

### Welcome

A warm welcome to the Summer 2022 issue of the START newsletter. START is an NIHR-funded programme aiming to support the development of attention, regulation and thinking skills amongst toddlers with a family connection to autism or ADHD. Through our newsletter we aim to keep you up to date about our research activities, plans and emerging findings. We look forward to letting you know about continuing progress of the START project in our next issue planned for Summer 2023. Dr Alex Hendry (Chief Investigator)

### First round of START pilots complete

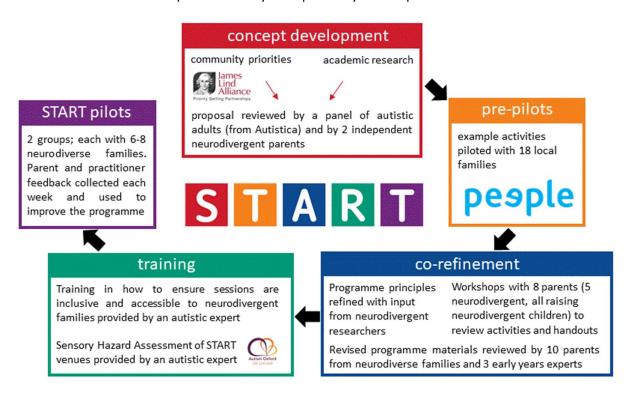
And we're off! The first pilot sessions ran from April to July 2022. The feedback has been very positive and participants have arranged to stay in touch with each other. Learnings from the pilots will be used to improve the programme further.

I didn't realise how much my child would really love the attention games and songs!

It drew attention to things I was already doing but didn't realise why they were beneficial

# Development of the START programme - a collaborative effort

This diagram shows the development of the START programme to date. Huge thanks to the contributors who have helped us so far: your input really has shaped START for the better.



## Now recruiting for the second round of pilots

The second round of pilots will begin in September 2022, in Oxford. We will still have spaces for a couple of families so if you know anyone with a child born between June and December 2020, who has a sibling or parent who is autistic or has ADHD, please ask them to get in touch.



# Latest news... developing neurodiversity-affirming measures of parenting

One of the aims of START is to support parents as toddlers' first teachers and source of emotional support. To understand if we have been successful we need measures that recognise that there is more than one way to be a supportive, responsive parent. Existing ways of understanding and measuring parenting have generally been developed by and for neurotypical parents with neurotypical children. These measures often assume that all children do or should reach developmental milestones at particular ages, and create a narrow picture of what effective parenting should look like. Even where neurodivergent children and/or parents have been included, differences that are associated with autism and ADHD are still often considered only

#### **Key terms explained**

**Neurotypical**: Someone whose brain works in similar ways to the majority of people.

Neurodivergent: Someone whose brain works in different ways from the majority of people, for example because they are autistic or have ADHD.

in terms of problems to be overcome. In contrast, we take a broader view of parenting that allows for the fact that that children have different needs and develop different skills at different rates, and that the way parents support their children may vary according to their own needs, abilities and priorities, as well as their child's. We also recognise that the challenges and barriers faced by families where a parent and/or child is neurodivergent may be different from neurotypical families.

The University of Oxford have awarded us a grant to develop two neurodiversity-affirming measures of parenting. We will begin with a series of focus groups to identify themes that are important to parents who are neurodivergent and/or raising a neurodivergent child. We are currently seeking participants for these focus groups (ethics ref R82511/RE001).

To be eligible to take part you must:

- Be over 18, living in the UK, and able to speak and understand English fluently.
- Have a child aged 1 or over and either be neurodivergent yourself (e.g. autistic/ADHD) or be raising a neurodivergent child (with either a confirmed or suspected diagnosis of autism, ADHD, or another neurodevelopmental condition).
- Be able to take part in a 60- to 90-minute focus group discussion, either online or in Oxford, which will be scheduled at a time to suit you in September. As a thank you for your participation in the focus group, we will pay £20 (online voucher or bank transfer), and will reimburse travel expenses for in-person attendance. To find out more, and to sign up to take part, please email start@psy.ox.ac.uk.



### Introducing... 3 new members of the START team



**Maryna** will be helping with the START toddler assessments. Maryna has an MRes from UCL in Cognitive Neuroscience and joins us from Ukraine where she has many years' experience in diagnostic assessments, and working with children with special educational needs.



**Martina** is leading the development of our new parental self-efficacy measure. Martina has a Doctor of Education degree from University of Sheffield where her research explored the ways in which dominant socio-economic and normative psychological discourses construct the lives of disabled children and their parents. She is also a parent-carer to her eldest child who has a life-limiting epilepsy syndrome and various labels of learning disability.



**Victoria** is leading the development of our new measure of parent-child interaction. Victoria has a PhD in Psychology from University of Sussex. Her research has explored the role of parent-child bidirectional effects for the development of self-regulation abilities, and examined mental well-being for youth with special educational needs and disability.

## **Research briefing**

It's too soon to have published any findings from the START project yet, but we do have a new study out looking at the impact of variation in infants' home environment during the pandemic on their emotional, social and cognitive development. The study, published in the journal **Infancy**, highlights the importance of social support for parental mental health and in turn, infants' development. On the basis of these results, we argue for greater investment in universal services such as health visitors, as well as funding for community services which can provide peer-to-peer support to parents who are struggling. We would also encourage all parents of young children to reach out to family and friends to ask for help in those difficult first years. For more information visit: <a href="https://doi.org/10.1111/infa.12495">https://doi.org/10.1111/infa.12495</a>

# We're presenting at ITAKOM in March

We're delighted to have been invited to give a talk about START at the It Takes All Kinds of Minds in March 2023. This one-off neurodiversity conference is open to everyone and will include presentations from a diverse mix of personal, practitioner and academic expertise. Virtual and in-person tickets are on sale now if you'd like to join us <a href="https://itakom.org/">https://itakom.org/</a>



### Thanks to...

Finally, we'd like to give a shout out to Morwenna from Autism Oxford UK for the fantastic training she provided to the START delivery team and other collaborators. This thought-provoking session covered a wide range of topics, from how to help someone experiencing a meltdown, to how to make group settings more inclusive. Autism Oxford UK have agreed that this training can form part of the training programme for all START practitioners, as part of our commitment to ensuring that neurodivergent perspectives and expertise are central at all stages of the project.

