

## **PARTICIPANT INFORMATION SHEET**

### **YOU CAN PRINT OFF THIS INFORMATION SHEET**

#### **What is the research about?**

This research explores how parents of autistic children experience parental blame when they approach health, education and care services for support.

We are interested in hearing from anyone who meets the following description:

1. Parents of both children and young people, who are autistic (both diagnosed and undiagnosed)
2. The term parents is inclusive of; -  
Foster Carers /Kinship Carers/Special Guardian /Adopted parents/Carers and family members with key responsibility of autistic (both diagnosed and undiagnosed) children and young people.

Previous research tells us there are many barriers when parents/carers seek support for their autistic children. Our aim is to understand the ways that parents experience blame when they approach health, education, and care services for support.

#### **What does participating involve?**

##### ***Survey -***

Your data will be collected anonymously and only the researchers will have access to the raw data. This will take approximately 15 minutes. Taking part is voluntary and you can withdraw from the project at any time by clicking the indicated button on the survey page. As participation is anonymous it will not be possible to withdraw your data once you submitted the completed survey.

##### ***Interview -***

If you choose to take part, you will complete a semi-structured interview with one of the research team about your thoughts and experiences of parental blame. The interviews will last for approximately 45 minutes-1 hour.

If you complete the interview, we will analyse the data alongside other data we are gathering from other parent/carers.

We will look at the relationships between experiences and impact and other variables and identify key themes relevant to improving parent/carer experiences when seeking support.

##### ***What happens next?***

We will communicate the findings and key messages through published reports and presentations.

There will be an opportunity to let us know if you want us to keep you informed with the results of the research. We will ask you to share your email address for this purpose only, this is optional.

## **How will we use information about you?**

We will need to use information gathered from you for this research project. This information will include information about your characteristics (such as your age and ethnicity), but you will not be identifiable. We will write our reports in a way that no-one can work out that you took part in the study. We will use this information to help map trends and common themes.

We will keep all information about you safe and secure. Once we have finished the study, the data will be kept for five years so we can check the results.

## **What are your choices about how your information is used?**

You can stop being part of the study without giving a reason, if you withdraw from the survey without submitting, then all information will be deleted. Once you have pressed submit then we won't be able to retract your information.

If you withdraw from the interview at any time we will delete your data if you request this.

We need to manage your records in specific ways for the research to be reliable.

If you participate in the interview then we will send a transcript of the interview directly to the participant for you to check for accuracy by a given date. Should you not respond by the date given we will assume you are happy with the content and for us to include in the research.

## **Are there any risks in taking part?**

We acknowledge that sharing negative personal experiences may be upsetting for some people.

We will provide a list of resources and organisation that are able to offer support at the end of the survey and following the interview.

There are no specific risks expected, though in some circumstances we may need to break confidentiality (see below).

## **Confidentiality**

Your survey responses will be recorded anonymously. Please do not include any identifying information in your open field responses. If you include identifying information, we will treat it confidentially. Your interview data will be treated confidentially.

The only exception to complete confidentiality is if you tell us something that suggests you, or someone else, is at risk of harm. We will need to share this information with others and we may need to tell you if we do this.

We may use direct quotes from your data, but we will use a pseudonym and not use your real name. Your name, and anything else that might identify you, will not be used in any dissemination activity.

The raw data will be securely stored and will be separated from your contact information. Anonymised data may be used for other future research purposes but only by members of the same research team. It will not be shared with anyone else. For any publications, we will share the minimum data from multiple choice questions needed for others to check our statistics.

### **What if I want to know more?**

If you would like further information before you decide, please contact Laura Ferguson. She is one of the researchers and would be happy to answer your questions.

Laura Ferguson  
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The study is being conducted by researchers at ADASS West Midlands. It is funded by NHS England (Midlands Region).

If you have any concerns or complaints about this study and would like to speak to an independent person who is not a member of the research team, then please contact

Catherine Nolan  
ADASS West Midlands Regional Lead for Autistic People and People with a Learning Disability  
Email: [catherine.nolan@wm-adass.org.uk](mailto:catherine.nolan@wm-adass.org.uk)