



# Support in the Early Years

## PARTICIPANT INFORMATION SHEET

Version 1.3, 22/06/18

**Title of Project:** *Support in the Early Years*

**Name of researcher(s):** *Suzi Scott, Caitlin Murray, Dr Vaso Totsika, and Professor Richard Hastings*

### **Introduction**

We would like to invite you to take part in a research study. Before you decide, you need 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. You can talk to others about the study before you decide whether to take part.

Please ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether you wish to take part.

### **PART 1**

#### **What is the study about?**

This study aims to understand the experiences of parents/caregivers and families of young children aged 0-6 years old with diagnosed or suspected learning disabilities (sometimes referred to as intellectual disabilities, developmental delays) and/or autism, in the UK.

We want to find out what support families and children are currently receiving in the early years, such as support from professionals, early years services, and early intervention services. We are also interested in what helps families access support and what makes it difficult for families to access support.

We will also explore parent and family wellbeing for families during the early years. The early years are an important time, and this research aims to further understand how families are doing and how access to services, or lack of services, can impact the family.

#### **Who can take part in this study?**

We would like to invite parent/caregivers of a child aged 0-6 years old with a diagnosed or suspected learning disability and/or diagnosed or suspected autism to take part in this study. A learning disability may also be referred to as “intellectual disability” or “developmental delay”. Your child with a learning disability and/or autism might also have

other diagnosed conditions such as Down's syndrome, or other genetic syndromes. Your family must currently live somewhere in the UK to participate.

### **Do I have to take part?**

No. It is entirely up to you to decide.

Once you have read this information sheet, we will ask you to either tick boxes on a paper consent form or complete the form on the online survey to confirm that you have agreed to take part. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way. **You do not need to answer any questions that you are uncomfortable answering.**

### **What will happen to me if I take part?**

You will be asked to answer some questions about your child with a learning disability and/or autism and your family using an online survey. If you would prefer to complete a paper questionnaire, this can be requested on our website.

The survey takes about 30 minutes to complete. You will be asked for some anonymised information about you and your family, your child's skills and development, any disability diagnoses your child has been given, you and your family's wellbeing, what type of support you currently receive from services, how difficult you have found it to access services, as well as anything that has helped you with access to services.

### **What are the possible disadvantages of taking part in this study?**

We do not anticipate any risks to parents or their children as part of this research. We will not be asking for your name, to protect your anonymity. Most questions that we are asking have been used in several research studies before. However, it is possible that you will find some of the questions to be upsetting because we do ask about your wellbeing and some of the challenges faced by you, your family and your child with a learning disability and/or autism. If you are upset by any of the questions, you do not have to respond to them and you are under no obligation to continue with the survey.

If any of the survey or interview questions make you concerned for yourself or another family member's wellbeing, we recommend that you make contact with your General Practitioner (GP) or one of the helplines listed below:

Mencap: 0808 808 1111, Contact a Family: 01332 557 975, KIDS: 0207 359 3635

In addition, a factsheet on emotional wellbeing for parents/carers of children with a learning disability can be found at [www.cerebra.org.uk/help-and-information/guides-for-parents/factsheet-emotional-well/](http://www.cerebra.org.uk/help-and-information/guides-for-parents/factsheet-emotional-well/).

### **What are the possible benefits of taking part in this study?**

Involvement in this research provides an opportunity to share you and your family's experiences during the early years, as well as contribute to a greater understanding of access to early intervention and support for families of children with a learning disability and/or autism. It is planned that this research will lead to developing ways to increase access to early intervention and support for families of children with a learning disability and/or autism. The information you provide will help us to understand more about families like yours, to share this information, and to inform ways to better support families.

### **What if there is a problem?**

If you have a concern about any aspect of this study, you can speak to someone from the research team who will do their best to answer your questions (contact details on the last page). If you remain unhappy and wish to complain formally, please contact the University of Warwick (contact details can be found below in Part 2).

**This concludes Part 1.**

**If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.**

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## **PART 2**

### **Who is organising and funding the study?**

The University of Warwick is responsible for this research. The research project is funded by the University of Warwick, and the charities Cerebra and Mencap. Ambitious about Autism and ENABLE Scotland are partners in the project but have not directly provided funding.

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

You can withdraw from the study at any time, without giving a reason, and without affecting you in any way. Please note, that if you participate in the survey and later change your mind, we will only be able to remove your data if you decide to give us your full postcode. Otherwise, we will not be able to identify who you are.

### **Who should I contact if I wish to make a complaint?**

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

#### **Head of Research Governance**

Post: Research & Impact Services, University House, University of Warwick, Coventry, CV4 8UW

Email: [researchgovernance@warwick.ac.uk](mailto:researchgovernance@warwick.ac.uk)

Tel: 024 76 522746

**Will my taking part be kept confidential?**

Yes, all information about you will be handled in confidence and all information will be kept securely (in locked cabinets, or secure password protected computers) in an anonymised form. Information from the study will only be seen by the research team. Names and addresses used to send out paper versions of the survey will be deleted or shredded and no record of this will be kept. The survey asks you to provide your postcode. We would like this information because we can then get other information from the UK Census about the area in which you live. You do not have to provide this information. Postcodes will be kept separate from all other data and protected on an encrypted University of Warwick server.

Only members of the research team will have access to data. However, in some instances, officials from regulatory authorities may need to access data for checking the quality of the research. All members of the research team and regulatory bodies are trained in data protection issues. Study information will be kept securely for up to 10 years in line with the University of Warwick's policies.

**What will happen to the results of the study?**

We will publish reports and give presentations about the results of the study. Once the research study is complete, we will provide information about the results of the research on our website <https://warwick.ac.uk/fac/soc/cedar/familyresearch/supportearlyyears/> as well as through our social media pages. You may opt to follow us on Twitter ([@Family\\_RG1](https://twitter.com/Family_RG1)) and/or Facebook ([www.facebook.com/FamilyRG1](https://www.facebook.com/FamilyRG1)) to keep up-to-date with the research.

**Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the University of Warwick's Humanities and Social Science Research Ethics Committee (HSSREC): 57/17-18

**What if I want more information about the study?**

If you would like to ask questions before deciding whether to participate, please contact a member of the research team (Tel: 02476 524 139, Email:

[familyresearch@warwick.ac.uk](mailto:familyresearch@warwick.ac.uk)).

You can also contact Suzi Scott (Email: [S.Scott.8@warwick.ac.uk](mailto:S.Scott.8@warwick.ac.uk), Tel: 02476 575 866) or Caitlin Murray (Email: [C.Murray.7@warwick.ac.uk](mailto:C.Murray.7@warwick.ac.uk), Tel: 02476 575 866) directly if you would prefer.

**Thank you for taking the time to read this Participant Information Sheet**