



## Participant Information Leaflet

**Study Title:** An exploration of the role of fathers raising children with Intellectual and/or Developmental Disabilities (IDD) at different life stages.

**Investigator(s):** Dr Emma Langley

### Introduction

You are invited 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. Talk to others about the study if you wish.

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

### Who is organising and funding the study?

This study is led by Dr Emma Langley in the Department for Education Studies and is funded by The Faculty of Social Sciences Research Development Fund (RDF).

### What is the study about?

This is a small pilot study which aims to understand the role and involvement of fathers of individuals with Intellectual (learning) and/or Developmental Disabilities. We are particularly interested in hearing from dads of children across different age stages (childhood, adolescence, adulthood) to learn about how fathering changes as their child ages and the kinds of support dads may need at certain times in their child's life. We are looking for 9 fathers (three from each life-stage: childhood, adolescence, adulthood) to talk to us about their experiences including:

- Involvement in their child's life, the things they do together with their child
- Their roles and responsibilities as a dad
- Support they have received or would like to have received
- How their role has changed over time

We hope that the knowledge generated will help to inform a larger study and help shape future support for dads and their families.

### What would taking part involve?

Participation in the study would involve a 1-hour (approx.) interview with lead researcher Emma Langley about the topics mentioned above. The interview will take place over the phone or on Zoom (depending on your preference) and can be arranged at a time to suit you. With your permission, the interview will be audio-recorded using a voice recorder to ensure what you say is accurately captured. Prior to participating in the interview, you will be

asked to complete a short online form which will ask for your contact details (to take part in the interview) and demographic information (which is optional).

You will also be asked to complete two preparatory tasks to bring along to the interview: 1) a relationship map/family tree displaying the key family members and/or people in your life, 2) a timeline of significant events in your parenting journey. These tasks are optional but would help us to get to know you and your family better and give you time to reflect on things prior to the interview.

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

No. Participation in this study is completely voluntary and choosing not to take part will not affect you in any way. You can also choose to withdraw your participation without giving a reason. Further details about withdrawing from the study are provided later in this document.

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

Involvement in this research provides an opportunity to share your experiences of raising your child and contribute much needed research evidence on dads. The information you provide will help us to understand more about fathers' experiences and inform ways to better support dads in the future.

### **What are the possible disadvantages, side effects or risks, of taking part in this study?**

We do not anticipate any risk to taking part in the research, however the interview may discuss sensitive topics which make you feel upset or uneasy. You do not have to share anything that makes you feel uncomfortable and can request to skip a question. You can also pause, terminate, or reschedule the interview at any point. If any of the interview questions make you concerned for yourself or another family member's well-being, we recommend that you contact your General Practitioner (GP) or one of the helplines listed below:

Samaritans 0330 094 5717 Mencap: 0808 808 1111

### **Expenses and payments**

You will receive a £25 electronic shopping voucher as a thank you for participating in the study.

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

Interviews will be conducted over the telephone or on Zoom. The researcher will conduct the interview in a quiet and private place and ask you to also find a comfortable place to chat (if possible) to ensure that you are able to speak freely and that what you say is not overheard by someone else.

After the interview, the recording will be saved under an assigned participant ID number on the secure university server and shared with a university-approved third party transcription service Dictate2us Ltd who will transcribe the interview. Once transcribed, the interview transcript will be sent back to the lead researcher (Emma Langley) and stored on the secure university network (for up to 10 years) and will be kept separate to your contact details and any personal data you will have already provided. Direct quotations from the interview may be used in future reports and publications, however these will not be directly identifiable as pseudonyms (fake names) will be used.

If at any point during the study you disclose that you, or any other person, may be at risk of harm, the researchers have a duty of care to help you report this to the relevant authorities.

## What will happen to the data collected about me?

As a publicly-funded organisation, the University of Warwick have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, such as this, we will use your data in the ways needed to conduct the research study.

We will be using information from you to undertake this study and will act as the data controller for this study. We are committed to protecting the rights of individuals in line with data protection legislation. The University of Warwick will keep identifiable information about you for 10 years after the study has finished.

Research data will be pseudonymised as quickly as possible after data collection. This means all direct and indirect identifiers will be removed from the research data and will be replaced with a unique participant number. The key to identification will be stored separately and securely to the research data to safeguard your identity. You can request to withdraw any of your demographic and interview data until **30<sup>th</sup> June 2022**. After this date you will only be able to request for your contact details (name, email address, telephone number) to be withdrawn and deleted. All withdrawal requests should be emailed directly to Emma Langley at [e.langley.1@warwick.ac.uk](mailto:e.langley.1@warwick.ac.uk)

## Data Sharing

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. The University of Warwick has in place policies and procedures to keep your data safe.

This data may also be used for future research, including impact activities following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project.

For further information, please refer to the University of Warwick Research Privacy Notice which is available here: <https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice> or by contacting the Legal and Compliance Team at [GDPR@warwick.ac.uk](mailto:GDPR@warwick.ac.uk).

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

If you do agree to participate and then decide you no longer want to take part, you are free to withdraw and do not have to provide a reason. Any contact information that you have provided will be deleted. If you have already taken part in the study and wish to withdraw, you have the option for any information about you or provided during your interview to be withdrawn and destroyed until **30<sup>th</sup> June 2022**. After this date you will only be able to request for your contact details (name, email address, telephone number) to be deleted. All withdrawal requests should be emailed directly to Emma Langley at [e.langley.1@warwick.ac.uk](mailto:e.langley.1@warwick.ac.uk)

To safeguard your rights, we will use the minimum personally-identifiable information possible and keep the data secure in line with the University's Information and Data Compliance policies.

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

The findings of the study will be shared in a number of ways. Firstly, the results will be included in a report to the funders of the project and a short summary for participants who

indicate that they would like to receive updates. The findings will also be used to write peer-reviewed journal articles (aimed at academics) and a range of freely available articles for fathers, families and professionals. Findings may also be shared at academic conferences and at seminars and events for fathers and professionals.

**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) (HSSREC 37/21-22)

**Who should I contact if I want further information?**

Project lead Emma Langley: [e.langley.1@warwick.ac.uk](mailto:e.langley.1@warwick.ac.uk) / 02476 522 160

**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**

Research & Impact Services

University House

University of Warwick

Coventry

CV4 8UW

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

Tel: 02476 575733

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter: [DPO@warwick.ac.uk](mailto:DPO@warwick.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).

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