



Centre for Autism www.reading.ac.uk/autism
Email: autism@reading.ac.uk
Telephone: 0118 378 7558 (answerphone)

INFORMATION ABOUT THE CHILD AND FAMILY AUTISM RESEARCH DATABASE

Dr Fiona Knott, Clinical Psychologist, Centre for Autism, University of Reading, has established a research database to help find children and families who might be willing to help with research studies.

There are a number of researchers in the University and in Berkshire who have a keen interest in learning more about autism spectrum and associated conditions. By finding out more about the difficulties faced by both the individuals coping with these problems and their families, we may be able to improve the services provided. However, we also want to ensure that families are not overwhelmed by requests to take part in research studies. One good way of making sure this does not happen is to hold a list or 'database' of people who are happy to be contacted about research. Having such a database will help to ensure that individuals are only approached if they are interested in research studies, and also that they are not overloaded with requests. This project has been reviewed by the University of Reading Research Ethics Committee and has been given a favourable opinion for conduct.

You have been invited to join our research database because your child has autism spectrum disorder. It's up to you whether or not you and your son/daughter take part. There are no consequences if you decide that you do not want to be on the database or take part in any research.

Being on the database does not mean that you are committed to taking part in research. If you receive a request to participate in research, you will be free to decide whether or not to go take part at that time. Being on the database simply means that we will let you know about studies you might be interested in.

What do I have to do next?

If you would be interested in being part of our database, then please read the information in this information sheet which tells you more about how your information will be used, and how your confidentiality will be protected. A separate sheet is available for you to show your child, if you think this would be helpful. Then go back to the registration site and please tick each item in the consent pages, before completing the registration section. If your child is aged 16 or 17, and does not have a significant learning disability, please ask them to complete an online consent form to show they are willing to be part of the database.

If you do not want to be on the database, you do not have to do anything. Your name will not be on the database unless you complete the survey.

If you have any questions about the database, you are very welcome to contact us.
Email autism@reading.ac.uk or ring the Centre for Autism on: 0118 378 7558 (answerphone)

Further Information about the database

How will the details I provide be used?

If you agree to be part of the database, then the information you provide will be placed on a secure database held on a networked computer at the University of Reading. The database will be password protected. *Your details will be completely confidential and no-one will know if you choose not to participate.*

The database will be used by researchers to find participants for psychology research studies. All projects will have received ethical permission to go ahead from the University of Reading Research Ethics Committee and all researchers will have received Disclosure and Barring Check (DBS) where appropriate, to help ensure the safety and wellbeing of participants. The database administrator (currently Dr Fiona Knott) will act as a gatekeeper. This will help make sure that individuals on the database do not receive too many requests to take part in research. *Your details will not be passed to researchers unless the study has ethical approval.* However, you may receive requests to take part in other reputable studies from other researchers who do not know about the database, and who approach you through other means.

Will my child's medical records be used?

No, we will not access your child's medical or educational records if you are on the database. Some researchers may ask for your permission to do this in connection with a particular project, but you can choose not to take part.

What will happen if my child's name is put forward for a research project?

You will first be sent a letter about the research study by the researcher. They will make it clear that they have been given your details via the database. Sometimes researchers will telephone participants about the project, but this will only happen after you have been sent a letter or email. You will be given full information about each study and you will be asked for consent to take part. Your child will also be asked for assent to take part if they are old enough, and all young people who are 16 or 17 will be asked for their consent. You can opt out of the study at any stage, and you can ask to have your name removed from the database at any time.

What happens to my information if I take part in a project?

If you take part in a project, researchers may ask you to complete some standardised assessments to confirm the diagnosis, or to provide background information such as intellectual ability. With your permission, this information will be included on the database so that other people do not need to ask you for the same information at a later date. The information that you give us will only be shared with researchers in the Centre for Autism and our immediate collaborators. You will be asked to give your consent for information to be put on the database each time you take part in a study, as our studies include a variety of types of information and we want to make sure you are happy for each type to be shared.

What about data protection?

The database will comply with the University of Reading's Data Protection Policy. You have the right to view your details on the database and to have them removed at any time. The database will be maintained securely as described above. If researchers are members of the University, they will be given temporary access to the database to obtain relevant information about participants. If they are not member of the University, the relevant information will be copied onto a disk which will be passed in person to the researcher and destroyed after use.

What happens if I want my name to be taken off the database?

Your child's name will stay on the database until they are 18. However, if you would like your details to be removed at any time, then you should contact the database administrator (currently Dr Fiona Knott) by email, phone or letter via the Centre for Autism. Your name will be removed without question and there will be no consequences for you or your family in terms of the services you receive from the Centre for Autism or any other organisation.

What happens when my child turns 18?

When your child is 18, their name and details will be removed from the Child and Family Database. We will write to them to thank them for being part of our child database and will ask if they would like to sign up to our adult research database. They will of course be free to ignore this request and there will be no consequence for them in terms of any of the services they receive from the Centre for Autism or any other organisation.

Please see the Centre for Autism website www.reading.ac.uk/autism for more information about us and our research