



## Project Referral Partners Information Sheet: START Feasibility Trial

Ethics approval reference: R67115/RE001

### About this study

Previous research has indicated that children with a family connection to autism or ADHD may benefit from additional support in developing attention, regulation and thinking skills (sometimes called executive functions). The START team, led by Dr Alexandra Hendry and in collaboration with *Peeples*, have developed a programme which aims to provide that support, starting in toddlerhood.

Dr Hendry is a developmental psychologist at the University of Oxford. She specialises in understanding the development of early executive functions – the thinking and regulation skills that allow us to control our impulses, think flexibly to solve problems, and set and work towards goals. *Peeples* are a charity whose main purpose is to support parents or carers, babies and children to learn together. Their evidence-based Learning Together Programme (<https://www.peeples.org.uk/ltp>) is a strengths-based approach to working with families, focusing on doing *with* rather than doing *to* parents. The Learning Together Programme provides the foundations for the START programme but the content has been specifically developed with the needs and interests of parents and toddlers with a family connection to autism or ADHD in mind. The START programme has been developed with input from autistic parents and parents who have a child with autism or ADHD. The content has also been reviewed by Speech and Language and Early Years practitioners.

This Feasibility Trial is the first stage in investigating whether the programme is useful or not. We will be collecting information from families in 2 areas of the UK. The information we collect will help us to improve the programme and decide whether to progress to a larger trial.

### Who is the START programme for, and why?

Toddlers with a family connection of autism or ADHD are more likely than average to be later diagnosed with autism or ADHD. Some toddlers with a family connection of autism or ADHD will not meet the clinical cut-off levels for a diagnosis, but will still show higher autistic or ADHD traits. Autism and ADHD are both conditions that are associated with executive function difficulties in later childhood and adulthood, so supporting early executive development may help these toddlers to thrive in later life.

Many toddlers with a family connection of autism or ADHD will be neurotypical – that is they will not show any signs of a developmental condition. Supporting early executive development may still be beneficial for these toddlers as strong executive functions are associated with higher levels of health, wealth and happiness in typically-developing populations too.

### What approach does the START programme take?

The aim of the START programme is to support all children to thrive, whether they are neurodivergent (i.e. autistic/ADHD) or neurotypical (have no developmental conditions). The programme training and materials place an emphasis on inclusivity and valuing neurodiversity. The

programme is **not** about training children to perform neurotypical behaviours or reducing likelihood of a later diagnosis of autism or ADHD. The programme is also not designed to address specific developmental needs such as language delay, but can be used alongside clinical services or educational supports. The programme focuses on supporting children's ability to pursue their own goals and empowering them to cope with the day-to-day demands of life. It will do so in part through 'upskilling' – i.e. supporting the development of children's executive function skills – and in part through improving environmental fit so that children's executive function skills are not taxed beyond their current capacity.

The START programme is based around parent-child play sessions, using songs, games and stories to provide enjoyable opportunities for toddlers' skill development. The sessions will have a large element of parent-to-parent peer support and the session materials include insights provided by the parents involved in the programme development.

### **Who can take part in the START feasibility trial?**

To be eligible for this study parents must:

- Have a child who is aged under 20 months who has a close biologically-related family member (e.g. their mum, dad, brother or sister) who is autistic or who has ADHD (either diagnosed or suspected).
- Be willing and able to attend weekly 1-hour parent-toddler sessions located within **X miles of XXXX or XXX**, over a 3-month period.
- Be able to understand spoken English (so that they can take part in the parent-toddler sessions).

### **What will happen in the feasibility trial?**

If they take part in the trial, this is what families would be asked to do:

1. Answer a screening questionnaire, either online or by phone to check eligibility for the trial. This will generally take about 10 minutes, but may involve a follow-up questionnaire about the relative(s) with suspected autism/ADHD if they don't have a confirmed diagnosis.
2. When their child is around **20 months old**, parents will be asked to fill in a questionnaire, either online, by post or by phone about their child's health, personality, strengths and difficulties, and about their family background and mental health. This will take around 40 minutes to complete, but can be completed in stages. To thank parents for their time we will send them a £10 online shopping voucher after this questionnaire set is completed.

We will also arrange an assessment visit. Families can choose for these assessments to take place in their home or at the Oxford BabyLab, which has a welcome area with a range of toys, and baby-changing facilities. After talking parents through the plan for the assessment and answering any questions they might have, the researcher will place some sensors on the child's chest to measure their heart activity, which can be used as an index of attention. There will then be a range of games and activities for the child to play, some involving toys and objects, and some games on an iPad. Some of the games are specially-designed to measure toddlers' attention, thinking and regulation skills. Others are standardised assessments of developmental ability and autism traits. The session is designed to be enjoyable for toddlers, and we can take breaks whenever they need. Parents will be in the room with their child the whole time, but will sometimes be filling in another questionnaire

whilst they play. The games and assessments are expected to take no more than 2 hours in total, but visits will be scheduled for 2.5-3 hours to allow plenty of time for breaks. We will provide children with a small gift to thank them for their time, and reimburse parents for travel costs.

3. After the first assessment visit families will be assigned at random to either the START programme group or Usual Practice group of the trial. There is a 50% (equal) chance of being assigned to either group.

If families are assigned to the START programme they will be invited to take part in a 12-week programme of parent-child sessions, starting when their child is between **21 and 27 months**. Parents will be contacted by the facilitator running the sessions in their area to find out which times and days would be most suitable, and discuss parents' aims and expectations for the programme. They will also find out whether there are specific adjustments we could make to make the programme sessions accessible for families. This could involve providing help arranging or covering costs for transport or childcare for other children, making sure the venue has ramps, or adjusting the set-up of the room to suit sensory needs. As this is a group programme, it may take a few months for enough other families to be recruited to run the sessions. The facilitator will contact families when the sessions are ready to start, and make sure they have the information they need.

If families are assigned to the Usual Practice group they do not need to do anything for 10 months. They can continue to access any services, supports or parenting groups they would have otherwise accessed.

4. When their child is around **31 months old**, parents will be asked to fill in a questionnaire, either online, by post or by phone about their child's health, personality, strengths and difficulties, and their day-to-day life and experiences as a parent. This will take around 40 minutes to complete, but can be completed in stages. To thank parents for their time we will send them a £10 online shopping voucher after this questionnaire set is completed.

5. When their child is around **36 months old**, parents will be asked to fill in a similar questionnaire. This will take around 30 minutes to complete, but can be completed in stages. To thank parents for their time we will send them a £10 online shopping voucher after this questionnaire set is completed. We will also arrange an assessment visit, which will be similar to the assessment visit at 20 months. We will provide children with a small gift to thank them for their time, and reimburse parents for travel costs.

### **What will happen in the START sessions?**

Two specially-trained facilitators will lead the sessions each week. In the group discussion part of the session, one facilitator will share the topic and key information for the session, and encourage parents to share tips and ideas about the topic. The other facilitator is on hand to play with the toddlers whilst parents chat, but children can stay as close to their parent as they want.

In the activities part of the session, the facilitators will share out toys and suggest some ways of playing that are related to the session topic, and which may help toddlers to practise some important skills. Parents are encouraged to adapt the activity ideas to suit their child. Each session will end with some new and familiar songs, and the facilitator will share a story with the toddlers.

Each week parents will be given some resources to take away, so that they can carry on trying and adapting the activity ideas at home. These will include a mixture of ideas sheets and toys.

Each session lasts an hour. There are 12 sessions in total, at the same time and location each week. There will be between 4 and 8 parents in a group, each with a child aged between 21 and 24 months (at the first session).

### **Where and when will the sessions be held?**

The sessions will be held in family-friendly venues in <area 1> and <area 2>. The facilitator leading the sessions will talk parents through the options and ask if they have any specific access needs. They will also arrange a phone call with parents to find out which times and days would be most suitable, and explain how to get travel costs reimbursed.

### **Are the sessions just for parents?**

The study is open to anyone who has parental responsibility or legal guardianship to an eligible toddler. We ask that whichever adult has enrolled in the study is the main person who attends the sessions. Any family member or carer who regularly looks after the child is welcome to come along with the lead parent to a session. Parents are also welcome to bring along another adult with them if it would make the session more accessible.

### **Do families need to go every week?**

If they can, we'd love families to come every week during the 12-week period that their group sessions are running. But we know that life is busy and complicated so that might always not be possible, and we have built into the session plans time to go over important content that was missed.

### **Will you cover travel expenses?**

Yes. Parents will be able to claim up to £5 without a receipt, or £15 with a receipt, to cover travel or childcare costs associated with attending each START programme session.

### **Can parents bring their other children?**

The sessions themselves are just for toddlers and their parents, but if they have an older child it may be possible (depending on the venue, and their needs) for them to relax in a nearby room during the session. The practitioner leading the sessions will discuss this with parents before the first session, to work out what is best. If it is not possible to bring the older child along, and parents need to arrange for paid childcare for them instead, we will help to cover those costs (up to £15 per session).

**If you have any other questions about the START programme please contact the team on [start@psy.ox.ac.uk](mailto:start@psy.ox.ac.uk) and we will do our best to answer them.**