

Storage of your information

Research into child development is complex and these studies can take many years. We plan to keep all information collected for this study. As soon as you enter the study, your child and family will be given a code number. All of the information that we collect will be labelled with this code number, and NOT your name. This will ensure your information is kept private. The information from the surveys and behavioural tests will be kept in a locked filing cabinet at the Telethon Kids Institute. This information will also be stored in an electronic database. This database will be secured with passwords, and only seen by the researchers in this study. The videos will be stored on a secure server at the Telethon Kids Institute.

Use of your information

The information we collect is very valuable to researchers. The information we get from the surveys and behavioural tests will be used by our research team to understand the factors that influence early child development. We would also like the information we collect from you to be available to other researchers around Australia and the world. Sharing information between research groups is critical to making research advances, and we would like this study to be part of this important process. We will only ever do this when we are sure that ethical and privacy approvals are in place. There may be occasions where the data we collect from you and your child are published along with our research articles. Your data will always be labelled with a code, and no identifying information (names, addresses) will be revealed. Please note that the videos we record as part of this project will not be shared with anyone outside of the study team unless we have your permission.

Withdrawing consent

You are free to stop taking part in this study at any time. Your decision to stop will not influence the care your child receives from anyone in this study.

What happens to the results of the study?

We will use the information we collect to publish scientific reports with important discoveries. We will also communicate our findings to the public through presentations. Published reports on the results will not mention any identifying information, such as names or addresses.

Who do I contact if you have any concerns about the running of the study?

If you have any concerns or complaints about this study, you can contact the following people and your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study:

Director of Clinical Services, Perth Children's Hospital
E | CAHS.Ethics@health.wa.gov.au

Who do I contact for more information?

If you would like any more information about this study, please do not hesitate to contact the Study Coordinator, Alena Clark. She will be very happy to answer your questions.

Alena Clark
Study Coordinator
T | (08) 9489 1690
E | Alena.Clark@telethonkids.org.au

Thank you for your time

PARENT/GUARDIAN INFORMATION SHEET

Group therapy to boost infant communication skills



Why are we doing this study?

Some children have difficulties with their early communication skills. Most children will catch up without the need for any therapy, but a small number of children will experience ongoing difficulties. The aim of this research is to understand how children learn social and language skills and how we can best help children to reach their full potential. This research will also test a new group therapy that helps families understand more about their child's communication abilities. We want to test whether this therapy may provide extra help for children to develop social and communication skills. This research is important because it will help us know how best to support children with their development.

Who is carrying out the study?

The study is being conducted by a team of researchers based in Perth. The researchers are from the Telethon Kids Institute and the Child Development Service (WA Health), Child and Adolescent Health Services. The study leaders are Dr Kandice Varcin and Professor Andrew Whitehouse, who are based at the Telethon Kids Institute, Perth and Associate Clinical Professor John Wray, who is based at the Child and Adolescent Health Service, Child Development Service.

Why have I been invited to take part?

You have been told about this study because you have a child who has been referred to the Child Development Service for a concern about their development. Often these concerns will resolve naturally, without the need for therapy. However, as we do not know which children will need ongoing therapy, we promote supporting all children referred to the Child Development Service with their development. A screen recently completed with you over the telephone indicated that your child may benefit from support to enhance their early communication skills.

Please do not be overly concerned that your child may have more serious developmental concerns. Many children who have early delays with their development do not go on to have a serious developmental condition

What will happen if I give permission to take part?

You will have been told about this study by a staff member at the Child Development Service. If you agree to take part in the study, your information will be passed onto a study team member based at Telethon Kids Institute. The team member at Telethon Kids Institute will make a time for your first study assessment, which will be at the Telethon Kids Institute. At the first session, you will have another opportunity to ask any questions that you may have. After the first appointment, you will be assigned to one of two therapy pathways: (1) current best practice offered as part of the Child Development Service, or (2) group-based parent-mediated therapy in addition to regular services offered by the Child Development Service. Both of these therapies are designed to help your child's communication skills. The assignment to one of these therapies is completely random and is not based on your child's performance at their research assessment.

The group based therapy involves between 7-9 sessions. The first session will be a one-on-one appointment with a therapist (1-2 hours in length) in your home. You will then participate in five, weekly 'group sessions' (each two hours in length), which involve the same therapist and up to five other parents whose infants are showing similar developmental concerns. These sessions will take place at the Child Development Service or Telethon Kids Institute. Following these group sessions, there will also be a one-on-one booster session (one to two hours in length) occurring in your home, with the option of up to two additional booster sessions, if required.

Session Name	Child's age	What Happens?	Where does this happen?	How long does it take?
Pre-assessment	7-15 months of age	Parents complete surveys	In your home	1 hour
Assessment 1 (Baseline)	7-15 months of age	You will be asked to sign a consent form. Your child will complete behavioural tests. We would also like to video record you playing with your child.	Telethon Kids Institute	2 hours
Therapy period	7-15 months of age - 12-20 months of age	Families receive one of two types of therapy (current best practice or group therapy)	Child Development site or Telethon Kids Institute	Over a 5 month period
Assessment 2 (Follow-up)	13-21 months of age	Child completes behavioural tests, Parents complete surveys, and we video record parent-child play.	Telethon Kids Institute	3.5 hours

Six months after your first research assessment with us, we will invite you back to the Telethon Kids institute to see your infant again for their follow-up assessment.

What is the aim of the therapy?

The therapy involves teaching you a style of interacting with your infant. We will video record you playing with your child, and teach you new strategies that we hope will help improve their social and communication skills. The group sessions will be facilitated by the same therapist that you will have seen for the one-on-one session. The group sessions involve watching videos of other parents playing with their child, and discussing how the child is communicating with the parent. Our therapists (Speech and Language Pathologists, Clinical Psychologists) are specially trained to facilitate these groups in an open and enjoyable way. You will not be forced to share your video if you do not feel comfortable to do so. The ultimate aim of this therapy is to provide you with skills that can help boost your child's social and language development.

We would also like to collect:

1. Information from health and medical professionals who have previously seen your infant. We will request permission from you to discuss your child with these clinicians.
2. We will also conduct short video recordings of you playing with your child. These recordings will help us understand how parent interaction can support children's social and communication development.

Will my child be disadvantaged by taking part in this study?

No. Any child who takes part in this study will receive therapy that is designed to improve their early communication skills.

Are there any risks involved?

We have no reason to believe that you or your child are at any risk by taking part in this study.

