60 minutes.
 - You will have one session at the beginning of the programme, one midway through, and one at the end of the programme.

- You can meet on video call (camera does not need to be turned on) at a mutually convenient for you and your parent supporter. Your meeting will be recorded.
 - All conversations with your parent supporter are confidential.
 - Your parent supporter will only have access to your contact details needed for the session.
 - Please be aware that your parent supporter cannot complete the modules for you.
5. You might be invited to take part **in a meeting with a researcher to provide feedback** and help us to understand more about your experience of Stepping Stones Online. There are no right or wrong answers. We are interested in what you think and have to say.

What will happen if I am randomised to the comparison group?

This is the support that is usually provided in your local area. At the end of the study (after 12 months) you will be able to take part in the Stepping Stones Online Programme.

The 6-month and 12-month follow up

Everyone in the study will be asked to complete questionnaires 6-months and 12-months after you started the study. This will include questions about your well-being, parenting views, your relationship with your child, your quality of life and your child's quality of life.

- When it is time for you to complete these questionnaires, you will receive an email with a link. This link will take you directly to the questionnaires to complete.
- You can complete the questionnaires online or in paper format, or with help from a researcher by telephone, video call, or in person.
- If you have not been able to complete the questionnaires, we may need to email and/or phone to remind you.
- After 12 months, you may also be offered the opportunity to take part in an interview to share your experience of taking part in the DAISY study.

If you have any concerns about you or your child's wellbeing, make sure to contact your GP or another organisation:

Mencap – 0808 808 111, www.mencap.org.uk

Samaritans by calling 116 123

What are the possible benefits of taking part?

Stepping Stones Online is a new programme and we do not know yet if it will directly benefit children and families. By taking part in this study, you will be helping to answer whether Stepping Stones Online is beneficial to parent carers and children with a learning disability. The results of this study may benefit parent carers and children with a learning disability in the future.

What are the possible disadvantages and risks of taking part?

You will be asked to fill out questionnaires before the study begins and then 6 months and 12 months later. These questionnaires may take time to complete, and we ask that you do complete them. The questionnaires include positive things but will also ask you to reflect on challenges you may face with your child.

The questionnaires may make you think about upsetting events so you may feel uncomfortable or upset when answering the questions. If this is the case, you can find extra support here: **Mencap – 0808 808 111**, www.mencap.org.uk or talk to your GP.

We do not think that taking part in this study will pose any risk to parent carers or their child with a learning disability. Should you have any concerns, please contact the research team using the contact information at the end of this information sheet.

What will happen if I don't want to carry on being part of the study?

Taking part in this study is voluntary. You can leave the study at any time, without giving a reason, and without this affecting you or your child in any way. If you initially consent to take part in DAISY and then decide to leave the study, you may be asked which aspect of the study you would like to leave. These aspects could be:

- To leave the study
- To partially or fully leave from any further data collection (questionnaires, interviews)

A member from the research team will talk to you about the different options and will complete a withdrawal form on your behalf based on the information you may have provided.

Safety reporting – what you need to know.

We have a duty to keep your information secure and confidential. However, we are required to disclose information which suggests that you or a child may be at risk of harm. The reason for this is to work towards safeguarding and protecting a parent and the child.

If we become aware that an adult or child is at significant risk of harm, we may also share this information.

When sharing information, we will only do this when we genuinely believe there is a risk of harm. We may share this information with the local authority in your area or other statutory services who are meant to provide help.

Will I be paid for taking part in the study?

We cannot pay you to take part in this study. You will receive a voucher when you complete the questionnaires when the study begins (baseline), at 6- and 12-months (£15 at baseline, £25 at 6-month follow up, £50 at 12-month follow up), to say thank you for your time.

Who is organising and funding the study?

The study is being led/sponsored by University of Birmingham and is being carried out with the Centre for Trials Research at Cardiff University. The study is funded by the National Institute for Health and Care Research (NIHR).

Who has reviewed the study?

- This study has been reviewed by a Research Ethics Committee.
- We have partnered with the Council for Disabled Children, who bring together families, professionals, practitioners and policy-makers. We have a parent carer advisory group (PCAG) made up of parent carers and a professional's advisory group (PAG); both of whom will review and advise on different aspects of this study. Two parents with lived experience are investigators on this project.
- This study has been assessed as low risk and so there is no special compensation. By consenting to participate in the DAISY study, you are confirming you understand that should any harm be sustained due to your participation (that was not caused by negligence of the research team), we cannot offer compensation.

What will happen to the results of the study?

- A report of the research results will be completed and sent to the NIHR. The results will be published on the University websites, in scientific journals and presented at scientific meetings. You will not be identified in any report, publication or presentation.
- Details of the study will be made publicly available on the UK Clinical Trial Registry (ISRCTN). Nothing that can identify you will ever be included on ISRCTN.

Contact details

What if I have any questions about the study?

- If you have any questions, you can contact **Emma Scripps** at the **University of Birmingham** by email or phone: Daisy-online@contacts.bham.ac.uk or call Emma 07483123993 or Roan 07483656342
- Alternatively, you can contact the Trial Manager **Paula Foscarini-Craggs**, at Cardiff University by email: DAISYCardiff@cardiff.ac.uk

What if I would like to make a complaint?

- If you would like to make a complaint or provide feedback, we would ask you to speak to a member of the research team in the first instance. However, if you would like to speak to someone who is not part of the research team, complaints can be emailed to: **researchgovernance@contacts.bham.ac.uk**
- If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer at the University of Birmingham: **dataprotection@contacts.bham.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)** www.ico.org.uk or 0303 123 1113.

What information will be collected?

We will need to use information from you for this research study. This information will include the following:

1. Your initials,
2. Your name and surname,
3. Your telephone number,
4. Your home address
5. Your email address
6. Your device's IP address (your device's unique address when connected to a network will be automatically collected when completing the questionnaires to ensure network and information security. You don't need to know this information).

People will use this information to do the research or to check your records to make sure the research is being done properly.

People who do not know who you are will not be able to see your name or contact details. Your data will have a code number instead.

The University of Birmingham is the sponsor of this research and Cardiff University are helping to run this research study. Both the University of Birmingham and Cardiff University are responsible for looking after your information. We will share your information with the following organisation(s):

- Triple P Stepping Stones online

We will keep all information about you safe and secure by:

- Storing your signed paper consent forms in a locked room with restricted access.
- Storing your electronic consent forms on password protected computers and servers.
- Ensure that no-one can work out who you are from the reports we write about the research study. We will use the code and not your name.

We may share or provide access to data about you with other Universities, and or research organisations in the UK and outside the UK for research purposes.

If this happens, we will only share data that is needed. We will also make sure you can't be identified from the data that is shared. Your name and address will not be shared.

We will make sure your data is protected. Anyone who accesses your data outside the UK must do what we tell them so that your data has a similar level of protection as it does under UK law by doing the following:

- we do not allow those who access your data outside the UK to use it for anything other than what our written contract with them says
- we need other organisations to have appropriate security measures to protect your data which are consistent with the data security and confidentiality

obligations we have. This includes having appropriate measures to protect your data against accidental loss and unauthorised access, use, changes or sharing

- we have procedures in place to deal with any suspected personal data breach. We will tell you and applicable regulators when there has been a breach of your personal data when this is legally required. For further details about UK breach reporting rules visit the Information Commissioner's Office (ICO) website: <https://ico.org.uk/for-organisations/report-a-breach>

How will we use information about you after the study ends?

Once we have finished the study, we will keep the data so we can check the results. We will write the reports in a way that no-one can work out that you took part in the study.

The University of Birmingham and Cardiff University will keep your study data for 10 years. The study data will be fully anonymised and securely archived or destroyed.

What are my choices about how my information is stored?

- You can stop being part of the study any time, without giving a reason, but we will keep information about you that we already have.
- You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.
- If we have collected any information that could potentially identify you such as your name, address, phone number or email address, you can request that we destroy this within 28 days of you telling us that you no longer want to continue in the study. However, we will delete this information as standard at the end of the trial.

To find out more information, you can:

- Contact a member of the research team – contact details are on page 9.
- You can email the Data Protection Officer at the University of Birmingham - contact details are on page 9

Stepping Stones Online programme and data collection

- For the Stepping Stones Online programme, Triple P International is responsible for collecting and protecting your information generated through the online programme.
- Please read the Triple P – Positive Parenting Program Privacy Notice for Online Programs on the Triple P International website for detailed information
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I think I would like to participate in the study – what happens next?

Step 1: After 2 to 3 days after receiving this information sheet, the research team will contact you to discuss the study, check your eligibility to join the study and ask you some questions. You will also be able to ask any questions you may have about the study. The researcher will then arrange for you to complete a consent form.

Step 2: After a consent form has been completed and signed, you will be asked to complete some questionnaires (for the baseline).

Step 3: You will then be randomised by a computer to join the Stepping Stones group or the comparison group. In either group, you will be asked to complete the questionnaires at key stages, as discussed in this information sheet.

PARTICIPANT CONSENT FORM

A randomised controlled trial of a digital parent support programme for parents of children with intellectual disabilities: The Digital Family Support study (DAISY)

IRAS ID: Study Number:

Name of Researcher:

Participant identification number:

- Please tick each box
1. I confirm that I have read the information sheet V2 dated 28/04/2028 for the DAISY study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my health care or legal rights being affected.

3. I understand that information collected during the study will be looked at by the research team at the University of Birmingham, Cardiff University and regulatory authorities supervising the study.

4. I understand that personal information collected during the DAISY study will be kept strictly confidential and processed in compliance with data protection legislation.

5. I understand that any contact details that I share with the research team may be shared with Triple P International who provide Stepping Stones Online. If I take part in Stepping Stones Online, I understand that personal information will be collected by Triple P International.

6. I understand that some of the the findings and results of the study will be written up and published. The writing may include direct quotes but my name and personal details will not be used.

7. I understand that I may or may not be selected to take part in the Stepping Stones Online programme and this will be decided at random by a computer. If I am not selected to take part, I will be offered an opportunity to take part in Stepping Stones Online at the end of the study. I understand that my contacts details will be provided to the Stepping Stones Online team to allow me to access the online programme.

8. I understand that I will be asked to complete questionnaires at the start of the study, at 6 months and 12 months after the first agreeing to take part in the study
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9. I understand that the information collected for this study will be securely stored in line with University Birmingham policies for up to 10 years ☐
10. I understand confidentiality may need to be broken if the research team suspects that I or someone else is at risk of harm. ☐
11. I understand that if I am selected to take part in Stepping Stones Online that I may be invited to take part in an interview to answer questions and discuss about my experiences of taking part in the study. ☐
12. OPTIONAL: I understand that the information collected about me may be used to support other research in the future and may be shared anonymously with other researchers in the UK, abroad and with other universities and research organisations. Yes ☐ No ☐
13. I agree to take part in this study. ☐

Name of Participant

Date

Signature

Name of Person
seeking consent

Date

Signature