



16 February 2011

Explanatory Statement

Title: Attention profiles in children and adolescents with an intellectual disability

This information sheet is for you to keep.

My name is Nerelie Freeman and I am conducting a research project with Professor Kim Cornish, Head of Discipline, and Dr Kylie Gray, Senior Lecturer, in the Department of Psychology and Psychiatry towards a PhD at Monash University. This means that I will be writing a thesis which is the equivalent of a 300 page book.

I am looking for male and female students aged between 5 and 17 years who are attending school and have a diagnosis of: an intellectual disability, autism spectrum disorder (not Asperger Syndrome or high-functioning autism), Fragile X Syndrome, Down Syndrome or Williams Syndrome.

Aim/purpose of the research

The aim of this study is to develop a new rating scale that will examine the behaviours associated with attention-deficit hyperactivity disorder (ADHD) specific to students with an intellectual disability. It also aims to describe any differences in ADHD that may exist across children with different known causes of intellectual disability.

Possible benefits

There are currently no well-validated measures to assist with assessing the attention profiles of children and adolescents with an intellectual disability. The development of parent and teacher questionnaires will assist in evaluating the attention strengths and difficulties that some children may experience. The findings of this research will assist educators and health professionals in their understanding of the attention profiles of children with an intellectual disability, and this may enable them to tailor learning programs, treatments and interventions that are more specific to the needs of these children.

What does the research involve?

If your child has an intellectual disability, a cognitive (IQ) assessment will be completed if they have not had one in the last two years. This assessment will be done at school at a time negotiated with staff and will take approximately 45-75 minutes. If your child is given an assessment, you will be provided with a report on the results. These results may be of use to professionals involved in the care of your child. Copies of reports for other professionals will only be provided with your consent.

Your child's classroom teacher will also be asked to fill out questionnaires which ask about your child's behaviour, attentional difficulties and their daily living skills. This will take approximately 75 minutes.

If any specific difficulties or problems are identified, a referral to appropriate services will be arranged. If you express any concerns or need any help, this will also be arranged.

If you agree to be a part of this project, please complete the attached consent form. A member of our research team will then contact you about the project. You can return the form to us in the reply paid envelope which is attached to the form. No stamp is necessary.

Inconvenience/discomfort

There is no risk of physical or psychological harm in the study. If any specific difficulties or problems are identified, a referral to appropriate services will be arranged. If you have any concerns, questions, or need any help please feel free to directly contact Ms Nerelie Freeman or Dr Kylie Gray (contact details below).

Voluntary participation

Being in this study is voluntary and you are under no obligation to consent to participation. However, if you do consent to participate, you may only withdraw within 8 weeks of participating in the assessment phase of the study. Whether you take part or not, it will not make any difference to the funding or services which your child or your family currently receives.

Confidentiality

Data on computers is securely stored and deidentified (names are not used). Only the research team will have access to the data. There will be nothing in any reports of the study that could identify individual children or families. Reports on the study will be submitted for publication, but individual participants will not be identifiable in such reports. Participation in this project is voluntary. You are free to withdraw from the project within 8 weeks of participating in the assessment phase of the study.

Storage of data

Storage of the data collected will adhere to the University regulations and kept on University premises in a locked cupboard/filing cabinet for 5 years. Only the research team will have access to the data. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Results

If you would like to be informed of the aggregate research finding, please contact Dr Kylie Gray (see details below). The findings will be available from December 2012.

If you would like to contact the researchers about any aspect of this study, please contact:	If you have a complaint concerning the manner in which this research is being conducted, please contact:
Ms Nerelie Freeman or Dr Kylie Gray Centre for Developmental Psychiatry & Psychology Monash Medical Centre 246 Clayton Rd Clayton VIC 3168 Tel: +61 3 9594 1301 Fax: +61 3 9594 6333 Email: nerelie.freeman@monash.edu kylie.gray@monash.edu	Executive Officer, Human Research Ethics Monash University Human Research Ethics Committee (MUHREC) Building 3e Room 111 Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Fax: +61 3 9905 3831 Email: muhrec@adm.monash.edu.au

Thank you for taking the time to assist us with our research project.

Dr Kylie Gray

Prof Kim Cornish

Nerelie Freeman